DEVELOPMENTAL DISABILITIES IN NORTH DAKOTA:
THE YEAR 2004 REPORT

A study of the structure, financing and quality assurance of residential and community services

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DEVELOPMENTAL DISABILITIES IN NORTH DAKOTA:
THE YEAR 2004 REPORT
A STUDY OF THE STRUCTURE, FINANCING AND QUALITY
ASSURANCE OF RESIDENTIAL AND COMMUNITY SERVICES

INTRODUCTION

The North Dakota Year 2004 Report is a comprehensive update of two previous North Dakota studies of residential and community services for persons with developmental disabilities in North Dakota (Braddock & Hemp, 2000; Braddock, Hemp, & Rizzolo, 2002). In the present study, we have updated the analysis of financial and programmatic data through 2004\(^1\). Four quality assurance data sets analyzed in the previous report have been extended through 2003/2004, yielding in most instances an eight-year longitudinal analysis of private and public quality assurance systems affecting North Dakota’s citizens with developmental disabilities. These quality assurance systems are:

- Accreditation reviews of residential and community services agencies and the North Dakota Developmental Center in 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 Developmental Center;
- North Dakota’s Protection and Advocacy Agency, which investigates instances of abuse or neglect at residential and community services agencies and at the Developmental Center; and
- Special education unit surveys conducted under the rubric of the federal Individuals with Disabilities Education Act (IDEA).

The North Dakota Year 2004 Report has four major sections. The first section is an analysis of financial and programmatic trends in North Dakota developmental disabilities services through fiscal year 2004. This analysis focuses on residential and community services, individual and family support, private institutions, and the North Dakota Developmental Center at Grafton. The second section presents data descriptive of

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\(^1\) The FY 2004 data presented in the report were predicated on partial year data provided by the State of North Dakota through March 31, 2004. Full fiscal year 2004 estimates were extrapolated by the authors for the remainder of the fiscal year (April-June) based on the average monthly revenue, expenditure and participant data provided by the State through 3/31/04.
the four quality assurance systems for people with developmental disabilities in North Dakota. The third section consists of an executive summary of the Report’s findings, conclusions and recommendations. The final section of the Report consists of Appendices 1-15 that describe in detail the data emanating from the four quality assurance programs in North Dakota, and Appendix 16 that presents quality assurance data on an agency-by-agency basis for each of 28 North Dakota community agencies, and for the Developmental Center.

This report further illustrates the importance of longitudinal quality assurance data in assessing a state’s developmental disabilities services. The multi-year data identify issues of compliance with accreditation standards, ICF/MR requirements, and incidents of abuse, exploitation, and neglect for North Dakota residential and community agencies across 1996-2004. Discussion of the historical development of North Dakota’s services and the state’s quality assurance system can be found in our earlier report (Braddock & Hemp, 2000).

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

The census of state-operated institutions for people with developmental disabilities in the United States declined from a peak of 194,650 in 1967 to 44,252 in 2002. A total of 127 institutions have been closed since 1970 and nine states (Alaska, District of Columbia, Hawaii, Maine, New Hampshire, New Mexico, Rhode Island, Vermont, and West Virginia) no longer operate state institutions (Rizzolo, Hemp, Braddock, and Pomeranz-Essley, 2004).

Long-term care services in the states now consist primarily of community residential facilities for six or fewer persons and include a wide range of group homes, foster homes, Intermediate Care Facilities/Mental Retardation (ICFs/MR), and supported living arrangements, many of which are financed by the Home and Community Based Services (HCBS) Waiver. In 2002, 65% of individuals with developmental disabilities in out-of-home settings in the U.S. resided in settings for 6 or fewer persons and 12% resided in settings for 7-15 persons.
**The Structure of Residential Services in North Dakota**

In 1966, North Dakota’s two state-operated facilities, Grafton and San Haven, served 1,400 individuals with developmental disabilities (*Figure 1*). This peak in the State’s institutional population 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. This was one half the national institutional decline rate during that period. However, following the implementation of the consent agreement in *Association for Retarded Citizens of North Dakota v. Olson* (1982), the rate of institutional decline in North Dakota accelerated to 15% per year. San Haven closed in 1987. The number of average daily residents at San Haven and Grafton declined from 966 average daily residents in 1983 to 140 in 1995.

During the past nine years, after a 15% annual decline during 1983-95, there has been essentially no change in the average daily institutional population at the North Dakota Developmental Center at Grafton. The resident population increased from 140 in 1995 to 146 persons in 2004.
Public and Private 16+ Institutions

Figure 2 illustrates the total number of individuals residing each year in the North Dakota Developmental Center (public 16+), in privately operated 16+ settings [the Anne Carlson Center ICF/MR facility for 32 children and Minimally Supervised Living Arrangements (MSLA) for 40 persons], and in nursing facilities. The total residing in 16+ settings declined from 614 in 1988 to 350 in 2002. The number of individuals served in 16+ settings increased by 16 in 2003 before declining to 334 in 2004.

Individuals with mental retardation and related developmental disabilities in North Dakota nursing facilities declined from a peak of 220 in 1998 to 116 in 2004. These data provided by the State Developmental Disabilities Office represented persons residing in nursing facilities and receiving state case management services. The numbers provided by the State DD Office might therefore understate the total number of individuals with mental retardation and related disabilities in nursing facilities throughout the State. An estimated 5-10 nursing facility residents with MR and related conditions did
not receive case management services (V. Pederson, North Dakota Department of Human Services, personal communication, June 17, 2004).

**Development of Community Residential Services**

The nation’s system of residential and community services is defined largely in terms of community housing arrangements serving six or fewer individuals per setting, as is the North Dakota developmental disabilities system of services. By 2004, the North Dakota Developmental Center average daily population had declined to 146 and constituted 8% of the total of 1,921 persons residing in all types of residential settings in the State (*Figure 3*). The 72 children and adults residing in private 16+ institutions (the Anne Carlson ICF/MR and MSLAs) constituted 4% of the total, and the 116 individuals with mental retardation and related conditions in nursing facilities constituted 6%. All together, the Developmental Center, private institutions for 16 or more persons, and

![Figure 3
NORTH DAKOTA
Number of Individuals by Residential Setting: 2004](image)

nursing facilities accounted for 18% of the total of 1,921 persons.

Just over one quarter (26%) of the total number of individuals in residential settings resided in facilities for 7-15 persons. This was more than double the national average for 7-15 person settings, which constituted 12% of the U.S. total of 460,307 out-of-home residents. North Dakota’s 7-15 person ICFs/MR served 288 persons consisting of 179 adults and 48 children with developmental disabilities, and 61 persons with developmental and physical disabilities. The other settings in the state for 7-15 individuals totaled 203, consisting of Transitional Community Living Facilities (TCLFs) (118 people), MSLAs (40 people), and “senior congregate care” (45 people).

The majority of persons in North Dakota’s residential services in 2004 (57%) resided in settings for 6 or fewer persons, somewhat lower than the United States average of 65% in 2002. Participants in supported living in North Dakota constituted 80% of those served in settings for 6 or fewer persons. Supported living in North Dakota consisted of settings termed “supported living” with 127 participants, “individualized supported living arrangements—ISLAs” that supported 700 participants, and personal assistance for 53 persons, termed “Title XIX county waiver services.”

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

In 2002, North Dakota was second only to Iowa in total out-of-home placements per 100,000 of the state general population. The North Dakota utilization rate was 312 compared to the U.S. average of 160. The North Dakota rate declined slightly to 302 in 2004. The North Dakota 2002 utilization rate in settings for six or fewer persons was 177 compared to the U.S. average of 103. North Dakota ranked 10th among the states in utilization of settings for six or fewer persons. The North Dakota 2002 utilization rate of 80 per 100,000 for 7-15 person settings was more than four times the U.S. rate of 19 per 100,000 that year. Only two states, New York and South Dakota, exceeded North Dakota in 7-15 placement utilization. North Dakota’s six-person or fewer facility utilization rate dropped slightly from 2002-04 (177 to 172) as did the 7-15 person facility utilization rate (80-77).

North Dakota posted high utilization rates for state institutional and nursing facilities as well. The North Dakota state institution placement rate of 23 persons per
100,000 of the general population ranked 11th highest among the 42 states that still operated institutional services in 2002. The U.S. average was 15. Finally, the State’s 2002 nursing facility utilization rate was 16 per 100,000, 11th highest among the states, and increasing to 18 in 2004. This was substantially above the U.S. 2002 utilization rate of 11.

Summary of Residential Services Utilization

North Dakota is among the nation’s leaders in the utilization of out-of-home residential facilities (ranked 2nd) and in the utilization of settings for six or fewer persons (ranked 10th). The State, however, lags behind national out-of-home placement patterns in terms of:

- Extensive use of 7-15 person settings (ranked 3rd highest);
- High utilization of nursing facilities (ranked 11th highest);
- High utilization of state institutional services (ranked 11th highest).

Financing Developmental Disabilities Services in North Dakota

Total developmental disabilities residential and community services spending in North Dakota advanced from $28.3 million in 1977 (in 2004 inflation-adjusted dollars) to $134.9 million in 2004. Figure 4 presents the history of this funding by size of residential

![Figure 4](image-url)
facility. The gray bars represent spending for public and private facilities serving 7 or more persons per facility and the black bars represent spending for community residential services for six or fewer persons and related day programs and individual and family support services.

Total spending for persons residing in settings for six or fewer persons did not surpass spending for 7+ person facilities until 2002. Inflation-adjusted spending for 7+ public and private facilities in North Dakota increased by an average 13% per year during 1977-87 and declined 5% annually during 1987-95 following implementation of the *Arc of North Dakota v. Olson* lawsuit. Spending for settings for 7+ persons grew 5% per year during 1995 to 2000 and declined 4% per year during 2000-04. Community services spending for six or fewer persons has increased steadily since 1982, except for declines in 1994 and 1997. During 2000-04, community services spending increased significantly--by an average of 11% per year. This was the highest increase over a four-year period since the mid-1980s.

The substantial increase in community spending during 2000-04 was largely attributable to the State’s expansion of HCBS Waiver spending and spending for private ICFs/MR for six or fewer persons. The North Dakota legislature granted $.87 per hour in higher wages for community direct support staff during this period, along with an increase in their fringe benefit rate from 30% to 33% of salary (NDACF, 2003).

North Dakota, however, is one of only three states in which 25% or more of individuals in out-of-home settings reside in facilities for 7-15 persons. The State, in fact, expended 43% of total MR/DD residential and community services resources for services in 7-person or larger residential facilities in 2004 (*Figure 5*). Facilities for 7+ persons included the North Dakota Developmental Center, private ICFs/MR including the Anne Carlson Center, minimally supervised living arrangements, transitional community living facilities, and senior congregate care.

North Dakota committed 57% of total DD long-term care resources to settings for 6 or fewer individuals consisting 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
2002, the average state committed 68% of total MR/DD spending to settings for six or fewer persons; North Dakota ranked 39th in this regard.

**The ICF/MR Program and the HCBS Waiver**

Federal and state Medicaid spending in the U.S. advanced dramatically, from 19% of total developmental disabilities long-term care spending in 1977 to 77% of the total in 2002. In North Dakota, the Medicaid spending share advanced from 0% to 85% over that same period, and in 2004 constituted 86% of total DD spending in the State. The ICF/MR program and the HCBS Waiver are the two primary Medicaid sources for financing developmental disabilities 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.

**ICF/MR and the HCBS Waiver**

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 Michigan and Minnesota and a large number of other states. North Dakota first utilized ICF/MR funding in 1982 for private ICFs/MR serving 16 or more persons and also 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 in Grafton.

The other major Medicaid program for developmental disabilities long-term care, the HCBS Waiver, was authorized under the auspices of the Omnibus Budget Reconciliation Act of 1981 (PL 97-35). 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 2002 all fifty states and the District of Columbia had instituted HCBS Waiver services, and federal Waiver spending in the United States grew to $7.2 billion. The Waiver in 2002 constituted 48% of all federal Medicaid reimbursement for developmental disabilities long-term care spending in the U.S.

**North Dakota HCBS Waiver**

The North Dakota Waiver was established in 1984 (Figure 6) and by 2004 federal Waiver spending in the State constituted 46% of total federal Medicaid reimbursement.

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**Figure 6**  
**NORTH DAKOTA**  
Federal ICF/MR and Waiver Spending: 1977-2004

<table>
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<tr>
<th>Fiscal Year</th>
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**Source:** State of the States in Developmental Disabilities Project, University of Colorado, Coleman Institute and Department of Psychiatry, 2004.
This was slightly below the 2002 proportion of 48% in the United States. In 2002 North Dakota ranked 17th among the states in federal-state Waiver spending per capita of the general population, at $68 compared to the U.S. average was $45. The North Dakota per capita advanced to $84 in 2004.

As displayed in Figure 6, inflation-adjusted ICF/MR spending for public and private facilities in North Dakota grew an average annual 125% during 1982 to 1989, declined to 7% annual growth during 1989-02, and advanced 16% from 2002 to 2004. Spending for the North Dakota Waiver increased each year following the Waiver’s initiation in 1984, excepting slight declines in 1996 and 2001. The 2000-01 Waiver spending decline in North Dakota was 9%, but from 2002 to 2004 federal spending for the North Dakota Waiver advanced 19%.

The HCBS Waiver has proven to be a flexible method of reimbursement for a wide range of essential services in the states. In 2004 North Dakota used the HCBS Waiver to finance 85% of family support spending and 100% of supported living/personal assistance and supported employment spending. As noted, the North Dakota Waiver provides case management and personal care services, and in addition provides adult day health, family counseling/therapy, foster care, habilitation, homemaker services, pre-vocational services, respite care, supported employment, and family support (Eiken, Burwell, & Schaefer, 2004). North Dakota’s array of Waiver services includes many of the 77 services administered across the states, with the exception of some frequently used services in the states including assistive technology, adapted equipment, home modification, transportation, and speech, physical, and behavioral therapies.

Summary of Medicaid Trends

North Dakota ranked 17th in 2002 in federal-state Waiver spending per capita, a decline from the state’s rank of 7th in 1998. As noted, the per capita Waiver spending in North Dakota increased to $84 in 2004, placing the State at a ranking of 10th compared to all states’ 2002 per capita levels. North Dakota ranked 30th in federal-state Waiver spending as a percentage of total DD spending. Nationally, Waiver spending surpassed ICF/MR spending for the first time in 2001. In North Dakota, on the other hand, increased ICF/MR spending since 2002 nearly parallels the growth in HCBS Waiver
spending. *If the 2000-04 spending trends continue (adjusted annual spending growth of 6% for ICFs/MR and 8% for the Waiver) North Dakota would not achieve the national benchmark of Waiver spending surpassing ICF/MR spending for another decade--until 2014.*

**Individual and Family Support**

Rizzolo et al. (2004) 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 mental retardation/developmental disabilities (MR/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:** MR/DD state 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 MR/DD can earn competitive wages.

**Supported living and personal assistance:** Supported living was defined as 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 2002, the nation expended $4.4 billion for individual and family support, constituting 13% of the $34.6 billion in total developmental disabilities long-term care spending that year. Fifty-four percent of total individual and family support spending in
the United States was dedicated to supported living and personal assistance, 31% funded family support activities, and the remaining 15% funded supported employment.

**Individual and Family Support in North Dakota**

North Dakota expended $29.1 million for individual and family support services in 2004, constituting 22% of the $134.9 million in the State’s total developmental disabilities spending. Seventy-nine percent of North Dakota’s individual and family support spending was committed to supported living and personal assistance, 14% funded family support, and 7% funded supported employment (**Figure 7**).

As illustrated in the figure, 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, albeit at a slower annual rate than during 1987-96. Spending for supported living grew 10% between 2002 and 2004. North Dakota family support spending and supported employment spending were flat (no real increase) from 1996 to 2004.
North Dakota ranked 3rd behind Iowa and Washington in supported living/personal assistance utilization (per 100,000 of the population). North Dakota ranked 35th in families supported per 100,000 and ranked 14th in supported employment utilization. In terms of supported employment workers as a percentage of total day/work participants, North Dakota’s rate in 2002 was 23%. The U.S. average was 24% and North Dakota ranked 27th among the states in this regard. The North Dakota supported employment rate decreased to 20% in 2004. As noted, North Dakota in 2004 used the HCBS Waiver to finance 85% of family support spending and 100% of spending for supported living, personal assistance, and supported employment.

**Fiscal Effort**

Fiscal effort is a ratio that can be utilized to rank states according to the proportion of their total statewide personal income devoted to the financing of developmental disabilities services (Braddock & Fujiura, 1987). 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. Fiscal effort is defined as a state’s spending for developmental disabilities services per $1,000 of total state personal income.

**State Funds Fiscal Effort (Federal Funds Excluded)**

Important limitations apply to the evaluation of fiscal effort in North Dakota compared to other states. Sparsely populated states cannot achieve the same economies of scale as the states with larger populations (Gray, 1990). In 2002 eight states (Alaska, Delaware, District of Columbia, Montana, North Dakota, South Dakota, Vermont, and Wyoming) had populations of less than one million. Four of the eight states (North Dakota, South Dakota, Vermont, and Wyoming) ranked 19th or higher in total fiscal effort for developmental disabilities services that year.

One useful measure of North Dakota’s fiscal effort is *state spending* per $1,000 of personal income. This excludes federal funds. State and local government fiscal effort 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
accomplished by a dramatic decline in state spending as a proportion of state personal income.

Total state funds fiscal effort dropped from a peak of $4.34 in 1986 to $1.71 in 2004 (Figure 8). Community (15 or fewer) effort dropped from $2.23 in 1988 to $1.32 in 2004. The marked decline from 2002 and 2004 reflects growth in both ICF/MR and Waiver federal Medicaid reimbursement, and the impact of enhanced federal medical assistance percentage (FMAP) rates authorized by the Jobs Growth Tax Relief Reconciliation Act of 2003 (Pub. L. 108-27). That Act provided North Dakota $50 million through enhanced federal medical assistance percentage (FMAP) rates from January 2003 to June 2004 (Dalton, 2004; NCSL, 2004). In 2002, North Dakota ranked 5th in state fiscal effort for community services (<15) among the 8 states with populations of less than 1,000,000. Community state fiscal effort in Alaska, Delaware, DC and Vermont surpassed the North Dakota effort level2.

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2 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 5th nationally in total spending, 5th in community spending, and 7th in institutional spending fiscal effort. However, the State’s total fiscal effort declined slightly from 2002-04, from $6.94 to $6.92.
Waiting Lists

Our society is aging (U.S. Census Bureau, 2001). The longevity of individuals with developmental disabilities is also increasing (Janicki, 1996; Janicki, Dalton, Henderson, & Davidson, 1999). As we previously reported (Braddock & Hemp, 2000; Braddock et al., 2002), many states including New Jersey, New York, Connecticut, and Massachusetts have established substantial funding initiatives to reduce waiting lists. [As of April 2004, there were 26 waiting list lawsuits in 23 states (Smith, 2004).]

These three critical 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, 1999). Prouty, Smith, & Lakin (2003) reported that no persons with developmental disabilities in North Dakota awaited residential services as of June 30, 2002. However, in 2004, there were an estimated 1,662 children and adults with developmental disabilities in North Dakota living with family caregivers aged 60 years or more (Figure 9).

The estimate of the 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 developmental disabilities 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, 2001), 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, 2002).

In 2004 there were an estimated 10,039 persons with developmental disabilities in North Dakota; 1,921 (19%) resided in the State’s out-of-home residential care system (see Figure 3 on page 5), 26% resided alone or with housemates, and the balance of 5,520 (55%) resided with family caregivers. The estimated number of caregivers aged 60 years of age or older in North Dakota (1,662) reflected the fact that the State has the fifth highest proportion (14.7%) of aged citizens compared to the U.S. average of 12.4% (U.S. Census Bureau, 2001). Many of the estimated number of age 60+ family caregivers are likely to require increased levels of support from the North Dakota developmental disabilities service system in future years. This will be an intensifying challenge for service providers in North Dakota and other states. For example, the number of Americans aged 65 years or more will double between 2000 and 2030 (U.S. Census Bureau, 2001).

The other factor, in addition to aging caregivers, that is impacting the need for services in North Dakota is a growing number of young adults aging out of special education programs. According to data for school year 1999/2000 (U.S. Department of Education, 2002), 73 North Dakota students with mental retardation 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 2004/05 biennium, more than
150 students with mental retardation exiting special education can be expected to present a need for supported living, residential service, or other supports.

North Dakota state officials indicated that there was ongoing collaboration between 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**

High turnover in residential programs for individuals with developmental disabilities has a negative impact on the individuals served. Costs of turnover that divert resources from services include compensatory administrative costs for replacing staff (Lakin, 1988; Zaharia & Baumeister, 1978). Phillips (1990) estimated that the true cost of turnover was 1.5 times an employee’s salary. In a state-by-state analysis of compensation and turnover, Braddock & Mitchell (1992) found that lower adjusted average wages were associated with higher crude separation (i.e., turnover) rates. Schalock (1983) reported that over 78% of all personnel who interact with individuals with developmental disabilities in residential programs were direct care staff. Individuals with developmental disabilities rely on direct support staff for consistent nurturing and friendship, and disruption of these relationships because of employee turnover could have a detrimental effect (Lakin, 1988). Interactions with residents are also affected between the time one employee leaves and another is hired and trained (Lakin & Bruininks, 1981).

The lower compensation and poorer benefits of community residential staff compared to state institution personnel continues to be a national issue (Association of Developmental Disabilities Providers, 1999; Larson, Lakin, & Bruininks, 1998; Rubin, Park, & Braddock, 1998). Researchers in several states including Illinois, Massachusetts, Minnesota, and Pennsylvania have identified direct support staff wages as a critical issue in the quality of developmental disabilities long-term care services.
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, peer mentoring for new staff, and realistic job previews (c.f. Bachelder & Braddock, 1994).

**Current Direct Support Wages in North Dakota**

In 2002, the North Dakota Association of Community Facilities sponsored a survey of compensation in 26 organizations. Wage data were available for 548 direct contact staff that worked at 6 of the 26 organizations participating in the survey. Based on those preliminary data, average (mean) pay was $7.78, ranging from $6.00 to $10.62. The median pay was $7.55 (Tom Newberger, personal communication, North Dakota Association of Community Facilities, June 27, 2002). According to the May 2003 newsletter of the North Dakota Association of Community Facilities (NDACF, 2003), the community wage in 2003 was $8.86 and the Developmental Center wage was $3.00 higher, or $11.86 (p. 2).

*Figure 10* displays the 2002 federal poverty level, on an hourly basis, for a family

![Figure 10](https://example.com/figure10.png)

**Sources:** Bureau of Labor Statistics (2003); Lakin et al. (2003); BDO Seidman (2002); ASPE (2003); NDACF (2003); all data are for 2002, except the 2003 data, as noted, for North Dakota wages and the federal poverty level.
of four with one wage earner (ASPE, 2003), the average wage for all U.S. workers (Bureau of Labor Statistics, 2003), nursing aides’ average wage (BDO Seidman, 2002), and the U.S. average state-operated institution and community facility wages (Lakin, Polister, & Prouty, 2003). The North Dakota community wage (NDACF, 2003) is barely above the federal poverty-level wage.

The North Dakota legislature in the 1997 session had 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. Finally, in the developmental disabilities 2004-05 biennium budget, the legislature authorized an additional $.87 per hour for direct contact staff, to $8.86 per hour, and also increased the fringe benefit rate from 30% to 33% of salary. With these increments the North Dakota average direct support wage has advanced from $6.23 in 1997 to $8.86 in 2003, an inflation-adjusted 22% increase over the 6-year period. Nevertheless, the State’s community direct support wage is still $3.00 below the average wage at the North Dakota Developmental Center.

Leadership from the State’s legislature should be acknowledged for taking those actions to address what is a serious and continuing issue for direct support staff in the community developmental disabilities programs in North Dakota.

Summary: Residential and Community Services

North Dakota continues to rank relatively high among the states on measures including residential placements per capita of the general population and placements in smaller, 6-or-fewer person settings. However, North Dakota also ranked high in the utilization of 7-15 person settings (ranked 3rd), institutions (11th), and nursing facilities (11th). Given the clear national trend away from such larger settings, it is likely that the North Dakota utilization rates will rank even higher when 2003 and 2004 data are available for all the states.

Fiscal Effort Declines

Despite North Dakota’s primary rank among the states in federal-state fiscal effort in 2002, there has been a four-year decline (2000-04) in the State’s fiscal effort levels. Total MR/DD fiscal effort declined 1%, community (<15) effort was flat (0% growth),
and there was a 6% decline in institutional (16+) fiscal effort. In 2002, North Dakota ranked 5th in state-fund community fiscal effort among the eight states with populations below one million. There has also been over a decade of decline in state funds fiscal effort for both community and total MR/DD services, and a marked decline during 2002-04. In our previous report (Braddock et al., 2002) we stated that the relative lack of commitment of state funding to match increased federal reimbursement compounded the State’s declining fiscal effort. Since 2000, North Dakota federal ICF/MR spending, adjusted for inflation, increased an average 6% per year and federal Waiver spending increased 8% per year. Federal/state Medicaid as a share of total spending in North Dakota, which dropped to 81% in 2002 increased to 86% in 2004.

In fiscal year 2004 North Dakota utilized all available state and local funding to match the expanded federal Medicaid reimbursement. Nevertheless, due to comparative growth rates during 2000-04 for ICF/MR and Waiver spending in the State, it will be 2014 before North Dakota attains the benchmark of HCBS Waiver spending surpassing ICF/MR spending, achieved nationwide in 2001. The enhanced FMAP rates that were authorized by Congress in the 2003 fiscal relief legislation (PL 108-27) expire at the end of state fiscal year 2004. To maintain fiscal effort levels, the State will need to appropriate additional state funds, at least at the level to match the lost federal revenue. (Senators Rockefeller, D-WV, and Smith, R-OR, recently introduced S. 2671 that would provide $6 billion in temporary fiscal relief to the states through fiscal year 2005.)

**Utilization of Institutional Settings**

The number of persons served in non-specialized nursing facilities, reported by the Department of Human Services, dropped from 184 in 2000 to 116 in 2004. According to DHS officials, this marked decline was due to a combination of factors: 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 MR/DD; and c) alternative placement in community-based residential services (Braddock et al., 2002).

The North Dakota Developmental Center census increased slightly from 144 in 2002 to 146 in 2004 and the number of persons with MR/DD in nursing facilities
increased from 101 in 2002 to 116 in 2004. There was 31% decline in the number of individuals in 16+ private facilities, from 105 to 72.

**Individual and Family Support**

There was no growth in inflation-adjusted spending for family support between 1996 and 2004, nor any growth in spending for supported employment. The lack of supported employment spending growth in North Dakota is related to a lack of resources for staff and service providers (Mercer, 2004). Spending for supported living and personal assistance, including Individualized Supported Living Arrangements (ISLAs), increased an inflation-adjusted 8% during 2002-04. However, there are an estimated 1,662 individuals with MR/DD living with caregivers 60 years or older. This impending need for services as well as the service needs of youth exiting special education and of alternative placements required for residents of public and private institutions, demand continued expansion of ISLA options.

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

Discrepancies in direct staff wages in state-operated institutions compared to community settings remains a serious problem. Average wages at the North Dakota Developmental Center have surpassed the U.S. average institutional wage, but North Dakota community wages are barely above the poverty wage level for a family of four. The North Dakota legislature, especially in the budget for the 2004/05 biennium, has continued to address the issue of wages for direct support staff. Moreover, the North Dakota Department of Human Services is collaborating with the North Dakota Center for Persons with Disabilities in the development of a career ladder with wage incentives for employees who complete college-based training and education programs (NDCPD, 2004). The Center is the State’s University Center of Excellence in Developmental Disabilities (UCEDD) at Minot State University. Community-based provider employees can receive job certificates, associate degrees, and bachelor degrees in this cooperative DHS and UCEDD effort.
II. QUALITY ASSURANCE OVERVIEW AND STUDY RESULTS

In this section of the report, we review the most recent data from four distinct quality assurance programs affecting services for 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 monitoring reports for North Dakota’s special education units. 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 (Braddock et al., 2002).

This 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 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.

Council Accreditation

The Standards and the Survey Process

Accreditation in North Dakota was administered by the private association entitled The Council on Quality and Leadership in Supports for People with Disabilities (“The Council”). In 1993 The Council substantially reformed both the standards and on-site survey procedures, moving from "compliance with organizational process" to "responsiveness to people" (Gardner, Nudler, & Chapman, 1997, p. 295). The 1993
Council accreditation standards were developed based on an analysis of the results of 447 interviews and 54 accreditation reviews. This produced seven major factors and 30 standards (Gardner, Nudler, & Chapman, 1997).

The 1997 edition of the Personal Outcome Measures deleted six standards (choice of time, due process afforded, personal possessions, health services, economic resources, and insurance) that were present for over 90% of the participants interviewed, i.e., that were no longer discriminating (The Council, 2000). In the accreditation surveys that were conducted in North Dakota during 1998-2004, The Council utilized a set of 25 standards for residential and community services agencies (Table 1). The standards consist of the

<table>
<thead>
<tr>
<th>Table 1</th>
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<tbody>
<tr>
<td>The Council’s Accreditation Standards for Residential and Day/Work Services</td>
</tr>
<tr>
<td>For Surveys from 1998 - 2003¹</td>
</tr>
<tr>
<td>1. Choice of goals</td>
</tr>
<tr>
<td>2. Choice in living</td>
</tr>
<tr>
<td>3. Choice in work</td>
</tr>
<tr>
<td>4. Intimate relationships</td>
</tr>
<tr>
<td>5. Satisfied with services</td>
</tr>
<tr>
<td>6. Satisfied with life situation</td>
</tr>
<tr>
<td>7. Choice in routine</td>
</tr>
<tr>
<td>8. Privacy</td>
</tr>
<tr>
<td>9. When to share personal information</td>
</tr>
<tr>
<td>10. Use environments</td>
</tr>
<tr>
<td>11. Integrated environments</td>
</tr>
<tr>
<td>12. Participate in community life</td>
</tr>
<tr>
<td>13. Interact with community</td>
</tr>
<tr>
<td>14. Perform social roles</td>
</tr>
<tr>
<td>15. Have friends</td>
</tr>
<tr>
<td>16. Respected</td>
</tr>
<tr>
<td>17. Choice of services</td>
</tr>
<tr>
<td>18. Realize goals</td>
</tr>
<tr>
<td>19. Connect to natural support</td>
</tr>
<tr>
<td>20. People are safe</td>
</tr>
<tr>
<td>21. Exercise rights</td>
</tr>
<tr>
<td>22. Treated fairly</td>
</tr>
<tr>
<td>23. Best health</td>
</tr>
<tr>
<td>24. Free from abuse, neglect</td>
</tr>
<tr>
<td>25. Continuity and security</td>
</tr>
</tbody>
</table>

¹Thirty 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 current set of 25 standards.
24 standards remaining from the 1997 Council publication, 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.”

The Council’s surveyors visit an agency for one or more days. Surveyors select a random sample of participants, ranging from two to 11 participants in the North Dakota surveys reviewed in this 2004 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 developmental disabilities served by the agency, including those 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 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 eight years of accreditation results in North Dakota is presented in *Table 2*. 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 5, 2000 to October 14, 2003. Eight agencies’ most recent surveys were in 2003, 14 were in 2002, five in 2001 and one in 2000.

The table summarizes those standards on which 30% or more North Dakota agencies were in noncompliance. In determining the 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 the outcome and the support for all 25 standards, the score for the agency would be 100%. Any survey, in which The Council determined that individuals sampled were not receiving either outcome or support for any of the 25 standards, would result in a score of less than 100%.
### Table 2
Accreditation Council Survey Results for Residential and Community Services Agencies in North Dakota, 1996-2003

<table>
<thead>
<tr>
<th>Number and Description of Council Standard</th>
<th>Proportion of Sample Not Receiving Outcome/Support for Surveys in:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Choice of goals</td>
<td>50%</td>
</tr>
<tr>
<td>2. Choice in living</td>
<td>42%</td>
</tr>
<tr>
<td>3. Choice in work</td>
<td>33%</td>
</tr>
<tr>
<td>4. Intimate relationships</td>
<td>37%</td>
</tr>
<tr>
<td>6. Satisfied w/ life situation</td>
<td>53%</td>
</tr>
<tr>
<td>9. When to share personal info</td>
<td>32%</td>
</tr>
<tr>
<td>11. Integrated environments</td>
<td>55%</td>
</tr>
<tr>
<td>14. Perform social roles</td>
<td>42%</td>
</tr>
<tr>
<td>15. Have friends</td>
<td>41%</td>
</tr>
<tr>
<td>17. Choice of services</td>
<td>46%</td>
</tr>
<tr>
<td>19. Connect to natural support</td>
<td>37%</td>
</tr>
<tr>
<td>21. Exercise rights</td>
<td>33%</td>
</tr>
<tr>
<td>22. Treated fairly</td>
<td>30%</td>
</tr>
<tr>
<td>23. Best health</td>
<td></td>
</tr>
<tr>
<td>15. Due process afforded (1996-97)</td>
<td>60%</td>
</tr>
</tbody>
</table>

**Number of Agencies Surveyed:** 5 17 7 15 13 6 14 8 28

**# Awarded 4-Year Accreditation:** 1 1

**# Awarded 3-Year Accreditation:** 5 6 1 8 6 3 12 5 21

**# Awarded 2-Year Accreditation:** 11 6 6 7 3 2 2 6

**# Awarded 1-Year Accreditation:** 1

---

### Surveys by Year

The North Dakota annual averages during 1996-2003 were 83%, 73%, 78%, 78%, 78%, 78%, 81%, and 79%, 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 seven standards that were particularly problematic for North Dakota agencies across most or all of the eight years included *choice of goals*, *choice in living*, *choice in work*, *integrated environments*, *perform social roles*, and *choice of services*. The standard addressing *intimate relationships* was problematic for agencies surveyed in only one year, 1997, and *best health* was problematic only in 2002 and 2003. The standard *satisfied with life situation* was above the 30% criterion in 1996 and 1997. The standard *have friends* was cited for 30% or more consumers in 1997 and 2003. The two standards, *connect to natural support* and *due process afforded*, respectively, were cited for 37% and 60% of the agencies surveyed in 1997, and *connect to natural support* was also cited...
in 2003 (*due process afforded* was dropped from the revised standards). Finally, the standard *treated fairly* emerged as problematic in 1998, 1999 and again in 2002.

The table also indicates how many North Dakota agencies each year received 3-year, 2-year, or 1-year Council accreditation awards. North Dakota agencies’ performance was the strongest in 1996, 2002 and 2003 when the proportions of 3-year accreditation outcomes were 100%, 86% and 75% respectively. (Included with the 3-year accreditation percentage in 2003 was a 4-year accreditation that The Council awarded that year.) The smallest proportions of 3-year accreditation awards were in 1997 (35%), 1998 (14%), 1999 (53%), 2000 (46%) and 2001 (50%).

### Most Recent Surveys

With the exception of *choice of goals*, the most recently surveyed agencies as a group shared the same problematic standards as those for agencies surveyed across the years: *choice in living, choice in work, integrated environments and perform social roles*. As noted 22 of the 28 agencies’ most recent surveys, or 79%, resulted in 3-year (and one 4-year) accreditation awards.

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 3-year accreditation award (see the Agency Quality Assurance Profiles in *Appendix 16* for the individual agencies’ histories of accreditation outcomes). Tables in *Appendices 2-10* detail the scores for each North Dakota agency on each of the 25 standards applicable to surveys during 1998-2003 and on each of the 30 standards applicable to surveys during 1996-97. The individual agency score on each standard is compared to the nationwide average for that standard, and one can determine, from agency code numbers, which are re-surveys for agencies that received an accreditation decision in a prior year.

### Infant Development Program Accreditation

Six infant development programs surveyed in 1996, 1997, 1999 and 2000 all received 3-year accreditation awards from the Council. The programs achieved consistently high scores in each survey. The single infant development program surveyed
in 1998 and the one surveyed in 2001 each received 2-year accreditation awards. These programs, especially the program surveyed in 2001, had more problems with standards (Braddock et al., 2002).

North Dakota Infant Development Programs are no longer seeking accreditation by The Council (V. Pederson, Department of Human Services, personal communication, June 28, 2004). The North Dakota Center for Persons with Disabilities (UCEDD) and the state Departments of Human Services and Public Instruction have received a General Supervision Enhancement Grant from the U.S. Department of Education, Office of Special Education Programs (OSEP), to achieve a more results-focused approach for infant development programs that is in line with the federal “Continues Improvement Focused Monitoring System (CIFMS).”

The present system for early intervention services in North Dakota, the Continuous Improvement Monitoring System (CIMP), consists of a state level advisory committee, and eight Regional Interagency Coordinating Committees that monitor the quality of early intervention services. The Committees’ representatives include families of children with developmental delays or disabilities, special education staff, legislators, advocacy groups, childcare and medical providers, and early intervention and DD case management personnel. Using IDEA compliance standards the Regional teams monitor services for infants and toddlers, and address quality outcomes. The teams focus on five cluster areas: Child-find, Early Intervention Services in Natural Environments, Family Centered Services, Transition, and General Supervision. (D. M. Balsdon, Administrator, Family Support Programs, North Dakota Department of Human Services, personal communication, June 28, 2004).

**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. Both The Council’s private accreditation and the Medicaid certification procedures utilize published standards. However, the 377 federal Medicaid “program” requirements and 88 additional “life-safety code” requirements more closely resemble the early accreditation standards for residential facilities (ACF/MR, 1971) than do The Council’s most recent set of 25 standards.

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**

administered to 62 community-based ICFs/MR and four units at the Grafton Developmental Center. There was one fewer community-based ICF/MR survey in 2000, and three fewer in 2001. However, in 2002 there were an additional three surveys of ICFs/MR serving six or fewer individuals. We had access to a partial year’s data for 2003, consisting of 54 of the 62 residential and community services agencies and the four units at the North Dakota Developmental Center.

**Table 3** summarizes the program and life-safety code requirements that were cited as deficient for 10% of more of the North Dakota ICFs/MR, in one or more survey year. Twenty-four program requirements and 17 life-safety code requirements met this criterion. The most frequently cited program requirement deficiencies across all years were Individual Program Plan (IPP) and continuous active treatment, all drugs with physician’s order, infection control-active program, and dine according to developmental level. These ICF/MR requirements were cited for relatively high percentages of North Dakota ICFs/MR, although in the case of all drugs with physician’s order, agencies surveyed in 2002 and 2003 achieved much higher compliance than in earlier surveys.

The most frequently cited life-safety code deficiencies across all years were corridor walls, corridor doors, hazardous areas-separation, remote exits, and automatic sprinkler system. The requirements for corridor walls, hazardous areas-separation, patient room locks, and automatic smoke detection system also emerged as more critical life-safety issues in the surveys conducted in 2001-04. It should be noted that there were declining percentages of deficiencies cited over the years for construction type, doors in smoke partitions, exit access, exit lighting, emergency lighting, exit signs, testing of fire alarm, and sprinkler system maintenance.

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 11). The comparative statistic is the proportion of ICFs/MR in North Dakota, the Region, and the United States that were found deficient on each Medicaid requirement. There were 26 program requirements and 16 life-safety code requirements (including an “other”
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Table 3
ICF/MR Program Requirements Cited as Deficient in 10% or More North Dakota Facilities, 1997-2003

Year of survey and number of surveyed facilities:

<table>
<thead>
<tr>
<th></th>
<th>1997 (n=48)</th>
<th>1998 (n=66)</th>
<th>1999 (n=66)</th>
<th>2000 (n=65)</th>
<th>2001 (n=63)</th>
<th>2002 (n=66)</th>
<th>2003 (n=58)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number and % of facilities with deficiency:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>K0101</td>
<td># %</td>
<td># %</td>
<td># %</td>
<td># %</td>
<td># %</td>
<td># %</td>
<td># %</td>
</tr>
<tr>
<td>K0102</td>
<td>13 27%</td>
<td>23 35%</td>
<td>7 11%</td>
<td>3 5%</td>
<td>4 6%</td>
<td>4 8%</td>
<td>3 7%</td>
</tr>
<tr>
<td>K0107</td>
<td>3 6%</td>
<td>5 8%</td>
<td>12 18%</td>
<td>14 22%</td>
<td>8 13%</td>
<td>6 12%</td>
<td>7 16%</td>
</tr>
<tr>
<td>K0108</td>
<td>21 44%</td>
<td>19 29%</td>
<td>18 27%</td>
<td>15 23%</td>
<td>13 21%</td>
<td>8 16%</td>
<td>6 19%</td>
</tr>
<tr>
<td>K0109</td>
<td>11 17%</td>
<td>13 17%</td>
<td>6 9%</td>
<td>3 5%</td>
<td>4 6%</td>
<td>1 2%</td>
<td>3 7%</td>
</tr>
<tr>
<td>K0110</td>
<td>14 25%</td>
<td>11 17%</td>
<td>24 30%</td>
<td>35 38%</td>
<td>35 38%</td>
<td>10 31%</td>
<td>16 32%</td>
</tr>
<tr>
<td>K0103</td>
<td>5 10%</td>
<td>2 3%</td>
<td>1 2%</td>
<td>0 0%</td>
<td>3 5%</td>
<td>0 0%</td>
<td>1 2%</td>
</tr>
<tr>
<td>K0104</td>
<td>2 4%</td>
<td>2 4%</td>
<td>9 12%</td>
<td>3 5%</td>
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Year of survey and number of surveyed facilities:

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<td>11 22%</td>
<td>18 42%</td>
</tr>
</tbody>
</table>

ICM/S (HCFA) Regional Office Flags.

category not specified by surveyors) in which North Dakota facilities surveyed in 2003 had higher deficiency percentages than both the regional and national averages. Twelve program requirements and two life-safety code requirements were also found deficient for 10% or more of the North Dakota ICFs/MR.
Appendix 12 details the North Dakota facilities’ performance on ICF/MR certification surveys during 1998-2003. 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 one or more North Dakota ICFs/MR, in one or more of the years spanning 1998-2003. During those years, North Dakota agencies were cited for 14%, 11%, 10%, 14%, 12% and 15%, respectively, of the total 377 applicable program standards. (As noted, survey data for 2003 were for a partial year; however, the 58 surveys that year represented 88% of the 66 surveys that were conducted in 2002.)

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 (PL 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 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.

The 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 (Hysjulien, 2004).

The North Dakota P&A Project’s abuse, exploitation, and neglect data are no longer available on a site-by-site basis as were the P&A data reported previously
(Braddock & Hemp, 2000). Therefore, the individual Agency Quality Assurance Profiles (Appendix 16) no longer detail abuse, exploitation, or neglect data on an agency-by-agency basis.

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

Abuse, exploitation, and neglect data were examined over an eight-year period, 1996-2003. The 2000 data afforded no detail within the broad areas of abuse, exploitation, and neglect (Table 4). Across the eight years, there were 241 substantiated incidents of abuse, 38 incidents of exploitation, and 762 incidents of neglect (part-year data only were available for 1996). Except for 2000, data each year were reported across eight categories of abuse, two categories of exploitation, and eight categories of neglect.

#### Table 4

<table>
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<th>97</th>
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<th>00</th>
<th>01</th>
<th>02</th>
<th>03**</th>
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<td>218</td>
<td>113</td>
<td>267</td>
<td>120</td>
</tr>
</tbody>
</table>

* Spike in 2000 attributable to neglect: medication errors; see discussion in text

** In 2003, all sites included only day programs, group homes, ISLA/SLA, and family support
In our previous study (Braddock et al., 2002) we reported abuse, exploitation and neglect data for the first quarter of 2002. In this study, we received data for April through December 2002. The previously reported data for the first quarter of 2002 were combined with data for the remaining three quarters of 2002. We received a complete year’s data for 2003 (all four quarters).

In the area of abuse there were no reported incidents in 2002 or 2003 in five categories: *threats of retaliation, sexual abuse, inappropriate/excessive meds, other abuse*, and *involuntary aversive behavior therapy*. Furthermore, in 2003 there were declines in the numbers of substantiated incidents in the other three categories (*physical abuse, verbal abuse, and restraint/isolation/seclusion*) compared to 2002. In the area of exploitation, *financial exploitation* declined in 2003 and there were two incidents of *other exploitation* in 2002 and in 2003.

Finally, in the area of neglect, there were declines in five of six categories of reported incidents from 2001 to 2003. The number of incidents for the sixth category, *other neglect*, increased slightly from eight in 2001 to ten in 2003. (There were no reported incidents in the other two categories during 2001-03).

Jim Jacobson, Deputy Director, North Dakota Protection and Advocacy Project (personal communication, August 2, 2002) reported that substantiated incidents of *medication errors* accounted for 120 of the total 181 incidents of neglect in 2000. Jacobson noted that a number of agencies were in the process of upgrading incident reporting, and that he believed that when all agencies achieved “deemed status” with the North Dakota Protection and Advocacy Project, such artifacts of reporting would diminish and yield more representative data (Braddock et al, 2002, pp. 31, 32). As indicated in **Table 4**, the number of incidents of *medication errors* declined from the estimated 120 in 2000 to 26, 70 and 38, respectively, in 2001, 2002, and 2003.

Other important caveats apply to the interpretation of these abuse, exploitation, and neglect data. For example, comparatively more substantiated incidents were recorded in those settings that served the largest proportion of individuals (Appendix 13). It 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” resulting, for example, from staff turnover or other variations in the resources of the P&A Agency...
investigation team over time, 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 result in greater reports of abuse.

Appendix 13 provides detail by type of setting, year, and category of abuse, exploitation, or neglect. The table in the appendix provides two totals across all categories—a grand total of 1,041, and a total of 823 that excludes the 2000 data that were not allocable by category of abuse, exploitation, and neglect, or by type of setting. For 1996 to 1999 combined with 2001 to 2003, 48% of the 823 substantiated incidents of abuse, exploitation, and neglect was documented at group homes, 30% at ISLA/SLA and apartment settings, 11% at day programs, 7% at units of the North Dakota Developmental Center, and 3% at congregate/ICFs/MR. Substantiated incidents at all other categories of setting (family support, parent/school, long-term care/nursing home, foster care, hospital, and transportation) constituted 1% or less of the total for all sites during the six years. (Note: The North Dakota Protection and Advocacy Project did not report any substantiated incidents of abuse, exploitation or neglect at the North Dakota Developmental Center in 2002 or 2003.)

Data on “repeat” incidents of abuse, exploitation, or neglect, presented in Appendix 13, were available for 2001, 2002, and 2003. Across these three years, there were 18 repeat incidents of abuse, four repeat incidents of exploitation, and 122 repeat incidents of neglect.

Special Education Unit Monitoring

The quality assurance system in place for North Dakota’s 30 special education units was separate and distinct from the residential and community services agency quality assurance data sets. The North Dakota Department of Public Instruction (DPI) Office of Special Education conducted site visits and prepared 9 to 27-page reports on the outcomes of the visits. The number of site visits by year was: 1994 (5), 1995 (9), 1996
There was a substantial change between 1998 and 2000 in the numbers and categories of regulations employed in the site visits.

In the 2002-03 special education site visits, 50% or more special education units were in non-compliance with five regulations in one category, *free and appropriate public education* (*Table 5*). Non-compliance was not found in the categories *zero reject*

<table>
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<td>44%</td>
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<tr>
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<td>Incomplete evaluation planning forms</td>
<td>31%</td>
<td>33%</td>
</tr>
<tr>
<td>300.534</td>
<td>Determination of eligibility</td>
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<td>11%</td>
</tr>
<tr>
<td>300.536</td>
<td>Reevaluation</td>
<td>31%</td>
<td>22%</td>
</tr>
<tr>
<td>300.540</td>
<td>Additional procedures for evaluating children with specific LDs**</td>
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<td>56%</td>
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<td>300.541</td>
<td>Criteria for Determining Existence of a Specific LD</td>
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<tr>
<td>300.543</td>
<td>Written Report</td>
<td>50%</td>
<td>22%</td>
</tr>
</tbody>
</table>

**in 2000-01 this regulation was listed as Additional Team Numbers, but in the 2002-03 data, non-compliance in this area was often indicated as 300.540-300.543: Additional requirements... and did not indicate the specific regulation.
or parent involvement. In the category procedural safeguards, the highest percentage of non-compliance was 44% and in the category least restrictive environment the highest percentage was 33%.

The table compares special education units’ performance in the most recent site visits in 2002-03 to site visits in 2000-01. Between 2000-01 and 2002-03, special education compliance improved on seven regulations in the category nondiscrimination evaluation, on seven regulations in free and appropriate public education, and on one regulation in least restrictive environment. However, for five of the regulations in the category free and appropriate public education there was markedly higher noncompliance in 2002-03. Those regulations were: transition services, annual goals and short-term objectives/contents of IEP, present level of educational performance (PLEP), characteristics of services, and requirement that PLEP address all areas of functioning (which was not applicable in 2000-01 and resulted in 78% noncompliance in 2002-03). Appendix 15 presents details on special education units’ performance.

In the 1994-98 site visits, there were seven applicable categories of IDEA regulations: local application requirements, procedural safeguards, confidentiality of information, individual education program (IEP), least restrictive environment, protection in the evaluation process, and additional procedures for learning disabilities (LD). In 1994-98 there were problematic regulations in all seven categories. That is, 50% or more of the special education units were in non-compliance with one or more regulations in each of the seven categories (Braddock et al., 2002).

**Agency Quality Assurance Profiles**

Appendix 14 consists of Agency Quality Assurance Profiles for 28 North Dakota residential and community service agencies, including the North Dakota Developmental Center. Data for two agencies, # 5 and # 10, presented in our previous report (Braddock, et al., 2002), were not available in the present study.

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 # 25 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 13 for a breakout by type of setting/site.)

In the accreditation section of the Agency Quality Assurance Profiles (Appendix 16), it is possible to view the organization’s history of accreditation survey dates and outcomes. The Profiles also illustrate agencies’ problematic standards in the two most recent surveys. These are standards 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 two most recent surveys 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 66 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, and these data are integrated with composite North Dakota ICF/MR deficiency data that also pertain to community based ICFs/MR. The Developmental Center units’ accreditation data are not integrated with the residential and community service agency data that are presented in Appendices 2-10, but are detailed in the Developmental Center Quality Assurance Profile in Appendix 16.

**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 July 2003. The facility received a 2-year award. There had been five successive 2-year accreditation awards from 1989 to 1998, and a 3-year award in the previous survey in May 2000. The nine standards that were problematic for the facility in
the most recent survey were integrated environments (0% compliance), choice of services (18%), choice in living (27%), connect to natural support (45%), participate in community life (45%), use environments (59%), interact with community (73%), intimate relationships (73%), and choice of routine (82%). 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.

On the other hand, the Developmental Center (DC) attained scores on seven 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 when to share personal information (46% greater and 100% DC compliance), people are safe (24% greater and 100% DC compliance), satisfied with services (11% greater and 100% DC compliance), respected (10% greater and 100% DC compliance), treated fairly (9% greater and 100% DC compliance), satisfied with life situation (8% greater and 100% DC compliance), and realize goals (7% greater and 100% DC compliance). The Developmental Center is a state institution and cannot attain the standards related to integrated environments; nevertheless, the facility performed relatively well on several other Council standards.

**Medicaid Survey and Certification**

In the analysis of the Developmental Center’s most recent Medicaid ICF/MR certification results (Appendix 14, agency code #40), the Center’s four units were cited on ten, five, three, and zero program deficiencies, respectively. Two program deficiencies, train for privacy, independence and individual program plan and continuous active treatment, received “Regional flags” at the first and second Developmental Center ICF/MR units (it was a repeat deficiency at the second unit), and individual program plan (IPP) specific objectives was flagged as deficient in the third of the Developmental Center’s four ICF/MR units.

There were other problematic requirements for Developmental Center units (i.e. requirements for which 10% or less of North Dakota and Region 8 ICFs/MR were cited). The first ICF/MR unit had a total of six such problematic requirements: clients exercise rights as clients and citizens; objectives reflect appropriate developmental progression;
nursing services per need; education, training in maintenance of oral health; drugs must be properly secured; and clients actually evacuated at least 1 drill per shift.

For the second ICF/MR unit, there were three problematic requirements: report alleged abuse, neglect immediately; policies and procedures must promote the growth, development, and independence of client; and drugs must be properly secured. The third ICF/MR unit also was cited for the requirement, clients actually evacuated at least 1 drill per shift, and the fourth unit was not cited for any program requirement deficiencies.

**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 2003 all agencies had undergone from seven to nine progressively more successful accreditation surveys. North Dakota’s agencies met or exceeded all but nine of the 30 national average standards’ scores in 1997. The nine not met were choice of goals, perform social roles, have friends, connect to natural support, intimate relationships, when to share personal information, integrated environments, insurance, and satisfied with life situation. In 2001 North Dakota agencies met or exceeded all but three of the 25 national averages. The three not met were realize goals, people are safe, and continuity and security. In 2003, North Dakota agencies exceeded the national average on all but two of 25 standards (*when to share personal information* and *integrated environments*).

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 12 program and three 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 16*). 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.

III. REPORT SUMMARY AND CONCLUSION

Major accomplishments, and some important continuing challenges, emerged from analysis of the structure, financing, and quality assurance of North Dakota’s developmental disabilities service system. Issues and challenges include limitations in the State’s financial commitment to developmental disabilities services; excessive reliance on public and private institutional settings, which is manifest in continuing Intermediate Care Facility/Mental Retardation (ICF/MR) spending growth competing with Home and Community Based Services (HCBS) Waiver expansion; and the absence of sustained, growing financial commitments for family support, supported employment, and supported living services.

Quality assurance challenges in North Dakota include deficiencies on critical standards in accreditation and Medicaid survey/certification reviews. Although North Dakota has continued to perform generally well in terms of national and regional comparisons, the State lost ground during 2002 to 2003.

*Structure and Financing of Residential and Community Services*

We identified seven core challenges in the structure and financing of residential and community services in North Dakota.

1. *The four-year decline in North Dakota’s fiscal effort for developmental disabilities services needs to be reversed.*
During 2000-2004, total fiscal effort (federal funds included) was down 1%, community fiscal effort was up slightly (0.2%), and institutional fiscal effort declined 6%. Declining institutional fiscal effort is positive if accompanied by the reallocation of institutional resources to community services and individual and family support. This has not been the case recently in North Dakota. State fiscal effort (federal funds excluded) for North Dakota developmental disabilities services has also declined dramatically--from a peak of $4.34 in 1986 to $2.09 in 2002 and there was a further 18% decline to $1.71 in 2004.

The 2002-04 drop reflected the more complete “Federal Medicaiding” of North Dakota Developmental Disabilities services, and also the temporary increase in federal Medicaid funding during January 2003 through June 2004 from the federal Jobs Growth Tax Relief Reconciliation Act of 2003. However, with the lapsing of the enhanced Federal Medical Assistance Percentage (FMAP) rate on June 30, 2004 under the Jobs Growth Act, and the prospect of continued budget problems across the states, North Dakota will be challenged to increase state funding for needed DD services in fiscal year 2005 and beyond. If passed by Congress and signed by the President, S. 2671 would grant an additional $6 billion in Medicaid relief to the states through fiscal year 2005. North Dakota should strongly support this legislation.

2. **North Dakota should significantly expand the HCBS Waiver over the next decade.** Although HCBS Waiver spending increased substantially in 2004, it still lags the State’s ICF/MR spending level and will continue to do so if recent trends continue.

In 2002, North Dakota ranked 30th among the states in federal-state Waiver spending as a percentage of total MR/DD spending. Inflation-adjusted federal Waiver spending in North Dakota declined 2% per year from 2000 to 2003, while the State’s ICF/MR spending expanded 3% per year. Despite 19% Waiver growth in 2004, if the 2000-2004 spending trends for the North Dakota ICF/MR program and the Waiver continue, it will be 2014 before the State’s Waiver spending surpasses ICF/MR spending. This important benchmark was attained nationwide in 2001.

3. **North Dakota over-utilizes public and private 16+ institutions and 7-15 person settings.**
The state-operated institutional utilization rate in North Dakota ranked 11th among the 42 states that still financed state-operated institutions. Nursing facility utilization also ranked 11th. Only New York and South Dakota surpassed North Dakota in 7-15 person facility utilization.

4. North Dakota must maintain its leadership in supported living, spending for which declined from 2000 to 2003.

North Dakota was a national leader in the implementation of supported living and personal assistance services, and continues to rank in the top five states in the nation in supported living spending and in the number of participants per capita (per citizen of the general population). However, inflation-adjusted supported living spending growth declined by 3% from 2000 to 2003. It increased by 14% in 2004. Continued growth in supported living spending will provide additional alternatives for individuals in public and private institutions, for the State’s 7-15 person group living arrangements, and, as noted below, to address other pressing needs for residential support.

5. Family support and supported employment spending has not grown since 1996.

In real economic terms, North Dakota’s spending for family support and for supported employment are at the same level as in 1996, at $4 million and $2 million, respectively. During 2000 to 2004, inflation-adjusted family support spending increased 1% per year and supported employment spending declined 1% per year. As noted, the North Dakota Waiver finances 85% of family support spending and 100% of supported employment spending. The State has therefore availed itself of the opportunity from the Balanced Budget Act of 1997 to expand Waiver-reimbursed supported employment services, but despite this Waiver support, there has been no real growth in spending for supported employment.

6. Demand for MR/DD services in North Dakota will be driven by: a) youth aging out of special education; b) individuals in public and private institutions requiring community homes and supported living; and c) family support needs, including, d) individuals residing with aging caregivers.
Although recent research reports and discussions with North Dakota officials indicate that there are no individuals with MR/DD on formal waiting lists in North Dakota, there are emerging demographic and service system pressure points that must be addressed over the next decade. Over the 2004/05 biennium, more than 150 students will exit special education, as estimated 1,600 individuals with developmental disabilities live with family caregivers who are aged 60 years or older, and there is a continued need to move away from the State’s congregate-care orientation in public and private 16+ and 7-15 person settings. This can be accomplished by expanding support for families and extending supported living alternatives.

7. **Continue North Dakota Association of Community Facilities collaboration with the North Dakota legislature to further increase direct support staff wages.**

Achieving adequate wage and benefit levels for direct care staff working with children and adults with developmental disabilities is a critical issue in all the states. In 2004, North Dakota’s direct support staff benefited from a legislatively sanctioned hourly increase of $.87 and an increase in fringe benefits from 30% to 33% of salary. However, the increased average direct support wage of $8.86 still lags the North Dakota Developmental Center wage by $3.00 per hour, and is less that 20 cents above the U.S. poverty wage for a family of four. In collaboration with the North Dakota Association of Community Facilities, the North Dakota legislature is considering providing an additional increase of approximately $1.00/hour to the community direct support wage level (D. Brunette, Executive Director, Friendship, Inc., personal communication, June 29, 2004).

**Quality Assurance**

Section II of the report analyzed data sets on quality assurance: accreditation by The Council on Quality and Leadership in Supports for People with Disabilities; ICF/MR survey and certification surveys; incidents of substantiated abuse, exploitation, and neglect; and the monitoring of special education units.
Accreditation

For an individual agency, if all sampled participants were receiving both outcome and support for a given standard, the agency’s score would be 100% on that standard. If none of the sample was judged to be receiving the required outcome but all were receiving the required support, the agency’s score on that standard would be 50%. As summarized in Table 2 in the main body of the Report, all five agencies surveyed in 1996 received 3-year accreditation awards (100%). The proportions of surveyed agencies that received 3-year accreditation in the other seven survey years, 1997-2003, were 35%, 14%, 53%, 46%, 50%, 86%, and 75%, respectively.

North Dakota’s 28 residential and community service agencies and the North Dakota Developmental Center performed generally better than the national average on most of the 25 Council accreditation standards (Appendix 10). The eight North Dakota agencies’ 2003 survey scores also outperformed the national average. In the case of four standards (choice of services, choice of goals, exercise rights, and treated fairly), North Dakota exceeded the national average by 75-95%.

However, there were two standards on which the national averages surpassed the North Dakota agencies.

- When to share personal information (32% North Dakota deficiency vs. 25% nationally)
- Integrated environments (69% North Dakota vs. 62% nationally)

There were also six standards on which North Dakota agencies surveyed in 2003 were found deficient in 23% to 69% of consumers’ outcomes/supports, and the performance on each standard was substantially below that of surveys in 2002 (Figure 11).

- The standards choice in work and integrated environments were problematic for 52% and 69%, respectively, of the sampled participants in North Dakota agencies and perform social roles for 50%.

These three standards, along with exercise rights, were the four most problematic standards for agencies surveyed nationally by The Council. The two standards that proved problematic for 52% and 69% of North Dakota agencies’ participants sampled by The Council are in The Council’s category of “affiliation,” meaning connections to other
people and choice about with whom time is spent and participation in community environments and events including church, school sports, retirement centers, and beauty shops. The standard integrated environments refers to the integration of residential, day, recreation, and other services and supports, and how much time the participant spends in environments with others who do not have disabilities. The standard perform social roles refers to the extent to which participants interact positively with members of the community and are seen to contribute to the community.

The regression from 2002 to 2003 of North Dakota accreditation scores in these areas points to a continued need for the State to expand integrated residential, work, and other support services. Community agencies must continue to work to expand opportunities for individuals to interact with people without disabilities, and to become contributing members of the community.
ICF/MR Certification

Fifty-four ICFs/MR in North Dakota, and four units at the North Dakota Developmental Center, were compared to ICFs/MR in the Region (Colorado, Montana, North Dakota, South Dakota, Utah, and Wyoming) and in the nation as a whole on their most recent surveys in 2003 (Appendix 11). “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 2003, twelve program requirements and two 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.

- **Four program requirement deficiencies related to health and safety.**
  - Evacuation drills held at least quarterly (36% North Dakota deficiency)
  - Alleged abuse, mistreatment, neglect, investigated thoroughly (14%)
  - Individual medication administration record for each client (12%)
  - Clients actually evacuated at least 1 drill per shift (quarterly) (10%)

- **In addition, eight program deficiencies related to the effectiveness of training programs, the interaction of staff with residents of the ICF/MR, and individual program planning.**
  - Train for privacy and independence (40% North Dakota deficiency)
  - Clients taught to self-administer drugs if appropriate (26%)
  - Individual program planning and continuous active treatment (26%)
  - Dine according to developmental level (19%)
  - Individual program plan (IPP) has specific objectives (14%)
  - Privacy during care and treatment is ensured (12%)
  - Objectives provide measurable indices of performance (12%)
  - Individual program plan data in measurable terms (10%)

It should be noted that 1) infection control: active program; 2) alleged abuse, mistreatment, neglect, investigated thoroughly; and 3) policies: conduct between staff and residents were problematic for the North Dakota ICFs/MR reported in our previous study (Braddock et al., 2002). These were no longer deficiencies in the current study.

- **The two life safety code deficiencies problematic for North Dakota facilities addressed physical plant health and safety issues.**
Remote exits (42% North Dakota deficiency)

Corridor walls (16%)

North Dakota facilities were not deficient at the 10% criterion for any additional program deficiencies. However, there were two life-safety code requirements that were problematic for 10% or more of North Dakota ICFs/MR. They were: automatic sprinkler system (23%) and corridor doors (19%).

Abuse, Exploitation, and Neglect

As we have discussed, reports on abuse, exploitation, and neglect from the North Dakota Protection and Advocacy organization are no longer identifiable by agency or program site. The following is a list of the most frequently cited incidents, across all sites during 1996-03. It should also be noted that data for 2003 were only provided for the four categories day programs, group homes, ISLA/SLA, and family support; 2002 and 2003 data were not provided for the North Dakota Developmental Center. Some of the reported trends may be an artifact of these missing data (see Appendix 13).

Four categories of neglect and three categories of abuse were cited 40 times or more during 1996-2003.

- Neglect: Personal safety (178 incidents)
- Neglect: Medication errors (134 incidents)
- Neglect: Personal care (104 incidents)
- Abuse: Physical (63 incidents)
- Abuse: Threats of retaliation (48 incidents)
- Neglect: Written habilitation plan (45 incidents)
- Abuse: Restraint/isolation/seclusion (41 incidents)

Two categories of neglect, personal safety and personal care, were reported consistently over the years, although in each case there was a decline in the number of incidents from 2002 to 2003. There were slight declines as well in 2003 for other categories of neglect.

In addition, there were 30 substantiated incidents of exploitation: financial across all sites during 1996-03; however, reported incidents declined from 2002 to 2003. The number of incidents in three categories of abuse--physical abuse, verbal abuse, and restraint/isolation/seclusion--declined from 2002 to 2003 and there were no incidents of
any of the other five categories of abuse in either 2002 or 2003 (threats of retaliation, sexual abuse, inappropriate/excessive meds, other abuse, or involuntary/aversive behavior therapy).

**Special Education Site Visits**

In the 2002-03 site visits, regulations were organized into six categories: zero reject, nondiscrimination evaluation, free appropriate public education, least restrictive environment (LRE), parent involvement, and procedural safeguards. No North Dakota special education unit receiving site visits during 2002-03 was cited for regulations in the categories zero-reject or parent involvement.

- Four or more (44% or more) of the nine units surveyed in 2002-03 were cited for non-compliance with the eight regulations listed below:

  **Nondiscrimination Evaluation**
  - Evaluation procedures (44%)
  - Additional procedures for evaluating children with specific learning disabilities (LD) (56%)

  **Free Appropriate Public Education**
  - Transition services (56%)
  - Annual goals and short-term objectives/contents of individualized education plan (IEP) (89%)
  - Present level of education performance (PLEP) (56%)
  - Characteristics of services (56%)
  - Requirement that PLEP address all areas of functioning (78%)

  **Procedural Safeguards**
  - Record locator (44%)

**Conclusion and Priorities**

North Dakota, like many other states, has responded positively in the past to challenges to improve the capacity and quality of developmental disabilities residential and community services. However, this is a particularly difficult period for state human service systems. State governments confronted a collective $20 billion budget shortfall in fiscal year 2003 and had a brief reprieve enhanced by increased federal Medicaid funding in 2004 under the Jobs Growth Act (NCSL, 2003, 2004). Many states now face significant budget problems in 2005, however.
North Dakota has fared better than most states in the recent financial crisis. In an analysis of state fiscal strength as of May 2004, Federal Funds Information for States (2004) identified nine states and North Dakota as those with the strongest financial outlook for fiscal year 2005. North Dakota was also among the 15 states with fiscal year 2004 general fund balances of 5% or more.

North Dakota, therefore, has a comparatively stronger state budget with which to address developmental disabilities service needs in FY 2006 and possibly beyond. In this context, principal priorities for North Dakota in developmental disabilities services are:

1. Assuring that the state priority will be growth of the HCBS Waiver to finance a steadily increasing proportion of community residential and related support services;

2. Concomitantly, reducing reliance on ICF/MR funding for 16+ and 7-15 person residential settings is an important objective for the State as well; this entails continuing to reduce the census of public and private 16+ institutions including Grafton, and the development of appropriate community alternatives;

3. Increasing the level of financial resources for family support, supported employment and for Individualized Supported Living Arrangements (ISLA) and other supported living options to meet the ongoing need for services; and

4. Continuing community provider/state agency efforts with the State Legislature to substantially enhance wages and benefits for direct support staff. Parity with wages at the North Dakota Developmental Center is an appropriate near-term goal.

Quality Assurance Challenges

In general, North Dakota agencies and facilities compare reasonably well to others in the region and across the nation. Nevertheless, quality assurance data analyzed in this report reveal significant and recurring problems in key areas, and at individual facilities, that require the attention of state officials and residential and community services agencies.

Critical accreditation standards including choice in living, choice in work and integrated environments underscore the lack of resources in supported employment and supported living, and the continued, and inappropriate, congregate-care orientation of many North Dakota residential settings. Medicaid ICF/MR certification requirements also
point to the need to develop more integrated settings, and expand opportunities for community participation.

The accreditation standard *people are safe* was problematic for 15% of consumers. Deficiencies for ICFs/MR included *evacuation drills, investigating abuse, mistreatment or neglect*, and *adequate medication records*. Incidents of abuse, exploitation or neglect including *personal safety, medication errors, and personal care* were also noted. More direct incidents of abuse--*physical* and *verbal*--are apparently declining, but any incidents are very serious matters for agencies and the State to respond to immediately. Problematic areas revealed in critical accreditation standards, ICF/MR deficiencies, and in abuse, exploitation, and neglect incident investigation procedures are important priorities for direct service staff and manager training programs, and especially for the orientation and training of new staff.

The North Dakota Department of Human Services is collaborating with the North Dakota Center for Persons with Disabilities at Minot State University to develop a comprehensive developmental disabilities training and education curriculum and a meaningful career ladder for direct support staff, professionals, and supervisory staff (NDCPD, 2004). This collaboration is a very significant contribution. We also acknowledge the Center’s initiative (Midewin Institute, 2003) in preventing abuse and neglect.
IV. REFERENCES CITED


Minot State University, North Dakota Center for Persons with Disabilities, a University Affiliated Program.