



Intellectual and Other Developmental Disabilities

The federal definition of a developmental disability (DD), a definition inclusive of an intellectual disability,^a is a severe, chronic disability which is attributable to a mental or physical impairment or a combination of mental and physical impairments; manifests before the age of 22; is likely to continue indefinitely; and reflects a person's need for a combination of special interdisciplinary or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.^b Individuals with intellectual and other developmental disabilities (I/DD) have substantial functional limitations in three or more of the following areas:

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

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

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

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

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

b 42 U.S.C. §6000 et, seq.

c NCGS §122C-3(12a)

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

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

Causes

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

Prevalence

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

Services and Supports For Individuals with Intellectual and Other Developmental Disabilities

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

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

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

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

Medicaid services

Targeted case management

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

State developmental centers

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

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

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

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

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

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

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

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

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

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

^h 42 CFR §435.1009.

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

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

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

Other Medicaid Community Alternatives Program Waivers

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

State-funded services

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

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

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

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

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

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

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

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

Financing Services and Supports

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

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

State developmental centers

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

Private Intermediate Care Facilities for Persons with Mental Retardation

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

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

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

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

Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities

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

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

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

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

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

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

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

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

Non-Medicaid eligible individuals

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

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

Services and supports provided by other agencies

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

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

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

Department of Public Instruction

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

North Carolina Community College System

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

Division of Vocational Rehabilitation

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

Social Security Administration

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

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

⁵ More information on the early intervention program can be found at <http://www.ncei.org/ei/index.html>.

Other Services and Supports

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

References

- 1 National Institute of Child Health and Human Development. Birth defects and developmental disabilities. National Institute of Child Health and Human Development website. <http://www.nichd.nih.gov/womenshealth/research/pregbirth/birthdefects.cfm>. Published September 18, 2006. Accessed February 13, 2009.
- 2 Braddock D, Hemp R, Rizzolo MC. *The State of the States in Developmental Disabilities, 2008*. Seventh ed. Washington, DC: American Association on Intellectual and Developmental Disabilities; 2008.
- 3 US Census Bureau. Table A1: interim projections of the total population for the United States and states. US Census Bureau website. <http://www.census.gov/population/projections/SummaryTabA1.pdf>. Published April 21, 2005. Accessed February 23, 2009.
- 4 Thompson S. Data for assessing the developmental disability services and supports system of North Carolina. Presented to: the North Carolina Institute of Medicine Task Force on Transitions for People with Developmental Disabilities; October 1, 2008; Morrisville, NC.
- 5 Parish SL. A national picture of developmental disabilities. Presented to: the North Carolina Institute of Medicine Task Force on Transitions for People with Developmental Disabilities; October 1, 2008; Morrisville, NC.
- 6 Shattuck PT, Parish SL. Financial burden in families of children with special health care needs: variability among states. *Pediatrics*. 2008;122(1):13-18.
- 7 Burnette R. Services and supports for individuals with developmental disabilities. Presented to: the North Carolina Institute of Medicine Task Force on Transitions for People with Developmental Disabilities; December 17, 2008; Morrisville, NC.
- 8 Division of Medical Assistance, North Carolina Department of Health and Human Services. Targeted Case Management for Mentally Retarded/Developmentally Disabled (MR/DD) individuals: North Carolina Medicaid special bulletin. <http://www.dhhs.state.nc.us/DMA/bulletin/DDTargetedCaseMgmt.pdf>. Published October 27, 2008. Accessed March 3, 2009.
- 9 Donin C. Transitioning individuals from state operated developmental centers to the community. Presented to: the North Carolina Institute of Medicine Task Force on Transitions for People with Developmental Disabilities; October 1, 2008; Morrisville, NC.
- 10 Division of Medical Assistance, North Carolina Department of Health and Human Services. Intermediate Care Facility for Persons with Mental Retardation, clinical coverage policy no. 8E. <http://www.dhhs.state.nc.us/dma/bh/8E.pdf>. Published June 1, 1991. Updated August 1, 2007. Accessed February 27, 2009.
- 11 Burnette R. Services and supports for people with developmental disabilities. Presented to: the North Carolina Institute of Medicine Task Force on Transitions for People with Developmental Disabilities; December 17, 2008; Morrisville, NC.
- 12 Holtzman A. *Special Data Run: Average Age of Individuals Residing in Different Developmental Disability Residential Settings*. Raleigh, NC: Division of Mental Health, Developmental Disabilities and Substance Abuse Services, North Carolina Department of Health and Human Services; 2009.
- 13 Holtzman A. *Special Data Run*. Raleigh, NC: Division of Mental Health, Developmental Disabilities and Substance Abuse Services, North Carolina Department of Health and Human Services; 2009.
- 14 Lakin CK, Doljanac R, Byun S, Stancliffe RJ, Taub S, Chiri G. Factors associated with expenditures for Medicaid home and community based services (HCBS) and intermediate care facilities for persons with mental retardation (ICF/MR) services for persons with intellectual and developmental disabilities. *Intellect Dev Disabil*. 2008;46(3):200-214.
- 15 Rosenzweig LY. Serving the aging developmentally disabled population. *Top Clin Nutr*. 2008;23(2):98-102.