Cross-Cutting Issues

Chapter 6

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

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

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

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

Leadership

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

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

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

Recommendation 6.1: Statewide Transition Plan (PRIORITY RECOMMENDATION)

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

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

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

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

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

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

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

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

a) **The North Carolina General Assembly should appropriate $222,000 in recurring funds to the Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) to hire three developmental disability transitions**

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

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

1) **Identifying barriers, including state policies and practices, which prevent people from successfully transitioning from one life setting to another.**
2) **Working with the state developmental centers, private Intermediate Care Facilities for Persons with Mental Retardation (ICFs-MR), community providers, and families to develop a transition plan to help people with I/DD move from large facilities into housing arrangements that promote independence, self-determination, and community inclusion.**

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

1) **Documenting that funds are used to support developmental disability staff with specific responsibility for systems change needed to support successful transitions.**
2) **Demonstrating evidence of positive partnerships with other agencies that provide services and supports to people with I/DD, including Vocational Rehabilitation; schools; community colleges; employment agencies/services; housing providers; medical, dental, and behavioral health professionals; parent advocacy groups; and representatives of other organizations needed to facilitate successful transitions for the variety of needs experienced by target populations.**
3) **Increasing the numbers of individuals who have successfully transitioned from state developmental centers or large ICFs-MR to more independent living, youth who have successfully transitioned from secondary to postsecondary or competitive work, and/or adults with I/DD who have successfully transitioned from their homes with aging caregivers into more independent living arrangements or remained in their family home with supports.**

Aside from state and local developmental disability leadership, successful transitions are contingent on having community capacity to address the needs of people with I/DD. However, it is hard for North Carolina to develop a plan to expand community capacity or to know what services and supports are most needed without adequate data.

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

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

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

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

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

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

[c] Pub L No. 111-005.

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

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

Recommendation 6.3: Enhanced Data Collection (PRIORITY RECOMMENDATION)

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

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

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

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

  4) The North Carolina General Assembly should appropriate $320,000 in non-recurring funds in SFY 2010, $298,734 in recurring funds in SFY 2011 and $3.1 million in non-recurring funds in SFY 2011, and $2 million in recurring funds thereafter to DMHDDSAS to develop an EHR system.

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

1) The numbers of people with I/DD who have been found to be eligible for developmental disability services and supports and who are unable to be served immediately because of lack of funding or service availability.

2) What services or supports the individual is waiting for and date of initial placement on the list, including health, behavioral health, dental, specialized therapy services, residential, vocational, educational, assistive technology, and other support services.

3) The age of individuals waiting for services and supports.

4) Which individuals on the waiting list are receiving or are potentially eligible for Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities.

5) Any other data needed to identify unmet needs for specific groups of people with I/DD.

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

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

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

Financing

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

Equitable Allocation of Limited State Resources

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Thus, the Task Force recommends:

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

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

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

b) Data from the assessment instrument should be used:

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Recommendation 6.5: Consumer-Directed Supports

The Task Force supports the implementation of a consumer-directed budgeting option through the approved North Carolina Supports Waiver beginning in November 2009. The Division of Mental Health, Developmental Disabilities and Substance Abuse Services should systematically move to expand consumer-directed budgeting to other people with I/DD who have more significant needs, and should report its progress on reaching this goal to the Joint Legislative Oversight Committee on Mental Health, Developmental Disabilities, and Substance Abuse Services no later than October 1, 2010.

Flexible Funding

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

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

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

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

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

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

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

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

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

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

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

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

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

Recommendation 6.6: Flexible Funding

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

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

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

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

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

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

Case Management

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

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

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

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

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

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

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

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

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

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

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

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

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

To improve case management services, the Task Force recommends:

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

a) The Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS), in collaboration with the Division of Medical Assistance (DMA) and other stakeholders, should establish clear accountability standards for case managers. The standards should be designed to improve outcomes for the people with intellectual and other developmental disabilities (I/DD) served and should help to improve retention of qualified case management staff. As part of the plan to ensure accountability of case managers, DMHDDSAS should:

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

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

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

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

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

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

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

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

d) DMHDDSAS should report its findings and recommendations to the Joint Legislative Oversight Committee on Mental Health, Developmental Disabilities, and Substance Abuse Services no later than October 2010.

Community Capacity

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

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

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

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

Crisis Services

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

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

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

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

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

Recommendation 6.8: Expansion of Crisis Services

a) **The North Carolina General Assembly should appropriate $2.7 million in recurring funds to the Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) to fully fund the existing Systematic, Therapeutic Assessment, Respite and Treatment (START) teams and $6.7 million in recurring funds to double the availability of regional crisis interdisciplinary teams and crisis/respite beds for adults with intellectual and other developmental disabilities, available as part of the START model.**

b) **DMHDDSAS should contract to do a gap analysis to determine the need for crisis services for children. DMHDDSAS should present the findings, recommendations and any costs to the Joint Legislative Oversight Committee on Mental Health, Developmental Disabilities, and Substance Abuse Services no later than April 1, 2010.**

Housing

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

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

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

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

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

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[t] 10 NCAC 27G .2101.

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

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

[w] 10 NCAC §27G.5601.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

[cc] NCGS §168-22.

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

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

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

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

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

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

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

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

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

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

b) **The North Carolina General Assembly should appropriate $73,765 in recurring funds in SFY 2010 and SFY 2011 to DMHDDSAS to support one position dedicated to housing to implement the recommendations in Recommendation 6.9-6.11.**

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

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

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

f) **DMHDDSAS will report its findings and any recommendations to the Joint Legislative Oversight Committee on Mental Health, Developmental Disabilities, and Substance Abuse Services no later than January 2010.**

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

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

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

The Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) should work with the Division of Health Service Regulation, Local Management Entities, parent advocacy groups, residential providers, and other appropriate individuals to develop a plan to promote shared living arrangements that promote greater self-direction and more inclusive housing. In developing this plan, DMHDDSAS should:

a) Develop criteria for shared living arrangements that will promote inclusion and integration into the community while at the same time ensuring health and safety.

b) Explore the experience in other states that have successfully developed and expanded shared living arrangements.

c) Determine whether modifications are needed to state licensure rules or statutes to facilitate the development of shared living arrangements.

d) Explore the option of licensing shared living agency coordinators or service providers rather than licensed housing units.

[ee] 10 NCAC § 27G.5601.

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

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

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

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

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

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

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

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

  1) The assessment should be conducted by independent mental health or developmental disability certified professionals.

  2) DMHDDSAS should review the assessment instrument prior to placement in an assisted living facility to ensure that placement is the best option possible to meet the unique needs of the individual and not based solely on the person's developmental disability.

  3) DMHDDSAS should involve the Local Management Entity (LME) transition specialist prior to admission to ensure that the person with intellectual and other developmental disabilities (I/DD) is receiving appropriate services and supports. The LME's staff should work with the individual, his or her family, and case managers to determine if there are alternative housing options that would promote greater self-direction and less restrictive living environment. LME staff should also help arrange for services and supports in the community to enable the person to live as independently as possible or arrange for appropriate services and supports in the assisted living facility if placement is determined to be appropriate.

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

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

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

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

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

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

The North Carolina General Assembly should amend NCGS §108A-47.1 to allow State/County Special Assistance In-Home funds to be used to pay the same maximum payment rates to individuals in their own homes, alternative family living, or host families as would be provided in licensed facilities.

Expanding Employment Opportunities

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

[hh] 42 USC §1347f.

[ii] NCGS §108A-40 et. seq.

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

[kk] NCGS §108A-47.1.

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

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

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

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

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[ll] 34 CFR §363.6(c)(2)(i).

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

- ***School to Life services:*** DVR works with Local Education Agencies (LEAs) to help students who are transitioning out of secondary school to jobs or careers. DVR can provide vocational guidance and help eligible students with training, job placement, and other services. In FFY 2007, DVR served 16,237 youth ages 22 or younger and provided services to 9,068 high school students.
- ***Employment services:*** Employment services can include college or vocational training, on-the-job training, job coaching, or supported employment, depending on the individual's employment plan. DVR also helps individuals with some of the skills needed to obtain a job, including writing resumes and interviewing skills, as well as providing assistance in locating a job. In FFY 2007, DVR helped 6,271 North Carolinians with disabilities attain successful employment outcomes.[26]
- ***Services to employers:*** DVR also provides services to employers, including screening (to match the right employee to the worksite), on-the-job training, and engineering consultation to ensure that the physical workplace can be adapted to meet the needs of the person with disabilities.
- ***Rehabilitation engineering and assistive technology:*** DVR offers rehabilitation engineers that can help people with disabilities overcome physical or communication barriers. Services can include adaptive computer access; augmentative communication; home, vehicle, or worksite modifications; or other technology to help with mobility, daily living activities, communication, education, or leisure. In FFY 2007, DVR worked with 1,213 people to remove barriers at their homes and modified vehicles for 158 consumers.[26] DVR also provided 2,682 individuals with consultation and information about assistive technology services, made 5,409 equipment loans, and provided assistive trainings for 14,616 individuals (see Assistive Technology section).
- ***Community rehabilitation:*** In addition to the 77 local DVR offices, DVR partners with community rehabilitation programs that provide more intensive employment services to people with disabilities. There are 52 community rehabilitation programs in the state. Community rehabilitation programs offer a range of services. They can assist people in obtaining a job, help with job training, provide job coaches to help people while on the job site, offer individual or group supported employment (described below), and offer work adjustment activities to help individuals improve their work skills. Community rehabilitation programs may offer an Adult Developmental Vocational Program

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

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

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

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

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

[mm] 34 CFR §§ 363.6(c)(2),(3).

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

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

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

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

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

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

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

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

Rec. 6.13: Employment First (PRIORITY RECOMMENDATION)

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

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

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

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

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

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

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

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

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

Assistive Technology

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

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

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

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

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

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

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

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

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

Health Care

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

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

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

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

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

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

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

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

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

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

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

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

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

Recommendation 6.14: Training for Health Care Professionals

The Area Health Education Centers (AHEC) program, health professional schools, and Division of Mental Health, Developmental Disabilities and Substance Abuse Services should work collaboratively with health professional associations, self-advocacy groups, parents, or parent advocacy groups to enhance the training provided to health professionals about providing services for people with intellectual and other developmental disabilities (I/DD). The trainings should include, but not be limited to:

- **a) Education for health care professionals (including physicians, dentists, nurses, allied health, and other health care practitioners) to provide better health care services for persons with I/DD.**
- **b) Establishing a primary care medical home for people with I/DD.**
- **c) Transitioning adolescents with I/DD from pediatric care to adult care and self-management.**

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

a) **The Division of Medical Assistance (DMA) should examine existing utilization data and other data sources to determine whether Medicaid recipients with intellectual and other developmental disabilities (I/DD) can access medical, dental, therapy, psychological, or other behavioral services. If DMA determines that Medicaid recipients with I/DD, or a subset of these individuals, have unique or special barriers accessing medical, dental, psychological/behavioral, or therapy services, then DMA should work with the Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) and other provider groups to identify the barriers and options to improve access to care. Specifically, DMA should consider, but not be limited to:**

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

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

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

Direct Support Workers

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

Direct support workers often facilitate connections to the greater community.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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