

# A Strategic Analysis for Change *Planning Context*

Responding to the Needs of People with  
Intellectual and Other Developmental  
Disabilities in North Carolina

August 2011



**Human Services Research Institute**

7690 SW Mohawk Street

Tualatin, OR 97062

Voice: 503-924-3783 • Fax: 503-924-3789

[www.hsri.org](http://www.hsri.org)

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## *Planning Context*

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August 2011

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#### Prepared for:



North Carolina Council on Developmental Disabilities  
3801 Lake Boone Trail, Suite 250  
Raleigh, NC 27607  
919-420-7901  
[www.nccdd.org](http://www.nccdd.org)

#### Prepared By:



John Agosta, Valerie Bradley, Kerri Melda,  
Elizabeth Pell & Drew Smith

Human Services Research Institute  
7690 SW Mohawk St.  
Tualatin, OR 97062  
503-924-3783  
[www.hsri.org](http://www.hsri.org)

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All opinions expressed herein are solely those of the authors and do not reflect the position or policy of the North Carolina Council Developmental Disabilities.

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## About the Authors

Human Services Research Institute (HSRI), a non-profit, tax-exempt corporation, was founded in 1976 to improve the availability and quality of supports for children and adults with special needs and other vulnerable populations. Working in the fields of intellectual and other developmental disabilities, mental health, physical disabilities, and child welfare, HSRI staff strongly support efforts to improve community-centered responses to human needs, leading to service approaches that are family and person driven and most apt to result in increased independence and self sufficiency. HSRI has assembled a five-person team to complete this work.

This report was prepared by the following staff:

**John Agosta, Ph.D.** is a Vice President at the Human Services Research Institute and has worked with people with disabilities for over 30 years. Dr. Agosta completed his doctorate in Rehabilitation Research at the University of Oregon, specializing in research methods and community supports for people with disabilities. Additionally, he has extensive experience with community supports, having worked in direct services and administrative positions within agencies offering early intervention, residential, vocational, or family support services.

Employed at HSRI since 1983, Dr. Agosta has worked under contract with state and federal agencies on a variety of projects focusing on community integration for people with intellectual and other developmental disabilities. He has conducted analyses of state systems, and studied specific facets of the field (e.g., supported employment, family support, self-advocacy, Medicaid funding trends, and self-directed supports). He helped found the national Self Advocate Leadership Network and The Riot!, a national e-newsletter designed with and for self-advocates. Presently, he is involved with projects related to exploring innovative means for supporting individuals with disabilities and their families, evaluating what states may do to reform service systems to improve performance, and establishing resource allocation protocols to provide individualized budgets for service recipients while making systems more efficient and equitable.

**Valerie Bradley, M.S.** is the President of the Human Services Research Institute. Ms. Bradley, who has a lifelong interest in public policy, has guided the Institute since its inception in 1976 to become a leading resource for public managers in human services across the country. After getting her Masters in Political Science at the Eagleton Institute of Politics, she began her work in the 1960s as a staffer to the California General Assembly where she contributed to the development of landmark legislation in mental health and intellectual and other developmental disabilities. Her interest in reform has been manifest in her involvement in a number of important issues including quality improvement, family support, deinstitutionalization, and performance measurement.

More recently, Ms. Bradley helped the Institute to forge important collaborations – the most important of which is with the National Association of State Directors of Intellectual and other developmental disabilities. This partnership has resulted in the creation of National Core Indicators – a performance measurement system that facilitates state by state comparisons and that has generated perhaps the largest database of individuals with intellectual and intellectual and other developmental disabilities in the country if not internationally.

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**Kerri Melda, M.S.** is a Policy Associate at HSRI. Ms. Melda has been employed with HSRI since 1992, and her primary responsibilities include project leadership, policy and statistical analyses, program evaluation, and provision of training and technical assistance. Specifically, her work focuses on projects related to family support policy and practice, person-centered funding, performance gap analyses, and studies assessing the impact of change on service recipients. Ms. Melda currently serves as Director of HSRI's Juntos Podemos (Together We Can) Family Center, connecting Latino families who have children with disabilities to community services and supports. She oversees the family support related activities of the National Core Indicators project, which analyzes family support satisfaction data across 25 states. She recently completed a study of the impact of service reductions on Florida's service population, and has worked on reimbursement projects in Colorado, Rhode Island, and Virginia. Ms. Melda holds a Master's Degree in Public Policy and Administration (University of Oregon) and a Bachelor's Degree in Special Education (Indiana University).

**Elizabeth Pell, M.S.** is a Policy Analyst at HSRI. Ms. Pell has worked in the advocacy field on behalf of persons with mental and physical disabilities for over twenty years. At HSRI, she has coordinated evaluation projects such as the National Evaluation of the Protection and Advocacy for Individuals with Mental Illness (PAIMI) Program and worked on numerous quality improvement projects involving individuals and families with intellectual and other developmental disabilities. Prior to HSRI, Ms. Pell worked as a Legal Advocate for persons with developmental and psychiatric disabilities with the federal Protection and Advocacy systems in Alabama and Massachusetts, as Director of an Elder Abuse and Protection department in Massachusetts, and as Director of Social Services with a hospice agency in Oregon.

**Drew Smith, B.A.** is a Policy Analyst at HSRI. Mr. Smith works on several projects related to developing person-centered funding strategies, assessing the impacts of service changes and reductions, and supporting self-advocacy. While at HSRI, Mr. Smith has worked on resource allocation projects in Colorado, Florida, Oregon, Rhode Island, North Dakota and Virginia, as well as strategic planning projects in Texas, Florida, New Jersey, Illinois and North Carolina. He is a graduate of Portland State University in Business Administration

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# Introduction

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In 2008, the North Carolina Council on Intellectual and other developmental disabilities (NCCDD) convened a summit of intellectual and other developmental disabilities stakeholders in a series of three meetings to discuss areas of system change that should form the agenda for the next Governor. These meetings resulted in a report, prepared by the Human Services Research Institute (HSRI), that outlined issues and proposed recommendations for solution, referred to as *Looking Forward: A Summit on the Intellectual and other developmental disabilities System in North Carolina*.

The Summit report advanced recommendations for policy and administrative reform, organized to reflect the overarching issues facing the intellectual and other developmental disabilities system in North Carolina. The Council chose to focus on five domains: Viable Direct Support Workforce; Quality Management and Quality Improvement; Improving Case Management; Empowering Individuals and Families; and Fostering Leadership and Innovation. HSRI also provided a supplemental report<sup>1</sup> that described best practices nationally that could be applied to the implementation of the recommendations.

Building on this work, the NCCDD more recently engaged HSRI to develop *A Strategic Analysis for Change* for North Carolina's system for serving people with intellectual and other intellectual and other developmental disabilities (I/DD)<sup>2</sup>. This is the first of two reports prepared by HSRI for the NCCDD. Here, we provide an analysis of the Planning Context within which policy makers must act in North Carolina. A second report<sup>3</sup> offers a series of Action Steps for implementing the plan.

## Analysis Framework

Prior to making a series of policy choices aimed at re-positioning the North Carolina developmental disabilities service system, it is essential to gain a perspective on the present issues confronting the system. After all, the system is not being designed from scratch. Rather, its current status results from past decisions made over many years; these have resulted in current policy preferences, funding patterns, and service arrays. Taken together, these system factors comprise the planning context or platform upon which the *Strategic Analysis for Change* must be built.

To gain a better understanding of the planning context, we conducted a review of the present contextual circumstances in North Carolina and a gap analysis, during which the performance of

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<sup>1</sup> Bradley, V. *Best Practices for Implementing the Recommendations of "Looking Forward: A Summit on the Intellectual and other developmental disabilities System in North Carolina" Technical Report*. October 16, 2008.

<sup>2</sup> The Federal Government and the State of North Carolina have each established definitions of "intellectual and other developmental disabilities." Though similar in some respects, there are differences. For the purposes of this report, the term "developmental disability" is generally not applied to refer specifically to either definition. When referring to state data, however, reported findings are tied to the state definition. More information to illustrate the difference between these terms is provided in the "Key Terms."

<sup>3</sup> Agosta, J. et al. *A Strategic Analysis for Change: Action Steps*. (2011). North Carolina Council on Intellectual and other developmental disabilities. Raleigh, North Carolina.

North Carolina’s current service system was assessed against five benchmarks. For ease of review, a list of “key terms” is provided following this introductory section.

### Data Sources

To complete this work, we:

- **Reviewed state and national literature relevant to the North Carolina long-term services system.** Project staff researched and compiled various materials regarding the North Carolina long-term services system for people with intellectual and other developmental disabilities. Our search identified analyses, papers, correspondence, administrative rules, legislation and other documentation pertaining to the North Carolina disabilities services system. These sources were carefully reviewed and contributed to our understanding and overall impressions of the North Carolina service system, its strengths and weaknesses, and the political and social context within which it operates.
- **Compiled available state and national data.** HSRI worked with national experts and North Carolina state staff to gather data from 2000-2009 relevant to the North Carolina intellectual and other developmental disabilities services system. We gathered information from the following sources:
  - Data available from the Research and Training Center on Community Living (RTCCL), Institute on Community Integration/University Center on Excellence in Intellectual and other developmental disabilities (UCEDD) at the University of Minnesota. The research team at RTCCL/UMN collects information by state on the numbers served and related expenditures associated with Medicaid-funded developmental disability programs, including Intermediate Care Facilities for the Mentally Retarded (ICFs/MR)<sup>4,5</sup> and Home and Community-Based Services (HCBS) waivers and other long-term care services. This resource provided us with data through 2009<sup>6</sup> and is cited in this report as (Lakin, et al. 2010).
  - Data available through the National Core Indicators ([www.nationalcoreindicators.org](http://www.nationalcoreindicators.org)). The National Core Indicators (NCI) began in 1997 as a collaborative effort between the National Association of State Directors of Intellectual and other developmental disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI). The goal of the program was to encourage and support NASDDDS’ member agencies, state developmental disability authorities, to develop a standard set of performance measures that could be used by states to manage quality, and make cross-state

<sup>4</sup> It is important to note that the term “intermediate care facility for the mentally retarded” is not in line with best practice terminology today. This report refers to these facilities as ICFs/MR, however, the term individuals with “intellectual and other developmental disabilities” is the preferred language.

<sup>5</sup> Periodically, in this report the word “retarded” or “retardation” may be found. We remind the reader that such language does not reflect present best practice. In October 2010, President Obama signed into law Rosa’s Law, which changes references in federal law from *mental retardation* to *intellectual disability*, and references to *a mentally retarded individual* to *an individual with an intellectual disabilities*. Several states have moved in ways consistent with the federal law to remove “R-words” from its laws, service labels, operational language, rules, regulations and so forth.

<sup>6</sup> Lakin, K.C., Larson, S.A., Salmi, P. and Webster, A. (2010) *Residential services for persons with intellectual and other developmental disabilities: Status and trends through 2009*. Minneapolis. University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

comparisons and set benchmarks. Fifteen states initially stepped forward to work on the Core Indicators Project, as it was originally known, and pooled their resources to develop valid and reliable data collection protocols. Over time, NCI has become an integral piece of over half the states' quality management systems and aligns with basic requirements for assuring quality in HCBS Waivers. NCI states and project partners continue to work toward the vision of utilizing NCI data not only to improve practice at the state level but also to add knowledge to the field, to influence state and national policy, and to inform strategic planning initiatives for NASDDDS. Currently, 25 states are participating in the NCI survey, including North Carolina. For this report, the following North Carolina<sup>7</sup> specific and national NCI surveys were used:

- Adult Consumer Survey 2008-09: North Carolina completed 913 Consumer Surveys. Total surveys from all participating states: 11,569
- Adult Family: North Carolina did not participate in this survey during 2008/2009 due to too low of a sample size. As a result, we utilize Adult-Family Survey from 2007-08 where 172 surveys were completed. During 2007-2008, 15 states administered the Adult Family Survey. Total surveys: 6,321
- Family Guardian: North Carolina did not participate in this survey during 2008/2009. Again, the Family-Guardian Survey from 2007-8 was used where North Carolina completed 220 surveys. During 2007-08, 11 states administered the Family Guardian Survey. Total surveys: 4,828
- **Conducted interviews with statewide stakeholders in the North Carolina intellectual and other developmental disabilities service system.** Project staff conducted 30 interviews with critical stakeholders in North Carolina's intellectual and other developmental disabilities services program. Stakeholders included policy makers, providers, self-advocates and consultants. During the interview process, HSRI staff asked interview participants questions regarding six major topic areas. The topic areas include: (a) what trends are currently being seen within the State intellectual and other developmental disabilities service system, (b) what aspects of the current service system are viewed as progressive in moving the state forward, (c) what are the perceived opinions on the State's move to the section 1915(b)(c) waiver program, (d) what are perceived to be the biggest issues with the current service system, (e) what can be done to address the noted issues, and (f) what is being done to push forward or hold back efforts to address the noted issues.

To assess performance against the five benchmarks, we often compared North Carolina to other states and the national average. Comparison states were selected using two criteria: (a) states within the same federal Medicaid region as North Carolina (Region 4<sup>8</sup>); and (b) states

<sup>7</sup> NCI State Report: North Carolina 2008-2009. Human Services Research Institute. Cambridge, MA.

<sup>8</sup> Georgia falls under both categories, CMS Region 4 and large population.

with populations between 7.5 – 12 million<sup>9</sup>. North Carolina’s 2009 state population was 9,380,884. The states selected for this comparison include:

CMS Region	2009	2009	7.5-12 Mill. in Pop.	2009	2009
	Pop	FMAP		Pop	FMAP
Alabama	4,708,708	76.6	New Jersey	8,707,739	58.8
Florida	18,537,969	67.6	Ohio	11,542,645	70.3
Georgia	9,829,211	73.4	Virginia	7,882,530	58.8
Kentucky	4,314,113	77.8			
Mississippi	2,951,996	83.6			
South Carolina	4,561,242	78.6			
Tennessee	6,296,254	73.3			

The Federal Medical Assistance Percentages (FMAPs) are used in determining the amount of Federal matching funds for state expenditures for assistance payments for certain social services, and state medical and medical insurance expenditures. The Social Security Act requires the United States Secretary of Health and Human Services to calculate and publish the FMAPs each year<sup>10</sup>. The American Recovery and Reinvestment Act (ARRA) was developed to help states battle budget shortfalls due to the stagnant economy<sup>11</sup>. The plan called for a temporary increase in FMAP through FY2010. For North Carolina, the 2008 match rate was 64.05 percent, and during the duration of the Recovery Act it was 74.98 percent.

### Gap Analysis

A *gap analysis* compares an enterprise’s actual, to its potential, or desired, performance. It is an assessment of the distance between what an enterprise is currently doing and what it seeks to do in the future. A gap analysis flows from benchmarking the level of performance achieved and other assessments of requirements as well as current system capabilities.

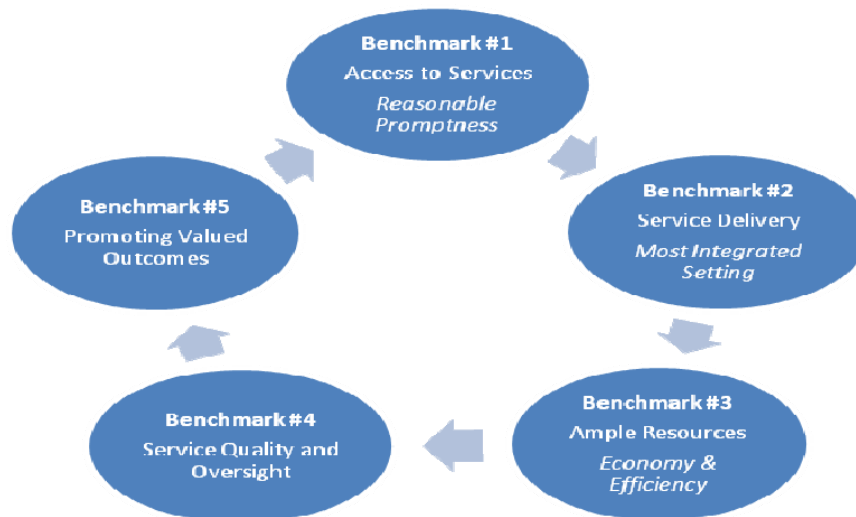
The gap analysis begins with defining the expectations for desired system performance. These expectations serve as the basis for appraising current performance. For the purpose of this gap analysis, we identified five fundamental, top-level performance benchmarks against which to gauge the provision of publicly funded services and supports for people with intellectual and other developmental disabilities in North Carolina. These benchmarks were derived from HSRI’s nationally recognized work in developing quality assurance indicators (i.e., the “Quality Framework” for the Centers for Medicare and Medicaid Services, and the National Core Indicators utilized by 25 states). As illustrated by the graphic below, the benchmarks are related to service access, service delivery, system efficiency, service quality and oversight and achievement of valued outcomes.

<sup>9</sup> Michigan, while having a 2009 population of roughly 10 million people, was not included as a comparison state for this analysis. Michigan’s developmental disability service system operates under a managed care framework, making direct comparisons problematic, compared to North Carolina’s current service system.

<sup>10</sup> <http://aspe.hhs.gov/health/fmap.htm>

<sup>11</sup> <http://www.cbpp.org/cms/index.cfm?fa=view&id=2647>





### Five Performance Benchmarks

1. **People with intellectual or intellectual and other developmental disabilities have access to and receive necessary publicly-funded services and supports with reasonable promptness.** Publicly-funded systems should be capable of ensuring that those needing services receive them within a reasonable period of time. This requires sound system infrastructure in order to ensure a diverse and agile service delivery capacity. When services are not furnished promptly, individuals and families experience negative life outcomes
2. **Services and supports are provided in the most integrated setting appropriate to the needs of the individual.** The U.S. Supreme Court’s *Olmstead* decision has established the clear benchmark that publicly-funded services must be furnished in the most integrated setting possible, given the individual’s needs. The decision mandates that states operate services so that individuals are not unnecessarily institutionalized or otherwise served in overly restrictive programs or settings.
3. **The system must have ample resources and promote economy and efficiency in the delivery of services and supports.** This means that the State must seek out the most cost effective services and supports, building on the supports that families and communities provide, and effectively utilize federal funding. Systems that do not stress economy and efficiency are not sustainable.
4. **Services must continuously meet essential quality standards and there must be confidence that quality oversight systems function effectively and reliably.** Quality assurance systems must ensure that individuals are not exposed to abuse, neglect and exploitation. Appropriate oversight must be in place to protect the health and welfare of vulnerable people.
5. **The provision of services results in the achievement of promoting valued outcomes for people with intellectual and other developmental disabilities.** Services should promote such outcomes as personal independence, employment and community integration. Services that effectively address functional and other limitations that impede the achievement of personal outcomes by individuals must be available.

These five benchmarks serve as the framework for the following analysis. In this regard, however, it should be noted that we understand that many other aspects of the North Carolina intellectual and other developmental disabilities service system might have been reviewed but fell outside the scope of this report.

### **Organization of the Strategic Analysis**

This report is organized by offering information on the current circumstances within North Carolina, followed by a review of the previously mentioned five benchmarks. Each of the five benchmarks covers the following: (a) the national trends within the intellectual and other developmental disabilities service structure related to the specific benchmark; and, (b) North Carolina's status related to the specific benchmark. Following the five benchmarks is the conclusions section of the report.

## Key Terms

In this report, services and housing arrangements for people with intellectual or other intellectual and other developmental disabilities within the state of North Carolina are examined. Below, is a list of key terms used commonly throughout this report, as well as their meaning/definition.

### Federal Definition of Intellectual and other developmental disabilities

(A) The term "developmental disability" means a severe, chronic disability of an individual that:

(i) is attributable to a mental or physical impairment or combination of mental and physical impairments;

114 STAT. 1684 PUBLIC LAW 106-402-OCT. 30, 2000

(ii) is manifested before the individual attains age 22;

(iii) is likely to continue indefinitely;

(iv) results in substantial functional limitations in 3 or more of the following areas of major life activity:

(I) Self-care.

(II) Receptive and expressive language.

(III) Learning.

(IV) Mobility.

(V) Self-direction.

(VI) Capacity for independent living.

(VII) Economic self-sufficiency; and

(v) reflects the individual's need for a combination and sequence 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) INFANTS AND YOUNG CHILDREN - An individual from birth to age 9, inclusive, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting 3 or more of the criteria described above if the individual, without services and supports, has a high probability of meeting those criteria later in life.

### North Carolina Definition of Intellectual and other developmental disabilities

North Carolina General Statute 122C-3(12a) defines a developmental disability as "a severe, chronic disability of a person which:

- is attributable to a mental or physical impairment or combination of mental and physical impairments;
- is manifested before the person attains age 22, unless the disability is caused by traumatic head injury and is manifested after age 22;
- is likely to continue indefinitely; results in substantial functional limitations in three or more of the following areas of major life activity:
  - self-care
  - receptive (understanding) and expressive language
  - learning mobility (ability to move)
  - self-direction (motivation)
  - the capacity for independent living
  - economic self-sufficiency
- reflects the person's need for a combination or sequence of special, interdisciplinary, generic services, individual supports, or other forms of assistance which are of a lifelong or extended duration and are individually planned and coordinated;
- an individual from birth to age 9, inclusive, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting at least three of the above 'areas of major life activities,' if the individual, without services and supports, has a high probability of meeting those criteria later in life."

**HCBS WAIVERS SECTION 1915(c)**

States may offer a variety of services to consumers under an HCBS waiver program and the number of services that can be provided is not limited. These programs may provide a combination of both traditional medical services (i.e., dental services, skilled nursing services) as well as non-medical services (i.e. respite, case management, environmental modifications). Family members and friends may be providers of waiver services if they meet the specified provider qualifications. However, in general spouses and parents of minor children cannot be paid providers of waiver services.

**Application & Approval Process**

The State Medicaid agency must submit to the Center for Medicare and Medicaid Services (CMS) for review and approval an application for an HCBS waiver, and the State Medicaid Agency has the ultimate responsibility for an HCBS waiver program, although it may delegate the day-to-day operation of the program to another entity. Initial HCBS waivers are approved for a three-year period, and waivers are renewed for five-year intervals.

**Program Requirements**

Within the parameters of broad Federal guidelines, States have the flexibility to develop HCBS waiver programs designed to meet the specific needs of targeted populations. Federal requirements for states choosing to implement an HCBS waiver program include:

- Demonstrating that providing waiver services to a target population is no more costly overall than the cost of services these individuals would receive in an institution.
- Ensuring that measures will be taken to protect the health and welfare of consumers.
- Providing adequate and reasonable provider standards to meet the needs of the target population. Ensuring that services are provided in accordance with a plan of care.

States have the discretion to choose the number of consumers to serve in a HCBS waiver program. Once approved by CMS, a state is held to the number of persons estimated in its application, but has the flexibility to serve greater or fewer numbers of consumers by submitting an amendment to CMS for approval.

**INTERMEDIATE CARE FACILITY FOR PERSONS WITH MENTAL RETARDATION (ICF/MR) (1905(d) of the SSA)**

An institution (or distinct part thereof) for the mentally retarded or persons with related conditions if --

1. the primary purpose of such institution (or distinct part thereof) is to provide health or rehabilitative services mentally retarded individuals and the institution meets such standards as may be prescribed by the Secretary;
2. the mentally retarded individual with respect to whom a request for payment is made under a plan approved under this title is receiving active treatment under such a program; and
3. in the case of a public institution, the State or political subdivision responsible for the operation of such institution has agreed that the non-Federal expenditures in any calendar quarter prior to January 1, 1975, with respect to services furnished to patients in such institution (or distinct part thereof) in the State will not, because of payments made under this title, be reduced below the average amount expended for such services in such institution in the four quarters immediately preceding the quarter in which the State in which such institution is located elected to make such services available under its plan approved under this title.
4. Institution for persons with mental retardation means an institution (or distinct part of an institution) that: 1. Is primarily for the diagnosis, treatment, or rehabilitation of the mentally retarded or persons with related conditions; and 2. Provides, in a protected residential setting, ongoing evaluation, planning, 24-hour supervision, coordination, and integration of health or rehabilitative services to help each individual function at his greatest ability. (42 CFR 435.1009)

# Present Circumstances in North Carolina

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The purpose of this section is to offer a summary review of the system in terms of the many contextual factors that underpin and influence system performance. This activity should not be taken as a systematic evaluation of the service system. Instead, the information included here can be used to gain insight into system performance, and later used to guide an effective series of actions steps to improve the system. What follows is: (a) a description of administrative structures used to deliver services, (b) a description of the service categories available to individuals, and (c) a summary of selected major factors that are presently influencing policy decisions in North Carolina.

## State Administrative Structure and Complementing Organizations.

This report focuses on people with intellectual and intellectual and other developmental disabilities. In North Carolina a wide array of public and private organizations work together to provide support to these individuals. Chief among them is the North Carolina Department of Health and Human Services (DHHS). Multiple agencies within DHHS are in turn joined by local efforts involving Local Management Entities (LMEs) and a network of service providers. Overall, the main components of the support network include:

- **The Department of Health and Human Services (DHHS).** Within DHHS several divisions or offices have responsibilities related to supporting these citizens. It is the largest agency in state government, responsible for ensuring the health, safety and well being of all North Carolinians. DHHS provides human services to various vulnerable populations, such as those with a need for mental health and substance abuse services, seniors, people who are deaf or blind , people with intellectual and other intellectual and other developmental disabilities and others. The agency is divided into 30 divisions and offices, and oversees 17 facilities, including centers for people with intellectual and other developmental disabilities, psychiatric hospitals, alcohol and drug abuse treatment centers, schools, early intervention programs, and one special care center. DHHS has over 19,000 employees and an operating budget of about \$14 billion. (Go to: <http://www.ncdhhs.gov>).

Within DHHS, these elements have the most relevance to people with intellectual and other intellectual and other developmental disabilities (I/DD):

- The Secretary and Deputy or Assistant Secretaries. The Secretary of DHHS is appointed by the governor, and leads the Department and through its agencies is responsible for ensuring the health, safety, and well being of North Carolinians. There are five Deputy Secretaries:
  - Health Services. Oversees the administrative and policy functions of six divisions and offices within DHHS, including the Divisions of Public Health; Mental Health/Intellectual and other developmental disabilities/Substance Abuse services; Medical Assistance (Medicaid); Health Service Regulation; State-Operated Healthcare Facilities; Office of Rural Health.

- Long Term Care and Family Services. Oversees the programs and activities of the Divisions of Aging and Adult Services, Child Development, Services for the Blind, Services for the Deaf and Hard of Hearing, Social Services and Vocational Rehabilitation, as well as the Office of Economic Opportunity and the NC Council on Intellectual and other developmental disabilities.
- Finance and Business Operations. Has responsibilities over the DHHS support divisions which include the Controller’s Office, Information Resource Management, Human Resources, Internal Audit, Central Purchasing, Medicaid Management Information Systems, Property and Construction, DMA and DSS Appeals and several smaller offices.
- Mental Health, Intellectual and other developmental disabilities, and Substance Abuse Services. Helps provide the strategic planning necessary to anticipate the future needs of North Carolina for state-provided services, to increase capacity for MH/DD/SAS services to those parts of the state where providing community care options has already begun, and to expand it into the parts of the state where the capacity is lacking.
- Health Information Technology. Facilitates the development of statewide interoperable health information systems that will ultimately improve health and healthcare in North Carolina.
- The Division of Mental Health, Intellectual and other developmental disabilities, and Substance Abuse Services (DMH/DD/SAS) has primary responsibility for establishing and maintaining a system of community services for people with intellectual and other developmental disabilities. Overall, the mission of DMH/DD/SA is to support individuals by providing “people with, or at risk of, mental illness, intellectual and other developmental disabilities and substance abuse problems and their families the necessary, prevention, intervention, treatment, services and supports they need to live successfully in communities of their choice to live, learn, and work in their community.”
- Division of Medical Assistance (DMA) is charged with providing access to high quality, medically necessary health care for eligible North Carolina residents through cost-effective purchasing of health care services and products. For instance, DMA offers North Carolina Health Choice for Children, a free or reduced price comprehensive health care program for children. A primary means for offering health care, however, involves Medicaid. Medicaid is a health insurance program for low-income individuals and families who cannot afford health care costs. The budget for the fiscal year 2009 Medicaid program was \$11.4 billion – which is supported by \$8.4 billion in revenue (mostly federal Medicaid funds) and \$3 billion in state appropriations. This budget is one of the largest in NC government – second only to primary and secondary education.

Community ICFs/MR are under DMA, although these facilities for are licensed and regulated through the Division of Health Service Regulation. DHSR oversees these facilities to assure that individuals are safe and receive appropriate support.

# Department of Health and Human Services

Secretary of DOH & HS  
 Deputy - Health Services  
 Deputy - Long Term Care and Family Services

Deputy -Finance & Business Operations  
 Assis. Secr. -MH/DD/SA  
 Deputy -Health Information Technology

**Medical Assistance**  
 Director  
 Chief Business Operations  
 Chief Clinical Operations

[www.ncdhhs.gov/dma/](http://www.ncdhhs.gov/dma/)

**Mental Health Develop Disabilities Substance Abuse**  
 Director  
 Chief Comm. Policy Management  
 Chief Resource/Regulatory Mgmt  
 Chief Advocacy & Comm. Service  
 Chief Operations Support

[www.ncdhhs.gov/mhddsas/divisioninfo.htm](http://www.ncdhhs.gov/mhddsas/divisioninfo.htm)  
[www.ncdhhs.gov/mhddsas/developmentaldisabilities](http://www.ncdhhs.gov/mhddsas/developmentaldisabilities)

**State Operated Health Facilities**  
 Director

[www.ncdhhs.gov/dsohf](http://www.ncdhhs.gov/dsohf)

## Divisions

- Medical Assistance
- Mental Health/ Intellectual and other developmental disabilities/ Substance Abuse
- State Operated Health Facilities
- Health Service Regulation
- Public Health
- Social Services
- Aging & Adult Services
- Child Development
- Deaf & Hard of Hearing
- Vocational Rehabilitation
- Health Services Regulation

## Offices

- Rural & Community Health Care
- Citizen Services
- Economic Opportunity
- State Center for Health Statistics
- Vital Records

## Boards, Commissions and Councils

Boards, commissions and councils either (a) have rulemaking authority; and/or (b) are legislatively created by federal or state statute (either as an advisory body or having some authority/defined responsibilities); and/or (c) are established

**Mission:** to provide access to high quality, medically necessary health care for eligible North Carolina residents through cost-effective purchasing of health care services and products.

**Medicaid** is a health insurance program for low-income individuals and families who cannot afford health care costs. The budget for the 2009 FY Medicaid program was \$11.4 billion – which is supported by \$8.4 billion in revenue (mostly federal Medicaid funds) and \$3 billion in state appropriations. This budget is one of the largest in NC government – second only to primary and secondary education.

**North Carolina Health Choice** for Children is a free or reduced price comprehensive health care program for children.

**Community ICFs/MR** are under DMA though are licensed and regulated through the Division of Health Service Regulation. DHSR oversees these facilities to assure that individuals are safe and receive appropriate support.

**Money Follows the Person** is a special project under DMA to help seniors and people with disabilities leave nursing homes or ICFs/MR for alternative community living arrangements.

**Mission:** to provide people with, or at risk of, mental illness, intellectual and other developmental disabilities and substance abuse problems and their families the necessary, prevention, intervention, treatment, services and supports they need to live successfully in communities of their choice.

**Guiding Principles:** Participant driven, community based, prevention focused, recovery outcome oriented, reflect best treatment/support practices, and cost effective.

The Community Alternatives Program for Persons with Mental Retardation/ Intellectual and other developmental disabilities (**CAP-MR/DD**) is a special Medicaid program started in 1983 to serve individuals who would otherwise require care in an intermediate care facility for people with the mental retardation/intellectual and other developmental disabilities (ICF/MR). It allows these individuals the opportunity to be served in the community instead of residing in an institutional or group home setting.

Other services aside from CAP are available (e.g., FDSNT, day services, case management, )

- Alcohol & Drug Abuse Treatment Centers
- **Developmental Centers**
- Neuro-Medical Treatment Centers
- Psychiatric Hospitals
- Residential Programs for Children

The Division holds a dual role as manager and provider of state-operated healthcare facilities and is held to the same quality and best practice standards as are the local management entities (LMEs) in overseeing local service delivery.

The Division of State Operated Health Facilities is responsible for defining the purpose, roles and responsibilities of state operated healthcare facilities.

The four developmental centers are certified as Intermediate Care Facility/Mental Retardation (ICF/MR) level of care by CMS.

Local Management Entities (LMEs) and their Member Counties  
 As of July 1, 2010



24 Local Management Entities (LMEs) are agencies of local government-area authorities or county programs-that are responsible for managing, coordinating, facilitating and monitoring the provision of mental health, intellectual and other developmental disabilities and substance abuse services in the catchment area served. LME responsibilities include offering individuals 24/7/365 access to services, developing and overseeing service providers, and handling complaints and grievances.

[www.ncdhhs.gov/mhddsas/lmedirectory.htm#lmelist](http://www.ncdhhs.gov/mhddsas/lmedirectory.htm#lmelist)

\*HB 916 calls for the consolidation of the LMEs into a more concise operating structure. This change would reduce the number of LMEs while increasing LME responsibilities. (House Bill 916/S.L. 2011-264. North Carolina General Assembly.)

Money Follows the Person is a special initiative under DMA to help seniors and people with disabilities leave nursing homes or ICFs/MR for alternative community living arrangements such as HCBS funded community residences (i.e., “group homes”), supervised living in apartments, in-home support while living with family, or other supported shared living arrangements with individuals with or without disabilities.

- **State Operated Health Care Facilities:** The division oversees and manages 14 state operated healthcare facilities that treat adults and children with mental illness, intellectual and other developmental disabilities and substance use disorders. Three developmental centers for people with I/DD include Caswell Developmental Center, J. Iverson Riddle Developmental Center and the Murdoch Developmental Center. SOHF also oversees two neuro-medical treatment centers, Black Mountain Neuro-Medical Center and O’Berry Neuro-Medical Center. Both neuro-medical centers serve individuals with intellectual and other developmental disabilities as well as the aging population. Further, both typically house individuals with significant medical needs.
- **Local Management Entities.** The North Carolina General Assembly House Bill 2436 Section 10.15 (x) requires the Department of Health and Human Services to return service authorizations, utilization reviews, and utilization management functions to the Local Management Entities (LMEs) for all service recipients.

LMEs are agencies of local government-area authorities or county programs--that are responsible for managing, coordinating, facilitating and monitoring the provision of mental health, intellectual and other developmental disabilities and substance abuse services in the catchment area served. LME responsibilities include offering individuals 24/7/365 access to services, developing and overseeing providers, and handling consumer complaints and grievances. House Bill 916<sup>12</sup> is requiring the reduction in the number of LMEs through merging LMEs into new catchment areas.

(Go to: <http://www.ncdhhs.gov/mhddsas/lmebyname.htm>)

The accompanying graphic above illustrates these primary structural components. In addition, we recognize that other public and private entities also contribute to the available service network. Within DHHS, for example, individuals may receive services from the Division of Vocational Rehabilitation. Public services outside of DHHS may also be available through the Department of Instruction. Likewise, in the private sector, supports may also be offered locally through various community serving organizations or private businesses.

### Service Categories

North Carolina utilizes three primary service categories to offer services to individuals with intellectual and other developmental disabilities. The service categories are: developmental and neuro-medical centers (often referred to as state-operated institutions), community intermediate care facilities for the mentally retarded (ICFs/MR)<sup>13</sup> and the Community

<sup>12</sup> House Bill 916/S.L. 2011-264. North Carolina General Assembly.  
<http://www.ncga.state.nc.us/gascripts/billlookup/billlookup.pl?Session=2011&BillID=H916>



Alternatives Program – Mental Retardation/Intellectual and other developmental disabilities (CAP/MR-DD) 1915(c)waiver program (Home and Community-based Services waiver)<sup>14</sup>. In a presentation given by Steve Jordan<sup>15</sup> (State Director, DMH/DD/SAS) in November 2010, he notes that:

To be eligible for services either under the developmental center or community ICF/MR categories, the State uses the level of care determination that an individual meet the following criteria:

- The individual shall require active treatment necessitating the ICF/MR level of care (42 CFR 435.1009; 42CFR 483.440) and shall have a diagnosis of mental retardation or a closely related condition.
- Intellectual and other intellectual and other developmental disabilities (I/DD)
- Individuals with I/DD needing comprehensive, 24 hour supports to maintain or improve the health and functioning

For consideration for admission to a developmental center:

- Individuals must be 18 years of age and older with a diagnosis of I/DD \* (with the exception of time limited specialized programs for children and adolescents with I/DD)
- Individuals with complex behavioral challenges and/or medical conditions whose clinical treatment needs exceed the level of care available in the community.
- The local management entity and the developmental center’s admission committee work together to determine need.

Services provided under each of these categories include:

Developmental Center Facility Services		Community ICF/MR Services	
• Medical- physician	• Nursing, radiology	• Medical- physician & nursing	• Psychiatry
• Pharmacy, etc.	• Dental		
• Psychiatry	• Physical Therapy	• Physical Therapy	• Occupational Therapy
• Occupational Therapy	• Speech Therapy	• Occupational Therapy	• Speech Therapy
• Chaplaincy	• Transition	• Transition	• Advocacy
• Advocacy	• Dietary/Nutrition	• Case Management	• Dietary/Nutrition
• Adaptive Equipment	• Residential	• Adaptive Equipment	• Residential
• Social Work	• Education	• Social Work	• Education
• Psychology	• Recreation Therapy	• Psychology	• Recreation Therapy
• Vocational	• Other	• Vocational	• Other

<sup>14</sup> North Carolina also furnishes services under smaller programs, including: (a) the Piedmont Behavioral Health Innovations wavier (1915(b)(c)), (b) a supports waiver under the CAP-MR/DD waiver, and (c) other state only funded services. To keep similar comparisons, state-only funded services were not utilized in this report.

<sup>15</sup> ICF/MR Cost Analysis and Comparison with CAP/MR-DD Services. Joint Legislative Oversight Committee on Mental Health, Intellectual and other developmental disabilities, and Substance Abuse Services. November 9, 2010. Presented by Steve Jordan, Director.

To be eligible for Home and Community Based waiver services, an individual shall require the same level of care provided by an ICF/MR. During the comprehensive clinical assessment process, the LME shall make an initial determination as to whether the individual potentially meets the ICF/MR level of care and provides it to the case manager for the person-centered planning process.

CAP/MR-DD services include:

CAP/MR-DD Services	
<b>Periodic Services</b>	<b>Services Provided in a Person’s Home by Family</b>
• Adult Day Health	• Home Supports
• Behavioral Consultant	<b>Residential Services</b>
• Crisis Respite	• Residential Support Services
• Crisis Services	<b>CAP-MR/DD Services</b>
• Day Supports	Additional Supports:
• Home and Community Supports	• Augmentative Communication Devices
• Individual Caregiver Training and Education	• Vehicle Adaptations
• Long-Term Vocational Supports	• Transportation
• Personal Care Services	• Specialized Equipment and Supplies
• Respite Care—All Levels	• Home Modifications
• Specialized Consultative Services	• Personal Emergency Response System (PERS)
• Supported Employment	• Individual Goods and Services (Self-Direction Only)

North Carolina also furnishes Medicaid-financed services under the CAP/MR-DD waiver through the NC Supports waiver for individuals not requiring residential services. Typical service offered for individuals under this option consist of day services programs, respite services, personal care and supported employment<sup>16</sup>. The maximum amount an individual is eligible for under the Supports waiver is \$17,500 per year, compared to a maximum of \$135,000 per year under the CAP/MR-DD waiver.

**Key Policy Factors Influencing Present Policy-Making**

Three primary factors that are presently having a significant impact on decision making in North Carolina include: (a) changing expectations over what constitutes “best practice” in service delivery, (b) chronic state revenue shortfalls, and (c) discussion over design and implementation of Medicaid 1915(b)(c) waivers.

**1. Changing Expectations Concerning Best Practices**

**Four Primary Factors Influencing Policy**

1. Changing expectations concerning best practices
2. Chronic state revenue shortfalls
3. Implementation of Medicaid “b” and “c” waivers

<sup>16</sup> Details for NC Supports Waiver (3.5) (0663.R00.00). Centers For Medicare and Medicaid. Updated March 2010. <http://www.cms.gov/MedicaidStWaivProgDemoPGI/MWDL/itemdetail.asp?filterType=dual,keyword&filterValue=NC Supports&filterByDID=0&sortByDID=2&sortOrder=ascending&itemID=CMS1216770&intNumPerPage=10>

Forty years ago there were few, if any, community-centered services for people with intellectual and other developmental disabilities. While most stayed home with families without the services they or their families needed, significant numbers were relocated to state-run, public facilities. In fact, for decades, these facilities comprised the State's primary service response to people with significant intellectual and related disabilities. In 1970, 186,743 people in the United States resided in large state public institutions.

From 1960 through 2009, however, 192 of 354 (54 percent) of these facilities were closed. Likewise, the daily population at such facilities in the U.S. dropped by 82 percent to 33,682. No dedicated facility has been closed in North Carolina, though a unit at Broughton Hospital in Morganton closed in 1994, and we understand this unit housed some people with intellectual and other developmental disabilities.

Based on decades of legislative action, court decisions and evolving thought, present best practice centers on a continuing emphasis on community integration and "self-determination" principles. Increasingly, people with intellectual and other intellectual and other developmental disabilities want to live their lives in the community, just like everyone else. They also want control over their lives. Based in great measure on these demands, the changes that are emerging in service systems are part of a continuing evolution that began decades ago. Along the way, words like *normalization*, *dignity of risk*, *inclusion*, *participation* and *natural supports* served as rallying points to push along further change. More recently, the concept of *self-determination* has taken root, carrying great implications for reforming how systems are run and to what ends. In "self-directed" systems, individual service recipients have considerable authority over what supports they receive, how they are received and from whom and with significant control of their allocated budget for services.

At issue is how best to offer a community-centered service array to achieve these ends. In addition, what equally challenges policy makers is deciding what to do with a legacy, i.e., outdated, array of services (e.g., developmental centers) that still plays a role in delivering services and that maintains a dedicated, supportive constituency.

## **2. Chronic State Revenue Shortfalls**

Across the country, states are experiencing significant budget shortfalls. The crisis in the national economy has left state budgets in their worst shape in decades. As a result, nearly every state has scrambled to balance its budget. Since 2008, cuts in budgets were enacted in at least 46 states, plus the District of Columbia. Cuts occurred in all major areas of state services, including public health (31 states), services to the elderly and people with disabilities (29 states and the District of Columbia), K-12 and early education (34 states and the District of Columbia), higher education (43 states), and state work force (43 states and the District of Columbia). North Carolina was one of 15 states to report cuts in all these areas.<sup>17</sup>

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<sup>17</sup> Johnson, N., Oliff, P. & Williams, E. (2010). *An update on state budget cuts*. Center on Budget and Policy Priorities. <http://www.cbpp.org/cms/index.cfm?fa=view&id=1214>

Medicaid, an essential funder of many human services, was obviously vulnerable to cuts. The program functions as a federal-state partnership where, for each “Medicaid dollar” a state spends, it is reimbursed a percentage by the federal government (known as the Federal Medical Assistance Percentage or “FMAP”). In 2008 North Carolina was reimbursed 64.05 percent of each dollar spent.

In February of 2009, however, President Obama signed legislation entitled the “American Recovery and Reinvestment Act of 2009.” Among many other facets, this Act provides a temporary increase in the share of the Medicaid program paid by the federal government. The provision took effect immediately and provided states with approximately \$87 billion in assistance over nine calendar quarters (October 1, 2008 through December 31, 2010). During this time, North Carolina’s match rate was increased from 64.05 percent to 74.98 percent through FY 2010.<sup>18</sup>

With the sunset of the Recovery Act, states are facing additional revenue shortfalls, but without federal assistance through the enhanced FMAP. A recent study illustrates that 44 states are projecting FY 2012 revenue shortfalls totaling \$124.7 billion. Among these states, North Carolina reported a \$3.8 billion shortfall, which amounted to 20% of its FY 2011 budget. Only nine states reported a higher percentage with Illinois (44.9 percent) and Nevada (45.2 percent) topping the list.<sup>19</sup>

Not surprisingly, services for people with intellectual and other intellectual and other developmental disabilities are caught up in the enduring budget crisis. In some states, family support or personal assistance programs have been cut, with increased emphasis placed on “shared” living (i.e. two or more individuals residing in a shared apartment or house) or day service options. Efforts to reduce waiting lists have also slowed. Provider payments have been delayed and/or reduced. Around the country, many provider organizations have laid off staff, and some have gone out of business altogether due to state budget cuts.

North Carolinians have felt the impacts of the present recession. Going forward, policy makers will undoubtedly be required to make decisions with a strong regard for present and future budget limitations.

### **3. Implementation of Medicaid 1915(b)(c) Waivers**

The prevalent means for establishing community service systems involves use of a 1915(c) Home and Community-based Services (HCBS) waiver. When approved by the Center for Medicaid and Medicare Services (CMS), this type of waiver typically allows states to bypass or “waiver” certain requirements of the Social Security Act to target a particular group (e.g., people with intellectual and other intellectual and other developmental disabilities) and/or people living in particular parts of the state. The CAP-MR/DD comprehensive and supports waivers are examples of 1915(c) waivers in North Carolina.

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<sup>18</sup> <http://www.statehealthfacts.org/comparetable.jsp?ind=184&cat=4>

<sup>19</sup> McNichol, E., Olif, P. & Johnson, N., (2011). *States Continue to Feel Recession's Impact*. Center on Budget and Policy Priorities. <http://www.cbpp.org/cms/?fa=view&id=711>

Other types of waivers are possible. The CMS explains that a 1915(b) waiver, for example, permits states to make mandatory the enrollment of beneficiaries in Medicaid managed care plans, use local entities to manage services, deliver additional services generated through savings and restrict providers using selective contracting. If the State uses section 1915(b) to deliver services using a managed care delivery system, a managed care contract is required and the State must submit the contract to the appropriate CMS Regional Office for approval. Recently, states have sought to utilize these two authorities together within a combination 1915(b)(c) waiver.

Consistent with these requirements, as explained on the DHHS website,

In April 2005, DHHS began the “Piedmont Cardinal Health Plan,” a pilot project where Medicaid-funded services for mental health, substance abuse, and intellectual and other developmental disabilities are provided on a capitated basis in a five-county area through a prepaid inpatient health plan (PIHP). PBH, formerly known as Piedmont Behavioral Healthcare, a local management entity (LME), operates the PIHP and manages state-funded mental health, substance abuse, and intellectual and other developmental disabilities services.

In May of 2009, DHHS elected to expand this pilot project beyond PBH, to be phased-in statewide. Toward this goal, DMH/DD/SAS and the DMA worked in partnership, to submit on behalf of DHHS waiver amendment requests to CMS in December 2009 to expand the pilot project through the modification of the existing Piedmont Cardinal Health Plan 1915(b) Freedom of Choice waiver and the modification of the 1915(c) Innovations Home and Community Based Services (HCBS) waiver.

In February 2010, DHHS solicited applications from LMEs to participate in the expansion. Four LMEs responded to the request for application (RFA) and submitted applications to participate in the State's 1915 (b)(c) Medicaid Waiver in April 2010. DMHDDSAS and DMA issued [Special Implementation Update #74](#) and [Special Implementation Update #80](#), announcing the selections of Mecklenburg County Area MH/DD/SAS and Western Highlands Network as the next two LMEs to participate in the 1915(b)(c) Medicaid Waiver<sup>20</sup>. In 2011, the General Assembly instructed the Department to expand the 1915(b)(c) waiver statewide. The Department reissued the request for applications and received seven applications from LMEs. The Department issued plans of correction to the other two LMEs (East Carolina Behavioral Health and Sandhills Center) that originally applied in 2010 and will work with them to begin managed care operations by July 2012<sup>21</sup>.

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<sup>20</sup> <http://www.ncdhhs.gov/mhddsas/waiver/>

<sup>21</sup> Partnering for Success: Strategic Plan for Statewide Implementation of the 1915 (b)/(c) Medicaid Waiver. July 1, 2011 – June 30, 2013. Draft July 27, 2011.

House Bill 916 from the North Carolina General Assembly calls for DHHS’s plan to do all of the following through this effort<sup>22</sup>:

- 1 Establish accountability for the development and management of a local system that ensures
- 2 Maintain fidelity to the Piedmont Behavioral Health (PBH) demonstration model, a proven system
- 3 Designate a single entity to assume responsibility for all aspects of Waiver management. The
- 3(a) Merger model: A single larger LME is formed from the merger of two or more LMEs.
- 3(b) Interlocal agreement among LMEs: A single LME is identified as the leader for all Waiver
- 4 Use managed care strategies, including care coordination and utilization management, to reduce
- 5 As the 1915(b)/(c) Medicaid Waiver expands statewide, phase out the 6 current CAP-MR/DD
- 6 Design the Innovations Waiver in such a way as to serve the maximum number of individuals
- 7 Require LMEs approved to operate a 1915(b)/(c) Medicaid Waiver to do all of the following:
  - 7(a) Maintain a local presence in order to respond to the unique needs and priorities of localities.
  - 7(b) Implement a process for feedback and exchange of information and ideas to ensure
  - 7(c) Establish and maintain systems for ongoing communication and coordination regarding the care
  - 7(d) Comply with the following operational requirements:
    - 7(d)(1) Maintain disability specific infrastructure and competency to address the clinical, treatment,
    - 7(d)(2) Maintain administrative and clinical functions, including requirements for customer service,
    - 7(d)(3) Maintain full accountability for all aspects of Waiver operations and for meeting all contract
    - 7(d)(3).I Information systems.
    - 7(d)(3).II Customer service (including call center) operations.
    - 7(d)(3).III Claims processing.
    - 7(d)(3).IV Provider, enrollment, credentialing, and monitoring.
    - 7(d)(3).V Professional services.
    - 7(d)(3).VI Treatment Plan development.
    - 7(d)(3).VII Referral to services.

The PBH effort, along with DHHS’s plan to expand the initiative statewide, was not uniformly welcomed among all constituencies in North Carolina. There are no guaranteed benefits or failings associated with combined HCBS 1915(b)(c) waivers<sup>23</sup>. The “angels and devils” are in the details. The State and service recipients may realize benefits associated with improved system efficiency and performance to yield enhanced quality of life for participants. Yet, lacking ample and capable management, a managed care system may fail to match the expectations policy makers set for it.

<sup>22</sup> House Bill 916. North Carolina General Assembly. Third Addition Engrossed 6/1/2011.

<sup>23</sup> Gettings, Bob. Reassessing the Impact of Managed Care in the Developmental Disabilities Sector. Policy Insights Bulletins. Volume 1, Issue 1. Feb. 2011. National Leadership Consortium.

# Gap Analysis

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## Benchmark #1: Serving Individuals with Reasonable Promptness

**Assessment:** North Carolina does not furnish services with reasonable promptness to its citizens with intellectual and other intellectual and other developmental disabilities. When compared to the national average, North Carolina provides Medicaid funded services to 29% fewer people. State and local agencies report a waitlist of 8,191 people. In addition, HSRI's analysis of projected unmet demand also suggests significant wait lists.

Most of the 5 million people with intellectual and other intellectual and other developmental disabilities (I/DD) in the United States are supported by their families, live independently with only intermittent publicly funded support, or get along without any specialized, publicly-funded intellectual and other developmental disabilities services. Public intellectual and other developmental disabilities service systems provide services and supports to a relatively small percentage (about 20-25 percent) of all individuals with intellectual and other intellectual and other developmental disabilities. Public systems focus principally on people who have significant functional limitations and require services over and above the supports that their families are able to provide or that they can obtain through generic human services programs.

Demand for publicly-funded intellectual and other developmental disabilities services is growing nationwide. Generally, demand has been increasing at a rate greater than population growth alone. This increase in demand is the product of several factors. One of the most important factors is the increased longevity of people with intellectual and other intellectual and other developmental disabilities. The life span of people with I/DD has increased dramatically as the result of better health care and is approaching the average lifespan of the general population. This increased longevity has two ramifications for intellectual and other developmental disabilities service systems: (a) turnover among individuals receiving services is reduced (consequently, there is less capacity to absorb new demand); and (b) there is a growing cohort of individuals who live in households with aging primary caregiver(s) who are less able to perform essential supports. About 25 percent of people with I/DD in the United States reside in households in which the primary caregiver is age 60 or older. As caregivers grow older, their capacity to continue to support individuals with I/DD diminishes. Increased demand also is the result of other factors, including the development of community services and supports that better meet the needs of individuals and families.

The demand for intellectual and other developmental disabilities services is dynamic. Each year, significant numbers of youth with intellectual and other intellectual and other developmental disabilities exit special education systems and need ongoing services and supports as young adults. Other people seek services because their families cannot continue to

support them or they need extra assistance. Based on national comparisons by the University of Minnesota Research and Training Center on Community Living and on work completed elsewhere, it is not uncommon to observe year-to-year increases in the expressed demand for intellectual and other developmental disabilities services of 4 percent<sup>24</sup> or more.

States generally operate their intellectual and other developmental disabilities service systems under fixed capacity limits. Only a handful of states (e.g., AZ and CA) provide for automatic annual caseload increases to accommodate additional eligible individuals. Systems manage by capping dollars or “slots” (service openings and eligibility criteria), or a combination of both. Likewise, capacity is regulated by changes in funding from year to year.

Capped system capacity, coupled with rising demand for services, has resulted in individuals spilling over onto “waitlists.” The number of people on a waitlist measures the gap between current system capacity and expressed service demand. This gap grows when the expansion of system capacity does not keep pace with growth in service demand. The waitlist queue will lengthen even though there may have been some growth in system capacity.

... people who have critical near-term needs should be able to count on receiving services within 6-9 months.

The Federal Medicaid Act ((42 C.F.R. § 435.930(a)) states that states “must furnish Medicaid promptly to recipients without any delay caused by the agency’s administrative procedures.” At issue is the interpretation of the mandate for reasonable promptness. Several court cases have tested this requirement and found states in violation of 42 U.S.C. § 1396a(a)(8) when access to Medicaid services is delayed or denied. Overall, federal court decisions have indicated that responding to service needs with reasonable promptness means that individuals enrolled in Medicaid who have emergency or crisis needs must receive Medicaid-funded services within 90 days. People who have critical unmet needs should be able to count on receiving services within 6-9 months. If they do not receive the services required, their needs can rapidly turn into an emergency or crisis situation.

### North Carolina’s Status

#### Service Utilization Rate

Our review of the North Carolina intellectual and other developmental disabilities service system finds that the State serves far fewer than the national average of individuals with I/DD per 100,000 (i.e., 100K) in the general state population.

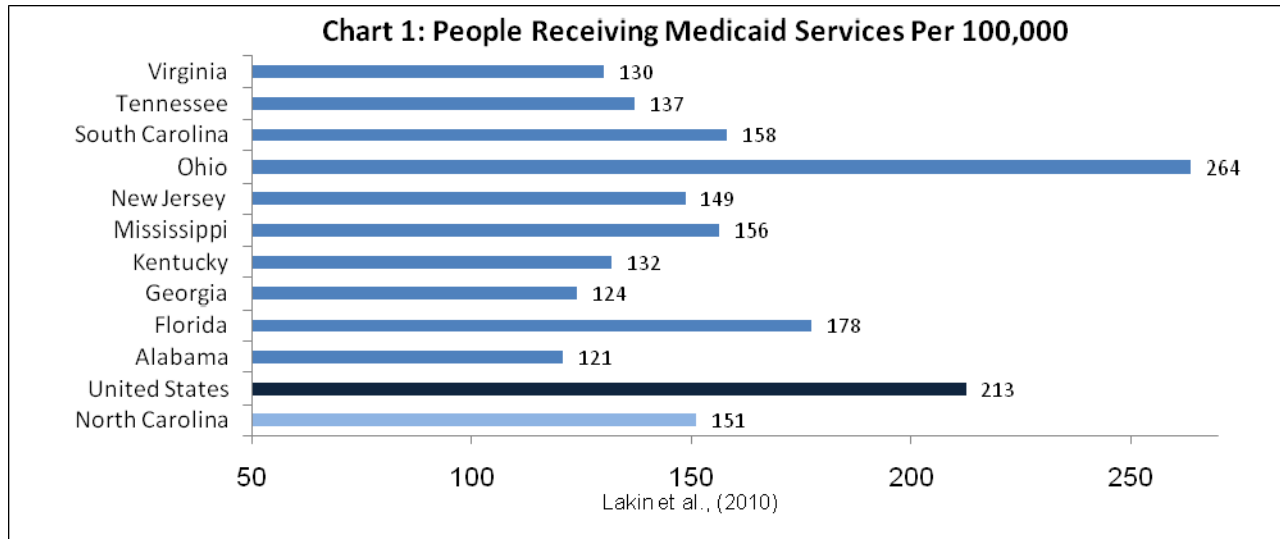
Service utilization patterns can be used to benchmark a state in terms of how many individuals receive services. In 2009, North Carolina provided Medicaid-funded services (Home and Community Based waiver Services (HCBS)) and services in Intermediate Care Facilities for the

<sup>24</sup> Prouty, R., Smith, G. and Lakin, K.C. (eds.) (2008). *Residential Services for People with Intellectual and other developmental disabilities: Status and Trends Through 2007*. Minneapolis: University of Minnesota, Research and Training Center on Community Living.



Mentally Retarded (ICF/MR)) to 14,187<sup>25</sup> individuals. This amounts to 151 people per 100K in general population in North Carolina<sup>26</sup>.

Chart 1 shows this finding along with the service use rates in selected other states and the national average. As shown, North Carolina outperforms several of the comparison states, but serves 29 percent fewer than the national average (151 in North Carolina versus 213 per 100K population nationwide).



For North Carolina to have served the national average of people per 100K population in 2009, the State would have had to provide services to roughly 5,750 more people in that year, or 62 people more per 100K of general population.

**Service Use and Waitlists**

When providing services, North Carolina relies primarily on HCBS waiver services with 73% of service recipients getting some form of waiver service. Another 27% utilize ICF/MR services. This compares to 86% of service recipients nationally receiving waiver services, and 14% receiving ICF/MR services.

Since 2000, North Carolina has expanded its capacity to deliver HCBS and ICF/MR services. From 2001-2009 North Carolina enrolled an additional 4,303 people to HCBS and ICF/MR services (478 people per year on average). Table 1 depicts the year to year system change.

<sup>25</sup> This total only includes individuals enrolled and receiving services under the Medicaid-financed HCBS waiver, and individuals receiving services in ICF/MR certified settings. Individuals living at home with family, or in host/foster care homes are not counted in this total. (Lakin et al. 2010)

<sup>26</sup> To date, North Carolina has not furnished data to the University of Minnesota on the number of people receiving services in the Piedmont Behavioral Health (PBH) LME catchment area. All data presented from Lakin, et.al excludes individuals receiving services from PBH.

**Table 1: HCBS and ICF/MR System Capacity Trends for North Carolina (2000-2009)**

Year	HCBS Recipients	% Change from Prior Year	ICF/MR Recipients	% Change from Prior Year	HCBS and ICF/MR Service Recipients	% Change from Prior Year
2000	5,364		4,520		9,884	
2001	6,141	14%	4,493	-0.6%	10,634	8%
2002	6,013	-2%	4,645	3.4%	10,658	0.2%
2003	5,692	-5%	4,500	-3.1%	10,192	-4%
2004	6,011	6%	3,875	-13.9%	9,886	-3%
2005	6,753	12%	4,306	11.1%	11,059	12%
2006	7,831	16%	4,091	-5.0%	11,922	8%
2007	9,309	19%	4,124	0.8%	13,433	13%
2008	9,700	4%	4,176	1.3%	13,876	3%
2009	10,333	7%	3,854	-7.7%	14,187	2%

(Lakin et al., 2010)

While these data show that North Carolina has increased its system capacity in this period, the rate falls well below the national average. Between 2000-2009, North Carolina had an increase in service capacity of 44%, compared to the national increase of 60%. This pace of growth contributes to a low overall service use rate (151 people per 100k population), and not surprisingly results in a waitlist for services.

In response, in the 2009 General Assembly Session for North Carolina, House Bill 673 (Ratified Bill) stated:

“The General Assembly of North Carolina enacts: **SECTION 1.** G.S. 122C-115.4(b) is amended by adding the following new subdivision to read: (b) The primary functions of an LME are designated in this subsection and shall not be conducted by any other entity unless an LME voluntarily enters into a contract with that entity under subsection (c) of this section. The primary functions include all of the following:

Each LME shall develop a waiting list of persons with intellectual or intellectual and other developmental disabilities that are waiting for specific services. The LME shall develop the list in accordance with rules adopted by the Secretary to ensure that waiting list data are collected consistently across LMEs. Each LME shall report this data annually to the Department. The data collected should include numbers of persons who are:

- a. Waiting for residential services.
- b. Potentially eligible for CAP-MR/DD.
- c. In need of other services and supports funded from State appropriations to or allocations from the Division of Mental Health, Intellectual and other developmental disabilities, and Substance Abuse Services, including CAP-MR/DD.”<sup>27</sup>

Recently, the State developed a methodology to begin to capture data about individuals waiting for, but not receiving Medicaid-funded services. In October 2010, MH/DD/SAS presented plans

<sup>27</sup> General Assembly of North Carolina: Session 2009. House Bill 673; Ratified Bill. <http://www.ncga.state.nc.us/Sessions/2009/Bills/House/PDF/H673v5.pdf>

for collecting and analyzing data.<sup>28</sup> At that time, MH/DD/SAS noted that Local Management Entities (LMEs) were providing data to the State regarding the number of people waiting for services in the different regions. As of October 2010, a reported 8,191 individuals were waiting for but not receiving services. The Department noted that the long-term goal of the information being collected would include an analysis of the data collection for future use.

The data presented, however, are not so easily interpreted, largely due to the absence of information related to the urgency of need for services which can greatly alter one's understanding of projected service need. Of the 8,191 individuals on the waitlist, it is not known how many need services urgently, in the near term, or at some unspecified time in the future. Some individuals may be on the list simply because they want to be in the queue so that they will not be bypassed later. Further, the present waitlist data offers little understanding of *what* services it is for which individuals are waiting for. Some may prefer out-of-home residential services or in-home support. Others may seek a day service only, or a particular type of day service (e.g., supported employment). Without such clarifying information, it is difficult to make use of the available waitlist data for forecasting purposes.

Notably, however, the State is taking action to understand the individuals waiting for, but not receiving, services. The State is also looking at expanding the utilization of functional assessment tools that could help define and prioritize those individuals waiting for services.

### Projected Unmet Demand

Given the difficulties regarding the waitlist data available, we utilized an alternative method for estimating North Carolina's potential waitlist. Based on our work in other states and a review of national data bases (e.g., Lakin et al., 2010), we surmise that states serving closer to 250 people per 100K/general population tend to have small to no waitlists for services. This estimate is not a guaranteed number. In any particular state, waitlist numbers may be higher or lower, and may fluctuate with time. Still, serving 250 people per 100K is a reasonable goal.

Using this marker, to project the extent of unmet service needs in North Carolina, we considered the state's population (about 9.4 million) in relation to the number served in 2009 (14,187 people) to calculate the additional number the State would have to serve to reach a service use rate of 250 per 100K/population. Complicating matters, however, we note that in most states, waitlists grow at a rate greater than population growth alone.

To project unmet service demand, we review the following data points:

- *Projected population growth.* According to the US Census Bureau, the North Carolina population is growing a higher rate than the national population. Between 2000 and 2009, the North Carolina population grew by 17 percent, from 8.05 million to 9.38 million. In comparison, during this same period of time, the United States population increased by only 9 percent, from 282 million to 307 million.

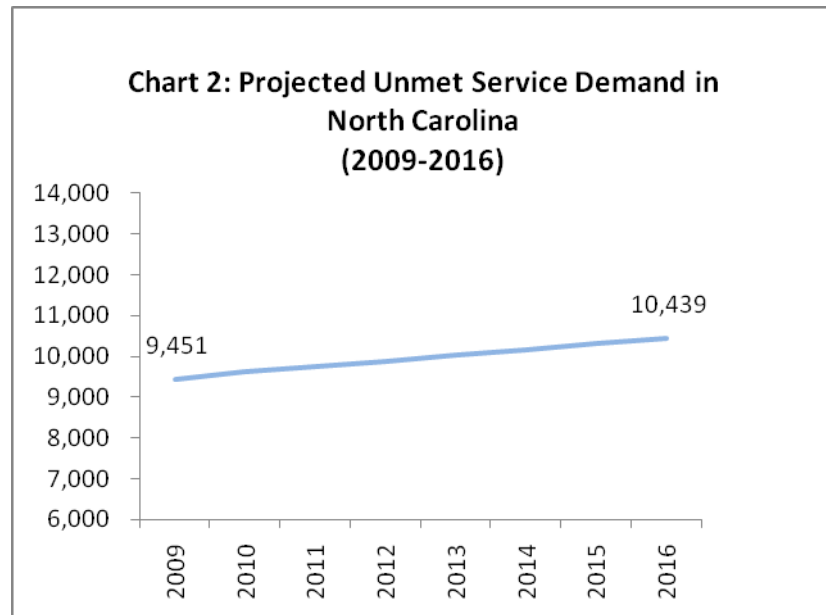
<sup>28</sup> Implementation Update of the CARP-MR/DD Tiered Waivers. Joint Legislative Oversight Committee on Mental Health, Intellectual and other developmental disabilities and Substance Abuse Services. Presented by Rose Burnette. October 13, 2010.

For our purposes, we base our estimates on information made available by the Office of State Budget and Management for North Carolina. This source estimates that from 2009 to 2016 the state’s population will grow by about 956,000 to 10,337,681, a 10 percent increase.

- *Service utilization rate.* Given these estimates, we can project unmet service demand from 2009-2020 based on the gap between North Carolina’s current service utilization rate (151 per 100K) and a service utilization rate of 250 per 100K, amounting to a gap of 99 people per 100K in population. The gap of 99 people per 100K of general population is kept constant throughout the projection period.

- *Factoring in service demand rate above population growth.*

As previously noted, HSRI’s work elsewhere indicates that service demand rates grow at a higher pace than population growth alone. It is not uncommon to observe year-to-year increases in expressed demand



of four percent or more. Thinking more conservatively, this analysis assumes a service demand rate growing at 2 percent higher each year than growth in the population rate.

Chart 2 offers a forecast of unmet service demand in North Carolina if nothing more was done to address the need. The scenario is based on a consistent gap in service use of 99 people per year (151 vs. 250 people served per 100K<sup>29</sup>) but shows growth in unmet service demand based on demand that grows 2% over population growth year-to-year. As shown by this projection, unmet service demand would grow to 10,439 by 2016, or by an average of 139 new people per year. It is important to note, however, that this does not mean that North Carolina could decrease system growth to 139 new individuals a year and not have unmet demand. Rather, the state would need to add, on average, 344<sup>30</sup> new service recipients per year to service.

<sup>29</sup> A growth in waitlists is calculated by reviewing year-to-year growth in the list over the past five years and then projecting the growth forward, given the anticipated increase in population according to the North Carolina Office of State Budget and Management.

<sup>30</sup> The 344 new service recipients include the 139 individuals in the unmet demand calculation, as well as, an average increase of 205 individuals to maintain a system service utilization rate of 151 per 100K.

## Benchmark #2: Serving Individuals in the Most Integrated Setting

**Assessment:** North Carolina relies on Developmental Centers, community ICFs/MR, nursing homes and to serve people with intellectual and other developmental disabilities to an extraordinary extent. As a result, opportunities for individuals to receive services in the most integrated setting are reduced.

In its landmark 1999 decision, *Olmstead v. LC & EW*, the United States Supreme Court affirmed that, under Title II of the Americans with Disabilities Act (ADA), states are obliged to operate their programs for people with disabilities in a manner that ensures that individuals receive services in the *most integrated setting* appropriate to their needs. The *Olmstead* decision established benchmarks for the operation of publicly-financed programs for people with disabilities.

As a practical matter, “most integrated setting” means that individuals are supported in community settings that are as similar as possible to typical living arrangements for people without disabilities. The *Olmstead* decision sent the strong message that people should not be unnecessarily institutionalized or otherwise served in segregated environments. The decision also established affirmative expectations for the transition of people from institutional settings to the community.

Since this decision, numerous states have crafted and sought to implement plans to come into compliance with the decision. In addition, the Center for Personal Assistance Services (2010)<sup>31</sup> reports 165 *Olmstead* or *Olmstead*-related lawsuits, including two in North Carolina.

In October 2010, a final settlement agreement in the original Georgia *Olmstead* case was released (*US v. Georgia*, Civil No. 1:10-CV-249-CAP). Regarding people with intellectual and other developmental disabilities, the agreement calls for Georgia to:

- Cease all admissions of individuals with intellectual and other developmental disabilities into the state hospitals (i.e., state institutions or developmental centers) by July 1, 2011;
- Transition all individuals with intellectual and other developmental disabilities currently living in state hospitals into community settings by July 1, 2015;
- Create 1,150 HCBS waivers for eligible individuals by July 1, 2015;
- Provide sufficient support coordination to those receiving HCBS;
- Provide family supports to 2,350 eligible individuals by July 1, 2015;
- Serve individuals receiving HCBS under the Agreement in their own home or their family’s home consistent with each person’s choice;
- Have six mobile crisis teams by July 1, 2012; and
- Establish 12 crisis respite homes by July 1, 2014.

<sup>31</sup> <http://www.pascenter.org/olmstead/index.php>

Generally, service trends in the United States have been consistent with the thrust of the *Olmstead* decision. Twenty years ago in the intellectual and other developmental disabilities field, the majority of individuals were served in large congregate settings (i.e., settings where seven or more people reside). According to the University of Minnesota's Research and Training Center on Community Living (Lakin, et al 2010) in 1987, only 27.3 percent of all people who received residential services in the United States were supported in living arrangements for six or fewer people. About one-half of all individuals were served in very large settings accommodating sixteen or more individuals, including 95,000 people who resided in state-operated public institutions.

States With No Institutions or 150 or Fewer People in Institutions <sup>32</sup> (Table2)		
States With No Institutions State	States with 150 or Fewer People in Institutions	
	States	# Served
Alaska	Minnesota	22
District of Columbia	Oregon	22
Hawaii	Nevada	47
Maine	Montana	64
Michigan	Delaware	72
New Hampshire	Idaho	74
New Mexico	Wyoming	82
Rhode Island	Colorado	103
Vermont	North Dakota	123
West Virginia	Arizona	123
	Maryland	129
	Indiana	134
	South Dakota	146

Lakin, et al., (2010)

Since then, the nation has significantly reduced its reliance on large, congregate care options in favor of smaller, more personalized residences and supported living arrangements. In fact, at present, nine states plus the District of Columbia have no large (16+), publicly-operated residential institutions serving people with intellectual or other intellectual and other developmental disabilities. Of note, in March of 2009 California completed the closure of the Agnews Developmental Center, which was opened in 1888. The State worked diligently to relocate individuals into the community prior to closing the campus permanently. Table 2, shows the ten states without institutions, as well as 13 states that have decreased the number of individuals in remaining state-run institutions to 150 or fewer people.<sup>33</sup>

Nationally, the use of the federal "Money Follows the Person" Rebalancing Demonstration Program (MFP) initiative has helped states move away from the use institutional settings. The MFP Program was authorized by Congress in the Deficit Reduction Act of 2005 and was designed to provide assistance to states to balance their long-term service systems and to help Medicaid participants transition from institutions to the community. The MFP Program reflects a growing consensus that long-term supports must be transformed from being institutionally-based and provider-driven to "person-centered," consumer-directed and community-based. Congress initially authorized up to \$1.75 billion in federal funds through federal fiscal year (FFY) 2011 to:

- Increase the use of HCBS and reduce the use of institutionally-based services

<sup>32</sup> Institutions are classified, in this report, as state-operated residential facilities housing sixteen or more individuals with intellectual or other intellectual and other developmental disabilities.

<sup>33</sup> In June 2009, Oregon had 22 individuals residing in the Eastern Oregon Training Center. This facility closed on October 31, 2010. Oregon no longer has any individuals residing in state-operate institutions.

- Eliminate barriers and mechanisms in state law, state Medicaid plans, or state budgets that prevent or restrict the flexible use of Medicaid funds to enable Medicaid-eligible individuals to receive long-term services in the settings of their choice. “Choice” in this context excludes preferences to live in developmental centers or community ICFs-MR;
- Strengthen the ability of Medicaid programs to assure continued provision of Home and Community Based waiver Services (HCBS) to those individuals who choose to transition from institutions; and,
- Ensure that procedures are in place to provide quality assurance and continuous quality improvement of HCBS.

In March 2010, President Obama signed into law the Affordability Care Act (ACA). The ACA provisions reflect a long-awaited commitment to independence, choice, and dignity for countless Americans who want to live and receive long-term services and supports in their own homes and communities. It gives states many of the tools they need to help "rebalance" their long-term care systems. Section 2403 of the ACA provides an opportunity for those states that are presently participating in the program to continue building and strengthening their Money Follows the Person (MFP) Demonstration Programs and for additional states to participate. The “Money Follows the Person” (MFP) initiative is a federal grant program wherein the Centers for Medicare and Medicaid (CMS) provide support to states working to transition individuals out of large, state-operated institutions (e.g., developmental centers) into home and community-based services. Under this program, funding allocated to providing services to the individual in an institutional setting is reallocated to provide services in community alternatives. Currently, 30 states are participating in the program. The ACA extends the MFP Program through September 30, 2016, and appropriates an additional \$450 million for each fiscal year from 2012-2016, totaling an additional \$2.25 billion. Any remaining MFP appropriation at the end of each fiscal year carries over to subsequent years.

Under the Affordable Care Act, individuals that reside in an institution for more than 90 consecutive days are now eligible to participate in the demonstration. However, one exception applies in the expanded definition of eligibility: days that an individual was residing in the institution for the sole purpose of receiving short-term rehabilitation services that are reimbursed under Medicare are excluded and will not be counted toward the 90-day required period.<sup>34</sup>

In a related vein, nationally about 70 percent of those receiving residential services live in homes of fewer than six people, with the average home size now under three individuals per setting. More recently, states are emphasizing “in-home” support options where individuals receive services while living with a family member (e.g., parents, sibling). In 2008, 57 percent of those receiving developmental disability services lived at home with a family member. Another eleven percent lived in their own homes<sup>35</sup>.

<sup>34</sup> Centers for Medicare and Medicaid Services. Money Follows the Person. Last Modified 09/20/2010. [https://www.cms.gov/CommunityServices/20\\_MFP.asp](https://www.cms.gov/CommunityServices/20_MFP.asp)

<sup>35</sup> The majority of individuals included in this data point do not own their own home, but are leasing apartments.

While most people with intellectual or other intellectual and other developmental disabilities live with their families, states have not always been inclined to provide in-home supports. Given growing service demands and finite resources to meet such demands, however, policy makers increasingly realize that they cannot afford to accommodate all those needing an out-of-home option. As a result, states are steadily investing in less expensive, in-home support services.

### North Carolina's Status

To some extent, North Carolina policy makers have come into step with national trends. For instance, the State has an "Olmstead Plan" that it seeks to implement. In May 2008, DMH/DD/SAS provided an "Olmstead Report"<sup>36</sup> to various legislative committees to describe its activities related to its plan. The primary premise of the plan is as follows:

"The Department of Health and Human Services shall conduct an analysis of the individual patient service needs and shall develop and implement an individual transition plan, as appropriate, for patients in each hospital. The State shall ensure that each individual transition plan, as appropriate, shall take into consideration the availability of appropriate alternative placements based on the needs of the patient and within resources available for the mental health, intellectual and other developmental disabilities, and substance abuse services system. In developing each plan, the Department shall consult with the patient and the patient's family or legal representative." (*House Bill 1473 10.49(u)*)

Likewise, under the auspices of the Division of Medical Assistance (DMA), since 2008 North Carolina has operated its own "Money Follows the Person" program.<sup>37</sup> This state demonstration project assists Medicaid-eligible North Carolinians who live in ICFs/MR and Skilled Nursing Facilities to move into their own homes and communities with supports.

North Carolina states that the four main objectives of the MFP initiative are to:

1. "Increase the use of home and community-based services (HCBS) and reduce the use of institutionally based services;
2. Eliminate barriers and mechanisms in state law, state Medicaid plans, or state budgets that prevent or restrict the flexible use of Medicaid funds to enable Medicaid-eligible individuals to receive long-term care in the settings of their choice;
3. Strengthen the ability of Medicaid programs to assure continued provision of HCBS to those individuals who choose to transition from institutions; and,
4. Ensure that procedures are in place to provide quality assurance and continuous quality improvement of HCBS."<sup>38</sup>

In January 2011, Mathematica Policy Research, Inc. submitted a state progress report on MFP to the Centers for Medicare and Medicaid.<sup>39</sup> The report offers details for each state

<sup>36</sup> <http://www.ncdhhs.gov/mhddsas/statspublications/reports/LOC/loc-05-08-olmsteadreport.pdf>

<sup>37</sup> <http://www.ncdhhs.gov/dma/MoneyFollows/>

<sup>38</sup> Money Follows the Person Overview. NC Division Of Mental Health, Intellectual and other developmental disabilities And Substance Abuse Services. <http://www.ncdhhs.gov/mhddsas/moneyfollowsperson/overview12-10.pdf>. December, 17, 2010.

<sup>39</sup> Denny-Brown, N., Lipson, D., Stone, C., and Ross, J. *Money Follows the Person Demonstration: Overview of State Grantee Progress, January-June 2010. January 2011*. Mathematica Policy Research, Inc. Cambridge, MA.



participating in MFP, indicating where the state is in process of transitioning individuals into HCBS services relative to their goal for the year. The report offers data between January and June 2010.

Data presented by Mathematica shows:

- North Carolina transitioned a total of 47 individuals<sup>40</sup> into HCBS since the inception of the program;
- During 2009, North Carolina completed 35.6 percent of their transition goal, transitioning 31 of 87 individuals;
- Between January-June 2010, in North Carolina 16 individuals had been transitioned to HCBS, 14 of which were individuals with intellectual and other developmental disabilities. This equaled 18.4 percent of their total transition goal of 87<sup>43</sup> individuals, ranking them 26<sup>th</sup> out of the 30 participating states; and
- During the first half of 2010, 4 individuals were re-institutionalized (2 elders and 2 individuals with intellectual and other developmental disabilities).

In this report, Mathematica notes programmatic issues that several states are dealing with when implementing MFP:

- North Carolina achieved less than 20 percent of its 2010 transition target. Mathematica suggest that this showed a need either to : “(a) invest substantially more resources or adjust the program design to significantly increase transition volume, or (b) reduce transition goals for subsequent years through amendments to their operational protocols, so as not to jeopardize their ability to receive supplemental MFP grant funds.”
- Nearly two-thirds (19) of all states reported difficulty reaching their transition goals this period, due to several factors (in order of importance): (1) shortages of affordable and accessible housing; (2) statutory restrictions on housing options that can be used in MFP; (3) complex needs of the target population; (4) transition candidates not choosing to reside in an MFP-qualified residence; and (5) family opposition, particularly among candidates with intellectual and other developmental disabilities. Other challenges included a shortage of slots in their home and community-based service (HCBS) waiver programs or lack of waivers for a particular target population; contracting delays; cuts in the state budget; transition candidates not meeting the minimum length of the institutional stay requirement; inadequate service capacity; lack of caregiver supports; staff turnover; low census in facilities; decreased participation due to the transitions to a managed long-term care system; and difficulty identifying MFP-eligible transition candidates.
- A number of states indicated their MFP programs have been affected by cuts to Medicaid HCBS. North Carolina reported to Mathematica significant cuts to case

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<sup>40</sup> This number includes individuals under the following categories (elders, people with physical disabilities, people with MR/DD, people with mental illness and other).

management and other community-based services that have destabilized the community support structure.

- Several other states (Hawaii, Maryland, North Carolina, Michigan, Illinois, and California) indicated that small group or assisted living options are available, but often exceed the required four-bed limit. Some states, such as North Carolina, are engaging small group home providers to reduce their size to qualify for MFP.
- In line with the MFP initiative, the North Carolina Council on Intellectual and other developmental disabilities funded an initiative called *Seeing is Believing* (SIB) between 2008-2010. The initiative aimed at building capacity in the community housing infrastructure, and helping individuals residing in community ICFs/MR, or other residential placement options transition into more integrated settings of their choice. Though similar to the MFP program, SIB helped individuals already residing in smaller residential settings (e.g., six-bed ICF-MR group homes) move into more integrated settings and helped providers effect voluntary conversions of ICF-MR to smaller settings, preferably funded by the HCBS. Table 3 shows the transition for individuals within the SIB program.

**Table 3: SIB Movement Summary**

Moved From							Moved To					
Family home	Group Home (non-ICF)	Private ICF	Public ICF	Public Other	Apartment	Total	Apt / House	Shared Living	AFL/Spec. Foster	Student Housing	Family Home	Total
4	1	1				6	3	1	1			6
	3				2	5	4				1	5
21	3					24	11	2		11		24
		6				6	5		1			6
	1	9	1	1		12	7	2	3			12
25	8	16	1	1	2	53	30	5	5	12	1	53
<b>Immediate Pending</b>												
Family home	Group Home (non-ICF)	Private ICF	Public ICF	Public Other	Apartment	Total	Apt / House	Shared Living	AFL/Spec. Foster	Student Housing	Family Home	Total
	1			1		2	1		1			2
		2				2	1				1	2
	1	2		1		4	2	0	1	0	1	4

NCCDD, 2010

As shown in the table, overall, 53 individuals, with intellectual and other developmental disabilities or other qualifying disabilities utilized the program, with an additional 4 waiting on transitions. Of this number, 24 individuals have transitioned from public or private ICFs/MR to other community-based residential options.<sup>41</sup>

<sup>41</sup> <http://www.nc-ddc.org/publications/NCCDD-Annual-Report-2008-2009.pdf>

Finally, for 2009 we note that in North Carolina 59.5% (14,694) of all those receiving developmental disability services lived at home with a family member.<sup>42</sup> The national average in 2009 was 57.7%. Clearly, North Carolina's performance regarding its commitment to in-home support is consistent with this national marker.

Of interest, however, are the 14,187 individuals with intellectual or other intellectual and other developmental disabilities served through North Carolina's Medicaid-funded services, including the Home and Community-Based Services (HCBS) waiver, as well as in ICFs/MR. Data presented by Lakin et al. (2010) shows that in 2009:

- About 67 percent (4,730) of the 7,049 people receiving residential services in North Carolina lived in homes of 1-6 people,<sup>43</sup> compared to the national average of 57 percent.
- North Carolina provided residential services to 3,854 people in public and private ICFs/MR and another 10,333 through HCBS waiver funding. In all, ICF/MR placements comprise 27 percent of those receiving residential services, compared to 14 percent nationally. ICF/MR use in North Carolina is nearly double the national average.
- 1,592 individuals resided in state-run developmental centers and neuro-medical centers, or 17.0 individuals per 100K compared to 10.7 nationally. The utilization rate for developmental centers in North Carolina is 57% higher than the national average.
- 1,798 individuals resided in private ICFs/MR. This is 14.8% of the 12,131 served in community ICFs/MR or receiving HCBS, more than twice the national average of 6.5%.
- 2,141 individuals, including the 1,593 in state-run developmental centers and neuro-medical centers, live in facilities of 16+ people. This amounts to 21.4% of all those receiving residential services in North Carolina. This compares to 13.6% nationally who receive residential services.
- 949 individuals with intellectual and other developmental disabilities resided in skilled nursing facilities, roughly 10.1 people per 100K compared to 9.6 nationally.

These data reveal that, in comparison to national averages, North Carolina utilizes ICFs/MR and large congregate facilities for individuals with intellectual and other intellectual and other developmental disabilities at a significantly greater rate than is being done nationally.

### **Focus on State Developmental Centers**

North Carolina, like many other states, has reduced its reliance on state-run institutions. From 1977-2009, North Carolina cut its population in these centers by over half from 3,753 to 1,593 individuals. Still, developmental centers and neuro-medical centers in North Carolina play a prominent role within the service array.

<sup>42</sup> Some individuals receiving services in the home of a family member are getting HCBS waiver services. Others are getting services funded through other sources (e.g. state-funded services).

<sup>43</sup> This only includes provider operated congregate care group homes, and does not include individuals in their own home or apartment.

North Carolina currently operates three, public, residential facilities or state-operated institutions for individuals with intellectual and other intellectual and other developmental disabilities. The facilities are regionally located across the state.

- The J.I. Riddle Developmental Center is located in the western region of the state in Morganton, North Carolina. The center serves individuals from 37 counties in the state and has roughly 325 residents.
- The Murdoch Developmental Center serves the central region of the state and is located in Butner, North Carolina. The center serves individuals from 25 counties and has roughly 568 residents, 42 of which are children.
- The Caswell Developmental Center is located in the eastern region of the state in Kinston, North Carolina. The center serves 37 counties and has roughly 430 residents.

Beyond services offered through the developmental centers, the State also maintains and operates two neuro-medical centers.

- The Black Mountain Neuro-Medical Treatment Center is located in Black Mountain. In this facility, North Carolina serves individuals with intellectual and other developmental disabilities, medically fragile and aging people with development disabilities and individuals with Alzheimer's. Residents are served from 62 of 100 North Carolina counties in the central and western part of the state.
- The O'Berry Neuro-Medical Center is located in Goldsboro, North Carolina and serves individuals with intellectual and other developmental disabilities from 65 of 100 counties in the eastern and south-central areas of the state. According to the Center's website<sup>44</sup>, the average age of residents is over 50 years old, and most have significant health-related challenges.

Precise differences in populations served by state developmental centers and neuro-medical centers are difficult to determine, though some claim that the medical centers, unlike the developmental centers, support people who do not benefit from "active treatment." The North Carolina Institute of Medicine reports that while similar populations are served, neuro-medical centers differ from the developmental centers because they are classified as specialized nursing facilities rather than an ICF/MR classification<sup>45</sup>.

In 2007, the North Carolina General Assembly adopted a law that included a plan by which the State was to reduce the utilization of the developmental centers. The provision is as follows:

*"The Appropriations Bill Session Law 2007-323 Section 10.50 calls for the Department to "ensure that the downsizing of the State's Developmental Centers is based upon individual needs and the availability of community-based services with a targeted goal of four percent (4%) each year." The Department must "ensure that placements for ICF/MR level of care shall be made to appropriate community-based settings" and "admissions to a State-operated ICF/MR facility is permitted only as a last resort. The*

<sup>44</sup> <http://www.ncdhhs.gov/dsohf/oberry/about.htm>

<sup>45</sup> North Carolina Institute of Medicine Task Force on Transitions for People with Intellectual and other developmental disabilities. *Successful Transitions for People with Intellectual and other developmental disabilities: A Report of the NCIOM Task Force on Transitions for People with Intellectual and other developmental disabilities*. Morrisville, NC: North Carolina Institute of Medicine; 2009.

bill also requires that *“budgets for each of the Developmental Centers be reduced, and positions shall be eliminated as the census of each facility decreases in accordance with the Department’s budget reduction formula”* and that the Department of Health and Human Services report on the progress made in complying with this section.”<sup>46</sup>

Divisions of DHHS have worked to achieve these goals. According to Lakin et al. (2010), the census from 2008-2009 was reduced by 71 people, from 1,666 in residence to 1,592. This amounts to a 4.4% reduction in census. Table 4 shows the residents in each facility for 2008 and 2009, as well as the total discharges and deaths. Notably, of the 71-person decrease in census, 77 percent (55 individuals) was due to death and 23 percent (16 individuals) due to discharge from the facilities. Put another way, 16 individuals out of 1,666 (census in 2008) were moved out of large-state operated developmental centers into other residential placements during the FY 2009. This equates to 0.96 percent of the total center population transitioning.

**Table 4: Census of State-Operated Facilities for Individuals with IDD<sup>47</sup>**

Center	Residents 6/30/08	Residents 6/30/09	FY 2009 Discharges	FY 2009 Deaths
Black Mountain	84	85	1	5
Caswell	422	409	4	9
Murdoch	536	487	3	19
O’Berry	291	288	2	9
J. Iverson Riddle	333	323	6	13
Total	1666	1592	16	55

Lakin et al. (2010)

In contrast with these findings, according to a report focused on developmental centers only to the Senate Appropriations Committee on Health and Human Services in May 2009, the reduction in census did not reach 4 percent, and ended the year at a 1.2 percent reduction. Further, the report states:

“The developmental centers continue with downsizing efforts to comply with this legislation. Between July 1, 2007 and June 30, 2008, 32 individuals moved from the developmental centers to the community. These individuals moved to a variety of settings, including the Intermediate Care Facility for The Mentally Retarded (ICF/MR) group homes, supervised living group homes, alternative family living homes and to their natural families’ homes. During this same time period, 52 individuals were admitted to the developmental centers, many of whom came from licensed community residential settings, including ICF/MR group homes. These admissions were due to behavioral and/or medical needs that could not be addressed in the individual’s community setting and were requested after other community resources were explored and exhausted. It is anticipated that 29 of the individuals admitted to

<sup>46</sup> General Assembly of North Carolina; Session 2007. Session Lax 2007-323; House Bill 1473. Pg. 126-127. <http://www.ncga.state.nc.us/sessions/2007/bills/house/pdf/h1473v10.pdf>

<sup>47</sup> This data includes developmental centers (ICF-MR) and neuro-medical centers serving individuals with IDD, and does not include time-limited specialty programs in the developmental center..

the developmental centers last fiscal year will be ready to return to the community within two years, while the remaining 23 will likely remain at the developmental centers for an extended period of time due to the complex nature of their disabilities. For all individuals admitted to the developmental centers, reintegration to the community is the goal.”<sup>49,48</sup>

It is apparent that the Department, though it seeks to reduce its developmental center census, is having a difficult time doing so. As individuals are discharged, others take their place. In fact, according to a presentation, based on 2008-2010 data and given by staff of the Division of State Operated Healthcare Facilities to the Legislative Oversight Committee in December 2010<sup>49</sup> the census actually increased by 28 people in this three-year period.<sup>50</sup>

<b>Fiscal Year</b>	<b>Number of Admissions General Population</b>	<b>Number of Discharges General Population</b>	<b>Number of Admissions Specialty Programs</b>	<b>Number of Discharges Specialty Programs</b>	<b>Total Admissions</b>	<b>Total Discharges</b>	<b>Overall Change in Census</b>
<b>2008</b>	<b>23</b>	<b>7</b>	<b>29</b>	<b>25</b>	<b>52</b>	<b>32</b>	<b>+20</b>
<b>2009</b>	<b>22</b>	<b>14</b>	<b>15</b>	<b>13</b>	<b>37</b>	<b>27</b>	<b>+10</b>
<b>2010</b>	<b>12</b>	<b>13</b>	<b>26</b>	<b>27</b>	<b>38</b>	<b>40</b>	<b>-2</b>

Certainly, there are individuals residing in these facilities with extraordinarily challenging behaviors or with complex medical needs. Yet, other states have illustrated that such individuals can be served within appropriately staffed and funded community HCBS alternatives. As noted previously, there are several states with no state-operated institutions and these states are serving individuals with high levels of support need in the community. Others, with more complex behavioral challenges, such as those committed by the courts or who pose a notable threat to others or the community at large, may be justifiably segregated from the community, though not necessarily in developmental centers.

It is important to note that North Carolina does try to utilize the NC START program. According to the *NC START: FAQ – Assessing NC START Services*<sup>51</sup>, the NC START (North Carolina Systemic, Therapeutic Assessment, Respite and Treatment) Program is exclusively available to serve adults (age 18 y/o and above) that have a primary diagnosis of Developmental Disability (DD) and challenging behaviors, often with a co-occurring mental illness. Part of the mission of this

<sup>48</sup> Data presented to the Senate Appropriations Committee included the time-limited specialty programs.

<sup>49</sup> Donin, C. Myers, A. Presentation to the Legislative Oversight Committee: *North Carolina’s Developmental Centers*. December 8, 2010

<sup>50</sup> Data reported by Lakin, et al. (2010) on state-operated centers includes the three Developmental Centers as well as the Neuro-Medical Centers. In the data presented to the Legislative Oversight Committee, data was reported for the three Developmental centers, but not the Neuro-Medical Centers.

<sup>51</sup> [http://www.durhamcenter.org/uploads/docs/documents\\_forms/system\\_of\\_care/developmental\\_disabilities/NC\\_START\\_Access\\_FAQ.pdf](http://www.durhamcenter.org/uploads/docs/documents_forms/system_of_care/developmental_disabilities/NC_START_Access_FAQ.pdf)

program is to intervene in crisis situations prior to individuals being admitted into hospitals or developmental centers.

The NC START program is divided into three regions (East, Central and West) and each region consists of two clinical teams and one respite home. The two clinical teams provide 24/7 crisis response and consultation as well as on-going preventative cross-systems crisis planning for eligible individuals. The crisis prevention component of NC START also involves working with the existing DD and mental health systems of care to provide technical assistance, consultation and support when working with individuals eligible for NC START.

The NC START clinical teams will continue to work with referred individuals and their service/support system up to one year following a referral. Within that time the NC START team will work with the individual and their system of services and supports to systemically prepare for crises and reduce the frequency of restrictive interventions, hospital admissions and overall crisis events.

The NC START regional respite homes each have two beds reserved for eligible individuals in crisis and two beds reserved for planned caregiver respite of eligible individuals (4 beds total).

### **Focus on Community ICFs/MR**

In addition to state-run developmental centers, in 2009 North Carolina also funded 305 non-state, privately run, community ICFs/MR. In 2009, 287 residences were licensed for six or fewer individuals, and 18 facilities were licensed for 16-plus residents. Overall, these facilities served 1,798 individuals or 14.8 percent of those served by Community ICF/MR or HCBS. Although the state does utilize smaller ICF/MR settings, the reliance on the service is more than twice as high as the national average.

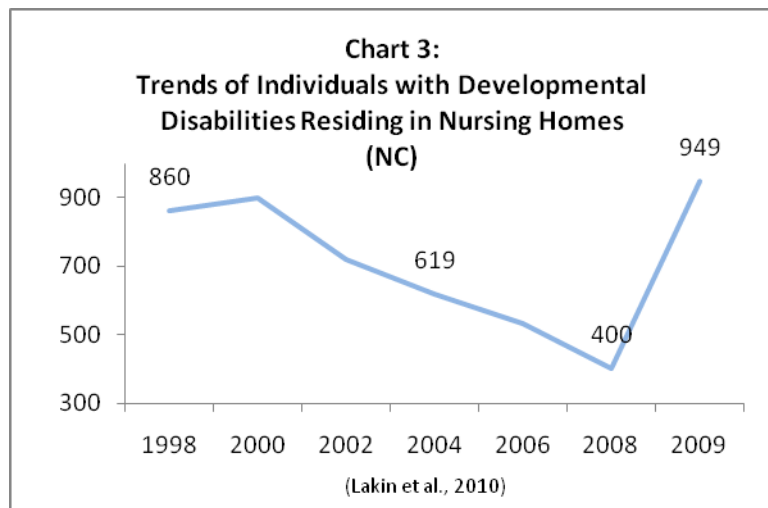
Further, in comparison to an HCBS waiver approach, limitations on an ICF/MR model concern: (a) the regulatory restriction on the types of living arrangement possible (i.e., must be four or more beds), (b) a service emphasis on habilitation and “active treatment” as opposed to support,<sup>52</sup> and (c) necessary contractual arrangements whereby all dollars (and thus the recipients of services) are controlled by the ICFs/MR service provider.<sup>53</sup> On each point, more progressive thought concerning the administration of service systems favors an HCBS waiver approach. Policy makers and service recipients alike favor flexibility in living arrangements so that fewer than four people can live together, a support-driven approach can replace habilitation, and contractual arrangements that encourage self-direction over provider-driven systems can take root.

<sup>52</sup> “Active treatment” refers to the skill-training that individuals receive to help them function as independently as possible. Often, the approach encourages that individuals must be made ready through skill acquisition to advance to higher levels of independence. To contrast, a “supports model” assumes that individuals are “already ready.” Teaching, as warranted, is combined with support offered by staff or others so that the individual can live or work in integrated, less restrictive, settings.

<sup>53</sup> An ICF-MR service provider is authorized to offer services in a licensed ICF-MR facility and has authority over who is served and the rules of the facility (consistent with ICF-MR regulation.) By contrast, HCBS options offer greater flexibility for individuals over the services they receive according to their support plan, and providers are reimbursed under “fee for service arrangements.” In fact, self-directed options offered in several states provide individuals opportunity to have significant authority over a budget allocation awarded to them.

### Focus on Skilled Nursing Facilities

Of further concern is the State's use of skilled nursing facilities for individuals with intellectual and other developmental disabilities. Nationally, the trend over the past 15 years has been to decrease the number of such individuals served in nursing facilities. Chart 3 shows the number of nursing facility residents with intellectual and other developmental disabilities in North Carolina. As the chart illustrates, between 1999-2008, North Carolina has shown a steady decrease in the number of people with intellectual and other developmental disabilities served in nursing homes. However, between 2008 and 2009, the number reported has more than doubled from 400 in 2008 to 949 in 2009. In 2009 the State served 10.1 individuals per 100K of general population in skilled nursing facilities, compared to 9.6 nationally. Several individuals interviewed noted concern in the use of this service, mainly due to the lack of community integration and high cost of the service.



### Focus on Community Adult Care Homes

The Division of Aging and Adult Services indicates that there are over 1,400 Adult Care Homes (ACHs) in North Carolina and that these homes:

“are residences for [seniors and adults with disabilities] who may require 24-hour supervision and assistance with personal care needs. People in adult care homes typically need a place to live, some help with personal care (such as dressing, grooming and keeping up with medications), and some limited supervision. Medical care may be provided on occasion but is not routinely needed. Medication may be given by designated, trained staff. These homes vary in size from family care homes of two to six residents to adult care homes of more than 100 residents. These homes were previously called "domiciliary homes." Some people refer to them as "rest homes." The smaller homes, with 2 to 6 residents, are still referred to as *family care homes*. In addition, there are Group Homes for Developmentally Disabled Adults, which are licensed to house two to nine developmentally disabled adult residents.” (<http://www.ncdhhs.gov/aging/agh.htm>)



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In 2009, the General Assembly mandated that the NC Institute of Medicine conduct a study of the co-location of different populations in these homes.<sup>54</sup> Among its many findings, the Task Force assembled to complete this assignment reports that:

- ACHs serve more than 18,000 individuals with disabilities by providing a place to live, assistance with activities of daily living (i.e., dressing, cooking, eating), and medication management. This number represents more than 60% of residents. Those with disabilities include individuals with mental illness, intellectual or intellectual and other developmental disabilities, or Alzheimer disease/dementia diagnosis.
- Individuals with disabilities often require services and supports in their daily lives. Most individuals with disabilities live on very limited incomes and need assistance with daily activities. Due to a shortage of more appropriate community options for individuals with disabilities and the financial incentives embedded in the system, many individuals with disabilities move into ACHs to gain access to needed supports.
- A cost comparison of State-County Special Assistance (SA) for recipients in ACHs and in their own homes reveals a bias for ACH residence. SA provides a cash supplement to low income individuals to help pay for the care they need. In specific terms, on average, the average value of SA for individuals in ACHs is \$435 per month, or \$5,220 per year. To contrast, the average value of SA for those living at home is \$359 per month, or \$4,308 per year in 2010. Overall, the Task Force concludes that “people who enter an ACH or other type of facility can obtain certain financial assistance, services, and supports that are not equally available to people with similar levels of disability and financial need who choose to remain in their own homes” (p. 32).
- Further, from a systems view, in 2007 the North Carolina Division of Aging and Adult Services (DAAS) compared the costs for Supplemental Assistance provided to recipients in ACHs and others living at home. DAAS found that when including federal, state, and county costs, ACH recipients cost 38.5% more per month, on average, than do in-home recipients. Over the course of a year, ACH recipients cost \$30,768 and in-home recipients cost \$22,224, on average.

Considering these findings, the Task Force concluded that “large numbers of individuals with disabilities are being served in ACHs even though best practices research indicates that these individuals may be better served in different settings” (page 31). As a result, among other recommendations the Task Force advised an expansion of housing and support services to enable people with disabilities to live more independently in their communities.

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<sup>54</sup> North Carolina Institute on Medicine. (2011) *Short-and long-term solutions for co-location in adult and family care homes: A report of the NCIOM Task Force on the co-location of different populations in adult care homes*. Morrisville, NC: NCIOM. (<http://www.nciom.org>)

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## Benchmark #3: Economy and Efficiency

**Assessment:** North Carolina under-spends overall for intellectual and other developmental disabilities services and to a notable degree spends the resources it does allocate inefficiently.

There is no doubt that appropriately supporting people with intellectual and other developmental disabilities requires a substantial financial commitment on the part of a state. Intellectual and other developmental disabilities are life-long. People with intellectual and other developmental disabilities have significant functional impairments and many require day-to-day services and supports throughout their lives. Intellectual and other developmental disabilities services are among the most costly long-term services. In 2009, Lakin et al. (2010) reports that nationally 32.7 percent of all Medicaid Long-Term Care expenditures were directed at ICFs/MR and HCBS. In fact, such expenditures amounted to 10.3 percent of all Medicaid spending.

As a result, it is important that a state: (a) invest ample resources in financing services to this population, and (b) employ effective financial management practices that promote economy and efficiency in the delivery of services.

There is significant variability among the states with respect to their level of financial effort in supporting services for people with intellectual and other developmental disabilities. State fiscal capacity varies due to underlying economic and other differences. All other things being equal, however, states where there is a relatively low level of financial effort in support of intellectual and other developmental disabilities services usually have large waitlists for services. Service providers struggle to survive in the face of low payment rates that, in turn, result in major problems in meeting basic quality standards and stabilizing in the disability services workforce.

Effective financial management of intellectual and other developmental disabilities services is complex and multi-faceted. Key facets include:

- **Managing the use of federal Medicaid dollars.** To the extent that a state can qualify services for federal Medicaid cost sharing, it can stretch its own dollars to serve more people with intellectual and other developmental disabilities. Medicaid financing can play a major role in underwriting the expansion of system capacity to meet service demand. It presents states with alternative pathways to securing federal dollars to pay for services. As a consequence, there are major differences among the states in their utilization of Medicaid dollars to finance services.
- **Promoting economical service delivery.** It is in a state's best interest to channel service demand into less expensive, more economical service alternatives. Some models of intellectual and other developmental disabilities service delivery are extremely costly due to regulatory and other requirements. In an environment of limited budgets,

reliance on high cost service models obviously will foreshorten a state's ability to meet current and future service demand.

- **Purchasing of services.** Government is the principal – indeed, virtually the only -- purchaser of intellectual and other developmental disabilities services. Consequently, state purchase-of-service policies and practices have major marketplace ramifications. The rates that a state pays for services affect the viability, quality and availability of services. To the extent that state payments are not based on a realistic appraisal of legitimate provider costs, quality will suffer and there will be an insufficient supply of providers to support individuals.

How a state addresses these system management issues has major consequences for the state's ability to support its citizens with I/DD. Among the states, there have been several noteworthy national trends and developments pertaining to the financing and management of intellectual and other developmental disabilities services. With respect to Medicaid financing, the trend for more than 20 years has been for states to concentrate on expanding HCBS waiver services to people with I/DD while concurrently reducing the utilization of more costly ICF/MR services.

Between 2000 and 2009, states increased the overall number of individuals with I/DD enrolled in Medicaid-funded long-term services by a little over one-third. Most states that increased enrollment fueled this expansion by an aggressive leveraging of community services, through the Medicaid home and community-based waiver authority. Leveraging, including converting community-based ICFs/MR to waiver funding, helped states to capture partial reimbursement for their expenditures, an attractive outcome for states. In turn, this allowed states to weather downturns in state revenue and/or expand services. The HCBS waiver program now is the principal source of federal financial assistance to states to underwrite the costs of intellectual and other developmental disabilities services. In terms of expenditures, in 2009 federal/state spending on HCBS waiver services accounted for 66.2 percent of the \$37.3 billion in Medicaid spending nationwide for intellectual and other developmental disabilities long-term services.

Another important development has been the emergence of new approaches to purchasing services. Several states have implemented or are designing relatively sophisticated rate-setting systems. These systems are designed to ensure that payments for services match up with their underlying service needs of each individual along with provider agency costs. For example, Arizona has implemented a rate system that takes into account market wages, complexity of service delivery, and geographic differences, as well as other factors that affect provider costs. Likewise, Colorado, Georgia, Oregon, Louisiana, Rhode Island, Virginia have all sought to reform their resource allocation methods. In these states, policy makers seek to set budget allocations to be consistent with their level of need and to do so in ways so that people with intellectual and other developmental disabilities who have similar support needs receive similar allocations. The approach encourages system equity (i.e., fairness) and efficiency.

Overall, states have a keen interest in allocating sufficient resources to accommodate all those in need but want to do so in a manner that is efficient and effective. This is especially true given the fiscal challenges faced by states. Even while absorbing significant revenue losses from

2008-2011, states are bracing for addition shortfalls through 2012. As noted earlier,<sup>55</sup> 44 states project budget shortfalls amounting from 2.0 - 45.7 percent of 2011 state budget. North Carolina reported a \$3.8 billion projected shortfall for 2012; this amounts to 20 percent of its 2011 budget, ranking its shortfall as the 35<sup>th</sup> highest among the 44 states.

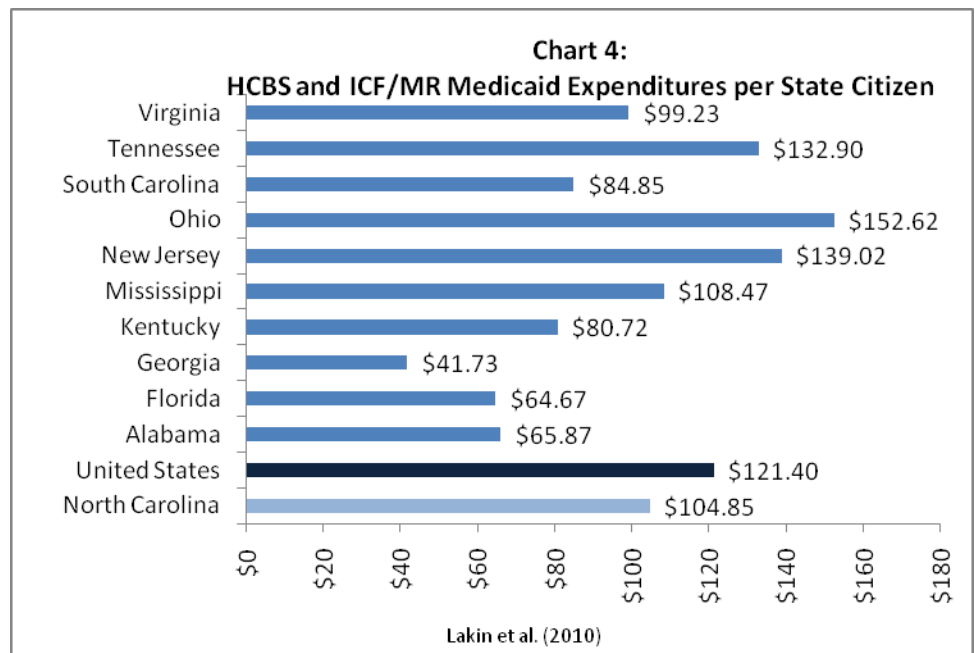
In this regard, we note that in 2009, Lakin et al. (2010) reports that the average cost per person nationally at \$57,126. In North Carolina, the cost per person was \$69,331, or 21.3 percent higher than the national marker. At issue across all states, including North Carolina, is how to identify and implement a means for reducing the cost per person, where possible, to achieve greater efficiencies while not sacrificing service quality.

### North Carolina's Status

Our analysis of North Carolina's service delivery system finds that the State is allocating an insufficient amount of resources into the system, and the resources being allocated are being used inefficiently. Put another way, as is illustrated below, the State has fewer dollars available for services, compared to other states, and dollars available are being used disproportionately in high cost services options.

### Less Than Average Spending

One of the most common ways to measure a state's overall level of financial effort in supporting its citizens with intellectual and other developmental disabilities is to review the expenditures per state citizen. That is, total intellectual and other developmental disabilities expenditures divided by the state's population. Chart 4 compares North Carolina's expenditures per citizen to the nation as a whole and to other selected states in 2009.



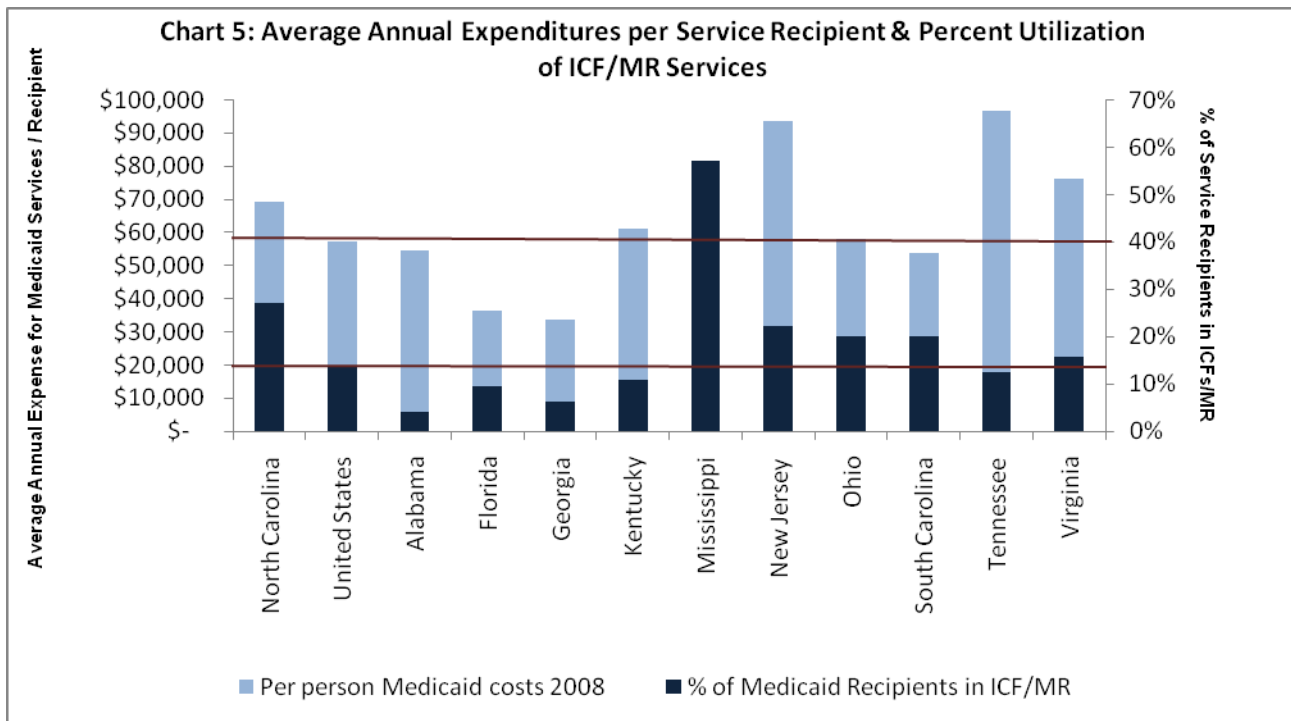
As shown, fiscal effort across states varies with three states (Tennessee, Ohio, and New Jersey) spending above the national average. North Carolina spent \$104.85 per citizen for intellectual and other developmental disabilities services. The nationwide average of \$121.40 per citizen was \$16.55 dollars, or 15.7 percent, per person higher. North Carolina's 2009 spending for

<sup>55</sup> McNichol, E., Olif, P. & Johnson, N., (2011). *States Continue to Feel Recession's Impact*. Center on Budget and Policy Priorities. <http://www.cbpp.org/cms/?fa=view&id=711>.

intellectual and other developmental disabilities services would have had to have been \$155,253,630 higher in 2009 to match the nationwide average.

**Inefficient Use of Resources**

Measured in another fashion, Chart 5 illustrates the average Medicaid expenditures per service recipient, as well as the percentage of Medicaid recipients in ICF/MR settings in 2009 among the comparison states. North Carolina expended \$69,331 per person on average for HCBS and ICF/MR services or 21.3 percent more than the national average of \$57,126 per person. Chief among the explanations for this circumstance is the state’s heavy reliance, in comparison to other states, on developmental centers and community ICFs/MR as a prominent service option.



Interestingly, as illustrated by Chart 5, of the seven states shown as having a higher cost per person for Medicaid services, five states (North Carolina, Mississippi, New Jersey, Ohio and Virginia) also utilize ICF/MR services at a higher rate than the national average. Based on Chart 5, findings indicate that most often, states that rely more heavily on the utilization of ICFs/MR have a higher average per person cost, most likely driven by the high cost nature of the ICF/MR service.

Charts 6 and 7 shows the distribution of funding for HCBS and ICF/MR. As can be seen, the national trend is to draw more heavily on funding HCBS waiver services (66.3 percent) compared to ICF/MR services (33.7 percent). In North Carolina, however, spending on ICF/MR and HCBS waiver services are nearly equal. North Carolina spends a smaller percentage of funding on HCBS services (48 percent) than on ICF/MR services (52 percent).

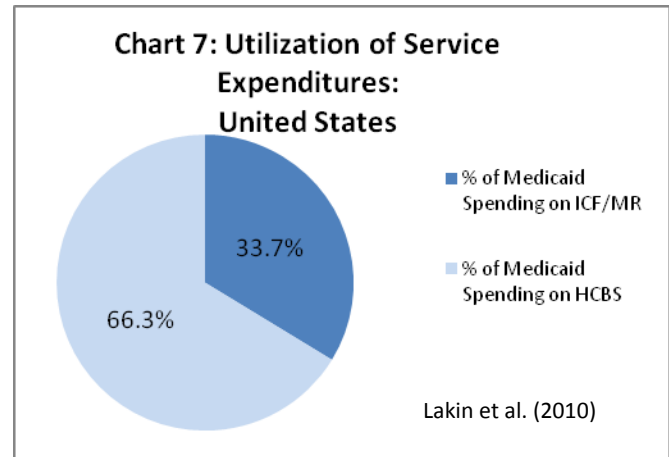
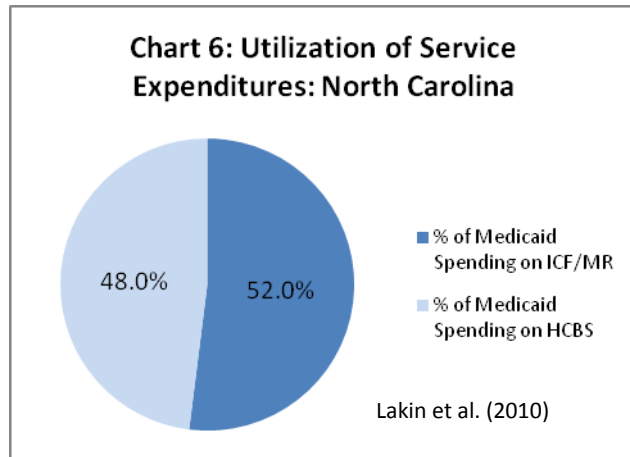
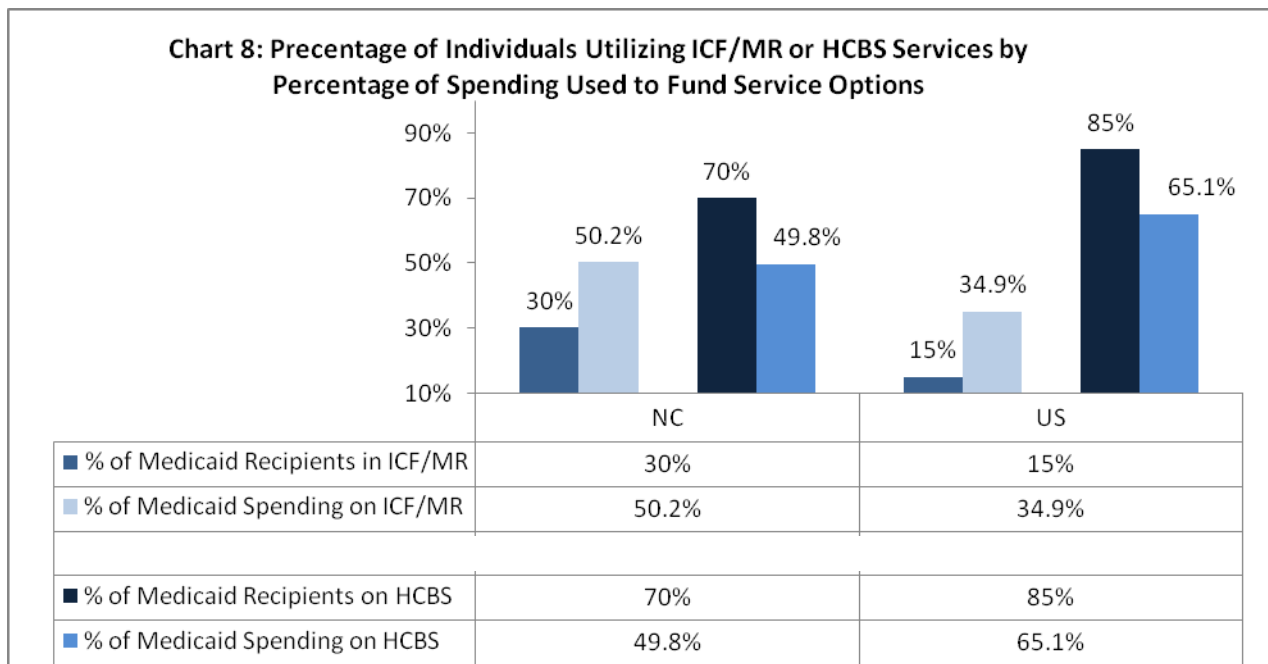


Chart 8 takes the data presented in Charts 6 and 7 and adds the percentage of individuals in each of the corresponding services. As shown, in 2009 North Carolina allocated roughly 50 percent of funding resources to 30 percent of service recipients under ICF/MR services. This left 70 percent of the population under HCBS services just under 50 percent of available resources. Nationally, the trend has been an increasing allocation of money toward the HCBS services program. In 2009, 65.1 percent of resources served 85 percent of the population of service recipients under the HCBS waiver, and 15 percent of service recipients received ICF/MR services and utilized roughly 35 percent of the funding.



Clearly, North Carolina relies more heavily on ICFs/MR than do other states. The negative consequence of this pattern rests with the comparative costs of the available options. Put bluntly, over time a system strategy based in ICFs/MR costs more per person and in the aggregate than one centered on use of HCB services. Consider that:

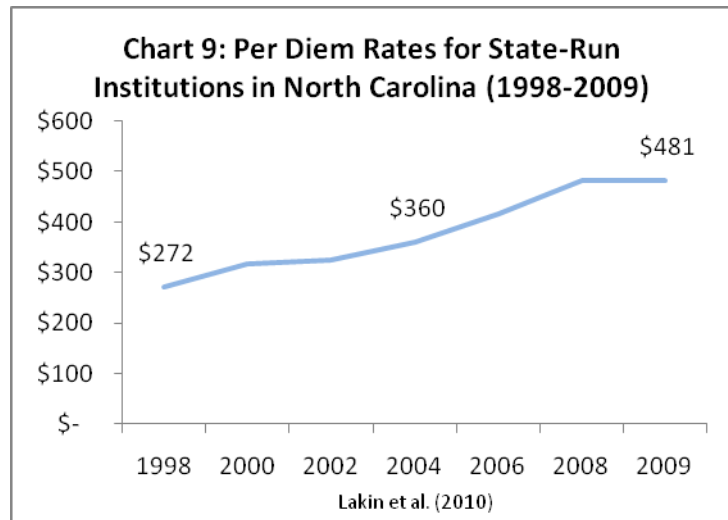
- As illustrated by Chart 9, the average per diem cost to serve an individual in a North Carolina developmental center is steadily rising. In 2009 it was \$481 per day or roughly \$175,000 annually.

Yet, there is reason to believe that many of the individuals currently served in these centers could be supported as well or better in alternative community settings. It is important to note

that a formal study of individual level of need was not conducted for this project. Such a study is outside the scope of this project. However, it would be a valuable study for state staff to consider. Given experiences elsewhere (e.g., TX, NE), it would not be surprising to find that the great majority of individuals served in North Carolina's centers have a "twin" with similar support needs who is being served in the community.

An example of this pattern was found in a report conducted by HSRI in the state of Texas.<sup>56</sup> Data in Texas indicated that there was a modest tendency to support people with more significant disabilities in ICFs/MR settings. The trending, however, was not absolute. The percentage of people with a "Limited Level-of-Need" served in either ICFs/MR or waivers was roughly equivalent (44.8 percent ICFs/MR to 42.9 percent in waivers). However, 2,768 individuals or 24.8 percent of all those served in community waivers had extensive support needs compared to 38.36 percent or 1,085 people in ICFs/MR. Meanwhile, 13.5 percent or 1,573 of those with intermittent needs were served in ICFs/MR settings, compared to 32.31 percent or 3,605 served through the waivers. These data raised issues as to why so many people in Texas with intermittent (low level) needs were in ICFs/MR. Likewise, the data show that community-based waivers served significant numbers of people with extensive (moderate to high) levels of need.

- The average cost of serving an individual in a community ICF/MR in North Carolina in 2010 is \$92,906.<sup>57</sup> The average cost of serving an individual on the CAP/MR-DD waiver in North Carolina is \$61,291.<sup>24</sup>

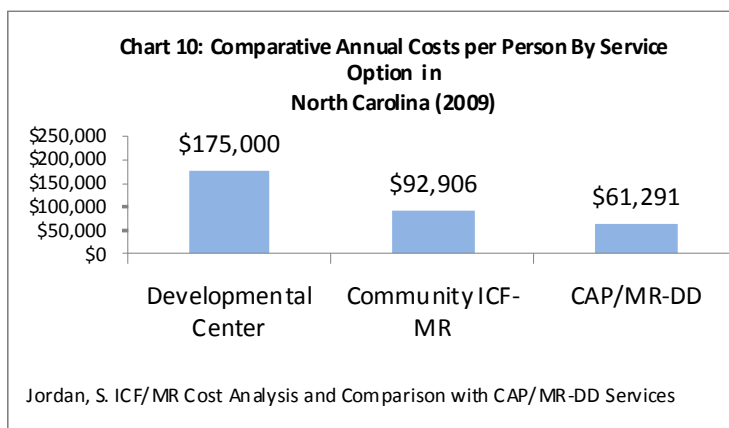


<sup>56</sup> Agosta, J., Fortune, J., Smith, D., Melda, K., Gettings, R., and Bradley, V. *Closing the Gap in Texas: Improving Services for People with Intellectual and Intellectual and other developmental disabilities*. October 2008. HSRI. Portland, OR 97224.

<sup>57</sup> ICF/MR Cost Analysis and Comparison with CAP/MR-DD Services. Joint Legislative Oversight Committee on Mental Health, Intellectual and other developmental disabilities, and Substance Abuse Services. November 9, 2010. Presented by Steve Jordan, Director.



Chart 10 illustrates these comparative costs. As shown, the ICF/MR options, including developmental centers and community ICFs/MR, are substantially higher than the HCBS waiver options offered through CAP/MR-DD. It is easy to see how these relative costs coupled with the state's strong reliance on ICFs/MR options yields a high per person annual cost when compared to the national average. Recall that North Carolina spends 21.3 percent more per person than is spent on average nationally for ICF-MR and HCBS combined.



**Table 6: States with Lowest ICF-MR Use and Annual Costs Per Person Compared to North Carolina (2009)**

State	Number Receiving ICF-MR Services per 100k Population	Combined Annual per Person Costs (ICF-MR & HCBS)
Alaska *	0.0	\$64,017
Michigan *	0.0	\$45,265
Oregon *	0.6	\$40,885
Vermont *	1.0	\$54,127
New Hampshire*	1.9	\$40,912
Colorado	2.3	\$43,807
Maryland	2.3	\$51,668
Arizona	3.0	\$27,660
Alabama	4.9	\$54,483
Montana	5.3	\$40,441
Hawaii *	7.0	\$43,735
Georgia	7.7	\$33,633
Washington	11.4	\$46,947
New Mexico *	11.5	<b>\$73,338</b>
Massachusetts	13.1	<b>\$73,244</b>
Missouri	13.1	\$60,766
Maine *	13.9	<b>\$84,126</b>
Wisconsin	15.0	\$45,333
Wyoming	15.1	\$52,309
Florida	16.7	\$36,431
<b>US Average</b>	<b>29.4</b>	<b>\$57,126</b>
<b>North Carolina</b>	<b>41.1</b>	<b>\$69,331</b>

\* Designates state with no public state institutions-Lakin et al. (2010)

We understand that some argue that there are those with complex needs that require an ICF-MR level of support, and that their needs justify an associated high cost per person. Experience, however, illustrates that significant investment in HCBS over ICFs-MR pay off over time.

Regarding long-term services across multiple Medicaid populations (e.g., seniors, disability), studies show that: (a) Medicaid spending growth is greater for states offering limited community services than for states with large, well-established, community programs<sup>58</sup>, and (b) cost savings from an emphasis on HCBS investment are realized over time, so that states that invest in HCBS experience slower growth in Medicaid expenditures than states with low HCBS spending.<sup>59</sup> In other words, investing in community centered HCBS over ICFs-MR holds Medicaid costs down over time.

<sup>58</sup> Kaye, H.S., LaPlante, M & Harrington, C. Do non-institutional Long Term Care Services reduce Medicaid spending? *Health Affairs*, 28, no. 1 (Jan/Feb 2009).

<sup>59</sup> Mollica, R, Kassner, E, Walker, L. & Howser, A. Taking the long view: Investing in Medicaid home and community based services is cost effective. *Insight on the Issues*, I26 (March 2009). Washington, DC: AARP Public Policy Institute.

Specific to developmental disability services, Table 6 shows the twenty states with the lowest utilization rates of ICF/MR services per 100k in population, as well as the associated rate and cost in North Carolina. As shown, all but three of these states (i.e., MA, ME, NM) have a lower annual per person expenditure for long-term supports than does North Carolina. Further, note that in 2010 Oregon became the first state with no service recipient receiving ICF/MR services in-state or in an out-of-state placement. Finally, eight of the 20 states have no public state insitutions (i.e., developmental centers). Collectively, these states demonstrate that high reliance on ICF/MR services is unwarranted. The support needs of their citizens, even those with complex needs, can be addressed through HCB services, and typically at a lower cost per person than North Carolina presently spends.

## Benchmark #4: Service Quality and Oversight

**Assessment:** North Carolina has a quality management system in place that monitors both LMEs and providers. This system, though, places more emphasis on meeting administrative requirements and minimum service standards, than pushing the system forward to achieve assure individual health and well being or to promote best practices valued by individuals and their families.

It is essential that a state operate effective quality assurance/quality management systems that ensure that people with intellectual and other intellectual and other developmental disabilities are safe and secure and the services they receive meet essential standards. People with I/DD are vulnerable to abuse, neglect, and exploitation. Consequently, it is important that health and welfare be regularly monitored.

The shift of the delivery of services to the most integrated setting poses substantial challenges for the operation of effective quality assurance/management systems. In particular, the number of sites where services are delivered has grown geometrically over the past several years and significant numbers of people reside with their families. In 2009, people with intellectual and other developmental disabilities nationwide received residential services and supports at over 173,000 sites. In 1999, residential services were delivered at approximately 113,000 sites. Many of the sites where residential services are now furnished are not licensed residences. Consequently, states have had to develop alternative oversight methods for services that are furnished in regular community housing.

A key to ensuring that individuals receive services that enhance their health and well-being is the presence of a trained cadre of case managers who function independently of the provision of service. Case managers are the system's eyes and ears and represent the first line of defense against the possibility of abuse, neglect and exploitation and are, as well, advocates for person-centered supports. In the majority of states, case management agencies are free-standing, rather than attached to provider organizations, thereby eliminating the possibility of a conflict of interest. Best practice also entails that case managers apply standardized monitoring procedures across the state so that data regarding performance can be aggregated at the state level.

State quality assurance systems are undergoing considerable change. In part, this change is being propelled by the ongoing growth of community services and supports. States are devoting more resources to quality management to keep pace with the growth of service systems. Some states are coping with this growth by sampling providers to gauge performance. The federal Centers for Medicare and Medicaid Services (CMS) have, furthermore, heightened their expectation of states with respect to the operation of comprehensive HCBS waiver quality management systems. States are now required to develop and implement a comprehensive Quality Improvement Strategy (QIS) that spans a wide range of HCBS waiver operations, including assuring the health and welfare of waiver participants. States also are expected to

compile evidence about the operation of the QIS, including the extent to which problems that are unearthed are appropriately remediated.

- Best practice in quality assurance/quality management now includes the operation of data systems that are capable of aggregating and analyzing information about the results of quality assurance processes to identify the extent to which problems are being discovered at the provider and system levels. Such data systems must have the capability to integrate quality information. For example, the results of routine monitoring of services should be linked to information gleaned from periodic provider agency quality reviews.

A well-trained, stable workforce is central to assuring the quality of services. When community agencies experience problems in recruiting and retaining direct support professionals, major problems are encountered in assuring quality. Many quality problems are directly traceable to workforce problems.

### North Carolina's Status

#### Quality Review in North Carolina

The following is an overview of North Carolina's quality management system and the specific approach to provider monitoring.

- **Standardized Quality Management System.** In North Carolina, MH/DD/SAS has taken action in recent years to standardize quality management processes and procedures, in an effort to assure quality, effectiveness and accountability across the state. Among these actions, the Division now maintains performance contracts directly with each of the LMEs. The scope of work covered in the LME performance contracts covers a wide range of responsibilities including: administration and governance; accounting and management of funds; information management, claims processing; provider support and monitoring; access, screening and referral; review and evaluation; care coordination; community relations; system of care; and quality management.

Quarterly, the Division prepares reports documenting LME performance in submitting required data and materials to the Division. These reports focus on process measures related to meeting timelines, and submitting complete and accurate forms in areas such as incident reporting, fiscal monitoring, work initiative reports, support needs assessment, and participation in the National Core Indicators surveys.

The Division's goal is to increase the efficiency and effectiveness of all LMEs and providers. Progress on this goal is described in the *DMH/DD/SAS Report on Strategic Planning for 2010-2013*; that report lists:

- An increase in the percentage of LMEs meeting 65% of the contract performance measures: between the 1<sup>st</sup> quarter of SFY08 and 3<sup>rd</sup> quarter of SFY10, the percentage of LMEs meeting performance standards for 65% or more of the Community System Progress Report Performance Indicators has risen from 40% to 79%;

- Standard processes for service authorizations and claims submissions have been recommended;
  - A revision of system-wide performance measures was completed, with increased performance targets to reflect improvements in performance;
  - There is now quarterly reporting of LME performance contract measures in the Community Systems Progress Reports; and
  - Semi-annual reports are submitted to the Joint Legislative Oversight Committee on Mental Health, Intellectual and other developmental disabilities and Substance Abuse.
- **Provider Monitoring.** Within the LME performance contract, LMEs are expected to assure appropriate and timely provider endorsements and monitoring. In North Carolina, MH/DD/SAS has partnered with The Council on Quality and Leadership (CQL) to accredit agencies providing community services. In 2010, 136 provider agencies had received such accreditation through CQL. Also, as part of the Division's standardization process, LMEs now utilize the same Provider Monitoring Tool across the state. This tool uniformly and regularly requires LMEs to address provider quality management, protection of individuals from harm (and responses to incidents and complaints), staff competencies, person-centered planning and service delivery, and protection of individual rights. The monitoring, however, is generally applied across MH/DD/SAS and only includes a modicum of attention to specific DD programmatic issues.

The new processes, however, are not without their frustrations. Some stakeholders are concerned that there continues to be no state-wide data collection system; that each LME has its own data set and can negotiate different rates for services; or that a lack of statewide data limits potential analysis and use in future strategic planning. Others fear that the new standardized processes focus too much on data submissions, and too little on consumer outcomes.

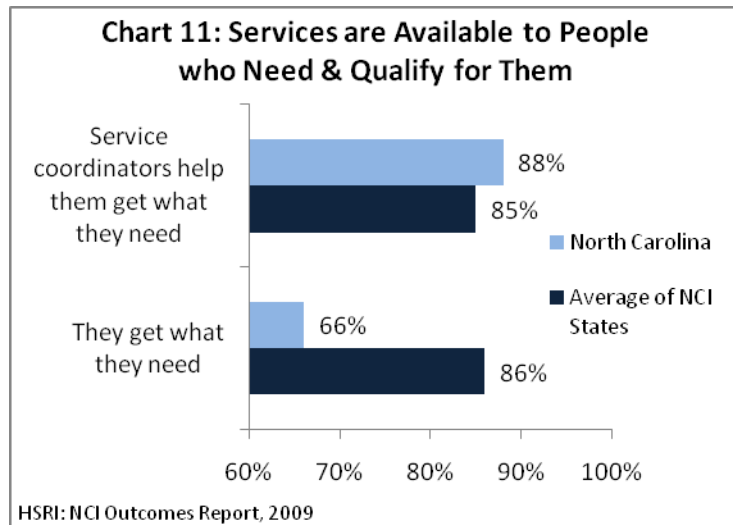
With regard to specific indicators of service quality across North Carolina, insight can be gained from individual and family responses to National Core Indicator interviews (Source: NCI Consumer Outcomes Report: 2008-2009 Data) and surveys. North Carolina participates annually in NCI's Consumer Survey, and bi-annually in NCI's Adult Family Surveys (one surveying family members of adults living at home, a second surveying family members of individuals living out of the family home). The benefits of the State's participation in NCI could be greatly enhanced if the Division of MH/DD/SAS worked with statewide and regional groups of consumers and families to interpret and reflect on the results.

### **Overall Satisfaction with Services**

The quality of a service system, overall, can be gleaned by two determining factors: (a) whether individuals are getting the services and supports they need; and (b) whether they are satisfied with those services.

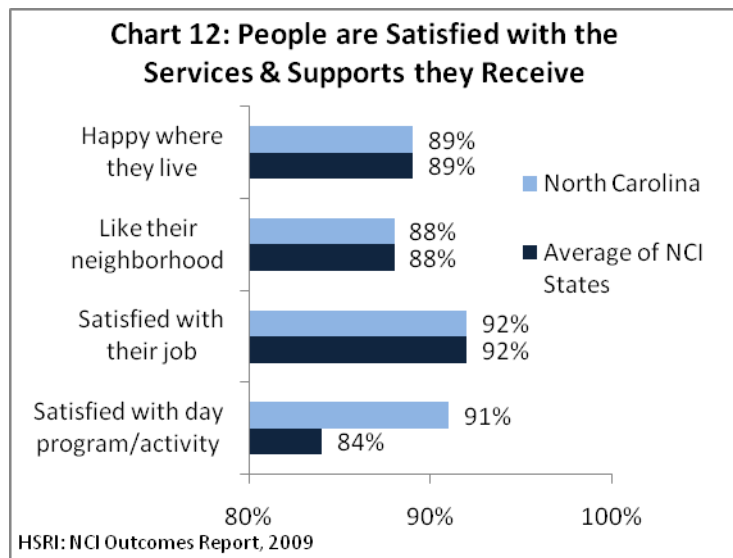
North Carolina is one of 25 states that participate in the National Core Indicators.<sup>60</sup> State performance on these markers provides insight into the quality of services offered. What follows are findings stemming from 2008-2009 NCI results.

- Getting help from service coordinators.** In North Carolina, 88% of service recipients report that their service coordinators help them get what they need. This is on par with the national average of 85%. A smaller percentage (66%), however, report actually getting the services they need, significantly below the national average of 86% (see Chart 11).



- Satisfaction with residence and daytime activities.** One way to assess whether individuals are satisfied with the services and supports they receive, overall, is to determine whether they are pleased with the end result, that is, where they live, work, or spend their day.

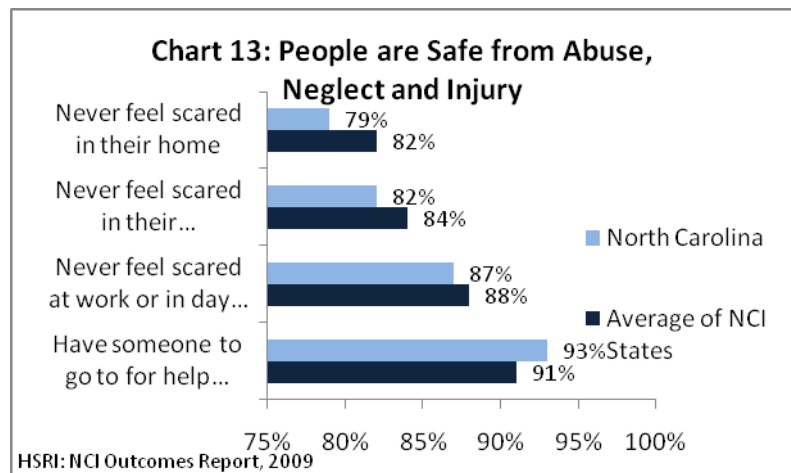
Chart 12 illustrates that, for the most part, North Carolinians are on par with others across the country: 89% like where they live; 88% like their neighborhood; 92% are satisfied with their job; and 91% are satisfied with their day program or activity. With regard to day program or activity, North Carolina has a significantly higher percentage of



<sup>60</sup> NCI began in 1997 as a collaborative effort between the National Association of State Directors of Intellectual and other developmental disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI). The goal of the program was to encourage and support NASDDDS member agencies to develop a standard set of performance measures that could be used by states to manage quality and across states for making comparisons and setting benchmarks. The current set of performance indicators includes approximately 100 consumer, family, systemic, cost, and health and safety outcomes - outcomes that are important to understanding the overall health of public intellectual and other developmental disabilities agencies. Associated with each indicator is a source from which the data is collected. Sources of information include consumer survey (e.g., empowerment and choice issues) family surveys (e.g., satisfaction with supports), provider survey (e.g., staff turnover), and state systems data (e.g., expenditures, mortality, etc.). ([www2.hsri.org/nci](http://www2.hsri.org/nci))

satisfied individuals.

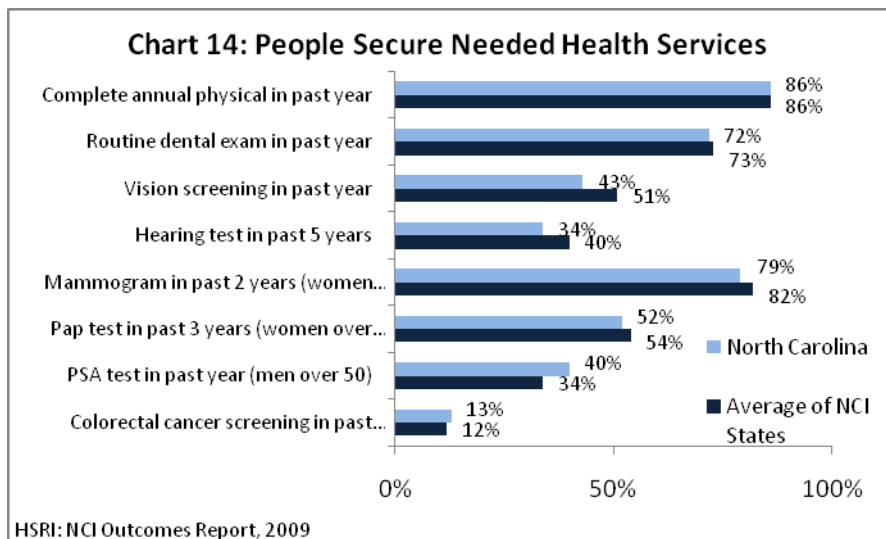
- Safety and security.** A required element of quality management is assuring that service recipients are safe from abuse, neglect and injury. In North Carolina, the Frequency and Extent of Monitoring Tool (FEM) and the Provider Monitoring Tool (PMT) are used, in part, to assess provider compliance with safety and security responsibilities, as well as responses to incidents and complaints. As noted in the *Semi-Annual Report to the Joint Legislative Oversight Committee on Mental Health, Intellectual and other developmental disabilities and Substance Abuse Services* (April 1, 2010), the predominant percentage of service providers (59%) earned a rating of “Moderate” with regard to the level of provider confidence in assuring basic service quality (based on LME assessments after evaluating provider longevity, staff competencies and experience, local collaboration efforts, data submission, quality management, provider status with other agencies, incident reporting, responsiveness to incidents and complaints, and patterns of incidents and complaints). Additionally, 27% of providers earned a “High” rating, and the remaining 14% earned a “Low” rating of provider confidence.



North Carolina’s NCI results tied to whether individuals feel afraid at home or in the community, and whether they have someone to talk with for support when they feel afraid, are comparable to national averages. About 8 in 10 feel safe and secure in their home and neighborhood, and about 9 in 10 feel safe in their work or day environment.

Additionally, 9 in 10 have someone to go to for support when they are feeling unsafe or afraid (see Chart 13).

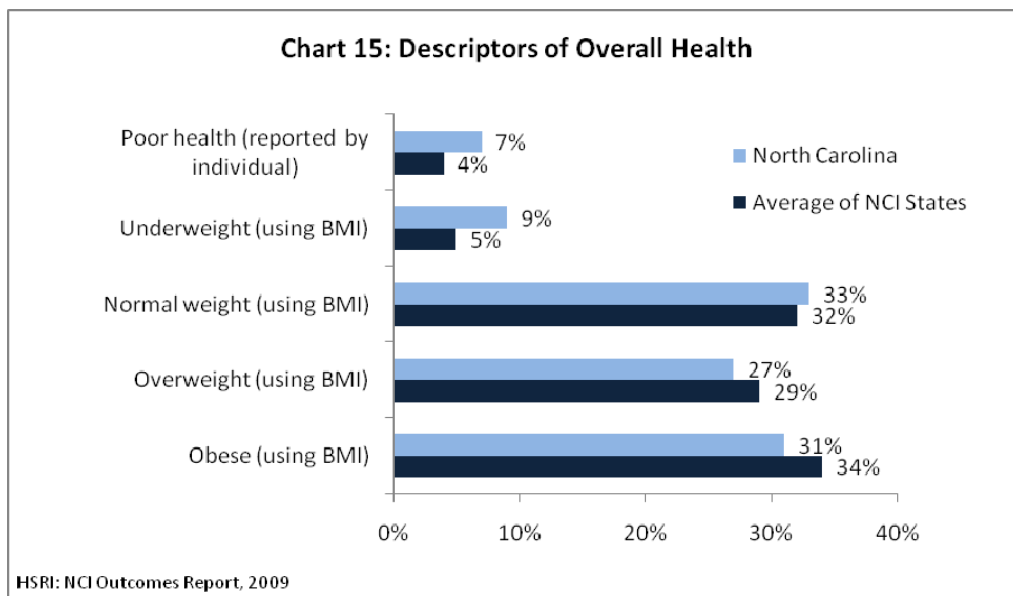
- Health and welfare.** Securing needed health services for individuals with intellectual and other intellectual and other developmental disabilities is essential



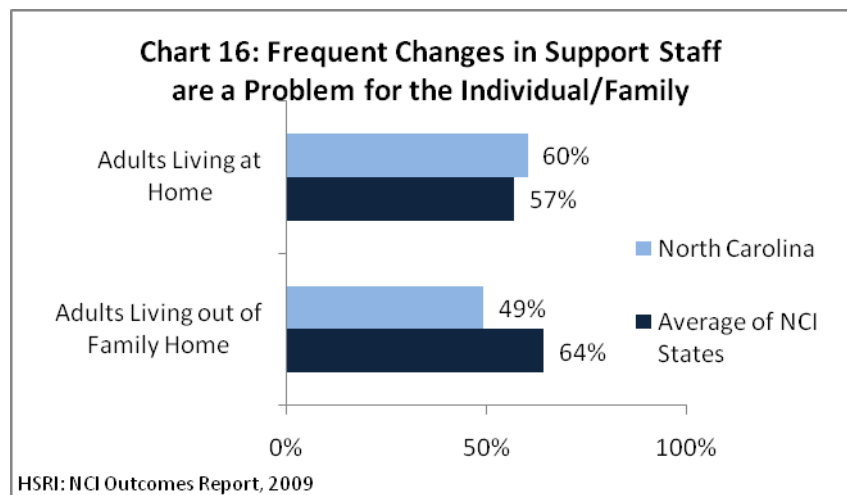
within any long-term service system.

North Carolina’s NCI results for key health indicators are, on the whole, consistent with national averages (see Chart 14). Two exceptions are vision screenings and hearing tests, where, in both areas, North Carolina results were significantly lower than the national average.

Looking at indicators of overall health, 7% of service recipients in North Carolina have “poor health”, significantly above the national average of 4%. Body mass index (BMI) is another indicator of overall health, measuring a person’s body fat based on their height and weight, and is applicable for both adult men and women. In North Carolina, BMI results indicate that 9% of service recipients with I/DD are underweight, 58% are overweight or obese, and 33% are at a normal or healthy weight. These results are consistent with national averages, with the exception of North Carolina’s “underweight” population (9%) which is nearly double the 5% national average (see Chart 15).



- Well-trained and stable workforce.** Conventional wisdom in North Carolina tells us that turnover rates among direct support workers are high, wages are low, and a strategy for assuring adequate training for workers is lacking. Results from NCI’s two family surveys reinforce the challenges that high





turnover rates pose for many service recipients and their families. Chart 16 illustrates that 49% to 60% of family respondents experienced staff turnover, causing problems for the individual with intellectual and other intellectual and other developmental disabilities or their family. These results are consistent with national NCI results, and with other national turnover rates for direct support workers providing in-home supports (50%) and residential supports (65%) for people with intellectual and other developmental disabilities.

In July 2010, under funding from the NC Council on Intellectual and other developmental disabilities, the North Carolina Providers Council produced the *North Carolina College of Direct Support Demonstration Project Final Report*, identifying the need for a statewide, systematic training curriculum for direct support professionals, and the results from a nine-agency demonstration project. The study concluded that test scores for knowledge in 27 key training areas rose an average of 24.5% for training participants, and that turnover in all but one agency decreased after participation.

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## Benchmark #5: Promoting Valued Outcomes

**Assessment:** North Carolina falls short of achieving outcomes for integrated employment, promoting healthy lifestyles and prevention of chronic diseases. The State operates competing community and institutional service systems. North Carolina supports fewer than one-third of individuals in community-based employment, oversees a high use rate of prescribed medication for behavior, and has demonstrated little success supporting service recipients to exercise at levels that result in health benefits. Nor has sufficient achievement been demonstrated supporting people to be in relationships beyond service providers, relationships that reduce risk of abuse and neglect, decrease loneliness and positively impact physical and mental health.

The delivery of intellectual and other developmental disabilities services should result in the achievement of valued outcomes for individuals and families -- outcomes such as living in community homes (discussed in previous chapters), integrated employment and maintaining optimal health. Service systems should be held accountable for achieving these outcomes for individuals and routinely be measured against performance benchmarks. The outcomes that a service system can achieve are impacted by the services that the system offers, the allocation of resources within the system, and the extent to which a state promotes the achievement of valued outcomes.

Integrated employment is an outcome valued by people receiving services. The positive effects on a person that employment offers (income to pay rent, self-esteem, opportunity for friendships and other relationships, etc.) has a profound impact on one's physical and mental health. Integrated employment basically means a workplace where a mix of people with and without disabilities are employed. Our federal government set a national goal in "Healthy People": to eliminate disparities in employment rates between working-aged adults with and without disabilities. The "Healthy People" initiative promulgated by the U.S. Department of Health and Human Services in November 2000 contains targeted, science-based performance objectives for promoting health and preventing disease.<sup>61</sup>

State performance on individuals with intellectual and other developmental disabilities in integrated employment shows wide variation. The Institute on Community Integration (ICI) collects information on state performance related to employment for people with intellectual and other developmental disabilities. ICI's data show that in some states relatively few people have community employment; in other states, 30 percent or more have integrated community jobs.<sup>62</sup> The state with the highest percent of individuals in services with integrated employment is Washington (87.5 percent). More typical high performing states are Connecticut and Oklahoma; both report 55 percent of service recipients with integrated employment.

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<sup>61</sup> U.S. Department of Health and Human Services, Healthy People: <http://www.healthypeople.gov/hp2020/>

<sup>62</sup> Institute for Community Inclusion (2009), State Data: the National Report on Employment Services and Outcomes 2008. [www.statedata.info](http://www.statedata.info)

State policies play a critical role in establishing a vision and direction for promoting achievement of valued outcomes. In Vermont, state officials set policy to limit and eventually prohibit the use of state funds to pay for day services in congregate sheltered workshops. This policy change resulted in a significant increase in the percentage of adults with integrated community jobs, nearly 55 percent. Another state, Florida, set a goal to secure integrated jobs for one-half of all individuals served in facility-based day programs and is moving toward achievement. Clearly, as service system leaders set direction to decrease facility-based work and non-work, integrated employment numbers grow.

Another valued outcome is the ability to maintain one's best possible health. Adults with intellectual and other intellectual and other developmental disabilities are more likely than adults without disabilities to lead sedentary lifestyles. This heightens their risk for diseases and chronic conditions resulting from substantial weight gain. In addition, people with intellectual and other intellectual and other developmental disabilities are less likely than people without disabilities to receive preventive health care such as cancer screenings and routine oral health care. Recognizing that people with disabilities experience higher morbidity and mortality rates than people without disabilities, the federal government included a new national goal in "Healthy People": to reduce the proportion of older adults with disabilities who use inappropriate medications. Even when taking medications appropriately, people with I/DD are at high risk for being prescribed medications with serious side effects, side effects that can lead to increased risk of falls and injury.

Also valued is being connected to others. Research shows that people who have close friendships report being happier and are physically and mentally healthier. "Healthy People" includes the objective to: increase the proportion of adults with disabilities reporting sufficient emotional support. Where people live and work impacts the nature and depth of connections to others and thus their emotional and physical health.

Information about the service system performance is necessary to ensure the effective delivery of services and tracking the achievement of valued outcomes for individuals. The National Core Indicators (NCI) provides states with tools not only to measure outcomes, but to benchmark performance over time within a state and compare with other states,<sup>63</sup> is the main source for data available around outcomes for individuals with intellectual and other intellectual and other developmental disabilities receiving services. South Dakota uses NCI to assess the performance of its community system and engage in quality improvement activities. Wisconsin and other states build the assessment of outcomes directly into their basic community agency quality review processes.

### **North Carolina Status**

DMH/DD/SAS leadership articulates a Vision and Guiding Principles that attest to valued outcomes for people receiving services and family members.<sup>64</sup> Guiding principles include

<sup>63</sup> National Core Indicators provides participating states with performance indicators on 101 system outcome measures. States receive reports on their individual performance as well as benchmarked against other participating states.

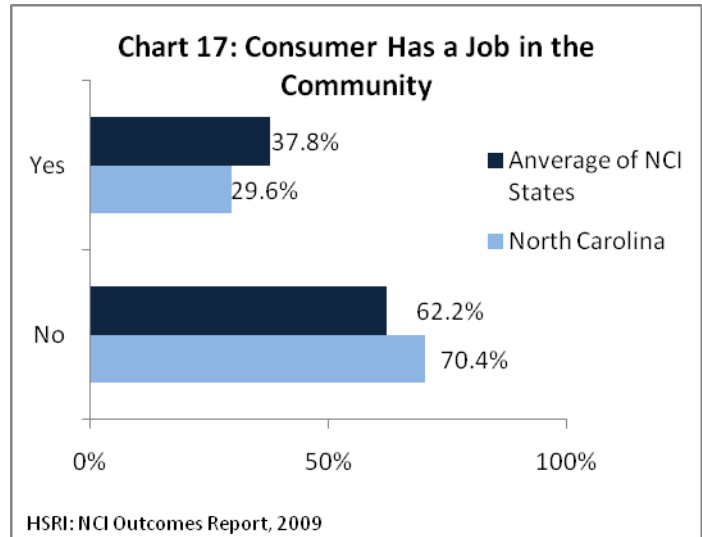
[www.nationalcoreindicators.org](http://www.nationalcoreindicators.org)

<sup>64</sup> DMHDDSAS State Strategic Plan 2010-2013.

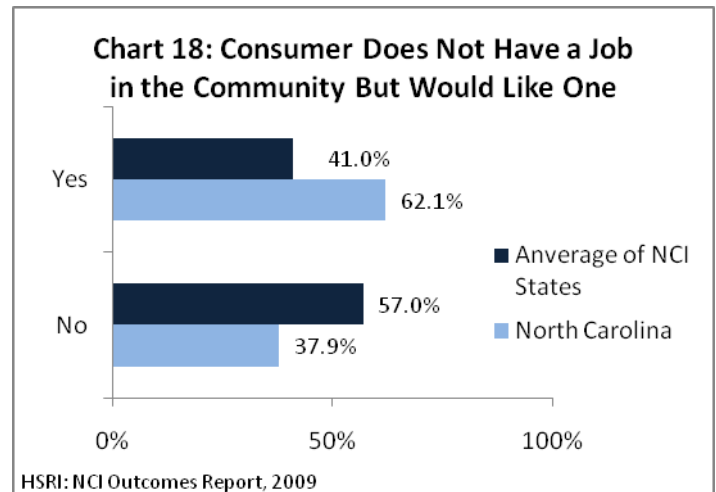
providing services that are participant-driven, community-based and prevention-focused. Through its participation in NCI, North Carolina collects data across the system on how individuals and families view access to services, assistance with planning services, service delivery, employment, housing, community integration, protection of rights, and the impact of services on their lives. North Carolina performance data, found in the latest NCI reports, offer important information on the outcomes of integrated employment, health indicators, and relationships.

**Integrated Employment**

NCI integrated employment data for North Carolina show that close to 30 percent of individuals receiving services have some amount of community-based work. This is progress, but is significantly below what other NCI states report (37.8 percent) for those of working age. See Chart 17 below.



A majority of adults that do not have community-based employment (62 percent) report they would like a job in the community. Chart 18 below illustrates the percent of individuals in North Carolina and in other NCI states who want integrated employment. North Carolina shows significantly more demand than individuals in other states. What the data doesn't tell us is whether this is because fewer people in North Carolina are employed, or because the option to work is more desired in this state, or both.



The Institute for Community Inclusion's national survey on employment reveals that in North Carolina most people in community-based settings are engaged in non-work (51 percent). Of those that do work, the majority of individuals do so in facility-based locations (45 percent). With respect to integrated work, North Carolina's performance approximates or is below national averages<sup>65</sup>.

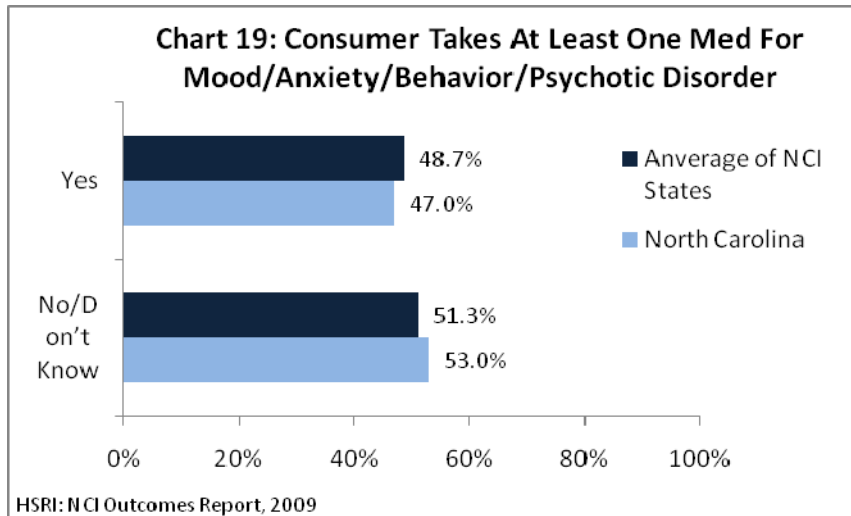
**Use of Prescribed Behavioral Medication**

The utilization of mood and behavior-altering psychotropic medications for individuals with intellectual and other intellectual and other developmental disabilities has reached alarming proportions.

<sup>65</sup> Butterworth, J. Smith, F., Hall, A., Migliore, A., and Winsor, J. State Data: The National Report on Employment Services and Outcomes; 2009. Institute for Community Inclusion (UCEDD). University of Massachusetts Boston. 2010.

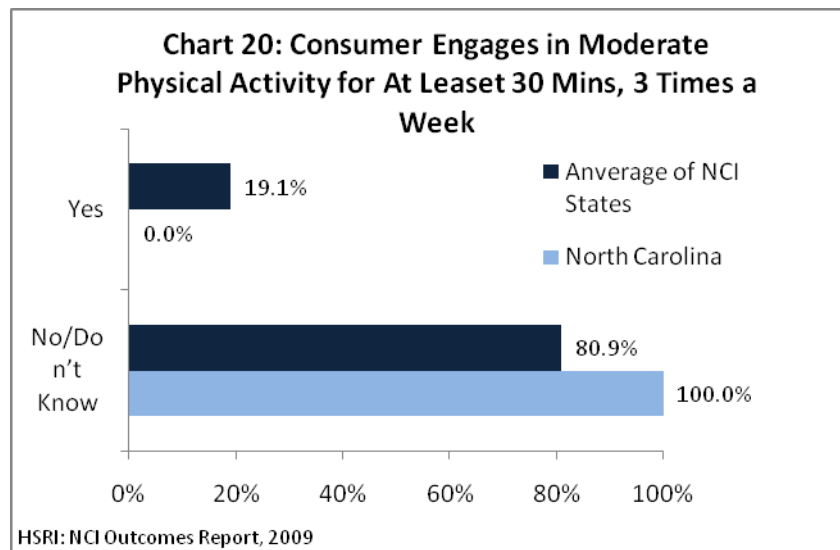
Nearly half (47%) of those receiving services in North Carolina are prescribed medications to control mood, anxiety and/or behavior. Sadly, this is not atypical, but akin to findings across all NCI states. (Refer to Chart 19.)

The question has been asked if where people live has a relationship to being prescribed mood and behavior altering medications. When NCI data is analyzed this way, we learn that the largest cohort of people who are prescribed psychotropic medications are those living in community group homes (67 percent



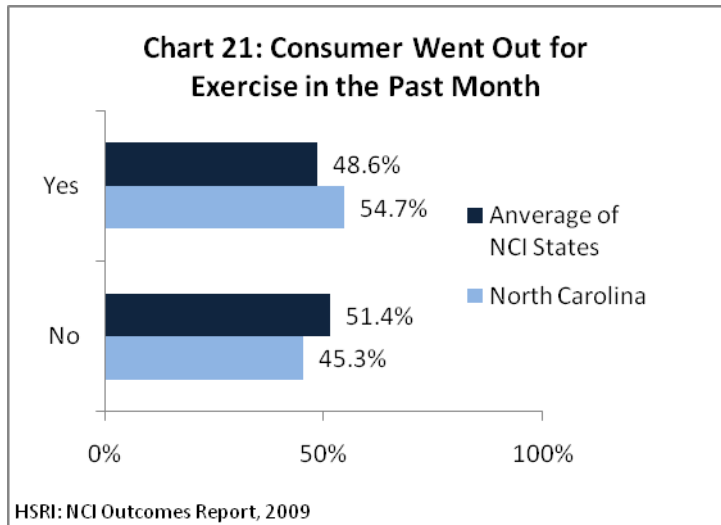
nationally). This raises the question of whether medication is prescribed for the person’s benefit and is truly needed, or if other environmental factors such as staff convenience may be an influence.

Even when medication is being closely monitored, the interactive effects and side effects of many of these medications are detrimental to overall health. A common side effect of medications taken to control mood, anxiety, or behavior is weight gain. The relationship between being overweight and increased health risks is well established. NCI data contains information on



individuals’ Body Mass Index, known as BMI. BMI is an estimate of body fat and used to gauge one’s risk for diseases that can occur with more body fat, diseases such as heart disease, high blood pressure, Type 2 diabetes, gallstones, breathing problems, and certain cancers. The majority of people in the intellectual and other developmental disabilities service system in North Carolina are either overweight (27 percent) or obese (30.8 percent).

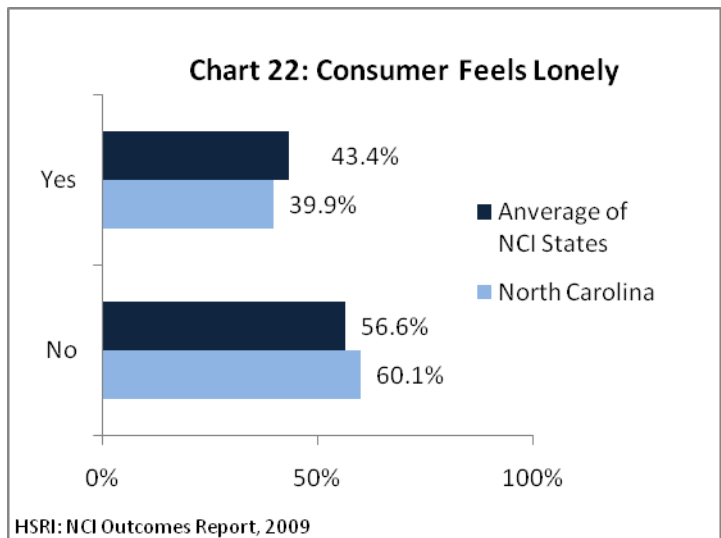
A contributing factor to taking medications with weight gain as a side effect is that so few people regularly exercise at an intensity level sufficient for health benefits. The most recent NCI data for North Carolina shows that 0% of individuals receiving services exercise at the federally recommended level of exercise to achieve health benefits – 30 minutes at least 3 times a week. See Chart 20. However, slightly over half of individuals receiving services do report exercising in the past month (54.7%). See Chart 21. On average, those who exercise do so at an average of 7.5 times a month.



North Carolina’s performance on supporting individuals to exercise regularly is slightly higher than other NCI participating states, though far below intensity and frequency requirements for achieving and maintaining one’s optimal health.

**Relationships**

As is true with all people, individuals with intellectual and other intellectual and other developmental disabilities need meaningful relationships in their lives. Though family relationships are very important, it is imperative that individuals have the ability to socialize with people outside of their family and provider networks. Research has clearly shown that connection to others positively impacts our physical and mental health. For those with I/DD, connection to those who are not service providers lessens the risk of abuse and neglect by those who are service providers.



NCI data shows that the majority of individuals receiving services in North Carolina are friends with people who are not family or staff (78.4 percent) and report they can see their friends when they want to (79.2 percent). This performance is reassuring, but as seen in Chart 22, a substantive cohort report they feel lonely some or most of the time (39.9 percent).

If we examine where people live who report being lonely, we learn that living in group settings increases loneliness. Insufficient data was collected from individuals in institutions to evaluate loneliness by this type of residence, but those residing in group homes in the community were

substantially more likely to express they felt lonely some or most of the time (47 percent) than those living in their own homes (35 percent) or living with family members (38 percent).

North Carolina's performance on supporting people to be in relationship with others is similar to other NCI participating states. All states have room for improvement in this area.



# Conclusions

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In several respects, the performance of North Carolina’s system of services for people with intellectual and other intellectual and other developmental disabilities is on par with most other states. For instance, the State matches the national average regarding the percentage of those served while living with family. Of those living in out-of-home residences, North Carolina also matches the national average regarding the percentage living in residences for 1-6 people. Likewise, regarding service quality, results generated through the State’s participation in the National Core Indicators project reveal that North Carolina places near the NCI average on many counts. In addition, we note that some interview respondents from across the state offered examples of innovative and promising practices.

We understand that individual experiences across the state likely vary. Some might complain about their services, while others might offer praise. Yet, overall, in several areas the State’s performance, while it could well be improved, is much like performance elsewhere.

In other respects, however, North Carolina’s system faces extraordinary challenges and has not kept pace with national trends or performance. To most in North Carolina, this observation is not surprising. Over the past several years, policy makers and stakeholders alike have been engaged in energetic discussion, sometimes disagreement, over policy-related direction and decisions.

We observe that:

- In North Carolina, the overall service system and policy direction for people with intellectual and other intellectual and other developmental disabilities has suffered for most of the past two decades from a **lack of definitive and unified leadership and vision**.. Many of those interviewed noted that contributing to this circumstance is the present administrative system structure within DHHS and MH/DD/SAS. Many argued that it is extraordinarily complex, so that structurally no one agency or person seems to be “in charge” of setting and implementing cohesive policy. Consider, that
  - DHHS retains four Deputy Secretaries or Assistant Secretaries, each with some responsibility for aspects of the intellectual and other developmental disabilities system. Meanwhile, several DHHS Divisions carry responsibility for different parts of the system.
  - DMA oversees the ICF/MR network, but facilities are licensed and regulated through the Division of Health Service Regulation.
  - The DSOHF has responsibility for managing the three developmental centers and two neuro-medical centers.
  - DMH/DD/SAS is responsible for managing Medicaid waiver services for people with I/DD, and other aspects of the community system, including the expansion of the 1915(b)(c) initiative.
  - 24 Local Management Entities, in turn, are charged with managing, coordinating, facilitating and monitoring the provision of intellectual and other developmental

disabilities services in the catchment area served. Not forgetting, the proposed consolidation of the LMEs under HB 916.

At its core, the mission of DHHS is as follows : “in collaboration with our partners, [DHHS] protects the health and safety of all North Carolinians and provides essential human services.” There is a need for a unified vision as to how this mission is carried out across state Divisions and LMEs for people with I/DD. Is the State committed to downsizing its census at its developmental centers, or not? Is the State committed to de-emphasizing its reliance on ICFs/MR, or not? Is the State committed to an “employment first” service response concerning day-time services, or not? Is the State committed to developing a strong in-home support system, including family supports, or not? Questions like these can easily ignite difficult discussion among policy makers and stakeholders.

Without clear direction, stakeholders are emboldened to politicize with hardened positions. For instance, some stakeholders want to see the service system change significantly to de-emphasize, even phase out, options associated with large congregate care. Meanwhile, others work hard to maintain the current array, contending that individuals should have available a full range of choices.

Inevitably, scarce resources, a unmet service demand and a lack of policy clarity fuels a contentiousness among stakeholders where no particular point of view gains a significant advantage.

Likewise, there is varying opinion about the state’s intent to utilize a 1915(b)(c) HCBS waivers to manage developmental disabilities services. Presently, the state operates a 1915(b)(c) waiver at PBH LME and is expanding it statewide by 2013. Some feel these actions are necessary for managing the service system more efficiently and effectively. Others argue the opposite, expressing considerable doubt about the approach and its impact on service recipients. Many issues pertaining to the design and implementation of a 1915 (b)(c) HCBS waiver statewide still must be addressed, leading very likely to continued unrest among policy makers and community stakeholders.

- The system **lacks capacity to respond to the needs of all those in need**, so that the present wait list is unsurprising and will likely grow. We note that:
  - In 2009, North Carolina spent \$104.85 per citizen for intellectual and other developmental disabilities services. The nationwide average (\$121.40 per citizen) was \$16.55 dollars, or 15.7 percent, per person higher.
  - North Carolina’s 2009 spending for intellectual and other developmental disabilities services would have had to have been \$155,253,630 higher to match the nationwide average.
  - Several interview respondents indicated that the system lacks capacity to respond to specialty service needs, especially regarding people with behavioral challenges.

- North Carolina serves 29 percent fewer people per 100k of population with Medicaid-financed services than the national average (151 in North Carolina<sup>66</sup> versus 213 per 100K population nationwide).
- For North Carolina to have served the national average of people per 100K population in 2009, the State would have had to provide services to roughly 5,750 more people in that year, or 62 people more per 100K of general population.
- The system's **extraordinary reliance on developmental centers and the ICF/MR option** in general is inconsistent with the Supreme Court's Decision in *Olmstead v. L.C.* and is inefficient. We note that:
  - 1,593 individuals resided in state-run developmental centers, or 17.0 individuals per 100K, compared to 10.7 nationally. The utilization rate for developmental centers in North Carolina is 57 percent higher than the national average.
  - In 2007, House Bill 1473 called for DHHS to "ensure that the downsizing of the State's Developmental Centers is based upon individual needs and the availability of community-based services with a targeted goal of four percent (4%) each year." The department has had great difficulty reaching this goal, given that even as individuals are discharged others are enrolled. Data presented by DHHS to the legislature reveals that from 2008-2010, the census for the three centers actually grew by 28 people. Looking back further, Lakin et al. (2010) reports that overall from 1998-2009 the census was reduced from 2,084 to 1593. Yet this amounts to 2.1%, about half of the targeted annual goal. When the census for neuro-treatment centers are factored in, Lakin et al. (2010) reports an overall decrease in census of 71 people in 2009, though 55 of this total were discharged due to death.
  - Between 1999-2008, North Carolina showed a steady decrease in the number of people with intellectual and other developmental disabilities served in nursing homes. However, between 2008 and 2009, the number reported has more than doubled from 400 in 2008 to 949 in 2009. In 2009 the State served 10.1 individuals per 100K of general population in nursing home facilities, compared to 7.7 nationally.
  - North Carolina provided residential services to 3,854 people in ICFs/MR and another 10,333 through HCBS waiver funding. In all, ICF/MR placements comprise 27 percent of those receiving residential services, compared to 14 percent nationally. ICF/MR use in North Carolina is nearly double the national average.
  - 1,798 individuals resided in community ICFs/MR. This amounts to 14.8% of the 12,131 served either in community ICFs/MR or receiving HCBS. This is more than twice the national average of 6.5%.

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<sup>66</sup> Again, to date, North Carolina has not furnished data to the University of Minnesota on the number of people receiving services in the Piedmont Behavioral Health (PBH) LME catchment area. All data presented from Lakin, et.al excludes individuals receiving services from PBH.

- 2,141 individuals, including the 1,593 in state-run developmental and neuro-medical centers, live in facilities of 16+ people. This amounts to 21.4% of all those receiving residential services in North Carolina. This compares to 13.6% nationally who receive residential services.
- Interview respondents indicated that initiatives to reduce reliance on ICFs/MR in favor of increased reliance on HCBS services continue to struggle for a variety of reasons, including (a) an absence of consensus state-level commitment to such change, (b) fiscal and administrative barriers to change, and (c) perceived weaknesses in the present HCBS waiver that dissuade ICF/MR providers from making the switch.
- North Carolina expended \$69,331 per person on average for HCBS and ICF/MR services. In 2009, the national average was \$57,126 per person. North Carolina spends 21.3 percent more per person than the national average.
- Average costs of service illustrate that the cost of serving an individual in a developmental center amounts to \$175,000 per year, compared to \$92,906 in a community ICF/MR and \$61,291 for CAP/MR-DD waiver services.
- Experience elsewhere suggests that any individual with intellectual and other developmental disabilities can be served within appropriate HCBS alternatives.
- Experience shows that among the 20 states with the lowest use of ICFs/MR, 17 have a lower cost per person than North Carolina. Eight of these states have no state institution.
- North Carolina, compared to other states, **falls short on a number of indicators** of service performance or quality. North Carolina state and local staff work hard to field a high quality service system. Yet, the State can improve performance in a variety of areas. We note that:
  - Interview respondents observe that the system lacks capacity to respond to specialty service needs, especially regarding people with behavioral challenges.
  - Most interview respondents agreed that while the future system will necessarily need to depend more heavily on people living at home with families for extended periods, the State needs to do more to improve its “in-home supports system.
  - The State falls short of achieving outcomes for integrated employment, promoting healthy lifestyles and prevention of chronic diseases. It also oversees use of a high use rate of prescribed medication for behavior. There also has not been sufficient achievement been demonstrated supporting people to be in relationships beyond care providers.

In the past four decades, the State has invested heavily in maintaining its developmental centers for people with intellectual and other developmental disabilities, as well as a network of community ICFs/MR. While it has steadily increased its investment in smaller, community-centered options funded through Medicaid HCBS waivers, present circumstances illustrate that the State is positioned to continue its historical reliance on legacy systems.

North Carolina is at a crossroads. Our findings indicate that there is some drive in the state to build on strategies that promote community integration and self-direction, and that there is a growing momentum among service recipients, family members, service providers and others in support of such change.

Change, however, will not come easy. As illustrated above, there are numerous contextual factors in play that inhibit the State's capacity to make significant speedy change. Certainly, the idea that legacy options might be phased out in favor of various community alternatives is a proposition that is met with enthusiasm from some stakeholders and resistance from others.