

# **DEVELOPMENTAL DISABILITIES IN NORTH DAKOTA: 2009**

*A report on the structure, financing,  
and quality assurance of residential and  
community services*

**David Braddock, Ph.D.  
Richard Hemp, M.A.**

**Department of Psychiatry  
University of Colorado  
January 2, 2009**

## Contents

Introduction .....	1
I. Residential and Community Services in North Dakota and the United States ...	2
Residential Services in North Dakota .....	2
Financing Intellectual/Developmental Disabilities Services .....	7
The Medicaid Program for People with I/DD .....	9
Individual and Family Support .....	11
Fiscal Effort .....	13
North Dakota Ranks First in Overall State Economic Momentum: 2008 ..	15
Waiting Lists.....	15
Recruiting and Retaining Qualified Staff .....	17
Summary: Residential and Community Services .....	19
II. Quality Assurance Overview .....	22
The Council Accreditation .....	22
Medicaid ICF/MR Survey and Certification.....	26
Protection and Advocacy Agency Investigations.....	29
Special Education District Performance Reports.....	33
Agency Quality Assurance Profiles .....	34
The North Dakota Developmental Center Quality Assurance Profile .....	35
Summary: North Dakota Quality Assurance Programs .....	37
III. Executive Summary and Conclusion .....	39
Structure and Financing of Residential and Community Services.....	40
Quality Assurance .....	47
Conclusion .....	52
IV. References Cited.....	55

## Listing of Figures and Tables

<u>Figure 1:</u> North Dakota Developmental Centers at Grafton and San Haven: Average Daily Residents: 1960-2008.....	3
<u>Figure 2:</u> Number of Persons in Public and Private Institutions.....	4
<u>Figure 3:</u> Number of Individuals by Residential Setting: 2008 .....	5
<u>Figure 4:</u> Trends in Developmental Disabilities Spending: 1977-2008.....	7
<u>Figure 5:</u> Developmental Disabilities Spending by Size of Setting: 2008 .....	8
<u>Figure 6:</u> Federal ICF/MR and Waiver Spending: 1977-2008 .....	10
<u>Figure 7:</u> Individual and Family Support Spending.....	12
<u>Figure 8:</u> State Fiscal Effort (Federal Funds Excluded).....	14
<u>Table 1:</u> Index of Economic Momentum in the Top Five States .....	15
<u>Figure 9:</u> Aging Family Caregivers: 2008 .....	16

<u>Figure 10</u> : Wage Comparisons for I/DD Direct Support Workers: 2008 .....	18
<u>Table 2</u> : The Council's Accreditation Standards for Residential and Day/Work Programs .....	23
<u>Table 3</u> : Accreditation Council Survey Results for Residential and Community Agencies in North Dakota, 1996-2008 .....	24
<u>Table 4</u> : ICF/MR Program and Life-Safety Code Requirements, 2003-2008 .....	28
<u>Table 5</u> : Substantiated Incidents of Abuse, Exploitation, or Neglect, 1996-2008.....	31
<u>Figure 11</u> : Percentage of State Spending for Six-Person or Fewer Residential and Community Services: FY 2006 .....	41
<u>Figure 12</u> : Institutional Census Per Capita in North Dakota and the Mountain West/Plains States: 1990-2006 .....	42
<u>Figure 13</u> : Average Annual Residential Services Spending for I/DD Recipients in Four New England States Closing Their Institutions, 1991-2006 .....	45
<u>Figure 14</u> : Most deficient standards for 28 agencies' recent survey and in 2008 surveys .....	48

**APPENDICES 1-11: Analysis of Data Emanating from Quality Assurance-Programs in North Dakota**

<u>APPENDIX 1</u> : Notes on residential and community services quality assurance .....	A-1
<u>APPENDICES 2-5</u> : Residential and community services agency accreditation data, 2006, 2007, and 2008 and all agencies' most recent survey .....	A-8
<u>APPENDIX 6</u> : ICF/MR requirements cited in a greater percentage of North Dakota facilities than the N.D. Region and the U.S. 2006-2008 .....	A-13
<u>APPENDIX 7</u> : Number and percentage of North Dakota ICFs/MR with program and life-safety code deficiencies, 2000-2008.....	A-16
<u>APPENDIX 8</u> : Substantiated incidents of abuse, exploitation, and neglect, 1996-2008.....	A-18
<u>APPENDIX 9</u> : Special education unit technical notes .....	A-21
<u>APPENDIX 10</u> : Special education unit quality assurance data .....	A-23
<b>APPENDIX 11: Agency Quality Assurance Profiles .....</b>	<b>A-26</b>

- Consolidated accreditation and ICF/MR quality assurance data are presented in individual profiles for each of 28 residential and community services agencies and for the North Dakota Developmental Center at Grafton (pp. A-22 to A-61).

# **DEVELOPMENTAL DISABILITIES IN NORTH DAKOTA: 2009 A REPORT ON THE STRUCTURE, FINANCING AND QUALITY ASSURANCE OF RESIDENTIAL AND COMMUNITY SERVICES**

## **INTRODUCTION**

*The North Dakota 2009 Report* is a comprehensive update of four previous North Dakota studies of residential and community services for persons with intellectual and developmental disabilities (I/DD) in North Dakota (Braddock & Hemp, 2000; Braddock, Hemp, & Rizzolo, 2002; Braddock & Hemp, 2004; Braddock & Hemp, 2007). In the present study, we have updated the analysis of financial and programmatic data through fiscal year 2008. The analysis of four quality assurance data sets was also extended through 2008, yielding a 13-year (1996-2008) longitudinal analysis of quality assurance systems affecting North Dakota's citizens with I/DD. Quality assurance systems include:

- Accreditation reviews of residential and community services agencies and the North Dakota Developmental Center at Grafton, conducted by The Council on Quality and Leadership in Supports for People with Disabilities;
- Medicaid certification for privately operated Intermediate Care Facilities/Mental Retardation (ICFs/MR), and for the four ICF/MR units at the North Dakota Developmental Center at Grafton;
- North Dakota's Protection and Advocacy Agency investigations of abuse or neglect at residential and community services agencies and at the North Dakota Developmental Center; and
- Special education school district performance reports across the State in 189 districts.

*The North Dakota 2009 Report* includes four major sections. The first is an analysis of financial and programmatic trends in North Dakota I/DD services for fiscal years 1977-2008. This analysis is based, in part, on data emanating from the State of the States in Developmental Disabilities Project's longitudinal data base (Braddock, Hemp, & Rizzolo, 2008). The 2009 Report on North Dakota focuses on comparative analyses of trends in residential and community services, individual and family support services, and the North Dakota Developmental Center at Grafton. The second part of this report presents a comparative analysis of four quality assurance systems for people with I/DD utilized in North Dakota. Section III is an executive summary of the *Report's* findings, conclusions, and recommendations. The *Report's* concluding section consists of *Appendices 1-10*. These appendices describe in detail data emanating from the four

quality assurance programs in North Dakota. *Appendix 11* presents quality assurance data on an agency-by-agency basis for each of the 28 North Dakota community services agencies, and for the North Dakota Developmental Center at Grafton.

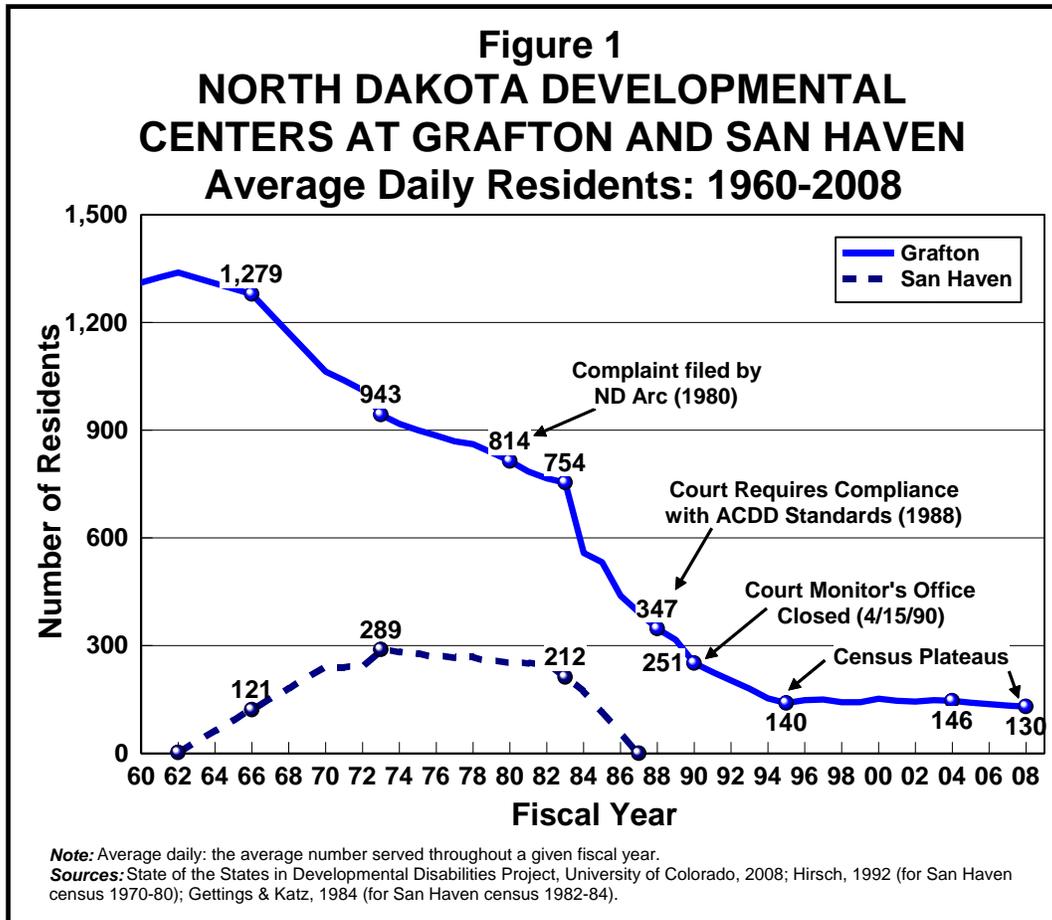
## I. RESIDENTIAL AND COMMUNITY SERVICES IN NORTH DAKOTA AND THE UNITED STATES

The census of state-operated institutions for people with I/DD in the United States declined from a peak of 194,650 in 1967 to 41,214 in 2006. A total of 140 institutions have been closed since 1970 and nine states (Alaska, Hawaii, Indiana, Maine, New Hampshire, New Mexico, Rhode Island, Vermont, West Virginia) and the District of Columbia no longer operate state institutions for people with intellectual and developmental disabilities (Braddock, Hemp, & Rizzolo, 2008).

In 2008, residential services for people with I/DD in the states consist primarily of community living arrangements for six or fewer persons. Community residential services are provided in group homes, supervised apartments, host homes, foster homes, Intermediate Care Facilities/Mental Retardation (ICFs/MR), and supported living arrangements. In 2006, 70% of individuals with I/DD in out-of-home settings in the U.S. resided in settings for six or fewer persons; 11% resided in settings for 7-15 persons; and 19% lived in public or private institutions for 16 or more persons..

### ***Residential Services in North Dakota***

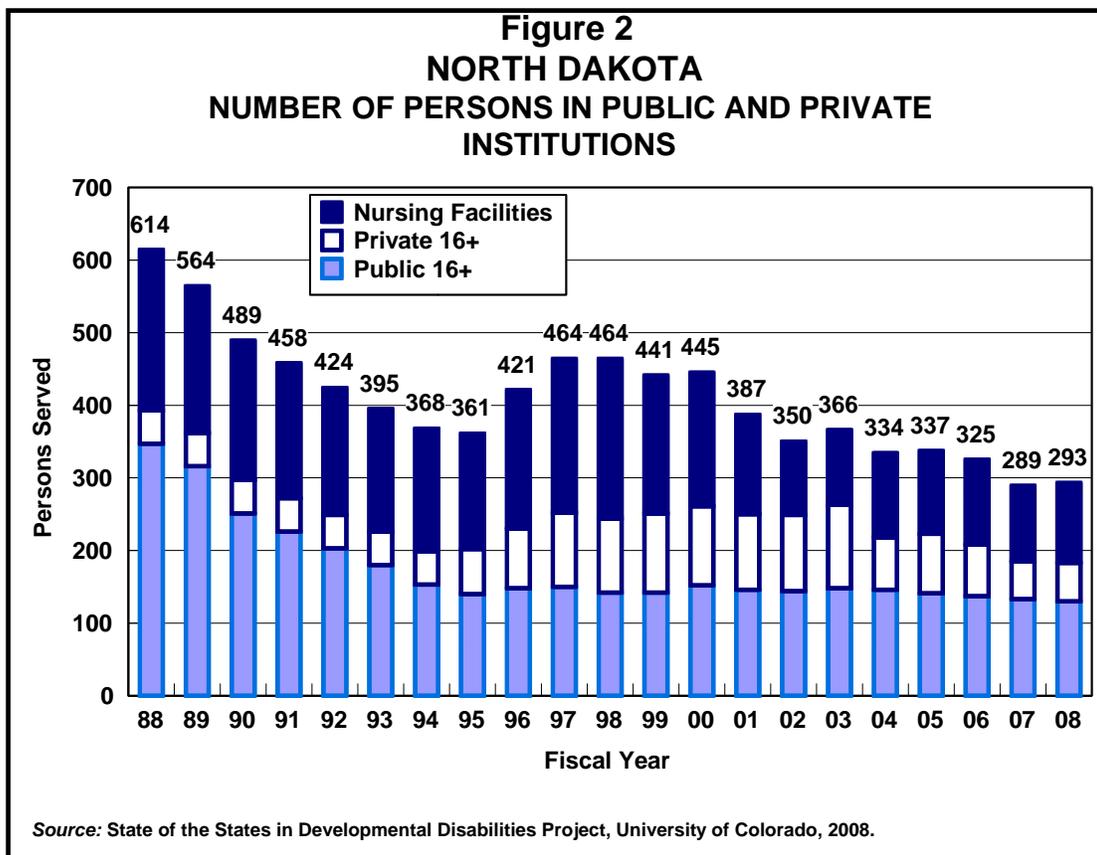
In 1966, North Dakota operated two state facilities, the North Dakota Developmental Center at Grafton and the satellite facility, San Haven. The facilities served 1,279 and 121 individuals with I/DD respectively, a total of 1,400 persons (*Figure 1*). This peak in the State's institutional population at the North Dakota Developmental Centers at Grafton and San Haven occurred one year prior to the apex of 194,650 in the nation as a whole. From 1966 to 1983, the census of North Dakota's institutions declined by an average 2% per year, to 966 persons (754 at the North Dakota Developmental Center at Grafton and 212 at San Haven). This institutional decline rate was one half the national rate of decline during that period.



Following the implementation of the consent agreement in *Association for Retarded Citizens of North Dakota v. Olson* (1982), San Haven closed in 1987 and the rate of census reduction in North Dakota institutional services accelerated to 15% per year during 1983-95. Thereafter, census reduction stalled. The resident census actually increased from 140 in 1995 to 146 persons in 2004 then declined to 130 for fiscal year 2008.

### Public and Private 16+ Institutions

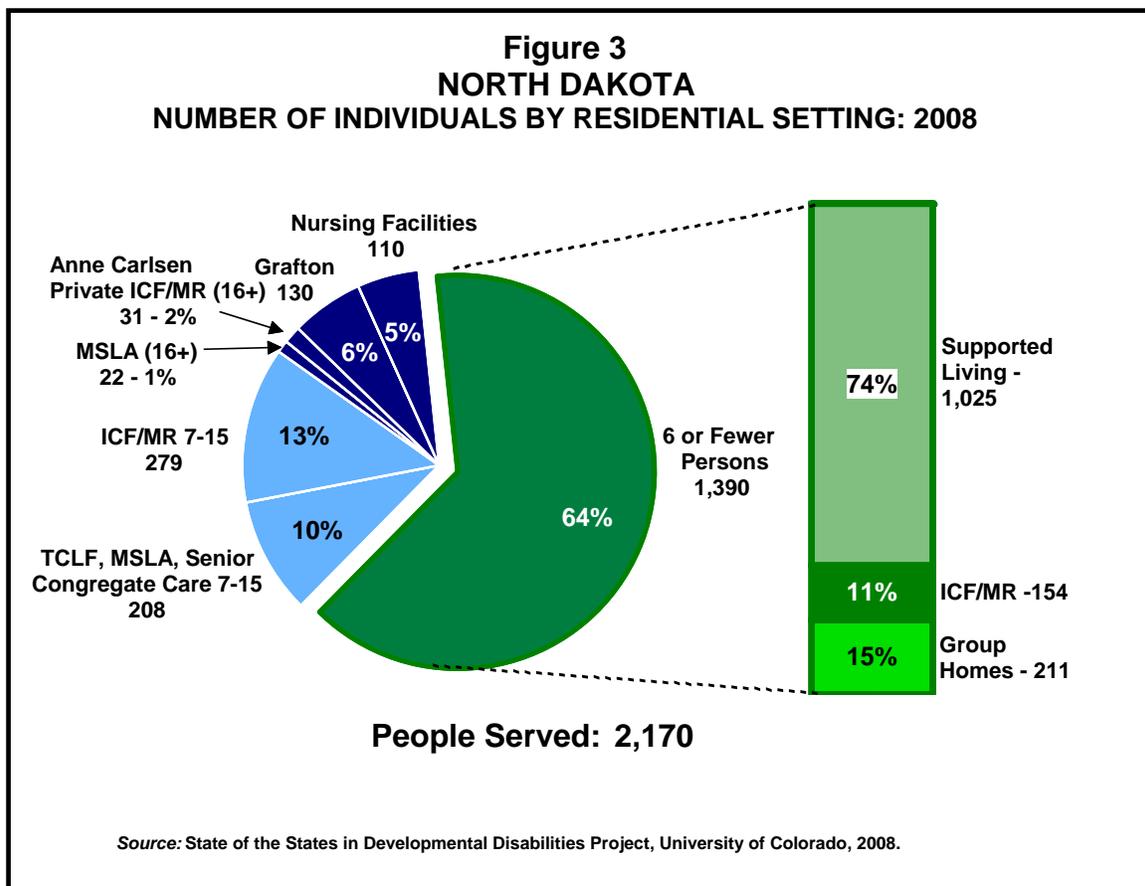
*Figure 2* illustrates the total number of individuals residing each year in nursing facilities, the North Dakota Developmental Center (public 16+), and in privately operated 16+ settings consisting of the Anne Carlsen Center ICF/MR facility for children and Minimally Supervised Living Arrangements (MSLAs), serving 31 and 22 persons, respectively, in 2008. The total number of individuals residing in 16+ settings declined from 614 in 1988 to 293 in 2008. Individuals with intellectual and developmental



disabilities in North Dakota nursing facilities declined from a peak of 220 in 1998 to 110 in 2008, and the number of persons in private 16+ settings in North Dakota declined from a peak of 115 in 2003 to 53 in 2008. *During 2006-08 the census in public/private institutions fell by 32 persons, a 10% reduction; however the census increased by four persons between 2007 and 2008.*

### Development of Community Residential Services

Residential and community services systems in the U.S. and in North Dakota principally consist of community housing arrangements serving six or fewer individuals per setting. In 2008, the North Dakota Developmental Center average daily population constituted six percent of the total of 2,170 persons residing in all types of residential settings in the State (*Figure 3*). The 53 children and adults residing in private 16+ institutions (the Anne Carlsen ICF/MR and MSLAs) constituted three percent of the total, and the 110 individuals with I/DD in nursing facilities constituted five percent. All together, the Developmental Center, private institutions for 16 or more persons, and



nursing facilities accounted for 14% of the total of 2,170 persons. This is a reduction from 17% of 1,936 persons with I/DD in out-of-home placements in 2006.

Twenty-three percent of the total number of individuals with I/DD in residential settings in North Dakota resided in facilities for 7-15 persons. This was more than double the national proportion for 7-15 person settings, which for the U.S. constituted 11% of the total of 532,830 out-of-home residents in 2006. North Dakota’s 7-15 person ICFs/MR served 279 persons consisting of 168 adults and 57 children with I/DD, and 54 persons with developmental and physical disabilities. The other settings in the state for 7-15 individuals served 208 persons, and consisted of Transitional Community Living Facilities (TCLFs) (116 people), MSLAs (51 people), and “senior congregate care” (41 people). The average facility size of North Dakota’s 7-15 person settings was 7.5 persons. During 2006-08, there were sixteen fewer persons in 7-15 person settings, a three percent reduction.

The majority of persons in North Dakota’s residential services in 2008 (64%) resided in settings for 6 or fewer persons; however, this was lower than the United States

average of 70% in 2006. Participants in supported living in North Dakota constituted 74% of those served in settings for six or fewer persons. Supported living in North Dakota consisted of settings termed “supported living” with 231 participants, “individualized supported living arrangements” (ISLAs) that supported 744 participants, and personal assistance for 50 persons. During 2006-08, an additional 222 persons resided in settings for six or fewer persons, an increase of 19%.

### **Utilization Rates for Individuals Served in Out-of-Home Settings**

In 2006, North Dakota ranked sixth among the states in total out-of-home utilization rate per 100,000 of the general state population. Iowa, South Dakota, Minnesota, Wisconsin, and West Virginia were the top five ranked states. North Dakota’s utilization rate for settings for six or fewer persons was 174 per 100,000 compared to the U.S. average of 126 per 100,000, and North Dakota ranked fifth nationally. However, North Dakota’s utilization rate for 7-15 person settings was nearly four times the U.S. rate--79 vs. 20 per 100,000. Only New York State (98 per 100,000) exceeded North Dakota in 7-15 placement utilization. During 2006-08, North Dakota’s six-person or fewer facility utilization rate increased substantially, from 174 to 217 per 100,000; and the State’s 7-15 person facility utilization rate declined marginally from 79 to 76. It should be stressed, however, that the average size for these 7-15 person settings in North Dakota is 7.5 persons, compared to a 2006 national average of 9.8 persons in 7-15 person settings.

North Dakota posted high utilization rates for the state institution and for nursing facilities as well. The North Dakota institutional placement rate of 22 persons per 100,000 of the general population ranked 9<sup>th</sup> highest among the 41 states that still operated institutional services in 2006. The U.S. average was 13. The State’s 2006 nursing facility utilization rate was 18 per 100,000, 9<sup>th</sup> highest among the states, and substantially above the U.S. nursing facility utilization rate of 11.

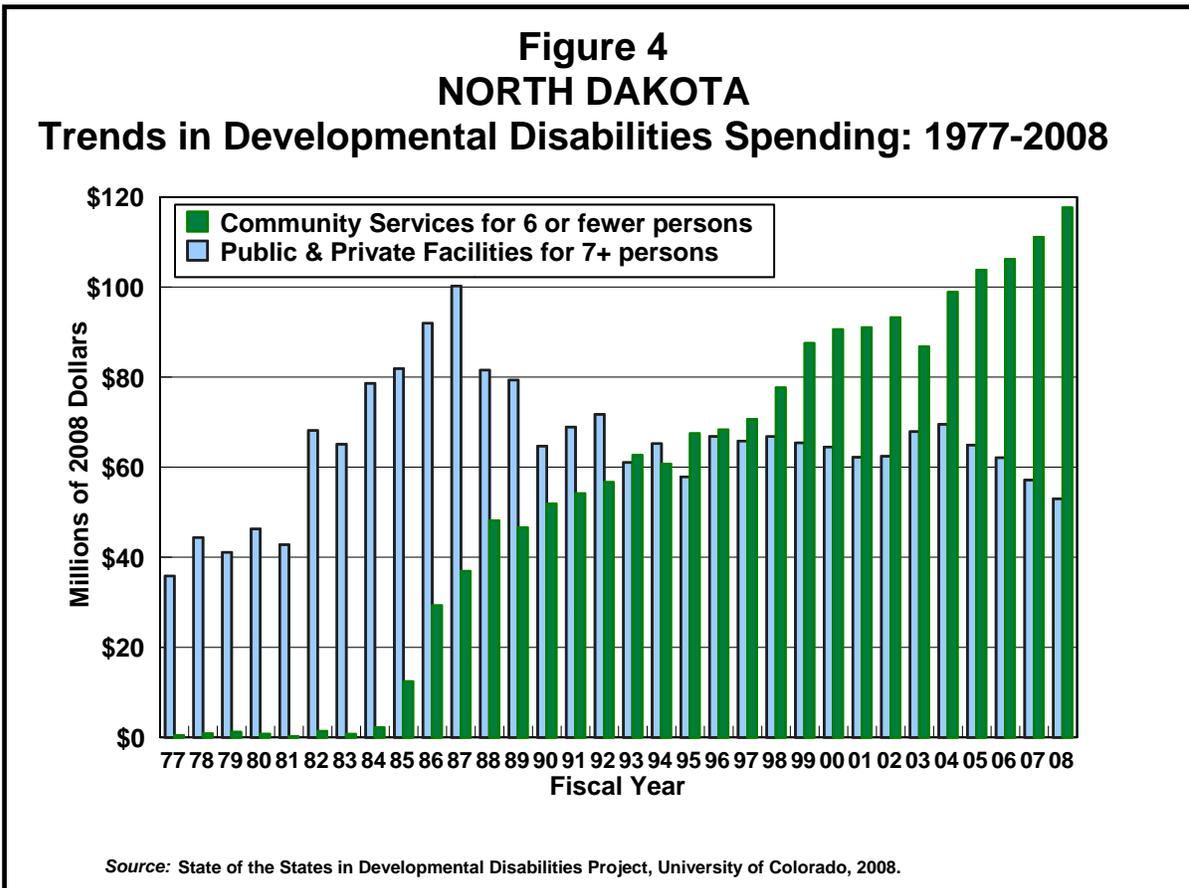
In summary, North Dakota remains among the nation’s leaders in the utilization of out-of-home residential facilities (ranked 6<sup>th</sup>) and in the utilization of settings for six or fewer persons (ranked 5<sup>th</sup>). The State, however, continues to be at significant variance with national out-of-home placement patterns in having high utilization rates for:

- Settings for 7-15 persons (ranked 2<sup>nd</sup> highest);
- Nursing facilities (ranked 9<sup>th</sup> highest); and
- State institutional services (ranked 9<sup>th</sup> highest).

**Financing Intellectual/Developmental Disabilities Services**

Total I/DD residential and community services spending in North Dakota was \$170.6 million in 2008. **Figure 4** presents the history of this funding by size of residential facility. The gray bars represent inflation-adjusted spending for public and private facilities serving 7 or more persons per facility and the black bars represent adjusted spending for community residential services for six or fewer persons, related day programs, and individual and family support services.

Total spending for persons residing in settings for six or fewer persons surpassed spending for 7+ person facilities in 1995. Inflation-adjusted spending for 7+ public and private facilities in North Dakota increased by an average 12% per year during 1977-87 and declined 6% annually during 1987-95 following implementation of the *Arc of North*

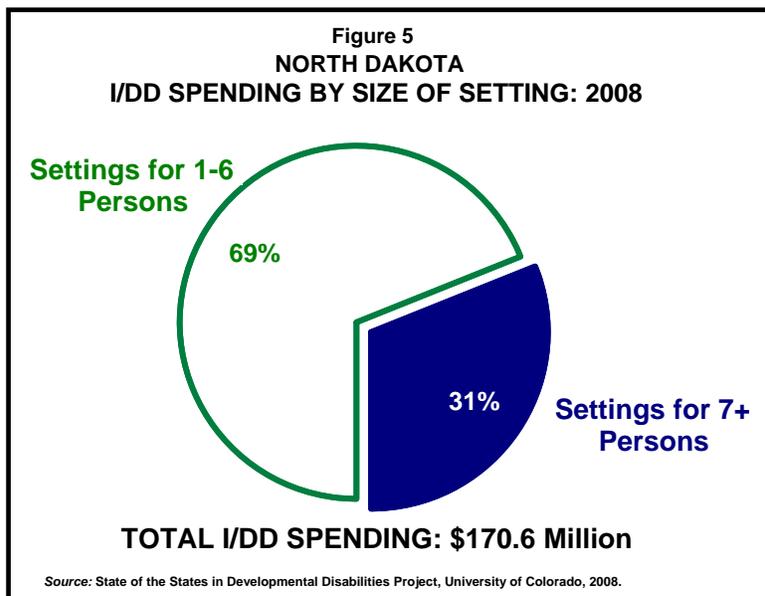


*Dakota v. Olson* lawsuit. Spending for settings for 7+ persons grew 2% per year during 1995 to 2000 and declined 2% per year during 2000-08. Community services spending for six or fewer persons has increased steadily since 1984, except for declines in 1989, 1994 and 2003. During 2000-08, community services spending increased an average of 4% per year.

The increase in community spending during 2000-08 was largely attributable to the State’s expansion of the Home and Community Based Services (HCBS) Waiver. In addition, the North Dakota legislature granted increases of \$.80 per hour in 1998/1999 and \$.87 per hour in 2003 in higher wages for community direct support staff during this period. There was also an increase in direct support staff fringe benefit rates from 30% to 33% of salary (NDACF, 2003; NDACF, 2008).

*In 2006, however, North Dakota was one of only three states in which 25% or more individuals in out-of-home settings resided in facilities for 7-15 persons.* The State, in fact, expended 31% of total I/DD residential and community services resources for services in 7-person or larger residential facilities in 2008 (**Figure 5**). Facilities for 7+ persons included the North Dakota Developmental Center, private ICFs/MR, minimally supervised living arrangements, transitional community living facilities, and senior congregate care. Community services for six or fewer individuals consisted of group homes, ICFs/MR, supported living arrangements, and a range of day programs and supported employment, family support and other community services including case management and infant development.

In 2006, the average state committed 75% of total I/DD spending to settings for six or fewer persons; North Dakota ranked 44<sup>th</sup> in this regard. In 2006, North Dakota committed 63% of total I/DD long-term care resources to settings for six or fewer persons.



## ***The Medicaid Program for People with I/DD***

The ICF/MR program and the HCBS Waiver are the two primary Medicaid sources for financing I/DD long-term care in the U.S. Other “optional” Medicaid services that the Secretary of the U.S. Department of Health and Human Services can approve for Medicaid State Plans consist of rehabilitative and clinic services to finance day programs, targeted case management, and personal assistance services. North Dakota provided case management and personal care as part of the State’s approved HCBS Waiver services. Other North Dakota Waiver services included homemaker, respite, adult day health, habilitation (day supports, residential habilitation, supported employment), family training (infant development), adult residential care and adult foster care to individuals with I/DD (Waiver # 0337.90.R4, effective 4/1/1994 through 3/31/2009). Federal and state Medicaid spending in the U.S. advanced from nine percent of total I/DD long-term care spending in 1977 to 78% of the total in 2006. In North Dakota, the Medicaid spending share advanced from 0% to 81% over that same period, and in 2008 the Medicaid share remained at 81% of total I/DD spending in the State.

The federal government initiated certification of ICF/MR facilities for 15 or fewer persons in 1974, and these ICF/MR group homes became a major component of community service systems in a large number of states. North Dakota first utilized ICF/MR funding in 1982 both for private facilities serving 16 or more persons and 15 or fewer persons. In 1983 ICF/MR reimbursement was established at North Dakota’s developmental centers, and continues to finance the North Dakota Developmental Center at Grafton.

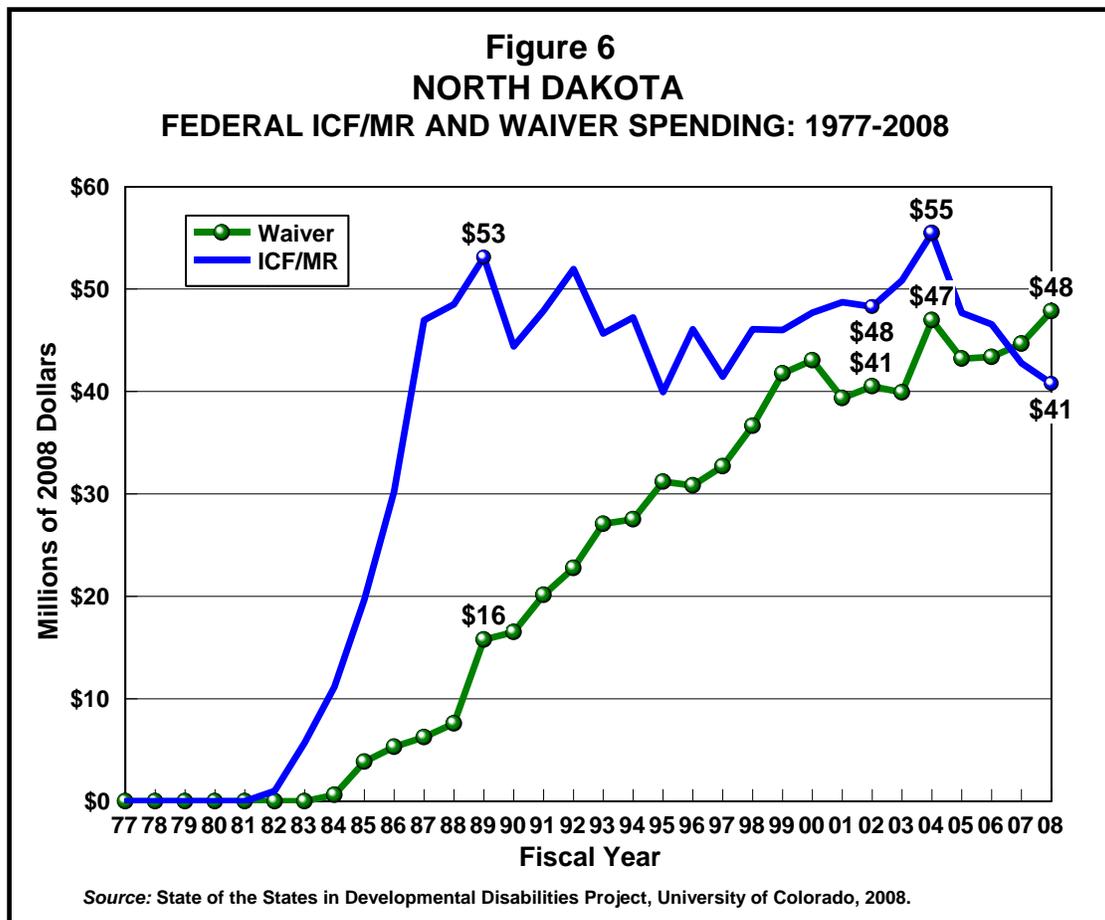
The HCBS Waiver was authorized under the auspices of the Omnibus Budget Reconciliation Act of 1981 (Pub. L. 97-35). In the 1990s, the Centers for Medicare and Medicaid Services (CMS, formerly the Health Care Financing Administration), greatly facilitated states’ Waiver application procedures by granting 5-year renewal periods. In 2006 all fifty states and the District of Columbia had instituted HCBS Waiver services, and federal Waiver spending in the United States grew to \$11.0 billion. In 2006 the Waiver constituted 58% of all federal Medicaid reimbursement for I/DD long-term care spending in the U.S. In 2008, federal spending for the HCBS Waiver in North Dakota constituted 54%, below the 2006 proportion of 58% in the U.S. The HCBS Waiver has

proven to be a flexible, popular method of reimbursement for a wide range of essential services in the states.

### North Dakota HCBS Waiver

In 2008 North Dakota used the HCBS Waiver to finance 94% of family support spending and 100% of supported living/personal assistance and supported employment spending. The North Dakota Waiver was established in 1984 (*Figure 6*). In 2006 North Dakota ranked 15<sup>th</sup> among the states in federal-state Waiver spending per capita of the general population, at \$93 compared to the U.S. average of \$66. The North Dakota per capita advanced to \$117 in 2008. Waiver spending in the U.S. surpassed ICF/MR spending in 2001 and North Dakota achieved that benchmark in 2007. In 2006, only 10 states and North Dakota were still spending more for ICFs/MR than for the Waiver. The other states were Arkansas, DC, Idaho, Illinois, Iowa, Louisiana, Mississippi, New Jersey, North Carolina and Texas. It is estimated that four of these states (Arkansas, Idaho, Iowa, and New Jersey) and DC will achieve the benchmark by 2008.

As displayed in *Figure 6*, inflation-adjusted ICF/MR spending for public and



private facilities in North Dakota grew an average 109% per year during 1982 to 1989, declined to 0% annual growth during 1989-02, advanced 7%/year from 2002 to 2004, then declined 7%/year during 2004-08. Inflation-adjusted spending for the North Dakota Waiver increased annually following the Waiver's initiation in 1984, except for a slight decline in 1996, a nine percent decline in 2001, and another slight decline in 2003. Waiver spending increased 18% in 2004, but dropped by 8% in 2005 and posted no growth (0%) in 2006. Waiver spending then grew three percent in 2007 and seven percent in 2008. During 2006-08, adjusted HCBS Waiver spending increased 10%. There was an increase of 123 Waiver participants, a four percent increment.

### ***Individual and Family Support***

Braddock et al. (2008) defined *individual and family support* to include family support, supported employment, supported living, and personal assistance. The definitions for individual and family support components were:

**Family support:** Community-based services administered or financed by the state intellectual/developmental disabilities (I/DD) agency providing for vouchers, direct cash payments to families, reimbursement, or direct payments to service providers that the state agency identified as family support. Examples of family support programs included cash subsidy payments, respite care, family counseling, architectural adaptation of the home, in-home training, sibling support programs, education and behavior management services, and the purchase of specialized equipment.

**Supported employment:** State I/DD agency-financed programs for the long-term support of individuals in integrated work settings, work stations in industry, enclaves, or work crews, where the primary goals are developing independent work skills so that individuals with I/DD can earn competitive wages.

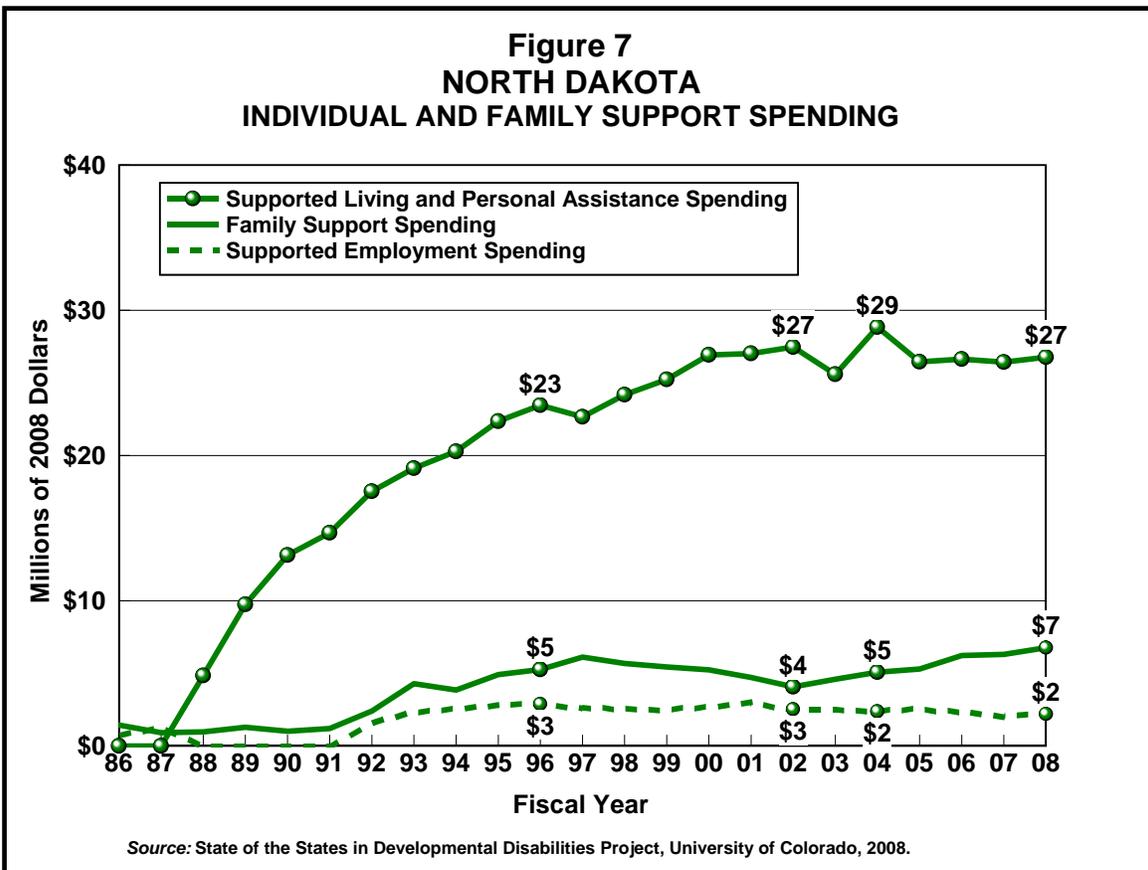
**Supported living and personal assistance:** Housing in which individuals choose where and with whom they live, and housing where ownership is by someone other than the support provider (i.e., by the individual, the family, a landlord, or a housing cooperative). The individual has a personalized support plan that changes as her or his needs and abilities change. Personal assistance, a sub-component of supported living, was defined as support provided to people living in their own home, and financed by either state or Medicaid funds.

In 2006, the nation expended \$7.87 billion for individual and family support, constituting 18% of the \$43.84 billion in total I/DD long-term care spending that year. Sixty-two percent of total individual and family support spending in the United States was dedicated to supported living and personal assistance, 29% funded family support activities, and the remaining nine percent funded supported employment.

### Individual and Family Support in North Dakota

North Dakota expended \$35.7 million for individual and family support services in 2008, constituting 21% of the \$170.6 million in total I/DD spending in the State. Seventy-five percent of North Dakota’s individual and family support spending was committed to supported living and personal assistance, 19% funded family support, and six percent funded supported employment (*Figure 7*).

As illustrated in the figure, inflation-adjusted supported living spending in North Dakota grew rapidly from 1987 to 1996, dropped back in 1997 to the 1995 level, then continued to increase during 1998-2002, although at a slower annual rate than during 1987-96. Spending for supported living grew 5% between 2002 and 2004, but declined



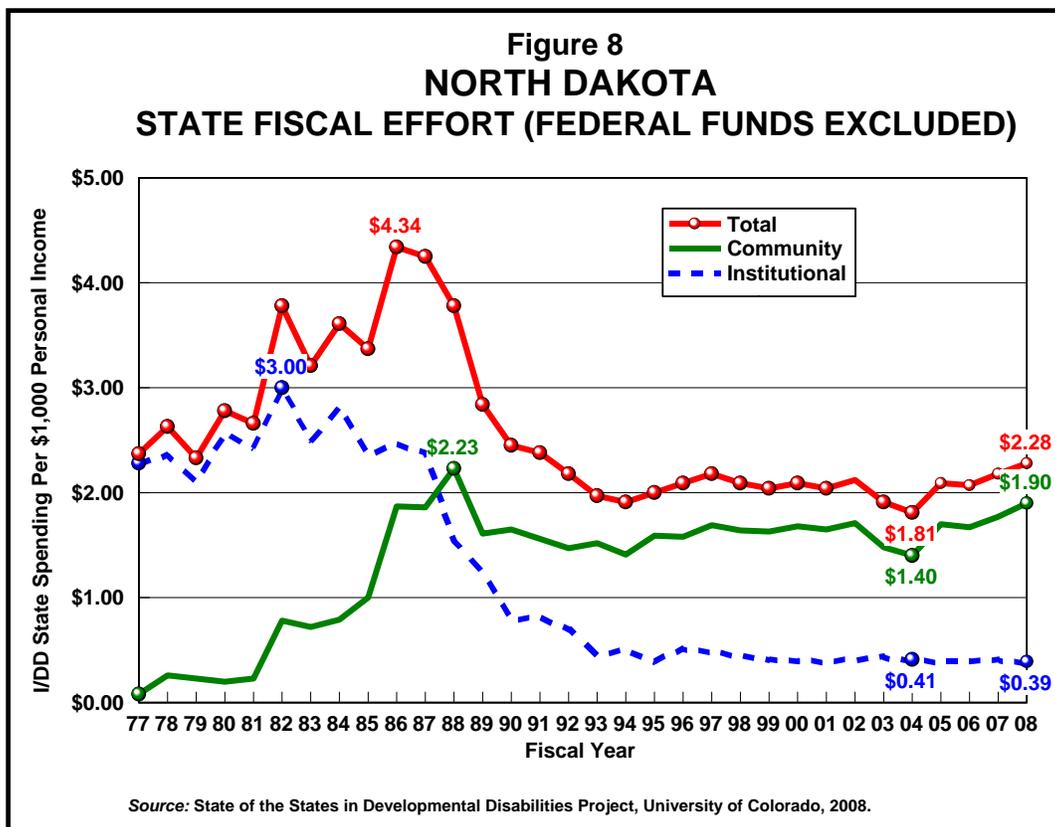
seven percent during 2004-08. Supported employment spending was essentially flat (no real increase) from 1996 to 2008, but family support spending advanced 66% during 2002-08 (nine percent annually), after experiencing a steady decline in real terms during 1997-2002. During 2006-08, adjusted supported living spending increased one percent and the number of supported living participants increased by 95 persons (10%). During 2006-08, family support spending (adjusted for inflation) increased 33%, but the number of families supported declined by three percent.

North Dakota ranked 5<sup>th</sup> behind Iowa, Ohio, Washington and West Virginia in supported living/personal assistance utilization (per 100,000 of the general population). The State ranked 34<sup>th</sup> in families supported per 100,000 and 17<sup>th</sup> in supported employment utilization. Only 15% of total day/work participants in North Dakota in 2006 were supported employment workers. The U.S. average was 21% and North Dakota ranked 37<sup>th</sup> among the states in this regard. The supported employment rate in North Dakota increased to 17% in 2008. During 2006-08, adjusted supported employment spending declined by seven percent. The number of participants with I/DD in supported employment in North Dakota increased from 306 in 2006 to 391 in 2008, a 28% increment.

### ***Fiscal Effort***

Fiscal effort is defined as a state's spending for I/DD services per \$1,000 of total statewide aggregate personal income. The analysis of fiscal effort enables distinctions to be made between those states that are making a strong effort in financing developmental disabilities services and those that are not (Braddock & Fujiura, 1987). State and local government fiscal effort (excluding federal funds) gauges a state's own-source financial commitment over time. In North Dakota, the expansion of Medicaid ICF/MR and Waiver funding since the late 1980s has been accompanied by a decline in state spending as a proportion of state personal income.

Total I/DD fiscal effort for state funds in North Dakota dropped from a peak of \$4.34 in 1986 to \$2.28 in 2008 (**Figure 8**). Community effort dropped from \$2.23 in 1988 to \$1.90 in 2008. Following the peaks in 1986 and 1988, both total and community state funds fiscal effort in North Dakota reached their lowest levels in 2004 (\$1.81 and



\$1.40, respectively). The marked decline in 2004 reflected growth in federal Medicaid ICF/MR and Waiver reimbursement, and the impact of enhanced federal medical assistance percentage (FMAP) rates that were authorized by the Jobs Growth Tax Relief Reconciliation Act of 2003 (Pub. L. 108-27). That Act brought \$50 million to North Dakota through enhanced Medicaid federal medical assistance percentage (FMAP) rates there were effective January 2003 through June 2004 (Braddock & Hemp, 2007; Dalton, 2004; NCSL, 2004). In 2006, North Dakota ranked 6<sup>th</sup> in state fiscal effort for community services among the eight states with populations of less than 1,000,000. State fiscal effort for community services surpassed North Dakota’s level<sup>1</sup> in the District of Columbia and several states with small populations: Delaware, Vermont, Alaska, and Wyoming.

<sup>1</sup> When federal funds are included in the calculation of fiscal effort and when community services are defined in terms of persons in settings for 15 or fewer individuals, North Dakota ranked 17<sup>th</sup> nationally in total spending, 18<sup>th</sup> in community spending, and 19<sup>th</sup> in institutional spending fiscal effort in 2006. During 2006-08, fiscal effort increased one percent, from \$7.36 to \$7.45. Institutional fiscal effort declined nine percent, and community fiscal effort increased three percent.

**North Dakota Ranks First in Overall State Economic Momentum: 2008**

North Dakota ranked first nationwide in “economic momentum” in September 2008. Economic momentum is the weighted average growth in population, personal income, and employment (Federal Funds Information for States, 2008).

Table 1 INDEX OF ECONOMIC MOMENTUM <sup>1</sup> IN THE TOP FIVE STATES: September '08		
U.S. RANK	STATE	INDEX
1	North Dakota	3.12
2	Texas	2.10
3	Wyoming	1.91
4	South Dakota	1.48
5	Oklahoma	1.02
<b>UNITED STATES</b>		<b>0.00</b>

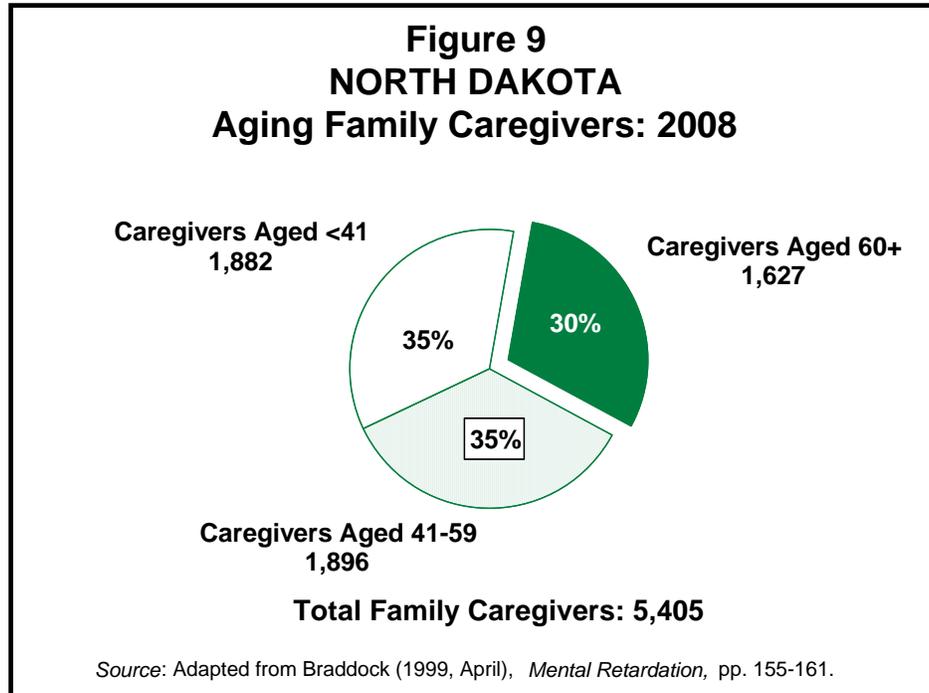
<sup>1</sup>Index of economic momentum: Weighted average growth in personal income, employment and population (Federal Funds Information for States, September 2008).

Among the CMS Region 8 states, only Wyoming and South Dakota rank higher. Nevertheless, their economic momentum indices are 39% and 53%, respectively, below North Dakota’s index (*Table 1*). North Dakota, at least in this measure of state economic health, is positioned well to address the pressing need for intellectual and developmental disabilities services now confronting North Dakota and other states.

**Waiting Lists**

Three factors--aging caregivers, increased longevity, and growing waiting lists--are impacting state delivery systems’ abilities to meet current and projected demands for residential, vocational, and family support services (Braddock, Hemp, & Rizzolo, 2008). Prouty, Alba, & Lakin (2008) reported that no persons with developmental disabilities in North Dakota awaited residential services as of June 30, 2007. However, in 2008, there were an estimated 1,627 children and adults with I/DD in North Dakota living with family caregivers aged 60 years or older (*Figure 9*).

The estimated number of aging caregivers in a state is predicated on a developmental disabilities prevalence rate of 1.58% (Larson, Lakin, Anderson, Kwak, Lee, & Anderson, 2001) and the 1991 Survey of Income and Program Participation (SIPP) data set (U.S. Bureau of the Census, 1992). In an analysis of the data set, Fujiura (1998) reported that 60% of all persons with I/DD resided with family caregivers and that 40% lived on their own or within the formal out-of-home residential care system. On a



national basis, 25% of individuals with DD supported by family caregivers lived with caregivers 60 years of age or older.

Braddock (1999) developed a methodology to estimate aging caregivers in each state predicated on the 1.58% prevalence rate (Larson et al., 2001), the SIPP analysis of the proportion of aging caregivers (Fujiura, 1998), an index based on the specific proportion of aged citizens in each state (U.S. Census Bureau, 2008), and the proportion of citizens with developmental disabilities residing in out-of-home residential services based on the nationwide State of the States in Developmental Disabilities data base (Braddock et al., 2008).

In 2008 there were an estimated 10,117 persons with developmental disabilities in North Dakota; 2,170 (21%) resided in the State's out-of-home residential care system, 2,542 (25%) resided alone or with housemates, and the balance of 5,405 (53%) resided with family caregivers. The large number of caregivers aged 60 years of age or older in North Dakota (1,627) reflected the fact that the State has the sixth highest proportion (14.6%) of aged citizens compared to the U.S. average of 12.6% (U.S. Census Bureau, 2008). Many of the estimated number of family caregivers aged 60 years or more are likely to require increased levels of support from the North Dakota I/DD service system

in future years. This will be an intensifying challenge for service providers in the states, since the number of Americans aged 65 years or more will double between 2000 and 2030 (U.S. Census Bureau, 2001).

The longevity of individuals with intellectual and developmental disabilities is increasing (Janicki, 1996; Janicki, Dalton, Henderson, & Davidson, 1999). Furthermore, there is a growing number of young adults aging out of special education programs. According to data for school year 2006/2007 (U.S. Department of Education, 2008), 172 North Dakota students with mental retardation, autism, and traumatic brain injury graduated with a diploma, received a certificate, reached the maximum special education age, or dropped out of North Dakota's special education system. Over the 2009/2011 biennium, nearly 350 students with mental retardation, autism and TBI exiting special education in North Dakota can be expected to present a need for supported living, residential service, or other supports.

North Dakota state officials have previously indicated that there was ongoing collaboration between Department of Humans Services (DHS), the Department of Public Instruction, and local education agencies to identify and assist in the transition of students leaving special education for the adult service system. Adult Education Transition Services were developed to take advantage of federal Medicaid participation for students with disabilities aged 18-21 years who have received maximum benefit from school based transition programs and are ready for adult services (Hysjulien, 2004).

### ***Recruiting and Retaining Qualified Staff***

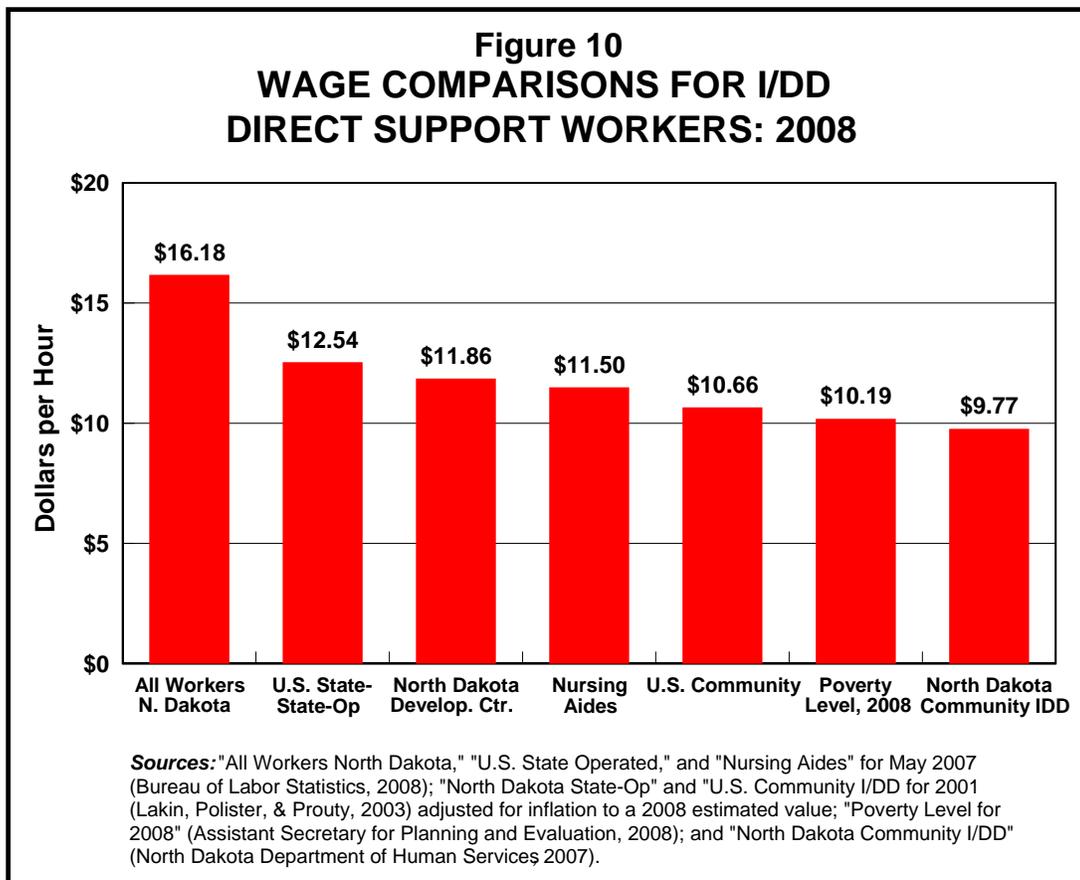
As we reported in 2007, high turnover in residential programs for individuals with developmental disabilities has a negative impact on the individuals served. Costs of turnover, such as compensatory administrative costs for replacing staff, divert resources from services. Furthermore, lower adjusted average wages are associated with higher crude separation rates. Moreover, because individuals with developmental disabilities rely on direct support staff for consistent nurturing and friendship, disruption of these relationships because of employee turnover can have detrimental psychological effects.

Reduced compensation and benefits of community residential staff compared to those provided for state institution personnel continues to be a national issue. Vassiliou &

Ferrara (1997) surveyed 610 staff from 20 residential and community services agencies in North Dakota to identify factors related to staff longevity and turnover. Their recommendations included providing special recognition for staff, being realistic about both the benefits and drawbacks of hiring college and university students, proposing peer mentoring for new staff, and realistic job previews.

### Current Direct Support Wages in North Dakota

Despite a number of wage increases for direct support staff in North Dakota, wages in 2008 were still below the poverty level for a family of four. **Figure 10** displays the 2008 federal poverty level, on an hourly basis, for a family of four with one wage earner (ASPE, 2008); the average wage for all U.S. workers, nursing aides, and for U.S. state-operated institutions in 2007 (Bureau of Labor Statistics, 2007); and U.S. community facility and the North Dakota Developmental Center at Grafton wages (Lakin, Polister, & Prouty, 2003, adjusted for inflation). The North Dakota Department of Human Services (2007) reported a \$0.60 direct support wage increase effective July 1, 2007 (fiscal year 2008). This, in addition to annual increases since 1997, brings the



average wage to \$9.77.

In 1997, the North Dakota legislative session authorized an increase of \$.44 per hour for direct care staff (in addition to the general 2.2% cost of living increase). In the 1999 session, all community agency staff received a \$.36 per hour increase and fringe benefit payments were increased to 30% of wages. Subsequently, there has been an increase of \$.10 per hour effective July 1, 2001; an increase of \$.87 per hour and an increase to 33% for fringe benefits July 1, 2003; and an increase of \$.15 per hour coupled with a 2.65% inflation increase July 1, 2005 (state fiscal year 2006). For July 1, 2006 (fiscal year 2007) there was an increase of \$.20 per hour and a 2.65% inflation increase, bringing the total to \$9.17 for fiscal year 2007 (Braddock & Hemp, 2007).

For fiscal year 2008, as noted, the \$0.60 increase results in a total average direct support wage of \$9.77. There was also, for the fiscal year 2007-2009 biennium, a four percent inflation increase for the first year (FY 2008) and a five percent increase in the second year (FY 2009). With these increments the North Dakota average direct support wage has advanced from \$6.23 in fiscal year 1997 to \$9.87 in fiscal year 2008, an inflation-adjusted three percent increase over the 12-year period. The State's community direct support wage is still an estimated \$2.00 below the average wage at the North Dakota Developmental Center, and three percent below the 2008 poverty level for a family of four.

### ***Summary: Residential and Community Services***

North Dakota continues to rank high among the states on residential placements per capita of the general population. However, the State also ranked high in 2006 in the utilization of 7-15 person settings (ranked 2<sup>nd</sup> nationally), public institutions (9<sup>th</sup>), and nursing facilities (9<sup>th</sup>). Given the clear national trend away from utilization of such settings, North Dakota utilization rates are expected to rank even higher when comparable nationwide data for 2007 and 2008 are available for all the states.

### **Fiscal Effort Increases 2004-08**

North Dakota ranked 4<sup>th</sup> among the states in federal-state fiscal effort in 2006. Fiscal effort increased slightly (one percent) during 2006-08. However, institutional effort declined nine percent and there was a three percent increase in community fiscal

effort. In 2006, North Dakota ranked 6<sup>th</sup> in state funds-only community fiscal effort among the eight states with populations below one million. In the past 12 years in North Dakota (1997-2008), state funds fiscal effort increased five percent overall, 12% for community services, and a decline of 20% for institutional services.

### **Utilization of Institutional Settings**

The number of persons served in non-specialized nursing facilities for 16+ residents, reported by the Department of Human Services (DHS), dropped from 220 in 1998 to 110 in 2008. As we noted previously (Braddock & Hemp, 2004), DHS officials attributed the nursing facility decline to: a) fewer nursing facility admissions of persons with mental retardation and related developmental disabilities; b) deaths of older or terminally ill nursing facility residents with I/DD; and c) alternative placement in community-based residential services. The North Dakota Developmental Center census decreased slightly from 140 in 1995 to 130 in 2008, and the number of individuals in private facilities for 16+ persons declined from a peak of 115 persons in 2003 to 53 persons in 2008.

### **Individual and Family Support**

*Inflation-adjusted spending for supported living in North Dakota declined seven percent from 2004 to 2008 and supported employment spending plateaued; however, family support spending advanced 33% from 2004 to 2008.* The lack of supported employment spending growth in North Dakota may have been related to a lack of resources for staff and service providers (Mercer, 2004). Other service needs include an estimated 1,627 individuals with I/DD living with caregivers 60 years or older, the needs of youth exiting special education, and alternative placements required for residents of public and private institutions. Although there was a 10% increase in supported living participants during 2006-08, adjusted spending was flat in this area. Continued expansion of Individualized Supported Living Arrangement funding should be a priority in North Dakota.

### **Recruitment and Retention of Qualified Direct Support Staff**

Discrepancies in direct staff wages in state-operated institutions compared to those in community settings remains a serious issue. Average wages at the North Dakota

Developmental Center at Grafton are approaching the U.S. average institutional wage, but North Dakota community wages are below the poverty wage level for a family of four. The North Dakota legislature, especially in the budget for the 2007-09 biennium, has continued to address the issue of wages for direct support staff. Moreover, the North Dakota Department of Human Services has collaborated with the North Dakota Center for Persons with Disabilities in the development of a career ladder with wage incentives for employees who completed college-based training and education programs (NDCPD, 2006). The Center, located at Minot State University, is the State's University Center of Excellence in Developmental Disabilities (UCEDD). Community-based provider employees receive job certificates, associate degrees, and bachelor degrees in this cooperative DHS and UCEDD effort.

## II. QUALITY ASSURANCE OVERVIEW

In this section of the report, we review the most recent data from four quality assurance systems for services to children and adults with developmental disabilities in North Dakota. The quality assurance data sets are private accreditation results; Medicaid survey and certification data; state Protection and Advocacy agency substantiated instances of abuse, exploitation, or neglect; and IDEA performance reports for North Dakota's special education districts. North Dakota has a system of licensure of community residential services that is managed by the state Department of Human Services, Division of Disability Services. In addition, a Regional system of case management services helps to track outcomes related to individual needs, and identifies any follow-up that is needed to assure the individual's health and safety and quality of services and supports.

The following discussion of North Dakota quality assurance has three components: a) an overview and longitudinal study results for each of the four quality assurance programs, b) a summary of the individual Agency Quality Assurance Profiles constructed in the previous study and extended here for 28 North Dakota residential and community service agencies and for the North Dakota Developmental Center, and c) a concluding summary on the North Dakota quality assurance program for individuals with intellectual and developmental disabilities. References are made in the following discussion to detailed appendices addressing the accreditation, survey/certification, abuse/exploitation/neglect, and special education data sets.

### ***The Council Accreditation***

#### **The Standards and the Survey Process**

Since the 1980s, accreditation in North Dakota has been administered by the private association entitled The Council on Quality and Leadership in Supports for People with Disabilities ("The Council"). As we noted earlier (Braddock & Hemp, 2004), the Council in recent years substantially reformed both the standards and on-site survey procedures, moving from "compliance with organizational process" to "responsiveness to people."

In the accreditation surveys that were conducted in North Dakota during 1998-2006, The Council utilized a set of 25 standards for residential and community services agencies (*Table 2*). The standards consisted of 24 standards remaining from 1997, and one new standard, *treated fairly*. The table presents shortened descriptive phrases of The Council's standards. Although not illustrated in the table, each Council standard has two components: assessment of "outcome" and of "support." In surveys

beginning in 2006, the Council started phasing in a new set of 21 standards. The new set consists of the standards in *Table 2*, excepting numbers 5, 6, 7, and 8 (*satisfied with services, satisfied with life situation, choice of routine, and privacy*). These four standards were utilized in previous surveys during 1996-2006.

The Council's surveyors visit an agency for one or more days. Surveyors select a random sample of participants, ranging from three to 12 participants, in the North Dakota surveys reviewed in this 2009 study. The surveyors consider the "outcome" and "support" accreditation results for each of the individuals in this sample. Surveyors review records and talk with staff and with individuals with I/DD served by the agency, including those

**Table 2**  
**THE COUNCIL'S ACCREDITATION STANDARDS FOR RESIDENTIAL AND DAY/WORK SERVICES<sup>1</sup>**

1. Choice of goals
2. Choice in living
3. Choice in work
4. Intimate relationships
5. Satisfied with services<sup>2</sup>
6. Satisfied with life situation<sup>2</sup>
7. Choice of routine<sup>2</sup>
8. Privacy<sup>2</sup>
9. When to share personal info
10. Use environments
11. Integrated environments
12. Participate in community life
13. Interact with community
14. Perform social roles
15. Have friends
16. Respected
17. Choice of services
18. Realize goals
19. Connect to natural support
20. People are safe
21. Exercise rights
22. Treated fairly
23. Best health
24. Free from abuse, neglect
25. Continuity and security

<sup>1</sup>Thirty Council accreditation standards were applicable to North Dakota Agencies surveyed in 1996 and 1997. Six standards (*choice of time, due process afforded, personal possessions, health services, economic resources, and insurance*) were dropped, and one standard, *treated fairly*, was added to constitute the set of 25.

<sup>2</sup>These four standards, beginning with some North Dakota agencies surveyed during 2006-08, are no longer applicable.

in the random sample. Family members and citizens who do not work at the surveyed agency may be interviewed as well.

The Council surveyors develop an accreditation score for the agency by determining the number of participants in the sample who, for each of the 25 (or newer set of 21) standards, are experiencing the desired outcome and/or are receiving the required support from the organization. The accreditation scores for outcome and support that The Council reports to the agency are expressed as “mean number of outcomes present” and “mean number of supports present.”

### Analysis of Accreditation Survey Data

A summary of 13 years of accreditation results in North Dakota is presented in **Table 3**. These data are organized according to the calendar year of survey, and there is a final column for each of the 28 agencies’ most recent surveys occurring from June 4, 2004 to January 21, 2008. Six of the North Dakota residential and community services agencies’ most recent surveys were in 2008, five were in 2007, nine in 2006, five in 2005, and one in 2004. These data exclude the North Dakota Developmental Center at Grafton.

The table summarizes those standards on which 30% or more North Dakota agencies were in noncompliance, or the inverse of a “compliance” percentage. In

**Table 3**  
**ACCREDITATION COUNCIL SURVEY RESULTS FOR RESIDENTIAL AND COMMUNITY SERVICES**  
**AGENCIES IN NORTH DAKOTA, 1996-2008**

Number and Description of Council Standard	Proportion of Sample Not Receiving Outcome/Support for Surveys in:													
	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	Most Recent
1. Choice of goals	50%	68%	40%	41%			31%							
2. Choice in living		42%			38%	39%	33%	46%	32%	39%	34%	39%	44%	34%
3. Choice in work	33%	55%	36%	40%	30%	42%		52%		30%		31%		31%
4. Intimate relationships		37%												
6. Satisfied w/ life situation	53%	52%												
9. When to share personal info								32%						
11. Integrated environments	55%	77%	51%	47%	46%	56%	46%	70%	54%	50%	65%	52%	33%	53%
14. Perform social roles	42%	73%	58%	49%	57%	55%	41%	50%	55%	62%	44%	46%	35%	49%
15. Have friends		41%					30%		33%	36%		31%	45%	35%
17. Choice of services	46%	34%	41%	30%	38%									
19. Connect to natural support		37%					31%				34%	33%		
21. Exercise rights	33%	72%		47%	35%		35%							
22. Treated fairly			30%	32%										
23. Best health														
15. Due process afforded (1996-97)		60%												
<b>NUMBER OF AGENCIES SURVEYED</b>	<b>5</b>	<b>17</b>	<b>7</b>	<b>15</b>	<b>13</b>	<b>6</b>	<b>14</b>	<b>8</b>	<b>6</b>	<b>14</b>	<b>9</b>	<b>5</b>	<b>6</b>	<b>28</b>
<b># AWARDED 4-YEAR ACCREDITATION</b>								1			2	3	4	9
<b># AWARDED 3-YEAR ACCREDITATION</b>	5	6	1	8	6	3	12	5	5	11	6	2	2	18
<b># AWARDED 2-YEAR ACCREDITATION</b>		11	6	6	7	3	2	2	1	3	1			1
<b># AWARDED 1-YEAR ACCREDITATION</b>				1										
<b>Percentage of 3/4-year Accreditation</b>	<b>100%</b>	<b>35%</b>	<b>14%</b>	<b>53%</b>	<b>46%</b>	<b>50%</b>	<b>86%</b>	<b>75%</b>	<b>83%</b>	<b>79%</b>	<b>89%</b>	<b>100%</b>	<b>100%</b>	<b>96%</b>

determining the compliance percentages, we consolidated The Council's "outcome" and "support" scores for each standard. That is, if all individuals in the surveyors' sample were judged to have received both outcome and the support for all 25 (or 21) standards, the score for the agency would be 100% compliance (0% noncompliance). An example of less than 100% might include an agency, with four participants in the sample, in which all four were determined to receive the desired outcome on a particular standard, but only three of the four received the required support. This compliance percentage would be seven of a possible eight, or 87.5%, and the noncompliance percentage would be 12.5%. The Council does not attribute differing weights to the 25 standards, and we therefore determine average compliance and noncompliance "scores" for an agency as the means of scores on the 25 (or 21) standards.

### Surveys by Year

The North Dakota annual average compliance scores based on the 25 standards during 1998-2008, some agencies surveyed with 21 standards during 2006-08, and the 30 standards during 1996-97 were 83%, 73%, 78%, 78%, 78%, 78%, 81%, 79%, 82%, 81%, 83%, 79%, and 85%, respectively. In each year the average score for North Dakota agencies was above the United States average of all agencies surveyed by The Council.

The five standards that were particularly problematic for North Dakota agencies across all or most of the 13 years included *choice in living*, *choice in work*, *integrated environments*, *perform social roles*, and *have friends*.

**Table 3** also indicates how many North Dakota agencies each year received 4-year, 3-year, 2-year, or 1-year Council accreditation awards. North Dakota agencies' performance was the strongest in 1996, 2002, 2006, 2007, and 2008 when the proportions of 3 or 4-year accreditation outcomes were 100%, 86%, 89%, 100%, and 100%, respectively. The smallest proportions of 3 or 4-year accreditation awards were during 1997-2001 (35%, 14%, 53%, 46% and 50%, respectively).

### Most Recent Surveys

The most recently surveyed agencies as a group shared the four problematic standards as those for agencies surveyed across the years: *choice in living*, *choice in work*, *integrated environments*, *perform social roles* and *have friends*. As noted, 18 of the

28 agencies' most recent surveys, or 64%, resulted in 3-year awards; there were nine 4-year and one 2-year accreditation awards in agencies' most recent surveys.

The majority of North Dakota's agencies first received accreditation surveys in the early to mid 1980s. Agencies generally progressed from an initial accreditation survey result of "deferred," or "working toward accreditation," through 1-year, 2-year, and, ultimately, a 4-year accreditation award (see the Agency Quality Assurance Profiles in *Appendix 11* for the individual agencies' histories of accreditation outcomes). Tables in *Appendices 2-4* detail the scores for each North Dakota agency on each of the 25 (or 21) standards applicable to surveys during 2006, 2007, and 2008, and each agency's most recent survey is summarized in *Appendix 5*. The individual agency score on each standard is compared to the nationwide average for that standard, and each agency's score for any standard that is one or more standard deviations below the North Dakota mean is highlighted with an underline and bolding.

## ***Medicaid ICF/MR Survey and Certification***

### **The Standards ("Requirements") and the Survey Process**

In North Dakota, agency participation in Council accreditation is mandated by the state Department of Human Services. Medicaid certification is administered by the federal Centers for Medicare and Medicaid Services (CMS), formerly termed the Health Care Financing Administration (HCFA). Medicaid certification is a requirement for facilities to continue receiving federal financial participation on behalf of the residents they serve. In North Dakota, the CMS delegates authority for survey/certification to the state's Department of Health.

The federal Centers for Medicare and Medicaid Services utilizes the ICF/MR certification surveys to determine a facility's continued eligibility for federal financial participation (FFP). The ICF/MR certification survey process consists of two separate visits. The first generates a "plan of correction," whereby the surveyed facility responds to any cited ICF/MR program requirements that were found deficient. The second survey determines life-safety code (LSC) deficiencies. The second survey culminates in the issuing of an "On-Line Survey, Certification and Reporting" (OSCAR) report that

consolidates the surveyed facility's program and life-safety code deficiencies and presents regional and national comparisons.

Medicaid program requirements pertain to staff qualifications, individual program planning, medication controls, and physician, nursing and other professional services. Life-safety code requirements address environmental issues including emergency exits, adequacy of room and corridor design, and other physical plant safety issues. The ICF/MR certification standards also distinguish those requirements that are "conditions of participation" (COP), essential to be met for the surveyed facility to continue to receive ICF/MR reimbursement. Examples of COP requirements are provisions related to individual program planning (IPP) and continuous active treatment, medical care plans, assignment and performance of each resident's Qualified Mental Retardation Professional (QMRP), staff training, and privacy and independence. The CMS regional (i.e., multi-state) offices also have discretion to identify, with "regional flags," those standards that they feel must receive special attention in the surveyed agencies' plans of correction.

### **North Dakota ICF/MR Survey and Certification Results**

We analyzed 48 ICF/MR certification surveys in 1997, 66 in 1998 and in 1999, 65 in 2000, 63 in 2001, 66 in 2002, 58 in 2003, 64 in 2004, 67 in 2005, 70 in 2006, and 62 in 2007. We had access to a partial year's data for 2008, consisting of 28 of the 63 residential and community services agencies' ICFs/MR and the four ICF/MR units at the North Dakota Developmental Center at Grafton.

**Table 4** summarizes the program and life-safety code requirements that were cited as deficient for 10% or more of the North Dakota ICFs/MR, in one or more survey year during 2003-2008. Thirteen program requirements and 12 life-safety code requirements met this criterion.

- The most frequently cited program requirement deficiencies across all years were *Individual Program Plan (IPP) specific objectives; train for privacy, independence; IPP and continuous active treatment; IPP in measurable terms; promote the growth, development and independence of clients; individual medication administration record for each client; all drugs administered without error; and dine according to developmental level.*

**Table 4**  
**ICF/MR Program Requirements Cited as Deficient in**  
**10% or More North Dakota Facilities, 2003-2008**

**Year of survey and number of surveyed facilities:**

2003 (n=58)	2004 (n=64)	2005 (n=67)	2006 (n=70)	2007 (n=62)	2008 (n=28)
----------------	----------------	----------------	----------------	----------------	----------------

**Number and % of facilities with deficiency:**

	#	%	#	%	#	%	#	%	#	%	#	%
W154 Investigate all alleged incidents of abuse, neglect	8	14%	2	3%	7	10%	1	1%	9	15%	0	0%
W227 IPP specific objectives	8	14%	12	19%	12	18%	6	9%	4	6%	2	7%
W242 Train for privacy, independence	23	39%	8	13%	9	13%	10	14%	11	18%	4	14%
W249 C.O.P. IPP and continuous active Tx	15	25%	15	23%	10	15%	17	24%	13	21%	10	36%
W252 *IPP data in measurable terms	6	10%	3	5%	5	7%	6	9%	5	8%	1	4%
W262 Committee review of risks; IPP	4	7%	7	11%	4	6%	3	4%	8	13%	0	0%
W268 Promote the growth, development and independence of client	3	5%	4	6%	7	10%	3	4%	5	8%	6	21%
W365 Individual medication administration record for each client	7	12%	3	5%	3	4%	2	3%	7	11%	4	14%
W368 All drugs with physician's order	2	3%	8	13%	7	10%	1	1%	3	5%	0	0%
W369 All drugs administered without error	2	3%	7	11%	6	9%	5	7%	9	15%	6	21%
W371 Clients taught to self-administer drugs if appropriate	15	25%	6	9%	2	3%	5	7%	1	2%	0	0%
W455 Infection control: active program	1	2%	0	0%	3	4%	4	6%	6	10%	3	11%
W488 Dine according to developmental level	11	19%	12	19%	7	10%	12	17%	5	8%	9	32%

**ICF/MR Life Safety Code Requirements Cited as Deficient in**  
**10% or More North Dakota Facilities, 2003-2008**

**Year of survey and number of surveyed facilities:**

2003 (n=58)	2004 (n=64)	2005 (n=67)	2006 (n=70)	2007 (n=62)	2008 (n=28)
----------------	----------------	----------------	----------------	----------------	----------------

**Number and % of facilities with deficiency:**

	#	%	#	%	#	%	#	%	#	%	#	%
K0017 Corridor walls	7	12%	7	11%	6	9%	14	20%	1	2%	1	4%
K0018 Corridor doors	8	14%	8	13%	18	27%	13	19%	9	15%	4	14%
K0029 Hazardous areas - separation	3	5%	5	8%	6	9%	0	0%	3	5%	7	25%
K0032 Remote exits	18	31%	11	17%	7	10%	9	13%	5	8%	3	11%
K0043 Patient room locks	3	5%	4	6%	6	9%	7	10%	1	2%	2	7%
K0051 Fire alarm system	3	5%	1	2%	17	25%	51	73%	18	29%	2	7%
K0053 Automatic smoke detection system	2	3%	4	6%	16	24%	16	23%	16	26%	0	0%
K0056 Automatic sprinkler system	10	17%	27	42%	32	48%	38	54%	19	31%	6	21%
K0130 Other (Surveyors did not specify)	18	31%	12	19%	26	39%	28	40%	30	48%	17	61%
K0148 Smoking regulations	na	na	na	na	na	na	15	21%	1	2%	0	0%
K0149 Noncombustible ashtrays	na	na	na	na	na	na	9	13%	10	16%	1	4%
K0152 Evacuation drills	0	0%	0	0%	6	9%	7	10%	16	26%	3	11%

<sup>1</sup>CMS (HCFA) Regional Office Flags  
"na" ICF/MR requirement not applicable in surveys that year.

These ICF/MR requirements were cited for relatively high percentages of North Dakota ICFs/MR.

The most frequently cited life-safety code deficiencies across all years were

- *Corridor doors; hazardous areas-separation; remote exits; fire alarm system; automatic smoke detection system; automatic sprinkler system; other (surveyors did not specify); and evacuation drills.*

The performance of North Dakota ICFs/MR on Medicaid survey and certification can be compared to the ICFs/MR surveyed in CMS Region 8 (Colorado, Montana, North Dakota, South Dakota, Utah, and Wyoming), and in the nation as a whole (see *Appendix 6*). The comparative statistic is requirements for which North Dakota ICFs/MR had a higher proportion of deficiencies than both the Region and the United States in the three most recent years, 2006-08, and for which North Dakota ICF/MR deficiency percentages were 10% or more:

### ***Program Deficiencies***

- Treatment program implemented when IPP formulated (a *Condition of Participation* in the Medicaid program)
- Promote the growth, development, and independence of client
- Individual medication administration record for each client
- All drugs administered without error
- Infection control: Active program
- Dine according to developmental level

### ***Life Safety Code Deficiencies***

- Corridor doors
- Hazardous areas – separation
- Remote exits
- Other (Surveyors did not specify)

*Appendix 7* details the North Dakota facilities' performance on ICF/MR certification surveys during 2000-08. The appendix indicates the number and percentage of agencies each year that were cited on each of the standards. Although there were 377 applicable ICF/MR program requirements, we have included only those that were found to be deficient for 10% or more North Dakota ICFs/MR, in one or more of the years spanning 2000-08. During those nine years, North Dakota agencies were cited for 10%, 14%, 12%, 15%, 11%, 12%, 12%, 14% and 8%, respectively, of the total 377 applicable program standards. (As noted, survey data for 2008 were for a partial year; the 28 surveys that year represented 45% of the 62 surveys that were conducted in 2007.)

### ***Protection and Advocacy Agency Investigations***

Investigations of abuse, exploitation, and neglect have their foundation in the Protection and Advocacy for Persons with Developmental Disabilities (PADD)

provisions contained in the Developmental Disabilities Assistance and Bill of Rights Act of 1975 (Pub. L. 94-103), and the Protection and Advocacy for Individual Rights (PAIR) provisions in the 1993 Rehabilitation Act. The North Dakota Protection and Advocacy (P&A) Agency is mandated by this legislation to investigate allegations of abuse and neglect affecting individuals with intellectual and developmental disabilities in the State. The P&A staff must determine whether or not the allegation is substantiated, and assign each alleged incident to the appropriate category of abuse, exploitation, or neglect.

North Dakota Department of Human Services (DHS) policy DDD-PI-006 outlines the reporting and investigation requirements for licensed developmental disabilities providers regarding abuse, neglect, and exploitation. According to state officials, the Centers for Medicare and Medicaid Services, in its January 22, 2004 report on the North Dakota HCBS waiver, noted that North Dakota's reporting of abuse, neglect and exploitation has been integrated into the quality enhancement process that ensures the health and welfare of consumers. CMS also noted that North Dakota has standards for providers and that the state's philosophy encouraged providers to report incidents of abuse, neglect, and exploitation (Braddock & Hemp, 2004; Hysjulien, 2004).

The North Dakota P&A Project's abuse, exploitation, and neglect data were not provided for analysis on an agency or facility basis, except for the North Dakota Developmental Center at Grafton. Therefore, the individual Agency Quality Assurance Profiles (*Appendix 11*) do not detail abuse, exploitation, or neglect data on an agency-by-agency basis.

### **Analysis of Abuse, Exploitation, and Neglect Data**

Aggregate statewide abuse, exploitation, and neglect data were examined over a 13-year period, 1996-2008 (*Table 5*). [The 2000 data afforded no detail within the broad areas of abuse, exploitation, and neglect.] Across the 13 years, there were 440 substantiated incidents of abuse, 73 incidents of exploitation, and 1,575 incidents of neglect (part-year data only were available for 1996 and again in 2008). Except for 2000, data each year were reported across eight categories of abuse, two categories of exploitation, and eight categories of neglect.

In the area of abuse there were no reported incidents in 2004-08 in three categories: *threats of retaliation*, *inappropriate/excessive meds*, and *involuntary aversive*

**Table 5  
SUBSTANTIATED INCIDENTS OF ABUSE,  
EXPLOITATION, OR NEGLECT, 1996-2008**

	ALL SITES													ALL YEARS
	96	97	98	99	00 <sup>1</sup>	01	02	03 <sup>2</sup>	04 <sup>3</sup>	05 <sup>3</sup>	06 <sup>3</sup>	07 <sup>3</sup>	08 <sup>3,4</sup>	
ABUSE: Physical	5	5	13	12		9	15	4	19	13	20	15	14	144
ABUSE: Verbal	0	0	0	0		9	13	5	17	12	8	22	11	97
ABUSE: Restraint/Isolation/Seclusion	3	6	12	6		3	9	2	6	9	6	7	4	73
ABUSE: Threats of retaliation	10	12	11	15		0	0	0	0	0	0	0	0	48
ABUSE: Sexual	2	0	1	2		0	0	0	2	0	0	0	0	7
ABUSE: Inappropriate/excessive meds	3	4	0	3		0	0	0	0	0	0	0	0	10
ABUSE: Other	1	4	2	1		2	0	0	2	5	0	6	1	24
ABUSE: Involuntary Aversive Beh. Therapy	1	0	2	0		0	0	0	0	0	0	0	0	3
<b>ABUSE SUM</b>	<b>25</b>	<b>31</b>	<b>41</b>	<b>39</b>	<b>34</b>	<b>23</b>	<b>37</b>	<b>11</b>	<b>46</b>	<b>39</b>	<b>34</b>	<b>50</b>	<b>30</b>	<b>440</b>
EXPLOITATION: Other	0	1	0	0		0	2	2	4	5	3	1	2	20
EXPLOITATION: Financial	5	8	3	1		3	7	3	2	7	5	3	3	50
<b>EXPLOITATION SUM</b>	<b>5</b>	<b>9</b>	<b>3</b>	<b>1</b>	<b>3</b>	<b>3</b>	<b>9</b>	<b>5</b>	<b>6</b>	<b>12</b>	<b>8</b>	<b>4</b>	<b>5</b>	<b>73</b>
NEGLECT: Other	1	10	10	6		8	9	10	9	7	2	4	15	91
NEGLECT: Personal safety	11	21	28	18		30	40	30	41	45	57	71	40	432
NEGLECT: Medication errors	0	0	0	0	<sup>1</sup>	26	70	38	42	56	45	53	36	366
NEGLECT: Personal care	8	16	16	19		12	20	13	19	35	30	50	27	265
NEGLECT: Fail to provide medical tx	1	2	8	8		2	7	6	11	4	7	9	3	68
NEGLECT: Habilitation/discharge planning	0	0	0	0		9	15	7	22	26	20	8	19	126
NEGLECT: Written hab plan	8	13	14	10		0	0	0	0	0	0	0	0	45
NEGLECT: Diagnosis/other med. eval.	1	0	0	0		0	0	0	0	0	0	0	0	1
<b>NEGLECT SUM</b>	<b>30</b>	<b>62</b>	<b>76</b>	<b>61</b>	<b>181</b>	<b>87</b>	<b>161</b>	<b>104</b>	<b>144</b>	<b>173</b>	<b>161</b>	<b>195</b>	<b>140</b>	<b>1,575</b>
<b>GRAND TOTAL</b>	<b>60</b>	<b>102</b>	<b>120</b>	<b>101</b>	<b>218</b>	<b>113</b>	<b>207</b>	<b>120</b>	<b>196</b>	<b>224</b>	<b>203</b>	<b>249</b>	<b>175</b>	<b>2,088</b>

<sup>1</sup> Spike in 2000 attributable to *neglect: medication errors*; see discussion in Braddock, Hemp, & Rizzolo, 2002.

<sup>2</sup> In 2003, all sites included only *day programs, group homes, ISLA/SLA, and family support*

<sup>3</sup> In 2004-08, all sites included only *day programs, group homes, ISLA/SLA, family support, developmental center, supported employment program/extended employment program (SEP/EP), and community*

<sup>4</sup> Incomplete year of data in 2008 (through 8/18/08 for the developmental center; through 5/2/08 for day programs, 5/12/08 for ISLA/SLA, 5/08/08 for group homes, 5/9/08 for family support, 4/18/08 for community, and 3/16/08 for SEP/EP.

behavior therapy, and no reported incidents of *sexual abuse* during 2005-08. In addition, there were no reported incidents of neglect during 2004-08 in two categories: *written habilitation plan* and *diagnosis/other medical evaluation*. Both categories of exploitation, *financial* and *other*, declined from 2006 to 2007. However, between 2006 and 2007 there was a nearly three-fold increase in the category *verbal abuse*. Based on the roughly five months now reported (through May 2008), it would appear that complete 2008 data on substantiated instances of verbal abuse would meet or exceed the number of incidents reported in 2007.

There were increases between 2006 and 2007 in four categories of neglect (*personal safety, medication errors, personal care, and failure to provide medical treatment*). There was a slight increase in the neglect category *other*, and a decline in the category *habilitation and discharge planning*.

As reported previously, important caveats, in addition to the partial year data for 2008, apply to the interpretation of the abuse, exploitation, and neglect data. For example, comparatively more substantiated incidents were recorded in those settings that served the largest proportion of individuals (*Appendix 8*). It therefore would not be appropriate to infer the superiority of one type of setting over another based solely on these abuse, exploitation, and neglect data. Potential “artifacts of reporting” include staff turnover or other variations in the resources of the P&A Agency investigation team over time, which could differentially affect the investigation and reporting of incidents at various types of settings.

There might also be comparatively more restrictions on investigators’ access to individuals or their records in some settings, or relatives or advocates might tend to more readily identify, and call for investigation of, alleged incidents of abuse, exploitation, or neglect in certain settings. Finally, more conscientious staff could contribute to increased reporting of abuse for a given residential and community service or developmental center setting.

*Appendix 8* provides detail by type of setting, year, and category of abuse, exploitation, or neglect. [Data were not available by agency.] The table in the appendix provides two totals across all categories—a grand total of 2,088, and a total of 1,870 that excludes the 2000 data that were not allocable by category of abuse, exploitation, and neglect, nor by type of setting. For 1996 to 1999 combined with 2001 to 2008, 44% of the 1,870 substantiated incidents of abuse, exploitation, and neglect was documented at group homes, 29% at ISLA/SLA and apartment settings, 13% at day programs, 11% at units of the North Dakota Developmental Center, and one percent at congregate/ICFs/MR and at “community.” Substantiated incidents at all other categories of setting (family support, parent/school, long-term care/nursing home, foster care, hospital, and transportation) together constituted one percent of the total for all sites during the 12 years (1996-2008, excluding 2000). Data on “repeat” incidents of abuse, exploitation, or neglect, presented in *Appendix 8*, were available for 2001-08. Across these eight years, there were 39 repeat incidents of abuse, seven repeat incidents of exploitation, and 420 repeat incidents of neglect.

## **Special Education District Performance Reports**

In our previous reports, we utilized North Dakota Department of Public Instruction (DPI) monitoring reports that summarized, for 31 special education units, the degree of compliance with IDEA regulations (Braddock & Hemp, 2007). For this 2009 study, such monitoring reports were not available. However, we were provided with North Dakota Special Education District Performance “Report Cards” for 189 districts across the state. The two-page Reports summarized several indicators, such as graduation rate, drop-out rate, participation/proficiency rates in reading and math, transition success, post-secondary outcomes, and parent involvement. There were columns for “2005-06 target,” “2005-06 State Rate,” “2005-06 District Rate,” and “Did District Meet the Target.”

While data were incomplete for a number of the indicators, there were nearly complete data for “Least Restrictive Environment (LRE) for Students,” measured in terms of the percent of children with IEPs aged six through 21 years in regular classrooms 80% or more of the time, separate classrooms, and in separate facilities. For most districts the three listed environments did not add to 100%, and information was not available on what the remaining LRE categories were. However, it would be reasonable to assume that the majority of this “other” category is for the remaining LRE category, “outside the regular classroom 21-60% of the time.”

With the available data, we have provided descriptive statistics on the LRE status of the 189 special education districts. Thirty-three of the 189 districts had fewer than 10 special education students, and the LRE status, due to confidentiality concerns, could not be printed in the performance reports. Following, therefore, are summary statistics for the 156 special education districts in North Dakota that reported LRE data for school year 2005-06.

**Regular Classroom:** Sixteen districts reported that 100% of their special education students remained in their regular classroom, 80% or more of the day. The statewide average percentage of special education students in regular classrooms was 79%. Ninety of the districts, in addition to the 16 with 100% regular classroom attendance, exceeded the statewide average. The remaining 50 districts that were below the statewide average had student participation rates in regular classrooms ranging from 78% to 31%. Nineteen districts’ students had below 70% participation rates in regular classrooms.

**Separate Classrooms:** More than half, 84 of the 156 special education districts, reported no LRE placements in separate classrooms (i.e., no students were removed from regular classes for more than 60% of the day). For the 72 districts that utilized separate classrooms, the rates ranged from 1-18% of the district's students in such separate classes. Forty-five districts exceeded the statewide average rate of 4% for separate classroom placement, and in 16 districts separate classroom usage was 7% or greater.

**Separate Facilities:** Fifty-three North Dakota special education districts reported using "public or private separate schools, residential placements, or homebound or hospital placements." The rates ranged from 0.7-13% of students, and 39 of the 53 districts were above the statewide average of 2%. In fact, 14 districts had in excess of 5% of their special education students in separate facilities.

**Appendix 10** summarizes the LRE data for 156 special education districts in North Dakota.

### **Agency Quality Assurance Profiles**

**Appendix 11** consists of Agency Quality Assurance Profiles for 28 North Dakota residential and community service agencies, and for the North Dakota Developmental Center at Grafton. Data for one agency, # 5, were last available in 2002 (Braddock, et al., 2002) and data for agency # 10 were first included in a previous report (Braddock & Hemp, 2004).

Each profile consists of two sections summarizing data on accreditation surveys and ICF/MR surveys. In the appendix we describe an Agency Quality Assurance Profile, utilizing Agency # 29 as an example. The agency is fairly typical in that it operates two ICFs/MR, and is subject to accreditation standards. Some North Dakota residential and community services agencies did not operate ICFs/MR; however, all received accreditation surveys by The Council. Furthermore, all agencies were under the purview of the federally-mandated abuse, exploitation, and neglect investigations undertaken by the North Dakota Protection and Advocacy Project, but, as noted above, these agency-by-agency data are no longer available. (See the discussion above of the multi-year trend in substantiated incidents of abuse, exploitation, and neglect, and **Appendix 8** for a breakout by type of setting.)

The accreditation section of the Agency Quality Assurance Profiles (*Appendix II*) presents for each organization its history of accreditation survey dates and outcomes. The Profiles illustrate agencies' problematic standards in the most recent survey and whether any of these problematic standards were repeated from the previous accreditation survey. The problematic standards identified in the Profile are those on which the agency performed at one or more standard deviation below the North Dakota mean. The Profiles also indicate agencies' over-all scores on the most recent survey compared to the North Dakota and United States averages.

The ICF/MR Survey and Certification sections of the Agency Quality Assurance Profiles in the appendix compare agencies' ICF/MR survey results to all 67 ICFs/MR that were surveyed in North Dakota. They are also compared to all ICFs/MR surveyed in the six-state region (Colorado, Montana, North Dakota, South Dakota, Utah, and Wyoming).

The North Dakota Developmental Center units are certified as ICF/MR, but these data are not integrated with composite North Dakota ICF/MR deficiency data pertaining to community based ICFs/MR. The Developmental Center units' accreditation data also are not integrated with the residential and community service agency data that are presented in *Appendices 2-5*, but are detailed in the Developmental Center Quality Assurance Profile in *Appendix 11*, and the Center's Profile is discussed in detail here.

## ***The North Dakota Developmental Center Quality Assurance Profile***

### **Accreditation**

The Council's most recent survey of the North Dakota Developmental Center at Grafton was in September 2007. The facility received a 4-year award. There had been five successive 2-year accreditation awards from 1989 to 1998, a 3-year award in the 2000, a 2-year award in 2003, and a 3-year award in 2005. The two standards that were problematic for the facility in the most recent survey were *choice in living* (33% compliance) and *participate in community life* (67%). These are the standards on which the Developmental Center scored one or more standard deviation below the North Dakota average for community agency surveys that year. Both of these problematic standards were also problematic in the previous survey in 2005 (i.e., they were repeat deficiencies).

The North Dakota Developmental Center attained scores on 13 of 21 standards that were 20% or more above the North Dakota community agency average score, and/or the Center attained 100% compliance on the standard. The Developmental Center's survey results were superior to the North Dakota residential and community service agency averages on the standards *choice of goals* (27% greater and 100% Developmental Center compliance); *intimate relationships* (25% greater and 100% Developmental Center compliance); *when to share personal information* (15% greater and 100% Developmental Center compliance); *use environments* (8% greater and 100% Developmental Center compliance); *perform social roles* (25% greater and 67% Developmental Center compliance); *have friends* (52% greater and 83% Developmental Center compliance); *respected* (4% greater and 100% Developmental Center compliance); *realize goals* (22% greater and 100% Developmental Center compliance); *connect to natural support* (24% greater and 83% Developmental Center compliance); *people are safe* (9% greater and 100% Developmental Center compliance); *treated fairly* (35% greater and 100% Developmental Center compliance); *best health* (20% greater and 100% Developmental Center compliance); and *free from abuse, neglect* (8% greater and 100% Developmental Center compliance). The Developmental Center is a segregated state-operated residential institution and cannot attain the standards related to integrated environments.

### Medicaid Survey and Certification

In the analysis of the Developmental Center's most recent Medicaid ICF/MR certification results, the Center's four units (coded A, B, C, and D) were cited on three, two, five, and one program deficiencies, respectively (see Agency Quality Assurance Profile # 40, in *Appendix II*). One program deficiency at the first Developmental Center ICF/MR unit, *train for privacy, independence* and two at the third ICF/MR unit, including the one cited at the first unit and also *IPP in measurable terms* received "Regional flags." The former requirement cited was a repeat deficiency at the third North Dakota Developmental Center ICF/MR unit.

There were other problematic requirements for Developmental Center units (i.e. requirements for which 10% or less of North Dakota and CMS Region 8 ICFs/MR were cited). The first ICF/MR unit had two such problematic requirements: *mistreatment*,

*neglect, abuse of client prohibited; and education, training in maintenance of oral health.* For the second ICF/MR unit, there was one problematic requirement: *infection control: sanitary.* The third unit was cited for deficiencies in three such problematic requirements: *IPP data in measurable terms; clients taught to self-administer drugs if appropriate; and drugs, biologicals kept locked.* The fourth unit was cited for one program requirement deficiency meeting the 10% criterion: *complete objectives in IPP.*

### **Summary: North Dakota Quality Assurance Programs**

Accreditation in North Dakota was mandated for residential and community services agencies as a result of *The Association for Retarded Citizens of North Dakota v. Olson* (1982) litigation. By the year 2008 nearly all agencies had undergone from eight to thirteen generally more successful accreditation surveys. In 2004, North Dakota agencies exceeded the national average on all of the 25 standards. In 2006, North Dakota agencies' averages were slightly lower than the national averages for two standards: *integrated environments* and *connect to natural support.* In 2007 three North Dakota averages were slightly lower: *have friends, realize goals, and connect to natural support.* In 2008, the North Dakota average was also somewhat lower than the national averages on *connect to natural support.*

North Dakota's ICFs/MR in the aggregate compare relatively well to all ICFs/MR surveyed in CMS Region 8 in terms of the frequency of cited program and life-safety code deficiencies. However, there were six program and four life-safety code requirements on which 10% or more North Dakota ICFs/MR were found deficient, and on which the North Dakota percentage of deficient facilities exceeded both the regional and national averages.

The data set now has historic ICF/MR survey outcome data, and we have noted the instances in which individual facilities have repeat deficiencies (see Agency Quality Assurance Profiles in **Appendix II**). Requirements cited as non-compliant for individual ICFs/MR in North Dakota can be compared to percentages of non-compliance for ICFs/MR surveyed across North Dakota and across the CMS Region. When percentages are relatively low for all ICFs/MR surveyed in the State and the Region, this constitutes a problematic requirement for the individual ICF/MR.

The North Dakota P&A project data on abuse, exploitation, and neglect data have no regional or national reference points. As discussed above, the spike in incidents of neglect pertaining in 2000 to *medication errors* must be understood in the context of improved reporting and other issues including “artifacts of reporting” related to staff turnover or the level of P&A Agency resources. Other issues noted were possible restrictions on investigators’ access to some individuals or their records, more attention to reporting in some settings by relatives or advocates, or more conscientious staff reporting incidents of abuse, exploitation, or neglect.

### III. EXECUTIVE SUMMARY AND CONCLUSION

The executive summary of study results is presented in two parts. The first provides findings and recommendations specific to the structure and financing of residential and community services. The findings/recommendations pertain to: 1) utilization of institutional and 7+ person group home settings; 2) accessing federal funding for expanding Home and Community Based Services; and 3) continuing the enhancement of wages and benefits for community services staff.

The second part of the executive summary provides an overview of the quality assurance component of the study. Quality assurance challenges in North Dakota include deficiencies on critical standards in accreditation surveys conducted by The Council on Quality and Leadership in Supports for People with Disabilities and Medicaid ICF/MR survey/certification reviews. Although North Dakota has continued to perform generally well in terms of national and regional comparisons, the State faces significant continuing challenges in providing services in integrated environments, connecting participants to natural supports, promoting participation in community living, and insuring health and safety.

In summary, this analysis of the structure, financing, and quality assurance of North Dakota's intellectual and developmental disabilities service system has identified continuing issues as well as some recent advances. Although North Dakota has made some progress during 2006-08, much remains to be done. To be addressed are continued reliance on public and private institutional settings and large group homes. This is manifest in the State's over-utilization of federal-state funding for Intermediate Care Facilities/Mental Retardation (ICFs/MR), and its comparative underutilization of the federal-state Home and Community Based Services (HCBS) Waiver program. North Dakota's rate of utilization of its state-operated developmental center exceeded the comparison states (Idaho, Montana, South Dakota, and Wyoming) by a factor of two to one. North Dakota has recently slightly reduced the census at the North Dakota Developmental Center from 146 persons in 2004 to 130 persons in 2008. The State, however, had previously increased the census of persons with I/DD at the North Dakota Developmental Center during 1995-2004. Census reduction at the Developmental Center has plateaued since the April 15, 1990, closing of the Court Monitor's office.

A key issue is the fact that the Accreditation Council is accrediting the North Dakota Developmental Center even though the facility does not comply with the Council's community integration standards. In fact, compliance with the Court Order of 1989 was tied to compliance with "ACDD standards." The Arc of North Dakota and other organizations representing disability interests in North Dakota should reconsider whether failure to enforce compliance with the Council's integration standards represents appropriate practice for individuals with I/DD currently residing at the North Dakota Developmental Center at Grafton.

### ***Part I Structure and Financing of Residential and Community Services***

#### **Total I/DD Spending Increases Negligibly in North Dakota During 2006-08**

***1. Total I/DD spending essentially plateaued during 2006-08, when adjusted for inflation.***

- Total adjusted I/DD spending increased only one percent during 2006-08. However, 16+ public and private facility spending declined nine percent during this period. Community spending increased by three percent.
- North Dakota's fiscal effort also increased negligibly (1%) during 2000-08. Institutional fiscal effort declined nine percent, and community services fiscal effort for persons in 1-15 person settings increased three percent.

#### **Over-Utilization of Institutional 16+ Person Settings and 7+ Group Homes Continues**

***2. North Dakota continues to over-utilize public and private 16+ institutions and 7+ group homes as well. Resource commitments should be enhanced for smaller, family-scale settings for six or fewer persons.***

- During 2006-08, the average daily census of residential settings for 16 or more persons declined by from 325 to 293, a 10% reduction.
- The decline was made up of a nursing facility reduction of seven persons (- 6%), a decline of seven persons at the North Dakota Developmental Center at Grafton (- 5%), and a decline of 20 persons in private 16+ residential settings (- 27%).
- During 2007-08, however, the census of 16+ residential settings increased by four persons. The North Dakota Developmental Center at Grafton reduced its

population by three persons, but nursing facilities increased by six persons and the Anne Carlsen Center ICF/MR increased by one person.

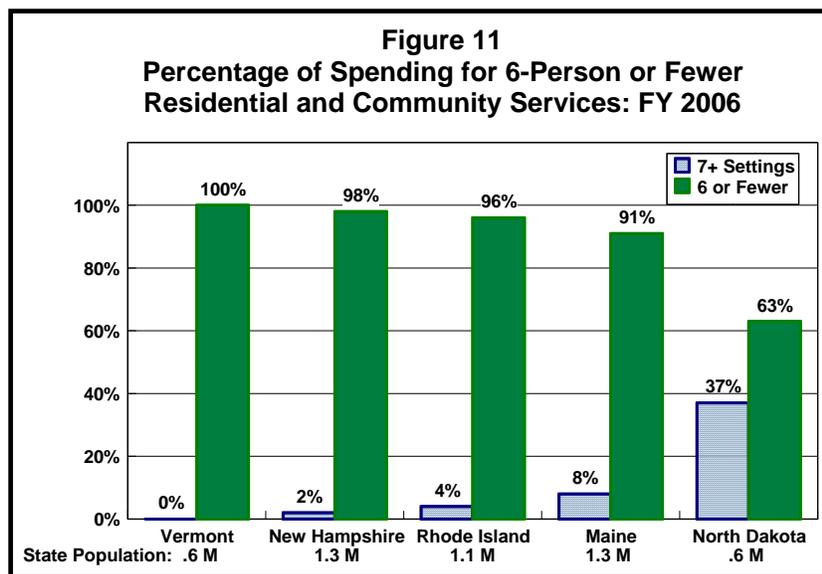
- Persons in 7+ group settings declined by 16 persons (- 3%) during 2006-08. This entailed a reduction of eight persons in 7+ ICFs/MR (- 3%) and a reduction of eight persons in group homes (- 4%).
- After the momentum of the 1980-93 Arc lawsuit diminished, census reduction at the North Dakota Developmental Center stalled, and actually increased during 1995-2004.

North Dakota ranked 9<sup>th</sup> nationally in 2006 in state-operated institutional utilization per 100,000 of the general population among the 41 states that still financed state-operated institutions. Nursing facility utilization in North Dakota also ranked 9<sup>th</sup> highest nationally. Only New York ranked higher than North Dakota in 7-15 person facility utilization. (North Dakota ranked 2<sup>nd</sup> nationally.) North Dakota also significantly lags the dominant national trend in the proportion of resources dedicated to six or fewer person settings, ranking 44<sup>th</sup> in 2006.

**Figure 11** compares North Dakota on utilization of six or less and 7+ person measures to four New England states with roughly the same state general population as North Dakota which in 2008 had a 0.6 million general population. North Dakota’s proportion of I/DD spending committed to larger settings of seven or more persons was four times that of each of the New England comparison states in 2006.

The Mountain West/Plains states are an even more useful comparison group of states than the New England region. These four states include: South Dakota (0.8 million

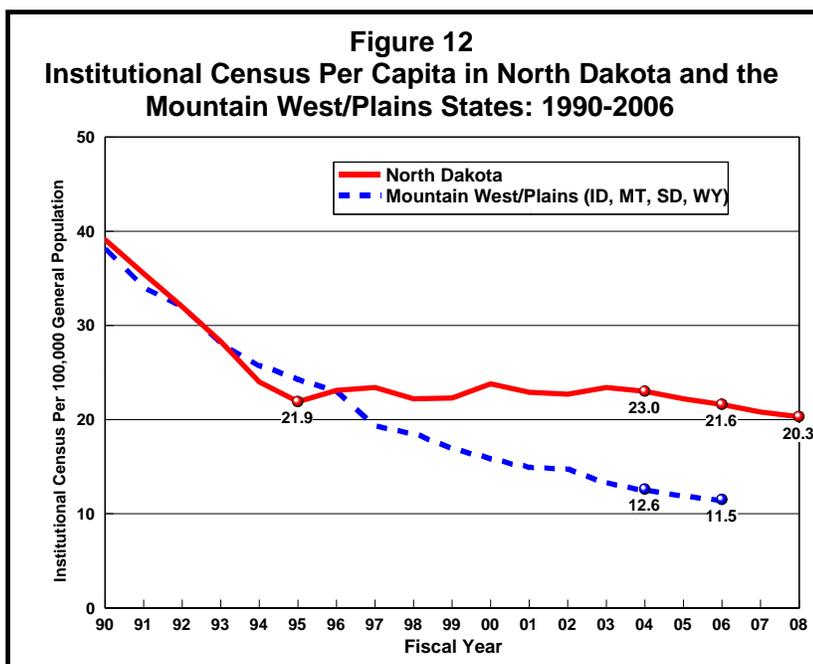
population), Wyoming (0.5 million), Montana (1.0 million), and Idaho (1.5 million). Each of these states, like North Dakota, also has one remaining institution. Their 2006 I/DD institutional censuses were 77 (MT), 90 (ID), 88 (WY), and 162 (SD),



compared to 137 in North Dakota. Although South Dakota's census in 2006 was larger than North Dakota's, all four of these comparison states had lower institutional utilization rates per capita (per 100,000 of the state general population).

The four mountain west/plains comparison states diverged significantly from North Dakota in institutional utilization in 1997, as shown in *Figure 12*. In 2006, North Dakota's institutional utilization rate exceeded the aggregate of the four comparison states by 88% (21.6 vs. 11.5). Moreover, each of the four comparison states committed a considerably larger

share of total I/DD spending to six-person or fewer residential and community services (91-100%) compared to only 63% in North Dakota. North Dakota's utilization rate for state-operated institutional care has been essentially stable during 1995-



2008. However, there was modest census reduction in North Dakota during 2004-08.

On a highly positive note, in 2007 North Dakota received \$8.9 million for a “Money Follows the Person” grant from the Centers for Medicare and Medicaid Services (CMS). Effective June 2008 through September 2011, the grant is designed to move approximately 110 persons with mental and physical disabilities from nursing facilities and ICFs/MR to community-based settings. In the case of individuals with I/DD, this involves movement of 30 persons from ICFs/MR (Lipson et al., 2007; North Dakota Department of Human Services, 2008).

<p style="text-align: center;"><b>Home and Community Based Services Waiver Expansion is Recommended</b></p>
---

**3. *Although HCBS Waiver spending in North Dakota surpassed ICF/MR spending in 2007, the State still lags behind most states in Waiver spending. Expansion of the HCBS Waiver should continue.***

- The HCBS Waiver in North Dakota was the means by which much of the progress in developing new six person or fewer residential settings and providing family support funding was accomplished during 2006-08.
  - The census of six person or fewer residential settings increased by 222 persons during 2006-08 (19%).
  - Private ICFs/MR for six or fewer persons increased by 22 persons during 2006-08 (17%); six person or fewer group homes increased by 106 persons (101%), and supported living increased by 95 persons (10%).
- Also during 2006-08, North Dakota's adjusted HCBS Waiver spending increased 10%, and the number of Waiver participants increased by 123 persons (4%).
- Total adjusted ICF/MR spending during 2006-08 decreased by 11%, and the number of ICF/MR recipients increased by eight persons (1%), primarily due to an increased number of persons in six person/fewer private ICFs/MR, coupled with declines in the Developmental Center and in 7+ person ICFs/MR.
- Due to the 2006-08 Waiver spending increase and the ICF/MR spending reduction, North Dakota's HCBS Waiver spending surpassed ICF/MR spending for the first time in 2007.
- Waiver spending per participant, adjusted for inflation, declined from \$19.8 thousand in 2006 to \$19.1 thousand in 2008 (- 4%).

In 2006, North Dakota ranked 38<sup>th</sup> among the states in federal-state Waiver spending as a percentage of total I/DD spending, a decline from the rank of 33<sup>rd</sup> in 2004. North Dakota HCBS Waiver spending only surpassed ICF/MR spending in 2007. (In 2006, only nine states and DC had failed to attain this benchmark. Four of these states and DC are expected to do so in 2008.) The HCBS Waiver is the principal means of expansion of individual and family support, community residences, and related community support services throughout the State. North Dakota should continue to expand the number of HCBS Waiver participants vigorously.

**4. *North Dakota should consider preparing an application for the HCBS "Supports Waiver."***

Supports Waivers have relatively low dollar caps on the services authorized for each beneficiary, but they have flexibility in the selection of services utilized within the cap, and there is the expectation that unpaid family caregivers will provide significant support to Waiver participants. Currently, 18 states have Supports Waivers emphasizing employment services, support brokers, financial management services, and person-directed goods and services. (Smith, Agosta, & Fortune, 2007). The 18 states are: Alabama, Colorado, Connecticut, Florida, Illinois, Indiana, Louisiana, Missouri, Montana, Nebraska, Ohio, Oklahoma, Oregon, Pennsylvania, South Dakota, Tennessee, Texas, and Washington State. Nationwide Supports Waivers information can be accessed at <http://www.hcbs.org> (use search term “supports waivers”).

<p style="text-align: center;"><b>Strengthen Programs and Funding in Supported Living, Supported Employment, and Family Support</b></p>
---

5. *Adjusted for inflation, spending for supported living in North Dakota declined from 2002 to 2008. Continuing the growth of this vital program is strongly encouraged.*

#### **Supported Living**

- During 2006-08, supported living spending (adjusted for inflation) increased one percent. The number of participants increased by 95 persons, however.

North Dakota is a national leader in the implementation of supported living and personal assistance services. In 2006 North Dakota ranked eighth in the nation in supported living spending and fifth in the number of participants supported per capita (per citizen of the general population). However, total inflation-adjusted supported living spending declined by three percent from 2002 to 2008. Growth in supported living spending continues to be needed in North Dakota to provide residential support services for individuals exiting 16+ person public and private institutions and 7+ person group living arrangements and also some individuals with I/DD completing special education programs.

- The HCBS Waiver financed 100% of supported living and supported employment spending, and 94% of family support spending in North Dakota in 2008.

6. *Programs in supported employment and family support should continue to be strengthened.*

### Supported Employment

- Supported employment spending, adjusted for inflation, declined by seven percent during 2006-08. However, the number of workers supported increased by 85 workers (a 28% increment).

North Dakota's spending for supported employment in 2008 remained below its adjusted 1996 level. The HCBS Waiver finances 100% of supported employment spending. The Balanced Budget Act of 1997 authorized Waiver-reimbursed supported employment services. Despite this Waiver support, adjusted overall spending for supported employment declined two percent per year during 1997-2008.

### Family Support

- During 2006-08, adjusted family support spending increased by 33%, but the number of families supported declined by three percent.
- Adjusted cash subsidy spending declined 43% during 2006-08, and there was a reduction of 59 families supported.
- Non-subsidy family support spending, adjusted for inflation, increased by 15% during 2006-08 and the number of families supported increased by 39.

### Implications of Closing the North Dakota Developmental Center at Grafton

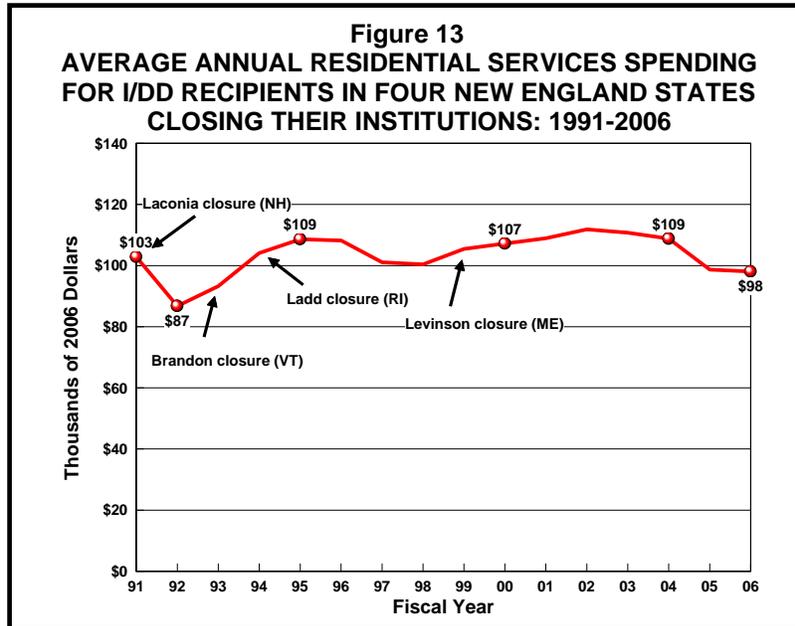
#### *7. What are the implications of possibly closing the North Dakota Developmental Center at Grafton?*

Four New England states (Maine, New Hampshire, Rhode Island, and Vermont) offer historical perspectives on post-closure costs of providing community services in lieu of institutional care. These states closed their I/DD institutions during 1991-99. New Hampshire closed Laconia in 1991, Vermont closed Brandon in 1993, Rhode Island closed Ladd in 1994, and Maine closed Levinson in 1999 (Braddock et al., 2008).

We updated through 2006 our previous 1991-2004 analysis of I/DD spending trends after institutional closures in the four New England states (Braddock, 2006). From the dates of the first closure (Laconia in 1991) through 2006, annual spending per statewide residential recipient in the four New England states declined from \$103,000 to \$98,000 in constant 2006 dollar terms (*Figure 13*). In addition, the number of aggregate I/DD recipients served in the four states increased by 91% during 1991-06. The number

of recipients post-closure increased by 156% in Maine, by 88% in New Hampshire, by 73% in Vermont, and by 47% in Rhode Island.

The closure of a state institution can generate savings for state government over time because it: 1) eliminates the high fixed cost of operating a state-owned



facility, originally built for many more residents than live there at the time of closure; 2) shifts some fiscal responsibilities from state government tax revenues to federal Supplemental Security Income (SSI) and, in some cases, to local government sources; 3) increases the likelihood that individuals will engage in productive employment in a local community because they now live closer to employment markets; 4) utilizes less costly social, educational, religious, and recreational resources in the community rather than the relatively expensive, specialized services provided in the institution; and, 5) by renting/leasing residences, the expensive institutional capital construction and remodeling costs necessary for most older institutions to remain open and certified for receipt of federal reimbursement are avoided.

**Continue Wage and Benefit Enhancements  
for Community Staff**

**8. *The North Dakota legislative effort to increase direct support staff wages and benefits is commendable and should be continued.***

Wage and benefit deficiencies for direct care staff working with children and adults with intellectual and developmental disabilities is a critical issue across the country. Higher wages reduce employment turnover and is correlated with an increase in

the quality of services. In 2006 and 2007, North Dakota's direct support staff benefited from legislatively sanctioned hourly increases and reached an average statewide wage of \$9.77 in 2008. The average direct support wage still lags the North Dakota Developmental Center wage by an estimated \$2.00 per hour, and remains three percent below the 2008 U.S. poverty wage for a family of four.

<p style="text-align: center;"><b>Aging Caregivers Stimulates Demand for Services</b></p>
---

9. *Demand for community I/DD services in North Dakota will continue to be driven by: a) youth aging out of special education; b) individuals in public and private 16+ person institutions seeking alternative placement in community living settings; c) growing supported employment and family support needs; and d) increasing numbers of individuals with I/DD residing with aging caregivers, and requiring residential supports in the future.*

During the 2007/09 biennium, approximately 350 students with intellectual disability, autism and brain injuries will complete special education programs in North Dakota's public schools. An estimated 1,627 individuals with intellectual and developmental disabilities currently live with family caregivers who are aged 60 years or older (*Figure 9*). A total of 780 persons in North Dakota currently reside in 7+ person public and private residential facilities. Thus, demand for community and family supports and supported living will continue to grow in the foreseeable future.

## **Part II Quality Assurance**

Section II of the report analyzed data sets on quality assurance in: 1) Accreditation by The Council on Quality and Leadership in Supports for People with Disabilities; 2) ICF/MR survey and certification surveys; 3) Incidents of substantiated abuse, exploitation, and neglect; and, 4) LRE performance measures for special education districts across the State.

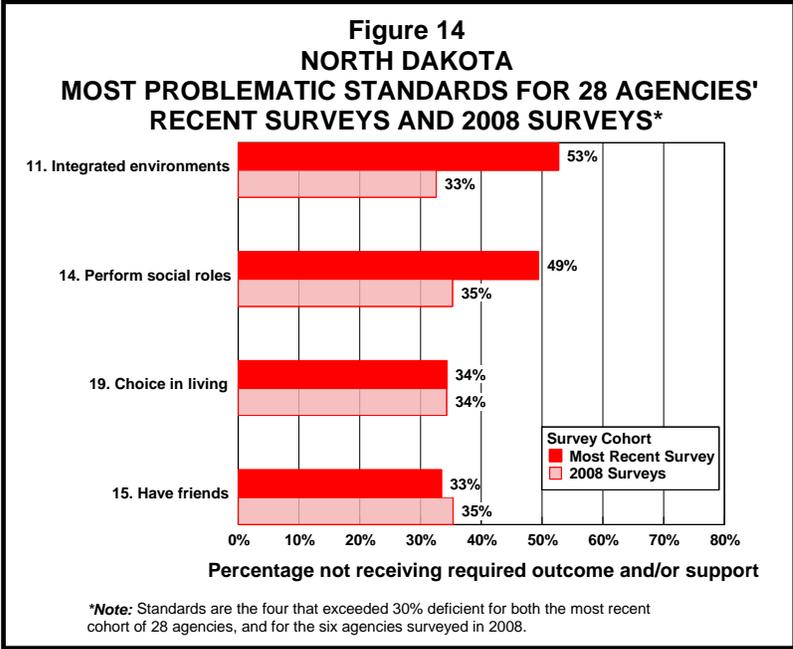
**Analysis of Accreditation Results**

There were four standards on which both the cohort of North Dakota agencies surveyed in 2008 and the 28 agencies’ “most recent surveys” cohort were found deficient on more than 30% of consumers’ outcomes/supports (*Figure 14*).

- *The standards integrated environments, perform social roles, choice in living, and have friends were problematic for more than 30% of the 28 agencies’ most recent surveys and for the six 2008 surveys.*

One of these standards, *integrated environments*, was the most problematic for agencies surveyed in North Dakota and also those agencies surveyed nationally by The Council. The standards that proved problematic for North Dakota agencies’ participants, in addition to *integrated environments*, were *perform social roles*, *choice in living*, and *have friends*. These standards relate to making connections to other people, choice about with whom time is spent, participation in community environments, and in events such as church, sports, retirement centers, and beauty shops.

It should be noted that although only six agencies were surveyed in 2008, there was some apparent improvement compared to the cohort of all 28 agencies’ most recent surveys during 2004-08 (*Appendix 5*). These were the standards *integrated environments* and *perform social roles*. There was no difference in the deficiency percentage for *choice in living*; and, for the six agencies surveyed in 2008, there was a slight regression in the standard *have friends*. The North Dakota accreditation scores in these areas point to a continuing need for the State to expand integrated



residential, work, and other support services. Community agencies must also continue to expand opportunities for individuals to interact with people without disabilities.

### Analysis of ICF/MR Surveys and Certification

Sixty-eight ICFs/MR in North Dakota, and four units at the North Dakota Developmental Center, were compared to ICFs/MR in CMS Region 8 (Colorado, Montana, North Dakota, South Dakota, Utah, and Wyoming) and in the nation as a whole on their surveys in 2006-08 (*Appendix 6*). “Problematic program and life-safety code requirements” were those on which 10% or more North Dakota ICFs/MR were found deficient, and (simultaneously) on which North Dakota’s deficiency percentages were greater than both the regional and national averages.

In 2008, six program requirements and four life-safety code (LSC) requirements were problematic for North Dakota facilities both absolutely (i.e., 10% or more North Dakota ICFs/MR deficient) and relative to the Region and the United States (i.e., deficiency percentage greater than both the Region and the U.S.).

- ***Three program requirement deficiencies related to health and safety.***
  - *Individual medication administration record for each client* (14% North Dakota deficiency)
  - *All drugs administered without error* (21%)
  - *Infection control, active program* (11%)
  
- ***In addition, three program deficiencies related to the effectiveness of training programs, the interaction of staff with residents of the ICF/MR, and individual program planning.***
  - *Treatment program implemented when Individual Program Plan (IPP) formulated* (36% North Dakota deficiency) (Note: This requirement was a *Condition of Participation* in the Medicaid program.)
  - *Promote the growth, development and independence of client* (21%)
  - *Dine according to developmental level* (32%)

It should be noted that five program requirements were no longer problematic deficiencies in the current study compared to our 2007 study: 1) *treatment risk, can refuse*; 2) *report alleged abuse, neglect immediately*; 3) *individual program planning and*

*continuous active treatment; 4) train for privacy and independence; and 5) individual program plan data in measurable terms.*

• ***The four life-safety code deficiencies problematic for North Dakota facilities addressed physical plant health and safety issues.***

- *Corridor doors* (14% North Dakota deficiency)
- *Hazardous areas - separation* (25%)
- *Remote exits* (11%)
- *Other (surveyor did not specify)* (61%)

<b>Review of Trends for Incidents of Abuse, Exploitation, and Neglect</b>
---

Reports on abuse, exploitation, and neglect from the North Dakota Protection and Advocacy organization are, as previously noted, no longer identifiable by agency or program site. The following is a list of the most frequently cited incidents, across all sites during 1996-2008. It should also be noted that data for 2008 were for a partial year (through August 2008 for the Developmental Center and through May 2008 for other programs). There were seven categories: day programs, group homes, ISLA/SLA, family support, developmental center, supported employment/extended employment (SEP/EP), and community. Some of the reported trends may be an artifact of these missing data (see *Appendix 8*).

• ***Seven categories of neglect and four categories of abuse were cited 45 times or more during 1996-2008. They are listed in rank order by category.***

***Neglect***

- *Personal safety* (432 incidents)
- *Medication errors* (366 incidents)
- *Personal care* (265 incidents)
- *Habilitation/discharge planning* (126 incidents)
- *Other* (91 incidents)
- *Failure to provide medical treatment* (68 incidents)
- *Written habilitation plan* (45 incidents)

***Abuse***

- *Physical* (144 incidents)
- *Verbal* (97 incidents)
- *Restraint/isolation/seclusion* (73 incidents)
- *Threats of retaliation* (48 incidents)

The number of incidents in one category of abuse--*verbal abuse*—increased nearly three-fold from 2006 to 2007 (from 8-22). Moreover, the number of reported incidents based on partial data for 2008 (11) is likely to meet or exceed the number of *verbal abuse* incidents reported for the full year 2007. There were no incidents in four categories of abuse during 2006-08 (*threats of retaliation, sexual abuse, inappropriate/excessive meds, or involuntary/aversive behavior therapy*). Three categories of neglect, *personal safety, medication errors* and *personal care*, have been reported consistently over the years of our analysis, and they continued to increase in 2007. There was a decline in the number of reported abuse incidents for *habilitation/discharge planning*. In addition, there were 50 substantiated incidents of *exploitation: financial* across all sites during 1996-08.

### Special Education District Performance Reports

In this 2009 report, as noted, we received North Dakota Special Education District Performance “Report Cards” for 189 districts across the state. There were 156 districts large enough for data to be published (i.e., more than 10 special education students). We calculated summary statistics on Least Restrictive Environment (LRE) placements of special education students across the state.

#### ***Regular Classroom:***

- Sixteen of the 156 districts reported that 100% of their special education students remained in their regular classroom 80% or more of the day;
- The statewide average regular classroom percentage of participation was 79%;
- Ninety of the districts, in addition to the 16 with 100% regular classroom attendance, exceeded the statewide average;
- The remaining 50 districts that were below the statewide average had student participation rates in regular classrooms ranging from 31-78%; and
- Nineteen districts’ students had regular classroom participation rates below 70%.

#### ***Separate Classrooms:***

- More than half, 84 of the 156 special education districts, reported no LRE placements in separate classrooms (i.e., no students were removed from regular classes for more than 60% of the day);
- The statewide average for use of separate classrooms was 4%;
- For the 72 districts that utilized separate classrooms, rates ranged from 1-18%; and

- Forty-five districts exceeded the statewide average for separate classroom placement rate, and in 16 districts separate classroom usage was 7% or greater.

#### ***Separate Facilities:***

- Fifty-three of the 156 North Dakota special education districts reported using “public or private separate schools, residential placements, or homebound or hospital placements”;
- The statewide average for use of separate facilities was 2%;
- Thirty-nine of the 53 districts were above the statewide average;
- The rates for the 53 districts using separate facilities ranged from 0.7-13%; and
- Fourteen districts had in excess of 5% of their special education students in separate facilities.

### ***Conclusion***

The nation is now facing many economic and budgetary challenges. Forty-one states confront budget shortfalls in this fiscal year (FY 2009) and/or the next. The total projected nationwide budget gap in 2009 is \$72 billion--12.2% of the states' general fund (McNichol & Lav, 2008). North Dakota is not one of the 41 states projecting fiscal year 2009 or 2010 budget gaps. In fact, in 2008 North Dakota posted a \$740 million budget surplus, “a staggering figure for a state that ranks 48<sup>th</sup> in population and whose general fund budget is about \$1.2 billion a year” (Fehr, 2008, p. 1).

North Dakota's cheery circumstance...can be explained by an odd collection of factors: a recent surge in oil production...; a mostly strong year for farmers...; and a conservative, steady, never-fancy culture that has nurtured fewer sudden booms of wealth like those seen elsewhere...and also fewer tumultuous slumps (Davey, 2008).

North Dakota's fiscal year 2009 began with a \$366 million balance, and the State projects an ending 2009 balance of \$116 million (National Governors Association, 2008). Moreover, as noted, North Dakota in 2008 lead all states in economic momentum (Federal Funds Information for States, 2008).

North Dakota has responded positively in the past to challenges to improve the capacity and quality of intellectual and developmental disabilities residential and community services. North Dakota has a remarkably strong state budget with which to address pending service needs. In this context, principal priorities for North Dakota in I/DD services are as follows:

1. Continue to prioritize growth of HCBS Waivers, including possibly a Supports Waiver, to finance community residential and related support services;
2. Replace outdated eight-bed group homes with more family-scale individualized living arrangements in community settings;
3. Increase family support and supported employment programs;
4. Continue to enhance wages and benefits for direct support staff; and
5. Steadily reduce reliance on and ultimately close the North Dakota Developmental Center. Develop appropriate individualized community residential services and supports such as Individualized Supported Living Arrangements (ISLA) and similar options. Analysis revealed that since the District Court dismissed the *Arc v. Sinner* case in 1990 (Chronology, 1990) and closed the Court Monitor's office, the reduction in the census of the North Dakota Developmental Center slowed down dramatically. In fact, from 1995-2004 the census at the Developmental Center actually increased from 140 to 146 persons.

### Quality Assurance Challenges

North Dakota agencies and facilities compare reasonably well to others in the region and across the nation. However, quality assurance data analyzed in this report reveal significant and recurring problems in key areas, and at individual facilities. The accreditation standards *integrated environments* and *perform social roles* were problematic for nearly 50% of all consumers in agencies' most recent surveys. Deficiencies for ICFs/MR included *individual medication administration records*, *administering drugs without error*, and *infection control*. Incidents of abuse, exploitation or neglect including *verbal abuse*, *personal safety*, *medication errors*, and *personal care* were also noted. Problematic areas revealed in critical accreditation standards, ICF/MR deficiencies, and in abuse, exploitation, and neglect incident investigation procedures are also priorities for direct support staff and manager training programs.

As noted in our 2007 study, critical accreditation standards in *choice in living*, *choice in work* and *integrated environments* represent a lack of resources in supported employment and supported living, and the congregate-care orientation of many North Dakota residential settings. The analysis of Medicaid ICF/MR certification requirements also pointed to the need for consumers to be more integrated into local communities. Part I of this report focused on limitations in the structure and financing of services. The findings of the quality assurance component of this study remain, as in our previous

studies, consistent with those fiscal limitations noted. Although modest progress has been achieved in North Dakota during 2006-08, program development and funding challenges in I/DD services in North Dakota remain quite similar to those noted in our study of two years ago.

## IV. REFERENCES CITED

- Assistant Secretary for Planning and Evaluation. (2008). *The 2008 HHS poverty guidelines*. Washington, DC: Office of the Assistance Secretary, U.S. Department of Health and Human Services. [On-line]. Available: [www.aspe.hhs.gov/poverty/](http://www.aspe.hhs.gov/poverty/).
- Association for Retarded Citizens (Arc) of North Dakota v. Olson*, 561 F. Supp. 473 (D.N.D. 1982), 6 MDLR 374, *aff'd*, 713 F.2d 1384 (8<sup>th</sup> Cir. 1983), 7 MDLR 465; *Arc of North Dakota v. Sinner*, No. 90-5397; *rev'd and remanded*, 942 F. 2d 1235 (8 Cir. 1991), 16 MPDLR 43; *Arc of North Dakota v. Schafer*, 87 F. Supp. 689 (D. N.D. 1995), 19 MPDLR 171.)
- Braddock, D. (2006). *Closing the North Dakota Developmental Center: Issues, implications, guidelines*. University of Colorado, Department of Psychiatry.
- Braddock, D. (1999). Aging and developmental disabilities: Demographic and policy issues affecting American families. *Mental Retardation*, 37, 155-161.
- Braddock, D., & Fujiura, G. (1987). State government financial effort in mental retardation. *American Journal of Mental Deficiency*, 91, 450-459.
- Braddock, D., & Hemp, R. (2007). *Developmental disabilities in North Dakota: The year 2007 report*. Boulder, CO: University of Colorado, Department of Psychiatry.
- Braddock, D., & Hemp, R. (2004). *Developmental disabilities in North Dakota: The year 2004 report*. Boulder, CO: University of Colorado, Department of Psychiatry.
- Braddock, D., & Hemp, R. (2000). *Developmental disabilities in North Dakota: The year 2000 report*. Chicago: University of Illinois at Chicago.
- Braddock, D., Hemp, R., & Rizzolo, M.C. (2008). *The state of the states in developmental disabilities, seventh edition, 2008*. Washington, DC: American Association on Intellectual and Developmental Disabilities.
- Braddock, D., Hemp, R., & Rizzolo, M.C. (2004). State of the states in developmental disabilities: 2004. *Mental Retardation*, 42, 356-370.
- Braddock, D., Hemp, R., & Rizzolo, M.C. (2002). *Developmental disabilities in North Dakota: The year 2002 report, a study of the structure, financing, and quality assurance of residential and community services*. Boulder: University of Colorado, Department of Psychiatry.
- Braddock, D., Hemp, R., Rizzolo, M.C., Coulter, D., Haffer, L., & Thompson, M. (2005). *The state of the states in developmental disabilities, 2005*. Boulder: University of Colorado, Department of Psychiatry and Coleman Institute for Cognitive Disabilities.
- Bureau of Labor Statistics. (2008). State average annual pay for 2008. Washington, DC: U.S. Department of Labor, Bureau of Labor Statistics.
- Chronology. (1990). *A.R.C. vs. Sinner et al., A1-80-141*. Grand Forks: Federal Court Monitory Robert C. Eelkema, MD, MPH.
- Dalton, P.A. (2004, May 7). *Temporary state fiscal relief: GAO letter to The Honorable Don Nickles, Chairman, Committee on the Budget, United States Senate* (GAO-040736R). Washington, DC: United States General Accounting Office.
- Davey, M. (2008, December 6). A placid North Dakota asks, Recession? What recession? *New York Times*.

- Federal Funds Information for States. (2008, September). Index of state economic momentum. *State Policy Reports*, 26(18), 2-7.
- Fehr, S.C. (2008, July 8). Squeeze spares some states. Accessed 12/3/08 at: [www.stateline.org/live/printable/story?contentId=323920](http://www.stateline.org/live/printable/story?contentId=323920)
- Fujiura, G.T. (1998). Demography of family households. *American Journal on Mental Retardation*, 103, 225-235.
- Hirsch, D. (1992, November 1). *Services to persons with mental retardation in North Dakota: A review*. Topeka, KS: Author.
- Hysjulien, G. (2004, September 14). *Letter to Dianne Sheppard, Executive Director, Arc-Upper Valley, regarding "Developmental Disabilities in North Dakota: The 2004 Draft Report."* Bismarck, ND: North Dakota Department of Human Services.
- Lakin, K.C., Polister, B., & Prouty, R.W. (2003). Trends & Milestones: Wages of non-state direct-support professions lag far behind those of public direct-support professionals and the general workforce. *Mental Retardation*, 106, 231-252.
- Larson, S.A., Lakin, K.C., Anderson, L., Kwak, N., Lee, J., & Anderson, D. (2001). Prevalence of mental retardation and developmental disabilities: Estimates from the 1994/95 National Health Interview Survey Disability Supplements. *American Journal on Mental Retardation*, 106(3), 231-252.
- Lipson, D., Gruman, C. Schimmel, J., Colby, M., Denny-Brown, N., Peterson, S., & Williams, S.R. (2007, August 31). *Money follows the person demonstration grants: Summary of state MFP program applications*. Washington, DC: Mathematica Policy Research, Inc.
- McNichol, E., & Lav. I.J. (2008, November 12). State budget troubles worsen. Washington, DC: Center on Budget and Policy Priorities.
- Mercer, M. (2004). *Money changes everything*. Minot, ND: North Dakota Center for Persons with Disabilities.
- Gettings, R.M., & Katz, R.E. (1984, December 20). *Establishing standards applicable to community services for developmentally disabled adults in North Dakota*. Alexandria, VA: National Association of State Mental Retardation Program Directors, Inc.
- National Governors Association and National Association of State Budget Officers. (2008, June). *The fiscal survey of the states*. Washington, DC: Author.
- North Dakota Association of Community Facilities (NDACF). (2008, October). Message from the executive director. *NDACF News*, 13, pp.1.
- North Dakota Association of Community Facilities (NDACF). (2003, May). President's message: Part two: How the system works. *NDACF News*, 5 (May 2003), pp.1, 2.
- North Dakota Center for People with Disabilities. (2006). Community staff training project. Minot, ND: Minot State University, A University Center of Excellence. [accessed 12/15/06 at: <http://ndcpd.misu.nodak.edu/proj/current/cstp.htm>].
- North Dakota Department of Human Services. (2008). *Money follows the person: Developmental disabilities program information and transition services*. Bismarck: Author. [Accessed 12/4/08 at: <http://www.nd.gov/dhs/info/pubs/mfp.html>]

- North Dakota Department of Human Services. (2007). Highlights of the North Dakota Department of Human Services budget. *Human Services Connection*, Spring, 2007, pp. 1-3.
- Prouty, R., Alba, K., & Lakin, K.C. (Eds.). (2008, August). *Residential services for persons with developmental disabilities: Status and trends through 2007*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration/UCEDD.
- Smith, G.A. (2006, October 9). *Status report: Litigation concerning home and community services for people with disabilities*. Tualatin, OR: Human Services Research Institute.
- U.S. Census Bureau. (2008, May 1). *Estimates of the population by selected age groups for the United States, regions, states, and Puerto Rico: July 1, 2007 (SC-EST2007-01)*. Washington, DC: Population Division.
- U.S. Census Bureau. (2007, December 27). *Annual estimates of the population for the United States, regions, states, and Puerto Rico: April 1, 2000 to July 1, 2007 (NST-EST2007-01)*. Washington, DC: Population Division.
- U.S. Census Bureau. (2007). *The 65 years and older population: 2000. Census 2000 Brief* [On-line]. Available: <http://www.census.gov/prod/2001pubs/c2kbr01-10.pdf>.
- U.S. Census Bureau. (1992). *Survey of income and program participation 1991 panel: Technical documentation* (June 1992 revision). Washington, DC: U.S. Department of Commerce.
- U.S. Department of Education, Office of Special Education Programs, Data Analysis System. (2008, July 15). *Students with disabilities exiting special education, 2006-07*. Washington, DC: Author.
- Vassiliou, D., & Ferrara, J. (1997). *Factors related to staff longevity and turnover in facilities serving North Dakota citizens with developmental disabilities*. Minot, ND: Minot State University, North Dakota Center for Persons with Disabilities, a University Affiliated Program.