2016 UPDATE TO SUCCESSFUL TRANSITIONS FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

Life transitions can be challenging events for many people. People with intellectual and other developmental disabilities (I/DD) may experience more difficulties than others during transition periods such as moving from adolescence into adulthood, changing a living situation, or experiencing the death of a family member or caregiver.[a]

In the United States, more than 4.7 million people, approximately 1.5% of the population, are estimated to have an intellectual or other developmental disability. In North Carolina it is estimated that more than 100,000 people have an intellectual and/or other developmental disability. 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] Some of the supports typically needed by people with I/DD include regular medical and dental care, 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.

People with I/DD need coordinated services and supports from multiple organizations and agencies to help them through life transitions. Some organizations and agencies that provide or oversee services include the North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services (DMHDDSAS), Local Management Entity-Managed Care Organizations (LME-MCOs), the Division of Medical Assistance (DMA), and the Division of Health Services Regulation (DHSR).[c] Medicaid and non-Medicaid state funds are the largest sources of funding for non-educational services for people with I/DD. Children and adolescents with I/DD also receive public school-based services and supports.

At the request of The North Carolina General Assembly (NCGA), the North Carolina Institute of Medicine (NCIOM) convened a task force in 2009 to study transitions for persons with developmental disabilities from one life setting to another, including barriers to transition and best practices in successful transitions.[d] The Task Force was co-chaired by James Bodfish, PhD, former Director, Center for Development and Learning, Carolina Institute for Developmental Disabilities, University of North Carolina at Chapel Hill; Adonis T. Brown, CEO/Founder, EnVisioned Independent Living; and Leza Wainwright, former Director, Division of Mental

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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 disability (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 state definition of developmental disabilities is similar but includes people with traumatic brain injuries, regardless of the age at which the injury occurred. definition is discussed more fully in Chapter 2.

[c] It should be noted that since 2009 there have been significant changes in the structuring of Local Management Entities (LMEs). The 100 LMEs have been consolidated into 7 regional managed care organizations (LME-MCO's).

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

Health, Developmental Disabilities, and Substance Abuse Services. It included 40 additional Task Force and Steering Committee members.

In examining transitions for people with I/DD, the NCIOM was tasked with studying three topics:

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

This 2016 update includes information about the progress, or lack thereof, in implementing the 2009 Task Force Recommendations. In total, progress has been made in implementing 22 (79%) of all the Task Force recommendations. No action has been taken to implement 6 (21%) of the 28 recommendations. Information contained in this updated was collected between 2014 and 2016 by NCIOM staff.

Total Recommendations: 28

- ***Fully Implemented*: 3 (11%)**
- ***Partially Implemented*: 19 (68%)**
- ***Not Implemented*: 6 (21%)**

TRANSITIONS FROM SCHOOL TO POSTSECONDARY OR COMMUNITY SETTINGS

Recommendation 3.1 — **PARTIALLY IMPLEMENTED**

The State Board of Education (SBE) 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 (IEP) development at the beginning of each school year to ensure that children with I/DD are receiving appropriate education to achieve their maximum potential.**

The State Board of Education has not specified how long students in the Occupational Course of Study have to complete required hours of competitive paid employment. However, individual school districts have developed policies allowing students to have additional time to complete the requirements. For example, some districts allow students up to age 22 to complete the required hours.

The SBE requires that progress in the general curriculum, as evidenced in the North Carolina

Standard Course of Study, be addressed during Individualized Education Plan (IEP) development. IEP goals must directly align with Standard Course of Study grade-level standards in assessed areas (currently Language Arts, Math, Writing, and Science). These goals should not simply restate general curriculum content standards, but should address specific areas, knowledge, skills, and competencies required to progress on specific standards. However, specific guidelines for using end-of-course assessment data in IEP development at the beginning of each school year continue to be determined by individual districts based on their goals and needs rather than the SBE.

Recommendation 3.2 **NOT IMPLEMENTED**

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 Commission for Mental Health, Developmental Disabilities, and Substance Abuse Services and to the Joint Legislative Education Oversight Committee no later than February, 2010.

The recommended additional questions have not been included in the school outcome data collection survey for students with disabilities. The survey questions are still developed based on the U.S. Department of Education's requirements for reporting. As of 2014, the U.S. Department of Education requires that students with disabilities must make at least minimum wage, and must work at a job for at least 90 days to be considered employed.

Recommendation 3.3 **NOT IMPLEMENTED**

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.

The recommended funding has not been provided by the North Carolina General Assembly to support community-based instruction for students with intellectual and other developmental disabilities.

Recommendation 3.4 **PARTIALLY IMPLEMENTED**

The North Carolina General Assembly (NCGA) should promote interagency coordination before a child transitions out of secondary schools. 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.**

Some progress has been made toward improving transitions for students with I/DD transitioning out of secondary schools.

The Individuals with Disabilities Education Act (IDEA) requires that a student's IEP meeting must include a representative of the public agency providing and supervising the transition activities and, if appropriate, representatives of other participating agencies. In almost all situations the familiar district representative required for all IEP meetings would qualify as this representative. If appropriate, the student should also be there to ensure her or his needs, preferences, and interests are addressed. If the student cannot attend, other methods of participating must be used.[e]

The Department of Public Instruction is currently in conversation with the Exceptional Children's Assistance Center to look at including a checklist and resource list in the transition tool kit.

The number of of students with I/DD in a community college jurisdiction are not given directly to community colleges or LME-MCOs. Instead, this information is provided to these institutions on an individual basis if community college is a part of the individual's IEP goal.

Recommendation 3.5 NOT IMPLEMENTED

The North Carolina General Assembly should allocate $60,000 to the Department of Public Instruction (DPI) to contract with an independent organization that has

[e] 34 CFR 300.344(c)(3)

expertise in assistive technology (AT) to conduct a study to determine the extent to which the assistive technology needs of students with disabilities, including intellectual and other developmental disabilities (I/DD), are being met.

a) **The study should assess the needs for assistive technology 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 Individual Education Program and then implemented.**
d) **The contractors should report their findings to DPI and to the 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.**

The recommended funding has not been provided by the North Carolina General Assembly to contract or conduct an assessment of assistive technology needs of students with disabiliites.

Since 2007, the Department of Public Instruction has contracted with the Carolina Institute for Developmental Disabilities (CIDD) to train teams of educators on assistive technology (AT). The teams, identified through LEAs, must include at least one speech therapist and one occupational therapist. Potential teams apply for a 2-year training program. Year one includes four in-person trainings with DPI staff and one site visit. Year two includes two in-person trainings with DPI staff and several additional site visits. Since 2014, six new teams have been selected annually to receive AT training. CIDD provides an end-of-year evaluation of the training process to DPI. Participants also complete an evaluation composed of questions about how much more prepared they feel to implement AT with students. They are also able to give suggestions on how to improve future training sessions.

In addition, DPI has produced an AT guidance document and a Wiki research page, posted online in spring of 2016. In 2015, DPI formed the Assistive Technology Advisory Council, with the aim of increasing equity in provision of AT to students with disabilities. The advisory

council includes parent representatives and school personnel. DPI continues to focus on improving training, and has begun survey research on AT capacity for students with disabilities.[f]

Recommendation 3.6 (PRIORITY RECOMMENDATION) PARTIALLY IMPLEMENTED

- **a) The North Carolina Community College System (NCCCS) should contract for an independent evaluation of NCCCS educational and vocational programs available to people with 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 that 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 package or other federal legislation.**
- **d) NCCCS should report its findings and plans to expand services to people with I/DD to the 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.**

[f] Layman, R. Exceptional Children Consultant, Significant Cognitive and Multiple Disabilities/ Assistive Technology, North Carolina Department of Public Instruction. Personal communication. March 24, 2016.

In 2009, a stakeholder group including educators, agency representatives, a legislator, and advocates met at the Carolina Institute for Developmental Disabilities (CIDD) to discuss providing continuing education after high school for students with intellectual and developmental disabilities (I/DD). The Higher Education Opportunity Act (reauthorization of Individuals with Disabilities Education Act) fostered a national movement in program development for these students; at that time there was only one postsecondary program in the state: Beyond Academics at UNC-Greensboro (UNCG). The NC Postsecondary Education Alliance (PSEA) was established to investigate additional options.

Strategic planning in 2010 charted a pathway for support of program development and systems change. For example, the Compensatory Education Program in the NC Community College System (NCCCS) was revised as recommended by the North Carolina Institute of Medicine Task Force. Deb Zuver and Donna Yerby facilitated quarterly meetings of the PSEA at the CIDD and other university and community college campuses. PSEA members hosted and presented at conferences, distributed a quarterly newsletter, and established a website to disseminate information and increase public awareness.

In 2012, NCCCS, in collaboraton with PSEA, received the College Access Challenge Grant to support the first annual PSE-Capacity Building Summit: a one-day conference at Wake Tech University attended by 100 educations and transition coordinators. In 2013, the CIDD applied for and received additional funding from the College Access Challenge Grant and, in collaboration with UNCG, hosted the second annual summit: a two-day event with 200 participants. At this summit, Deb Zuver and Donna Yerby facilitated regional workshops to encourage networking across the state. Additionally, participation expanded to target school counselors and secondary school teachers.

The University Participant (UP) program at Western Carolina University (WCU) serves a a model for postsecondary education for individuals with I/DD. Currently, 27 additional community colleges and universities in North Carolina have some type of inclusive program. Some of these colleges assessed local community industry needs and developed classes and certificates that prepare students to meet those needs.

Table 1 below illustrates the currently existing post-secondary education programs in North Carolina for individuals with I/DD:

Table 1. North Carolina Post-Secondary Education Programs: Community Colleges At a Glance

North Carolina Postsecondary Education Alliance Program Information Grid (2016). *Post-Secondary Education Opportunities in North Carolina for Students with Intellectual Disabilities.*

Community College or University and Program Name	Focus on Employment Skills	Inclusive Courses	Inclusive Housing	Internship Opportunity	Peer Support/ Campus Community Inclusion	Certificate or Award
Alamance Community College - Career College	✓	N/A	✓	✓	✓	✓
Appalachian State University - Scholars with Diverse Abilities	✓	✓	✓	✓	✓	✓
Cape Fear Community College - Adult Basic Education Essentials	✓	✓	N/A	✓	✓	✓
Carteret Community College - Adult Basic Education Classes		✓	N/A		✓	
Central Carolina Community College - B.E.L.L Academy: Bridge to Earning, Learning & Living		✓	N/A	✓	AY: 2017-2018	✓
Central Piedmont Community College -	✓	✓	N/A	✓		✓

Community Transitions and Project Search						
Carolina Institute for Developmental Disabilities at UNC Chapel Hill - Self Advocacy Leadership Training	✓	N/A	N/A	N/A	✓	N/A
Cleveland Community College - ConneXions		✓	N/A		✓	✓
College of the Albemarle - Pathways to an Accessible College Experience	✓	✓		✓	✓	✓
Craven Community College - Transition Academy		✓	N/A		✓	
Forsyth Tech Enrichment Center						
Haywood Community College: Career College	✓	✓	N/A	✓	✓	✓
Mayland Community College: Work Skills Academy		✓	N/A	✓	✓	

Nash Community College: Foundational Adult Basic Education (FABE)	✓	✓	N/A		✓	✓
Pitt CC: Career Exploration		✓	N/A			
Randolph Community College - Career College		✓	N/A	✓		✓
Robeson Community College: Project SEARCH		✓	N/A	✓	✓	✓
Rockingham Community College: Career College		✓	N/A		✓	✓
Sandhills Community College - START Hospitality Program	✓	✓	N/A			✓
South Piedmont Community College: Compass Education		✓	N/A		✓	✓
Southwestern Community College: Project SEARCH		✓	N/A	✓		

Surry Community College: Adult Basic Education		✓	N/A			✓
University of North Carolina at Greensboro - Beyond Academics	✓	✓	✓	✓	✓	✓
Wake Technical Community College - START Hospitality Program	✓	✓	N/A	✓		✓
Western Carolina University - University Participant Program	✓	✓	✓	✓	✓	✓
Wilkes Community College: Career Track	✓	✓	N/A	In Progress	✓	✓
Wilson Community College: Basic Literacy Skills		✓	N/A			

Recommendation 3.7 **PARTIALLY IMPLEMENTED**

a) The North Carolina General Assembly (NCGS) 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) NCGS 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 Person 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

Beyond Academics expanded to a 4-year certificate curriculum, currently called Integrative Community Studies (ICS), in fall 2009. The last NC Mental Health Transformation Grant from DMHDDSAS was allocated in the fall of 2009 in the amount of $200,000. In the Fall of 2016, ICS had 59 students enrolled and 34 graduates.[g]

The NCGS did not allocate funding for the evaluation of Beyond Academics. However, the North Carolina Council on Developmental Disabilities previously funded a development and evaluation grant for the program. The evaluation and development activities continued through 2011 and are continuing internally within UNCG, but not at the same level as when funding from the DD Council was provided. Internally, UNCG receives funding from

- Home and Community Based Waiver Services (HCBS)- State Plan supported by Federal Medicaid Funds
- State Developmental Disability Services
- Self Directed HCBS Waiver Funds- Other States
- Student Grants for Support- NPO
- Private –Pay Fee for Service Support Plans- Monthly Fees based on range of service hours provided
- State Combined Campaign

In 2010, DMH provided five CAP slots for Beyond Academics to assist with student. The CAP slots were used to provide supplemental support above and beyond the routine accommodations provided for college students. UNCG provided tuition waivers for these students through 2011.

See Table 1 for information on postsecondary education programs for individuals with I/DD in North Carolina

[g] https://beyondacademics.uncg.edu/wp-content/uploads/2016/08/Insight_29_F.pdf

Recommendation 3.8 **FULLY IMPLEMENTED**

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 I/DD 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.**

See Recommendation 3.7 for information on expanded postsecondary educational opportunities for students with I/DD in North Carolina.

Recommendation 3.9 **PARTIALLY IMPLEMENTED**

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 other developmental disabilities or mental health needs. Children who have been determined to have mental health needs or intellectual and other developmental disabilities should be linked into the Local Management Entity system.

There have been no policy changes regarding this recommendation; however, there are ongoing efforts to ensure that children entering the foster care system receive appropriate and timely assessments. Fostering Health NC, a project of the North Carolina Pediatric Society, is focused on building and strengthening medical homes for infants, children, adolescents, and young adults in foster care through integrated communication and coordination of care through a unique partnership among local Departments of Social Services, Community Care North Carolina (CCNC) Networks, the pediatric care team, the child, and the child's family.
Fostering Health NC is developing a medical home framework to address these concerns. The adoption of a health oversight coordination plan for foster children will also address these issues.

The following are current policies for child welfare social workers within county departments of social services:

- Children in foster care placements shall have physical examinations scheduled within 7 days of the date of their placement.
- Children in foster care placement shall receive services designed to assure their emotional and developmental needs are met. Children shall also receive services that help mitigate the feelings of grief and loss that result from removal from the home.
- The agency shall ensure that the child receives all needed evaluations, medical care and psychological treatment services needed through referral to other agencies and providers.
- Youths aged 16 and 17 shall be assessed to determine their needs for services to prepare them for making the transition from foster care to independent living. Specific areas of need, as listed on the Out of Home Family Services Agreement (dss-5240), must be

assessed including education, vocation/job preparation, basic living skills, and personal/social/emotional development.

- Youth ages 16 and older shall receive independent living services as indicated by their personal needs assessment, which the social worker shall complete. The plan for independent living services shall be documented on the Transitional Living Plan of the Out of Home Family Services Agreement (dss-5240). If a youth will not be able to live independently due to profound developmental, physical, or mental disabilities, the basis for this determination must be documented, and a Transitional Living Plan is not required. Youth who are mildly or moderately disabled and who can benefit from aspects of the program shall be offered services appropriate to their needs, and a Transition Living Plan is required. Refer to the Family Services Manual, Volume I, Chapter IV, 1201, Adolescent Services for information on developing a Transitional Living Plan.

While the framework for both Fostering Health NC and the health oversight coordination plan is still being developed, both initiatives are working to implement additional policies. DMHDDSAS has been a part of the health oversight coordination planning.

Recommendation 4.1 **PARTIALLY IMPLEMENTED**

a) **Each of the state-operated developmental centers should have an admissions review committee that includes representatives of multiple Local Management Entities, 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 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.

Each of the large I/DD Centers has an admission committee comprised of members of LME-MCOs, community service providers, and families who review each request submitted for state development center admission. This is true for both regular admission and admission to model demonstration programs. If admission to the center or program is recommended by the committee, a discharge plan is developed soon after admission to insure that the community, family, and center staff understand that the placement is time-limited.

The Intermediate Care Facilities do not have admissions review committees. The LME-MCOs, with input from individuals and families, make decisions about whether the consumer is eligible for and needs this level of care. No plan is made for discharge on admission.

Placements are reviewed at least annually in the I/DD Centers as well as the Intermediate Care Facilities.

The (b)(c) Waiver and the application of B-3 services increase the flexibility to use existing state funds to support community transitions. The (b)(c) waiver also helps discourage providers from moving individuals with more significant I/DD or behavioral health needs into state developmental centers or private Intermediate Care Facilities by providing necessary supports and services to successfully maintain the individual in the community. Services approved under these documents are not included in the Home and Community Based (Innovations) waiver. However, these services may be added for those eligible for the waiver or used instead of the waiver for those who are not eligible. Unfortunately, deep cuts in state dollars for support of individuals with I/DD and mental illness decrease the amount of flexible dollars available for these services.

Recommendation 5.1 **PARTIALLY IMPLEMENTED**

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.

Care Coordinators do not use a formal future planning process but risk assessments do include discussion around safety supports. LME-MCOs are doing some work around future planning, including workshops to engage families on this issue. MCOs also have waiver slots for individuals with developmental disabilities at risk for abuse and housing specialists who, in partnership with group home providers and DSS, help individuals with developmental disabilities find emergency housing and support options when needed.

Recommendation 5.2 **FULLY IMPLEMENTED**

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.**

LME-MCOs conduct outreach to older adults providing support to people with I/DD. DMHDDSAS has worked with hospice and Area Agencies on Aging to ensure that people are aware of the services and resources that exist for people with I/DD and their families. Additionally, First in Families, a North Carolina nonprofit dedicated to offering support to individuals with I/DD, held a workshop series on supports and future planning for individuals with I/DD and their aging families. This work was funded by DMHDDSAS.

Recommendation 6.1 (PRIORITY RECOMMENDATION) PARTIALLY IMPLEMENTED

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, 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 or 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 Local Management Entities (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 the Division, 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 on the plan to the Joint Legislative Oversight Committee for Mental Health, Developmental Disabilities, and Substance Abuse Services no later than October 1, 2010.

In 2009, DMHDDSAS implemented Money Follows the Person, a state demonstration project that helps Medicaid-eligible North Carolinians living in inpatient facilities move into individual homes and communities with supports.

Funding to support successful transitions, particularly flexible funds that can be used to pay for one-time expenses or other services and supports not otherwise covered through existing programs, is primarily provided by Medicaid.

A performance-based accountability plan with incentives and contract requirements between DMHDDSAS and LME-MCOs has not been developed; however, DMHDDSAS includes outcome measures in the costs waiver. In all transition initiatives, it is a part of DMHDDSAS's mission to assure that consumer choice is honored by maintaining and expanding options for services and supports appropriate to meet the broad range of consumer and family needs.

Recommendation 6.2 (PRIORITY RECOMMENDATION) **PARTIALLY IMPLEMENTED**

a) The North Carolina General Assembly (NCGA) 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 disability (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.**

The NCGA has not yet appropriate funding. Since funding has not been appropriated, a position for an I/DD transition specialist to support transition services across the state and report directly to state leadership at DMHDDSAS has not been created. However, with full implementation of the Money Follows the Person (MFP) project, a number of objectives have been achieved, including the development of several transition coordinator positions at each LME-MCO. These coordinators are required to receive specialized training in transition coordination functions and work with community Intermediate Care Facilities as well as state developmental centers in transitioning individuals from those settings. Additionally, specific slots under the Innovations waiver have been identified specifically for MFP to fund individuals' transitions into communities. A transition planning document that outlines the process of transitioning individuals from institutions to the community also been developed.

Other progress toward transition outside of MFP has included:

- Implementation of the Intermediate Care Facility bed transfer project in which 30 beds at the state developmental centers were transferred to community care facility beds specifically to support individuals currently residing in the centers with high acuity of medical or behavioral needs. To date approximately 27 of those beds have been filled in the community.
- Implementation of a transition project by the state neuro-medical treatment centers and the developmental centers to develop creative approaches to transitions, including service definition development. This has been a collaborative process between Division of State Operated Healthcare Facilities, DMHDDSAS, Division of Medical Assistance, and families.

Recommendation 6.3 (PRIORITY RECOMMENDATION) NOT IMPLEMENTED

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 6.3b, and that can be used to determine progress in building community capacity.**
4) **The North Carolina General Assembly (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.**

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 CAP-MRDD.**
    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 Legislative Oversight Committee 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 wait 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 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.

As of 2016, there is no statewide electronic health record system. Per the LME-MCO contracts with DMHDDSAS and DMA, each LME-MCO maintains a wait list of individuals in need of services. The Registry of Unmet Needs is used to document those individuals that may be potentially eligible for NC Innovations services; there also a wait list for individuals to receive state funded services. The registry and waitlist numbers are reported to DMHDDSAS through a monthly LME-MCO monitoring report.

There have been no additional appropriations to create a dedicated staff position to manage and analyze the waitlist. The Quality Management Team within DMHDDSAS monitors the waitlist number for state funded services.[h]

Recommendation 6.4 (PRIORITY RECOMMENDATION) **PARTIALLY IMPLEMENTED**

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 or 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. Case managers should use the information from a standardized assessment instrument, along with other medical or professional assessments, to help the individual with I/DD develop his or her Person Centered Plan. The development of the Person Centered Plan 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

[h] Lewis, M. I/DD Program Manager II and I/DD Team Leader. Division of Mental Health, Developmental Disabilities and, Substance Abuse Services, North Carolina Department of Health and Human Services. Written (email) communication. March 31, 2016.

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.**

In 2012, SIS use was expected to surpass NC SNAP use once it was put in place. However, it is unclear at this time which evaluation is more prevalent. As of 2014, as part of the NC Innovations Waiver, any individual who is eligible for services under that waiver is required to complete a Supports Intensity Scale (SIS) assessment. The results of the SIS Assesment will be used to help inform/develop individual PCP's

Recommendation 6.5 **FULLY IMPLEMENTED**

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 (DMHDDSAS) 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 Legislative Oversight Commission on Mental Health, Developmental Disabilities and Substance Abuse Services no later than October 1, 2010.

DMHDDSAS has expanded consumer-directed budgeting to other people with intellectual and other developmental disabilities who have more significant needs. DMHDDSAS has not reported its progress to the Legislative Oversight Commission on MHDDSAS.

Recommendation 6.6 **PARTIALLY IMPLEMENTED**

- **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.**

Through the North Carolina Money Follows the Person (MFP) federal grant, a number of resources and processes have been established to support successful transitions. Those resources include specified numbers of Innovations waiver slots to support people to transition. Specifically, the North Carolina Innovations Waiver is a resource for funding services and supports for people with intellectual and other related developmental disabilities that are at risk for institutional care in an Intermediate Care Facility for Individuals with Intellectual Disabilities. Individuals who transition from state developmental centers using an MFP slot also have Transition Year Stability Funds available to them in the amount of $3000. Those dollars may be used to purchase needed household items, adaptive equipment, and home modifications, as well as fund pre-transition training for staff who will be working with the individual. MFP also provides training to identified transition coordinators who work with individuals, family members, the developmental centers and providers in the transition process to ensure its

success. In addition to MFP resources, North Carolina also uses staff of developmental centers to assist in training community staff who will be working with the person. Developmental center staff also participate fully in transition planning and serve as a resource once the person has transitioned. Finally, North Carolina uses the NC START crisis prevention and intervention program to support people during the transition process who have behavioral health issues or challenging behaviors.

Recommendation 6.7 (PRIORITY RECOMMENDATION) PARTIALLY IMPLEMENTED

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, 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 Division of Medical Assistance 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 Legislative Oversight Committee on Mental Health, Developmental Disabilities, and Substance Abuse Services no later than October 2010.**

The case coordination system has been revised to include new standards to improve effectiveness and competency. With the implementation of LME-MCOs, case management was phased out and care coordination was implemented. Care coordination is an administrative function within the LME-MCO, and the LME-MCO is responsible for training care coordinators.

In 2015, as part of state planning for the NC Innovation waiver application, DMA, DMHDDSAS, LME-MCOs, and the I/DD state stakeholder group developed a list of I/DD care coordination core competencies and training. This document outlined the trainings and competencies that would be required and recommended for an I/DD care coordinator. This information will become part of the NC Innovations policy when the waiver amendment is approved by CMS.[i]

There has been no development of a statewide electronic health record (see recommendation 6.3).

Recommendation 6.8 **PARTIALLY IMPLEMENTED**

a) **The North Carolina General Assembly (NCGA) 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 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 (I/DD), available as part of the Systemic, Therapeutic, Assessment, Respite and Treatment (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 Legislative Oversight Committee on Mental Health, Developmental Disabilities, and Substance Abuse Services no later than April 1, 2010.**

The NC START program has been implemented throughout the state. The original funding for NC START was $2,437,2047. This money funded 3 teams (Eastern, Central & Western). In FY

[i] Lewis, M. I/DD Program Manager II and I/DD Team Leader. Division of Mental Health, Developmental Disabilities and, Substance Abuse Services, North Carolina Department of Health and Human Services. Written (email) communication. March 31, 2016.

16 the legislator appropriated an additional $1,544,000 to supported services to children and adolescents and respite services for both children and adults.[j]

DMHDDSAS has determined a large need for crisis services for children, but has not presented these findings or recommendations to the Legislative Oversight Committee on MHDDSAS.

Recommendation 6.9 **PARTIALLY IMPLEMENTED**

- **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 NC 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 (NCGA) should appropriate $73,765 in recurring funds in SFY 2010 and SFY 2011 to the DMHDDSAS to support one position dedicated to housing to implement the recommendations in Rec. 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.**

[j] Lewis, M. I/DD Program Manager II and I/DD Team Leader. Division of Mental Health, Developmental Disabilities and, Substance Abuse Services, North Carolina Department of Health and Human Services. Written (email) communication. March 31, 2016.

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 Legislative Oversight Committee on Mental Health, Developmental Disabilities and Substance Abuse Services no later than January 2010.**

No action has been taken to assess the availability and adequacy of permanent supportive housing, housing subsidies, and support services to enable people with I/DD to live in the community or to assess the association between costs, personal outcomes, level of support needs, and living arrangements. Additional funding has not been provided to support a housing specialist within DMHDDSAS.

Up to three people with I/DD may live together without licensure under current legislation, and DMHDDSAS is working to provide services and supports to meet the housing needs of these and other individuals with I/DD.[k]

Recommendation 6.10 **PARTIALLY IMPLEMENTED**

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.**

Up to three people with I/DD may live together without licensure under current legislation, and DMHDDSAS is working to provide services and supports to meet the housing needs of these and other individuals with I/DD.

Recommendation 6.11 **PARTIALLY IMPLEMENTED**

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 PASARR, to determine whether people with**

[k] SECTION 1. G.S. 122C-22(a) is amended by adding a new subsection to read: "§ 122C-22. Exclusions from licensure; deemed status.

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.**

The PASRR assessment screening is required for any individual who is being considered for admission into an Adult Care Home regardless of the source of payment. As of March 1, 2013, it is required that any adult care home licensed under G.S. 131D-2.4 must assure that any individual admitted to the home for care and services is screened prior to admission using the North Carolina PASRR Medicaid Level I screening form. This screening should be completed by an independent screener or an Adult Care Home staff member who is a certified health care professional.[l]

Recommendation 6.12 **NOT IMPLEMENTED**

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.

The General Assembly included a provision in the 2013 budget bill that called for a study of a "tiered Special Assistance (SA) program." However, in a report to the General Assembly, DHHS noted that no county agreed to participate in the pilot.

[l] Lewis, M. I/DD Program Manager II and I/DD Team Leader. Division of Mental Health, Developmental Disabilities and, Substance Abuse Services, North Carolina Department of Health and Human Services. Written (email) communication. March 31, 2016.

The pilot would have had two primary components. First, it would have implemented a tiered rate structure within the SA program for individuals residing in group homes, adult care homes, and in-home living arrangements. The pilot would have tested the feasibility and effectiveness of a tiered rate structure that addresses program participants' intensity of need, including medication management. The individual's SA tiered payment would have been determined by an independent assessment of the individual's need for room, board, and assistance with activities of daily living, including medication management. Second, the pilot would have determined the best way to implement a block grant for the SA program statewide. A block grant would mean a capped budget to operate the SA program.

Recommendation 6.13 (PRIORITY RECOMMENDATION) PARTIALLY IMPLEMENTED

- **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 the Community Alternatives Program for Person with Mental Retardation/Developmental Disabilities (CAP-MR/DD) 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, the 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 economic recovery legislation 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.

On October 24, 2012, a Memorandum of Understanding between DVR and DMHDDSAS was signed, with the intention of strengthening the partnership between the two divisions. DMHDDSAS has worked to clarify expectations for Long Term Vocational Supports (LTVS) with LME-MCOs. Initiatives included the facilitation of community forums with each LME-MCO discussing Supported Employment and LTVS recommendations. These forums have focused on authorizations, funding, and practice expectations. DVR offices also participated in the forums.

In addition, DMHDDSAS continues to work in partnership with DMA/DVR and the LME-MCOs to expand employment services for individuals with I/DD. DMHDDSAS funding for the State Employment Leadership Network ended in 2015. However, DMHDDSAS was selected to participate in the Employment First State Leadership Mentoring program, offered by the Office of Disability Employment. As of 2016, DMHDDSAS is participating in the second year of this program. Program participants include several state agencies, including DVR, DMA, and the Department of Commerce. Intensive technical assistance has been given for the implementation of Workforce Innovation and Opportunity Act (WIOA), including guidance on several low cost and high cost employer engagement models to increase employment opportunities for individuals with disabilities. DVR has partnered with WorkSource East and employment providers to train transition students and adult support teams on low/high technology accommodations for increased successful work outcomes.

Further work must be done to ensure funds are dedicated only for these services and to monitor utilization and outcome performance data.[m]

Recommendation 6.14 **PARTIALLY IMPLEMENTED**

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, parents, or parent advocacy groups to enhance the training provided to health professionals about providing services for people with intellectual and other developmental disabilities. The trainings should include, but not be limited to:

[m] Lewis, M. I/DD Program Manager II and I/DD Team Leader. Division of Mental Health, Developmental Disabilities and, Substance Abuse Services, North Carolina Department of Health and Human Services. Written (email) communication. March 31, 2016.

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 intellectual or developmental disabilities.**
b) **Establishing a primary care medical home for people with intellectual and other developmental disabilities (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.**

State stakeholders, including AHEC, offer several educational activities and programs that train health professionals on providing services for individuals with I/DD. Programs are offered throughout the year, with varied topics and intended audiences. There have not been additional appropriations to AHEC for programs specifically aimed at training individuals who may provide services to individuals with I/DD.

Recommendation 6.15 **PARTIALLY IMPLEMENTED**

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. (CCNC) should work with DMA and DMHDDSAS to explore the possibility of creating a CCNC 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.**

The DMHDDSAS Practice Improvement Collaborative DD Committee and other partners met with CCNC in 2012 to review Medicaid claims data and discuss options for expanded data collection and analysis. The current North Carolina Council on Developmental Disabilities request for applications on medical and health homes may provide a future opportunity to examine utilization data.

Recommendation 6.16 (PRIORITY RECOMMENDATION) NOT IMPLEMENTED

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 personnel, 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 the direct support workers (DSW). In developing and implementing this plan, the Division should:**
    1) **Identify and approve competency-based curricula that will ensure that DSW 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 DSW have the necessary competencies.**
    2) **Examine the option of instituting credentialing standards for direct support personnel who have achieved certain competencies. The credentials should be portable between agencies serving people with I/DD.**
    3) **Identify barriers that prevent direct support personnel 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 direct support personnel that demonstrate certain proficiencies.**
    5) **Explore the implications of these options on recruiting qualified staff to serve as direct support personnel. Specifically, DMHDDSAS should examine whether these requirements would make it more difficult to recruit family members of people with I/DD to serve as direct support personnel.**
    6) **Examine best practices for competency-based training and skills building and credentialing requirements for direct support personnel in other states.**

b) **DMHDDSAS should also work with these groups to develop a plan to improve retention among direct support personnel. As part of this plan, the Division should:**

1) **Collect information on the average salary and benefits of direct support workers 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 direct support personnel in different agencies or organizations providing services or supports to people with I/DD.**
3) **Identify strategies to provide mentoring and other support for direct support personnel in their jobs.**
4) **Identify opportunities for career advancement of direct support personnel, including the development of a career pathway.**
5) **Examine best practices for recruitment and retention of direct support personnel in North Carolina or in other states.**

c) **DMHDDSAS should report its findings and recommendations, including associated costs to implement the recommendations, to the Legislative Oversight Committee on Mental Health, Developmental Disabilities, and Substance Abuse Services no later than October 2010.**

Several LME-MCOs are using online trainings that have outcome measures and individual criteria. There is no pay differential unless it is from the providers themselves.[n]

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