Executive Summary

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).

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 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. 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.

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.

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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