

DEVELOPMENTAL DISABILITIES IN NORTH DAKOTA: 2009

EXECUTIVE SUMMARY

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

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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 Grafton from 146 persons in 2004 to 130 persons in 2008. The State, however, had previously increased the census of persons with I/DD at Grafton during 1995-2004. Census reduction at Grafton 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.*

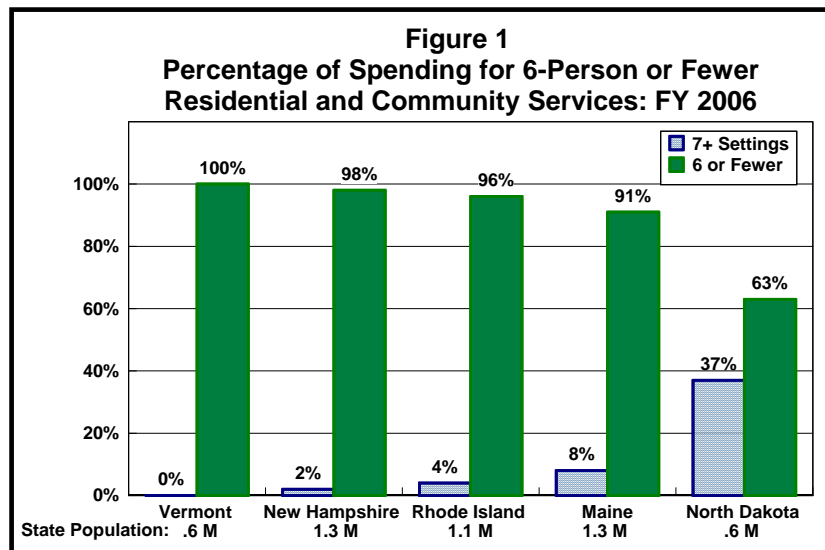
- During 2006-08, the average daily census of residential settings for 16 or more persons declined by from 325 to 293, a 10% reduction.
- The decline was made up of a nursing facility reduction of seven persons (- 6%), a decline of seven persons at the North Dakota Developmental Center at Grafton (- 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. 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 at Grafton stalled, and actually increased during 1995-2004.

North Dakota ranked 9th 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 9th highest nationally. Only New York ranked higher than North Dakota in 7-15 person facility utilization. (North Dakota ranked 2nd nationally.) North Dakota also significantly lags the dominant national trend in the proportion of resources dedicated to six or fewer person settings, ranking 44th in 2006.

Figure 1 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

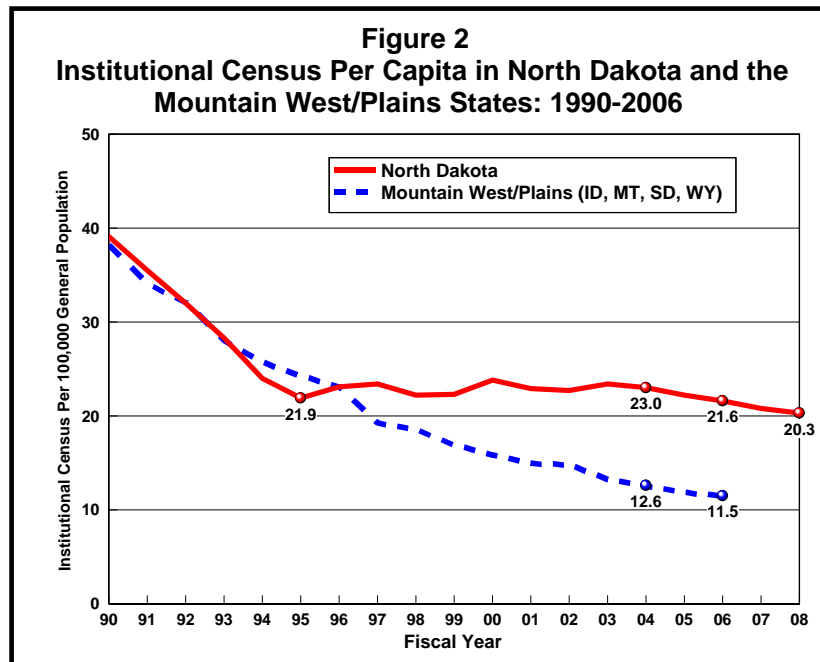


million population), Wyoming (0.5 million), Montana (1.0 million), and Idaho (1.5 million). Each of these states, like North Dakota, also has one remaining institution. Their 2006 I/DD institutional censuses were 77 (MT), 90 (ID), 88 (WY), and 162 (SD),

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 2*. 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).

**Home and Community Based Services Waiver
Expansion is Recommended**

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 38th among the states in federal-state Waiver spending as a percentage of total I/DD spending, a decline from the rank of 33rd 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”).

Strengthen Programs and Funding in Supported Living, Supported Employment, and Family Support
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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

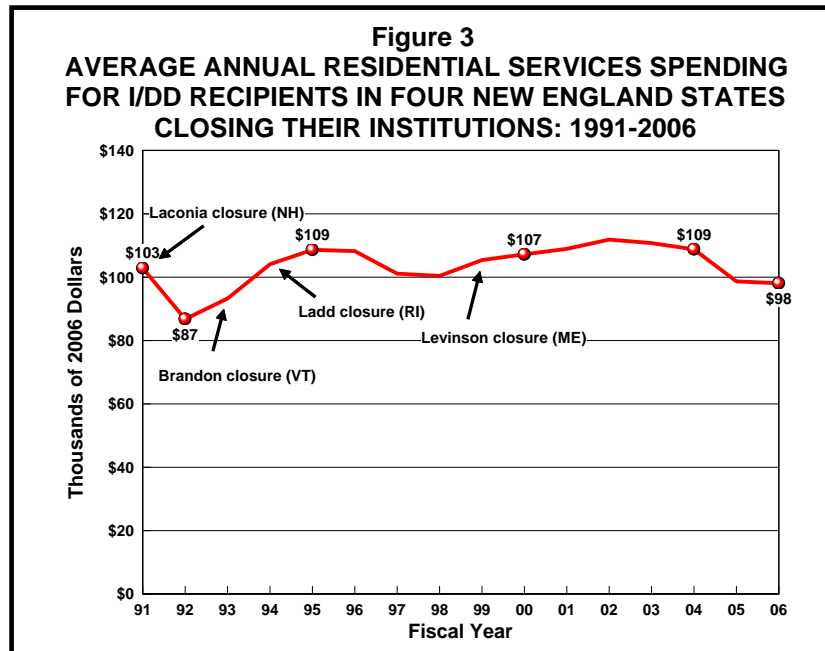
7. *What are the implications of possibly closing the North Dakota Developmental Center at Grafton?*

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 3*). 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;">Aging Caregivers Stimulates Demand for Services</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 (see **Figure 9**, page 16 of the full report). 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

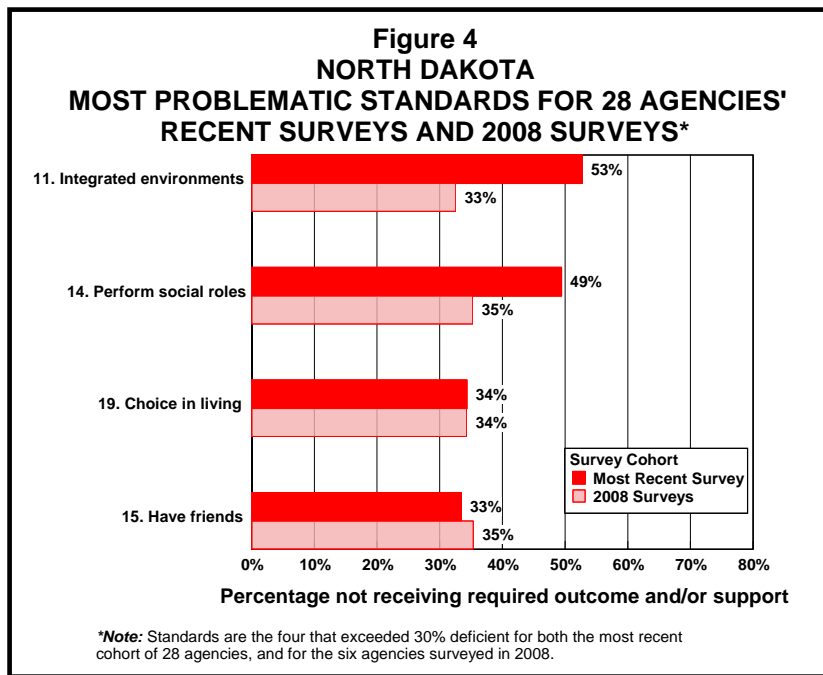
Section II of the report analyzed data sets on quality assurance in: 1) Accreditation by The Council on Quality and Leadership in Supports for People with Disabilities; 2) ICF/MR survey and certification surveys; 3) Incidents of substantiated abuse, exploitation, and neglect; and, 4) LRE performance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

- *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 (see *Appendix 5* of the full report). 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 (see *Appendix 6* of the full report). “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%)

Review of Trends for Incidents of Abuse, Exploitation, and Neglect

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 48th 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 at Grafton. 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 at Grafton 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.

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