

Where  
Does  
North  
Carolina  
Stand?

1998-2008

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A COMPARISON OF MEDICAID-FUNDED RESIDENTIAL SERVICE  
TRENDS, NATIONALLY AND IN NORTH CAROLINA, FOR PEOPLE  
WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

PREPARED FOR  
THE NORTH  
CAROLINA  
COUNCIL ON  
DEVELOPMENTAL  
DISABILITIES

# **Where Does North Carolina Stand?**

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AND IN NORTH CAROLINA, FOR PEOPLE WITH INTELLECTUAL AND  
DEVELOPMENTAL DISABILITIES

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**Prepared for:**

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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 on Developmental Disabilities. The authors would like to acknowledge the contributions of Michael Mayer and Charlie Lakin.

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## INTRODUCTION

This is the fourth edition of *Where Does North Carolina Stand?* This paper provides a review of the trends in Medicaid-funded residential service utilization, residential living arrangements and service expenditures over the past decade (1998 – 2008), both nationally and within North Carolina.

The original version of this report was prepared by Gary Smith, and released in 1997 as an appendix to a report entitled, *Choice, Change and Community*. In 1998 and 1999, updates were prepared on behalf of the North Carolina Council on Developmental Disabilities, which also sponsored the preparation of *Choice, Change and Community*.

The statistics contained in this report are drawn from two national data sets.

- The first is data compiled by the University of Minnesota's Research and Training Center on Community Living (RTCCL). Each year RTCCL researchers conduct an in-depth survey to compile both nationwide and state-by-state data concerning residential and other related services for people with developmental disabilities. The RTCCL data contained here is from the Center's most recent report: K. Charlie Lakin, Sheryl Larson, Pat Salmi & Naomi Scott (Eds.) (2009). Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2008<sup>1</sup>. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. (Cited in this report as Lakin et al., 2008).
- The second source of data is the biennial survey of state expenditures for developmental disabilities services that is conducted by the Department of Psychiatry and the Coleman Institute for Cognitive Disabilities at the University of Colorado. This information is contained in: David Braddock, Richard Hemp and Mary C. Rizzolo (2008). The State of the States in Developmental Disabilities 2008. Washington DC: American Association on Intellectual and Developmental Disabilities.

"Where Does North Carolina Stand?" provides updated information concerning the scope of publicly-funded services for the state's citizens with intellectual and developmental disabilities (I/DD)<sup>2</sup>. To lend perspective to this information, comparisons are made between North Carolina and the nation as a whole. The report's aim is to provide stakeholders a picture of North Carolina's developmental disabilities service system to inform their discussions concerning the direction the service system might take in the future.

The report begins by looking at utilization patterns for developmental disabilities services in North Carolina and the United States as a whole. Next, information is furnished concerning residential services. Attention then turns to how Medicaid dollars are used to pay for services and supports.

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<sup>1</sup> Information pertaining to the Piedmont Behavioral Health Local Management Entity was not included in this data set. As a result, about 1,000 individuals receiving services are not accounted for in tabulations presented in this report.

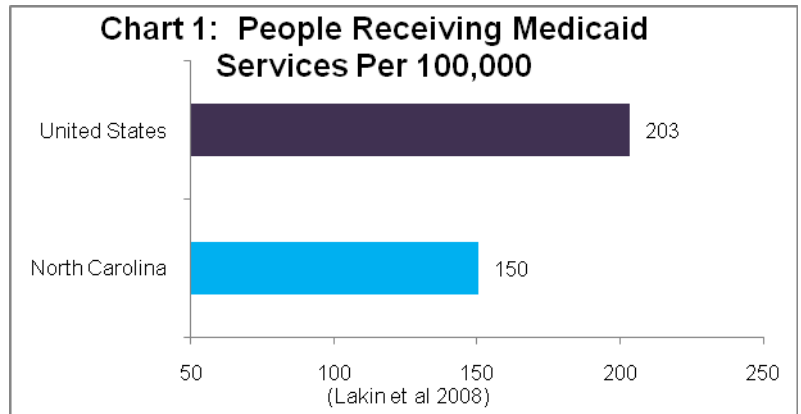
<sup>2</sup> Intellectual and Developmental Disabilities (I/DD) are disabilities characterized by significant limitations both in intellectual functioning and in adaptive behavior, which cover many everyday social and practical skills. Federal and state definitions vary slightly. The federal and North Carolina definitions can be found at the following site: <http://www.ncddc.org/home/definition.html>.

## SERVICE UTILIZATION PATTERNS

From 2000 to 2008, North Carolina added 3,992 people receiving Medicaid-funded services to its developmental disabilities service system, or about 499 per year. As shown in **Table 1**, this equals 40.4% growth over the 8-year period, but lags behind the average growth in other states (51.7%) by approximately 11%.

| North Carolina            |                          |                                     |                | United States            |                                     |                |
|---------------------------|--------------------------|-------------------------------------|----------------|--------------------------|-------------------------------------|----------------|
| Year                      | Total Service Recipients | # of People Added to Service System | Percent Change | Total Service Recipients | # of People Added to Service System | Percent Change |
| 2000                      | 9,884                    | N/A                                 | N/A            | 407,696                  | N/A                                 | N/A            |
| 2001                      | 10,634                   | 750                                 | 7.6%           | 441,839                  | 34,143                              | 8.4%           |
| 2002                      | 10,658                   | 24                                  | 0.2%           | 484,818                  | 42,979                              | 9.7%           |
| 2003                      | 10,192                   | -466                                | -4.4%          | 508,969                  | 24,151                              | 5.0%           |
| 2004                      | 9,886                    | -306                                | -3.0%          | 526,921                  | 17,952                              | 3.5%           |
| 2005                      | 11,059                   | 1,173                               | 11.9%          | 545,429                  | 18,508                              | 3.5%           |
| 2006                      | 11,922                   | 863                                 | 7.8%           | 577,656                  | 32,227                              | 5.9%           |
| 2007                      | 13,433                   | 1,511                               | 12.7%          | 597,916                  | 20,260                              | 3.5%           |
| 2008                      | 13,876                   | 443                                 | 3.3%           | 618,283                  | 20,367                              | 3.4%           |
| Difference from 2000-2008 | 3,992                    |                                     | 40.4%          | 210,587                  |                                     | 51.7%          |

Service use patterns can also be viewed in terms of how many individuals receive services per 100,000 (100K) in population. North Carolina furnished Medicaid-funded services (i.e., Home and Community Based Service (HCBS) waivers and Intermediate Care Facilities for People with Mental Retardation (ICFs/MR)) to 13,876 individuals in 2008<sup>3,4</sup>. Given a state population of 9,222,414, this totals 150 people per 100,000 general



population. The national average is 203 per 100,000 (**Chart 1**), leaving North Carolina 26% below this national marker. To reach the national average, North Carolina would have to serve 53 people per 100,000 more than it does, or 4,887 people. One may note that our experience shows that states serving about 300 people/100,000 come closest to having no wait-list for services.

<sup>3</sup> An ICF/MR is a facility that serves 4 or more individuals. For a facility to be certified as ICF/MR and thereby become eligible for Medicaid payments, it must comply with an extensive set of federal regulations and requirements. The home and community-based services (HCBS) waiver program waiver was established in 1981. It allows states to waive specified requirements of Section 1915 of the Social Security Act so that states may develop community-based alternatives to ICFs/MR.

<sup>4</sup> Note, this count does not include individuals receiving supports in the home of a family member, or individuals receiving state-only dollars. MHDDAS reported that overall 25,106 individuals received services in residential or family home settings in 2008.

## RESIDENTIAL PATTERNS

Residential services claim the majority of state expenditures for developmental disabilities services. In 1982, the majority of residential services in the United States were furnished in large, state-operated residential facilities. Since then, states have been shifting residential services away from larger congregate settings to smaller living arrangements in the community. Nationwide, in 2008, states provided residential services to 436,866 individuals. Of this total, 47,389 (11%) were in facilities of 16 or more people with most (35,035) living in large state-operated facilities. Complementing this trend, states have fostered the provision of services in living arrangements that are owned or rented by people with intellectual and developmental disabilities rather than in facilities or sites that are controlled by provider agencies. In fact, nationally 27% of those receiving residential services own or lease their own home, compared to 16% in North Carolina.

### Residential Services - Overall

Residential services include not only large state-operated facilities but also other Medicaid-funded “community” ICFs/MR, Alternate Family Living, other group-living arrangements, and supports furnished to an individual who lives in his or her own home. **Table 2** shows the number of North Carolinians with intellectual and developmental disabilities who received publicly funded residential services (including North Carolina’s institutional settings referred to as “State Developmental Centers” and “Neuro-Medical Treatment Centers,”<sup>5</sup> from now on referred to as “Centers” in this report) on June 30 of each year during the period 1998 - 2008 and comparable figures for the nation as a whole.

| Year                      | North Carolina             | Per 100,000 Population | United States | Per 100,000 Population |
|---------------------------|----------------------------|------------------------|---------------|------------------------|
| 1998                      | 7,485                      | 99                     | 348,264       | 129                    |
| 1999                      | 7,753                      | 101                    | 361,172       | 132                    |
| 2000                      | 11,329                     | 141                    | 374,595       | 133                    |
| 2001                      | 11,857                     | 145                    | 387,745       | 136                    |
| 2002                      | 12,188                     | 147                    | 392,740       | 136                    |
| 2003                      | 12,466                     | 154                    | 402,281       | 143                    |
| 2004                      | 11,861                     | 139                    | 420,202       | 143                    |
| 2005                      | 11,932                     | 137                    | 411,215       | 139                    |
| 2006                      | 12,058                     | 136                    | 424,462       | 142                    |
| 2007                      | 11,834                     | 131                    | 437,707       | 145                    |
| 2008                      | 10,581                     | 115                    | 436,866       | 144                    |
| <b>% Change 1998-2000</b> | <b>+ 41.3%<sup>6</sup></b> | <b>+16.2%</b>          | <b>+25.4%</b> | <b>+11.6%</b>          |

<sup>5</sup> North Carolina’s five large state-operated facilities are the Black Mountain and O’Berry Neuro-Medical Treatment Centers and the Caswell, Murdoch, and J. Iverson Riddle Developmental Centers.

<sup>6</sup> Between 1998 and 2003 North Carolina’s out-of-home placement utilization increased quickly, peaking at 154 per 100K in 2003. Since then, it has cycled down, reaching 115 per 100K in 2008.

The figure shows that the number of individuals who received out-of-home residential services in North Carolina grew considerably over this period and at a brisker rate than the nation as a whole (i.e., 41.3% growth in NC compared to 25.4% nationally). The table also indexes these services to population (i.e., the number of people receiving these services per 100,000 general population) and also reveals growth at a quicker pace than nationally (16.2% to 11.6%).

### **Waiting for Residential Services**

Like elsewhere, over a ten year period, North Carolina achieved a net increase in the availability of residential services relative to population. Yet, despite such growth, as illustrated above, North Carolina furnishes residential services per 100,000 in population to fewer individuals than nationally (i.e., 115 per 100,000 population in North Carolina to 144 nationally). We note, however, that between 1999 and 2003, the expansion of residential services in North Carolina exceeded the rate of state population growth, and surpassed the nation's average service rate. Since then, North Carolina has slowed its pace of growth so that by 2008, the gap per 100,000 population in residential services between North Carolina and the nation was unchanged from 1998 and 2008. The nation serves about 30 people more per 100,000 population than does North Carolina. Given the state population of 9.2 million, to reach the national average in residential service use in 2008 about 2,675 additional individuals would need to be provided such services.

More specific to expressed service demand in North Carolina, in 2007, the State provided an estimate to the University of Minnesota that 1,350 people with intellectual and developmental disabilities had been identified as needing residential services but had been "wait-listed" because such services were not available<sup>7</sup>. Given that North Carolina provided residential services to 10,581 people in 2008, the need to serve these additional 1,360 people amounts to a shortfall in capacity of about 13%. Nationwide, the shortfall in residential service capacity was 26.0%.

There are North Carolinians with intellectual and developmental disabilities waiting for other types of services as well. According to the Arc of North Carolina, approximately 5,000 individuals are waiting for developmental disability services, residential or otherwise.

To gather more accurate waiting list data, the North Carolina Legislature passed legislation in 2009 requiring Local Management Entities (LMEs) to

"develop a waiting list of persons with intellectual or developmental disabilities that are waiting for specific services...[and] 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-MRDD.
- c. In need of other services and supports funded from State appropriations to or allocations from the Division of Mental Health, Developmental Disabilities, and Substance Abuse Services, including CAP-MRDD."

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<sup>7</sup> Note, the state did not furnish waitlist data for 2008.

**Large State-Operated Centers**

The number of individuals served in large, state-operated facilities has been declining in the United States for more than 30 years. These facilities are routinely operated as ICFs/MR. In 2008, eight states (AK, HI, ME, NH, NM, RI, VT, WV) and the District of Columbia had no large (16+) state-operated facilities, with several other states approaching this mark. In fact, in 2010 Oregon joined these states and became the first with none of its citizens residing in ICFs/MR of any size. Typically, these services are the most costly that a state provides, averaging in 2008 over \$500/day/resident nationally and \$481 in North Carolina.

**Table 3** shows the number of individuals served in North Carolina’s Centers over the period 1998 - 2008 and comparable nationwide figures. As shown, the number of individuals served in North Carolina’s Centers declined steadily between 1998 and 2008. Nationally, over this period the number dropped by 32%. However, in North Carolina, the decline was 20%. Additionally, over the past several years, the Center population has remained constant at about 1,650 people.

| Year             | North Carolina | Percent Change | United States  | Percent Change |
|------------------|----------------|----------------|----------------|----------------|
| 1998             | 2,057          | N/A            | 52,469         | N/A            |
| 1999             | 1,995          | -3.0%          | 50,094         | -4.5%          |
| 2000             | 1,939          | -2.8%          | 47,592         | -5.0%          |
| 2001             | 1,893          | -2.4%          | 46,236         | -2.8%          |
| 2002             | 1,885          | -0.4%          | 44,236         | -4.3%          |
| 2003             | 1,863          | -1.2%          | 43,289         | -2.1%          |
| 2004             | 1,801          | -3.3%          | 42,120         | -2.7%          |
| 2005             | 1,736          | -3.6%          | 40,532         | -3.8%          |
| 2006             | 1,675          | -3.5%          | 38,810         | -4.2%          |
| 2007             | 1,663          | -0.7%          | 37,172         | -4.2%          |
| 2008             | 1,651          | -0.7%          | 35,741         | -3.8%          |
| <b>1998-2008</b> | <b>-406</b>    | <b>-20%</b>    | <b>-16,728</b> | <b>-32%</b>    |

Shown another way, **Table 4** illustrates utilization rates of these facilities in terms of the number served per 100,000 population in 1998 and 2008. The table reveals that the rate in North Carolina decreased by 33% during the period (27.3 to 18.1 people/100,000). Nationally, the rate dropped by 41% (19.4 to 11.5 people/100,000). Overall, then, it is apparent that while North Carolina has steadily reduced its census, it has done so at a pace slower than the national average and maintains a significant number of people in large, state-operated facilities.

| Year | North Carolina | United States | North Carolina's<br>Difference in Utilization |
|------|----------------|---------------|---|
| 1998 | 27.3           | 19.4          | +40%  |
| 2008 | 18.1           | 11.5          | +57%  |

**Children in Large, State-Operated Facilities**

Nationwide, the population of children ages 0-21 in state centers has remained virtually constant since 1998 at 4%- 5% of the overall census (see **Table 5**). In North Carolina, while the percentages are lower than the national average, the trend shows growth – from 0% to 3% - over the past decade. In 2008 about 46 individuals aged 0-21 years resided in large state-operated facilities. Some, if not all, of this growth may have resulted from reclassifying a facility for children as an ICF/MR and placing it within the auspices of Murdoch Developmental Center<sup>8</sup>.

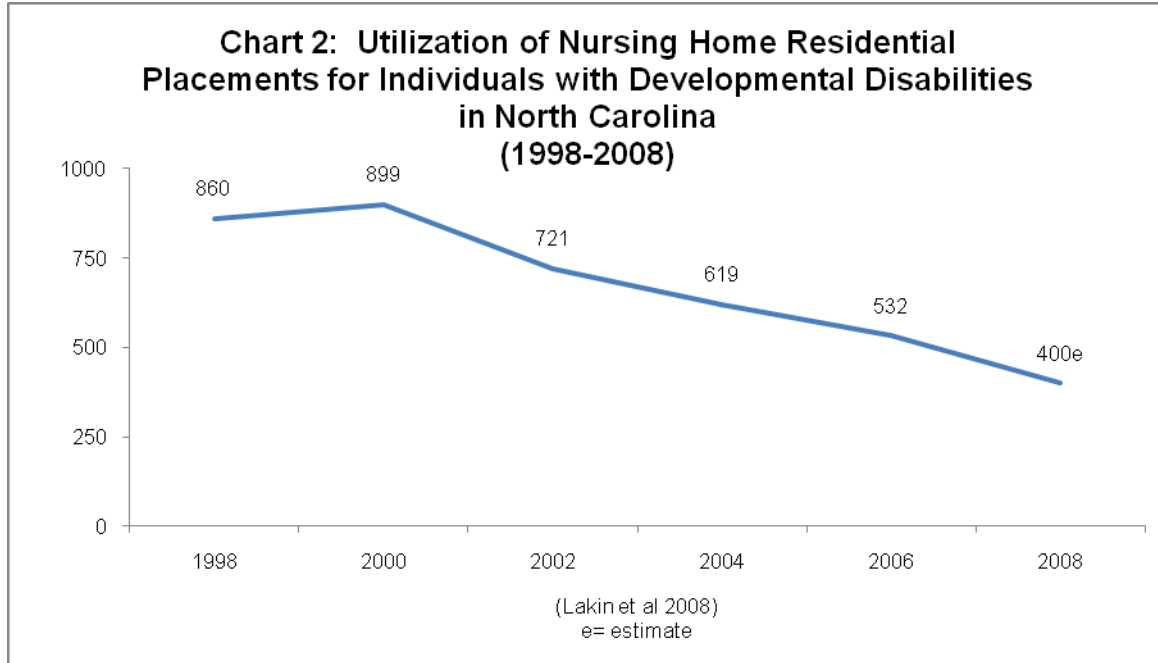
| Year | North Carolina | United States |
|------|----------------|---------------|
| 1998 | 0%             | 5%            |
| 2000 | 1%             | 4%            |
| 2002 | 2%             | 5%            |
| 2004 | 2%             | 4%            |
| 2006 | 2%             | 4%            |
| 2008 | 3%             | 5%            |

**Nursing Home Facilities**

The foregoing statistics do not include people with intellectual and developmental disabilities who reside in nursing facilities. Nursing home facilities provide long-term care and assistance with activities of daily living; patients in nursing homes do not require skilled nursing care on a daily basis. Medicaid or private insurance pays for nursing home stays with no statutory limits on duration. Over the past decade, utilization of nursing facilities has decreased at a quicker pace than in other states. In 2008, an estimated 400 people with intellectual and developmental disabilities were served in nursing facilities in North Carolina. It was about half as likely that a person with a developmental disability will be served in a nursing facility in North Carolina than in other states. When nursing facility and developmental disabilities residential services are

<sup>8</sup> MHDDSAS staff supplied the following information regarding children in large, state operated facilities. "In 2008, about 46 individuals aged 0-21 received services in state-operated developmental centers. Most of these individuals received services in the two, statewide, time-limited specialty programs at Murdoch Developmental Center. The Partners in Autism Treatment and Habilitation (PATH) program serves children with autism spectrum disorders and severe behavioral challenges. The Specialized Treatment for Adolescents in a Residential Setting (STARS) program serves adolescents who have a dual diagnose (developmental disabilities and mental illness) and demonstrate extreme behaviors. In keeping with its goal of short-term therapeutic treatment, the length of stay in PATH is two years while the length of stay in STARS is one year."

combined, a lesser percentage (about 3.6%) of North Carolinians with intellectual and developmental disabilities who receive a residential service of any type are served in nursing facilities than nationwide, where the percentage is 5.6%. This shows improvement over 1998, when North Carolina had a higher percentage (about 10%) to the nation's 6.7% average.<sup>9</sup>



### Community Residential Services

There is a particularly wide difference between North Carolina and the rest of the nation in terms of the availability of Medicaid-funded community residential services outside large state-operated facilities. Nationwide in 2008, residential services outside large state-operated facilities were furnished at the rate of 144 individuals per 100,000 population. In North Carolina the rate was 115 people per 100,000 population or roughly 20% less.

Over the past three decades, there has been a major shift in the provision of residential services away from larger congregate settings to smaller living arrangements. In 1977 nationwide, the average residential setting served 22.5 individuals; by 1998, the average had dropped to 3.3 individuals per site; and by 2008; the average had dropped further to 2.5. **Table 6** shows the distribution in North Carolina and nationwide of individuals receiving Medicaid-funded residential services by size of the facility or living arrangement in 1998 and 2008:

In 2008, the proportion of individuals receiving residential services in smaller (1-6 person) living arrangements was the same in North Carolina as the nation as a whole (74%). We note, however, that 21.7% of these residents live in ICFs/MR compared to 5.4% nationally.

<sup>9</sup> The data pertaining to nursing home facilities reflects aggregate figures offered to the University of Minnesota by state developmental disabilities staff. At this time, it is unclear if these numbers are inclusive of individuals residing in the neuro-medical centers, or receiving adult care home services.

North Carolina also served a considerably larger proportion of individuals in large congregate (16+ people) facilities. Overall, North Carolina followed the general national trend of shifting residential services to smaller, community living arrangements. However, in 2008, it was more common for North Carolinians with intellectual and developmental disabilities to be served in larger living arrangements than their counterparts in other states.

| <b>Table 6</b><br>Distribution of Individuals Receiving Residential Services<br>by Size of Living Arrangement (1998 and 2008)<br>(Lakin et al 2008) |                   |                     |               |                     |
|---|-------------------|---------------------|---------------|---------------------|
| Year/Setting  | North Carolina    | Percentage of Total | United States | Percentage of Total |
| 1998  |                   |                     |               |                     |
| 1-6 Beds  | 4,393             | 58.7%               | 204,571       | 58.7%               |
| 7-15 Beds   | 484               | 6.5%                | 54,474        | 15.6%               |
| 16+ Beds  | 2,608             | 34.8%               | 89,234        | 25.6%               |
| 2008  |                   |                     |               |                     |
| 1-6 Beds  | 7,852             | 74.2%               | 325,425       | 74.6%               |
| 7-15 Beds   | 528 <sup>10</sup> | 5.0%                | 53,424        | 12.2%               |
| 16+ Beds <sup>11</sup>  | 2,201             | 20.8%               | 57,462        | 13.2%               |
| % Change 1998-2008  |                   |                     |               |                     |
| 1-6 Beds  | 78.7%             |                     | 59.1%         |                     |
| 7-15 Beds   | 9.1%              |                     | -1.9%         |                     |
| 16+ Beds  | -15.6%            |                     | -35.6%        |                     |
| Average Number of People Per Setting - 2008   | DNF               |                     | 2.5           |                     |

**ICF/MR Services**

One avenue for securing federal Medicaid funding of specialized residences for people with intellectual and developmental disabilities is to certify such facilities as Intermediate Care Facilities for People with Mental Retardation (ICFs/MR). Starting in 1993, the utilization of ICF/MR services nationwide began to decline. This decline reflected both the ongoing downsizing and closure of large state-operated facilities (most of which are certified as ICFs/MR) and more recently the conversion of a growing number of private ICF/MR facilities to

<sup>10</sup> The University of Minnesota published that 528 individuals received Medicaid-funded residential services in homes with between 7-15 beds. State staff, however, report after reviewing a draft of this report that only 171 individuals resided in 7-15 bed homes.

<sup>11</sup> The numbers in this table differ from the numbers presented in Table 3 of this report, with these numbers being higher. In this table the numbers represent individuals living in both private and public large residential facilities. In North Carolina this difference is represented by an additional 550 individuals living in private large (16+) ICFs/MR.

funding under the HCBS waiver program. Due to both cost and programmatic considerations, most states have been reducing the role that ICFs/MR play in their service systems.

**Table 7** below shows the number of individuals who received Medicaid-funded ICF/MR services in North Carolina and nationwide during the period 1998 - 2008 as well as utilization indexed to population.

As shown, during this period the number of people served in ICFs/MR in North Carolina fell by 11% overall and 28% with respect to state population. This decline in ICFs/MR use is consistent with the trend nationwide. However, in 2008, about 45% more individuals were served in ICFs/MR in North Carolina relative to population than nationwide<sup>12</sup>.

| Year           | North Carolina | Per 100,000 Population | United States | Per 100,000 Population |
|----------------|----------------|------------------------|---------------|------------------------|
| 1998           | 4,705          | 62                     | 124,258       | 46                     |
| 1999           | 4,616          | 60                     | 117,917       | 43                     |
| 2000           | 4,520          | 56                     | 116,441       | 41                     |
| 2001           | 4,493          | 55                     | 113,907       | 40                     |
| 2002           | 4,645          | 56                     | 110,572       | 38                     |
| 2003           | 4,500          | 56                     | 107,065       | 38                     |
| 2004           | 3,875          | 45                     | 104,526       | 36                     |
| 2005           | 4,306          | 50                     | 101,821       | 34                     |
| 2006           | 4,091          | 46                     | 98,411        | 33                     |
| 2007           | 4,124          | 46                     | 96,427        | 32                     |
| 2008           | 4,176          | 45                     | 93,164        | 31                     |
| Percent Change | -11%           | -28%                   | -25%          | -32%                   |

### HCBS Waiver Services

The second major avenue available to states to secure federal Medicaid funding for specialized developmental services is the home and community-based services (HCBS) waiver program. Individuals who are eligible for ICF/MR services may instead be offered HCBS waiver alternative services. The eligibility criteria are the same. The HCBS services may be provided to individuals who are served in licensed residences, live in their own homes, or live with their

<sup>12</sup> Note that these data do not represent children receiving out-of-home placement options in private community ICF/MR facilities. Children ages 0-21 are only counted in the University of Minnesota's database in regard to state-operated institutional settings.

families. North Carolina first gained federal approval in 1983 to operate an HCBS waiver program for people with intellectual and developmental disabilities. The HCBS program offers a wide array of services.

**Table 8** shows the number of individuals with intellectual and developmental disabilities who participated in the HCBS program each year between 1998 and 2008 as well as the nationwide total number of participants in similar waiver programs. In each case, the table also shows the number of participants indexed relative to population.

As can be seen from the table, between 1998 and 2008, the number of individuals receiving HCBS waiver services in both North Carolina and nationwide more than doubled. The rate of growth in the number of people served through North Carolina’s HCBS program has been slightly greater than the rate of growth in HCBS waiver programs nationwide.

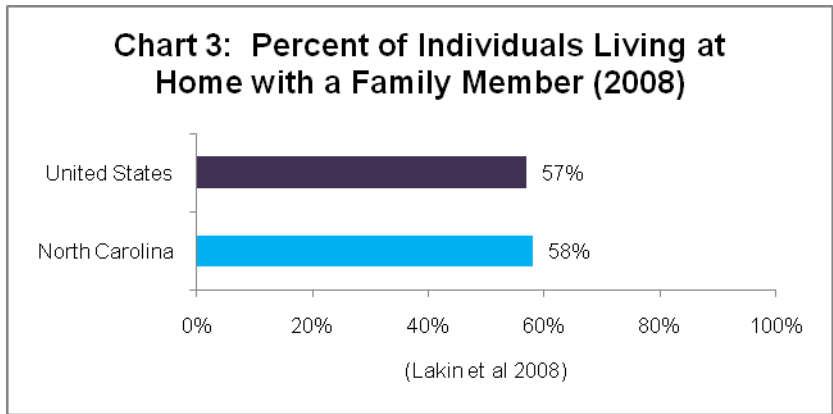
Relative to population, however, North Carolina provided HCBS waiver services to 105 people per/100,000 population compared to 173/100,000 nationally, or 39% fewer individuals. To reach the national average, North Carolina would have needed to serve 6,255 additional individuals through the HCBS waiver program.

| Year           | North Carolina | Per 100,000 Population | United States | Per 100,000 Population |
|----------------|----------------|------------------------|---------------|------------------------|
| 1998           | 3,986          | 53                     | 239,077       | 89                     |
| 1999           | 4,974          | 65                     | 261,930       | 96                     |
| 2000           | 5,364          | 67                     | 291,255       | 103                    |
| 2001           | 6,141          | 75                     | 327,932       | 115                    |
| 2002           | 6,013          | 72                     | 374,246       | 131                    |
| 2003           | 5,692          | 71                     | 401,904       | 143                    |
| 2004           | 6,011          | 70                     | 422,395       | 145                    |
| 2005           | 6,753          | 78                     | 443,608       | 150                    |
| 2006           | 7,831          | 88                     | 479,245       | 160                    |
| 2007           | 9,309          | 103                    | 501,489       | 166                    |
| 2008           | 9,700          | 105                    | 525,119       | 173                    |
| Percent Change | 143%           | 99%                    | 120%          | 95%                    |

**Individuals Living at Home**

Nationwide, states furnish in-home services and supports to more individuals who live with their families than are provided in specialized “out-of-the-family-home” residential facilities. In 2008, North Carolina officials reported that these in-the-family-home services were furnished to about 58% of the service population, or 14,525 individuals living with their families.

This compares to a smaller 10,581 individuals (42%) who received any residential services outside the family home in North Carolina. These percentages are consistent with what is happening in other states.



## EXPENDITURE PATTERNS

### Medicaid Funded Services

Nationwide, the single most important source of federal funding for the specialized services and supports that states furnish or purchase on behalf of people with intellectual and developmental disabilities is the Medicaid program. Through the Medicaid program, the federal government financially shares in meeting the costs of various types of services. In the case of North Carolina, the 2008 federal financial participation rate in Medicaid-reimbursable services is 64.05%<sup>13</sup>. In other words, for each \$1 spent on a Medicaid qualified service, about 64¢ is paid by federal Medicaid funds and 36¢ by the State of North Carolina.

In 2008, state-federal Medicaid payments accounted for roughly 78% of all dollars spent nationwide on developmental disabilities services (Coleman Institute). In North Carolina, the proportion was about the same - about 77%.

The two main Medicaid program categories used by North Carolina (and other states) to secure Medicaid funding for specialized developmental disabilities services are the ICF/MR and HCBS programs. In 2008, North Carolina's spending for these two programs in combination totaled \$919.8 million; federal payments to the state for these services came to \$588.7 million. Clearly the Medicaid programs play a critical role in underwriting developmental disabilities services in North Carolina. In the following sections, information is furnished concerning each of these programs individually and in combination.

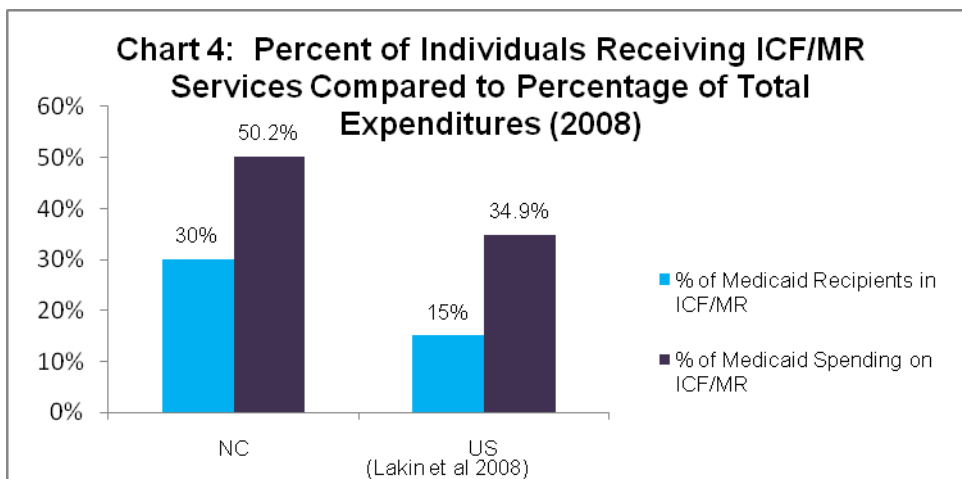
### ICF/MR and HCBS Waiver Services in Combination

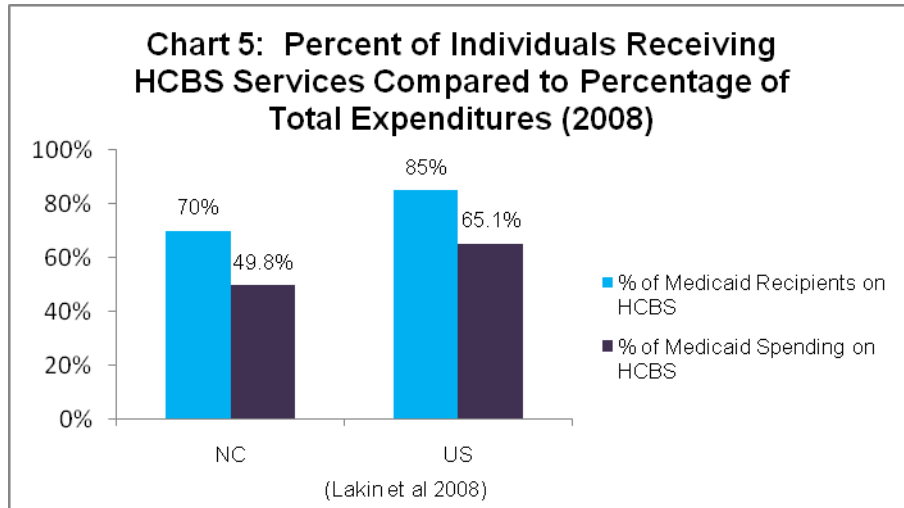
The same eligibility criteria apply in determining the eligibility of an individual for either ICF/MR or HCBS waiver services. In other words, both programs are intended to serve the same population. Therefore, in examining how Medicaid dollars are used in support of individuals with intellectual and developmental disabilities, it is useful to examine both programs in combination.

<sup>13</sup> Note that the Federal reimbursement rates were increased beginning in October 2009 to reflect additional Medicaid funding available under Section 5001 of the American Recovery and Re-investment Act of 2009. In 2010 the NC reimbursement rate is 71.33%

**Table 9** and **Charts 4 and 5** illustrate information concerning HCBS waiver and ICF/MR services in North Carolina and nationwide. These graphics show that between 1998 and 2008, North Carolina's spending for Medicaid services for people with intellectual and developmental disabilities grew 79%, increasing at a rate 24% slower than the nation as a whole. The number of individuals who received either ICF/MR or HCBS services grew by 60% during this period. Nationwide, the increase was greater at 70%. In 2008, nationwide, nearly 85% of individuals who received Medicaid funded services were served through the HCBS waiver program. In North Carolina, the proportion was significantly lower - about 70%.

| <b>Table 9</b><br>ICF/MR & HCBS Waiver Services<br>(Lakin et al 2008) |                 |            |                |            |
|---|-----------------|------------|----------------|------------|
|   | North Carolina  | % of Total | United States  | % of Total |
| Recipients - 1998   | 8,691           |            | 363,335        |            |
| ICF/MR  | 4,705           | 54%        | 124,258        | 34%        |
| HCBS  | 3,986           | 46%        | 239,077        | 66%        |
| Recipients - 2008   | 13,876          |            | 618,283        |            |
| ICF/MR  | 4,176           | 30%        | 93,164         | 15%        |
| HCBS  | 9,700           | 70%        | 525,119        | 85%        |
| Spending - 1998   | \$514.4 Million |            | \$16.9 Billion |            |
| ICF/MR  | \$380.2 Million | 77.4%      | \$9.8 Billion  | 58%        |
| HCBS  | \$134.2 Million | 22.6%      | \$7.1 Billion  | 42%        |
| Spending - 2008   | \$919.8 Million |            | \$34.3 Billion |            |
| ICF/MR  | \$462 Million   | 50.2%      | \$12 Billion   | 35.0%      |
| HCBS  | \$457.8 Million | 49.8%      | \$22.3 Billion | 65.0%      |



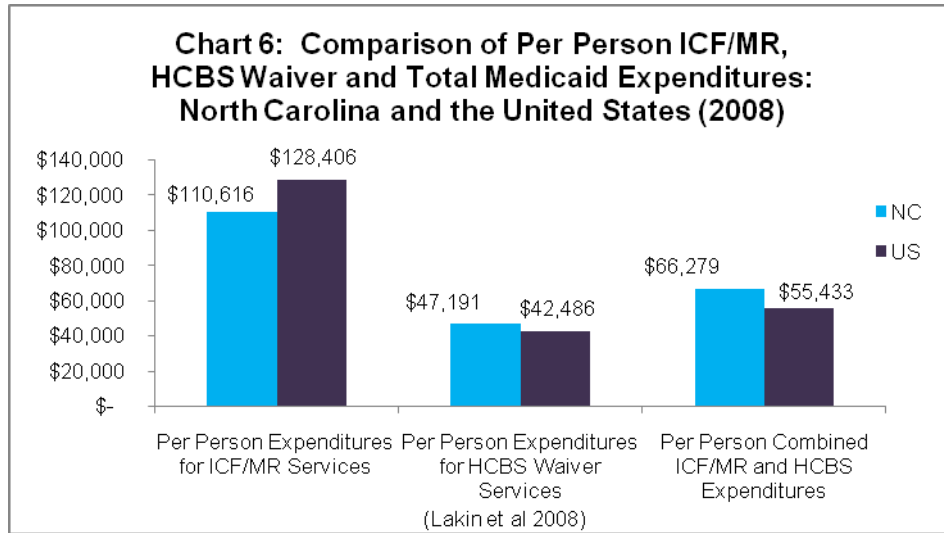


As was the case nationwide, North Carolina directed a significantly greater percentage of its Medicaid dollars to purchase home and community-based (HCBS) services in 2008 than it did in 1998. However, the proportion of dollars earmarked for HCBS waiver services was substantially lower in North Carolina than was the case nationwide. Both in North Carolina and nationwide, the percentage of Medicaid dollars spent on ICF/MR services was disproportionate to the proportion that ICF/MR residents represent of the total of all individuals who received Medicaid funded services (e.g., nationwide, 15% of Medicaid recipients were served in ICFs/MR in 1998, but spending for these services accounted for nearly 35% of the total).

|   | North Carolina  | United States  |
|---|-----------------|----------------|
| Total ICF/MR & HCBS Waiver Recipients     | 13,876          | 618,283        |
| Recipients per 100,000 Population         | 150             | 203            |
| Total Outlays                             | \$919.8 Million | \$34.3 Billion |
| Outlays Per Citizen                       | \$99.72         | \$112.72       |
| Average Annual Expenditures Per Recipient | \$66,279        | \$55,433       |

**Table 10** (above) and **Chart 6** furnish additional 2008 comparisons between North Carolina and the nation as a whole with regard to Medicaid-funded services for people with intellectual and developmental disabilities. Relative to population, North Carolina provided Medicaid-funded services to about 26% fewer individuals than was the case nationwide. When Medicaid spending is expressed on a per citizen basis, North Carolina's Medicaid spending for developmental disabilities services was approximately 12% lower than the nationwide level. There was a relatively large difference in the annual expenditures per Medicaid recipient in North Carolina compared to the remainder of the nation. Overall, in 2008 North Carolina spent \$919.8 million combined for ICF/MR and HCBS waiver services to support 14,362 people. This amounts to \$66,279 per person annually. The national average was \$55,433, or 17% less.

This difference stemmed in large part from North Carolina's heavier use of more costly ICF/MR services to meet the needs of individuals.



## CONCLUDING REMARKS

The following observations may be made concerning North Carolina's services for people with intellectual and developmental disabilities:

- In 1998 and 2008, relative to population, fewer North Carolinians with intellectual and developmental disabilities received Medicaid-funded long-term services (via the ICF/MR and HCBS waiver programs in combination) than nationwide. North Carolina would need to serve 26% more people to reach the average national utilization rate of 203 people/100,000 in population.
- In 1998 and 2008, Medicaid-funded out-of-home residential services overall (both ICF/MR and HCBS) were notably less available in North Carolina than nationally. While the number of people in the USA and North Carolina has risen, North Carolina continues to serve about 30 people/100,000 population fewer than the national average.
- North Carolina continues to serve more people with intellectual and developmental disabilities in its large state-operated Centers than the nationwide norm. While the numbers of individuals served in the Centers decreased by 406 people from 1998-2008, the rate of decline was slower than the nationwide rate and the North Carolina census has stabilized at about 1,650 people since 2006.
- In 1998, North Carolina furnished residential services in settings that were larger than was typical elsewhere in the country. By 2008, however, North Carolina served as many people proportionately in residences of 1-6 beds as the national average. Still, this finding is tempered by the state's high use of ICFs/MR for this size setting and high use of large (16+) state operated facilities.

- In 1998, North Carolina reported that it served no children aged 0-21 years in its large state-run residential facilities. By 2008, however, even as the overall census was reduced in the ten year period, the state reports serving about 46 children in these facilities, or 3% of the population living in large, state-run institutions.
- In 1998, a greater proportion of North Carolina's residential services for people with intellectual and developmental disabilities were provided in ICFs/MR than was the norm nationwide. This is still the case. While the HCBS program continues to expand, the state has not reduced its reliance on public and private ICFs/MR at the same brisk pace as the nation.
- In 1998 and 2008, the total Medicaid dollars available for ICF/MR and HCBS services was greater than in other states. In 2008 this amounted to \$66,279 per service recipient annually compared to \$55,433/person nationally. This is explained primarily by the state's enduring reliance on costly public and private ICFs/MR services relative to other states' greater use of less expensive HCBS waivers.

In summary, four primary observations about services for people with intellectual and developmental disabilities in North Carolina include:

1. North Carolina spends more per person than the national average with overall Medicaid expenditures for services in 2008 16% higher than the national average (\$66,249 vs. \$56,433 per person annually);
2. The number of individuals who received Medicaid-funded services in North Carolina in 1998 and 2008 was markedly lower than nationwide levels after controlling for population differences;
3. Along several dimensions, the state's reliance on large state facilities and community ICFs/MR as a chief service option endures; and
4. The state system is changing in ways consistent with national trends, but generally at a much slower pace.