Successful Transitions for People with Developmental Disabilities:

A Report of the NCIOM Task Force on Transitions for People with Developmental Disabilities

May 2009

North Carolina
Institute of Medicine
A report requested by the
North Carolina General Assembly

NCIOM

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The North Carolina Institute of Medicine (NCIOM) is a nonpolitical source of analysis and advice on important health issues facing the state. The NCIOM convenes stakeholders and other interested people from across the state to study these complex issues and develop workable solutions to improve health, health care access, and quality of health care in North Carolina.

The full text of this report is available online at
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Acknowledgements

At the request of the North Carolina General Assembly in 2008, the North Carolina Institute of Medicine (NCIOM) convened the Task Force on Transitions for People with Developmental Disabilities to study transitions for persons with developmental disabilities from one life setting to another. The Task Force was asked to examine barriers to transition and best practices in successful transitions.[a] Specifically, the North Carolina General Assembly instructed the Task Force to examine at least three topics: the transition for adolescents leaving high school, including adolescents in foster care; the transition for persons with developmental disabilities who live with aging parents; and the transition from developmental centers to other settings. The NCIOM was directed to report the Task Force findings and recommendations to the North Carolina General Assembly by March 2009. The Task Force met a total of six times between October 2008 and March 2009 to develop the final report and recommendations.

The NCIOM would like to extend appreciation to all of the Task Force members and Steering Committee members whose combined efforts made this report possible. The Task Force was led by three co-chairs, James Bodfish, PhD, Director, Center for Development and Learning, Carolina Institute for Developmental Disabilities, Professor of Psychiatry and Pediatrics, 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. There were 32 additional Task Force members who dedicated their time to research this issue. Members of the Task Force and eight additional individuals participated on the Task Force's Steering Committee, helping to shape meeting agendas and providing important input on the report and recommendations. A complete list of Task Force members and Steering Committee members can be found on pages 9-11 of this report.

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

Center; Mary LaCorte, Assistant Director, Exceptional Children's Assistance Center; Freda M. Lee, MAEd, Consultant for Intellectual Disabilities, Secondary Education, and Transition Services, Exceptional Children Division, North Carolina Department of Public Instruction; Betsy MacMichael, State Director, First in Families of North Carolina; Joan McAllister, MSW, LINKS State Coordinator, Division of Social Services, NC DHHS; Alexander Myers, PhD, Murdoch Developmental Center; Susan L. Parish, PhD, MSW, Assistant Professor, School of Social Work, University of North Carolina at Chapel Hill; Gina Price, MS, CRC, LCAS, CSI, Program Specialist, Division of Vocational Rehabilitation, NC DHHS; Genny Pugh, Executive Director, Turning Point Services; Michael Sanderson, MPH, Best Practices Unit Manager, Children and Youth Branch, Division of Public Health, NC DHHS; Sillar Smith, State Director, Compensatory Education and Special Populations, North Carolina Community College System; David Test, PhD, Project Co-Principal Investigator, Knowledge Generation, National Secondary Transition Technical Assistance Center, Department of Special Education and Child Development, University of North Carolina at Charlotte; Nancy Thaler, Executive Director, National Association of State Directors of Developmental Disabilities Services; Shealy Thompson, PhD, Community Policy Management, DMHDDSAS, NC DHHS; and Patte Whitfield, MS, OTR/L, Assistant Director, The Arc of North Carolina.

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The NCIOM served as staff for the Task Force and contributed to the Task Force's study and development of the final report. Pam Silberman, JD, DrPH, President and CEO of the NCIOM, and Mark Holmes, PhD, Vice President of the NCIOM, guided the work of the Task Force and assisted in writing and editing sections of the report. Kimberly Alexander-Bratcher, MPH, Project Director, served as project director for the Task Force and contributed to the report. In addition, Berkeley Yorkery, MPP, Project Director; Jesse Lichstein, MSPH, Project Director; David Jones, Research Assistant Intern; Julia Lerche, Research Assistant Intern; and Corey Davis, JD, Research Assistant Intern, helped write and edit sections of the report. Phyllis Blackwell, Assistant Managing Editor for the *North Carolina Medical Journal*, provided editorial assistance. Thalia Fuller, Administrative Assistant, coordinated Task Force meetings and helped with meeting logistics.

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Executive Summary

Transitions from one life setting to another are challenging, complicated events for most people. Moving from adolescence into adulthood, changing a living situation, or experiencing the death of parent or caregiver are difficult experiences. However, these challenges may be compounded for people with intellectual and other developmental disabilities (I/DD)—especially for those with more significant disabilities.

More than 100,000 people in North Carolina have an I/DD.[1] Individuals with I/DD have intellectual and/or other developmental disabilities that manifest before age 22 and lead 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. In addition, North Carolina's definition of developmental disabilities includes people who have experienced Traumatic Brain Injury (TBI) regardless of the age of injury.[a] The services and supports that individuals with I/DD need can vary considerably, depending on the person, the type and severity of the disability, and the availability of natural supports (including family and community supports). In addition to regular medical and dental care, people with I/DD may also need more specialized medical, mental health, or home health services. They may also require housing that is physically accessible, assistive technology, behavioral supports, educational supports, rehabilitative services, employment services, and social and environmental adaptive services. In addition, many people with I/DD need assistance from direct support personnel and case managers to plan, coordinate, and monitor service delivery.[2]

The services and supports that individuals with intellectual and other developmental disabilities need can vary considerably, depending on the person, the type and severity of the disability, and the availability of natural supports (including family and community supports).

The Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) is the lead agency charged with overseeing services 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. For example, the Division of Health Services Regulation (DHSR) licenses many of the providers who offer residential and/or other habilitation services, including Intermediate Care Facilities for Persons with Mental Retardation (ICFs-MR) and other developmental disability group homes. The Division of Medical Assistance (DMA) administers the Medicaid program that pays for and oversees some services and supports, including targeted case management, provided to people with I/DD. Local Education Authorities (LEAs) are required, under the Individuals with Disabilities Education Act (IDEA), to provide services and supports necessary to help children and adolescents with I/DD succeed in school. People with I/DD may also receive employment supports or help with independent living through the Division of Vocational Rehabilitation and may receive cash assistance through the Social Security Administration.

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[a] NCGS §122C-3(12a). The federal definition of developmental disabilities does not include Traumatic Brain Injury, unless the injury occurred before age 22.

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. Services are often fragmented across agencies. In addition, payments for services may come from different sources, each with its own eligibility rules and requirements.

People with I/DD need coordinated services and supports from multiple organizations and agencies to help them through life transitions. Relative to other people, individuals with I/DD may have fewer relationships to turn to for support. Interagency planning and coordination is particularly important during transitions, as is having a well-qualified workforce. Many youth with I/DD who age out of secondary school need linkages to postsecondary schools, vocational rehabilitation, and their Local Management Entity (LME), as well as community organizations (e.g. churches and YMCAs) to ensure that they become active participants in their communities. Older adults with I/DD may need to be linked into a variety of different services, supports, and housing if their aging caregiver or parent dies or can no longer provide services or supports for them. People who transition out of public developmental centers or private ICFs-MR will need access to an array of services and supports in the community, consistent, in some cases, with a higher level of need. Regardless of the reason for the transition, people with I/DD need access to a comprehensive array of individualized services and supports to enable them to maximize their independence, productivity, inclusion, and self-determination in the community.

People with intellectual and other developmental disabilities need access to a comprehensive array of individualized services and supports to enable them to maximize their independence, productivity, inclusion, and self-determination in the community.

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.[b] 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 Human Services. It included 40 additional Task Force and Steering Committee members, including legislators, DMHDDSAS staff, parents of people with I/DD, advocates, providers of services and supports to people with I/DD, representatives of LMEs, 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.

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

Transitions from School to Postsecondary or Community Settings

Schools play an important role in helping all youth acquire the skills and knowledge needed to be successful as adults. This is particularly true for individuals with I/DD, who may face additional challenges transitioning from childhood to adulthood. Currently there are five courses of study available to students with disabilities, including those with I/DD: Career Prep, College Tech Prep, College/University Prep, the Occupational Courses of Study, and the Extended Content Standards.[c] The Career, College Tech, and College/University Prep Courses of Study are available to all students and have fairly similar base graduation requirements. The Occupational Course of Study (OCS) is only available to students with disabilities and is designed for students with mild to moderate disabilities who need a modified general curriculum that focuses on post-school employment and independent living.[d] The Extended Content Standards provide guidance for developing individualized courses of study for students with significant disabilities.

Students need a high school degree to be competitive for work or eligible for postsecondary education…only 49.4% of students with disabilities graduate from high school.

Students need a high school degree to be competitive for work or eligible for postsecondary education. While the goal of the North Carolina public school system is to ensure that every student graduates from high school "globally competitive for work and postsecondary education and prepared for life in the 21st Century," only 49.4% of students with disabilities graduate from high school.[e,3,4] By this definition, more than 45% of students with disabilities are not prepared for competitive work or postsecondary education.[f] Even those who do graduate may have trouble transitioning from secondary school to postsecondary education or community settings. The low graduation rate for students with disabilities illustrates that many high schools are not fulfilling the promise of the Individuals with Disabilities Education Act (IDEA) for students with disabilities.

Individuals with I/DD who graduate or age out of secondary school need linkages to postsecondary schools, vocational rehabilitation, and LMEs to obtain postsecondary education, vocational training, workforce assistance, or other services and supports needed to help them become active participants in the community. Transition plans are supposed to build such links. North Carolina policy requires that the Individualized Education Program (IEP) team begin discussing transitions for students with disabilities during the year a child turns 14.[g] However, available state

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[c] Beginning in 2009-2010, entering students will choose between the Future Ready and Occupational Courses of Study and the Extended Content Standards.

[d] Lee FM. Consultant for Intellectual Disabilities, Secondary Education, and Transition Services, Exceptional Children Division, North Carolina Department of Public Instruction. Oral communication. February 11, 2009.

[e] Unless otherwise stated, "children with disabilities" refers to all children with disabilities, regardless of the type of disability. The federal government recognizes 13 categories under which a child may qualify for special education including autism, deaf-blindness, deafness, emotional disability, hearing impairment, cognitive disability, multiple disabilities, orthopedic impairment, other health impairment, speech or language impairment, traumatic brain injury, and visual impairment.

[f] The legislative charge to the Task Force was to examine transitions, including transitions from secondary school to other settings. Thus, the Task Force focused its analysis on school transitions, not issues about the adequacy of elementary and secondary school for children with intellectual and other developmental disabilities (I/DD).

[g] Individuals with Disabilities Education Act requires that transition services be a part of the Individualized Education Program (IEP) beginning with the IEP in effect when the child turns 16.

data suggest that North Carolina is not doing a particularly effective job in helping students link to competitive employment or postsecondary education settings.[5] Every year, the Department of Public Instruction surveys students with IEPs who left high school in the last year. The survey asks students if they have been employed in competitive employment or enrolled in postsecondary schools at some point in the last year. The 2007 survey showed that only 58% of students who left high school had been competitively employed, enrolled in postsecondary school, or both at some point in the past year. Little is known about what happens to students with disabilities who are not employed or in postsecondary education after leaving school.

Only 58% of students with Individualized Education Programs who left high school had been competitively employed, enrolled in postsecondary school, or both at some point in the past year (2007).

North Carolina's community colleges offer a free compensatory education program (CED) as part of the Basic Skills Program, which assists adults in becoming literate and obtaining the knowledge and skills necessary for employment and self-sufficiency. CED is for individuals with intellectual disabilities who are not prepared to take academic or vocational classes. The CED's purpose is to "compensate" adults for the lack of, or inadequate, education they may have received in the past. The programmatic aspect of both CED and Adult Basic Education are funded through federal funds and are restricted to providing compensatory education skills, not vocational or work-related skills. In addition to these programs, the North Carolina Community College System offers career and technical education courses. Applicants to these curriculum programs have to meet certain standards or must have taken certain required courses before enrollment. The courses in the curriculum programs have entrance requirements that are often difficult for students with I/DD to meet. Currently there are very few postsecondary education options designed specifically for individuals with I/DD. "Beyond Academics" at the University of North Carolina at Greensboro is one of the more promising options. North Carolina's community college and university systems need to improve the current system to better meet the needs of individuals with disabilities.

The following is a summary of the Task Force's recommendations dealing with secondary and postsecondary education. The full text of the recommendations is included in Chapter 3.

Recommendation 3.1: Improving Educational Outcomes of Children with Intellectual and Other Developmental Disabilities

The State Board of Education (SBE) should examine existing school policies to improve the educational outcomes for children with intellectual and other developmental disabilities.

Recommendation 3.2: Measuring Outcomes for Students with Intellectual and Other Developmental Disabilities

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.

Recommendation 3.3: Improving Transition Outcomes of Children with Intellectual and Other Developmental Disabilities

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 disabilities to help meet the life skills components of students' Individualized Education Program transition plans.

Recommendation 3.4: Improving Interagency Coordination for Transitions

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.

Recommendation 3.5: Use of Assistive Technology in the Schools

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.

Recommendation 3.6: Expanding Educational Opportunities in the Community College System (PRIORITY RECOMMENDATION)

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.

Recommendation 3.7: Expanding Postsecondary Education Opportunities in Colleges and Universities

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 FY 2010 and FY 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.

Recommendation 3.8: Collaboration Between the University of North Carolina System and the North Carolina Community College System

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.

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 traditional kinds of support—family, caring adults, mentors—that other youth have to help them through periods of transition. If identified early, children with I/DD in the foster care system can be connected to services and supports that can help them successfully transition from foster care into the community. Therefore, it is important to identify children with I/DD in the foster care system early so they receive services while in care and appropriate planning to ensure a smooth transition out of foster care.

Recommendation 3.9: Improving Care for Children with Intellectual and Other Developmental Disabilities in the Foster Care System

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.

Transitions from Large Congregate Settings to Community Settings

When offered appropriate supports and services, people with I/DD, families, and advocates generally prefer smaller community settings to larger residential settings.[6] Research also shows that people with I/DD experience better outcomes in adaptive behavior, social participation, choice-making, self-determination, and functional behavior when living in the community with appropriate and necessary services, compared to when living in larger residential settings.

Approximately 10% of North Carolinians with I/DD live in state developmental centers or private ICFs-MR with more than 16 individuals. While this percentage is similar to the national average, North Carolina could be more proactive in helping individuals with I/DD move and live more independently in the community when that is what they and their family members desire. However, recent efforts to move people from the state developmental centers to the community have met with limited success. Some of the barriers include lack of community capacity, communication difficulties between state developmental centers and LMEs, insufficient planning time for local case managers to arrange appropriate community services and supports, payment systems that discourage community providers from accepting people who have more intensive needs, and the preference of some individuals or their families to remain in the larger residential settings.[7]

Despite these barriers, many states have been more successful than North Carolina in transitioning people out of developmental centers and ICFs-MR and into community settings.[8] These states have had strong leadership who have developed a comprehensive transition plan focusing on building community capacity rather than immediately closing facilities. As a starting point while North Carolina is developing community capacity to facilitate transitions, the Task Force recommended that any placements into state developmental centers or private ICFs-MR be reviewed prior to admission. The full text of the recommendation is in Chapter 4.

When offered appropriate supports and services, people with intellectual and other developmental disabilities, families, and advocates usually prefer smaller community settings to larger residential settings.

Recommendation 4.1: Review of Placements in State Developmental Centers and Large Intermediate Care Facilities for Persons with Mental Retardation

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.

Transitions for Older Adults with Intellectual and Other Developmental Disabilities (I/DD) and People with I/DD Living with Aging Caregivers

As the general population ages, so do individuals with I/DD and their caregivers. Although adults with I/DD still have slightly lower life expectancies than the general population, these individuals are living significantly longer now than than they would have just a few decades ago. Many adults with I/DD can now expect to live as long as the general population.[9,10]

A large number of individuals with I/DD now live with their parents or other adults. However, the ability of these individuals to provide the services and supports needed by family members with I/DD decreases as the caregiver grows older.[11,12] Many people with I/DD living with their parents or other caregivers, including siblings, may need to transition out of that environment due to the death or diminishing capacity of their caregivers. Older parents of adults with I/DD are likely to need professional help with planning for their adult children's future. Planning can be complex because of the diverse set of needs that must be addressed once the parent or other caregiver is no longer able to assist the person with I/DD. The goal is to ensure that the individual and family have plans for how the financial, residential, security, medical, supports, legal, and social needs of the individual with I/DD will be met as the parent or caregiver ages or is no longer able to provide support.

Many people with intellectual and other developmental disabilities living with their parents or other caregivers, including siblings, may need to transition out of that environment due to the death or diminishing capacity of their caregivers.

In addition, some families have never been connected to the developmental disability system and may not know where to seek help. Thus, the state needs to do a better job in providing outreach to families of individuals with I/DD to provide them with information about available services and supports and to link older adults with I/DD into the aging network.

The Task Force recommended that the state help families develop plans for when parents or caregivers can no longer provide services and supports to the people with I/DD. In addition, the Task Force recommended instituting specific outreach efforts to reach families that have never been connected into the developmental disability system. A summary of the recommendations are listed below. The full recommendations are listed in Chapter 5.

Recommendation 5.1: Future Planning for Families that Provide Support to People with Intellectual and Other Developmental Disabilities

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. 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.

Recommendation 5.2: Outreach to Older Adults Who are Providing Support to People with Intellectual and Other Developmental Disabilities (I/DD) and Linkages into the Aging System for Older Adults with I/DD

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.

Cross-Cutting Issues

While there are unique challenges that people with I/DD face with specific transitions, some challenges are the same regardless of the cause of the underlying transition. People with I/DD need access to a comprehensive array of services and supports to help them during transitions. Leadership at the state and local level needs to be coupled with appropriate and flexible financing, case management services, and community capacity (e.g. housing, assistive technology, and supported employment) to ensure that there are sufficient services and supports to address the needs of these individuals. Additionally, North Carolina must ensure an adequate supply of well-qualified direct support workers and other professionals who demonstrate the competencies and person-centered values necessary to support people with I/DD in securing the quality of life that communities afford other people.

Leadership: One of the most critical factors needed to ensure successful transitions is professional leadership, with expertise specific to I/DD, at both the state and local levels. State leaders need to bring together people with I/DD, their families, service providers, and other stakeholders to develop a statewide transition plan that includes policies and practices to facilitate transitions. Leaders at the local level need to establish linkages with appropriate agencies and service providers to facilitate successful transitions, identify gaps in services and supports, and build community capacity. Aside from state and local developmental disability leadership, successful transitions are contingent on having community capacity to address the needs of people with I/DD. However, it is 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. North Carolina needs to institute 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 following is a summary of the Task Force's cross-cutting recommendations dealing with leadership and state data needs. The full set of recommendations is included in Chapter 6.

Recommendation 6.1: Statewide Transition Plan (PRIORITY RECOMMENDATION)

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, 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.

Recommendation 6.2: Transition Expertise at the State and Local Level (PRIORITY RECOMMENDATION)

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.

Recommendation 6.3: Enhanced Data Collection (PRIORITY RECOMMENDATION)

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.

Financing Community-Based Services and Supports: While leadership is critical, it is not sufficient to ensure successful transitions. One of the biggest challenges North Carolina faces is how to use its limited resources in the most equitable way possible. This is always an important consideration, but especially so during tight fiscal years. People with I/DD with similar functional abilities and concomitant needs for support often receive different levels of funding. 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, establish appropriate provider payments and identify overall system needs. North Carolina has already begun to test the use of the Supports Intensity Scale™ (SIS) to assess the support needs of people with I/DD. More work is needed to use data from assessment instruments to make more rational and equitable resource allocations.

One of the biggest challenges North Carolina faces is how to use its limited resources in the most equitable way possible.

Once the state develops a system that supports individual resource allocations, it can more easily move to consumer-directed budgeting. North Carolinians with I/DD are less likely to be involved in decision making about their lives than are people with I/DD in many other states. Consumer-directed budgeting helps support individual self-determination by giving consumers a certain budget and letting them decide what services and supports they want to purchase within this budget. North Carolina is beginning to test this model by offering the option to individuals who are part of the North Carolina Supports Waiver (a Medicaid home and community-based waiver program for individuals who are eligible for ICF-MR level of care, but who only need a limited amount of services). Other individuals with I/DD with more significant needs should also be given the opportunity for self-directed budgets.

One of the other problems the Task Force identified was the lack of flexible funding to assist people in their transitions. Often, individuals who are transitioning from a state developmental center or private ICF-MR to more independent living in the community need funding to help with one-time expenses, such as, but not limited to, security deposits or utility set up fees, household furnishings, moving expenses, or assistive technology.[13] LMEs may also need flexible funding to pay for services or supports that are not otherwise covered through existing funding streams.

The following is a summary of the Task Force's cross-cutting recommendations addressing financing and equitable distribution of resources. The full set of recommendations in included in Chapter 6.

Recommendation 6.4: Use of a Standardized Assessment Instrument (PRIORITY RECOMMENDATION)

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.

Recommendation 6.5: Consumer-Directed Supports

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 should systematically move to expand consumer-directed budgeting to other people with intellectual and other developmental disabilities who have more significant needs.

Recommendation 6.6: Flexible Funding

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.

Case Management: Case managers play a central role in working with an individual with I/DD and his or her family to ensure that the needs of the person are being met. Case managers must be 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. Just as good case managers can provide assistance to individuals to help them obtain the services and supports needed to optimize independent living, work opportunities, and community engagement, bad case managers can serve as obstacles to the individual and his/her family. Case managers must be properly trained, demonstrate core competencies, and have reasonable case loads to ensure effective case management services.

Both Medicaid and the state help pay for case management services. The federal Medicaid law allows states to pay for Targeted Case Management (TCM) services for people with I/DD who are transitioning out of state developmental centers. While federal law allows for 180 days of coverage, North Carolina has elected to pay for up to 60 days under the state Medicaid plan for both individuals receiving funding from the Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities (CAP-MR/DD) and for those who are on the traditional Medicaid program. This limited coverage makes it difficult to develop and implement transition plans for people leaving public and private ICFs-MR.

The following is a summary of the Task Force's recommendation to improve case management services:

Recommendation 6.7: Improving the Quality of Case Management Services (PRIORITY RECOMMENDATION)

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.

Community capacity: Individuals with I/DD need access to appropriate services and supports to help them live as independently as possible in the community. The range of necessary services and supports will vary, depending on the strengths and outstanding needs and preferences of each individual as well as any available natural supports. The needs for specific services and supports will also vary depending on whether a person is transitioning from one life setting to another or whether the person is in a stable living environment.

Crisis services can be particularly important during transitions. Last legislative Session (2008), the North Carolina General Assembly appropriated funding to implement Systemic, Therapeutic Assessment, Respite and Treatment (START) crisis services. NC START was developed in response to the problem of inappropriate admissions of people with I/DD to the state psychiatric hospitals. The START program provides community-based crisis prevention and intervention services to adults with I/DD and co-occurring mental illness and/or behavioral health needs. Further expansion of these services for adults and creation of similar crisis services for children is needed.

In addition to crisis services, people with I/DD need access to appropriate, affordable, and accessible housing. People with I/DD should have the opportunity to live in housing, integrated into the community, which promotes their maximum independence. They should have a choice in where they live and with whom they live. One of the barriers that prevents people from leaving state developmental centers or private ICFs-MR and moving into the community is the lack of appropriate housing options. Similarly, people who either need or want to transition from their family home need appropriate housing options. Even when housing is or could be made available, many people with I/DD will need some residential supports to help them live independently. Further, because so many people with I/DD have low incomes, they may also need help paying for their housing. Some of the existing governmental funds that can be used to pay for room and board have a distinctive institutional bias. For example, Medicaid will pay for room and board for individuals living in state developmental centers or private ICFs-MR as part of the person's active treatment, but will not pay for room and board for people who are receiving CAP-MR/DD waiver services. Through the State County Special Assistance program, the state pays more for individuals who live in licensed assisted living or developmental disability group homes than they do for a person living in their own home or with host families.

People with intellectual and other developmental disabilities should have the opportunity to live in housing, integrated into the community, which promotes their maximum independence.

Some people with I/DD also need assistive technology (AT), such as ambulatory aids, speech generating devices, educational software, and modified vehicles to increase their independence. Additional funds are needed to support the purchase of AT for people who do not have access to other funding.

Additionally, some adults with I/DD may need job coaches, assistive technology, or other supports to help them obtain and retain a job in an integrated community setting. The Division of Vocational Rehabilitation (DVR) within the North Carolina Department of Health and Human Services is the lead agency that helps people with disabilities obtain jobs. DVR provides supportive employment services to people with more significant disabilities (including I/DD) who need more intensive support services to help them transition into competitive employment. As part of supported employment, DVR funds can be used to provide job trainers for more intensive job skill training, social skills training, regular observation or supervision of the individual, facilitation of natural supports at the workplace, and regular follow-up with employers, the family, the person with I/DD, or others to stabilize the job placement. DVR's involvement ends once the individual, his or her employer, the counselor, and/or job coach agree that the person is performing his or her job successfully; however, some individuals with I/DD may need longer term employment supports to help them maintain their employment. Medicaid CAP-MR/DD and state funds are needed to provide longer-term support services; however, LMEs do not always help individuals with I/DD access these services.

Many people with I/DD also experience barriers that prevent them from accessing needed health services. People with I/DD, their families, and advocates report shortages of health care professionals who are willing to treat patients with I/DD.[14] The reasons for this are many and varied, ranging from communication difficulties to lack of training and experience, poor patient compliance with treatment plans, and unwillingness of some providers to accept Medicaid, under which many individuals with I/DD are covered.[15,16] Few health care professionals receive the training that prepares them to address some of the special needs of people with developmental disabilities, particularly those with significant intellectual disabilities.[14] Further, many people with I/DD have problems coordinating the health services they receive from multiple health care providers.[17] The Task Force recommended that providers receive better training to address the needs of people with I/DD.

People with intellectual and other developmental disabilities (I/DD), their families, and advocates report shortages of health care professionals who are willing to treat patients with I/DD.

One promising way to improve medical services provided to people with I/DD would be to develop a pilot program through North Carolina's Medicaid program to better manage the health care services provided to this population. Community Care of North Carolina (CCNC) was designed to provide care and disease management services to Medicaid recipients with complex or costly health conditions. The Task Force believes that more can be done to build on the state's successful CCNC model and expand access to care for Medicaid recipients with I/DD.

The following is a summary of the Task Force's cross-cutting recommendations aimed at building community capacity to support transitions. The full set of recommendations is included in Chapter 6.

Recommendation 6.8: Expansion of Crisis Services

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.

Recommendation 6.9: Expanding Housing Options for People with Intellectual and Other Developmental Disabilities

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.

Recommendation 6.10: Expanding the Availability of Shared Living and Alternative Family Arrangements

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.

Recommendation 6.11: Persons in Assisted Living

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.

Recommendation 6.12: State County Special Assistance

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.

Recommendation 6.13: Employment First (PRIORITY RECOMMENDATION)

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.

Recommendation 6.14: Training Health Professionals

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, and 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.

Recommendation 6.15: Expanding Access to Health and Dental Services and Developing a Community Care of North Carolina Pilot Initiative for People with Intellectual and Other Developmental Disabilities

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, behavioral, or other 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 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.

Direct Support Workers: Successful transitions are often dependent on having a well-qualified workforce that can provide the supports and services needed to help people with I/DD live, learn, work, play, socialize, and retire in the community. Aside from the person's family, direct support workers (DSW) are the people who provide most of the day-to-day support for individuals with I/DD. In addition to providing direct services and supports, DSWs often facilitate connections to the greater community. They must have an understanding of I/DD, the developmental disability system, and the services and supports in the community that can assist individuals with I/DD to lead full lives.

In North Carolina, there is not a state-approved training curriculum. Instead, training is typically provided on the job. DSWs in most employment settings are not required to pass an approved competency exam, nor are they required to be certified or have other credentials. In contrast, nurse aides who work in nursing facilities, hospitals, or home health agencies and have similar job responsibilities[h] are required to attend at least 75 hours of training in a state-approved educational curriculum, demonstrate certain core competencies by passing a state-approved examination, and be registered on the nurse aide registry before being able to work.[i] The Task Force recommended that more is needed to improve the skills and retention of DSWs.

The following is a summary of the Task Force's recommendation aimed at improving the competencies and retention of DSWs. The full recommendation is in Chapter 6:

Recommendation 6.16: Improving the Skills, Competencies, and Retention of Direct Support Workers (PRIORITY RECOMMENDATION)

The Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) should work with Local Management Entities, agencies that employ direct support workers (DSWs), the North Carolina Direct Care Workers Association, and other appropriate organizations to develop and implement a plan to improve the competencies and skills of 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.

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[h] These staff serve many of the same functions as many people who serve as direct support workers, including bathing, transferring people, feeding, and helping individuals with their toileting needs.

[i] 21 NCAC 36.0403(a); CFR 483.75, 483.150-154; https://www.ncnar.org/faq.html. The training must be at least 75 hours. https://www.ncnar.org/verify_listings1.jsp.

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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.

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Intellectual and Other Developmental Disabilities

The federal definition of a developmental disability (DD), a definition inclusive of an intellectual disability,[a] 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.[b] Individuals with intellectual and other developmental disabilities (I/DD) have substantial functional limitations in three or more of the following areas:

- Self-care
- Receptive and expressive language
- Learning
- Mobility
- Self-direction
- The capacity for independent living
- Economic self-sufficiency[b]

The definition of I/DD in North Carolina is similar, but not identical, to the federal definition, and allows for the manifestation of disability after the age of 22, if a person experiences traumatic head injury.[c]

I/DD typically involves impairments in the functioning of the brain, spinal cord, and nervous system, which manifest as impairments of learning, speech, and intellect, as well as behavioral and movement disorders. Conditions include, but are not limited to, intellectual disability, autism spectrum disorders, cerebral palsy, Fragile X syndrome, and Down syndrome.[d] It should be noted that many types of I/DD affect multiple body systems. Levels of I/DD range from mild to profound and require a variety of services and supports.

Intellectual and other developmental disabilities typically involve impairments in the functioning of the brain, spinal cord, and nervous system, which manifest as impairments of learning, speech, and intellect, as well as behavioral and movement disorders.

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[a] The authoritative definition of intellectual disability (mental retardation) is that of the American Association on Intellectual and Developmental Disabilities (formerly American Association on Mental Retardation). That definition, substituting intellectual disability for mental retardation, is as follows: "Intellectual disability is characterized by significant limitations in both intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18." (Definition of intellectual disability. American Association on Intellectual and Developmental Disabilities website. http://www.aamr.org/content_100.cfm. Accessed April 1, 2009.)

[b] 42 U.S.C. §6000 et, seq.

[c] NCGS §122C-3(12a)

[d] It is possible to have some of these conditions, such as cerebral palsy or autism spectrum disorder, and not meet the developmental disability definition. Most, but not all people with developmental disability have an intellectual disability.

Causes

I/DDs have a multitude of causes, both genetic and environmental, and can occur before, during, or after birth. Genetic mutations, inherited traits, changes in the number or structure of chromosomes, and other genetic factors can cause disabilities such as Down syndrome, Fragile X syndrome, and phenylketonuria. Environmental factors including infections (e.g. rubella or meningitis), trauma (e.g. stroke or head injury), diet, or exposure to toxic elements, alcohol, or drugs—both prenatally and after birth—can also cause I/DD. However, for many with I/DD, a specific and definite cause cannot be identified.[1]

Prevalence

In 2006, there were approximately 4.7 million children and adults with I/DD in the United States, nearly 1.5% of the total population.[2,3] While precise state level data are not available, it has been estimated that there are more than 100,000 people with I/DD in North Carolina.[4] In 2007, the Division of Mental Health, Developmental Disabilities and Substance Abuse Services estimated that approximately 50,000 adults and 53,700 children were in need of community I/DD services in North Carolina.[5] In general, mild disabilities are the most prevalent, followed by moderate disabilities. Only a small proportion of individuals with I/DD have more profound disabilities.

Intellectual and other developmental disabilities are life-long conditions and thus require ongoing services.

Services and Supports For Individuals with Intellectual and Other Developmental Disabilities

I/DDs are life-long conditions and thus require ongoing services. The services and supports that individuals with I/DD need can vary considerably, depending on the person, the type and severity of the disability, the availability of natural supports (including family or community supports), the person's preferences, availability of assistive technology, or for other reasons. In addition to regular medical and dental care, people with I/DD may also need more specialized medical, mental health, or home health services. They may also require assistive technology, educational supports, rehabilitative services, vocational services, assistance in securing housing, and/or social and environmental adaptive services.[6] The type of services that a person receives depends on the needs and preferences of the person, as determined in the person-centered planning process (discussed more fully in Chapter 6).

Services and supports for people with I/DD are overseen by the North Carolina Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS), the Division of Health Services Regulation, the Division of Medical Assistance, and/or Local Management Entities, depending on the type of service. In 2006, North Carolina spent over $1.2 billion on services for people with I/DD, with 53% ($643.2 million) of the funding coming from the federal government, 41% ($493.7 million) from the state,[e] and 6% ($67.4 million) from local sources.[2] Medicaid is the largest source of funding for the I/DD service

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[e] State funding includes state Medicaid matching funds, state augmentation of federal Supplemental Security Income (SSI) payments, and other state funds.

system in North Carolina, supplying 77% of total funding in 2006. (This includes both federal and state Medicaid funding.)[2] Medicaid helps pay for targeted case management, state developmental centers, Intermediate Care Facilities for Persons with Mental Retardation (ICFs-MR), and the Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities (CAP-MR/DD) Waiver. Medicaid also helps pay for other health-related costs for individuals who otherwise meet the eligibility requirements for the Medicaid program as well as nursing home costs for some. Non-Medicaid state funds are used to provide services and supports to people with I/DD who do not qualify for Medicaid. Non-Medicaid state funds can also be used to supplement services provided to Medicaid recipients (for example, to provide coverage for services not otherwise covered through Medicaid or the CAP-MR/DD program). State funds can be used to pay for respite services, personal care, supported employment, long-term support, residential services, developmental therapy, and vocational programs.[7]

Medicaid is the largest source of funding for the intellectual and other developmental disabilities service system in North Carolina, supplying 77% of total funding in 2006.

Medicaid services

Targeted case management

Targeted case management is a set of services, provided by a case manager, which includes assessments and assisting an individual with I/DD in developing his or her Person Centered Plan (PCP). Case managers help link the person to appropriate medical, social, educational, or other services and supports identified in the PCP. Case managers also monitor services and supports and provide follow-up to ensure effective implementation of the PCP. Case managers serve a key role in the coordination of services and supports and must be independent from agencies which provide the services needed by the individual.[8] The PCP is discussed more fully in Chapter 6.

State developmental centers

State-run developmental centers in North Carolina provide comprehensive, long-term residential services to individuals with significant intellectual or physical disabilities who have complex behavioral or medical challenges.[9] Services and supports in state developmental centers are all inclusive. They include room and board; various therapies including educational, dental, physical, communication, and occupational therapy; vocational and recreational services; psychological, medical, and other professional services; and other services and supports. State developmental centers are ICF-MR certified (as described below in the section on ICFs-MR) and are also referred to as public ICFs-MR. There are currently three named developmental centers in North Carolina.[f,g]

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[f] The three state facilities are J. Iverson Riddle Developmental Center (Morganton, NC), Murdoch Developmental Center (Butner, NC), and Caswell Developmental Center (Kinston, NC).

[g] Beginning in 2006, O'Berry Developmental Center was renamed O'Berry Neuro-Medical Treatment Center and has begun a several year conversion to a skilled nursing facility. O'Berry is still Intermediate Care Facility for Persons with Mental Retardation (ICF-MR) certified and continues to care for individuals with intellectual and other developmental disabilities. As such, the center continues to receive Medicaid ICF-MR funding. However, O'Berry no longer admits individuals who would be accepted to state developmental centers. Instead, O'Berry accepts individuals who need highly specialized residential services, targeting individuals with specific co-existing conditions whose needs exceed the level of care provided in traditional community placements.

Private Intermediate Care Facilities for Persons with Mental Retardation (ICFs-MR)

Intermediate Care Facilities for Persons with Mental Retardation (ICFs-MR) are licensed long-term care residential facilities that have four or more beds and function primarily as comprehensive residential, case management, and active treatment centers for the service and support of people with I/DD.[h] In order for an individual to be certified as needing an ICF-MR level of care, the person must be diagnosed as having an I/DD and must require active treatment necessitating that level of care.[i] Professionals at Murdoch Center review admission requests to determine if the person needs ICF-MR level of care. ICFs-MR provide a protected residential setting, ongoing evaluation, planning, 24-hour supervision, coordination, and integration of health and rehabilitative services.[10] The majority of individuals with I/DD living in private ICFs-MR reside in a small ICF-MR with six or fewer residents. In 2006, 3,759 individuals lived in private ICFs-MR in North Carolina; over three-fourths of individuals (77%) lived in a small private ICF-MR, and 23% lived in a large private ICF-MR (with more than six residents). Services include all medical, dental, crisis, service coordination, and work, educational, and recreational support programs in addition to residential and active treatment support.

In order for an individual to be certified as needing an Intermediate Care Facility for Persons with Mental Retardation level of care, the person must be diagnosed as having an intellectual and/or other developmental disability and must require active treatment necessitating that level of care.

Community Alternatives Program for Persons with Mental Retardation/ Developmental Disabilities (CAP-MR/DD)

The Community Alternatives Program for Persons with Mental Retardation/ Developmental Disabilities (CAP-MR/DD) is a home and community-based Medicaid waiver program serving individuals with I/DD who have a disability that would otherwise make them eligible to receive care in an ICF-MR (as described above).[j] The program allows these individuals to be served in the community instead of in a developmental center or private ICF-MR so long as the Medicaid cost of services and supports in the community is cost-effective in comparison to ICF-MR services and supports.

The CAP-MR/DD program provides home and community-based services, home supports, personal care services, residential supports, supported employment, day supports, adult day health, respite services, training and education for the individual and his or her family, augmentative communication devices, home modifications, long-term vocation support, crisis respite, behavioral consultation, and specialized equipment and vehicle modifications. However, the waiver does not cover room and board or medical, dental, or therapy services. People who receive CAP-MR/DD also receive regular Medicaid to pay for medical, dental, therapy, and other health-related services. In addition, some individuals who receive CAP-MR/DD can also receive state funds to help pay for services and supports not covered through the waiver.[11]

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[h] 42 CFR §435.1009.

[i] Active treatment refers to aggressive, consistent implementation of specialized and habilitative training, treatment, and health services.

[j] Some individuals who do not meet the more stringent financial eligibility requirements of regular Medicaid are eligible for the Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities due to the different income eligibility rules.

Unlike traditional Medicaid that pays for ICFs-MR and health-related services, the CAP-MR/DD waiver is *not* an entitlement program. The number of CAP-MR/DD "slots" is limited based on the number approved by the US Centers for Medicare and Medicaid Services (CMS) and the amount of funding the North Carolina General Assembly appropriates to support this program. As a result, people who may qualify for these services can be put on a waiting list or denied coverage for needed services. Because the state does not maintain a statewide waiting list for services, there is no way of knowing how many people are currently eligible for, but not receiving, CAP-MR/DD services. Many of the individuals potentially eligible for but not receiving CAP-MR/DD services are receiving state-funded services (see below) paid for through 100% state dollars. In January 2009, there were 10,130 people receiving CAP-MR/DD services.[k] Of these, 9,893 individuals with I/DD were eligible for the comprehensive CAP-MR/DD waiver and 237 were receiving the more limited supports waiver (which provides up to $17,500/year in coverage).[l]

Unlike traditional Medicaid... the Community Alternatives Program for Persons with Mental Retardation/ Developmental Disabilities is *not* an entitlement program…As a result, people who may qualify for these services can be put on a waiting list or denied coverage for needed services.

Other Medicaid Community Alternatives Program Waivers

Some individuals (age 18 and older) may also receive community services and supports through the Community Alternatives Program for Disabled Adults (CAP-DA), as the number of CAP-MR/DD slots is so limited. CAP-DA is available to people who would otherwise need services in a skilled nursing facility. North Carolina has more slots for CAP-DA than for CAP-MR/DD. In addition, medically fragile children who would otherwise need services in a hospital may receive services and supports from the Community Alternatives Program for Children (CAP-C). However, an individual may only receive services and funding from one waiver program at a time.

State-funded services

State-funded services are available to several groups of people:

- Individuals who have needs that meet the CAP-MR/DD level, but due to limited funding (and limited slots), cannot qualify for CAP-MR/DD funds and are not able to enroll.
- Individuals with I/DD who have less significant needs and do not meet the level of need necessary to qualify for CAP-MR/DD.
- Individuals with I/DD who are ineligible for Medicaid or CAP-MR/DD.[m]
- Individuals who have had a traumatic brain injury after age 22.

State funds pay for I/DD case management (for individuals not eligible for Medicaid), comprehensive clinical assessments, respite care, personal care services,

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[k] Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities slots are generally allocated to Local Management Entities on a per capita basis.

[l] Burnette R. Waiver Project Manager, Division of Mental Health, Developmental Disabilities, and Substance Abuse Services, North Carolina Department of Health and Human Services. Written (email) communication. March 3, 2009.

[m] Some individuals who do not meet the more stringent financial eligibility requirements of regular Medicaid are eligible for the Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities due to the different income eligibility rules.

supported employment, long-term vocational support, adult day vocational programs, and developmental therapy. In many ways, these services are similar to what is offered to other individuals with I/DD through the CAP-MR/DD program. Unlike CAP-MR/DD funds, state funds can be used to pay for an individual's room and board, as well as services and supports offered to individuals in a family living arrangement (typically provided to someone who lives in someone else's home), supervised living in an apartment setting, supervised living in a residence (with one to six individuals), or group living arrangements (with five or more individuals).

Financing Services and Supports

The primary sources of non-public school public funding for people with I/DD comes from Medicaid and state DMHDDSAS funds. People with I/DD who receive financial support from one or both of these sources can be roughly categorized as falling into one of five groups (although a person could move from one group to another during the year). These groups include: 1) people who reside in state developmental centers, 2) people who reside in private ICFs-MR, 3) people who are living in the community and receive CAP-MR/DD, 4) people living in the community who qualify for Medicaid, but do not receive CAP-MR/DD, or 5) those individuals who reside in the community and are not eligible for Medicaid services.

In 2008, the state developmental centers served approximately 1,600 people for a total cost of $239 million, or an average of $156,000 per person.

State developmental centers

People residing in state developmental centers are typically older than those living in private ICFs-MR or in the community. The average age of individuals residing in state developmental centers is 51, compared to 38 for individuals residing in private ICFs-MR and 27 for individuals receiving CAP-MR/DD waiver services.[n,12] In addition, Medicaid pays state developmental centers an all inclusive rate that covers *all* of the costs an individual may incur, including room and board; educational, vocational and recreational services; medical, dental, psychological, therapy and other professional services; medication; assistive technology; hospitalization and other services and supports. In 2008, the state developmental centers served approximately 1,600 people for a total cost of $239 million, or an average of $156,000 per person.[o,13]

Private Intermediate Care Facilities for Persons with Mental Retardation

People who reside in private ICFs-MR also rely on Medicaid to pay for their cost of services and supports. Services in the ICFs-MR include room and board and

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[n] State developmental centers closed their general admission to children in 1995, thus there are very few children residing in state developmental centers (the only children being admitted are admitted into short-term special programs). As a result, there is a high concentration of older adults in state developmental centers. Whereas 70% of people who reside in state developmental centers are 45 years or *older*, almost 70% of those residing in private Intermediate Care Facilities for Persons with Mental Retardation (ICF-MR) are 46 or *younger*, and 70% of those receiving Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities services are 33 or *younger*. (Holtzman A. Division of Mental Health, Developmental Disabilities and Substance Abuse Services, North Carolina Department of Health and Human Services. Special data run: age of individuals residing in different residential settings in North Carolina. March 17, 2009.)

[o] This number includes individuals residing at O'Berry Neuro-Medical Treatment Center, as it is still ICF-MR certified. They are included because Medicaid continues to pay the ICF-MR rate.

most other services and supports. However, Medicaid pays providers separately for the medical, dental, psychological, and other health services provided to people in the ICFs-MR. In 2008, there were approximately 2,600 people living in private ICFs-MR receiving Medicaid.[12] The Medicaid cost, including payments to ICFs-MR plus all other health care providers, was approximately $244 million, or an average of $94,000 per person.[13]

Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities

As noted earlier, people who qualify for CAP-MR/DD must need ICF-MR level of care. However, CAP-MR/DD only pays for waiver services for people living in the community. It does not cover room and board, medical care, or related health and therapy services. Medicaid pays separately for the costs of health care services. People who receive CAP-MR/DD can also receive state funds to help pay for other services and supports not covered through the waiver. In CY 2008, there were approximately 10,000 people who received Medicaid CAP-MR/DD services for all or part of the year. Of these, a little more than 1,700 people also received some funding through state DMHDDSAS funds. In total, the cost (including CAP-MR/DD, Medicaid payments to other providers not covered as part of the waiver services, and state DMHDDSAS funds) was approximately $560 million (annualized). The average cost per person was approximately $60,000 per year.[p,13]

People who do not receive Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities but who do receive Medicaid

There are many other people who have I/DD who receive Medicaid to help pay for their health care services but who do not receive CAP-MR/DD. DMHDDSAS may also help pay for services and supports not covered by Medicaid. Some of these individuals may have needs that would meet the CAP-MR/DD level. However, because of limited funding (and limited slots), some people who could qualify for CAP-MR/DD funds are not able to enroll. Other individuals in North Carolina with I/DD have less significant needs and do not meet the level of need necessary to qualify for CAP-MR/DD.[q] The state does not have a good system of capturing all of the costs paid on behalf of these individuals. The state can identify costs paid for I/DD-related services or when the provider identifies the individual as

In CY 2008, there were approximately 10,000 people who received Medicaid Community Alternatives Program for Persons with Mental Retardation/ Developmental Disabilities services for all or part of the year. Of these, a little more than 1,700 people also received some funding through state DMHDDSAS funds. In total, the cost…was approximately $560 million…[or] $60,000 per year.

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[p] In SFY 2008, the total Medicaid costs for people who received the Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities (CAP-MR/DD) for the full 12 months ranged from about $8,000-$430,000. This includes the costs of CAP-MR/DD plus other Medicaid costs. Most people in this group received services in the range of approximately $40,000-$71,000/year. (Holtzman A. Division of Mental Health, Developmental Disabilities and Substance Abuse Services, North Carolina Department of Health and Human Services. Special data run: costs of different residential settings in North Carolina. March 18, 2009.)

[q] Other states have set broader eligibility criteria for their home and community-based waiver (e.g. CAP-MR/DD) so that more people with intellectual and other developmental disabilities can qualify for waiver services in the community without also increasing the number of people who seek residential services in a state developmental center or private Intermediate Care Facility for Persons with Mental Retardation (ICF-MR). (Thaler N. Overview and national outlook. Presented to: North Carolina Institute of Medicine Task Force on Transitions for People with Developmental Disabilities; January 21, 2009; Morrisville, NC.)

having a diagnosis of I/DD.[r] However, other health services—such as dental, pharmacy, or most medical services—will not be captured through this mechanism. Given these limitations in the existing data, DMHDDSAS was able to identify almost 17,000 people with I/DD who received Medicaid-funded services only (e.g. these were individuals who were not residing in a public or private ICFs-MR or receiving CAP-MR/DD services). The state and federal government paid approximately $120 million, for an average cost of approximately $7,300 per person. During the same year, there were almost 5,600 people who received both Medicaid and DMHDDSAS financial support. The total cost paid on their behalf was $108 million, or approximately $19,400 per person.

Non-Medicaid eligible individuals

There were also a little more than 8,000 people with I/DD who only received support through the state DMHDDSAS funds. The state paid almost $36 million for an average cost of $8,100 per person.[13]

The amount of funding provided to support individuals in different settings varies considerably, with those in the public developmental centers receiving the greatest amount of support.

As these data show, the amount of funding provided to support individuals in different settings varies considerably, with those in the public developmental centers receiving the greatest amount of support. This is due, in large part, to the services provided in different settings. This may also be due to differences in the intensity of the individuals' support needs in different settings, although the state lacks good assessment data to know whether such differences exist (see Chapter 6). However, residents of developmental centers are typically older and may require greater intensity of services and supports than those in private ICFs-MR or the CAP-MR/DD program. National research that has tried to control for some of these differences found that the average cost of care in ICFs-MR was higher than the cost under the waiver. After controlling for multiple factors, the difference between average costs for ICF-MR recipients and waiver recipients was cut by more than half, from approximately $60,000 to approximately $25,000; in other words, accounting for differences in the people receiving services decreases the expenditure gap by roughly 50%, but ICFs-MR remain considerably more expensive.[14]

Services and supports provided by other agencies

DMHDDSAS helps manage and oversee and, along with DMA, helps finance most of the services and supports provided to people with I/DD. However, other agencies are also involved in financing and providing services and supports to these individuals. For example, the public school system provides supports to help children with disabilities, including I/DD, to succeed in school. The North

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[r] In developing the cost estimates for individuals who were receiving Medicaid but not living in a state developmental center, private Intermediate Care Facilities for Persons with Mental Retardation, or receiving Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities services, Division of Mental Health, Developmental Disabilities and Substance Abuse Services included the Medicaid costs for services provided directly by Local Management Entities (LMEs), child residential providers, mental health professionals, enhanced service providers (such as community support), psychiatric residential treatment facilities, state and private psychiatric hospitals, general hospitals (for behavioral health claims), emergency room, or physician services. The medical costs were only included if the provider listed a behavioral health diagnosis code among the first five reported. This excludes most of the medical services, pharmacy, personal care, dental, and other services when the provider did not list behavioral health issues as one of the top five diagnosis codes.

Carolina Community College System offers compensatory education and Adult Basic Education to some individuals with I/DD. People with I/DD also receive employment supports or help with independent living through the Division of Vocational Rehabilitation. In addition, people with I/DD may also receive financial support from either Social Security Disability Income or Supplemental Security Income (SSI).

Department of Public Instruction

Children born with I/DD, those at risk for I/DD, and children experiencing developmental delay are all eligible for early intervention services offered through the Individuals with Disabilities Education Act (IDEA). Early intervention services are available to eligible children from birth through age five.[s] The establishment of early interventions and the improvement in clinical care has led to increases in life-expectancy and better quality of life for individuals with I/DD.[15] Children from birth to age three, and their families, receive an Individualized Family Service Plan (IFSP). Children ages 3-21 with I/DD are eligible for an Individualized Education Program (IEP), which identifies the services and supports needed to help the child succeed in school. Children who are transitioning to adulthood are eligible for additional services depending on their disability. For example, IDEA requires that each child with an IEP receive a transition plan before leaving secondary school (transition planning should start at age 14).[5]

Children born with intellectual and other developmental disabilities, those at risk for intellectual and other developmental disabilities, and children experiencing developmental delay are all eligible for early intervention services offered through the Individuals with Disabilities Education Act.

North Carolina Community College System

Individuals with intellectual disabilities or traumatic brain injuries are eligible for compensatory education through the community college system. Depending on an individual's functioning level they may also be eligible for Basic Skills or curriculum courses through the community college system. There are very few postsecondary education opportunities for people with I/DD in the university system.

Division of Vocational Rehabilitation

Some individuals with I/DD are served by the Division of Vocational Rehabilitation (DVR), within in the North Carolina Department of Health and Human Services. DVR offers services to help people gain jobs skills and employment and to help people live independently.

Social Security Administration

Many individuals with I/DD receive Supplemental Security Income payments (SSI) or Social Security Disability Income. These payments help provide financial support to enable the person to meet basic subsistence needs. People with I/DD who receive SSI benefits are eligible to participate in SSI work incentive programs.

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[s] More information on the early intervention program can be found at http://www.ncei.org/ei/index.html.

Other Services and Supports

Adults with I/DD may be eligible for other services as well. Some adults with I/DD may qualify for help with housing through State County Special Assistance or special programs offered through the North Carolina Housing Finance Agency. In addition, older adults with I/DD may qualify for services through the Division of Aging and Adult Services, within the North Carolina Department of Health and Human Services.

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Transitions From School to Postsecondary or Community Settings

Chapter 3

Schools play an important role in helping all youth acquire the skills and knowledge needed to be successful as adults. This is particularly true for individuals with intellectual and other developmental disabilities, who may face additional challenges transitioning from childhood to adulthood.

Overview

The legislative charge to the Task Force was to examine transitions, including transitions from secondary school to adult life. Thus, the Task Force focused its analysis on school transitions, not issues about the adequacy of elementary and secondary school for children with intellectual and other developmental disabilities (I/DD). In general, students need a high school degree to be competitive for work or eligible for postsecondary education. While the goal of the North Carolina public school system is to ensure that every student graduates from high school "globally competitive for work and postsecondary education and prepared for life in the 21st Century," only 49.4% of students with disabilities graduate from high school with a diploma.[a,1,2] By this definition, 50% of students with disabilities are not prepared for competitive work or postsecondary education. Even those who do graduate may have trouble transitioning from secondary school to postsecondary education or community settings.

Schools play an important role in helping all youth acquire the skills and knowledge needed to be successful as adults. This is particularly true for individuals with I/DD, who may face additional challenges transitioning from childhood to adulthood. According to the Individuals with Disabilities Education Act (IDEA), all students with disabilities are required to have an Individualized Education Program (IEP) to help ensure they receive the individualized attention and supports to succeed in school. Even though students with disabilities have IEPs, many still lack the supports necessary to successfully complete high school. Through the adaptation of research-based interventions shown to improve outcomes for students with disabilities, improved professional development, greater use of assistive technologies, and better planning and coordination of transition plans for students with disabilities, North Carolina public schools can help ensure that students with disabilities graduate high school and are prepared for competitive work and postsecondary education.

Individuals with I/DD who graduate or age out of secondary school need linkages to postsecondary schools, vocational rehabilitation, and Local Management Entities (LMEs) to ensure they become active participants in the community. Currently there are very few postsecondary education options designed specifically for individuals with I/DD. North Carolina's community college and university systems need to improve the current system to better meet the needs of individuals with disabilities. Doing so will ensure that individuals with I/DD have access to the kinds of postsecondary training and education needed to join or advance within a competitive workforce. Transitions from secondary education to the workplace and community are discussed in Chapter 6.

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[a] Unless otherwise stated, "children with disabilities" in this chapter refers to all children with disabilities, regardless of the type of disability. The federal government recognizes 13 categories under which a child may qualify for special education including autism, deaf-blindness, deafness, emotional disability, hearing impairment, cognitive disability, multiple disabilities, orthopedic impairment, other health impairment, speech or language impairment, traumatic brain injury, and visual impairment.

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 traditional kinds of support—family, caring adults, mentors—that other youth have to help them through periods of transition. If identified early, children with I/DD in the foster care system can be connected to services and supports that can help them successfully transition from foster care into the community. Therefore, it is important to identify children with I/DD in the foster care system early so they receive services while in the system, and appropriate planning can ensure a smooth transition out of foster care.

Elementary and Secondary Schools

The Individuals with Disabilities Education Act (IDEA)

Children ages 3-21 with I/DD are eligible for special education and related services under the federal Individuals with Disabilities Education Act (IDEA), Part B. IDEA is intended to ensure that all children with disabilities have access to a free appropriate public education (FAPE).[b] IDEA applies to all children with disabilities, not just those with I/DD. IDEA requires that all states accepting funds for students with disabilities provide "a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living."[c] In 2007, nearly six million children, nationally, ages 6-21 received services under IDEA.[3]

The Individuals with Disabilities Education Act requires that all children with disabilities in elementary and secondary schools have Individualized Education Programs in place at the beginning of each school year.

States receiving IDEA funds must meet a number of conditions.[d] States must make FAPE available to all children ages 3-21 with disabilities no later than a child's third birthday and ensure that an IEP is in place by that date.[e] IDEA requires that all children with disabilities in elementary and secondary schools have IEPs in place at the beginning of each school year.[f] An IEP is a written statement for each child with a disability that details the educational plan that has been designed to meet their educational needs.[g] The IEP is created by the IEP Team which includes the parents, at least one regular education teacher (if the child is participating in or will participate in the general curriculum), at least one special education teacher, a representative of the Local Education Agency (LEA), an individual who

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[b] The Individuals with Disabilities Education Act (IDEA) was enacted in 1974 as the Education for All Handicapped Children Act and was renamed IDEA in 1990. IDEA has been amended many times since then, most recently in 2004.

[c] 34 CFR §300.1(a), 20 U.S.C §1400(d)(1)(A).

[d] 34 CFR §300.101-300.176.

[e] 34 CFR §300.101, U.S.C. 1412(a)(1)(A).

[f] IDEA does not apply to postsecondary education outside of the public school system.

[g] An Individualized Education Program (IEP) must include statements of the child's academic achievement and functional performance; measurable, annual educational and functional goals; how progress will be measured and when assessments of progress will be provided; the special education and related services to be provided and the program modifications or supports needed; the extent to which the child will not participate with students without disabilities in the general curriculum and extracurricular activities; any individual accommodations necessary; and the projected date for the beginning of transition services (for youth 16 or older) and the frequency, location, and duration of those services. According to IDEA, states must ensure that children with disabilities including children in public or private institutions or other care facilities are educated with children who are nondisabled. Furthermore, the removal of children with disabilities from the regular educational environment, such as special classes or separate schooling, is only allowed if education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily.

can interpret the implications of evaluation results, other individuals at the discretion of the parents or LEA, and, when appropriate, the child with a disability.[h] States are also required to ensure that children with disabilities are educated in the least restrictive environment appropriate to their needs, as determined annually.[i] IEPs must also include a plan for transition services, beginning no later than when the child reaches age 16.[j,k]

Children with Disabilities in North Carolina Schools

During the 2006-2007 school year, there were more than 61,000 children with disabilities ages 14-21 in North Carolina public schools. This figure includes all children with IEPs, including, but not limited to, children with I/DD. The most common disability category was specific learning disability (45.6%) followed by intellectual disability (20.8%), other health impairment (17.9%), and emotional disturbance (7.5%). (See Table 3.1.)

During the 2006-2007 school year, there were more than 61,000 children with disabilities ages 14-21 in North Carolina public schools…The most common disability category was specific learning disability (45.6%) followed by intellectual disability (20.8%), other health impairment (17.9%), and emotional disturbance (7.5%).

Of the 61,115 students with disabilities in grades 9-12 (2006-2007), more than half were in regular educational settings during 80% or more of their school day, 22.4% were in a resource setting and spent 40-79% of the day with other students without disabilities, and 21.9% were in a separate setting and spent 39% or less of their day with students without disabilities.[l,4,5] The remaining 4.3% of the students were in more restrictive settings such as public separate and residential schools, private separate and residential schools, and homebound or hospitalized.[6]

Increasing the Number of Students Who Successfully Complete High School

Currently there are five courses of study available to students with disabilities: Career Prep, College Tech Prep, College/University Prep, the Occupational Courses of Study, and the Extended Content Standards.[m] The Career, College Tech, and College/University Prep Courses of Study are available to all students and have fairly similar base graduation requirements. The Occupational Course of Study (OCS) is available only to students with disabilities and is designed for students with mild to moderate cognitive disabilities who need a modified general curriculum that focuses on post-school employment and independent living.[n] The Extended Content

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[h] 34 CFR §300.320-321, 20 U.S.C. 1414(d)(1)(A) and (d)(6)

[i] The Individuals with Disabilities Education Act (IDEA) also requires that states provide a continuum of placement services for children with disabilities including supplemental aids and services within regular classrooms as well as alternative placements such as separate classes for students with disabilities, separate schools, home schooling, or instruction in institutional settings. Additionally, IDEA requires that the child's placement be as close as possible to their home with the child being educated in the school he or she would attend if he or she did not have a disability, unless another arrangement is deemed most appropriate by the Individualized Education Program (IEP) Team. 34 CFR §300.114-116, 20 U.S.C. 1412(a)(5)

[j] Transition services include those necessary to assist the child in reaching postsecondary education goals such as training, education, employment, and independent living skills—all of which should be a part of the IEP beginning at age 16 or earlier if it is determined to be appropriate.

[k] 34 CFR §300.320, 20 U.S.C. 1414(d)(1)(A) and (d)(6)

[l] Resource setting refers to students receiving instruction outside of the general education classroom. Students typically receive individualized or small group instruction in a resource classroom.

[m] Beginning in 2009-2010, entering students will choose between the Future Ready and Occupational Courses of Study and the Extended Content Standards. More information is available online at http://www.ncpublicschools.org/curriculum/graduation/table.

[n] Lee FM. Consultant for Intellectual Disabilities, Secondary Education, and Transition Services, Exceptional Children Division, North Carolina Department of Public Instruction. Oral communication. February 11, 2009.

Table 3.1
Learning Disabilities and Intellectual Disability Are the Most Common Disabilities Among North Carolina Students Ages 14-21

Disability Category	Total	Percent
Specific learning disability	27,857	45.6%
Mental retardation[o]	12,689	20.8%
Other health impairment	10,938	17.9%
Emotional disturbance[o]	4,565	7.5%
Autism	1,976	3.2%
Multiple disabilities	903	1.5%
Hearing impairment	783	1.3%
Speech or language impairment	526	0.9%
Orthopedic impairment	333	0.5%
Traumatic brain injury	269	0.4%
Visual impairment	258	0.4%
Deaf-blindness	18	0.0%
Developmental delay	0	0.0%
Total	61,115	100.0%

Source: North Carolina Institute of Medicine calculations using Office of Special Education Data Analysis System. US Department of Education. ED*Facts*: North Carolina Report of Children with Disabilities for Ages 6 through 21 by Age and Disability for SY 2006-2007. http://www.ncpublicschools.org/docs/ec/data/childcount/december1/07disabilitybyage621.pdf. Published March 31, 2008. Accessed March 11, 2009.

Students with disabilities generally do not perform well on end-of-course tests, with less than 42% scoring level three (passing) or above.

Standards provide guidance for developing individualized courses of study for students with significant disabilities. The IEP Team makes recommendations as to which course of study is appropriate for each student based on his/her post-school transition needs and goals. The final course of study selection is made by the student and parent.[7]

Career, College Tech, and University Prep Courses of Study: North Carolina students in the Career, College Tech, and College/University Prep Courses of Study must meet certain course and credit requirements, testing standards, and performance requirements in order to receive a high school diploma. Students must earn a passing score on the end-of-course (EOC) tests for core academic areas (Algebra I, Biology, Civics and Economics, English I, and US History) unless exempted by the student's IEP. Students with disabilities generally do not perform well on these end-of-course tests, with less than 42% scoring level three (passing) or above.[6] (See Table 3.2.) Many students with disabilities also fail core academic

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[o] North Carolina no longer uses the terms mental retardation and emotional disturbance except when required to do so by the federal government for reporting purposes. Instead, North Carolina uses the terms intellectual disability and serious emotional disability. Mental retardation, based on the Federal definition of "child with a disability" in section 602(3)(A) of the Act. 20 U.S.C. 1401(3)(A), is the term used by the US Office of Special Education.

Table 3.2
Only One-in-Three Students with Disabilities Perform at or Above Proficient on End-of-Course Tests in Core Academic Areas

	Algebra I (% at or above Level III)	Biology (% at or above Level III)	Civics/ Economics (% at or above Level III)	US History (% at or above Level III)	English I (% at or above Level III)
Students without a Disability	69.4% (n=125,799)	67.6% (n=86,431)	68.2% (n=96,117)	66.3% (n=82,929)	75.9% (n=100,417)
Students with a Disability	33.2% (n=10,166)	37.6% (n=7,306)	37.4% (n=8,174)	41.8% (n=6,254)	35.4% (n=10,144)

Source: Data from Public Schools of North Carolina, State Board of Education/Department of Public Instruction. Report to the Joint Legislative Oversight Committee. North Carolina High Schools and Students with Disabilities: A Study of Educational Services and Outcomes. Session Law: 2007, Section 295. GS 115C-17. Report # DPI Chronological Schedule. March 1, 2008. Title in report is "2006-2007 North Carolina State Level Performance Data for Select End-of-Course Multiple Choice Tests."

courses because current State Board of Education policy requires that schools count the EOC tests as 25% of a student's grade.[8]

Occupational Course of Study (OCS): The OCS is a transition-focused curriculum that includes extensive career preparation. An informal Department of Public Instruction (DPI) survey of high schools in 2004 found that approximately 20% of high school students with disabilities selected to participate in the OCS.[p] The OCS is currently being revised for students entering high school in 2009. For students enrolled prior to 2009, the OCS requires:[q]

- 15 courses in English, mathematics, science, occupational preparation, and social studies.
- 300 hours of school-based vocational training, 240 hours of community-based vocational training, and 360 hours of paid employment.
- Creating a career portfolio documenting completion of course of study requirements (this is in place of an exit exam).
- Completion of healthful living and electives as needed to complete local graduation requirements.[r]

Students in the OCS who complete all requirements receive a high school diploma. If a student has not completed the competitive paid employment, but has completed

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[p] Lee FM. Consultant for Intellectual Disabilities, Secondary Education, and Transition Services, Exceptional Children Division, North Carolina Department of Public Instruction. Oral communication. March 3, 2009

[q] In January 2009, the US Department of Education notified the Department of Public Instruction that the testing requirements for the Occupational Course of Study (OCS) were not aligned closely enough with the general curriculum, as required by No Child Left Behind. The OCS is currently being revised to meet the new requirement. Beginning in 2009-2010, entering students enrolled in the OCS will be required to pass algebra to earn a high school diploma.

[r] Students in the OCS are not required to pass an exit exam or the computer skills test.

all other requirements, he or she currently receives a Certificate of Achievement and future students will receive a Graduation Certificate. Upon completion of the required hours of competitive paid employment, the student can receive his or her high school diploma.[s]

The OCS occupational preparation courses, part of the school-based vocational training, cover topics including self-determination, personal management, interpersonal relationship skills, career development, job seeking skills, and job performance.[9-11] Community-based instruction, or functional, hands-on learning in a natural setting, is a critical component of the life skills component of the OCS.[t] Instruction is intended to take place in the community and teaches students to use skills that will be needed to live independently, work, and participate in the community.

Although 49.4% of students with disabilities graduated high school with a diploma in the state in 2007, graduation rates vary widely by Local Education Agency (LEA). In 19 LEAs, fewer than 45% of high school students graduated with a diploma… 16 LEAs had more than 75%.

Extended Content Standards (ECS): The ECS provide guidance in the development of an individual course of study for students with significant cognitive disabilities. IEP Teams and teachers use the ECS to identify ways to provide all students access to the general curriculum, as required by No Child Left Behind. ECS guidance documents detail a continuum of ways for students to learn and demonstrate understanding of course content standards.[12] Students who participate in the ECS receive a Graduation Certificate at high school completion.

Although 49.4% of students with disabilities graduated high school with a diploma in the state in 2007, graduation rates vary widely by LEA and school.[13,u,v] In 19 LEAs, fewer than 45% of high school students with disabilities graduated with a diploma. In contrast, 16 LEAs had more than 75% of students with disabilities graduate with a diploma.[w] North Carolina's target is to have 70% of students with IEPs graduating with regular diplomas by 2011.[13] Students with disabilities who do not complete the requirements for a high school diploma can get a Graduation Certificate if the student:

- Passed all his or her IEP requirements and completed at least 21 course credits as defined in State Board of Education Policy HSP-L-004 (the core academic courses are not required as part of this policy), or
- Satisfied all state and local graduation requirements other than the proficiency standards as defined in HSP-N-000 (Student Accountability Standards), has been enrolled in the OCS, and has passed all the requirements of the OCS other than the 360 hours of competitive employment.

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[s] The amount of time a student has to complete the required hours of competitive paid employment varies by Local Education Agency.

[t] Community-based instruction might include teaching students how to shop for groceries, go to the health department, or access public transportation.

[u] The graduation rate for students with disabilities is the percentage of students with an Individualized Education Program who graduated with a regular high school diploma.

[v] The five year cohort graduation rate for students with disabilities was 53.6% for students entering the 9th grade in 2002-2003.

[w] Mannan MA. Senior Statistician for Policy, Monitoring and Audit Section, Exceptional Children Division, North Carolina Department of Public Instruction. Written communication. March 30, 2009.

IDEA requires that states create a Statewide Performance Plan (SPP) that describes how the state will improve implementation of IDEA and submit Annual Performance Reports.[x] As part of North Carolina's SPP, the North Carolina Department of Public Instruction (DPI) has begun Focused Monitoring in some LEAs to examine the experiences of students with disabilities. The purpose of Focused Monitoring is to find ways to increase achievement, decrease drop-out rates, and improve the provision of comprehensive transition services. Focused Monitoring activities include data analysis, initial on-site visits, follow-up technical assistance visits, student record reviews, and interviews with LEA staff, parents, and students. Focused Monitoring was piloted during the 2006-2007 school year and will be conducted in approximately four different LEAs each year until 2011.[13] Focused Monitoring findings from the 2006-2007 school year show that:

- For many students with disabilities, a full continuum of special education services was not available or used at the high school level, even when performance data indicated that a student was not experiencing success.
- The transition component of the IEP did not always have measurable postsecondary outcomes goals or the transition services needed to help the child reach those goals.
- Many students' IEPs did not have any documentation of a Career Development Plan.[y]
- Students with disabilities often enter high school with weak academic skills, based on end-of-grade performance, and few high schools have comprehensive literacy programs and other services to help students with disabilities.

These in-depth reviews highlight the need for both a larger array of services for students with disabilities and more detailed IEPs.[6]

Many students with disabilities are not graduating from high school with the skills needed to successfully transition to employment or postsecondary schooling.

In 2007, the North Carolina General Assembly asked DPI to review educational and other services provided to students with disabilities in high school. In the final report to the legislature, DPI made several recommendations on how to improve educational outcomes for students with disabilities. This Task Force supports those recommendations; however, since the focus of this group was on improving transitions, the Task Force recommendations are more narrowly focused.

Many students with disabilities are not graduating from high school with the skills needed to successfully transition to employment or postsecondary schooling. The low graduation rate for students with disabilities illustrates that many high schools are not fulfilling the promise of IDEA for students with disabilities. Therefore the Task Force on Transitions for People with Developmental Disabilities recommends:

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[x] 34 CFR §300.600, 20 U.S.C. 1416(a)

[y] Career Development Plans (CDPs) outline the accommodations or additional services students with disabilities need to be successful in career/technical classes. This information is required by federal law.

Recommendation 3.1: Improving Educational Outcomes of Children with Intellectual and Other Developmental Disabilities

The State Board of Education should examine existing school policies to improve the educational outcomes for children with intellectual and other developmental disabilities (I/DD). Specifically the State Board of Education should:

a) Develop a policy allowing students in the Occupational Course of Study who graduate with a Graduation Certificate because of not having completed the required hours of competitive paid employment to have four years to complete the work requirements necessary for receiving a high school diploma.

b) Develop guidelines for using end-of-course assessment data in Individual Education Program development at the beginning of each school year to ensure that children with I/DD are receiving appropriate education to achieve their maximum potential.

Individualized Education Program Transition Component

Individuals with I/DD who graduate or age out of secondary school need linkages to postsecondary schools, vocational rehabilitation, and/or LMEs to obtain postsecondary education, vocational training, workforce assistance, or other services and supports needed to help them become active participants in the community. The transition component of the IEP is supposed to build such links. North Carolina policy requires that the IEP Team begin discussing transitions during the year a child turns 14.[z] The transition component of the IEP must include "measurable postsecondary goals based upon age appropriate transition assessments related to training, education, employment, and, where appropriate, independent living skills; and the transition services (including course of study) needed to assist the child in reaching those goals."[aa,bb] The IEP transition services plan should be based on the child's needs, considering the child's strengths, preferences, and interests. If multiple agencies are involved in providing transition services, IDEA states that the IEP should include a statement of interagency responsibilities. Under IDEA, the LEA must invite participants from any agency that is responsible for providing transition services to the IEP meeting.[cc,dd]

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[z] The Individuals with Disabilities Education Act (IDEA) requires that transition services be a part of the Individualized Education Program (IEP) beginning with the IEP in effect when the child turns 16.

[aa] Postsecondary goals may include postsecondary education, vocational education, employment (including supported employment), continuing and adult education, adult services, independent living, and community participation.

[bb] 34 CFR §300.43, 20 U.S.C. 1401(34)

[cc] The Local Education Agency (LEA) must have the consent of the parents or child who has reached the age of majority before inviting representatives from participating agencies. If representatives from participating agencies do not attend the IEP meeting, the LEA is not required to take further steps to include them in IEP meetings.

[dd] 34 CFR §300.321, 20 U.S.C. 1414(d)(1)(B)–(d)(1)(D)

During the 2006-2007 school year, 72.5% of the sample of students with disabilities age 16 or older had an IEP with transition goals that met IDEA guidelines.[ee] Although this represents an increase from the 2005-2006 school year, it is well below DPI's goal and the requirements of federal law of 100%. To improve performance on this goal, DPI created Comprehensive Transition Training modules, trained 28 transition coordinators and Exceptional Children staff to become regional and LEA trainers who present the training modules, created a Statewide Transition Leadership Planning Team, and conducted numerous trainings for school administrators and teachers. Additionally, transition services were targeted in LEAs participating in Focused Monitoring. All schools were required to correct noncompliant IEPs within one year, and LEAs and schools without 100% compliance were required to develop a comprehensive training plan.[ff,13]

In addition to creating a transition component to the IEP, the school must inform the child of the rights provided under Part B of IDEA (which includes transition planning) that will transfer to the child when they reach the age of majority. The child must be informed of this transfer beginning at least one year before the child reaches the age of majority. The rights that transfer are all those that are accorded to parents of minor children, such as the right to participate in placement decisions, examine records, or file a due process complaint. Both the child and the parents must be notified of the transfer of rights when it happens.[gg]

Under IDEA reporting requirements, states must report the percent of youth who had IEPs, are no longer in school, and have been "competitively employed, enrolled in some type of postsecondary school, or both, within one year of leaving high school."[hh,ii] The North Carolina 2007 Post-School Exit Survey found that of those who responded to the survey, 30% had been competitively employed, 25% had been enrolled in postsecondary school, and 20% had been both competitively employed and enrolled in postsecondary school at some point in the last year. Twenty-five percent were neither working nor enrolled in postsecondary school. (See Figure 3.1.) Of the respondents with intellectual disabilities, 58% had been either competitively employed, enrolled in postsecondary school, or both at some point in the past year.[14] Unfortunately, due to response bias, the actual results may be worse than what is presented here. The survey responses overrepresent students with less severe disabilities, those who graduated with a diploma, and white students. Thus, postsecondary performance and competitive workforce engagement may be inflated, especially for those with more significant disabilities.

Students with intellectual disabilities are the least likely to be engaged in competitive employment or postsecondary education in the year after leaving high school, with 50% not in school and not competitively employed.

[ee] Each Local Education Agency is required to submit the Individualized Education Programs (IEPs) of 5% of the students with disabilities ages 16 or older (or at least five records). Submitted IEPs are reviewed to see if they meet the Individuals with Disabilities Education Act transition goals requirements.

[ff] It is too early to see the results of the comprehensive training plans that were developed in 2008.

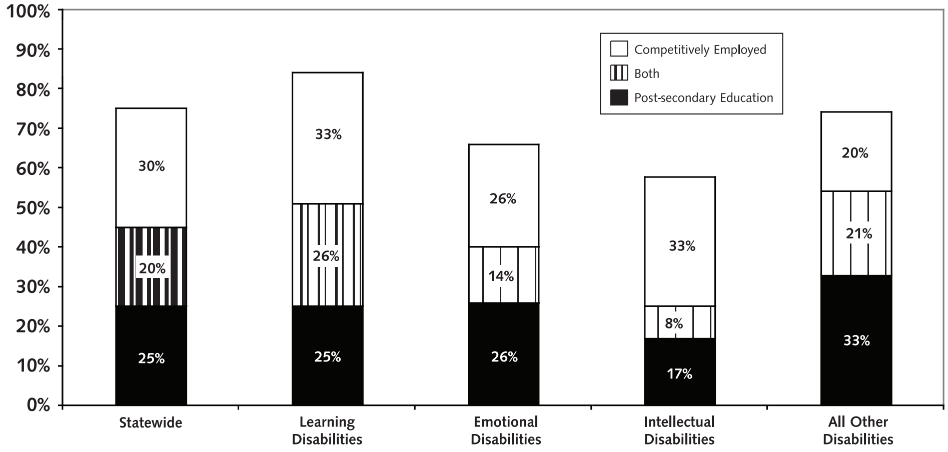
[gg] 34 CFR §300.320, 20 U.S.C. 1414(d)(1)(A) and (d)(6), 34 CFR §300.520, 20 U.S.C. 1415(m)

[hh] Competitive employment is defined work (i) in the competitive labor market that is performed on a full-time or part-time basis in an integrated setting and (ii) for which an individual is compensated at or above the minimum wage, but not less than customary wage and level of benefits paid by the employer for the same or similar work performed by individuals who are not disabled.

[ii] 20 U.S.C. 1416(a)(3)(B)

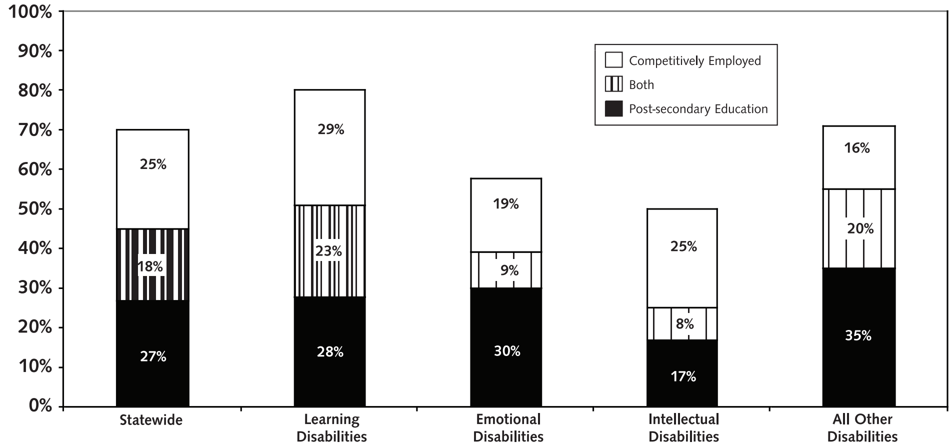
Schools are failing to help 50% of youth with intellectual disabilities gain the skills and knowledge they need to engage in postsecondary school or competitive employment.

Figure 3.1
The Majority of Young Adults with Disabilities are Engaged in Work or School *at Some Point* During the Year After Leaving High School



Source: Exceptional Children Division, North Carolina Department of Public Instruction. North Carolina Part B Annual Performance Report (APR) for 2006-2007. http://www.ncpublicschools.org/docs/ec/plan/2006-07apr.pdf. Published April 14, 2008. Accessed February 24, 2009.

Figure 3.2
50% of Young Adults with Intellectual Disabilities are *Not Currently* Engaged in Their Communities



Source: Exceptional Children Division, North Carolina Department of Public Instruction. North Carolina Part B Annual Performance Report (APR) for 2006-2007. http://www.ncpublicschools.org/docs/ec/plan/2006-07apr.pdf. Published April 14, 2008. Accessed February 24, 2009.

Students with intellectual disabilities are the least likely to be engaged in competitive employment or postsecondary education in the year after leaving high school, with 50% not in school and not competitively employed. (See Figure 3.2.) It is unclear what these young adults are doing once they leave high school.

Schools are failing to help 50% of youth with intellectual disabilities gain the skills and knowledge they need to engage in postsecondary school or competitive employment. Further, as previously noted, these survey results may not accurately reflect the experiences of those with more significant disabilities. Schools need to know what kind of skills young adults need to meaningfully engage in their communities and how well schools prepare youth to successfully transition into the community. Additionally, knowing why these students are not engaged in postsecondary education or competitive employment and what they are doing could help LMEs and other support systems reach these youth. Therefore, the Task Force recommends:

Recommendation 3.2: Measuring Outcomes for Students with Intellectual and Other Developmental Disabilities

The Department of Public Instruction (DPI) should add additional questions to the school outcome data collection survey for students with disabilities. The survey should include questions to further assess what students are doing in the area of employment (i.e. how many hours of work per week, how many months on the job, and average wages in the last year), what students are doing if not employed or enrolled in postsecondary education, how well students with disabilities feel their needs were met by schools, and what skills could help them meaningfully engage in their communities. DPI should oversample students with severe intellectual and other developmental disabilities. DPI should report survey results to the Joint Legislative Oversight Committee for Mental Health, Developmental Disabilities, and Substance Abuse Services and to the Joint Legislative Education Oversight Committee no later than February, 2010.

In order to ensure full implementation of IDEA and to help states build capacity and support for children with disabilities, the National Secondary Transition Technical Assistance Center (NSTTAC), part of the US Department of Education Office of Special Education Programs, identifies evidence-based and promising practices in transition. NSTTAC research has found a number of in-school predictors of post-school success in employment, education, and independent living. Students who have access to transition services and supports such as career awareness, paid work experience, social skills, student support, transition programs, self-care/independent living skills, parental involvement, school integration, self-advocacy/self-determination, and occupational courses are more likely to transition successfully to postsecondary education and work. The NSTTAC maintains a list of in-school evidence-based practices that improve post-school success.[15]

Teaching students functional life skills outside the classroom, through community-based instruction, is an evidence-based practice that improves students' likelihood of successfully living independently, a goal in many students' IEPs. Functional life skills include skills such as budgeting, banking, mobility, and safety. Community-based instruction involves taking students out into the community to practice skills learned in the classroom. Skills that are learned in the classroom, such as how to read a bus schedule, are reinforced and practiced when students go out in the community and use the public transportation system. Community-based instruction also provides students an opportunity to apply academic skills, such as reading and mathematics, in real life situations. When a student can successfully apply on their own the life skills they have learned in school, they are more likely to successfully transition into living independently. DPI should work with the North Carolina Community College System, colleges and universities, and the Division of Vocational Rehabilitation in order to identify the life skills that would facilitate transition from school to postsecondary education or competitive employment. Therefore, the Task Force recommends:

Recommendation 3.3: Improving Transition Outcomes of Children with Intellectual and Other Developmental Disabilities

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' Individuals Education Programs.

The NSTTAC also identified interagency collaboration as an in-school predictor of post-school success. When there is good interagency collaboration that begins when a child is young, agencies work together to help create the environment and work/community opportunities that are more likely to lead to a child's successful transition into postsecondary work and education.[15] Currently DPI collects data on disabilities using 13 federally-defined disability categories, which are different than the categories used by the Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS). DPI and DMHDDSAS should work together to determine the appropriate categories to report to LMEs. Once common categories are agreed upon, schools could help facilitate better collaboration by sharing data on the number of students with disabilities and the types of disabilities they have so that LMEs and other agencies that provide services and supports to people with I/DD can be better prepared. Therefore, the Task Force on Transitions for People with Developmental Disabilities recommends:

Recommendation 3.4: Improving Interagency Coordination for Transitions

The North Carolina General Assembly (NCGA) should promote interagency coordination before a child transitions out of secondary school. Specifically, the NCGA should direct the State Board of Education to develop policies to improve transition planning for children with intellectual and other developmental disabilities (I/DD), in collaboration with the Department of Health and Human Services. Transition planning should help

the students with I/DD reach their maximum independence, establish employment goals, and participate in community activities or other forms of civic engagement. In developing the transition component of Individualized Education Programs (IEPs), staff with the Local Education Agency (LEA) should:

a) **Encourage the active participation of appropriate agencies in developing the transition component of the IEP once the child reaches age 14, including, but not limited to, postsecondary educational institutions, vocational rehabilitation, Local Management Entities (LMEs), and community providers.**

b) **Develop a checklist for students and parents about issues they should consider in developing the transition component of the IEP and include other available resources in the community that may support the student as he or she transitions out of secondary school. This checklist should be provided to the student and his or her family or guardian annually, beginning at age 14.**

c) **Share data with LMEs and local community colleges on an annual basis about the unduplicated numbers of students with I/DD in their jurisdiction expected to transition out of the secondary school system. The data should include an unduplicated count and a clear delineation of the services and supports needed.**

Assistive Technology

Some students with disabilities benefit from the use of assistive technologies (AT). AT can aid children's learning by augmenting their abilities or by compensating for certain communication, mobility, or other functional barriers that impair their educational achievement. Any item used to increase, maintain, or improve the functional capabilities of a child with disabilities is considered an AT.[jj,kk] Modified desks and chairs, large print materials, computer hardware (large keyboards), software programs (to convert spoken words to text), and digital presentation recorders are all examples of AT used in schools. Most students with disabilities are able to be educated in general education classrooms with a few modifications or adaptations. AT can help students and teachers with these adaptations. IDEA requires that students be educated in the least restrictive, most appropriate environment, and AT are sometimes required for that to be possible. IDEA requires that the child's AT needs be considered when creating his or her IEP and that schools must ensure that AT devices, services, or both are available, free of charge, to a child with a disability if required by the child's IEP.[ll,mm] Additionally, home use of AT purchased by the school is allowable if the use of such technologies at home is necessary for the child to receive FAPE.[nn]

Assistive technologies can aid children's learning by augmenting their abilities or by compensating for certain communication, mobility, or other functional barriers that impair their educational achievement.

[jj] Assistive technology as used in the Individuals with Disabilities Education Act does not include implanted medical devices.

[kk] 34 CFR §300.5, 20 U.S.C. 1401(1).

[ll] 34 CFR §300.324, 20 U.S.C. 1412(a)(1), 1412(a)(12)(A)(i), 1414(d)(3), (4)(B), and (7); and 1414(e)

[mm] Assistive technology service refers to any service that aids a child with disabilities in the selection, acquisition, or use of an assistive technology, including the evaluation of the child's functional needs; purchasing, leasing or otherwise providing assistive technology devices; selecting, fitting, and maintaining assistive technology devices; coordinating use of such devices with other therapies, interventions, or services; and training or technical assistance for a child with a disability, his or her family, or his or her service providers. 34 CFR §300.6, 20 U.S.C. 1401(2)

[nn] 34 CFR §300.105, 20 U.S.C. 1412(a)(1), 1412(a)(12)(B)(i)

Although IDEA identifies schools as being responsible for providing AT for students with disabilities, schools may not have the funds to fully meet the needs of students. IDEA funding is limited and AT devices and services can be very costly. This makes it difficult for schools to fulfill IDEA requirements around AT. In 2008, the New Voices Foundation of North Carolina surveyed the public school Programs for Exceptional Children, the LMEs, and five physicians in university pediatric practice in Durham, Chatham, Orange, and Wake counties about the needs of children with disabilities. The survey asked how many children, ages 3-22, had severe communication and mobility problems and could benefit by a comprehensive assessment to determine their need for AT and other specialized services. In that four county area, 244 children were identified as having needs that could potentially benefit from AT.[16] IDEA does not require schools to report on the AT needs of students and how well they are being met, so it is unclear to what degree North Carolina schools are fulfilling this requirement of IDEA.

Access to AT and training to use the devices effectively are critical to ensuring that children with disabilities are able to succeed in their education. Currently North Carolina does not have the information to assess how well students' AT needs are being identified or met. Therefore, the Task Force on Transitions for People with Developmental Disabilities recommends:

Recommendation 3.5: Use of Assistive Technology in the Schools

The North Carolina General Assembly should allocate $60,000 to the Department of Public Instruction (DPI) to contract with an independent organization, that has expertise in assistive technology (AT), to conduct a study to determine the extent to which the AT needs of students with disabilities, including intellectual and other developmental disabilities (I/DD), are being met.

a) **The study should assess the needs for AT of a random sample of students with disabilities, including students with I/DD, who could potentially benefit from the use of AT to help them in school. The study should include students with disabilities from rural, low wealth, and urban school systems from across North Carolina.**

b) **The study should include a survey of teachers and school administrators to determine their level of understanding of AT and how AT can be appropriately integrated into the school setting. The contractors should also assess how well teachers are integrating AT training into the classroom so that students can effectively use AT.**

c) **The study should survey parents of the students included in the study to determine if AT options were discussed as part of the Individualized Education Program and then implemented.**

d) The contractors should report their findings to DPI and to the Joint Legislative Oversight Committee on Mental Health, Developmental Disabilities, and Substance Abuse Services and the Joint Legislative Education Oversight Committee no later than October, 2010. The report should include information on how well the schools are meeting the AT needs of students, any barriers which prevent appropriate use of AT, recommendations for how AT can be more appropriately utilized in the school setting, and the costs of statewide implementation of the proposed recommendations.

Postsecondary Education for Students with Intellectual or Other Developmental Disabilities

Data from DPI's 2007 post-school follow-up survey of students with disabilities show that 45% of respondents had continued their education after leaving high school.[oo] Students with disabilities who otherwise meet the admissions requirements can enroll in college or university classes or take academic or vocational courses at community colleges. However, the options available for students with I/DD are limited at the community college, college, and university levels. More postsecondary education opportunities need to be provided for students with I/DD. Additionally, those that do exist need to be better integrated into other systems. The linkages between secondary education, postsecondary education, vocational rehabilitation, and LMEs need to be strengthened to increase the likelihood that students finishing high school will be connected to the kinds of postsecondary opportunities that help facilitate successful transitions into adulthood and employment.

Currently, the North Carolina Community College System (NCCCS) is the primary provider of postsecondary education for individuals with I/DD. There are a limited number of programs available at the college and university level tailored to students with I/DD. Vocational rehabilitation is discussed further in Chapter 6.

Community Colleges

North Carolina's community colleges offer a free compensatory education program (CED) as part of the Basic Skills Program. The CED program is for individuals with intellectual disabilities who are not prepared to take academic or vocational classes. To be eligible to participate in the CED, individuals must be 17-years-old or older and must either be diagnosed with an intellectual disability or be functioning on a level equivalent to intellectual disability from head injury or brain damage. A diagnosis from a qualified professional (such as a doctor, psychologist, or psychiatrist) is required to enroll in the program.[17] The CED curriculum covers seven domains including language, math, social science, community living, consumer education, health, and pre-employment skills.[pp] The focus of the curriculum is to teach the skills adults with disabilities need to function as independently as possible. All students are tested at the beginning and end of each year to measure their progress.[17]

The options available for students with intellectual and other developmental disabilities (I/DD) are limited at the community college, college, and university levels. More postsecondary education opportunities need to be provided for students with I/DD.

[oo] Survey responses overrepresented students with less severe disabilities, those who graduated with a diploma, and white students. Due to response bias, postsecondary performance may be inflated.

[pp] The North Carolina Community College System is currently in the process of updating the curriculum.

The CED program was developed by the NCCCS in 1983 as a result of a lawsuit brought by The Arc of North Carolina. The lawsuit was in response to the failure of elementary and secondary schools to adequately educate children with intellectual disabilities. The CED's purpose when it was created was to "compensate" adults for the lack of or inadequate education received earlier. The compensatory education program served more than 6,000 students at all 58 community colleges during the 2007-2008 school year. Some community colleges' programs are unable to serve everyone who qualifies due to a lack of funding for the space and instructors needed to meet the need.[17]

The community college curriculum program courses can be much more difficult for students with intellectual and other developmental disabilities (I/DD) to enroll in… The courses in the curriculum programs have entrance requirements that are often difficult for students with I/DD to meet.

Adults with I/DD who perform above the compensatory education level or who have progressed through the CED curriculum can enroll at no charge in higher level adult basic education (ABE) courses that are part of the Basic Skills program. The ABE is designed for adults who need to improve their reading, writing, speaking, problem-solving, or computation skills to function effectively in the community or on the job. Courses include instruction in math, reading, writing, critical thinking, and problem solving. Additionally, students may enroll in other Basic Skills classes including General Educational Development (GED), English as a Second Language, or adult high school courses at no charge.[18]

The programmatic aspect of both CED and ABE are funded through federal funds and are restricted to providing compensatory education skills, not vocational or work-related skills. Limited state funds are available to help pay for coordination of services for CED. Most colleges use these funds to hire part-time CED coordinators.

In addition to the Basic Skills Program, which includes both CED and ABE, North Carolina Community Colleges offer career and technical education courses. Applicants to these curriculum programs have to meet certain standards or must have taken certain required courses before enrollment. Curriculum programs include those where students follow a specific course of study in order to earn a certificate, diploma, Associate in Applied Science, Associate in Arts, Associate in Fine Arts, Associate in Science, or Associate in General Education.

The community college curriculum program courses can be much more difficult for students with I/DD to enroll in, even if they have a high school diploma after completing the OCS. The courses in the curriculum programs have entrance requirements that are often difficult for students with I/DD to meet. If applicants do not meet the requirements they are placed in developmental education courses which are designed to help students develop the skills necessary to enroll in college-level courses.[qq,18]

Although there are a variety of opportunities for individuals with I/DD through the NCCCS, few students with I/DD are able to take classes that would prepare

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[qq] Developmental education courses are designed to address academic preparedness, workforce retraining, development of general and discipline-specific learning strategies, and affective barriers to learning. Developmental courses do not earn credit toward a degree, diploma, or certificate.

them for employment. Obtaining employment is a critical step in a successful transition into adulthood for everyone, including individuals with I/DD. While the CED and ABE programs serve some individuals with I/DD, many would benefit from being able to learn the kinds of vocational and technical skills needed for employment. Therefore, the Task Force on Transitions for People with Developmental Disabilities recommends:

Recommendation 3.6: Expanding Educational Opportunities in the Community College System (PRIORITY RECOMMENDATION)

a) The North Carolina Community College System (NCCCS) should contract for an independent evaluation of NCCCS educational and vocational programs available to people with intellectual and other developmental disabilities (I/DD). As part of this evaluation, the NCCCS should examine:

   1) The number of students with I/DD enrolled in basic skills (including, but not limited to, compensatory education), economic and workforce development, and curriculum programs by specific type of educational program.

   2) Information about the level of disability of students with I/DD served through the NCCCS system, including numbers of students with intellectual disabilities, the numbers of students using assistive technologies, and where students are receiving their education.

   3) Outcome information including, but not limited to, numbers of students with I/DD who successfully complete coursework, obtain a degree, pursue further postsecondary education, or engage in competitive work in a community-integrated employment setting.

   4) Barriers which may prevent students with I/DD from enrolling in vocational or technical training courses which would prepare them for community-integrated employment options.

b) The independent contractors should examine the experiences in North Carolina and in other states to identify best practices of providing meaningful postsecondary educational opportunities to people with I/DD in an integrated community setting, both in community colleges, colleges, and universities. As part of this study, the independent contractors should identify whether other states have different admissions requirements, enrollment procedures, educational curriculum, vocational or life skills training courses (including assistive technology training), or other student supports that contribute to valued outcomes for people with I/DD. 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 pilot test the plan in four community colleges. If successful, NCCCS should implement this statewide.

c) NCCCS should identify potential funding sources to help support enhanced educational and vocational training opportunities for people with I/DD including, but not limited to, use of existing funding through compensatory education or other educational funds that may be available through the federal Recovery and Reinvestment Act or other federal legislation.

d) **NCCCS should report its findings and plans to expand services to people with I/DD 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.**

Colleges and Universities

In North Carolina there are very few postsecondary educational opportunities geared towards people with I/DD other than the compensatory education program for individuals with intellectual disabilities. One program that is currently being implemented and evaluated is Beyond Academics. Beyond Academics is a model program for individuals with intellectual disabilities (ID) who have finished their studies in the public school system and need further education to gain the knowledge and skills needed to live independently. Beyond Academics is a non-degree program that provides education and life skills training to adults with ID who are not candidates for admission to college.[rr] The program is a partnership between The University of North Carolina at Greensboro (UNC-G), DMHDDSAS, the North Carolina Council on Developmental Disabilities, and a private provider of services for people with intellectual disabilities. Beyond Academics provides a unique opportunity for adults with ID to live and go to school with other students on a college campus. One of the main benefits of Beyond Academics and other similar postsecondary educational inclusion programs is the opportunity that students with ID have to live on or near campus with other students. Although Beyond Academics students are not enrolled in college, they take some of the same classes and live in off-campus housing with other college students. This is a benefit to both the student with ID and for UNC-G students, both of whom learn from each other. Additionally, students take courses in life skills such as personal safety, etiquette, personal finance, meal preparation, and conflict resolution. Students also have the opportunity to participate in internships related to their career interests.

Adults with I/DD can make meaningful progress in learning the skills needed to become contributing citizens of their communities; however, there are very few educational opportunities available that teach these skills. Therefore, the Task Force on Transitions for People with Developmental Disabilities recommends:

Recommendation 3.7: Expanding Postsecondary Education Opportunities in Colleges and Universities

a) **The North Carolina General Assembly (NCGA) should appropriate $400,000 in FY 2010 and 2011 to the Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) to support the expansion of Beyond Academics from a two-year to a four-year curriculum.**

[rr] Beyond Academics serves students with a wide range of intellectual disabilities, including those who meet the Intermediate Care Facility for Persons with Mental Retardation requirements. Beyond Academics is a new program and has developed and enrolled students in the first two years of curriculum. Two additional years of curriculum are being developed. The first cohort is expected to finish the four-year curriculum in 2011. The program is currently being evaluated; however, the outcomes data are not yet available.

b) **NCGA should appropriate $60,000 in SFY 2010 and 2011 to The University of North Carolina at Greensboro to complete the evaluation of Beyond Academics.**

c) **DMHDDSAS and the Division of Medical Assistance should allocate eight Community Alternatives Program for Persons with Mental Retardation/ Developmental Disabilities slots for new students in 2010 and 2011 to support students who will enroll in Beyond Academics.**

d) **The University of North Carolina System and private colleges and universities should expand inclusive postsecondary education programs for people with intellectual and other developmental disabilities based on the results of the Beyond Academics evaluation study, as well as other data on best practices.**

Ideally, adults with I/DD should have opportunities for meaningful postsecondary education at both the community college and university levels. While the NCCCS offers compensatory education to people with intellectual disabilities, this curriculum does not provide meaningful vocational or work-related skills. Beyond Academics offers the possibility of combining an integrated living experience with academics on a college campus, but this program is still in the development stages and has not been fully evaluated. The NCCCS and the University of North Carolina System (UNC) should work together to identify collaborative approaches to provide meaningful educational opportunities to these students and also to identify funding options to help subsidize the tuition costs, as well as the services and supports needed to facilitate their educational opportunity.

Recommendation 3.8: Collaboration Between the University of North Carolina System and the North Carolina Community College System

a) **The University of North Carolina System (UNC) and the North Carolina Community College System (NCCCS) should work together to expand the availability of postsecondary educational opportunities for students with intellectual and other developmental disabilities in both community college and university settings.**

b) **UNC and NCCCS should work with the Division of Mental Health, Developmental Disabilities and Substance Abuse Services and the Division of Medical Assistance to explore federal and other funding sources to support students in postsecondary education.**

Foster Care

Youth with I/DD in the foster care system face unique challenges both while in foster care and when they transition to adulthood. Children in the foster care system may not have an adult advocating for them to get access to needed services and supports while they are growing up. Furthermore, youth with I/DD who are not connected to services while in foster care may not have the knowledge or skills to connect to the appropriate support services when they age out of care. The transition to adulthood is difficult for many foster care youth because they often lack the traditional support systems that other youth have. Surveys of youth aging out of foster care in North Carolina show that 33% do not have sufficient income to live on; 14% do not have safe, stable housing; 26% do not have a diploma or GED; 20% are single parents; and 40% do not have a support network of five caring, supportive adults in their lives.[19] This transition is even more difficult for youth with I/DD because usually they need more services and supports to successfully transition into adulthood.[20]

The Centers for Disease Control and Prevention estimates that 17% of youth under age 18 have a developmental disability; however, studies have found that 20-60% of youth in the foster care system have developmental disabilities.[20,21] Data from North Carolina's Division of Social Services show that only 10.8% of foster children in North Carolina have disabilities.[19] It is unlikely that North Carolina's foster care youth have a lower prevalence of disabilities, but rather that North Carolina is not doing a very good job identifying children with I/DD in foster care. Early identification is critical so that children with I/DD are able to receive needed services while in the foster care system and to ensure that they are connected to the appropriate systems so that they continue to receive services and supports as they transition to adulthood. Therefore, the Task Force on Transitions for People with Developmental Disabilities recommends:

Recommendation 3.9: Improving Services and Supports for Children with Intellectual and Other Developmental Disabilities in the Foster Care System

The North Carolina 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 from a trained individual within three months of entering the foster care system to determine if they have any intellectual and/or other developmental disabilities (I/DD) or mental health needs. Children who have been determined to have mental health needs or I/DD should be linked into the Local Management Entity system.

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Transitions from Large Congregate Settings to Community Settings

The movement to deinstitutionalize people with intellectual and other developmental disabilities (I/DD) has been very successful, particularly in moving people out of large state developmental centers…Today only 9% of people with I/DD live in residential facilities in the United States.

Overview

Before 1970, most people with intellectual and other developmental disabilities (I/DD) received services in large residential developmental disability centers or lived with their families with very little support from the government. During the late 1960s and 1970s, the movement by advocates, families, individuals with I/DD, and others to deinstitutionalize people with I/DD challenged the idea that people with I/DD needed to receive services in large congregate settings. They argued that people with I/DD could live in the community with the appropriate supports.[1] As a result, states began moving towards a community-based system of services and supports for individuals with I/DD. The movement to deinstitutionalize people with I/DD has been very successful, particularly in moving people out of large state developmental centers.[a,2] Nine states and the District of Columbia have closed all state-operated developmental centers.[b,3] Today only 9% of people with I/DD live in residential facilities in the United States.[2]

While the total population of individuals with I/DD receiving residential services increased by more than 75% between 1977 and 2007, from 248,000 to 438,000, the percentage living in large settings has declined 47%, from 227,000 to 121,000.[4] As states have embraced the community-based system of services and supports for people with I/DD, there has been a dramatic shift towards serving individuals with I/DD in small (6 or fewer) settings.[c] In 1977, fewer than 10% of people with I/DD received residential services in small settings; by 2007, more than 70% of people with I/DD received residential services in small settings.

There are four factors that have contributed to the decline in the number of people living in large institutions nationally: 1) personal preferences for community living arrangements, 2) expansion of Medicaid funding for home and community-based services, 3) *Olmstead vs. LC*, 527 US 581 (1999), a US Supreme Court decision that supported greater choice in living arrangements for people with disabilities, and 4) the higher costs states incur serving people in large public and private Intermediate Care Facilities for Persons with Mental Retardation (ICFs-MR) (including state developmental centers).

People with I/DD, families, and advocates generally prefer smaller community settings to larger settings when offered appropriate supports and services.[5] Research also shows that people with I/DD experience better outcomes in adaptive behavior, social participation, choice-making, self-determination, and

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[a] Unless otherwise noted, large residential settings are those serving seven or more people.

[b] Alaska, District of Columbia, Hawaii, Indiana, Maine, New Hampshire, New Mexico, Rhode Island, Vermont, and West Virginia.

[c] Unless otherwise noted, small residential settings are those serving six or fewer people.

functional behavior when living in the community with appropriate and necessary services and supports.

Medicaid funding for home and community-based services has made it easier for states to pay for the services and supports needed to help people live in smaller, more family-like community settings. State Medicaid agencies have a number of different ways in which they can pay for community-based services. First, any individual who qualifies for Medicaid can obtain coverage for health-related services. Additionally, in 1981, Congress began to give states the option of covering a broader array of home and community-based services under Medicaid. Services under the Home and Community-Based Services (HCBS) program include service coordination and case management, in-home supports, vocational services (that are not covered under the Vocational Rehabilitation Act), day habilitation services, and respite care. HCBS funds cannot be used for room and board.[4]

In 1981, Congress began to give states the option of covering a broader array of home and community-based services under Medicaid…including service coordination and case management, in-home supports, vocational services, day habilitation services, and respite care.

In 1999, the US Supreme Court issued an opinion which gave further support for deinstitutionalization. In Olmstead vs. LC, the Supreme Court held that the unjustified institutionalization of people with disabilities could be considered unlawful discrimination under the Americans with Disabilities Act (ADA). The Court did not hold that all individuals had to be served in the community. Rather, the Supreme Court held that the individuals should be served in the community if the individual desired to live in the community, and treatment professionals determined that individual could be appropriately served in the community. Under the ADA, states must make reasonable accommodations to serve people in the community when the other two conditions are met. States are not, however, required to make "unreasonable" accommodations that would require fundamental alteration of the State's services and programs.[d] Nor are states required to close all institutions under the Olmstead opinion.

Some states have chosen to downsize or close large state-run developmental centers and large private ICFs-MR because of the cost. Operating private and public ICFs-MR while transitioning people into smaller community living arrangements is expensive, since there are certain fixed costs (e.g. facility costs and some staffing) that do not diminish proportionately as people are transitioned to community care settings.[3] As described in Chapter 2, state developmental center costs are higher than private ICFs-MR or Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities (CAP-MR/DD) services provided in the community. Part of the cost differential may be due to the different services covered in different settings. Part of the difference in payment may also be explained by the differences in level of needs among the populations living in both settings. However, national research has shown higher per person costs at state developmental centers compared to community-based settings after controlling for these characteristics.

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[d] The Supreme Court, in a plurality decision, provided some guidance on what is a reasonable accommodation. Reasonable accommodations include a consideration of the state's overall resources available to serve people with mental disabilities. Thus, the state need not allocate disproportionate resources to specific individuals to serve them in the community, if the state can show that providing these resources would impair their ability to serve a larger group of people with disabilities.

North Carolina

From 1977 to 2007, the number of individuals with I/DD receiving residential services increased more rapidly in North Carolina (167%) than the nation (75%).[e,f,4] In 2007, North Carolina had 11,834 persons with I/DD in a residential setting compared to 4,424 in 1977. Due to the large increase in the number of people being served, the number of individuals with I/DD served in large settings has declined less in North Carolina than the United States as a whole (15% vs. 47%). However, of those individuals with I/DD served in residential settings, the percent in a large setting is similar for North Carolina and the country as a whole (30% vs. 28%). In North Carolina in 2007, more than 3,500 individuals with I/DD lived in large residential settings, of which about half lived in state-run developmental centers.[4]

As states have embraced the community-based system of services and supports for people with intellectual and other developmental disabilities (I/DD), there has been a dramatic shift towards serving individuals with I/DD in small settings and with waiver services.

As states have embraced the community-based system of services and supports for people with I/DD, there has been a dramatic shift towards serving individuals with I/DD in small settings and with waiver services. In 1977, fewer than 10% of people with I/DD nationally received residential services in small settings; by 2007, more than 70% of people with I/DD received residential services in small settings with six or fewer individuals. In North Carolina, only 5% of individuals with I/DD receiving residential services lived in a small setting in 1977 compared to about 70% in 2007, indicating that North Carolina's transition away from large residential settings has been similar to that of the country as a whole.

Table 4.1
North Carolina Persons with Intellectual and Other Developmental Disabilities More Likely to Reside in Small Congregate Care Settings

	NC	US
All congregate	35.0%	28.3%
1-6 congregate	21.8%	16.0%
7+ congregate	13.2%	12.3%
Own/rent	7.0%	11.8%
Host family/Foster	2.4%	3.8%
Family	55.7%	56.2%
TOTAL	100%	100%

Source: Prouty R, Alba K, Lakin C, et al; Research and Training Center on Community Living, Institute on Community Integration/UCEDD, College of Education and Human Development, University of Minnesota. *Residential services for persons with developmental disabilities: Status and trends through 2007.* http://rtc.umn.edu/docs/risp2007.pdf. Published August 2008. Accessed February 12, 2009.

The major difference between North Carolina and the nation as a whole is the use of small congregate care settings.[g] (See Table 4.1.) Approximately 22% of North Carolinians with I/DD reside in these settings, compared to 16% nationally. Nationally, people with

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[e] In these data, Prouty et al. count people who are receiving some form of Medicaid-funded residential services or live in congregate care, host family, foster care, or the individual's own home. These data do not include people who are residing in psychiatric facilities, nursing facilities, or a person living in their natural or adoptive family's home.

[f] Another source for residential services for persons with intellectual and other developmental disabilities is *The State of the States in Developmental Disabilities* (Braddock, Hemp, and Rizzolo, 2008). Differences in survey methods and service definitions preclude direct comparisons, but when data are comparable, the conclusions are similar.

[g] Prouty et al. define congregate care as a residence owned, rented, or managed by the residential service provider.

I/DD are more likely to own or rent their own home (12% vs. 7%) or reside in a host family/foster care setting (3.8 % vs. 2.4 %) than in North Carolina. Residence in family settings is similar (both 56%) and, as stated above, North Carolina has a slightly higher use of large congregate care facilities.[4]

In North Carolina, there are currently three state-operated ICF-MR certified developmental centers for people with I/DD. Information for these centers is provided in Table 4.2.

Table 4.2
Developmental Disability Centers Serving North Carolina's Three Regions

Name of Center	Location	Region	Number of Residents as of 12/8/2008
J. Iverson Riddle Developmental Center	Morganton	West	332
Murdoch Developmental Center	Butner	Central	495
Caswell Developmental Center	Kinston	East	426

Source: Donin, C. Assessment of needs for individuals residing at the state operated developmental centers. Presented to: the North Carolina Institute of Medicine Task Force on Transitions for People with Developmental Disabilities; January 21, 2009; Morrisville, NC.

In addition to the developmental centers listed above, there are two other centers that were converted to specialized nursing facilities that continue to provide services and supports to residents with I/DD as of June 2007. The O'Berry Neuro-Medical Center in Goldsboro had 290 residents with I/DD, and Black Mountain Neuro-Medical Center had another 84 residents with I/DD as of June 2007.[4]

Almost 70% of the 1,253 residents of developmental centers are older than age 45… Almost 90% of developmental center residents have severe (17%) or profound (72%) levels of cognitive impairment.

Almost 70% of the 1,253 residents of the developmental centers listed in Table 4.2 are older than age 45.[6] Nearly 60% of residents of the state developmental centers have been in the centers for more than 30 years and 83% have been in the centers for more than 10 years.[7] In 1995, a moratorium was placed on developmental centers so that they could no longer admit children for long-term care. Almost 90% of developmental center residents have severe (17%) or profound (72%) levels of cognitive impairment.[6] Those with less severe cognitive impairments have self-injurious or aggressive behaviors or have severe medical needs (such as tube feeding). With regards to activities of daily living, about two-thirds of residents need help with dining (including 13% of residents who are tube fed), two-thirds of residents need assistance with toileting, three-quarters need assistance with dressing, and 86% need assistance with communications.[h] Developmental centers provide a full range of services and supports, including medical, dental, psychiatry, physical and occupational therapy; speech therapy; adaptive equipment; social work; education, recreation and vocational therapy; and advocacy.

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[h] Some of the common diagnoses among residents of institutions include seizure disorders, cerebral palsy, dual diagnosis of intellectual and other developmental disabilities and mental illness, myocardial infarction, autism, visually or hearing impaired, diabetes, and medically fragile.

In addition to the ICF-MR certified developmental centers discussed above, North Carolina has 315 private ICFs-MR.[4] These ICFs-MR had 2,524 residents with I/DD as of June 2007. The vast majority (273 of the 315, or 87%) of these facilities had six or fewer beds. North Carolina also has a number of people living in developmental disability group homes. There are currently approximately 1,336 of these supervised living facilities, with a total of 6,544 beds.[8] Most of these are homes with six or fewer people. (See Table 4.3.)

Table 4.3
Most Developmental Disability Group Homes in North Carolina are Small, with Six or Fewer Beds

	Number of DD Group Homes	
Facility Size	Adult	Child
4 beds or fewer	531	21
5-6 beds	714	29
7-15 beds	37	-
16 beds or more	4	-

Source: Donin C. Assessment of needs for individuals residing at the state operated developmental centers. Presented to: the North Carolina Institute of Medicine Task Force on Transitions for People with Developmental Disabilities; January 21, 2009; Morrisville, NC.

State/County Special Assistance funds are available to pay room and board costs to licensed group homes for individuals with I/DD. State funds can be used to cover room and board costs in developmental disability group homes of various sizes as well as the costs of a person living at home. CAP-MR/DD funds provide services and supports to eligible recipients.[i]

Approximately 10% of North Carolinians with I/DD live in state developmental centers or private ICFs-MR with more than 16 individuals. While this percentage is similar to the national average, North Carolina could be more proactive in helping individuals with I/DD live more independently in the community when that is what they and their family members desire. However, recent efforts to move people from the state developmental centers to the community have met with limited success. Some of the barriers include the following:[9]

- ***Communication/collaboration with Local Management Entities (LMEs):*** Successful transitions to the community require a significant amount of communication and collaboration between the developmental centers, providers, and the LMEs. In order to be successful, private providers need to be aware of those people who want to move to a community setting, and providers need to communicate to LMEs when they have openings for new people needing services. In addition, all of the parties need to collaborate and maintain open communications during the transition period.

In North Carolina, recent efforts to move people from the state developmental centers to the community have met with limited success.

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[i] As noted in Chapter 6, the state does not routinely collect data on the number of people with intellectual and other developmental disabilities who are living in assisted living facilities or private skilled nursing facilities.

- ***Case management issues:*** North Carolina only allows providers to bill for case management services for up to 60 days of transition planning prior to the person leaving the state developmental centers. Federal law allows coverage of case management services for up to 180 days of transition planning. Limiting coverage to 60 days allows insufficient time to successfully develop and implement a transition plan. In addition, there is a high turnover among case managers which can limit the effectiveness of the case managers in helping with the transition.

- ***Local Management Entity (LME) motivation:*** LMEs face competing priorities and may perceive a lack of resources to devote to community transitions. This is exacerbated by the fact that LMEs may view people in institutions as having safe and stable living conditions compared to others they are trying to serve. Further, LMEs have no authority to manage admissions, funding, or discharges from the private ICFs-MR.

- ***Private provider incentives:*** Private ICFs-MR and developmental disability group homes are reimbursed based on bed/home level rather than the intensity of a person's need or the actual cost of delivering services. This payment methodology creates a disincentive for providers to work with people who have more intensive needs (or conversely, provides an incentive to select consumers with less intensive needs). Reimbursement to these providers is the same regardless of the quality or effectiveness of the provider. As a result, some providers that do work with people with high needs may cut corners because of inadequate reimbursement.[j]

- ***Community capacity:*** Communities do not necessarily have the capacity to support the higher level of support that people who transition out of residential facilities may need. Though there have been some recent efforts to improve community capacity (for example through the use of the Systemic, Therapeutic, Assessment, Respite, and Treatment (START) team model), these programs have not been in place long enough to have an impact. In addition to crisis programs, individuals need access to other services and supports in the community to meet their health, dental, mental health, housing, vocational, educational, or other support needs that were previously provided in the developmental center.

In addition to crisis programs, individuals need access to other services and supports in the community to meet their health, dental, mental health, housing, vocational, educational, or other support needs that were previously provided in the developmental center.

- ***Supports for more intensive needs:*** Many of the people trying to transition out of the state developmental centers have more intensive medical, behavioral, and support needs that may not be easily supported at the community level. Community supports are not currently designed

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[j] Medicaid regularly provides inflationary increases in the reimbursement rates to providers (including Intermediate Care Facilities for Persons with Mental Retardation). However, rates for state-funded residential services are established by individual Local Management Entities in negotiation with providers. The Task Force heard from some of the providers that there has not been an inflationary increase for any state-funded services since the mid-1990s. Thus, these providers who rely on state-only funds to pay for services and supports have even more difficulty providing services to people with high needs.

or funded to provide the intensive and specialized 24-hour care provided at developmental centers. Community level providers may also be less experienced than center staff in working with such high need individuals and may not provide all of the services needed.[k] This inadequacy of services at the community level limits community placements.

- ***Residential preference:*** Many of the individuals in residential facilities are older and have lived in the facilities for decades. These individuals and their families may be happy with their living situation and not wish to transition into the community. In addition, community placements are not always available in the person's home community. Some guardians also prefer the state developmental centers over private ICFs-MR or other community placement because the developmental centers are perceived to provide more comprehensive services, on-site oversight, staff training, independent advocacy, and low staff turnover. Community supports are seen as being less stable. Some families have had experience with more than one unsuccessful attempt at community placement, while others have been forced to move from successful community placements when the community program closed.

As many people as possible should be moved to individualized settings of their choice.

Despite these barriers, several states have been successful in transitioning people out of developmental centers and into community settings.[10] First and foremost, these successes depended on strong, sensitive, and knowledgeable leadership to oversee the entire transition process, help create a shared vision built on common values, and then develop a comprehensive transition plan including both public and private providers of services and supports. Successful transitions focus first on building capacity within the communities rather than on closing institutions. States that have been successful have built the community service system by strengthening the training, supervision, and financing of community providers; developing comprehensive systems to manage community services; monitoring the health and welfare of individuals with I/DD; and implementing systems to monitor and improve quality of care. Creative options should be considered in building capacity. A successful transition plan includes open communication with staff and families of residents to build trust and credibility. Government administrators must be accessible and responsive to people with concerns and issues.

Transition planning for people with I/DD should be person-centered and should involve others who know the person. Successful efforts also include the maximization of opportunities to develop individualized supports at the time of

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[k] One of the difficulties in transitioning some people from state developmental centers into the community is the lack of community providers who are trained and willing to provide physical interventions. Some people with intellectual and other developmental disabilities engage in self-injurious or aggressive behaviors. These individuals may occasionally need physical interventions to prevent them from harming themselves or others. Providers who use physical interventions must have specially-trained staff and must provide extensive documentation of the need for physical interventions. Many providers decline to use hands on behavioral techniques because of the increased staffing and documentation requirements. As a result, it is more difficult to find community placements for people with significant behavioral problems. See 10A NCAC 27E.0104.

closure. As many people as possible should be moved to individualized settings of their choice. Alternative uses for the state developmental centers or large ICFs-MR should be considered that would continue to meet the needs of people with I/DD. The roles of developmental center staff should be considered both during and after the closure of the developmental center. Staff should be involved in transition planning and monitoring and should be provided opportunities to work in the community and provide support in new ways. When appropriate resources are available in the community, the state should restrict new admissions to state developmental centers or ICFs-MR. Many of these issues are discussed in more detail in Chapter 6, as these issues arise across many types of transitions.

Although the primary motivation for downsizing large residential facilities for people with I/DD and transitioning them to community-based services is to serve the needs and preferences of people with I/DD and their families, some expect that this strategy could lead to long-term savings for the state. It is important to note, however, that in the short-run, costs may increase as community-based services are being developed and state-run developmental centers continue to operate.[11]

The Task Force discussed the relative strengths and weaknesses of each type of setting, and there were many strongly held beliefs about which setting is "best." Although some members of the Task Force wanted to adopt strong language supporting particular strategies, these types of recommendations were beyond the scope of the Task Force, which was specifically charged to facilitate the transition from developmental centers to the community. Due to the highly emotional nature of this topic, especially among family members of people with I/DD, broader recommendations aimed at dramatically reconstituting the relative use of each setting would take much more research and discussion among key stakeholders.

To facilitate transitions from North Carolina's large I/DD residential facilities to small community residential settings, the Task Force recommends:

Recommendation 4.1: Preadmission Review of Placements in State Developmental Centers and Private Intermediate Care Facilities for Persons with Mental Retardation

a) **Each of the state-operated developmental centers should have an admissions review committee that includes representatives of multiple Local Management Entities (LMEs), the state or regional transition coordinator, family members, and others as deemed appropriate to review any request for general admission into the state developmental centers. 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. Only those individuals whose needs are reliably determined to require the most intense and costly array of services should be admitted into the state developmental centers. The centers should continue to be viewed as placements of last resort.**

b) **Private Intermediate Care Facilities for Persons with Mental Retardation (ICFs-MR) should create admission committees that are similarly comprised. The ICF-MR admissions committee should review the admission prior to placement to determine if the individual with I/DD could be appropriately served in a community-integrated setting within available funding.**

c) **If the placement in subsections a or b is determined to be appropriate, the committee should develop plans to transition the individual with I/DD into a more integrated setting in the community. Placements in public or private ICFs-MR should be reviewed at least annually.**

d) **The North Carolina General Assembly should provide the Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) with the authority to use existing state funds in a more flexible fashion to support community transitions or to avoid placements into state developmental centers or private ICFs-MR. Examples of funding strategies include blending of the Community Alternatives Program for Persons with Mental Retardation/ Developmental Disabilities (CAP-MR/DD) waiver funds with state dollars to support individuals with higher intensity of support needs. Other funding strategies may include the transition of more than one individual at a time to smaller residential settings of four or less individuals, with funds (and possible staff) from the state developmental centers following the individuals with I/DD, or increasing the level of in-home special assistance funds to the amount provided to support individuals in licensed group homes or assisted living facilities.**

e) **DMHDDSAS, the Division of Medical Assistance, and the Division of Health Services Regulation should implement policies to:**

    1) **Discourage providers from moving individuals with more significant I/DD or behavioral health needs into state developmental centers or private ICFs-MR.**

    2) **Help community providers provide the necessary supports and services to successfully maintain the individual in the community.**

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Chapter 5

Transitions for Older Adults with Intellectual and Other Developmental Disabilities (I/DD) and People with I/DD Living with Aging Caregivers

Overview

As the general population ages, so do individuals with intellectual and other developmental disabilities (I/DD) and their parents and other caregivers. Increasing numbers of aging adults with I/DD, supported by aging parents, other family members, or direct support workers present a growing challenge to the I/DD system. As individuals with I/DD age, their health care and other needs often increase at the same time that the ability of their aging support provider decreases. Improvement in and collaboration between health care, life planning, living arrangements, transportation, and other services are needed to ensure that individuals with I/DD receive appropriate and individualized supports as they age. North Carolina must take proactive steps to plan for and deal with these changes to ensure that needed support systems are in place and prepared for the transitions involving adults with I/DD, their families, and a workforce that are aging together.

As individuals with intellectual and other developmental disabilities age, their health care and other needs often increase at the same time that the ability of their aging support provider decreases.

Aging Individuals with Intellectual and Other Developmental Disabilities

The United States population is aging. By 2030, adults age 65 and older will account for 20% of the population, up from 13% in 2000. People 85 years and older comprise the most rapidly growing segment of the US population.[1] In 1998, there were an estimated 526,000 people 60 years or older with a developmental disability in the United States, and this number is projected to double by 2030.[2] It is estimated that between 5,170 and 12,926 North Carolinians with an I/DD are currently over the age of 60.[3]

Although adults with I/DD still have slightly lower life expectancies than the general population, these persons are living significantly longer than just a few decades ago, and many adults with I/DD can now expect to live as long as the general population.[4,5] One of the greatest gains in life expectancy has been for people with Down syndrome. Life expectancy for these individuals has increased from an estimated nine years in 1929 to nearly 60 years today.[5,6]

Experts identify three main criteria of successful aging: the reduction of disease and disability, the maintenance of high cognitive and physical functioning, and active engagement in life.[7] As suggested by this framework, most Americans identify good health, independence, relationships with friends and family, physical health, and remaining connected to the community as markers of successful aging.[8,7] Like all older individuals, people with I/DD want to have a successful aging experience. However, due to a myriad of reasons, these goals may be more difficult for persons with I/DD than for the general aging population. (Specific health care problems and health access issues are discussed more fully in Chapter 6).

Chapter 5 Transitions for Older Adults with Intellectual and Other Developmental Disabilities (I/DD) and People with I/DD Living with Aging Caregivers

Aging Families

Until the mid-1970s, increasing life expectancies among persons with I/DD had relatively little impact on family members and community services, since a large proportion of individuals with I/DD lived in institutional settings.[9] However, deinstitutionalization coupled with new laws and court decisions expanding the rights of persons with I/DD have led to an increasing demand for community services and greatly expanded the number of persons with I/DD who live with their families.[3]

As the population ages and life expectancies of persons with intellectual and other developmental disabilities (I/DD) continue to increase, the number of people with I/DD who will experience life transitions will increase. Many families have not made sufficient plans for this transition.

A large number of individuals with I/DD now live with their parents, siblings, or other adults, including direct support workers (DSW). Although it is difficult to determine the exact number, it is estimated that in the United States more than 479,000 adults with I/DD live with parents, age 60 or older, who serve as their primary support provider.[a] The ability of these parents to provide the support needed by family members with I/DD decreases as they grow older.[10,11] As the population ages and life expectancies of persons with I/DD continue to increase, the number of people with I/DD who will experience life transitions, including changes in their physical residence due to the death or diminishing capacity of their support providers, will increase. Many families have not made sufficient plans for this transition.[12]

Parents of adults with I/DD experience anxiety about what will happen when they are no longer able to provide the services and supports their family member needs. In one study, 74% of family members reported the concern, "what will happen to my relative when I am gone," as being their greatest source of distress.[11] Family members consistently report being troubled by planning for the future well-being of adult children with I/DD. Mothers, in particular, report that these worries have had a negative effect on their health.[13,10] Insufficient planning to ensure the availability of services and supports may thus result in considerable hardship for people with I/DD when families become unable to offer the level of support they previously provided.[14] This process can be extremely trying for all those involved, but advance planning can help alleviate some of the stress and anxiety of the transition from one living arrangement to another.

Older parents of adults with I/DD are likely to need professional help with planning for their adult children's future. Planning can be complex because of the diverse set of needs that must be addressed once the parent, sibling, or other natural support is no longer able to assist the person with I/DD. Parents need information to help them understand the implications of their actions on the well-being of the child with I/DD. For example, a direct inheritance could negatively impact on the child's continued receipt of Medicaid or Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities (CAP-MR/DD) services. Parents need to understand the financial

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[a] Developmental Disabilities Assistance and Bill of Rights Act. 42 U.S.C. 6001 et seq. 2000.

options that do exist to supplement the benefits that the child may be receiving. In addition, the parent may need to arrange for alternative housing if the individual with I/DD cannot continue to live in the family home. Similarly, the parent must arrange for medical care, services, and supports to help the individual with activities of daily living, as well as the provision of legal and financial services. Involving siblings in planning, whenever possible, is important since their insights about their brother or sister and potential resources within the extended family greatly enhance person-centered, future-oriented planning. Despite these concerns, planning among family members for the needs of their adult children with I/DD tends to be inadequate.[9] Many family caregivers of people with I/DD have not discussed future plans with either the person with I/DD or other family members.[9] This may be partly a result of the lack of coordination among different service systems for aging populations and for people with I/DD, lack of information available to families and professionals, and the need for support to families in the development and modification, with the passing of time, of these components of a Person Centered Plan.[3]

Many family caregivers of people with intellectual and other developmental disabilities (I/DD) have not discussed future plans with either the person with I/DD or other family members.

Many older parents do not access services to help in planning even when they are available. In a 1995 study, Smith et al. found that, of older mothers of adults with intellectual disabilities who lived at home, 20% had not yet made plans for the future care of their adult son or daughter, 35% were in some stage of planning, and 45% had made a definite plan.[15] A similar study of parents with adult children with intellectual disabilities found that 31% of the parents had not yet taken steps for future care, 42% were in the process of discussing or making a plan, and 27% had made a definite plan for the care of their family member after they became unable to provide care.[9]

The unexpected death or serious illness of a family member may precipitate a crisis for the person with I/DD, who potentially may be left without housing or other support services. Therefore the Task Force on Transitions for People with Developmental Disabilities recommends:

Recommendation 5.1: Future Planning for Families that Provide Support to People with Intellectual and Other Developmental Disabilities

a) **Local Management Entities (LMEs) and the Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) should help families providing services or supports for people with intellectual and other developmental disabilities (I/DD) with future planning. LMEs should assist families to develop their plans for the future so that the family's and the individual with I/DD's wishes are understood and agreed upon before a crisis occurs. Future planning should include, but not be limited to:**

   1) **An information sheet for families with specific information on the importance of making plans for what will occur when they are no longer able to support their loved one.**

  2) **A checklist for families about issues they should consider in meeting the future needs of the individual with I/DD, along with a list of available resources in the community that offer services and supports. This information should be made available to individuals with I/DD and their families through the LMEs directly and should be made available on the internet.**
  3) **Options and ideas for paying for some of the future planning expenses including, but not limited to, legal fees or financial planning fees.**
  4) **Plans for how the financial, residential, safety, medical, supports, legal, and social needs of the individuals with I/DD will be met as the parents age and may no longer be able to provide the same level of support**

b) **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 family member who provides services or supports.**

Preparing the System to Handle the Challenges Posed by Aging Individuals with Intellectual and other Developmental Disabilities and the Families Supporting Them

North Carolina will face a number of challenges in providing for the expanding population of older adults with I/DD and their aging parents and siblings. The state and community support system may become overwhelmed by the demand for services as adults with I/DD currently living in the family home begin to need services or supports from the state-funded I/DD or aging systems.[14,5] The first step is to identify people who are not being served, or who are underserved and link those individuals to existing services and supports. Beyond this, however, the state should identify family-centered policies for improving services and supports for this population, including not only appropriate health care, but also assistance in legal and financial matters, in developing "whole-family" approaches to family support, and in coordinating services among the various agencies from which these families seek assistance.

The state should identify family-centered policies for improving services and supports for older adults with intellectual and other developmental disabilities.

In 2002, the North Carolina Council on Developmental Disabilities, the North Carolina Division of Mental Health, Developmental Disabilities and Substance Abuse Services, the North Carolina Division of Aging, advocates for both older adults and adults with I/DD, service providers, constituents, and social service agencies established The North Carolina Task Force on Aging and Developmental Disabilities (TFADD) to identify areas where the elements of the aging and developmental disabilities services networks can work together to better serve this population.[3] TFADD formulated a number of proposals for addressing the increasing needs of adults with I/DD, particularly by fostering cooperation between the aging and I/DD service networks.

TFADD noted a number of barriers to service access and availability. Among these are the lack of low-cost, reliable transportation to persons in many communities, overspecialization among service providers, lack of knowledge about available services, inadequate funding, and large numbers of older adults with I/DD who remain unknown to the system. TFADD also identified the need to encourage families to seek formal support, the need for support services to address all needs, including emotional needs, of both older adults with I/DD and their families, and the need to address legal issues, including guardianship, faced by this population.[3] Finally, TFADD noted that there is currently a severe shortage of housing for persons with I/DD, as well as a lack of support services for those who live in the community outside of formal supportive housing.[3]

TFADD also identified proposed solutions to these barriers. Among these, TFADD recommended as a first step measure to determine the size of the population in need of cross-cutting services (that is, aging persons with I/DD) and to foster cooperation between agencies and organizations working with either or both of these populations (e.g. aging community or people with developmental disabilities). TFADD also recommended targeted outreach to this segment of the population; provision of information about available services, including legal, financial, and transportation services; the inclusion of family members in decision making regarding adults with I/DD; reform and standardization in the guardianship system; and expanded housing options for adults with I/DD.[3] Therefore the Task Force on Transitions for People with Developmental Disabilities recommends:

Recommendation 5.2: Outreach to Older Adults Who are Providing Support to People with Intellectual and Other Developmental Disabilities (I/DD) and Linkages into the Aging System for Older Adults with I/DD

Local Management Entities (LMEs) should work with appropriate community organizations including, but not limited to, Area Agencies on Aging, senior centers, home health and hospice services, the faith community, and other community groups to:

a) 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 to provide information about the availability of supports and services for people with I/DD and their families.

b) Ensure that older adults with I/DD and their families have appropriate access to the range of services and supports offered by those organizations.

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Cross-Cutting Issues

Chapter 6

The needs for services and supports change over a person's lifetime, as their skills, needs, natural supports, and life goals change. While all people experience changes in their needs and goals over their lifetime, certain periods cause greater upheaval. Life transitions—whether due to changes that come from moving into adulthood, major changes in housing or living situations, or the death of a parent or caregiver—can cause significant challenges to anyone. However, people with intellectual and other developmental disabilities (I/DD) may experience more difficulties during these transition periods than others.

Individuals with I/DD may need services and supports from multiple organizations or agencies to meet their needs. Relative to others, people with I/DD may also have fewer relationships to turn to for support during important life transitions. Interagency planning and coordination is particularly important during transitions, as is having a well-qualified workforce to assist during transitions. As noted in Chapter 3, many youth with I/DD who age out of secondary school will need linkages to postsecondary schools, vocational rehabilitation, and their Local Management Entity (LME), as well as community organizations (e.g. churches and YMCAs), to ensure that they become active participants in the community. Older adults with I/DD will need to be linked into a variety of different services, supports, and/or housing if their aging caregiver dies or can no longer provide services or supports for them (discussed more fully in Chapter 5). And people who transition out of public developmental centers or large private Intermediate Care Facilities for Persons with Mental Retardation (ICFs-MR) will need access to an array of services and supports in the community consistent with their needs. Regardless of the reason for the transition, people with I/DD will need access to a comprehensive array of services and supports to enable them to maximize their independence, productivity, inclusion, and self-determination in the community. These services and supports may include, but not be limited to, housing and residential supports; vocational services; medical, dental, psychological, or other professional services; assistive technology; and well-trained direct support personnel and case managers to support community integration. The scope of services and supports will vary from person to person, based on their individual needs, preferences, and natural supports.

People with intellectual and other developmental disabilities will need access to a comprehensive array of services and supports to enable them to maximize their independence, productivity, and self-determination in the community.

One of the most critical factors needed to ensure successful transitions is professional leadership, with expertise specific to I/DD, at both the state and local levels. State leaders need to bring together people with I/DD, families, LMEs, service providers, and other stakeholders to develop a statewide transition plan that includes policies and practices to facilitate transitions. Leaders at the local level need to establish linkages with appropriate agencies, service providers, and community members to facilitate successful transitions, identify gaps in services and supports, and build community capacity. While leadership is critical, it is not sufficient to ensure successful transitions. Leadership at the state and local level needs to be coupled with appropriate and flexible financing, case management services, and community capacity (e.g. housing, assistive technology, and supported employment) to ensure that there are sufficient services and supports to address the needs of individuals with I/DD and their families during times of transition. Additionally, North Carolina must ensure an adequate supply of well-qualified direct support workers and other professionals who demonstrate the competencies and person-centered values necessary to support people with I/DD in securing the quality of life communities afford other people.

Leadership

States that have been most successful in transitioning people from state developmental centers or large private ICFs-MR into community settings have had strong developmental disability leadership at the state level to develop a statewide transition plan and to ensure that resources are available to facilitate transitions.[1] To accomplish this, the developmental disability leadership within the Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) and the LMEs must have the authority to oversee developmental disability services provided by state developmental centers, as well as local public and private providers of services and supports. North Carolina needs I/DD-specific staff at DMHDDSAS to focus on transition planning, identify the barriers which prevent successful transitions (similar to those discussed in this report), identify the services and supports needed to facilitate transitions as well as potential funding sources available to support these transitions, and examine best practices from other states. The developmental disability system must be organized to prepare for and facilitate smooth transitions.

Similarly, the Task Force heard from state experts about the need for local LME transitions staff with expertise in developmental disabilities who can work with secondary schools, state developmental centers, or large private ICFs-MR to help people transition into the community.

To ensure strong leadership at the state and local level, the Task Force recommends:

Recommendation 6.1: Statewide Transition Plan (PRIORITY RECOMMENDATION)

a) **The North Carolina Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) should work with Local Management Entities (LMEs), community and institutional providers, the Department of Public Instruction (DPI), Division of Vocational Rehabilitation (DVR), Division of Medical Assistance (DMA), North Carolina Community College System, University of North Carolina System, individuals with intellectual and other developmental disabilities (I/DD)and their families, advocates, academics, and other appropriate people to develop a statewide transition plan. The plan should identify strategies to build community capacity to provide needed supports and services to people with I/DD. In developing this plan, DMHDDSAS should:**

    1) **Focus on transitions of people with I/DD from state developmental centers or large Intermediate Care Facilities for Persons with Mental Retardation to smaller community settings; from secondary school to postsecondary education, work, or other forms of community engagement;**

from foster care into adulthood; from home settings with natural supports to community supports and services; or due to the death or diminishing capacity of a parent or other caregiver.

2) **Identify the barriers which prevent successful transitions from one life setting to another, including state or local policies or procedures which create disincentives to successful transitions, and successful strategies from North Carolina or other states to address these barriers.**
3) **Identify positive, cost-effective examples of transitions in North Carolina to understand how to promote and sustain these practices throughout the state.**
4) **Identify the best practices from other states in more appropriately targeting resources to people based on the intensity of their needs.**
5) **Create a plan to provide targeted training and ongoing state-level support to LMEs and other appropriate organizations to assist with transition planning.**
6) **Identify the community supports and services needed to support successful transitions.**
7) **Assure that consumer choice is honored by maintaining and expanding options for service and supports appropriate to meet the broad range of consumer and family needs.**

b) **DMHDDSAS should identify the funding needed to support successful transitions, including the need for flexible funds that can be used to pay for one-time expenses or other services and supports not otherwise covered through existing programs. DMHDDSAS should explore all current funding sources, and, if appropriate, examine strategies to leverage existing state-only integrated payment and reporting system (IPRS) dollars to draw down additional federal Medicaid funds to serve people with I/DD.**

c) **DMHDDSAS should work with LMEs and providers to develop a performance-based accountability plan that includes incentives and contract requirements between DMHDDSAS, LMEs and providers. The plan should include meaningful transition performance measures for LMEs and providers to ensure that people with I/DD are provided the opportunity to maximize their independence and self-determination as they transition from one life setting to another and are served in the most integrated setting appropriate to their needs. The plan may include, but is not be limited to, financial incentive payments to overcome barriers to successful transitions.**

d) **DMHDDSAS should report on progress of the plan to the Joint Legislative Oversight Committee for Mental Health, Developmental Disabilities, and Substance Abuse Services no later than October 1, 2010.**

Recommendation 6.2: Transition Expertise at the State and Local Level (PRIORITY RECOMMENDATION)

a) **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 within DMHDDSAS and $2,660,000 to distribute to the Local Management Entities (LMEs) on a per capita basis to support developmental disability transition expertise at the local LMEs.

b) The developmental disability transition specialist within DMHDDSAS should be responsible for developing and monitoring the system to support transition services across the state. This specialist will report directly to the DMHDDSAS Division Director or a section chief for I/DD services and assist in:

  1) Identifying barriers, including state policies and practices, which prevent people from successfully transitioning from one life setting to another.

  2) Working with the state developmental centers, private Intermediate Care Facilities for Persons with Mental Retardation (ICFs-MR), community providers, and families to develop a transition plan to help people with I/DD move from large facilities into housing arrangements that promote independence, self-determination, and community inclusion.

c) Funding appropriated for the LMEs shall be allocated on a per-capita basis across LMEs. Funds shall be used to support knowledgeable developmental disability staff with transition expertise at the LME or regional level, including creation of transition teams with the variety of skills and expertise needed to support successful transitions. DMHDDSAS should establish clear performance expectations and outcome measures for the transition teams, including, but not limited to:

  1) Documenting that funds are used to support developmental disability staff with specific responsibility for systems change needed to support successful transitions.

  2) Demonstrating evidence of positive partnerships with other agencies that provide services and supports to people with I/DD, including Vocational Rehabilitation; schools; community colleges; employment agencies/services; housing providers; medical, dental, and behavioral health professionals; parent advocacy groups; and representatives of other organizations needed to facilitate successful transitions for the variety of needs experienced by target populations.

  3) Increasing the numbers of individuals who have successfully transitioned from state developmental centers or large ICFs-MR to more independent living, youth who have successfully transitioned from secondary to postsecondary or competitive work, and/or adults with I/DD who have successfully transitioned from their homes with aging caregivers into more independent living arrangements or remained in their family home with supports.

Aside from state and local developmental disability leadership, successful transitions are contingent on having community capacity to address the needs of people with I/DD. However, it is 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.

DMHDDSAS previously maintained an active, computerized waiting list to capture information on all the individuals who were eligible for developmental disability services in the state.[a] Prior to the reform of the state mental health, developmental disability, and substance abuse services system, local area programs (the precursor to LMEs) served as the single portal through which people received access to developmental disability services. The area programs maintained information in a standardized format on every person who was waiting for a developmental disability service (regardless of whether they were already receiving other services). The waiting list system also identified the number of people who were potentially eligible for or receiving Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities (CAP-MR/DD) Medicaid waiver services. With these data, DMHDDSAS could quantify the number of children and adults waiting for services by type of service and geographic area of the state. DMHDDSAS used these data for many different purposes, including identifying the need for additional services, examining trends in service utilization, and determining where to allocate new CAP-MR/DD slots. Maintenance of this statewide waiting list was discontinued in 2001 when the state abolished the single portal of entry system as part of mental health reform. The Task Force strongly believed that DMHDDSAS should reinstate a waiting list system to capture similar information about the unduplicated number of adults and children waiting for services and the types of services needed. It will be very difficult for North Carolina to develop an overall transition plan for the state or to build community capacity without reinstating the waiting list.

The Division of Mental Health, Developmental Disabilities and Substance Abuse Services should reinstate a waiting list system to capture information about the unduplicated number of adults and children waiting for services and the types of services needed.

Other data are needed to ensure the quality and adequacy of the community services and supports. One source, used by 30 states, is the National Core Indicators (NCI).[2,b] The NCI has more than 100 performance measures, including service use indicators, usage and satisfaction indicators, and outcome variables. North Carolina already collects some, but not all, of the performance measures. One of the advantages of collecting the full set of NCI measures is the ability to compare outcome and quality variables across states and across LMEs within the state, so that North Carolina can better identify and learn which investments yield better outcomes and why. DMHDDSAS should examine what other performance measures are available through the NCI that would assist in management of transition planning. These data would be helpful in shaping the state's overall state transitions plan and in building community capacity.

Some of these data may be able to be captured in electronic health records (EHRs). The American Recovery and Reinvestment Act provides $19 billion to develop standards for interoperability of Health Information Technology (HIT) and to support the implementation of EHR.[c] Governor Perdue has developed a working group to determine how these funds could be used to support the development

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[a] Porter P. Professor, University of North Carolina School of Medicine, Department of Allied Health Sciences. Written (email) communication. March 4, 2009.

[b] Information about the National Core Indicators is available at http://www.hsri.org/nci/.

[c] Pub L No. 111-005.

and implementation of EHRs in North Carolina. The North Carolina Department of Health and Human Services should ensure that the EHRs can also capture data on the case management, services, and support needs of people with mental health, substance abuse, or developmental disabilities. Developing EHRs that capture health, dental, mental health, substance abuse, and other support needs for people with I/DD will ensure that their needs are more easily coordinated by different providers of services and supports, leading to improved outcomes and more cost-efficient care.

To ensure that the state has the information needed to develop a statewide transition plan, the Task Force recommends:

Recommendation 6.3: Enhanced Data Collection (PRIORITY RECOMMENDATION)

a) The Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) should work with the Governor's office to ensure that state, Local Management Entities (LMEs), and private providers of mental health, developmental disabilities, and substance abuse services are part of the statewide health information technology (HIT) plan developed in response to the federal American Recovery and Reinvestment Act.

   1) DMHDDSAS should involve state developmental centers, LMEs, and private providers as it identifies or develops an electronic health record system (EHR) for people who receive mental health, developmental disability, or substance abuse services. In addition to health care information, the EHR should have the capacity to collect information on long-term supports and services provided for people with intellectual and other developmental disabilities (I/DD).

   2) The DMHDDSAS HIT system should ensure that the EHR can be accessed on a real time basis by the consumer and all of the agencies or providers who are proving health, behavioral health, developmental disability, case management, direct support, or other supports.

   3) The DMHDDSAS HIT system should also capture data in a uniform format that can be used to maintain waiting list information as described in Recommendation 6.3b, and to determine progress in building community capacity.

   4) The North Carolina General Assembly 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 EHR system.

b) DMHDDSAS should create a statewide waiting list system to maintain lists of people with I/DD who are waiting for specific services. DMHDDSAS should ensure that the EHR system will capture the waiting list data. However, until the data can be captured via the EHR system, DMHDDSAS should institute an active, computerized waiting list system. DMHDDSAS should develop standardized criteria to ensure that the waiting list data are collected consistently across LMEs. The system should include information on the following:

1) **The numbers of people with I/DD who have been found to be eligible for developmental disability services and supports and who are unable to be served immediately because of lack of funding or service availability.**
2) **What services or supports the individual is waiting for and date of initial placement on the list, including health, behavioral health, dental, specialized therapy services, residential, vocational, educational, assistive technology, and other support services.**
3) **The age of individuals waiting for services and supports.**
4) **Which individuals on the waiting list are receiving or are potentially eligible for Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities.**
5) **Any other data needed to identify unmet needs for specific groups of people with I/DD.**

c) **DMHDDSAS, in conjunction with the LMEs and public and private providers of developmental disability services should examine what data are needed to support successful transitions. As part of this analysis, DMHDDSAS should identify what data are already being collected that could be analyzed for transitions purposes and what new data are needed to better inform the state and LMEs to support successful transitions. DMHDDSAS should identify funding needed to support the data plan and present an overall data plan to the Joint Legislative Oversight Committee on Mental Health, Developmental Disabilities, and Substance Abuse Services no later than October 1, 2010.**

d) **The North Carolina General Assembly should appropriate $72,765 in recurring funds to DMHDDSAS in SFY 2010 and SFY 2011 to support one new position to manage and analyze data and to assist with waiting list coordination and management.**

e) **DMHDDSAS should use these data, along with information from individual assessments, for statewide planning, needs projections, and quality improvement. On an annual basis, DMHDDSAS should report to the Joint Legislative Oversight Committee on Mental Health, Developmental Disabilities, and Substance Abuse Services the services that are most in need throughout the state and plans to address unmet needs, as well as any cost projections to provide needed services.**

Financing

Most adults with I/DD receive either Supplemental Security Income or Social Security Disability Income to help them meet their basic subsistence needs. In addition, people with I/DD rely on Medicaid and/or state funds to help them pay for needed services and supports. As noted in Chapter 2, North Carolina spent a total of $1.2 billion in 2006 for people with I/DD.[3] Medicaid and state funds appropriated to the DMHDDSAS system are the primary sources of funding for services and supports for people with I/DD, although other state and federal funds are used to provide specific services and supports to people with I/DD (such as federal funds that support Vocational Rehabilitation or educational services for people with disabilities in the school setting). It is important for the state to use federal and state dollars in the most efficient way to provide services for individuals with I/DD, and to ensure that the funding is used to achieve ends most valued by people with I/DD and their families.

Equitable Allocation of Limited State Resources

One of the biggest challenges the state faces is how to use limited state resources in the most equitable way possible. This is always an important consideration, but especially so during tight fiscal years. In 2006, North Carolina was estimated to have spent over $1.2 billion on services for people with I/DD, with 53% ($643.2 million) of the funding coming from the federal government, 41% ($493.7 million) from the state,[d] and 6% ($67.4 million) from local sources.[3] Although this seems like a large amount of money, people with I/DD require comprehensive, life-long services and support. The Task Force heard from numerous people that the state is not currently reaching everyone in need, nor is it providing all the needed services and supports for the people who are currently receiving services. More funding will be needed to ensure an adequate array of community-based services and supports to help people with I/DD before, during, and after transitions. However, we also have a responsibility to ensure that limited state dollars are used as equitably and cost-effectively as possible.

In 2006, North Carolina was estimated to have spent over $1.2 billion on services for people with intellectual and other developmental disabilities…the state is not currently reaching everyone in need, nor is it providing all the needed services and supports for the people who are currently receiving services.

People with I/DD with similar functional abilities and concomitant needs for support often receive different levels of funding. This is due, in large part, to how funds are allocated. Five primary factors influence the amount of funds that are allocated to support people with I/DD: the quality of the assessment process, the individual's Person Centered Plan, skills of the case manager, availability of CAP-MR/DD slots, and where the person receives services.

- ***Individual assessment process:*** Everyone in the developmental disability service system currently has their need for services and supports assessed by using the North Carolina Support Needs Assessment Profile (NC-SNAP). As described more fully below, this is not a particularly effective tool in determining differences in the level of support needs among people in the developmental disability system. Individuals with I/DD may also receive different vocational or health assessments. The information from the different assessments is used in the person centered planning process.
- ***Person Centered Plan:*** A Person Centered Plan (PCP) is an individualized plan that involves the person with I/DD, parents, and those closest to the individual. The plan is developed in conjunction with an interdisciplinary team whose first responsibility is to get to know the individual and his or her talents and dreams. The plan is driven by the individual's and family's choices and preferences, individual assessments, and builds on the person's strengths, hopes, and aspirations.[4] The PCP helps identify the person's unique need for supports and services by examining the person's natural supports, type and intensity of needs (e.g. medical,

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[d] State funding includes state Medicaid matching funds, state augmentation of federal Supplemental Security Income (SSI) payments, and other state funds.

health, vocational, behavioral, communicative, and educational), and the individual's goals and aspirations.

- ***Skills of the case manager:*** The skills and knowledge of the case manager play important roles in helping the individual obtain needed services and supports. Knowledge and experience with people who have I/DD, understanding of the array of available services and the resources within a particular community, and access to funding are essential. Skilled and knowledgeable case managers act as care coordinators, helping to link the individual with available resources in the community. If one resource is not available, a skilled case manager can help identify other sources of needed medical, social, educational, or other services available in the community. Skilled case managers can also act as advocates for the person with I/DD, ensuring that the person receives the appropriate services and supports. In contrast, case managers who lack the necessary skills or knowledge can be an impediment to the individual with I/DD by linking them to inappropriate services or otherwise failing to act on the individual's behalf.

Skilled and knowledgeable case managers act as care coordinators, helping to link the individual with available resources in the community.

- ***Availability of CAP-MR/DD slots:*** As noted earlier, CAP-MR/DD is not an entitlement program. The availability of CAP-MR/DD slots is based on the number of slots the state seeks in its waiver application that is approved by the US Centers for Medicare and Medicaid Services (CMS) and the funding approved by the North Carolina General Assembly to fund those slots. To qualify, a person must need ICF-MR level of care and must be able to be maintained safely in the community with appropriate supports and services. Since the state limits the number of people it will serve through CAP-MR/DD based on the approved number of slots and legislative funding, there are people who would otherwise qualify for CAP-MR/DD who cannot receive those services. In January 2009, there were 10,130 people receiving CAP-MR/DD services.[e] Of these, 9,893 individuals with I/DD were eligible for the comprehensive CAP-MR/DD waiver, and 237 were receiving the more limited supports waiver (which provides up to $17,500/year in coverage).[f] While some state funding is available to people who would otherwise meet CAP-MR/DD needs, the state funds are more limited.
- ***Where the person receives services:*** Individuals with the same needs for services and supports may receive different levels of funding based on where they receive services. Residential providers (i.e. state developmental centers, private ICFs-MR, or group homes) are typically paid based on their licensure status. Thus, an individual who lives in a state developmental

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[e] Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities slots are generally allocated to Local Management Entities on a per capita basis.

[f] Burnette R. Waiver Project Manager, Division of Mental Health, Developmental Disabilities and Substance Abuse Services, North Carolina Department of Health and Human Services. Written (email) communication. March 3, 2009.

> center may use more state and federal dollars than the same individual if he or she moves to a private ICF-MR, developmental disability group home, or other residential setting. Some of the differences in payment are due to differences in the array of services and supports offered to the individual. Other differences are due to the state's payment structure, as the state (DMHDDSAS or the Division of Medical Assistance (DMA)) pays residential providers based on their licensure status rather than on the individual needs of the person.

Other states have begun to address the broader question of equitable allocation of limited resources …by using a reliable and validated assessment instrument…to obtain objective information about a person's needs for supports and services.

Other states have begun to address the broader question of equitable allocation of limited resources. In the past, North Carolina used the North Carolina Support Needs Assessment Profile (NC-SNAP) to assess the support needs of people with I/DD. It has never been used in the state for resource allocations. When properly administered by qualified independent assessors, some research has shown that the NC-SNAP is a reliable and validated instrument.[5] However, as currently administered, it does not show differences in level of support needs among people living in state developmental centers and private ICFs-MR.[g,6] The NC-SNAP is administered by people who have been trained and certified, but who often work for the provider agencies.[h] The assessments are not currently conducted by independent assessors (although independent assessors do a "look-behind" audit of a randomly selected sample of 5% of the assessments). Some of the members of the Task Force expressed concern that the lack of an independent assessment by trained professionals can lead to inaccurate level of support needs determinations, as there may be an incentive for providers to artificially inflate the NC-SNAP scores in order to justify placement or support needs.

Thompson et al. with the American Association on Intellectual and Developmental Disabilities, developed the Supports Intensity Scale™ (SIS) to assess the support needs of people with I/DD.[7] Ten other states are using it to obtain objective information about a person's needs for supports and services.[i,8] For example,

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[g] The Task Force heard that people in the state developmental centers generally have higher needs for services, supports, and health care than those living in private Intermediate Care Facilities for Persons with Mental Retardation (ICFs-MR) or receiving Community Alternatives Program for Persons with Mental Retardation/ Developmental Disabilities (CAP-MR/DD)-funded services. As noted earlier in the report, there is a significant age difference between the people in the three settings. The average age of individuals living in the state developmental centers is 51 compared to 38 for people living in private ICFs-MR and 27 for the CAP-MR/DD waiver. Given the age differences, and the information presented by some of the members of the Task Force, one would expect that the people in the state developmental centers would have higher needs for services and supports. Levels of need based on the current assessment instrument, the North Carolina Needs Assessment Profile (NC-SNAP), shows similar overall scores and scores for daily living supports, health care supports, and behavioral supports for individuals living in state developmental centers and those in private ICFs-MR. (The Task Force was unable to get the data from the NC-SNAP for people receiving CAP-MR/DD as it is part of a very large database, and there was insufficient time to obtain the data.).

[h] The NC-SNAP is often administered by case managers for people living in the community. The community ICFs-MR and state developmental centers have trained examiners who administer the Supports Intensity Scale (SIS) to their own individuals.

[i] The SIS is currently being used in Colorado, Georgia, Louisiana, Missouri, Nebraska, Oregon, Pennsylvania, Utah, Virginia, and Washington. Florida, Oklahoma and California are also considering using the SIS. North Carolina is using the SIS with Piedmont Local Management Entity and is being pilot tested in other parts of the state. (Carter C. Using the Supports of the Intensity Scale for determining the intensity of needs for persons with intellectual and developmental disabilities. Presented to: the North Carolina Institute of Medicine Task Force on Transitions for People with Developmental Disabilities. January 21, 2009; Morrisville, NC.)

Washington State is using the SIS to develop a standardized rate structure for its residential programs based on the support needs of the individual residents.[9] Louisiana is using the SIS to develop individual resource allocations.[10] The SIS instrument was developed for adults with intellectual disability, and a similar instrument for children is currently in development. The SIS has not been validated on individuals who have physical disabilities in the absence of intellectual disabilities. The SIS instrument has been validated on persons with I/DD and has high inter-rater reliability when administered by trained assessors.[11,12] North Carolina has begun to pilot test this instrument with a group of adults who currently reside in the community who are supported through the CAP-MR/DD or supports waiver. It is currently being piloted in seven LMEs and is being used as the assessment instrument for people with I/DD as part of the Piedmont LME innovations waiver.[8,j] These LMEs are using the SIS to gather data on the variation in needs for services and supports for different people with I/DD. Ultimately, North Carolina plans to use this information to help with the development of an objective system for individual resource allocations.

The SIS is an assessment tool that measures the intensity of daily supports an individual with I/DD needs to live as independently as possible in the community.[8] The SIS is comprehensive in scope and includes questions to assess home living, community living, lifelong learning, employment, health and safety, social protection and advocacy, exceptional medical support, and behavioral support needs.[k] The SIS is not intended to replace diagnostic or professional assessments, since its primary focus is on intensity of support needs of people with I/DD. Thus, the results of the SIS should be combined with other assessments (e.g. psychological, nursing, speech, occupational, or physical therapy assessments) to assist the individual, his or her family, and other support team members in establishing the Person Centered Plan (PCP).

The information from a reliable and validated assessment instrument can be used to support at least three purposes: setting budget caps, establishing appropriate provider payments, and identifying overall system needs.

Data for the SIS, or other similar assessment instruments, can be used to determine the supports and services needed by people with intellectual disabilities and their intensity of need. However, to be accurate, the assessment should be administered by independent, trained, and credentialed professionals who are not employed by a provider agency. The information from a reliable and validated assessment instrument can be used to support at least three purposes: setting budget caps (or tiered funding); establishing appropriate provider payments; and identifying overall system needs. First, the SIS results can be used, along with other information, to establish individual cost ranges, tiered payments, or individual resource allocations appropriate for people with different levels of support needs.[7] Under this system, people with more extensive support needs qualify for a higher personal budget, and those with lower support needs have a lower cap. This system looks both at the individual's strengths and needs and the level of the person's natural

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[j] The seven Local Management Entities that are piloting the Supports Intensity Scale (SIS) include Durham, East Carolina Behavioral Health, Five County, Guilford, Mecklenburg, Sandhills, and Smoky Mountain.

[k] The SIS measures support requirements in 57 life activities and 28 behavioral and medical areas. The assessment is done through an interview with the consumer and those who know the person well.

supports. For example, some states have developed formulas in which a person with extensive natural supports (e.g. family and friends) may receive a lower resource allocation than a person with an equivalent level of I/DD who has no natural supports. The state may either set a tiered funding level (e.g. a person with a specified level of need can qualify for a dollar range of support) or set individual resource allocations (e.g. a fixed amount of money that is dedicated to support an individual). In either case, the data from the assessment instrument would be combined with other professional assessments to determine the appropriate funding tier or resource allocation. The SIS could be used to assist in the development of the PCP as well as be used to determine what services and supports the person would receive within the tiered budget or individual resource allocation. Tiered budgets or individual resource allocations can also be used to support expansion of North Carolina's efforts to provide self-directed services and supports (described more fully below).

The Supports Intensity Scale can be used to adjust payments to providers to more accurately reflect the differences in the needs of people they serve.

Second, data from the SIS can be used to establish appropriate payment levels to providers.[7] As noted earlier, some providers are currently being paid based on their licensure status rather than on the specific needs of the individuals they are serving. This provides an incentive for providers to serve those with less intense needs, as they are paid the same regardless of whether they are serving people with more extensive or less intensive needs for services and supports. The SIS can be used to adjust payments to providers to more accurately reflect the differences in the needs of the people they serve. This is similar to the methodology that the state uses to set Medicaid payments to nursing homes.[13,l] Finally, information from the SIS can also be used to support statewide and local planning. These data, combined with other information from waiting lists will be very helpful in determining what types of services and supports are needed in particular communities and across the state.

North Carolina has already begun to implement the use of the SIS to assist in developing the PCP. However, using the SIS data to establish caps or tiered payments is a much more complicated process.[7] No assessment instrument can be used to determine individual resource allocations or tiered payments in isolation. Resource allocation is a complex process that includes not only information from a specified instrument, such as the SIS or NC-SNAP, that identifies intensity of support needs but also is inclusive of a host of other variables as well as professional assessments. Other variables may include age, diagnoses, level of functioning, and where individuals live (i.e. urban or rural areas). More work is needed before North Carolina can use the SIS—or other assessment instrument—to assist in the development of hard caps, tiered payments, or individual budgets.

Thus, the Task Force recommends:

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[l] In October 2004, the North Carolina Division of Medical Assistance implemented a case mix adjustment methodology to pay nursing facilities based on the level of nursing, nursing assistance, and therapy time needed by their residents. Residents are assessed to determine the level of needs and then classified into one of 34 different Resource Utilization Groups (RUGS) based on the results of the assessment. The nursing home is paid based on a weighted RUGS score.

Recommendation 6.4: Use of a Standardized Assessment Instrument (PRIORITY RECOMMENDATION)

a) The Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) should adopt a validated and reliable assessment instrument that can be used for people with intellectual and other developmental disabilities (I/DD) to provide information on the person's relative intensity of needs. The assessment instrument should be administered by independent, trained, and credentialed professionals who are not employed by provider agencies.

b) Data from the assessment instrument should be used:

1) To assist in the development of the Person Centered Plan (PCP). Case managers should use the information from a standardized assessment instrument, along with other medical or professional assessments, to help an individual with I/DD develop his or her PCP. The development of the PCP should be a collaborative process built upon the goals and aspirations of the person with I/DD or the family of a child.

2) For statewide and local planning purposes, data from an assessment instrument administered to all children and adults eligible for developmental disability services, along with information from the statewide waiting list, should be used to determine the types of community supports and services needed to support people with I/DD.

3) In determining an individual resource allocation, DMHDDSAS should use data from a standardized assessment instrument, in conjunction with other specified assessments and variables, to develop relative intensity of need measures for all persons eligible for developmental disability services in the state. The results of this testing for each person will allow assignment of that person to state-established individual resource allocations or tiered payment levels in order to more appropriately target state and federal funding based on the individual's intensity of needs.

4) In setting payment levels to specific providers, DMHDDSAS should use the data from a standardized assessment instrument to adjust payments to providers to ensure that the provider payments are based on the intensity of needs of the people served by the provider.

c) DMHDDSAS should develop a formula for a fair, equitable, and consistently applied allocation of resources that can be applied statewide. This formula should be based on a reliable and valid assessment of relative intensity of need for all children and adults who are receiving services. The North Carolina General Assembly should appropriate $463,924 to DMHDDSAS to continue to test the Supports Intensity Scale™ (SIS) to determine whether this assessment instrument can meet state needs as specified in subparagraph a. In identifying an appropriate assessment instrument, DMHDDSAS should examine the costs of implementing the SIS in comparison to the North Carolina Support Needs Assessment Profile (NC-SNAP) or other instruments already in use in North Carolina, the usefulness of these instruments in determining relative intensity of needs, and the experiences from other states that have used the SIS, the NC-SNAP, or other assessment instruments for these purposes.

To the maximum extent possible, individuals with I/DD should be involved in all aspects of decision making about their lives ("self-determination"). Most people in the United States take certain choices for granted, including the food they eat or the clothes they wear. Yet, people with I/DD are not always afforded these choices. Similarly, we all want to have some say in where we live, our friendships, job choices, and how we spend our leisure activities. Individuals with I/DD should be afforded these same choices. People with I/DD should participate in all aspects of decision making about their lives, including involvement in selecting the people who will provide them with needed services and supports from those qualified to provide services.

North Carolinians with I/DD are less likely to be involved in decision making about their lives than are people with I/DD in many other states. The NCI includes a consumer survey to find out whether people with I/DD report being involved in key decisions about their lives, from where they want to live, who they live with, where they work, or what to do on a daily basis. In most categories, North Carolinians are far less likely to report that they have a choice in these decisions than people with I/DD living in other states.[m] (See Table 6.1.)

North Carolinians with intellectual and other developmental disabilities (I/DD) are less likely to be involved in decision making about their lives than are people with I/DD in many other states.

Table 6.1
People with I/DD Who Report that Other People Make Important Decisions without Their Involvement

Percent Reporting that Someone Else...	NC	US
Chose the place where you live	66%	53.5%
Chose who you live with (or to live by yourself)	68.7%	60.3%
Chose where you work (or go during the day)	51.5%	42.6%
Decides your daily schedule	23.7%	20.5%
Chose your case manager/service coordinator	36.2%	46.1%

Source: National Core Indicators. Consumer Outcomes. A Collaboration of the National Association of State Directors of Developmental Disabilities Services and Human Services Research Institute. Phase X Final Report. 2007-2008 Data. Questions 35, 37, 39, 41, 45.

Consumer-directed budgeting, which is typically part of a consumer-directed program, is a more expansive form of self-determination. Typically, this is referred to as "self-direction." As part of a consumer-directed Medicaid program, consumers are given a certain budget and then can decide what services and supports they want to purchase within this budget. The budget amount—or individual resource allocation—would be based on the results of the standardized assessment instrument (noted above), other professional assessments, and the PCP. The person with I/DD, and his or her family, can purchase services and supports from specific agencies or funds can be used to hire family or friends to provide services and supports. In 2006-2007, Walker et al. conducted a national study to determine

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[m] People with intellectual and other developmental disabilities in 24 states participated in this consumer survey and responded to these questions.

where and how states were implementing consumer-directed budgeting for people with I/DD. The authors determined that 13 states offered families the option of consumer-directed budgeting for all Medicaid recipients with I/DD receiving waiver services, and an additional 11 states were pilot testing consumer-directed budgeting or offered it in limited areas.[14,n] (See Table 6.2 on following page.) North Carolina was not operating a consumer-directed budgeting program for people with I/DD under its waiver at the time of the study.

States are still in the early stages of testing the consumer-directed supports model, so there have been few studies of consumer-directed programs for people with I/DD. This model has been evaluated for older frail adults (outside the developmental disability system). Researchers found that consumers who directed their own budgets were more satisfied with the services they received, reported a higher quality of life, fewer unmet needs, and received more care.[15,16] The early studies of the consumer-directed budget program for people with I/DD in other states have also been positive.[14]

Early studies of the consumer-directed budget program for people with intellectual and other developmental disabilities in other states have been positive.

DMHDDSAS recently obtained approval from the US Centers for Medicare and Medicaid Services (CMS) to implement the North Carolina Supports Waiver. This is for people who are eligible for Medicaid waiver services, but because of natural or other supports only want or need a limited amount of services. The maximum payment under the Supports Waiver is $17,500/year. As part of the waiver request, DMHDDSAS sought authority to offer consumers the option of directing their own budget allocations. This consumer-directed budgeting option is scheduled to be implemented November 2009.

Recommendation 6.5: Consumer-Directed Supports

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 should systematically move to expand consumer-directed budgeting to other people with I/DD who have more significant needs, and should report its progress on reaching this goal to the Joint Legislative Oversight Committee on Mental Health, Developmental Disabilities, and Substance Abuse Services no later than October 1, 2010.

Flexible Funding

One of the other problems that the Task Force identified was the lack of flexible funding to assist people in their transition. Often, individuals who are

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[n] States have implemented the programs somewhat differently. Some of the key differences include: 1) who is eligible to participate in the consumer-directed supports program; 2) assistance offered in managing services and financial oversight; 3) guidelines for who can be hired to provide support services; and 4) systems to ensure quality and accountability. (Walker P, Hewitt A, Bogenshutz M, Hall-Lande J; Research and Training Center on Community Living, Institute on Community Integration/UCEDD, College of Education and Human Development, University of Minnesota. Implementation of consumer-directed services for persons with intellectual or developmental disabilities: a national study. http://ici.umn.edu/products/prb/201/default.html. Published January 2009. Accessed February 27, 2009.)

Table 6.2
Number of Individuals or Families with Individual Budgets by State (2006-2007)

	Individuals/ Families with Consumer Directed Budgets	Medicaid Waiver Participants with I/DD	Medicaid Waiver Participants with I/DD Controlling Own Budget
Available Statewide			
Vermont	1,060	2,102	50.4%
Oregon	4,000	9,416	42.5%
Michigan	3,000	8,283	36.2%
Utah	1,300	3,986	32.6%
South Dakota	815	2,522	32.3%
Connecticut	1,272	7,232	17.6%
New Hampshire	400	3,205	12.5%
Hawaii	245	2,363	10.4%
Texas	1,303	13,999	9.3%
Minnesota	1,300	14,291	9.1%
Rhode Island	114	3,073	3.7%
Massachusetts	200	11,460	1.7%
Tennessee	85	6,962	1.2%
Limited Area or Pilot Project			
Wisconsin	1,035	13,938	7.4%
New Jersey	450	9,611	4.7%
Florida	1,000	31,324	3.2%
Ohio	200	14,370	1.4%
Kansas	80	6,869	1.2%
Nebraska	22	3,238	0.7%
Missouri	30	8,183	0.4%
Oklahoma	15	5,043	0.3%
California	150	69,782	0.2%
New York	90	54,251	0.2%
Louisiana	13	5,484	0.2%

Source: Walker P, Hewitt A, Bogenshutz M, Hall-Lande J; Research and Training Center on Community Living. Implementation of Consumer-Directed Services for Persons with Intellectual or Developmental Disabilities: a national study. Policy Research Brief. http://ici.umn.edu/products/prb/201/default.html. Published January 2009. Accessed February 27, 2009.

Often, individuals who are transitioning from state developmental centers or large Intermediate Care Facilities for Persons with Mental Retardation or their home environment to more independent living in the community need funding to help with one-time expenses.

transitioning from state developmental centers or large ICFs-MR or their home environment to more independent living in the community need funding to help with one-time expenses, such as, but not limited to, security deposits or utility set up fees, and funding to purchase household furnishings, moving expenses, or assistive technology.[17] LMEs may also need flexible funding to pay for services or supports that are not otherwise covered through existing funding streams. CMS allows states to use Medicaid funds to pay for these one-time expenses for individuals who qualify under the CAP-MR/DD program. LMEs that receive single-stream funding also have some flexibility in addressing the unique transition needs for people with I/DD; however, with limited overall funding, using state funds for this purpose could mean fewer funds to support the needs of other people with mental illness, developmental disabilities, or substance abuse problems.[o] Other LMEs that receive categorical funding can use up to 5% of their state developmental disability funds to support transitions, but this flexibility is limited to support individuals who are seeking to move from a state developmental center back to the community.[p] In the first three months of operation (September 1, 2008-December 31, 2008), LMEs only reported using less than $5,000 to support transitions for eight individuals (four other individuals transitioned to the community using waiver funding only).[18] LMEs reported specific challenges moving people with I/DD from state developmental centers back to the community, including:

- State funding cuts which make it more difficult to meet the needs of consumers who are being served in the communities and are not receiving Medicaid-funded services.
- Difficulty finding appropriate community services and supports that meet the intensity of support needs of some individuals who live in the developmental centers.[q]
- Some guardians or family members are opposed to the transition out of the developmental center.

Ultimately, all Local Management Entities need additional flexible transition dollars to fill in gaps in what is available through other program funds.

Ultimately, all LMEs need additional flexible transition dollars to fill in gaps in what the state or federal CAP-MR/DD program normally supports. The flexible funding should be in addition to existing funding, so that the people who are currently being served by state funds do not lose services in order to provide flexible funding to support the needs of others in transition. However, until the North Carolina General Assembly appropriates new funding, the state should allow some flexibility in existing funding for this purpose. Therefore, the Task Force recommends:

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[o] Local Management Entities (LMEs) have to meet certain requirements to qualify for single stream funding. For example, LMEs must show that they have spent at least 85% of their allocated funding and must meet or exceed state performance benchmarks for a minimum of 65% of the designated performance measures. In addition, LMEs must provide certain assurances to the state. For example, the LME must assure that it will continue to provide services to target populations and that it will report on services provided on a monthly basis. (DMH/DD/SAS Standards for LME Qualification for Single Stream Funding for SFY 08 and SFY 09. Effective October 1, 2007. Available online at unce/commbulletins/commbulletin081/handoutstandards forsinglestreamfunding.pdf.)

[p] Section 10.15(t) of Session Law 2008-107.

[q] The state can limit the use of the most expensive settings to those individuals who clearly require the highest intensity of services by implementing the recommendations included in this report. Currently, there is no way of assuring that only individuals with the most substantial needs are being provided the high intensity services. If the state implements a standardized assessment instrument and uses that, along with other assessment data, to set resource levels, it will help ensure that individuals with the most substantial needs receive an intensity of supports that is appropriate to their needs.

Recommendation 6.6: Flexible Funding

a) The Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) should work with the Local Management Entities (LMEs) to examine the need for flexible funding to support transitions from state developmental centers or private Intermediate Care Facilities for Persons with Mental Retardation (ICFs-MR) to integrated settings in the community or to prevent individuals from being placed into state developmental centers or private ICFs-MR. As part of this analysis, DMHDDSAS and the LMEs should:

   1) Identify the services or supports that cannot be funded through existing funding sources or for which funding is so limited as to not support transition needs.

   2) Identify what resources can already be used to support successful transitions.

b) Until additional funds are appropriated for this purpose, DMHDDSAS should work with the LMEs to support more flexible use of existing state dollars.

   1) DMHDDSAS should create policies to enable LMEs that receive single stream funding to use their resources to pay for transition expenses. LMEs should be required to report on the amount of funding, how the funds were used, and source of funds used for transition purposes to help DMHDDSAS identify the amount of flexible funding needed statewide and the impact of allowing flexible funding on the provision of services to other people with mental health, developmental disabilities, or substance abuse needs.

   2) DMHDDSAS should seek legislative authority to have the discretion to review and approve LMEs' use of state developmental disability funds in excess of 5%, if being used to support specific transition plans for individuals transitioning from one life setting to another. LMEs must provide evidence of how the flexible state funds will be used to support specific transition plans in order to seek approval for flexible funding in excess of 5%. LMEs must report on the amount of funds and how the funds will be used to help DMHDDSAS develop a plan for flexible funding.

Case Management

Case managers play a central role working with an individual with I/DD and his or her family to ensure that the needs of the person are being met. Ideally, developmental disability case managers work with an individual, his or her family, and an interdisciplinary team to develop the Person Centered Plan (PCP). Once the PCP is developed, the case manager helps coordinate and monitor services. Case managers must be 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. Good case managers are well-trained, have a reasonable case load, and have the time to develop positive working relationships with an individual, his or her family, and their community. They serve a critical role in helping people transition from one life setting to another. Case managers help people with I/DD and their families identify their options and the appropriate medical, social, educational, vocational, and other services and providers for the person's unique needs. Additionally, they monitor the services being provided to ensure these meet the person's goals, as well as circumstances that merit changes in the PCP.

Both Medicaid and the state will help pay for case management services. The federal Medicaid law allows states to pay for Targeted Case Management (TCM) services for people with I/DD who are transitioning out of state developmental centers. While federal law allows for 180 days of coverage, North Carolina has elected to pay for up to 60 days under the state Medicaid plan for both individuals receiving CAP-MR/DD and for those who are on the traditional Medicaid program. North Carolina can also pay for case management services to assist people with I/DD living in the community obtain needed services and supports. North Carolina also helps pay for some case management services for people with I/DD who do not otherwise qualify for Medicaid.

Case managers play an especially important role during transitional periods, when the individual with I/DD is leaving one system of services and supports and moving into a new phase of life. For example, an individual who is living in one of the state's three developmental centers may have difficulties transitioning back to his or her community without a well-trained case manager who will work with the individual, his or her family, the developmental center, the LME, and local providers to ensure that the person has the necessary services and supports in the community. Case managers often play similar coordination roles when individuals age out of the secondary school system or when people leave their family home because family members can no longer care for them.

Case managers play an especially important role during transitional periods, when the individual with intellectual and other developmental disabilities is leaving one system of services and supports and moving into a new phase of life.

Just as good case managers can provide assistance to individuals to help them obtain the services and supports needed to optimize independent living, work opportunities, and community engagement, so bad case managers can serve as obstacles to the individual and his or her family. Case managers who are not well-trained or who do not understand the developmental disabilities system may not know all available options for services and supports. Case managers who have large case loads may not have the time to actively engage the individual with I/DD in developing the PCP and may not be able to adequately monitor the services provided to ensure the person is getting appropriate, high quality care. Further, the Task Force heard that there is high turnover among many case managers. This inhibits the provision of effective case management services.

Prior to reform of the mental health, developmental disability, and substance abuse system in 2001, Area Programs (the precursor to the LMEs) employed the case managers directly and had responsibility for the training and oversight of these staff. DMHDDSAS developed a case management training curriculum, and had the responsibility of providing regional training periodically to all new and experienced case managers. Under the current developmental disability system in North Carolina, LMEs contract with private organizations to provide case management services. Because of this structure, LMEs have less authority in supervising the quality of case management systems. Case managers can be employed by agencies that also provide services and supports. However, in order to reduce conflicts of interest, the state prohibits case managers from referring consumers to their own agency for services and supports.

As part of the Supports waiver recently submitted to CMS, DMHDDSAS defined basic requirements for case managers.[19] Under the waiver:

> "Case managers are professionals whose education, skills, abilities, and experience enable them to perform the activities that comprise Medicaid case management services. Qualified case managers shall meet the qualifications in (i) and (ii).
>
> (i) Be a qualified Developmental Disabilities Professional (QDDP) as defined below:
>
> An individual holding at least a baccalaureate degree in a discipline related to developmental disabilities and at least two fulltime years of supervised experience by a QDDP in working with the individuals with mentally retardation [sic] or who are otherwise developmentally disabled or hold a baccalaureate degree in a field other than one related to developmental disabilities and have three fulltime years of supervised QDDP experience in working with individuals with mentally retardation [sic] or who are otherwise developmentally disabled; and
>
> (ii) Staff must successfully complete First Aid, CPR, and other trainings required by DMH/DD/SA, and specific participant related competencies, along with any required refresher courses. Staff must have a criminal background check. Staff must have a valid North Carolina driver's license, a safe driving record and an acceptable level of automobile liability insurance, and North Carolina Health Care Registry."

While the Division of Mental Health, Developmental Disabilities and Substance Abuse Services has specified certain staff competencies for case managers, it has not instituted a minimum training requirement…nor has it instituted a statewide competency-based exam.

DMHDDSAS has established minimum requirements for case managers, including minimum educational requirements, First Aid, and CPR training, and not being listed on the North Carolina Health Care Registry.[r] DMHDDSAS has also identified other core competencies for professional and paraprofessional staff in order to be reimbursed under the CAP-MR/DD waiver. For example, staff must demonstrate the ability to support individuals based on the preferences and outcomes chosen by the individual, have a working knowledge of confidentiality rules and the

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[r] The North Carolina Division of Health Services Regulation (DHSR), within the North Carolina Department of Health and Human Services, maintains the Health Care Registry. The registry contains the name of any health care personnel involved in abuse or neglect of a resident in a health care facility (or home health), misappropriation of property, diversion of drugs, or fraud. Health care personnel include any unlicensed staff that has direct access to residents, clients, or their property. Health care facilities include, but are not limited to, state operated developmental disability centers, residential facilities, community-based providers of services for people with I/DD, or multiunit assisted housing with services. To be listed on the registry, DHSR must have screened the allegation and determined that an investigation is required or have found that the allegations are substantiated after an investigation. NCGS §131E-256.

consequences for not maintaining confidentiality, demonstrate the ability to implement the PCP, and understand the concepts of independence, productivity, integration, inclusion, and most integrated setting.[20] While DMHDDSAS has specified certain staff 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. Neither the state nor LMEs have responsibility to provide or assure training. Instead, agencies are required to show that the staff have been trained on these core concepts and must sign a paper to verify that the person has completed the training and understands these core concepts. In contrast, nurse aides who work in long-term care settings for the frail elderly must participate in a state-approved training curriculum and pass a state-approved competency exam (see the Direct Support Personnel section below).

The state could help improve the quality of case management services by implementing an electronic health record (EHR) that also includes case management capabilities. DMHDDSAS is currently in the exploration and design phase regarding the development of an EHR system that would capture health data for people with mental health, developmental disabilities, and substance abuse problems. The EHR would be standardized across providers and would enable real-time data sharing among LMEs, community service providers, case managers, and state mental health, developmental disability, and substance abuse facilities.

To improve case management services, the Task Force recommends:

Recommendation 6.7: Improving the Quality of Case Management Services (PRIORITY RECOMMENDATION)

a) 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 the people with intellectual and other developmental disabilities (I/DD) served and should help to improve retention of qualified case management staff. As part of the plan to ensure accountability of case managers, DMHDDSAS should:

   1) Examine the current training, oversight, and supervision requirements for case managers and make recommendations for how case management services can be improved. DMHDDSAS should identify and approve competency-based curricula that will ensure that people who have successfully completed the curriculum have demonstrated case management proficiencies for working with people with I/DD.

   2) Examine the option of instituting credentialing standards for case managers who have achieved certain competencies. The credentials should be portable between agencies serving people with I/DD.

   3) DMHDDSAS and DMA should ensure that case managers who are working with people with a dual diagnosis of mental illness and developmental disabilities are cross-trained and have specific competencies in both mental health and developmental disabilities.

4) Explore the option of requiring agencies that employ case managers to be licensed and demonstrate that their case management staff receive appropriate training and supervision, and that the agencies are in compliance with the state's accountability standards.

5) Examine different models of delivering case management services to ensure the competency, independence, and accountability of case managers. DMHDDSAS should examine the advantages and disadvantages of the existing case management system compared to statewide contracts for case management-only agencies, moving case management services back into Local Management Entities, or other options to improve case management services.

6) Explore the possibility of providing higher reimbursement to agencies and/or case managers that demonstrate certain proficiencies and/or have lower turnover rates.

b) The electronic health record system, developed in accordance with Recommendation 6.3, should allow case managers to have access to real time data to use to monitor changes in the health, behavioral, or functional status of the person with I/DD and to monitor services and supports provided to the person. The case management system should include intake, assessment, planning, monitoring, and quality assurance data and should be linked to the service billing systems to facilitate service coordination.

c) DMA should develop an approval process to authorize payment for up to 180 days of transition services as part of the Targeted Case Management under the Medicaid state plan for people moving out of state developmental centers or Intermediate Care Facilities for Persons with Mental Retardation.

d) 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.

Community Capacity

Individuals with I/DD need access to appropriate services and supports to help them live as independently as possible in the community. The range of necessary services and supports will vary, depending on the strengths and outstanding needs and preferences of each individual and any available natural supports. The needs for specific services and supports will also vary depending on whether a person is transitioning from one life setting to another or whether the person is in a stable living environment.

The state's developmental centers provide a full range of services and supports for people with more significant I/DD. In addition to providing stable housing with qualified staff, the developmental centers have 24-hour nursing or medical support, psychologists and psychiatrists to assist with mental health or behavioral issues, dental care, educational and vocational opportunities, recreational therapy, and access to assistive technology as well as special therapies and active treatment. As a result of the availability of these services, and because of the limited options (or limited exposure to viable options) in the community, some of the residents of the state developmental centers and their families prefer to have the individuals remain in the state-run facility.[21] They might be willing to move to the community if services appropriate to their family member's needs were available in the community.

Individuals who are transitioning out of secondary school and those who are transitioning from foster homes or out of their family homes may also need access to similar services and supports. Direct support workers (DSWs) provide many of the day-to-day services and supports. Thus, successful transitions are also contingent on the availability of an adequate supply of well-trained and caring DSWs.

Crisis Services

Transitions can be stressful. The transition may be as a result of illness or death of a family member who provides services or a closure of a group home. Moving from a known environment to one that is more unknown can be disconcerting to anyone. This is particularly true for some people with intellectual disabilities who may or may not fully understand what is happening or why they are changing their living environment. Stress can exacerbate behavioral problems. While not limited to transitions periods, stress can be exacerbated during transitions.

Last Session (2008), the North Carolina General Assembly appropriated funding to implement Systemic, Therapeutic Assessment, Respite and Treatment (START) crisis services. The START program provides community-based crisis prevention and intervention services to adults with I/DD and co-occurring mental illness and/or behavioral health needs. NC START provides 24/7 crisis response services, assessments and treatment planning, consultation, education, training, and respite services. Collaboration between service providers and service users is a critical component of the model. NC START operates statewide and is regionally based; there are two interdisciplinary teams and one respite home available in the east, central, and western regions of the state. Each respite home has four beds, two are designated as crisis beds, and two are to provide planned respite. The goal is to provide individually-based services and supports through cross-systems communication and collaboration.

The Systemic, Therapeutic Assessment, Respite and Treatment (START) Program provides community-based crisis prevention and intervention services to adults with intellectual and other developmental disabilities and co-occurring mental illness and/or behavioral health needs.

NC START was developed in response to the problem of inappropriate admissions of people with I/DD to the state psychiatric hospitals. In SFY 2007, there were a total of 1,028 admissions (representing 746 unduplicated individuals) to the state psychiatric hospitals for people with I/DD.[s] More than 90% of the admissions and readmissions involved consumers with I/DD and co-occurring mental health and/or substance abuse disorders. These data do not include the number of individuals who were referred to local community hospital emergency departments. In addition to state psychiatric hospital admissions, other people sought admission

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[s] Burnette R. Community Policy Management Section, Division of Mental Health, Developmental Disabilites and Substance Abuse Services, North Carolina Department of Health and Human Services. Oral communication. March 9, 2009.

to state-operated developmental centers. In the first half of SFY 2009, there were 120 admission inquiries. This is reflective of the need for comprehensive and accessible crisis services tailored to meet the support, behavioral, and health needs of people with I/DD. Although implementation of NC START will begin to address this need, additional crisis services are needed to make these services more readily available throughout the state, and to ensure that similar services are available for children with I/DD. To address this, the Task Force recommends:

Recommendation 6.8: Expansion of Crisis Services

a) **The North Carolina General Assembly should appropriate $2.7 million in recurring funds to the Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) to fully fund the existing Systematic, Therapeutic Assessment, Respite and Treatment (START) teams and $6.7 million in recurring funds 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 START model.**

b) **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 1, 2010.**

Housing

People with I/DD should have the opportunity to live in housing, integrated into the community, which promotes their maximum independence. They should have a choice in where they live and with whom they live. Yet too often, North Carolinians with I/DD report having little choice in where they live. Two-thirds of North Carolinians with I/DD who participated in the National Core Indicators (NCI) survey reported that they had no choice in where they lived or with whom they lived.[2] Being able to exercise choice in housing options, as with other key personal decisions, is critical to the overall well-being of the individual.

Two-thirds of North Carolinians with intellectual and other developmental disabilities who participated in the National Core Indicators survey reported that they had no choice in where they lived or with whom.

One of the barriers that prevent people from leaving state developmental centers or large ICFs-MR and moving into the community is the lack of appropriate housing options for people with I/DD. People with I/DD need access to a range of housing options, depending on their need for other services and support. Those with more intense or complex needs may need round the clock support or specialized medical/therapeutic services. Others may be able to live well on their own or with one or two other people. Housing must, at a minimum, meet the Americans with Disabilities Act standards for accessibility and must be affordable. People with I/DD may also need services to assist in the development of skills for daily living and these must be available to support and facilitate employment and/or postsecondary education.

There are many different community-based housing arrangements that may be appropriate for people with I/DD. These range from smaller ICF-MR group homes (with six or fewer beds) to homes owned or leased by the individual.

- ***ICFs-MR:*** ICFs-MR are licensed to provide services and supports for people with I/DD who have developmental disabilities and who need active treatment. These facilities must have at least one registered nurse or licensed practical nurse on the grounds at all times and at least one registered nurse on staff. Medical services must be available on a 24-hour basis.[t] These facilities must provide active treatment to meet the unique and specialized needs of each person who resides there.
- ***Group homes for adults with I/DD:*** Group homes are small residencies which care for two to nine adults who have I/DD. These homes serve people who are ambulatory. People in these homes participate in community activities or work.[u] Both group homes for adults with I/DD and Alternative Family Living arrangements are licensed as supervised living facilities.[v]
- ***Alternative Family Living:*** In some instances, people live in the home of someone who also provides services and supports. This home does not need to be licensed if the person is only providing services for one adult with I/DD. However, if the host family is caring for children, or more than one adult, then the home must be licensed as a supervised living residential facility. The licensure requirements are less stringent if the host family provides services for no more than three adults or children and no more than three children with developmental disabilities.[w]
- ***Host families:*** If the host family only offers room and board and no supportive services, then the home does not need to be licensed. Further, Alternative Family Living arrangements that provide services and supports to one adult do not need to be licensed.
- ***Supported apartments:*** These are independent apartment units that offer some supportive services, such as transportation, budgeting, and shopping. Some have staff that provide some assistance with daily living skills. These are generally not licensed facilities and do not have specific staffing requirements.

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[t] 10 NCAC 27G .2101.

[u] 10A NCAC 13H .0101 et. seq. People with intellectual and other developmental disabilities who live in public or private Intermediate Care Facilities for Persons with Mental Retardation may also work or participate actively in the community.

[v] Supervised living is a 24-hour facility which provides residential services to individuals in a home environment where the primary purpose of these services is the care, habilitation, or rehabilitation of individuals who have a mental illness, a developmental disability or disabilities, or a substance abuse disorder and who require supervision when in the residence. A supervised living facility shall be licensed if the facility serves either one or more minor clients or two or more adult clients. Minor and adult clients shall not reside in the same facility. Each supervised living facility shall be licensed to serve a specific population. Supervised living is inclusive of a facility in a private residence, which serves no more than three adult clients with a primary diagnosis of mental illness but may also have other disabilities or three adult clients or three minor clients whose primary diagnoses is developmental disabilities but may also have other disabilities who live with a family and the family provides the service. This facility shall also be known as an alternative family living or assisted family living arrangement (AFL).

[w] 10 NCAC §27G.5601.

- *Own home or natural family's home:* Some people with I/DD live in their own home or in a home with their natural family. Some of these individuals may need other services and supports, while others may be able to live independently or with his or her natural supports. These homes do not need to be licensed.

In comparison to other states, people with I/DD in North Carolina who receive residential supports are more likely to reside in small residences (with six or fewer residents) than the national average (71.3% compared to 70.1% nationally). However, North Carolinians who receive residential supports are less likely to reside in their own home or with a host family, and much more likely to live in a group home than the national average. (See Table 6.3.)

In comparison to other states, people with intellectual and other developmental disabilities in North Carolina who receive residential supports are…less likely to reside in their own home or with a host family, and much more likely to live in a group home than the national average.

Table 6.3
The Vast Majority of People with I/DD Receiving Residential Supports are Living in Smaller Group Settings with Six or Fewer Individuals (NC, US, 2004)

				Of the People Living in Residences with 1-6 People		
	All residents, all settings, all sizes	All residents, all settings, one to six residents	All settings of one to six as percent of all residents	Percentage living with host family	Percentage living in own home	Percentage living in agency home
NC	11,861	8,459	71.3%	(10.9%)	(26.3%)	(62.9%)
US	419,965	294,559	70.1%	(13.5%)	(36.4%)	(50.1%)

Source: Coucouvanis K, Prouty R, Lakin KC. Own home and host family options grouping rapidly as more than 70% of residential service recipients with ID/DD in 2004 live in settings of 6 or fewer. *Ment Retard.* 2005;43(4):307-309.

Although many people with I/DD are receiving residential supports and live in smaller group settings, the state is still unable to meet all of the housing needs of people with I/DD. Part of the problem is that most of the housing currently available for people with I/DD are licensed "facility-based" residential units.[22] That is, people in North Carolina are placed into a licensed facility when they are judged to have higher needs for support and services or when they are unable to obtain appropriate services and supports in the community.[x] The person can only stay in that housing unit as long as their level of need for services and supports does not change substantially. Individuals may have little ability in some licensed facilities to exercise choices about foods to eat, temperature of their rooms, or

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[x] The Division of Medical Assistance and the Division of Mental Health, Developmental Disabilities and Substance Abuse Services use the MR-2 form to certify that a person needs Intermediate Care Facility for Persons with Mental Retardation (ICFs-MR) level of care. ICF-MR level of care is a broad category that includes people who need more intensive level of services (typically provided through ICF-MR group homes) and those who could be served in the community through the Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities waiver. The MR-2 was not designed to distinguish between different ICF-MR levels of care. The Supports Intensity Scale, or standardized assessment instrument, discussed in Recommendation. 6.4 should be used to more adequately target resources based on the person's level of support needs.

when they come and go.[y] A person whose condition deteriorates may also be forced to move to a different residence. Not only does this cause disruption to the individual, his or her family, and the relationships he or she developed in the home, but it runs contrary to the state's goals of helping people live as independently as possible.

Another problem is the lack of housing options. Even when housing is or could be made available, many people with I/DD will need some residential supports to help them live independently. Further, many people with I/DD receive Supplemental Security Income (SSI) as their sole source of income ($674/month for an individual and $1,011/month for a couple in 2009). It is difficult for people to pay for room and board, residential supports, and also pay for other living expenses given the limited amount of funding that SSI provides. Thus, many people with I/DD need subsidies to help pay for housing and other supports.

One of DMHDDSAS's top priorities is to develop more options for permanent supportive housing.[23] With supportive housing, the services and supports are unbundled from the residential unit. Thus, the individual can tailor the services and supports to meet their specific need. As their needs change over time, so can their array of services and supports. Further, the person can continue to live in the housing unit as long as they meet their reciprocal obligations as a tenant or homeowner.[22]

In order to address the housing needs of people with I/DD, the state will need to develop new supportive housing options, expand the availability of residential supports, and identify new sources of housing subsidies. Each is described more fully below.

Expanding housing options: The state and private organizations have made significant progress over the last ten years to develop housing options for people with I/DD. There is at least one housing specialist in each LME. The housing specialists work with community service providers,[z] low-income housing developers, public and private housing agencies, advocacy groups, local and regional government, and faith-based organizations to expand the availability of affordable housing units for people with disabilities.[24] In addition, some housing specialists help individuals with disabilities access and maintain affordable housing and negotiate with providers to ensure that they provide reasonable accommodations to meet the needs of people with disabilities.

Limited state and federal funds are available to subsidize the development of new low-income housing units. Since 2002, the Department of Health and Human Services (DHHS) has partnered with the North Carolina Housing Finance Agency

Limited state and federal funds are available to subsidize the development of new low-income housing units… Since 2004, 10% of the Low Income Housing Tax Credit units developed in North Carolina must be set aside for people with disabilities.

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[y] Some of the members of the Task Force noted how residential housing rules, which limit the hours when a person can be outside the home, can interfere with job options that some people may have. Some jobs offer part-time employment in nontraditional work hours (e.g. after 5pm). If the individual is limited in when they can leave the residence, then they may not be able to accept those employment opportunities.

[z] For example, The Arc of North Carolina has developed housing options as an alternative to large institutional settings, including 211 group homes with five to six residents, 15 small supervised apartment buildings, eight two-bedroom condominiums, and four duplex apartment buildings.

(NCHFA) to make housing units available to persons with disabilities in the Low Income Housing Tax Credit (LIHTC) program. The LIHTC program helps subsidize the capital costs of new affordable housing. Since 2004, 10% of the LIHTC units developed in North Carolina must be set aside for people with disabilities. Units built with the LIHTC must accept Section 8 vouchers to help subsidize the rental price for lower income individuals.[aa] Due to the inadequate supply of Section 8 assistance, NCHFA and DHHS created the Key Program to make these units affordable to persons with incomes as low as SSI. The Key Program is a production-based operating subsidy that pays the property owner the difference between what a person on SSI can afford to pay as rent and a statewide operating standard that covers the cost of operating the units. In 2006, the North Carolina General Assembly expanded the partnership to other NCHFA development programs through the 400 Initiative and provided the first recurring funds for the Key Program. Since 2002, these programs combined only provided approximately 1,800 units for people with disabilities, insufficient to ensure enough affordable housing units for all people with disabilities.

Since 2002, the Key Program and 400 Initiative programs combined only provided approximately 1,800 units for people with disabilities, insufficient to ensure enough affordable housing units for all people with disabilities.

Another way to expand the available housing is to rehabilitate existing housing units to accommodate people with disabilities. Medicaid can help pay for home modifications for individuals who own their home or live in their family's home through the CAP-MR/DD program.[bb] Home modifications can include ramps, grab bars, widening of doorways, modification of bathrooms, and alarm systems.

Some local zoning ordinances make it difficult to develop or create new licensed group homes for people with I/DD. North Carolina state laws allow municipalities to adopt zoning restrictions that prohibit the location of any family group home (including developmental disability group homes) within a half of a mile of an existing licensed group home.[cc] Several cities have adopted these zoning restrictions, which have made it difficult to license or build new developmental disability group homes in urban locations with easy access to bus routes, shopping, recreational, or other city amenities. To compound this problem, there are other state laws which effectively force some people with I/DD to live in a licensed group home in order to receive help paying for room and board (see State County Special Assistance section below). As a result, these individuals may be forced to live outside city limits, in a neighborhood that is less accessible, in order to receive the State County Special Assistance support.

Home or residential supports: Currently, North Carolina offers an array of home or residential supports that help people with I/DD live as independently as

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[aa] The state provides limited funding to help subsidize the rental costs for some people with disabilities who live in one of the units developed through the Low Income Housing Tax Credit program. This subsidy is intended to operate as a bridge until the tenant can obtain a Section 8 voucher.

[bb] There are other resources that may be able to assist with home modifications. The North Carolina Housing Finance Agency provides funding to the Independent Living Programs, within the Division of Vocational Rehabilitation, to assist people with home modifications to enable people with disabilities to live independently. In addition, the North Carolina Division of Aging and Adult Services has some funds that can be used for home modifications for adults who are 60 years or older with the greatest economic or social needs. (Affordable Housing Primer. Raleigh, NC: North Carolina Housing Coalition; 2007)

[cc] NCGS §168-22.

possible. People who live in larger residential facilities (such as state-operated developmental centers or large private ICF-MRs) have residential supports available to them in the facility. These centers have direct support workers (DSWs) that can help individuals, as indicated on their PCP, with activities of daily living such as dressing, eating, bathing, or moving from one place to another (ambulation). In addition, larger facilities also offer 24-hour health services and provide educational, vocational, recreational, and other supports. People who live in the community should be given as broad an array of supports and services to choose from as is available in more restrictive settings.

Some individuals living in the community need DSWs available for part or all of the day to support more independent living. CAP-MR/DD will pay for DSWs during waking hours and will also pay for home or residential support to provide habilitation, training, and personal assistance for people who live with their families, on their own, or in licensed community residential settings, foster homes, or unlicensed alternative family living homes. CAP-MR/DD cannot be provided to people who live in ICF-MRs or in skilled nursing facilities. These home and residential supports can help the person build skills in daily living, social skills, and community living arrangements. Other services and supports are available to assist an individual in a job setting or in other structured day settings in the community.

Some individuals living in the community need direct support workers available for part or all of the day to support more independent living.

DMHDDSAS also provides funding through state dollars for residential supports to individuals living in the community. Although CAP-MR/DD can be used to pay for support services in the home, it will not pay for 24-hour services and supports.[dd] State funds can be used to fill in the gaps in the CAP-MR/DD services in order to provide 24-hour supervision or supports. State funds can also be used to support individuals who would not otherwise meet the level of need to qualify for CAP-MR/DD. However, the Task Force members reported there are not sufficient state funds in every LME to meet the needs of everyone who needs residential supports.

To expand the array of housing options that will help individuals with I/DD live as independently as possible, the Task Force recommends:

Recommendation 6.9: Expanding Housing Options for People with Intellectual and Other Developmental Disabilities

a) **The Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) should work with the North Carolina Department of Health and Human Services housing specialists, Local Management Entities (LMEs), housing service providers, the North Carolina Housing Finance Agency,**

[dd] The Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities will only pay for therapeutic services. It will not pay for direct support personnel who are on-site when the person is sleeping (in the event that the person wakes and needs assistance). State funds can be used for this purpose.

and other appropriate groups to examine the availability and adequacy of permanent supportive housing, housing subsidies, and support services to enable people with intellectual and other developmental disabilities (I/DD) to live in the community. In this analysis, DMHDDSAS should examine:

1) **Whether there are sufficient permanent supportive housing options available to meet the needs of people with I/DD.**
2) **Whether state funding provided to help pay for room and board for people with I/DD is sufficient to serve all the people who need and would otherwise qualify for residential services.**
3) **Whether support services available through the Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities (CAP-MR/DD) waiver, coupled with residential supports available through state funded services, are sufficient to support people with I/DD living in the community.**
4) **Whether any new federal funds are available through expansion of Section 8 certificates or other housing subsidies for low-income people with disabilities.**
5) **Whether there are other barriers including, but not limited to, local zoning restrictions, which prevent the development of permanent supportive housing for people with I/DD.**
6) **Whether the formal or informal rules in some supported housing create barriers which prevent people with I/DD from working. If DMHDDSAS determines that barriers exist, then DMHDDSAS should identify options to remove barriers to successful employment.**

b) **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 to implement the recommendations in Recommendation 6.9-6.11.**

c) **LMEs should develop an inventory of community housing options from the most restrictive facilities, to supported living arrangements, to independent living, and make this inventory available to families. The lists should be available in person through the LMEs and should be made available on the internet.**

d) **DMHDDSAS shall identify and detail what steps are being taken with current funding to promote alternatives to traditional group home living.**

e) **DMHDDSAS should examine the association between costs, personal outcomes, level of support needs, and living arrangements.**

f) **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.**

In addition to traditional group living arrangements, North Carolina has not done as much to promote shared living arrangements. North Carolina does allow for alternative family living arrangements (AFL). These are private family residences that serve no more than three adults or three minors whose primary diagnosis is developmental disabilities. The people with I/DD live with the family in the residence and the family provides the services. These facilities must be licensed to receive state funding if they provide services and supports to at least one minor or two or more adults.[ee] Many other states have promoted sharing living arrangements to help people transition from institutional settings to the community.[1] For example, when Pennsylvania closed its institutions, the state paid for some of the former residents to live in homes with some of the former staff who had developed relationships with them. This host family living arrangement creates a "win-win" situation; the individual with I/DD is able to move into a more homelike environment with someone who they already know and trust. In turn, the individual staff member continues to receive some salary and is able to continue to provide support to some of the same individuals with whom they worked.

Other states have been successful in supporting other types of shared living arrangements where two or more people with I/DD live and receive support services. These shared living arrangements help to promote greater self-direction and more inclusive housing options. However, shared housing that provides support services is currently required to be licensed in North Carolina. These licensure requirements create barriers that make it more difficult to create shared living or alternative family living arrangements. These same licensure rules are not required for families who serve as foster families for children.

Recommendation 6.10: Expanding the Availability of Shared Living and Alternative Family Arrangements

The Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) 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. In developing this plan, DMHDDSAS should:

- **a) Develop criteria for shared living arrangements that will promote inclusion and integration into the community while at the same time ensuring health and safety.**
- **b) Explore the experience in other states that have successfully developed and expanded shared living arrangements.**
- **c) Determine whether modifications are needed to state licensure rules or statutes to facilitate the development of shared living arrangements.**
- **d) Explore the option of licensing shared living agency coordinators or service providers rather than licensed housing units.**

[ee] 10 NCAC § 27G.5601.

Unfortunately, because of the lack of housing that can help people live as independently as possible, the Task Force heard examples of people with I/DD who remained in large group settings or were housed inappropriately in large assisted living arrangements (also known as adult care homes). DMHDDSAS does not routinely collect data to determine how prevalent this problem may be.

The Preadmission Screening and Annual Resident Review is intended to ensure that individuals with mental illness, intellectual and other developmental disabilities, or a related condition are not admitted to a nursing facility unless they have a paramount medical need and can be serviced appropriately by nursing level of care.

Federal Medicaid laws require that any individual seeking Medicaid coverage for a nursing home placement be assessed to determine if they need skilled nursing level of care. Prior to admission, a physician or other appropriate health care professional must fill out an FL-2 form to determine if the person has a medical condition which warrants skilled nursing level of care. The FL-2 must be approved by EDS (the state Medicaid claims processor). In addition to the FL-2, federal law requires Medicaid agencies to conduct an independent assessment prior to admission to determine if the person has a mental health, intellectual, or other developmental disability, or a related condition. The Preadmission Screening and Annual Resident Review (PASARR) is intended to ensure that individuals with mental illness, I/DD, or a related condition are not admitted to a nursing facility unless they have a paramount medical need and can be served appropriately by nursing level of care.[ff] PASARR is a two-stage assessment process. First, health professionals from the referring agency complete a screening instrument to identify people who have a mental health, intellectual, or other developmental disability, or related condition (Level 1). Second, people who are identified as having one of these conditions receive a more thorough face-to-face assessment (Level 2). The assessment is conducted by a mental health or developmental disability certified professional who works for an independent agency. The developmental disability professional assesses the individual to determine the type of I/DD (or other condition), intensity of support needs, medications, and need for behavioral supports. A psychiatrist is also involved in the assessment.

DMHDDSAS reviews the PASARR Level 2 assessment prior to admission to determine whether the placement is appropriate and, if so, whether additional services and supports are needed. DMHDDSAS involves local LMEs in arranging appropriate care for individuals with I/DD. LMEs will help the individual and his or her family arrange for other community services and supports if DMHDDSAS determines that placement in a nursing facility is not appropriate. LMEs will also help arrange for community-based services and supports to help a person transition out of the nursing facility when DMHDDSAS approves a short-term placement (i.e. to help stabilize a medical condition). LMEs may also be involved in arranging services and supports for people while in a nursing facility, if DMHDDSAS approves the placement but determines that the person needs additional services. Last year, the North Carolina General Assembly directed DMHDDSAS to create a

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[ff] 42 CFR 483.75(l)(5). North Carolina procedures are described in the North Carolina Provider Manual. (December 2005). http://www.providerlink.com/documents/PASARRProviderManualwithForms.pdf.

similar screening process for people in adult care homes.[gg] DMA and DMHDDSAS are working to design a similar process, but to date, this provision has not yet been implemented.

Recommendation 6.11: Screening for People with Intellectual and Other Developmental Disabilities Before Placement in an Assisted Living Facility

a) **The Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) and Division of Medical Assistance (DMA) should develop an assessment process, similar to the Preadmission Screening and Annual Resident Review (PASARR), to determine whether people with mental illness, intellectual, or other developmental disability or related disorder can be appropriately served in an assisted living facility and whether this is the most integrated setting appropriate to the person's needs.**

   1) **The assessment should be conducted by independent mental health or developmental disability certified professionals.**
   2) **DMHDDSAS should review the assessment instrument prior to placement in an assisted living facility to ensure that placement is the best option possible to meet the unique needs of the individual and not based solely on the person's developmental disability.**
   3) **DMHDDSAS should involve the Local Management Entity (LME) transition specialist prior to admission to ensure that the person with intellectual and other developmental disabilities (I/DD) is receiving appropriate services and supports. The LME's staff should work with the individual, his or her family, and case managers to determine if there are alternative housing options that would promote greater self-direction and less restrictive living environment. LME staff should also help arrange for services and supports in the community to enable the person to live as independently as possible or arrange for appropriate services and supports in the assisted living facility if placement is determined to be appropriate.**

b) **In the future, all individuals with I/DD should receive an independent assessment using the authorized level of need assessment identified as part of Recommendation 6.4 to determine intensity of need and appropriateness of placement.**

Providing subsidies to help people with I/DD pay for their room and board:
Even if personal assistance and residential services are available, many individuals with I/DD will need help paying for room and board. There are some federal funds

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[gg] The Joint Conference Committee Report on the Continuation, Capital and Expansion Budgets. The section reads: "Mental Health Screenings and Assessments in Adult Care Homes. Provides funding to implement a mental health screening program for residents of adult care homes. Non-recurring funds will allow for 7,800 evaluations in FY 2008-09; recurring funds will provide approximately 850 evaluations per year in future years." (House Bill 2436. North Carolina General Assembly. 2008 Session. July 3, 2008; p. G-9. Available at http://www.ncleg.net/sessions/2007/budget/2008/conferencecommitteebudgetreport.pdf. Accessed April 2, 2009).

available for this purpose, but funding is limited. Section 8 is a federal program that provides housing vouchers to low and moderate-income families to help subsidize the costs of rental property.[hh] The program is administered by public housing authorities. Unfortunately, because of inadequate federal funding, Section 8 cannot serve all in need. Most public housing units maintain long waiting lists for Section 8 vouchers.

In addition, North Carolina provides some assistance to low-income individuals residing in assisted living facilities or licensed group homes. State/County Special Assistance, funded through state and county funds, provides funding to help pay for room and board in a licensed assisted living facility or supervised living facility for people with I/DD.[ii,jj] To qualify, a person must have limited income and resources, have a disability, or be at least 65 or older. State/County Special Assistance funds can also be used to support individuals living in their own homes. The North Carolina Department of Health and Human Services can use up to 15% of State/County Special Assistance funds to pay for eligible individuals in in-home living arrangements.[kk] Payments made to support individuals in their own home are limited to 75% of the monthly payment that the individual would have received if he or she lived in an assisted living facility or supervised living facility. Providing the same level of payment to support people living in the community would give people greater opportunity to purchase the supports and other services needed to maintain housing in the community. Therefore, the Task Force recommends:

Recommendation 6.12: Expanding State/County Special Assistance to Provide Additional Support to People in Home Settings

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 to individuals in their own homes, alternative family living, or host families as would be provided in licensed facilities.

Expanding Employment Opportunities

Historically, many people with I/DD were placed into segregated vocational jobs or sheltered workshops that paid less than minimum wage.[25] Others might be served in an Adult Developmental Vocational Program rather than being offered the opportunity for meaningful, community-integrated work.

[hh] 42 USC §1347f.

[ii] NCGS §108A-40 et. seq.

[jj] The licensure rules for assisted living facilities are available at 10A NCAC §13F .0202 et. seq. The licensure rules for supervised living facilities for people with intellectual and other developmental disabilities are available at 10A NCAC 27G.5601

[kk] NCGS §108A-47.1.

A number of states have moved towards an "Employment First" philosophy. This philosophy is premised on the belief that adults with I/DD—just as other adults—want the opportunity to choose their jobs based on their interests and talents. Rather than relegate individuals with I/DD to segregated jobs that offer subminimum wages, these same individuals should be provided with the supports and services to enable them to obtain competitive jobs in integrated community settings. Competitive employment is defined as work that is provided on a part-time or full-time basis in an integrated setting (that employs both people with disabilities and those without disabilities) and which pays at or above minimum wage, but not less than the wages paid to people without disabilities who perform the same or similar work.[ll] However, ensuring that people with I/DD have opportunities for competitive employment is challenging. To be successful, people with I/DD need a sound basic education that will prepare them for work. They need job counseling, skills preparation, and basic life and social skills. Adults with I/DD may need job coaches, assistive technology, or other supports to help them obtain and retain a job. Employers need more information about the positive, on-the-job performance of people with I/DD and information about the ease, and generally low cost, of most of the reasonable accommodations necessary to support the person with I/DD in the workplace.

The Division of Vocational Rehabilitation and its partner agencies provide services that support people with intellectual and other developmental disabilities in their efforts to obtain meaningful work, with the goal of supporting people in competitive employment.

The Division of Vocational Rehabilitation (DVR) within the North Carolina Department of Health and Human Services is the lead agency that helps people with disabilities obtain jobs. Specifically, DVR helps people with disabilities with job development, placement, and training. DVR has 77 local offices. It received approximately $77.5 million in funding from the US Department of Education to support these activities (FFY 2008). DVR and its partner agencies provide services that support people with I/DD in their efforts to obtain meaningful work, with the goal of supporting people in competitive employment. Some of the services that DVR, local offices, or partner agencies provide include:[26]

- ***Evaluation and counseling:*** DVR will assess the individual to determine their interests, abilities, and aptitude for different jobs. As part of the initial assessment, DVR also gathers information about the person's job readiness, including their strengths, skills, and prior work and nonwork experience. The DVR counselors and the person with I/DD use this information to develop an employment plan. In FFY 2007, DVR provided vocational assessments to 13,218 individuals, offered counseling and guidance to 4,912 individuals, and provided diagnosis and treatment of impairments to 6,350 individuals.[26]
- ***Benefits counseling:*** Most people with I/DD are receiving some form of government assistance including, but not limited to, Supplemental Security Income (SSI) (cash assistance) or Medicaid. In the past, earning money could jeopardize ongoing receipt of these benefits. However,

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[ll] 34 CFR §363.6(c)(2)(i).

federal laws have changed, enabling people to continue to receive Medicaid and some cash assistance once the person with disabilities returns to work. DVR will assist people with I/DD to understand these options in order to remove disincentives to work.

- ***School to Life services:*** DVR works with Local Education Agencies (LEAs) to help students who are transitioning out of secondary school to jobs or careers. DVR can provide vocational guidance and help eligible students with training, job placement, and other services. In FFY 2007, DVR served 16,237 youth ages 22 or younger and provided services to 9,068 high school students.
- ***Employment services:*** Employment services can include college or vocational training, on-the-job training, job coaching, or supported employment, depending on the individual's employment plan. DVR also helps individuals with some of the skills needed to obtain a job, including writing resumes and interviewing skills, as well as providing assistance in locating a job. In FFY 2007, DVR helped 6,271 North Carolinians with disabilities attain successful employment outcomes.[26]

In FFY 2007, the Division of Vocational Rehabilitation served 16,237 youth ages 22 or younger and provided services to 9,068 high school students.

- ***Services to employers:*** DVR also provides services to employers, including screening (to match the right employee to the worksite), on-the-job training, and engineering consultation to ensure that the physical workplace can be adapted to meet the needs of the person with disabilities.
- ***Rehabilitation engineering and assistive technology:*** DVR offers rehabilitation engineers that can help people with disabilities overcome physical or communication barriers. Services can include adaptive computer access; augmentative communication; home, vehicle, or worksite modifications; or other technology to help with mobility, daily living activities, communication, education, or leisure. In FFY 2007, DVR worked with 1,213 people to remove barriers at their homes and modified vehicles for 158 consumers.[26] DVR also provided 2,682 individuals with consultation and information about assistive technology services, made 5,409 equipment loans, and provided assistive trainings for 14,616 individuals (see Assistive Technology section).
- ***Community rehabilitation:*** In addition to the 77 local DVR offices, DVR partners with community rehabilitation programs that provide more intensive employment services to people with disabilities. There are 52 community rehabilitation programs in the state. Community rehabilitation programs offer a range of services. They can assist people in obtaining a job, help with job training, provide job coaches to help people while on the job site, offer individual or group supported employment (described below), and offer work adjustment activities to help individuals improve their work skills. Community rehabilitation programs may offer an Adult Developmental Vocational Program

(ADVP) to work with people who are not yet job ready to learn vocational skills, social skills needed for the workplace, and life skills (such as budgeting). ADVP also helps integrate the individual into the community. Community Rehabilitation programs help provide supports to people engaged in competitive work in the community, and some run businesses that provide competitive work opportunities directly. In FFY 2007, 8,686 individuals received services from community rehabilitation programs.[26] Of that number, 2,284 realized their employment objectives.

- ***Supported employment:*** Supported employment is available for people with more significant disabilities (including I/DD) who need more intensive support services to help the individual transition into competitive employment. One of DVR's partnering organizations (such as Community Rehabilitation programs) provides ongoing supports to people to help them maintain employment. Agencies that provide ongoing support services typically visit the worksite at least twice monthly to assess employment stability. Depending on the needs of the individual, the agency may also provide job trainers for more intensive job skills training, social skills training, regular observation or supervision of the individual, facilitation of natural supports at the workplace, and regular follow-up with employers, the family, the person with I/DD, or others to stabilize the job placement.[mm] DVR cannot use federal funds to provide ongoing supports to individuals for more than 18 months. DVR's involvement ends once the individual, his or her employer, the counselor, and/or jobs coach agree that the person is performing their job successfully. In FFY 2007, DVR provided supported employment services to 3,496 people. Of that, 1,099 met their employment objectives.[26]

North Carolina currently has one of the highest numbers of people with disabilities who have received Supported Employment services from Vocational Rehabilitation and who have met the federal requirements for successful closure of their cases. In FFY 2006, North Carolina helped 1,003 persons achieve their employment objectives through Supported Employment.[27] While this number is third in the nation for total Supported Employment closures, this only represents 0.71% of the number of persons in the state ages 16 to 64 who have an employment disability.[nn] Only six states had higher service rates.[oo] Thus, more is needed to truly achieve an "employment first" philosophy in this state.

In FFY 2006, North Carolina helped 1,003 persons achieve their employment objectives through Supported Employment… this only represents 0.71% of the number of people in the state ages 16-64 who have an employment disability.

[mm] 34 CFR §§ 363.6(c)(2),(3).

[nn] An employment disability is a physical, mental, or emotional condition lasting six months or more that makes it difficult to work at a job or business. (US Census. American Community Survey. Puerto Rico Community Survey. 2007 Subject Definitions. Available at http://www.census.gov/acs/www/Downloads/2007/usedata/Subject_Definitions.pdf . Accessed April 1, 2009).

[oo] The six states with higher supported employment service rates include South Dakota (1.95%), Wyoming (1.58%), Nebraska (1.24%), Vermont (1.22%), Idaho (.82%) and Indiana (.77%).

One of DVR's key partnerships is with DMHDDSAS. DMHDDSAS has articulated an "employment first" philosophy in its most recent strategic plan (2007-2010): "Every individual served in the public system deserves the opportunity for education, employment and other meaningful daily life activities based on individual needs and choices."[23] Because of the limitations in federal Vocational Rehabilitation funds for supported employment, Medicaid CAP-MR/DD and state funds are needed to provide longer-term support services. This is particularly important to support individuals with more significant I/DD, who may need much longer support services to help them maintain employment. In 2007, the North Carolina General Assembly appropriated $4 million to DMHDDSAS for long-term supported employment.[28,29] These funds were used to support 1,864 individuals. Of these, approximately 83% were for adults with I/DD (the other 17% were adults with mental illness only).[pp,30] More than half of the state-funded long-term vocational supports are provided by five LMEs (including Wake, Guilford, Mecklenburg, Centerpointe, and Western Highlands).

The Division of Mental Health, Developmental Disabilities and Substance Abuse Services has articulated an "employment first" philosophy in its most recent strategic plan (2007-2010): "Every individual served in the public system deserves the opportunity for education, employment and other meaningful daily life activities based on individual needs and choices."

While DMHDDSAS had $4 million appropriated for this purpose, the LMEs only spent approximately $2 million in SFY 2008 for long-term vocational supports. In order to support people in their jobs, DMHDDSAS and LMEs need to do a better job ensuring that people who need long-term vocational supports receive these services. DMHDDSAS and LMEs are in the process of updating their existing Memorandum of Agreement to improve communications between the two agencies and to improve the utilization of long-term vocational support services. Additionally, some funding for long-term vocational supports is also available through the CAP-MR/DD program; however, these funds are also underutilized. Ultimately, additional funding may be necessary to meet the needs of people who warrant long-term supports.[qq] Additional funding is needed to provide long-term support services to people with I/DD.

The Task Force recognizes that it may be difficult to expand the array of meaningful work opportunities given the current economic turmoil. Many employers are downsizing their workforce, while other firms are closing. Nonetheless, the Task Force thought that it was important to develop the strategies and linkages needed to support an "employment first" philosophy. Thus, the Task Force recommends:

[pp] Rogers, J; Best Practice Team, Division of Mental Health, Developmental Disabilities and Substance Abuse Services, North Carolina Department of Health and Human Services. Written (email) communication. March 3, 2009.

[qq] The $4 million in recurring funds are only sufficient to provide an average of seven hours of support services per month (based on the current reimbursement rate of $44/hour), assuming that every person who graduated from the Division of Vocational Rehabilitation-supported employment programs last year needed ongoing support. People with "intellectual and developmental disabilities (I/DD) need varying levels of ongoing support. Some individuals may need as little as two hours a month to ensure that the individual is doing well in the job site. Others may need more intensive services, including more regular job coaching. Other individuals may need wrap-around services during nonwork hours. For example, many people with I/DD work part-time. This can cause hardships to families where the caregivers must work 40 hours, as some individuals with I/DD may not be able to stay alone when their family members are working.

Rec. 6.13: Employment First (PRIORITY RECOMMENDATION)

a) The Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) should work with the Division of Vocational Rehabilitation (DVR) and Local Management Entities (LMEs) to expand employment opportunities to more people with intellectual and other developmental disabilities (I/DD), including those with the most significant physical and intellectual disabilities. To expand the employment opportunities for all people with I/DD, including those with the most significant I/DD, DMHDDSAS should work with LMEs and DVR to:

   1) Assure that the funding appropriated by the North Carolina General Assembly for long-term vocational support is spent to help people with I/DD retain employment after completion of the job placement and the training phase through DVR. These supports should be available on a consistent basis across all LMEs. In addition, LMEs and providers should maximize the use of Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities funding in support of eligible individuals who require long-term employment support.

   2) Identify evidence-based and promising practices in North Carolina and in other states to assist all people with I/DD in finding and maintaining community-integrated employment. DMHDDSAS, in conjunction with LMEs and DVR, should pilot evidence-based and promising practices to determine what models are most successful in helping people with all levels of I/DD obtain and retain employment. DMHDDSAS should use existing funds appropriated for long-term vocational supports to support these pilots and to evaluate the programs. If successful, these pilots should be expanded throughout the state.

   3) Provide training to DVR rehabilitation counselors, Community Rehabilitation staff, DMHDDSAS and LME staff, and local case managers about evidence-based and promising practices to provide meaningful employment opportunities for people with I/DD, including those with the most significant disabilities.

b) In order to expand employment opportunities for people with I/DD, DVR will:

   1) Continue to strive to assure all DVR unit offices are following federal Vocational Rehabilitation guidelines in eligibility determination, including the utilization of the supplemental evaluation and community-based assessment models that include rehabilitation engineering and assistive technology services.

   2) Monitor and aggressively seek out any funding opportunities for job training, supported employment, or job placement that is or may become available under the federal Recovery and Reinvestment Act or any subsequent federal legislation.

   3) Evaluate existing federal standards and indicator criteria for more effective strategies in serving persons within the categories of “significant and most significant disabilities,” which would include individuals with more significant I/DD.

c) **The North Carolina Department of Health and Human Services should expand joint training efforts between DMHDDSAS, LME, and DVR staff to provide cross-training for state and local staff in all aspects of the provision of Supported Employment services for people with I/DD.**

Assistive Technology

Some people with I/DD benefit from the use of assistive technologies (AT). AT are those used to help increase the independence of individuals with I/DD, such as ambulatory aids, speech generating devices, modified tools, educational software, and modified vehicles. Utilization of AT can help facilitate transitions such as moving from state developmental centers or large ICFs-MR to the community or from school to work. Many individuals with I/DD are able to participate in school, work, and their community with a few modifications or adaptations such as those provided by AT.

Utilization of assistive technology (AT) can help facilitate transitions such as moving from state developmental centers or large Intermediate Care Facilities for Persons with Mental Retardation to the community or from school to work.

The North Carolina Assistive Technology Program (NCATP) provides AT services to individuals, including those with I/DD, regardless of age. NCATP provides both free and fee-based AT support services to people with I/DD, their families, health professionals, and educators. NCATP's free services include device demonstrations, device loans, and some technical assistance. NCATP also funds an AT exchange website that helps facilitate device reutilization by connecting AT users who are done with a device with those needing AT devices. NCATP's fee-based services include AT assessments, training on AT devices and services, and workshops and seminars. In SFY 2007, NCATP provided AT services to more than 8,500 individuals through the 12 NCATP centers across the state. NCATP does not pay for devices for individuals. Although NCATP does not provide funding for individuals in need of AT devices or services, NCATP does provide information on potential funding sources for AT in North Carolina.[31]

There are many AT funding sources for individuals with I/DD. There are funds to assist infants and toddlers, students ages 3-21 enrolled in public school, and children enrolled in Medicaid or NC Health Choice.[rr] Both children and adults may have access to AT funding through private health insurance, Medicaid, Medicare, or Community Alternatives Program (CAP) waivers.[ss] The Division of Vocational Rehabilitation (DVR) provides limited assistance for adults with I/DD who want to work and need AT devices and services to do so. DVR also provides funding for individuals with I/DD who are receiving services through the Independent Living program. For individuals with I/DD who want an AT device or services that are not otherwise covered, there are private funds and loan programs available. NCATP staff are available to aid individuals with identifying potential funding sources and strategies, however, individuals with I/DD are responsible for pursuing funding.[32]

[rr] More information on assistive technology for students is available in Chapter 3.

[ss] CAP waiver programs include the Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities (CAP-MR/DD), the Community Alternatives Program for Disabled Adults (CAP/DA), and the Community Alternatives Program for Children (CAP/C).

Medicaid is a major source of funding of medically-necessary AT for adults with I/DD. When Medicaid approves funding of AT for an individual who receives CAP-MR/DD waiver funding, the funds to pay for the AT are included in money budgeted to implement the Person Centered Plan (PCP). There are multiple CAP-MR/DD waiver service definitions that can be used to pay for AT; each definition has a maximum allowable cost per person per year.[tt] The cost of AT devices and services fluctuate, with large, one-time costs in one year followed by low costs until the device needs to be replaced. If an individual has a newly-identified AT need or an unexpected need for a replacement, the individual's PCP can be revised and the individual can seek authorization for the needed changes. If an individual fully expends the maximum allowable cost per person per year, they may not receive additional needed services. It is the responsibility of the case manager to work with the individual and family to ensure adequate planning for AT needs are included in the PCP and the expenditure of allowable funds are monitored.

A source of flexible funding is needed to help pay for AT for individuals who have AT needs that exceed the CAP-MR/DD maximum allowable cost or for those who have no other payment source. (See Recommendation 6.6.) In addition, AT services should be more readily available in the schools. (See Recommendation 3.5.)

National studies suggest that people with intellectual and other developmental disabilities are more likely to have certain chronic illnesses, as well as secondary conditions that arise out of their disability.

Health Care

Prevalence of most chronic health conditions in persons with I/DD appears to be largely similar to that of the general population, with cardiovascular diseases and cancer among the most common causes of death.[33-35] However, national studies suggest that people with I/DD are more likely to have certain chronic illnesses, as well as secondary conditions that arise out of their disability. For example, between 20% and 30% of people with an intellectual disability experience epilepsy, and many receive inadequate treatment for the condition.[36] Hypothyroidism is also found in elevated levels among people with I/DD and can be exacerbated by some medications commonly prescribed to people with I/DD.[37] Gastro-esophageal reflux disease (acid reflux) is also reported at higher levels in people with I/DD, as is osteoporosis.[38,39] Some studies also report that individuals with I/DD have higher rates of respiratory infections, dental disease, mental illness, or other behavioral health problems.[40] In addition, a recent review of the literature on cardiovascular disease (CVD) prevalence for people with I/DD concluded that adults with mild or moderate I/DD who live in the community (as opposed to an institutional setting) appear to have an elevated prevalence of CVD, an elevated CVD mortality, more CVD risk factors, and increased behavioral risk factors compared to both other adults with I/DD (i.e. those in institutions and those with more severe I/DD) and to the general population.[41]

Individuals with I/DD often have greater rates of obesity because of sedentary lifestyles and poor nutrition.[40-43] Fitness levels of adults with I/DD are consistently

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[tt] Service definitions are available online at http://www.dhhs.state.nc.us/MHDDSAS/cap-mrdd/index.htm#servicedefinitions.

lower than the general population and adults with I/DD typically demonstrate lower levels of strength and endurance and higher amounts of body fat.[44] The lower fitness levels may be due to multiple factors such as fewer opportunities for participation in exercise and community programs, limited motivational levels, lack of accessible facilities and exercise equipment, and a lack of understanding of the benefits of physical activity. Additionally, persons with I/DD have four to six times the preventable mortality of individuals in the general population, and they appear to have a high rate of accidental injury and a high level of emergency room use.[35]

Persons with specific I/DD conditions may face additional health problems. For example, people with Down syndrome tend to experience premature aging, with symptoms of aging generally occurring about 20 to 30 years earlier than in the general population. As a result, dementia is far more common in people with Down syndrome than in the general population, and persons with Down syndrome are at higher risk for a number of acute and chronic medical conditions throughout their lives.[45] Persons with cerebral palsy may suffer from chronic constipation, which in some cases may be so severe that it ends in death.[46]

Adults with intellectual and other developmental disabilities were significantly more likely to report being in fair or poor health than adults without disabilities.

A North Carolina study analyzed the self-reported health status of people with I/DD compared to others with disabilities or people without disabilities.[47] Adults with I/DD were significantly more likely to report being in fair or poor health than adults without disabilities and were more likely to report having diabetes. They were more likely than the general population to lead sedentary lifestyles and are nearly seven times as likely to report inadequate emotional support compared with adults without disabilities. However, the study also found that the percent who reported using tobacco or being overweight or obese was not statistically different from those without a disability. The findings in this North Carolina study appear to contradict findings in national studies which show greater rates of obesity among people with I/DD.

The health disparities that have been identified through the research may not fully describe all the differences in health status between people with I/DD and the general population. Researchers suggest that it is possible that rates of disease are underreported among people with I/DD, with many health issues going undetected because of a lack of awareness among caregivers, poor screening practices, or a lack of focus on health surveillance in general.[48-50]

Compounding these problems, many people with I/DD do not receive a level of health care commensurate with their needs. This same North Carolina study found significant disparities in health and medical care utilization for adults with I/DD compared to nondisabled adults.[47] Women with I/DD surveyed were significantly less likely to have received breast and cervical cancer screenings than the general population, and both men and women were less likely to have received recommended oral health care. Access to dental services is problematic for everyone on Medicaid in North Carolina; however, it is even more difficult for people with special health needs.[51,52]

There have been few national studies that have examined access to and utilization of a broader array of medical services for people with I/DD, and many of the studies that have been conducted have methodological limitations.[53] In a recent review of the research literature (2005), Hayden et al. found that while many people living in the community are receiving timely and accessible medical services, there are barriers which prevent some people from accessing needed health services.

Other studies report greater access barriers. The US Surgeon General reported that people with I/DD, their families, and advocates report shortages of health care professionals who are willing to treat patients with I/DD.[54] The reasons for this are many and varied, ranging from communication difficulties to lack of training and experience, poor patient compliance with treatment plans, and unwillingness of some providers to accept Medicaid, under which many individuals with I/DD are covered.[55,47] Few health care professionals receive the training that prepares them to address the special needs of people with I/DD, particularly those with significant intellectual disabilities.[54] Children have a particularly difficult time transitioning from pediatric care to adult services. Access to dental care is particularly problematic.[40,56] Further, many people with I/DD have problems coordinating the health services they receive from multiple health care providers.[57]

The US Surgeon General reported that people with intellectual and other developmental disabilities (I/DD), their families, and advocates report shortages of health care professionals who are willing to treat patients with I/DD.

The Task Force recommends that providers receive better training to address the needs of people with I/DD. The Mountain Area Health Education Center (AHEC) has been a national leader in developing a mini-fellowship in adult developmental medicine to enhance training for primary care providers. The mini-fellowship was initially funded as a project of the North Carolina Council on Developmental Disabilities (NCCDD). The state should support and expand this effort. In addition, the Task Force also recommends that all providers receive better training about the developmental disability system, so that they know how to work with case managers or other people who provide services and supports.

Recommendation 6.14: Training for Health Care Professionals

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 services for people with intellectual and other developmental disabilities (I/DD). The trainings should include, but not be limited to:

a) Education for health care professionals (including physicians, dentists, nurses, allied health, and other health care practitioners) to provide better health care services for persons with I/DD.

b) Establishing a primary care medical home for people with I/DD.

c) Transitioning adolescents with I/DD from pediatric care to adult care and self-management.

d) Training of psychiatrists, counselors, and other health care professionals in addressing the needs of individuals with I/DD who need mental health services.

e) Education for health care professionals about the developmental disability system and how to coordinate services with the family, case manager, and other direct support workers to assist in providing proper health care for persons with I/DD.

f) Internships and residency rotations in settings that routinely provide services to people with I/DD.

g) Support for continuation and expansion of mini-fellowships in developmental medicine.

h) The North Carolina General Assembly should appropriate $150,000 on a recurring basis to the AHEC program to support these efforts.

Little is known about the quality of health care provided to people with intellectual and other developmental disabilities (I/DD) in North Carolina, although there are data that show that people with I/DD were less likely to receive certain types of preventive screenings than others without disabilities.

Many people with I/DD rely on Medicaid as their source of insurance coverage. The Medicaid reimbursement rate is typically lower than commercial insurance. Nationally, the low provider reimbursement rate discourages providers from participating in Medicaid, which creates access barriers.[58] In North Carolina, the state pays primary care providers 95% of the Medicare reimbursement rate, which is higher than payments to primary care providers in many states. As a result, most Medicaid recipients can access primary care providers, as more than half of all primary care practices in the state participate in Medicaid.[59] In North Carolina, about 90% of the people with I/DD reported receiving a physical within the last year (2007-2008).[uu,2] Little is known about the quality of health care provided to people with I/DD in North Carolina, although there are data that show that people with I/DD were less likely to receive certain types of preventive screenings than others without disabilities.[47]

North Carolina has a unique Medicaid program, designed to improve the health care provided to people with chronic illnesses or complex health problems. The program, called Community Care of North Carolina (CCNC), is based around 14 local networks of care. Each network includes primary care providers, hospitals, local health departments, social service agencies, and other agencies that provide care to Medicaid recipients. LMEs are also included in many of the networks. These providers and agencies work together to manage the health of the Medicaid

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[uu] Data from the National Core Indicators may not be a good reflection of whether the individual can access appropriate medical services in the community. The National Core Indicators asks "When was [the person with intellectual and other developmental disabilities (I/DD)] last physical exam?" In the 2007-2008 survey, 89.8% reported that their last physical exam was within the past year. Nationally, the average number of ambulatory visits/year is four, according to the 2006 National Ambulatory Medical Care Survey (NAMCS) and National Hospital Ambulatory Medical Care Survey (NHAMCS). As many people with I/DD have more extensive medical needs than the general population, one might reasonably assume that they would also expect to make multiple visits to the provider in any given year. The National Core Indicators does not collect data on whether there were any times in the past year when the individual thought they needed to see a physician but could not access care.

recipients enrolled in their network. In January 2009, CCNC managed the care of more than 874,000 Medicaid enrollees and 95,000 children enrolled in NC Health Choice.[60]

Providers who participate in CCNC must agree to participate in disease management and care management activities to improve the quality of care and health of their enrolled population. CCNC pays primary care providers a small management fee per member per month (pmpm) to serve as the medical home for the individual Medicaid recipient. (This is in addition to the regular Medicaid reimbursement the provider receives to provide services to their patients.) Primary care providers who participate in CCNC and receive the case management fee must help manage the patient's health care services and link people to other services when needed. The providers must also participate in quality improvement activities to improve the care provided to those with certain chronic conditions.

In addition, the network receives another small pmpm payment to hire care coordinators, typically nurses or social workers, to help manage the care for patients with chronic health problems. The care managers work in collaboration with the providers and Medicaid recipients to help the Medicaid recipients manage their chronic illnesses. In addition, they help practices improve the quality of care provided to individuals with certain health conditions.

The current statewide disease and care management initiatives center around care for people with asthma, diabetes, and congestive heart failure. There are also statewide initiatives to help provide pharmacy management (typically for patients with eight or more medications), reduce unnecessary use of the emergency department, and provide case management of patients with high cost-high risk conditions. Many of the networks have also adopted additional quality improvement activities. One of these initiatives focuses on improving the care of people with mental health needs. In the past, treatment of a person's physical health has been isolated from the care provided for treatment of mental illness, developmental disabilities, or substance abuse. The ICARE partnership was created to improve communication and collaboration between CCNC primary care providers and behavioral health providers (including providers of mental health, developmental disability, and substance abuse services).[61] ICARE was also developed to improve the capacity of primary care providers to provide evidence-based behavioral health services and for behavioral health providers to recognize and refer patients for physical illnesses. CCNC has also developed integrated care models, where mental health and/or substance abuse specialists are colocated in a primary care practice or, in some cases, primary care providers are colocated in a behavioral health office.

Initially, these models have focused more heavily on providing services for people with mental illness, particularly focused on depression. Less has been done to create the same linkages to provide primary health care to people with I/DD. Up until recently, CCNC primarily served children and their parents. The program was not initially created to serve people who were receiving Medicaid because of disabilities or because they were older (65 or older). However, in 2005, the North Carolina General Assembly directed the Division of Medical Assistance (DMA) to expand CCNC to cover the elderly and people with disabilities. Recognizing that care for this population is more complex, DMA also increased the pmpm payment to the provider, as well as the pmpm network fee.[vv]

One promising way to improve medical services provided to people with intellectual and other developmental disabilities would be to develop a pilot program in Community Care of North Carolina to manage the care of this population.

One promising way to improve medical services provided to people with I/DD would be to develop a pilot program in CCNC to manage the care of this population. CCNC already targets people with complex or costly health conditions. Because of their complex health and behavioral health needs, people with I/DD are often among the most costly of the Medicaid population. Some work has already been done in this area, which could be expanded into a pilot. As part of a project funded by the the North Carolina Council on Developmental Disabilities (NCCDD), Moss et al. identified best practices for treating patients with I/DD.[62] This model is predicated on the coordination of services between developmental disability case managers (who are responsible for coordinating nonmedical services) and CCNC care managers. In addition, other states have developed care coordination systems for adults of working age with physical or behavioral disabilities.[57] North Carolina could examine the experiences of these states in developing a CCNC initiative for people with I/DD.

The Task Force believes that more can be done to build on the state's successful CCNC model and expand access to care for Medicaid recipients with I/DD. One of the first steps should be to examine access to and quality of care for this population. In addition, the state should explore the possibility of creating a separate pilot, to improve health care provided to people with I/DD. Therefore, the Task Force recommends:

Recommendation 6.15: Expanding Access to Health and Dental Services and Developing a CCNC Pilot Initiative for People with Intellectual and Other Developmental Disabilities

a) **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, psychological/behavioral, or therapy 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. Specifically, DMA should consider, but not be limited to:**

[vv] Effective October 2008, Community Care of North Carolina (CCNC) increased the monthly management fees paid to primary care providers and to local networks to care for older adults and people with disabilities. In the past, primary care providers were paid $2.50 per member per month (pmpm) to serve as the medical home for Medicaid recipients. Networks received an additional $2.50 pmpm to help with care and disease management for the patient population. When Medicaid expanded CCNC to older adults and people with disabilities, they increased the monthly management fees paid to providers to $5.00 pmpm, and the network fees to $8.00 pmpm.

1) **Examining the reimbursement rates to determine if the rates are adequate to compensate providers for additional time that they may need to spend with selected Medicaid recipients with I/DD, including behavioral issues.**
2) **Identifying or creating centers of excellence across the state with specific expertise working with people with I/DD. Centers of excellence would be responsible for assessments, treatment, consultation with other community practitioners, and training of other professionals, direct support workers, and family service providers.**
3) **The experience of other states in improving access to care for people with I/DD.**
4) **Other options to expand access to medical, dental, psychological, behavioral, or therapy services.**

b) **North Carolina Community Care Inc. should work with DMA and DMHDDSAS to explore the possibility of creating a Community Care of North Carolina care management model designed to meet the special needs of people with I/DD. The model should be based on the new chronic care model developed for older adults or people with disabilities, but should be targeted to address the transition, behavioral, health, and support needs that are specific to people with I/DD.**

Direct Support Workers

Successful transitions are often dependent on having a well-qualified workforce that can provide the supports and services needed to help the person with I/DD live, learn, work, play, socialize, and retire in the community. Aside from the person's family, direct support workers (DSWs) are the people who provide most of the day-to-day support for people with significant I/DD. In addition to providing direct services and supports, DSWs often facilitate connections to the greater community. They must have an understanding of I/DD, the developmental disability system, and the services and supports in the community that can help individuals with I/DD lead full lives.

Direct support workers often facilitate connections to the greater community.

DSWs have a broad range of responsibilities and are employed in many different settings, including state developmental centers, private ICFs/MR, supported employment programs, and private agencies. A DSW may be employed to help people with basic activities of daily living, such as bathing, dressing, grooming, feeding, or getting out of bed.[63] DSWs may also have more health-related responsibilities including ensuring the person's health and safety or monitoring their health status. They may assist the individual with getting to or maintaining a job, in facilitating social activities with friends, or in helping the individual learn the skills necessary for more independent living. The National Alliance for Director Support Professionals (NADSP, the national professional association for DSWs) has articulated a set of competency areas and skills that DSWs should have to provide services and supports to people with I/DD.[64] These competency areas include participant empowerment, community living skills and supports, crisis intervention, facilitation of services, organizational participation, documentation, community and service networking, providing person-centered supports, assessment, communication, supporting health and wellness, building and maintaining friendships, advocacy, education/training and self-development, and vocational/educational and career support. The College of Direct Supports (CDS) is an internet and competency-based curriculum, built around the NADSP competencies that could serve as the model of the state's training efforts.[ww] The NCCDD is currently pilot testing the CDS in collaboration with the North Carolina Council of Community Support Providers.

In addition to ensuring a well-qualified workforce, North Carolina needs to do more to improve worker retention and reduce turnover among direct support workers.

In North Carolina, DSWs must typically have a high school diploma or equivalent. There is not a state-approved training curriculum. Instead, training is typically provided on the job. Agencies are required to cover certain topics in their training (the same as those listed in the case management section) and "attest" that the person has shown the required competencies. However, DSWs in most employment settings are not required to pass an approved competency exam, nor are they required to be certified or have other credentials.

In contrast, certified nursing assistants (CNAs) who work in nursing facilities, hospitals, or home health agencies and have similar job responsibilities[xx] are required to attend at least 75 hours of training in a state-approved educational curriculum, demonstrate certain core competencies by passing a state-approved examination, and be registered on the nurse aide registry before being able to work.[yy] Nurse aides who are interested in career advancement can take additional training, demonstrate other competencies, and be registered with the Board of Nursing to perform other health-related functions. Depending on their training and demonstrated competencies, they can either assume the responsibilities of a Nurse Aide II[zz] or a Medication Aide in a nursing facility.[aaa]

In addition to ensuring a well-qualified workforce, North Carolina needs to do more to improve worker retention and reduce turnover among DSWs. North Carolina does not routinely currently collect data about the turnover rates among DSWs serving people with I/DD. North Carolina does collect more regular data

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[ww] Information about the College of Direct Supports curriculum is available at http://info.collegeofdirectsupport.com/. (Accessed March 9, 2009.)

[xx] These staff serve many of the same functions as many people who serve as direct support workers, including bathing, transferring people, feeding, and helping individuals with their toileting needs.

[yy] 21 NCAC 36.0403(a); CFR 483.75, 483.150-154; https://www.ncnar.org/faq.html. The training must be at least 75 hours. https://www.ncnar.org/verify_listings1.jsp.

[zz] 21 NCAC 36.0403(b), 36.0405(b); http://www.ncbon.org/content.aspx?id=392#Become_NAII. To qualify as a Nurse Aide II, the individual must complete a course approved by the Board of Nursing which includes a minimum of 80 hours of theory and 80 hours of supervised clinical instruction. Nurse Aide IIs can assist with oxygen therapy, suctioning, tracheostomy care, wound irrigation, IV fluid monitoring, ostomy care, gastrostomy feedings, and urinary catheters.

[aaa] https://www.ncnar.org/matcep.html; Board of Nursing Position Statement on Medication Aide available at http://www.ncbon.com/search.aspx?srch=medication%20aide#. Medication Aides can work in skilled nursing facilities. To work as a medication aide, a Certified Nurse Aide must successfully complete a 24-hour NC Board of Nursing-approved medication aide training program, pass the State medication aide exam, and be listed on the State Medication Aide Registry. Medication Aides can administer medications through the mouth, eye, ear, nose, skin, vagina, or rectum.

about the turnover rates among nurse aides working in nursing homes, assisted living, or home health and hospice agencies. In 2007, the most recent year available, there was a 109.7% turnover rate among CNAs in nursing homes, 108.6% in assisted living, and 47.5% in home health and hospice.[65] The most recent North Carolina turnover data for DSWs was from 1999 and found a staff turnover rate of 41%.[bbb,64] While not as high as in agencies serving older frail adults, the turnover rate is nonetheless significant. Further, Task Force members reported that turnover continues to be a problem plaguing agencies that employ DSWs. Nationally, studies suggest that people leave the workforce because of lack of wages and benefits, lack of a career ladder, little opportunity for continuing education, stress and burnout, poor supervision, and lack of recognition. Nationally, for example, DSWs working in state-operated facilities were paid an average of $11.67/hour in 2000, and those working in non-state community services received an average of $8.68/hour.[66] North Carolina only reported data on wages paid to DSWs for state-operated providers. State-operated facilities paid an average of $10.55/hour in 2000, and state-operated community services paid an average of $11.66/hour.[ccc] The state did not report data on wages paid to DSWs by non-state community providers. However, it is likely that the wages paid to DSWs by community providers is less than that offered in state developmental centers, if the national trend is true in North Carolina. In addition, the state developmental centers provide professional support, access to assistive technology, continuing education, career ladder, and worker benefits; thus the turnover rate is generally higher among community-based agencies than state-operated facilities.[66] More needs to be done to reduce the turnover rate among DSWs.

To improve the skills and retention of DSWs, the Task Force recommends:

Recommendation 6.16: Improving the Skills, Competencies, and Retention of Direct Support Workers (PRIORITY RECOMMENDATION)

a) **The Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) should work with Local Management Entities (LMEs), agencies that employ direct support workers (DSWs), pilot sites for the College of Direct Supports, and the North Carolina Direct Care Workers Association to develop and implement a plan to improve the competencies and skills of DSWs. In developing and implementing this plan, DMHDDSAS should:**

   1) **Identify and approve competency-based curricula that will ensure that DSWs who successfully complete the curricula have demonstrated competency and skills needed to provide needed supports and services to people with intellectual and other developmental disabilities (I/DD), or**

[bbb] Data on the turnover rates of direct support workers can be collected as part of the National Core Indicators.

[ccc] Salaries paid to direct support workers (DSWs) in state-operated community organizations in 2000 may have included salaries paid by area programs to DSWs, prior to the reform of the state mental health, developmental disabilities, and substance abuse system in 2001.

identify other strategies to ensure that DSWs have the necessary competencies.

    2) Examine the option of instituting credentialing standards for DSWs who have achieved certain competencies. The credentials should be portable between agencies serving people with I/DD.
    3) Identify barriers that prevent DSWs from obtaining the training needed to achieve certain competencies and implement strategies to address these barriers.
    4) Explore the possibility of providing higher reimbursement to agencies and/or DSWs that demonstrate certain proficiencies.
    5) Explore the implications of these options on recruiting qualified staff to serve as DSWs. Specifically, DMHDDSAS should examine whether these requirements would make it more difficult to recruit family members of people with I/DD to serve as DSWs.
    6) Examine best practices for competency-based training and skills building and credentialing requirements for DSWs in other states.

b) DMHDDSAS should also work with these groups to develop a plan to improve retention among DSWs. As part of this plan, DMHDDSAS should:
    1) Collect information on the average salary and benefits of DSWs employed in different agencies or organizations providing services or supports to people with I/DD, along with the payment differential of different payer sources.
    2) Collect information on the turnover rates among DSWs in different agencies or organizations providing services or supports to people with I/DD.
    3) Identify strategies to provide mentoring and other support for DSWs in their jobs.
    4) Identify opportunities for career advancement of DSWs, including the development of a career pathway.
    5) Examine best practices for recruitment and retention of DSWs in North Carolina or in other states.

c) 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.

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Conclusion

Chapter 7

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

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 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.[a] 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.

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

	NCGA	DMHDDSAS	LME	Providers	Other public agencies	Others
Secondary Transition						
Recommendation 3.1: The State Board of Education (SBE) should examine existing school policies to improve the educational outcomes for children with intellectual and other developmental disabilities.					✓ SBE	
Recommendation 3.2: 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.	✓ LOC				✓ DPI	✓ IDD
Recommendation 3.3: 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.	✓ $6m (R)				✓ DPI	
Recommendation 3.4: 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.	✓	✓	✓	✓	✓ DPI DVR NCCCS	✓ IDD Families
Recommendation 3.5: 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.	✓ $60k (NR) LOE				✓ DPI	✓ IDD Teachers School admin.

	NCGA	DMHDDSAS	LME	Providers	Other public agencies	Others
Recommendation 3.6: (PRIORITY RECOMMENDATION) **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.**	✓ LOC LOE				✓ NCCCS	
Recommendation 3.7: **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.**	✓ $400k (R) $60k (NR) (SFY2010 & SFY 2011)	✓			✓ UNC System Beyond Academics	
Recommendation 3.8: **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.**		✓			✓ UNC System NCCCS DMA	

	NCGA	DMHDDSAS	LME	Providers	Other public agencies	Others
Recommendation 3.9: 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.		✓	✓		✓ DSS	
Transition to Integrated Community Settings						
Recommendation 4.1: 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.	✓	✓	✓	✓ DC ICF-MR	✓ Others	✓ Family rep.
Transition from Aging Parents/Caregivers						
Recommendation 5.1: 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.		✓	✓			✓ I/DD Families

	NCGA	DMHDDSAS	LME	Providers	Other public agencies	Others
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.						
Recommendation 5.2: 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
Cross-Cutting Issues						
Recommendation 6.1: (PRIORITY RECOMMENDATION) 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
Recommendation 6.2: (PRIORITY RECOMMENDATION) 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

	NCGA	DMHDDSAS	LME	Providers	Other public agencies	Others
Recommendation 6.3: (PRIORITY RECOMMENDATION) 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.	✓ $320k (NR) $73k (R) (SFY2010) $3.1m (NR) $373k (R) (SFY2011) $2m (R) (SFY2012) LOC	✓	✓	✓ DC ICFs-MR Others	✓ Gov.'s Office	
Recommendation 6.4: (PRIORITY RECOMMENDATION) 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.	✓ $464k (NR)	✓				
Recommendation 6.5: 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		✓				✓ IDD Families

	NCGA	DMHDDSAS	LME	Providers	Other public agencies	Others
should systematically move to expand consumer-directed budgeting to other people with intellectual and other developmental disabilities who have more significant needs.						
Recommendation 6.6: 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.	✓	✓	✓			
Recommendation 6.7: (PRIORITY RECOMMENDATION) 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	
Recommendation 6.8: 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	

	NCGA	DMHDDSAS	LME	Providers	Other public agencies	Others
Recommendation 6.9: 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 Commitee on Mental Health, Developmental Disabilities, and Substance Abuse Services no later than January 2010.	✓ $74k (R) (SFY2010) $74k (R) (SFY2011) LOC	✓	✓		✓ DHHS HTFA	
Recommendation 6.10: 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.		✓	✓	✓ Others	✓ DHSR	✓ Families Others
Recommendation 6.11: 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.	✓	✓	✓	✓ NF ALF	✓ DHHS DHSR DMA	
Recommendation 6.12: 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.	✓					

	NCGA	DMHDDSAS	LME	Providers	Other public agencies	Others
Recommendation 6.13: (PRIORITY RECOMMENDATION) 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.		✓	✓		✓ DVR	
Recommendation 6.14: 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.	✓ $150k (R)	✓		✓ MD DDS Nurses Allied Health Others	✓ AHEC Health profession schools	✓ IDD Families Advocates Others
Recommendation 6.15: 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.		✓			✓ DMA CCNC	

	NCGA	DMHDDSAS	LME	Providers	Other public agencies	Others
Recommendation 6.16: (PRIORITY RECOMMENDATION) **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.**	✓ 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 Treament)

NCIOM Task Force on Transitions for People with Developmental Disabilities Meeting Topics and Presenters

Appendix A

Topics and Presenters

October 1, 2008

Overview of Task Force charge and North Carolina Institute of Medicine process
Mark Holmes, PhD
Vice President
North Carolina Institute of Medicine

Overview of the issue
Susan L. Parish, PhD, MSW
Assistant Professor
School of Social Work
University of North Carolina at Chapel Hill

System of supports and services
Carol Donin
Team Leader
Developmental Centers
North Carolina Division of Mental Health, Developmental Disabilities and Substance Abuse Services
North Carolina Department of Health and Human Services

What's happening in North Carolina? Data review
Shealy Thompson, PhD
Community Policy Management
North Carolina Division of Mental Health, Developmental Disabilities and Substance Abuse Services
North Carolina Department of Health and Human Services

November 19, 2008

North Carolina education options

Secondary options
Freda M. Lee, MAEd
Consultant for Intellectual Disabilities, Secondary Education, and Transition Services
Exceptional Children Division
North Carolina Department of Public Instruction

Transition
David Test, PhD
Project Co-Principal Investigator–Knowledge Generation
National Secondary Transition Technical Assistance Center
Department of Special Education and
Child Development
University of North Carolina at Charlotte

Post-secondary
Sillar Smith
State Director of Compensatory Education and Special Populations
North Carolina Community College System

Post-secondary options
Michael Sanderson, MPH
Best Practices Unit Manager
Children and Youth Branch
North Carolina Division of Public Health
North Carolina Department of Health and Human Services

Joan McAllister, MSW
LINKS State Coordinator
North Carolina Division of Social Services
North Carolina Department of Health and Human Services

Gina Price, LPC, MS, CRC, LCAS, CSI
Program Specialist
North Carolina Division of Vocational Rehabilitation
North Carolina Department of Health and Human Services

December 17, 2008

Overview of aging issues
Genny Pugh
Executive Director
Turning Point Services

State-funded services and supports
Rose Burnette
Waiver Manager
North Carolina Division of Mental Health, Developmental Disabilities and Substance Abuse Services
North Carolina Department of Health and Human Services

Housing options
Angela Harper
Housing Specialist
North Carolina Division of Mental Health, Developmental Disabilities and Substance Abuse Services
North Carolina Department of Health and Human Services

January 21, 2009

Overview of developmental centers
Carol Donin
Team Leader
Developmental Centers
North Carolina Division of Mental Health, Developmental Disabilities and Substance Abuse Services
North Carolina Department of Health and Human Services

Alexander Myers, PhD
Murdoch Developmental Center

Overview of national outlook
Nancy Thaler
Executive Director
National Association of State Directors of Developmental Disabilities Services

Christina Carter
Implementation Manager
Community Policy Management Section
North Carolina Division of Mental Health, Developmental Disabilities and Substance Abuse Services
North Carolina Department of Health and Human Services

February 23, 2009

Successful transitions: family perspective
Connie Hawkins
Executive Director
Exceptional Children's Assistance Center

Mary LaCorte
Assistant Director
Exceptional Children's Assistance Center

Betsy MacMichael
State Director
First in Families of North Carolina

Thea Gardner
Parent Representative

Successful transitions: community perspective
Cindy Ehlers, MS, LPC, CBIS
Assistant Area Director of Clinical Operations
East Carolina Behavioral Health Local Management Entity

Patte Whitfield, MS, OTR/L
Assistant Director
The Arc of North Carolina

Review and discussion of potential recommendations

March 16, 2009

Review of report

Prioritization of recommendations

Full Recommendations of the NCIOM **Appendix B**

Task Force on Transitions for People with Developmental Disabilities

Chapter 3: Transitions From School to Postsecondary or Community Settings

Recommendation 3.1: Improving Educational Outcomes of Children with Intellectual and Other Developmental Disabilities

The State Board of Education should examine existing school policies to improve the educational outcomes for children with intellectual and other developmental disabilities (I/DD). Specifically the State Board of Education should:

- a) **Develop a policy allowing students in the Occupational Course of Study who graduate with a Graduation Certificate because of not having completed the required hours of competitive paid employment to have four years to complete the work requirements necessary for receiving a high school diploma.**
- b) **Develop guidelines for using end-of-course assessment data in Individual Education Program development at the beginning of each school year to ensure that children with I/DD are receiving appropriate education to achieve their maximum potential.**

Recommendation 3.2: Measuring Outcomes for Students with Intellectual and Other Developmental Disabilities

The Department of Public Instruction (DPI) should add additional questions to the school outcome data collection survey for students with disabilities. The survey should include questions to further assess what students are doing in the area of employment (i.e. how many hours of work per week, how many months on the job, and average wages in the last year), what students are doing if not employed or enrolled in postsecondary education, how well students with disabilities feel their needs were met by schools, and what skills could help them meaningfully engage in their communities. DPI should oversample students with severe intellectual and other developmental disabilities. DPI should report survey results to the Joint Legislative Oversight Committee for Mental Health, Developmental Disabilities, and Substance Abuse Services and to the Joint Legislative Education Oversight Committee no later than February, 2010.

Recommendation 3.3: Improving Transition Outcomes of Children with Intellectual and Other Developmental Disabilities

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' Individual Education Programs.

Recommendation 3.4: Improving Interagency Coordination for Transitions

The North Carolina General Assembly (NCGA) should promote interagency coordination before a child transitions out of secondary school. Specifically, the NCGA should direct the State Board of Education to develop policies to improve transition planning for children with intellectual and other developmental disabilities (I/DD), in collaboration with the Department of Health and Human Services. Transition planning should help the students with I/DD reach their maximum independence, establish employment goals, and participate in community activities or other forms of civic engagement. In developing the transition component of Individualized Education Programs (IEPs), staff with the Local Education Agency (LEA) should:

a) Encourage the active participation of appropriate agencies in developing the transition component of the IEP once the child reaches age 14, including, but not limited to, postsecondary educational institutions, vocational rehabilitation, Local Management Entities (LMEs), and community providers.

b) Develop a checklist for students and parents about issues they should consider in developing the transition component of the IEP and include other available resources in the community that may support the student as he or she transitions out of secondary school. This checklist should be provided to the student and his or her family or guardian annually, beginning at age 14.

c) Share data with LMEs and local community colleges on an annual basis about the unduplicated numbers of students with I/DD in their jurisdiction expected to transition out of the secondary school system. The data should include an unduplicated count and a clear delineation of the services and supports needed.

Recommendation 3.5: Use of Assistive Technology in the Schools

The North Carolina General Assembly should allocate $60,000 to the Department of Public Instruction (DPI) to contract with an independent organization that has expertise in assistive technology (AT) to conduct a study to determine the extent to which the AT needs of students with disabilities, including intellectual and other developmental disabilities (I/DD), are being met.

a) The study should assess the needs for AT of a random sample of students with disabilities, including students with I/DD, who could potentially benefit from the use of AT to help them in school. The study should include students with disabilities from rural, low wealth, and urban school systems from across North Carolina.

b) The study should include a survey of teachers and school administrators to determine their level of understanding of AT and how AT can be appropriately integrated into the school setting. The contractors should also assess how well teachers are integrating AT training into the classroom so that students can effectively use AT.

c) The study should survey parents of the students included in the study to determine if AT options were discussed as part of the Individualized Education Program and then implemented.

d) The contractors should report their findings to DPI and 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. The report should include information on how well the schools are meeting the AT needs of students, any

barriers which prevent appropriate use of AT, recommendations for how AT can be more appropriately utilized in the school setting, and the costs of statewide implementation of the proposed recommendations.

Recommendation 3.6: Expanding Educational Opportunities in the Community College System (PRIORITY RECOMMENDATION)

a) The North Carolina Community College System (NCCCS) should contract for an independent evaluation of NCCCS educational and vocational programs available to people with intellectual and other developmental disabilities (I/DD). As part of this evaluation, the NCCCS should examine:

   1) The number of students with I/DD enrolled in basic skills (including, but not limited to, compensatory education), economic and workforce development, and curriculum programs by specific type of educational program.

   2) Information about the level of disability of students with I/DD served through the NCCCS system, including numbers of students with intellectual disabilities, the numbers of students using assistive technologies, and where students are receiving their education.

   3) Outcome information including, but not limited to, numbers of students with I/ DD who successfully complete coursework, obtain a degree, pursue further postsecondary education, or engage in competitive work in a community-integrated employment setting.

   4) Barriers which may prevent students with I/DD from enrolling in vocational or technical training courses which would prepare them for community-integrated employment options.

b) The independent contractors should examine the experiences in North Carolina and in other states to identify best practices of providing meaningful postsecondary educational opportunities to people with I/DD in an integrated community setting, both in community colleges, colleges, and universities. As part of this study, the independent contractors should identify whether other states have different admissions requirements, enrollment procedures, educational curriculum, vocational or life skills training courses (including assistive technology training), or other student supports that contribute to valued outcomes for people with I/DD. 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 pilot test the plan in four community colleges. If successful, NCCCS should implement this statewide.

c) NCCCS should identify potential funding sources to help support enhanced educational and vocational training opportunities for people with I/DD including, but not limited to, use of existing funding through compensatory education or other educational funds that may be available through the federal Recovery and Reinvestment Act or other federal legislation.

d) NCCCS should report its findings and plans to expand services to people with I/DD 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.

Recommendation 3.7: Expanding Postsecondary Education Opportunities in Colleges and Universities

a) The North Carolina General Assembly (NCGA) should appropriate $400,000 in FY 2010 and 2011 to the Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) to support the expansion of Beyond Academics from a two-year to a four-year curriculum.

b) NCGA should appropriate $60,000 in SFY 2010 and 2011 to The University of North Carolina at Greensboro to complete the evaluation of Beyond Academics.

c) DMHDDSAS and the Division of Medical Assistance should allocate eight Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities slots for new students in 2010 and 2011 to support students who will enroll in Beyond Academics.

d) The University of North Carolina System and private colleges and universities should expand inclusive postsecondary education programs for people with intellectual and other developmental disabilities based on the results of the Beyond Academics evaluation study, as well as other data on best practices.

Recommendation 3.8: Collaboration Between the University of North Carolina System and the North Carolina Community College System

a) The University of North Carolina System (UNC) and the North Carolina Community College System (NCCCS) should work together to expand the availability of postsecondary educational opportunities for students with intellectual and other developmental disabilities in both community college and university settings.

b) UNC and NCCCS should work with the Division of Mental Health, Developmental Disabilities and Substance Abuse Services and the Division of Medical Assistance to explore federal and other funding sources to support students in postsecondary education.

Recommendation 3.9: Improving Services and Supports for Children with Intellectual and Other Developmental Disabilities in the Foster Care System

The North Carolina 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 from a trained individual within three months of entering the foster care system to determine if they have any intellectual and/or other developmental disabilities (I/DD) or mental health needs. Children who have been determined to have mental health needs or I/DD should be linked into the Local Management Entity system.

Chapter 4: Transitions from Large Congregate Settings to Community Settings

Recommendation 4.1: Preadmission Review of Placements in State Developmental Centers and Private Intermediate Care Facilities for Persons with Mental Retardation

a) **Each of the state-operated developmental centers should have an admissions review committee that includes representatives of multiple Local Management Entities (LMEs), the state or regional transition coordinator, family members, and others as deemed appropriate to review any request for general admission into the state developmental centers. 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. Only those individuals whose needs are reliably determined to require the most intense and costly array of services should be admitted into the state developmental centers. The centers should continue to be viewed as placements of last resort.**

b) **Private Intermediate Care Facilities for Persons with Mental Retardation (ICFs-MR) should create admission committees that are similarly comprised. The ICF-MR admissions committee should review the admission prior to placement to determine if the individual with I/DD could be appropriately served in a community-integrated setting within available funding.**

c) **If the placement in subsections a or b is determined to be appropriate, the committee should develop plans to transition the individual with I/DD into a more integrated setting in the community. Placements in public or private ICFs-MR should be reviewed at least annually.**

d) **The North Carolina General Assembly should provide the Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) with the authority to use existing state funds in a more flexible fashion to support community transitions or to avoid placements into state developmental centers or private ICFs-MR. Examples of funding strategies include blending of the Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities (CAP-MR/DD) waiver funds with state dollars to support individuals with higher intensity of support needs. Other funding strategies may include the transition of more than one individual at a time to smaller residential settings of four or less individuals, with funds (and possible staff) from the state developmental centers following the individuals with I/DD, or increasing the level of in-home special assistance funds to the amount provided to support individuals in licensed group homes or assisted living facilities.**

e) **DMHDDSAS, the Division of Medical Assistance, and the Division of Health Services Regulation should implement policies to:**

   1) **Discourage providers from moving individuals with more significant I/DD or behavioral health needs into state developmental centers or private ICFs-MR.**

   2) **Help community providers provide the necessary supports and services to successfully maintain the individual in the community.**

Chapter 5: Transitions for Older Adults with Intellectual and Other Developmental Disabilities (I/DD) and People with I/DD Living with Aging Caregivers

Recommendation 5.1: Future Planning for Families that Provide Support to People with Intellectual and Other Developmental Disabilities

a) Local Management Entities (LMEs) and the Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) should help families providing services or supports for people with intellectual and other developmental disabilities (I/DD) with future planning. LMEs should assist families to develop their plans for the future so that the family's and the individual with I/DD's wishes are understood and agreed upon before a crisis occurs. Future planning should include, but not be limited to:

    1) An information sheet for families with specific information on the importance of making plans for what will occur when they are no longer able to support their loved one.

    2) A checklist for families about issues they should consider in meeting the future needs of the individual with I/DD, along with a list of available resources in the community that offer services and supports. This information should be made available to individuals with I/DD and their families through the LMEs directly and should be made available on the internet.

    3) Options and ideas for paying for some of the future planning expenses including, but not limited to, legal fees or financial planning fees.

    4) Plans for how the financial, residential, safety, medical, supports, legal, and social needs of the individuals with I/DD will be met as the parents age and may no longer be able to provide the same level of support

b) 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 family member who provides services or supports.

Recommendation 5.2: Outreach to Older Adults Who are Providing Support to People with Intellectual and Other Developmental Disabilities (I/DD) and Linkages into the Aging System for Older Adults with I/DD

Local Management Entities (LMEs) should work with appropriate community organizations including, but not limited to, Area Agencies on Aging, senior centers, home health and hospice services, the faith community, and other community groups to:

a) 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 to provide information about the availability of supports and services for people with I/DD and their families.

b) Ensure that older adults with I/DD and their families have appropriate access to the range of services and supports offered by those organizations.

Chapter 6: Cross-Cutting Issues

Recommendation 6.1: Statewide Transition Plan (PRIORITY RECOMMENDATION)

a) The North Carolina Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) should work with Local Management Entities (LMEs), community and institutional providers, the Department of Public Instruction (DPI), Division of Vocational Rehabilitation (DVR), Division of Medical Assistance (DMA), North Carolina Community College System, University of North Carolina System, individuals with intellectual and other developmental disabilities (I/DD)and their families, advocates, academics, and other appropriate people to develop a statewide transition plan. The plan should identify strategies to build community capacity to provide needed supports and services to people with I/DD. In developing this plan, DMHDDSAS should:

1) **Focus on transitions of people with I/DD from state developmental centers or large Intermediate Care Facilities for Persons with Mental Retardation (ICFs-MR) to smaller community settings; from secondary school to postsecondary education, work, or other forms of community engagement; from foster care into adulthood; from home settings with natural supports to community supports and services; or due to the death or diminishing capacity of a parent or other caregiver.**
2) **Identify the barriers which prevent successful transitions from one life setting to another, including state or local policies or procedures which create disincentives to successful transitions, and successful strategies from North Carolina or other states to address these barriers.**
3) **Identify positive, cost-effective examples of transitions in North Carolina to understand how to promote and sustain these practices throughout the state.**
4) **Identify the best practices from other states in more appropriately targeting resources to people based on the intensity of their needs.**
5) **Create a plan to provide targeted training and ongoing state-level support to LMEs and other appropriate organizations to assist with transition planning.**
6) **Identify the community supports and services needed to support successful transitions.**
7) **Assure that consumer choice is honored by maintaining and expanding options for service and supports appropriate to meet the broad range of consumer and family needs.**

b) DMHDDSAS should identify the funding needed to support successful transitions, including the need for flexible funds that can be used to pay for one-time expenses or other services and supports not otherwise covered through existing programs. DMHDDSAS should explore all current funding sources, and, if appropriate, examine strategies to leverage existing state-only integrated payment and reporting system (IPRS) dollars to draw down additional federal Medicaid funds to serve people with I/DD.

c) DMHDDSAS should work with LMEs and providers to develop a performance-based accountability plan that includes incentives and contract requirements between DMHDDSAS, LMEs and providers. The plan should include meaningful transition performance measures for LMEs and providers to ensure that people with I/DD are provided the opportunity to maximize their independence and self-determination as they transition from one life setting to another

and are served in the most integrated setting appropriate to their needs. The plan may include, but is not be limited to, financial incentive payments to overcome barriers to successful transitions.

d) DMHDDSAS should report on progress of the plan to the Joint Legislative Oversight Committee for Mental Health, Developmental Disabilities, and Substance Abuse Services no later than October 1, 2010.

Recommendation 6.2: Transition Expertise at the State and Local Level (PRIORITY RECOMMENDATION)

a) 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 within DMHDDSAS and $2,660,000 to distribute to the Local Management Entities (LMEs) on a per capita basis to support developmental disability transition expertise at the local LMEs.

b) The developmental disability transition specialist within DMHDDSAS should be responsible for developing and monitoring the system to support transition services across the state. This specialist will report directly to the DMHDDSAS Division Director or a section chief for intellectual and other developmental disabilities (I/DD) services and assist in:

  1) Identifying barriers, including state policies and practices, which prevent people from successfully transitioning from one life setting to another.

  2) Working with the state developmental centers, private Intermediate Care Facilities for Persons with Mental Retardation (ICFs-MR), community providers, and families to develop a transition plan to help people with I/DD move from large facilities into housing arrangements that promote independence, self-determination, and community inclusion.

c) Funding appropriated for the LMEs shall be allocated on a per-capita basis across LMEs. Funds shall be used to support knowledgeable developmental disability staff with transition expertise at the LME or regional level, including creation of transition teams with the variety of skills and expertise needed to support successful transitions. DMHDDSAS should establish clear performance expectations and outcome measures for the transition teams, including, but not limited to:

  1) Documenting that funds are used to support developmental disability staff with specific responsibility for systems change needed to support successful transitions.

  2) Demonstrating evidence of positive partnerships with other agencies that provide services and supports to people with I/DD, including Vocational Rehabilitation, schools, community colleges, employment agencies/services, housing providers, medical, dental, and behavioral health professionals, parent advocacy groups, and representatives of other organizations needed to facilitate successful transitions for the variety of needs experienced by target populations.

  3) Increasing the numbers of individuals who have successfully transitioned from state developmental centers or large ICFs-MR to more independent living, youth who have successfully transitioned from secondary to postsecondary or competitive work, and/or adults with I/DD who have successfully transitioned from their homes with aging caregivers into more independent living arrangements or remained in their family home with supports.

Recommendation 6.3: Enhanced Data Collection (PRIORITY RECOMMENDATION)

a) The Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) should work with the Governor's office to ensure that state, Local Management Entities (LMEs), and private providers of mental health, developmental disabilities, and substance abuse services are part of the statewide health information technology (HIT) plan developed in response to the federal American Recovery and Reinvestment Act.

   1) DMHDDSAS should involve state developmental centers, LMEs, and private providers as it identifies or develops an electronic health record system (EHR) for people who receive mental health, developmental disability, or substance abuse services. In addition to health care information, the EHR should have the capacity to collect information on long-term supports and services provided for people with intellectual and other developmental disabilities (I/DD).

   2) The DMHDDSAS HIT system should ensure that the EHR can be accessed on a real time basis by the consumer and all of the agencies or providers who are proving health, behavioral health, developmental disability, case management, direct support, or other supports.

   3) The DMHDDSAS HIT system should also capture data in a uniform format that can be used to maintain waiting list information as described in Recommendation 6.3b, and that can be used to determine progress in building community capacity.

   4) The North Carolina General Assembly 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 EHR system.

b) The DMHDDSAS should create a statewide waiting list system to maintain lists of people with I/DD who are waiting for specific services. DMHDDSAS should ensure that the EHR system will capture the waiting list data. However, until the data can be captured via the EHR system, DMHDDSAS should institute an active, computerized waiting list system. DMHDDSAS should develop standardized criteria to ensure that the waiting list data are collected consistently across LMEs. The system should include information on the following:

   1) The numbers of people with I/DD who have been found to be eligible for developmental disability services and supports and who are unable to be served immediately because of lack of funding or service availability.

   2) What services or supports the individual is waiting for and date of initial placement on the list, including health, behavioral health, dental, specialized therapy services, residential, vocational, educational, assistive technology, and other support services.

   3) The age of individuals waiting for services and supports.

   4) Which individuals on the waiting list are receiving or are potentially eligible for the Community Alternatives Program for Persons with Mental Retardation/Developmental Disability.

   5) Any other data needed to identify unmet needs for specific groups of people with I/DD.

c) **DMHDDSAS, in conjunction with the LMEs and public and private providers of developmental disability services should examine what data are needed to support successful transitions. As part of this analysis, DMHDDSAS should identify what data are already being collected that could be analyzed for transitions purposes and what new data are needed to better inform the state and LMEs to support successful transitions. DMHDDSAS should identify funding needed to support the data plan and present an overall data plan to the Joint Legislative Committee on Mental Health, Developmental Disabilities, and Substance Abuse Services no later than October 1, 2010.**

d) **The North Carolina General Assembly should appropriate $72,765 in recurring funds to DMHDDSAS in SFY 2010 and SFY 2011 to support one new position to manage and analyze data and to assist with waiting list coordination and management.**

e) **DMHDDSAS should use these data, along with information from individual assessments, for statewide planning, needs projections, and quality improvement. On an annual basis, DMHDDSAS should report to the Joint Legislative Oversight Committee on Mental Health, Developmental Disabilities, and Substance Abuse Services the services that are most in need throughout the state and plans to address unmet needs, as well as any cost projections to provide needed services.**

Recommendation 6.4: Use of a Standardized Assessment Instrument (PRIORITY RECOMMENDATION)

a) **The Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) should adopt a validated and reliable assessment instrument that can be used for people with intellectual and other developmental disabilities (I/DD) to provide information on the person's relative intensity of needs. The assessment instrument should be administered by independent, trained, and credentialed professionals who are not employed by provider agencies.**

b) **Data from the assessment instrument should be used:**

   1) **To assist in the development of the Person Centered Plan (PCP). Case managers should use the information from a standardized assessment instrument, along with other medical or professional assessments, to help an individual with I/DD develop his or her PCP. The development of the PCP should be a collaborative process built upon the goals and aspirations of the person with I/DD or the family of a child.**

   2) **For statewide and local planning purposes, data from an assessment instrument administered to all children and adults eligible for developmental disability services, along with information from the statewide waiting list, should be used to determine the types of community supports and services needed to support people with I/DD.**

   3) **In determining an individual resource allocation, DMHDDSAS should use data from a standardized assessment instrument, in conjunction with other specified assessments and variables, to develop relative intensity of need measures for all persons eligible for developmental disability services in the state. The results of this testing for each person will allow assignment of that person to state-established individual resource allocations or tiered payment levels in order to more appropriately target state and federal funding based on the individual's intensity of needs.**

   4) **In setting payment levels to specific providers. DMHDDSAS should use the data from a standardized assessment instrument to adjust payments to providers to ensure that the provider payments are based on the intensity of needs of the people served by the provider.**

c) DMHDDSAS should develop a formula for a fair, equitable, and consistently applied allocation of resources that can be applied statewide. This formula should be based on a reliable and valid assessment of relative intensity of need for all children and adults who are receiving services. The North Carolina General Assembly should appropriate $463,924 to DMHDDSAS to continue to test the Supports Intensity Scale™ (SIS) to determine whether this assessment instrument can meet state needs as specified in subparagraph a. In identifying an appropriate assessment instrument, DMHDDSAS should examine the costs of implementing the SIS in comparison to the North Carolina Support Needs Assessment Profile (NC-SNAP) or other instruments already in use in North Carolina, the usefulness of these instruments in determining relative intensity of needs, and the experiences from other states that have used the SIS, the NC-SNAP, or other assessment instruments for these purposes.

Recommendation 6.5: Consumer-Directed Supports

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 should systematically move to expand consumer-directed budgeting to other people with intellectual and other developmental disabilities who have more significant needs, and should report its progress on reaching this goal to the Joint Legislative Oversight Committee on Mental Health, Developmental Disabilities and Substance Abuse Services no later than October 1, 2010.

Recommendation 6.6: Flexible Funding

a) The Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) should work with the Local Management Entities (LMEs) to examine the need for flexible funding to support transitions from state developmental centers or private Intermediate Care Facilities for Persons with Mental Retardation (ICFs-MR) to integrated settings in the community or to prevent individuals from being placed into state developmental centers or private ICFs-MR. As part of this analysis, DMHDDSAS and the LMEs should:

    1) Identify the services or supports that cannot be funded through existing funding sources or for which funding is so limited as to not support transition needs.

    2) Identify what resources can already be used to support successful transitions.

b) Until additional funds are appropriated for this purpose, DMHDDSAS should work with the LMEs to support more flexible use of existing state dollars.

    1) DMHDDSAS should create policies to enable LMEs that receive single stream funding to use their resources to pay for transition expenses. LMEs should be required to report on the amount of funding, how the funds were used, and source of funds used for transition purposes to help DMHDDSAS identify the amount of flexible funding needed statewide and the impact of allowing flexible funding on the provision of services to other people with mental health, developmental disabilities, or substance abuse needs.

    2) DMHDDSAS should seek legislative authority to have the discretion to review and approve LMEs' use of state developmental disability funds in excess of 5%, if being used to support specific transition plans for individuals transitioning from one life setting to another. LMEs must provide evidence of how the flexible state funds will be used to support specific transition plans in order to seek approval for flexible funding in excess of 5%. LMEs must report on the amount of funds and how the funds will be used to help DMHDDSAS develop a plan for flexible funding.

Recommendation 6.7: Improving the Quality of Case Management Services (PRIORITY RECOMMENDATION)

a) 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 the people with intellectual and other developmental disabilities (I/DD) served and should help to improve retention of qualified case management staff. As part of the plan to ensure accountability of case managers, DMHDDSAS should:

   1) Examine the current training, oversight, and supervision requirements for case managers and make recommendations for how case management services can be improved. DMHDDSAS should identify and approve competency-based curricula that will ensure that people who have successfully completed the curriculum have demonstrated case management proficiencies for working with people with I/DD.

   2) Examine the option of instituting credentialing standards for case managers who have achieved certain competencies. The credentials should be portable between agencies serving people with I/DD.

   3) DMHDDSAS and DMA should ensure that case managers who are working with people with a dual diagnosis of mental illness and developmental disabilities are cross-trained and have specific competencies in both mental health and developmental disabilities.

   4) Explore the option of requiring agencies that employ case managers to be licensed and demonstrate that their case management staff receive appropriate training and supervision, and that the agencies are in compliance with the state's accountability standards.

   5) Examine different models of delivering case management services to ensure the competency, independence, and accountability of case managers. DMHDDSAS should examine the advantages and disadvantages of the existing case management system compared to statewide contracts for case management-only agencies, moving case management services back into Local Management Entities, or other options to improve case management services.

   6) Explore the possibility of providing higher reimbursement to agencies and/or case managers that demonstrate certain proficiencies and/or have lower turnover rates.

b) The electronic health record system, developed in accordance with Recommendation 6.3, should allow case managers to have access to real time data to use to monitor changes in the health, behavioral, or functional status of the person with I/DD and to monitor services and supports provided to the person. The case management system should include intake, assessment, planning, monitoring, and quality assurance data and should be linked to the service billing systems to facilitate service coordination.

c) The DMA should develop an approval process to authorize payment for up to 180 days of transition services as part of the Targeted Case Management under the Medicaid state plan for people moving out of state developmental centers or Intermediate Care Facilities for Persons with Mental Retardation.

d) 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.

Recommendation 6.8: Expansion of Crisis Services

a) The North Carolina General Assembly should appropriate $2.7 million in recurring funds to the Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) to fully fund the existing Systemic, Therapeutic, Assessment, Respite and Treatment (START) teams and $6.7 million in recurring funds 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 START model.

b) 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 1, 2010.

Recommendation 6.9: Expanding Housing Options for People with Intellectual and Other Developmental Disabilities

a) The Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) should work with the North Carolina Department of Health and Human Services housing specialists, Local Management Entities (LMEs), housing service providers, 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 to enable people with intellectual and other developmental disabilities (I/DD) to live in the community. In this analysis, DMHDDSAS should examine:

   1) Whether there are sufficient permanent supportive housing options available to meet the needs of people with I/DD.

   2) Whether state funding provided to help pay for room and board for people with I/DD is sufficient to serve all the people who need and would otherwise qualify for residential services.

   3) Whether support services available through the Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities (CAP-MR/DD) waiver, coupled with residential supports available through state funded services, are sufficient to support people with I/DD living in the community.

   4) Whether any new federal funds are available through expansion of Section 8 certificates or other housing subsidies for low-income people with disabilities.

   5) Whether there are other barriers including, but not limited to, local zoning restrictions, which prevent the development of permanent supportive housing for people with I/DD.

   6) Whether the formal or informal rules in some supported housing create barriers which prevent people with I/DD from working. If DMHDDSAS determines that barriers exist, then DMHDDSAS should identify options to remove barriers to successful employment.

b) 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 to implement the recommendations in Recommendation 6.9-6.11.

c) LMEs should develop an inventory of community housing options from the most restrictive facilities, to supported living arrangements, to independent living, and make this inventory available to families. The lists should be available in person through the LMEs and should be made available on the internet.

d) DMHDDSAS shall identify and detail what steps are being taken with current funding to promote alternatives to traditional group home living.

e) DMHDDSAS should examine the association between costs, personal outcomes, level of support needs, and living arrangements.

f) 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.

Recommendation 6.10: Expanding the Availability of Shared Living and Alternative Family Arrangements

The Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) 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. In developing this plan, DMHDDSAS should:

a) Develop criteria for shared living arrangements that will promote inclusion and integration into the community while at the same time ensuring health and safety.

b) Explore the experience in other states that have successfully developed and expanded shared living arrangements.

c) Determine whether modifications are needed to state licensure rules or statutes to facilitate the development of shared living arrangements.

d) Explore the option of licensing shared living agency coordinators or service providers rather than licensed housing units.

Recommendation 6.11: Screening for People with Intellectual and Other Developmental Disabilities Before Placement in an Assisted Living Facility

a) The Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) and Division of Medical Assistance (DMA) should develop an assessment process, similar to the Preadmission Screening and Annual Resident Review (PASARR), to determine whether people with mental illness, intellectual, or other developmental disability or related disorder can be appropriately served in an assisted living facility and whether this is the most integrated setting appropriate to the person's needs.

    1) The assessment should be conducted by independent mental health or developmental disability certified professionals.

    2) DMHDDSAS should review the assessment instrument prior to placement in an assisted living facility to ensure that placement is the best option possible to meet the unique needs of the individual and not based solely on the person's developmental disability.

    3) DMHDDSAS should involve the Local Management Entity (LME) transition specialist prior to admission to ensure that the person with intellectual and other developmental disabilities (I/DD) is receiving appropriate services and supports. The LMEs staff should work with the individual, his or her family, and case managers to determine if there are

alternative housing options that would promote greater self-direction and less restrictive living environment. LME staff should also help arrange for services and supports in the community to enable the person to live as independently as possible or arrange for appropriate services and supports in the assisted living facility if placement is determined to be appropriate.

b) **In the future, all individuals with I/DD should receive an independent assessment using the authorized level of need assessment identified as part of Recommendation 6.4 to determine intensity of need and appropriateness of placement.**

Recommendation 6.12: Expanding State/County Special Assistance to Provide Additional Support to People in Home Settings

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 to individuals in their own homes, alternative family living, or host families as would be provided in licensed facilities.

Recommendation 6.13: Employment First (PRIORITY RECOMMENDATION)

a) **The Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) should work with the Division of Vocational Rehabilitation (DVR) and Local Management Entities (LMEs) to expand employment opportunities to more people with intellectual and other developmental disabilities (I/DD), including those with the most significant physical and intellectual disabilities. To expand the employment opportunities for all people with I/DD, including those with the most significant I/DD, DMHDDSAS should work with LMEs and DVR to:**

   1) **Assure that the funding appropriated by the North Carolina General Assembly for long-term vocational support are spent to help people with I/DD retain employment after completion of the job placement and the training phase through DVR. These supports should be available on a consistent basis across all LMEs. In addition, LMEs and providers should maximize the use of Community Alternatives Program for Persons with Mental Retardation/Developmental Disability funding in support of eligible individuals who require long-term employment support.**

   2) **Identify evidence-based and promising practices in North Carolina and in other states to assist all people with I/DD in finding and maintaining community-integrated employment. DMHDDSAS, in conjunction with LMEs and DVR, should pilot evidence-based and promising practices to determine what models are most successful in helping people with all levels of I/DD obtain and retain employment. DMHDDSAS should use existing funds appropriated for long-term vocational supports to support these pilots and to evaluate the programs. If successful, these pilots should be expanded throughout the state.**

   3) **Provide training to DVR rehabilitation counselors, Community Rehabilitation staff, DMHDDSAS and LME staff, and local case managers about evidence-based and promising practices to provide meaningful employment opportunities for people with I/DD, including those with the most significant disabilities.**

b) In order to expand employment opportunities for people with I/DD, DVR will:

  1) Continue to strive to assure all DVR unit offices are following federal Vocational Rehabilitation guidelines in eligibility determination, including the utilization of the supplemental evaluation and community-based assessment models that include rehabilitation engineering and assistive technology services.

  2) Monitor and aggressively seek out any funding opportunities for job training, supported employment, or job placement that is or may become available under the federal Recovery and Reinvestment Act or any subsequent federal legislation.

  3) Evaluate existing federal standards and indicator criteria for more effective strategies in serving persons within the categories of "significant and most significant disabilities," which would include individuals with more significant I/DD.

c) The North Carolina Department of Health and Human Services should expand joint training efforts between DMHDDSAS, LME and DVR staff to provide cross-training for state and local staff in all aspects of the provision of Supported Employment services for people with I/DD.

Recommendation 6.14: Training for Health Care Professionals

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 services for people with intellectual and other developmental disabilities (I/DD). The trainings should include, but not be limited to:

a) Education for health care professionals (including physicians, dentists, nurses, allied health, and other healthcare practitioners) to provide better health care services for persons with I/DD.

b) Establishing a primary care medical home for people with I/DD.

c) Transitioning adolescents with I/DD from pediatric care to adult care and self-management.

d) Training of psychiatrists, counselors, and other health care professionals in addressing the needs of individuals with I/DD who need mental health services.

e) Education for health care professionals about the developmental disability system and how to coordinate services with the family, case manager, and other direct support workers to assist in providing proper health care for persons with I/DD.

f) Internships and residency rotations in settings that routinely provide services to people with I/DD.

g) Support for continuation and expansion of mini-fellowships in developmental medicine.

h) The North Carolina General Assembly should appropriate $150,000 on a recurring basis to the AHEC program to support these efforts.

Recommendation 6.15: Expanding Access to Health and Dental Services and Developing a CCNC Pilot Initiative for People with Intellectual and Other Developmental Disabilities

a) 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, psychological/behavioral, or therapy 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. Specifically, DMA should consider, but not be limited to:

   1) Examining the reimbursement rates to determine if the rates are adequate to compensate providers for additional time that they may need to spend with selected Medicaid recipients with intellectual and other developmental disabilities, including behavioral issues.

   2) Identifying or creating centers of excellence across the state with specific expertise working with people with I/DD. Centers of excellence would be responsible for assessments, treatment, consultation with other community practitioners, and training of other professionals, direct support workers, and family service providers.

   3) The experience of other states in improving access to care for people with I/DD.

   4) Other options to expand access to medical, dental, psychological, behavioral, or therapy services.

b) North Carolina Community Care Inc. should work with DMA and DMHDDSAS to explore the possibility of creating a Community Care of North Carolina care management model designed to meet the special needs of people with I/DD. The model should be based on the new chronic care model developed for older adults or people with disabilities, but should be targeted to address the transition, behavioral, health, and support needs that are specific to people with I/DD.

Recommendation 6.16: Improving the Skills, Competencies, and Retention of Direct Support Workers (PRIORITY RECOMMENDATION)

a) The Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) should work with Local Management Entities (LMEs), agencies that employ direct support workers (DSWs), pilot sites for the College of Direct Supports, and the North Carolina Direct Care Workers Association to develop and implement a plan to improve the competencies and skills of DSWs. In developing and implementing this plan, DMHDDSAS should:

   1) Identify and approve competency-based curricula that will ensure that DSWs who successfully complete the curricula have demonstrated competency and skills needed to provide needed supports and services to people with intellectual and other developmental disabilities (I/DD), or identify other strategies to ensure that DSWs have the necessary competencies.

  2) Examine the option of instituting credentialing standards for DSWs who have achieved certain competencies. The credentials should be portable between agencies serving people with I/DD.
  3) Identify barriers that prevent DSWs from obtaining the training needed to achieve certain competencies and implement strategies to address these barriers.
  4) Explore the possibility of providing higher reimbursement to agencies and/or DSWs that demonstrate certain proficiencies.
  5) Explore the implications of these options on recruiting qualified staff to serve as DSWs. Specifically, DMHDDSAS should examine whether these requirements would make it more difficult to recruit family members of people with I/DD to serve as DSWs.
  6) Examine best practices for competency-based training and skills building and credentialing requirements for DSWs in other states.

b) DMHDDSAS should also work with these groups to develop a plan to improve retention among DSWs. As part of this plan, DMHDDSAS should:
  1) Collect information on the average salary and benefits of DSWs employed in different agencies or organizations providing services or supports to people with I/DD, along with the payment differential of different payer sources.
  2) Collect information on the turnover rates among DSWs in different agencies or organizations providing services or supports to people with I/DD.
  3) Identify strategies to provide mentoring and other support for DSWs in their jobs.
  4) Identify opportunities for career advancement of DSWs, including the development of a career pathway.
  5) Examine best practices for recruitment and retention of DSWs in North Carolina or in other states.

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.

NOTE: The following are terms used throughout the report that describe functional limitations, service needs, or other concepts used in the developmental disability field.

Adult Basic Education: A program for adults, who have not completed an eighth-grade education, to increase basic reading, writing, computation, and critical thinking skills. The program is offered by community colleges.

Adult day health: Adult day health services are furnished four or more hours per day on a regularly scheduled basis for one or more days per week. Adult day health services are provided in an outpatient setting. They include both health and social services needed to ensure the optimal functioning of the participant.

Adult Developmental and Vocational Program (ADVP): A facility which provides developmental activities for adults with developmental disabilities to prepare the individual to live and work as independently as possible by fostering community integration and increasing age-appropriate actions, images, and appearance of the individual. Services and activities offered include vocational evaluation, vocational training, remunerative employment, personal and community living skill development, adult basic education, and long-term support and follow-up as well as support services for clients' families. (10A NCAC §27G .2301)

Alternative Family Living (AFL): A residential service program where individuals with developmental disabilities reside with a family that is not their own. The family provides supportive services, supervision, and monitoring of daily activities.

Assistive technology (AT): Technology used to help people with disabilities meet daily needs and to perform functions in all areas of life, including education, employment, transportation, and community living.

Assistive technology device: Any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities (29 USC 3001 et seq.) Examples include wheelchairs, adapted communication devices, modified household objects or systems, and voice translation into writing.

Augmentative communication devices:[a] Augmentative communication devices are used when a person is unable to communicate with normal speech and when a person's physical impairments make it difficult or impossible to use a gestural system to communicate. Augmentative communication devices include, but are not limited to, communication boards, computer driven devices, or voice synthesizers. Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities will only pay for up to $10,000 per year for augmentative communication devices.

Capacity for independent living: The ability of an individual to live in the community and maintain control over their daily lives without intensive medical or other supports and services. The capacity for independent living includes the ability to develop relationships, work, and receive an education. A person displays a significant functional limitation in this area when he/she requires assistance, supervision, or the presence of a second person more than half of the time.

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[a] Denotes a Community Alternatives Program for People with Mental Retardation/Developmental Disabilities (CAP-MR/DD) Waiver definition.

Community Alternatives Program for Children (CAP/C): A Medicaid home and community-based waiver that offers home and community supports and services for medically fragile children (age 0-18) at risk of having to live in an institution.

Community Alternatives Program for Disabled Adults (CAP/DA): A Medicaid waiver that offers home and community-based services to adults who would otherwise meet the level of need necessary to qualify for care in a skilled nursing facility.

Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities (CAP-MR/DD):[a] A Medicaid waiver that offers home and community services and supports for individuals with developmental disabilities who need the level of care offered in an Intermediate Care Facilities for Persons with Mental Retardation. The services and supports allow individuals with developmental disabilities to live in the community instead of living in a large congregate care setting.

Community inclusion: Full participation by a person in chosen community activities, organizations, and/or groups.

Community rehabilitation program: A program providing supervised work, vocational and basic education, and/or personal care training with the purpose of assisting individuals with intellectual and other developmental disabilities to acquire employment in the community or in the program.

Compensatory education: A community college program designed to help adults with intellectual and other developmental disabilities develop life skills they might not have received because their prior education was inadequate.

Competitive employment: Competitive employment is part-time or full-time work, in an integrated setting, which pays at or above minimum wage. The wages should not be less than wages paid to people without developmental disabilities that perform the same or similar work.

Consumer-directed budgeting: Consumer-directed budgeting means giving the person with a developmental disability control over his or her individual budget. The person with intellectual and other developmental disabilities can use funds allocated in his or her individual budget to purchases services and supports from specific agencies or funds can be used to hire family or friends to provide services and supports.

Crisis respite:[a] A short-term service designed for participants experiencing a crisis for which a period of structured support and/or programming is required. Crisis respite may be used when a participant cannot be safely supported in his/her home due to behaviors exhibited, when implementation of formal behavior interventions have failed to stabilize the behaviors, and/or when all other approaches to insure health and safety have failed. In addition the service may be used as a planned respite stay for participants who are unable to access regular respite due to the nature of behaviors they exhibit. The service is provided in a licensed respite facility.

Crisis services:[a] Crisis services provide one additional specially-trained staff person to provide services during an acute crisis so that the person can continue his/her daily routine and/or residential setting without interruption. The staff person is specially trained in behavior techniques. Crisis services are available 24 hours per day, seven days per week to support other direct care staff, family members, or primary caregivers. The goal is to avoid imminent institutional admission and to protect the person from harming him/herself or others.

Day programming: Programs, services, and supports provided to individuals with intellectual and other developmental disabilities during the day.

Day supports:[a] Day supports provide assistance to help an individual acquire, retain, or improve self-help, socialization, and adaptive skills. Day supports are provided in a nonresidential setting, outside of the home or facility in which the individual resides. Day supports focus on enabling the person to attain or maintain his or her maximum functional level. The services are coordinated with any physical, occupational, or speech therapies listed in the Person Centered Plan. Day supports may include prevocational activities (e.g. activities directed at underlying habilitative goals such as attention span, motor skills, attendance, and task completion), but may not be used for the provision of vocation services.

Developmental center: In North Carolina, a state-run Intermediate Care Facility for Persons with Mental Retardation. There are three state developmental centers in North Carolina, including J. Iverson Riddle Developmental Center (Morganton, NC), Murdoch Developmental Center (Butner, NC), and Caswell Developmental Center (Kinston, NC).[b] These developmental centers provide comprehensive, all-inclusive residential services for people diagnosed with severe intellectual and other developmental disabilities. In addition to room and board, these centers provide health-related services (including medical, dental, behavioral health, and special therapies), educational and vocational training, recreational supports, and assistance with activities of daily living.

Developmental disability: Under North Carolina law, developmental disability is defined as “A severe, chronic disability of a person which:

a. Is attributable to a mental or physical impairment or combination of mental and physical impairments;

b. Is manifested before the person attains age 22, unless the disability is caused by a traumatic head injury and is manifested after age 22;

c. Is likely to continue indefinitely;

d. Results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, capacity for independent living, learning, mobility, self-direction and economic self-sufficiency; and

e. Reflects the person's need for a combination and sequence of special interdisciplinary, or generic care, treatment, or other services which are of a lifelong or extended duration and are individually planned and coordinated; or

f. When applied to children from birth through four years of age, may be evidenced as a developmental delay.” (NCGS §122C-3(12a))

Developmental therapy: A service for individuals with intellectual and other developmental disabilities that provides assessment, habilitation and instruction in regards to the acquisition of activities of daily living skills.

Economic self-sufficiency: The ability to earn an income at a level that enables a person to support himself or herself without other monetary assistance.

Family centered: A family focused approach to planning and implementing services, which incorporates family members as key participants in developing and determining services and supports and in determining when, where, and how often these services will be provided.

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[b] Beginning in 2006, O’Berry Developmental Center was renamed O’Berry Neuro-Medical Treatment Center and has begun a several year conversion to a skilled nursing facility. O’Berry is still Intermediate Care Facility for Persons with Mental Retardation (ICF-MR) certified and continues to care for individuals with intellectual and other developmental disabilities. As such, the center continues to receive Medicaid ICF-MR funding. However, O’Berry no longer admits individuals who would be accepted to state developmental centers. Instead, O’Berry accepts individuals who need highly specialized residential services, targeting individuals with specific coexisting conditions whose needs exceed the level of care provided in traditional community placements.

Family-support services: Services and supports provided to families of individuals with disabilities as a means of supporting the family as the primary caregiver, preventing inappropriate out-of-home placement, and maintaining family relationships.

Group home: A 24-hour, licensed residential setting for people with disabilities. The number of residents and supports and services provided differ between homes, but the state dictates how services are provided and the methods of accountability for providing those services.

Habilitation: Teaching, training, services, and specialized therapies provided to people with developmental disabilities to maintain or increase functioning in a developmental skill area, such as self-help, fine and gross motor skills, language and communication, and cognitive and social skills. The purpose of habilitation is to maintain or increase a person's skills to maximize independent living. (NCGS §122C-3(16))

Home and community supports:[a] Home and community supports helps an individual acquire and maintain skills that will allow him or her to function with greater independence in the community. Home and community supports provide habilitation, training, instruction, and support. This service is different from personal care services, as this service includes training activities in combination with support, supervision, and monitoring as described in the Person Centered Plan. This service can be provided in a person's home or in a variety of community settings that the individual chooses to attend.

Home modifications:[a] Home modifications include equipment and physical modifications to a person's home to ensure the health, safety, and welfare of the individual and enable the person to function with greater independence in the home. Home modifications include, but are not limited to:

- Installation, maintenance, and repairs of ramps, grab bars, and handrails as well as portable ramps.
- Widening of doorways/passageways for handicap accessibility.
- Modification of bathroom facilities.
- Bedroom modifications to accommodate hospital beds and/or wheelchairs.
- Alarm systems/alert systems including auditory, vibratory, and visual to ensure the health, safety, and welfare of the participant (includes signaling devices for persons with hearing and vision loss).
- Hydraulic, manual, or electronic lifts, including portable lifts or lift systems that could be removed and taken to a new location that are used inside the participant's home.
- Fire safety adaptations.

Home supports:[a] Home supports are available to adults who live and receive supports from their family. Home supports includes assistance to help an individual acquire and retain skills related to activities of daily living, including personal grooming and cleanliness, household chores, eating and the preparation of food, and the social and adaptive skills needed to enable the participant to reside in a noninstitutional setting. Home supports are similar to residential supports.

Inclusion (often referred to as full inclusion): Integration of people with disabilities into the community so they can fully participate with those who do not have disabilities. The term inclusion also refers to the support services necessary to realize the goal of integration.

Independent living: The ability to live in the community in the residential setting of one's choice, participate in community activities, manage one's affairs, have and sustain relationships, and possibly maintain employment. Independent living also includes learning skills needed to enable people with intellectual and other developmental disabilities achieve these abilities.

Individual budget: An amount of funds that is under the control and direction of the person with intellectual and other developmental disabilities. The amount allocated to support an individual (the individual budget) would be based on results from standardized assessment instruments, other professional assessments, and the Person Centered Plan.

Individual/caregiver training and education:[a] Individual and caregiver training and education includes training and counseling services for an individual with intellectual and other developmental disabilities and his or her family members. The intent is to enhance the decision-making capacity of the family unit. The training and education includes information on community integration options and strategies, intervention strategies, and use of specialized equipment and supplies.

Individualized Education Program (IEP): A plan written for children with disabilities in the public school system, describing the child's present levels of performance, measurable annual goals, how progress is to be measured, services to be provided to the child, and the frequency and duration of the services. This plan is required for all students receiving services under the Individuals with Disabilities Education Act (IDEA).

Individual goods and services:[a] Individual goods and services are services, equipment, or supplies that would not otherwise be covered as part of the Community Alternatives Program for Persons with Mental Retardation/ Developmental Disabilities waiver or through the Medicaid State Plan. Individual goods and services may be covered for specific individuals if it meets certain requirements. The need for the goods and services must have been identified in the Person Centered Plan, and the person cannot have the funds to purchase the goods or services himself or herself. In addition, the item or service must be able to decrease the need for other Medicaid services, promote inclusion in the community, and/or increase the person's safety in the home environment. Individual goods and services are purchased from the individual's self-directed budget.

Integration: Exercising the equal right of individuals with developmental disabilities to access and use the same community resources as are used by and available to other individuals. (42 USC §15002)

Intellectual disability: See "Mental retardation." Intellectual disability is the preferred term.

Intermediate Care Facilities for Persons with Mental Retardation (ICFs-MR): Certified residential settings with four or more beds providing active treatment as defined by the Department of Health and Human Services. This includes 24-hour personal care and habilitation, as well as support services to people with developmental disabilities. This does not refer to individuals who are able to maintain independence with minimal assistance.

Job coach: A person who instructs and aids an individual with intellectual and other developmental disabilities to obtain and maintain employment. The job coach provides one-on-one training to help the person with a developmental disability learn to perform job tasks and to learn the necessary interpersonal skills needed for employment.

Learning: The cognitive ability to acquire new skills, behaviors, and information as well as use previous experiences to navigate new experiences. A substantial limitation in learning occurs when special interventions or programs are required to assist a person in learning.

Long-term vocational supports:[a] Long-term vocational supports include ongoing and periodic supports to assist working individuals with intellectual and other developmental disabilities with the social or environmental issues that are a part of successful employment. Long-term vocational supports are available to working individuals who no longer need the intense level of support, job coaching, and training available through supported employment services.

Mental retardation: Under North Carolina law: "Significantly sub-average general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested before age 22."[c] "Intellectual disability" is the preferred terminology.

Mobility: The development of gross and fine motor skills as well as the ability to use these skills. A substantial limitation in mobility occurs when assistance, from another person or from a mechanical device, is required.

North Carolina Supports Need Assessment Profile (NC-SNAP): The NC-SNAP is an assessment tool that was developed to measure an individual's level of support needs for developmental disability services and supports. Currently, everyone who is receiving or waiting to receive developmental disability services and who has a developmental disability diagnosis must have an NC-SNAP administered annually.

Person-centered planning: A service and support planning process focused on identifying the personal goals and needed services and supports of an individual with intellectual and other developmental disabilities. The individual with intellectual and other developmental disabilities is the key participant in developing and determining the goals, the services and supports needed to meet those goals, and where and how these services will be provided.

Personal care services:[a] Personal care services generally include the services, supports, and supervision needed to assist people with the activities of daily living, including eating, bathing, dressing, personal hygiene, transferring, ambulation, and other activities of daily living. The types of personal care services that can be provided and the providers who offer the services may vary, depending on whether the services are covered under the Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities waiver or the regular Medicaid program.

Enhanced personal care services are limited to people who are receiving Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities services. They are limited to individuals who have intense medical or behavioral needs, who either: 1) require the expertise and/or supervision of a Registered Nurse or Licensed Practical Nurse due to the complexity or critical nature of the activities provided or 2) who have complex or extreme behaviors that require a comprehensive behavioral plan because they are difficult to assess or effectively treat.

Personal Emergency Response System: Personal Emergency Response System (PERS) is an electronic device, which enables individuals at high risk of institutionalization to obtain help in an emergency. The PERS is connected to the person's phone and is programmed to send a signal to a response center when the "help" button is activated. Trained professionals who staff the response center respond to the emergencies.

Receptive and expressive language: The ability to use both verbal and nonverbal communication behaviors to express ideas and information to others and to understand ideas and information from others. These behaviors include reading, writing, listening, speaking, and the cognitive skills needed to use and process language. A substantial limitation occurs when another person or mechanical device is needed to effectively communicate or when a person is unable to articulate thoughts.

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[c] NCGS §122C-3(22).

Recreational supports: One type of service offered by Intermediate Care Facilities for Persons with Mental Retardation that includes using recreation as a source of therapy, education, or simply an opportunity to have fun.

Residential supports:[a] Residential supports are available to adults who live and receive supports from their family. Residential supports include assistance to help an individual acquire and retain skills related to activities of daily living, including personal grooming and cleanliness, household chores, eating and the preparation of food, and the social and adaptive skills needed to enable the participant to reside in a licensed community residential setting, foster home, or an unlicensed alternative family living home that serves one adult. Residential support also includes assistance to all individuals to participate in home or community activities and covers home and vehicle modifications. Residential support is similar to home support for people living in their family home.

Respite services:[a] Respite services provide periodic relief for the family or the primary caregiver who lives with an individual with intellectual and/or other developmental disability. There are different levels of respite services, which may be provided in the person's home or in an out-of-home setting. Respite services include:

- Enhanced level of respite for individuals who have behavioral or medical needs that require specially trained staff to provide personal care or behavioral services.
- Nursing level of respite for individuals who have medical needs that require nursing staff to conduct personal care services.
- Respite care institutional is respite provided in a state developmental center. Respite care institutional is used when community-based services are not available to care for the person.

Self-care: "Daily activities that enable a person to meet basic life needs for eating, hygiene, grooming, health and personal safety. A substantial limitation occurs when a person needs assistance at least one-half the time for one activity, or needs some assistance in more than one-half of all activities normally required for self-care. Assistance is usually in the form of the intervention of another person directly or indirectly by prompts, reminding and/or supervising someone."

Self-determination: As used in this report, self-determination means involving individuals with intellectual and other developmental disabilities in all aspects of decision making about their lives. Self-determination is often used interchangeably with the ability to control how public funds are allocated for a person's services and supports. However, in this document, the ability to control how public funds allocated for a person's services and supports are spent is called consumer-directed budgeting.

Self-direction: The ability of a person to make independent decisions regarding his or her own life, manage one's social activities, handle personal finances, and protect one's own self interest. A substantial limitation in this area occurs when a person requires direct or indirect assistance or supervision to successfully use these skills.

Services and supports: Programs, training, technologies, and other assistance for people with intellectual and other developmental disabilities that promote health, independence, productivity, integration, and inclusion in the community. Services and supports include, but are not limited to, medical, dental, behavioral health and special therapies; educational and vocational training; assistive technologies and other specialized equipment and supplies; home and vehicle modifications; recreational supports; assistance with activities of daily living; and residential programs.

Specialized consultative services: Specialized consultative services are specialized training and technical assistance for family members, caregivers, or other direct support workers. Family members and other paid/unpaid caregivers are trained by a licensed professional to carry out therapeutic interventions in particular specialty areas (e.g.

therapeutic recreation, speech therapy, occupational therapy, physical therapy, or nutrition) needed to support individuals who have long-term habilitative treatment needs.

Specialized equipment and supplies:[a] Specialized equipment and supplies include devices, controls, or appliances specified in a participant's Person Centered Plan to assist the person in performing activities of daily living, or in perceiving, controlling, or communicating with their external environment. Specialized equipment and supplies may include, but are not limited to, adaptive positioning devices (e.g. prone boards and attachments, positioning chairs and sitters), mobility aides to improve the individual's gross motor skills, or aids for daily living (e.g. adaptive eating equipment, adaptive switches and attachments, adaptive toileting chairs and bath chairs, adaptive clothing, bed rails, assistive listening devices for participants with hearing and vision loss).

Supervised living: A residential facility providing 24-hour residential services and supports to people living in a home environment. The services and supports provided are for the purpose of habilitation or rehabilitation of people with a mental illness, intellectual or other developmental disability, or substance abuse disorder requiring supervision.

Supported employment:[a] Supported employment services include services designed to help individuals choose, obtain, and maintain competitive jobs. Services include pre-job training or education to prepare an individual to engage in meaningful work-related activities (e.g. career/educational counseling, job shadowing, training in resume preparation, job interview skills), assistance in learning job skills necessary for job retention (e.g. work-related training, job coaching, monitoring and assistance in job tasks), transportation, and employer consultation to identify any work-related problems or needs and proactively work with the individual to address the problems. Supported employment also includes assisting an individual to operate a micro-enterprise.

Supports Waiver: The Supports Waiver is a Medicaid home and community-based waiver that is available to certain people with intellectual and other developmental disabilities who would otherwise meet the Intermediate Care Facilities for Persons with Mental Retardation level of care. The Supports Waiver is targeted to people who are receiving significant levels of unpaid support from family caregivers. The Supports Waiver has a relatively low dollar cap that can be authorized for the individual, but offers flexibility in the selection of services within that dollar limit. The Supports Waiver is distinguished from the more comprehensive Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities waiver that provides more extensive services for people who lack the same level of natural supports.

Transportation: Transportation can be provided to enable individual's access to Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities waiver services and other community services, activities, and resources specified by the Person Centered Plan. In addition, individuals eligible for Medicaid (and not Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities) can obtain transportation to help access medically necessary services. Subsidized transportation services are only available when the individual is unable to obtain transportation from family, neighbors, friends, or community agencies without charge.

Traumatic brain injury (TBI): An externally inflicted trauma causing mild to severe injury to the brain.

Vehicle adaptations:[a] Vehicle adaptations include devices, controls, or services that enable individuals to increase their independence and/or physical safety. They include, but are not limited to, door modifications; raising the roof to improve head clearance; lifting devices; devices for securing or transporting wheelchairs or scooters; adapted steering, acceleration, signaling, and braking devices; and seating modifications. Vehicle modifications will only be covered under the Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities waiver when it is cost effective as compared to alternative transportation services.

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Acronyms

Appendix C

ABE	Adult Basic Education
AHEC	Area Health Education Center
AFL	Alternative Family Living arrangement
AT	Assistive Technology
CAP/C	Community Alternatives Program for Medically Fragile Children
CAP/DA	Community Alternatives Program for Disabled Adults
CAP-MR/DD	Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities
CCNC	Community Care of North Carolina
CDS	College of Direct Supports
CED	Compensatory Education Program
CMS	United State Centers for Medicare and Medicaid Services
CY	Calendar Year
DHHS	North Carolina Department of Health and Human Services
DHSR	Division of Health Service Regulation
DMA	Division of Medical Assistance
DMHDDSAS	Division of Mental Health, Developmental Disabilities and Substance Abuse Services
DPI	Department of Public Instruction
DSW	Direct Support Worker
DVR	Division of Vocational Rehabilitation
ECS	Extended Content Standards
EHR	Electronic Health Record
FAPE	Free and Appropriate Public Education
GED	General Educational Development
ICF-MR	Intermediate Care Facility for Persons with Mental Retardation
ID	Intellectual Disability
I/DD	Intellectual and other Developmental Disabilities
IDEA	Individuals with Disabilities Education Act
IEP	Individualized Education Program
LEA	Local Education Authority
LIHTC	Low Income Housing Tax Credit
LME	Local Management Entity
NADSP	National Alliance for Direct Support Professionals
NCATP	North Carolina Assistive Technology Program

NCCCS	North Carolina Community College System
NCCDD	North Carolina Council on Developmental Disabilities
NCGA	North Carolina General Assembly
NCHFA	North Carolina Housing Finance Agency
NCI	National Core Indicators
NC-SNAP	North Carolina Supports Need Assessment Profile
NSTTAC	National Secondary Transition Technical Assistance Center
OCS	Occupational Course of Study
PASARR	Preadmission Screening and Annual Resident Review
PCP	Person Centered Plan
PMPM	Per Member Per Month
QDDP	Qualified Developmental Disabilities Professional
SBE	State Board of Education
SFY	State Fiscal Year
SIS	Supports Intensity Scale™
SPP	State Performance Plan
SSI	Supplemental Security Income
START	Systemic, Therapeutic Assessment, Respite and Treatment

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