

# LONG-TERM CARE COMMITTEE

The Long-Term Care Committee was assigned the following responsibilities:

1. Section 3 of Senate Bill No. 2109 (2007) directed a study of the long-term care system in North Dakota, including capacity, geographical boundaries for determining capacity, the need for home and community-based services, a methodology to identify areas of the state needing additional nursing home beds, access, workforce, reimbursement, and payment incentives.
2. House Concurrent Resolution No. 3022 (2007) directed a study of the availability and future need for dementia-related services, as well as funding for programs for individuals with dementias.
3. Senate Concurrent Resolution No. 4005 (2007) directed a study of the feasibility and desirability of establishing a transition to independence program for young adults with mental illness.
4. The Legislative Council assigned the committee responsibility to receive, before August 1, 2008, the following reports from the State Department of Health:
  - a. A report regarding the status of the demonstration project for voluntary surveys during major construction or renovation of basic care and long-term care facilities, pursuant to subdivision 4 of Section 12 of House Bill No. 1004 (2007).
  - b. A report regarding the impact of implementation of a survey process for basic care facilities, pursuant to Section 2 of House Bill No. 1488 (2007).

Committee members were Senators Dick Dever (Chairman), Joan Heckaman, Aaron Krauter, Judy Lee, and Tim Mathern and Representatives Larry Bellew, Karen Karls, Gary Kreidt, Ralph Metcalf, Jon Nelson, Vonnie Pietsch, Louise Potter, Clara Sue Price, Gerry Uglem, Benjamin A. Vig, and Alon Wieland.

The committee submitted this report to the Legislative Council at the biennial meeting of the Council in November 2008. The Council accepted the report for submission to the 61<sup>st</sup> Legislative Assembly.

## LONG-TERM CARE STUDY

Section 3 of Senate Bill No. 2109 (2007) directed a study of the long-term care system in North Dakota. The study was to include capacity, geographical boundaries for determining capacity, the need for home and community-based services, a methodology to identify areas of the state needing additional nursing home beds, access, workforce, reimbursement, and payment incentives.

### Background Information

#### Previous Studies

The committee reviewed previous studies relating to long-term care, including studies by the 2001-02 Budget Committee on Human Services relating to the long-term

care needs and nursing facility payment system in North Dakota; by the 1999-2000 Budget Committee on Health Care relating to the possibility of creating an incentive package to assist rural communities and nursing facilities significantly reduce bed capacity and provide alternative long-term care services; by the 1997-98 Budget Committee on Long-Term Care relating to a wide range of long-term care issues, including basic care rate equalization, Alzheimer's and related dementia population projects, American Indian long-term care needs, long-term care financing issues, and home and community-based services availability; and by the 1995-96 Budget Committee on Home and Community Care relating to the use of the state's resources and services in addressing the needs of elderly residents.

### Real Choice Systems Change Grant

The committee learned in September 2004, the Department of Human Services received a \$315,000 three-year Real Choice Systems Change federal grant to provide a single point of access to long-term support and care services for the elderly and individuals with disabilities. The Department of Human Services contracted with the North Dakota Center for Persons with Disabilities at Minot State University to conduct the project. The project, known as the Real Choice Systems Change Grant - Rebalancing Initiative, was to develop a plan for balancing funds between long-term care services and home and community-based services and a new system for providing a single point of entry for services for the elderly and individuals with disabilities. The initiative gathered and analyzed previously completed studies relating to North Dakota's continuum of care system and the goals resulting from the initiative included developing a system to provide a single point of entry for continuum of care services in North Dakota and a mechanism to balance state resources for continuum of care services to strengthen opportunities for choice and self-direction.

### Health Care Trust Fund/Long-Term Care Facility Loan Fund

The committee received information on the health care trust fund, which was established by the 1999 Legislative Assembly (Senate Bill No. 2168) for providing nursing alternative loans or grants. House Bill No. 1196 (2001) provided that money in the fund may be transferred to the long-term care facility loan fund for nursing facility renovation projects and for other programs as authorized by the Legislative Assembly. Money was generated for the health care trust fund as a result of the Department of Human Services participating in a government nursing facility funding pool at two government nursing facilities--McVile and Dunseith. The federal funds were deposited in the health care trust fund where they are invested by the State Investment Board and any investment earnings are retained in the fund. The federal government subsequently eliminated this intergovernmental transfer program. North Dakota

received a total of \$98.2 million under this program from 2000 to 2004. Of the total, \$11.3 million was used for long-term care facility loans and the remainder for other programs and purposes. The fund has a projected June 30, 2009, fund balance of \$2,019,842.

Under North Dakota Century Code (NDCC) Chapter 50-30, subject to legislative appropriations, money may be transferred from the health care trust fund to the long-term care facility loan fund for the purpose of making loans as approved by the Department of Human Services for renovation projects. Each loan is limited to \$1 million or 90 percent of the project cost, whichever is less. Under the program, 22 loans have been approved totaling \$11.3 million. As of June 2007, \$9.7 million of outstanding loans remain. Of the approved loans, 1 was for an assisted living facility, 13 for nursing home facilities, 1 for a basic care facility, and 7 for combination nursing, assisted living, and basic care facilities.

### **Continuum of Care Services for the Elderly**

The committee reviewed the following summary of the programs that comprise North Dakota's continuum of care for the elderly:

**Nursing home care** - Provides facility-based residential care to individuals who, because of impaired capacity for independent living, require 24-hour-a-day medical or nursing services and personal and social services.

**Basic care** - Provides facility-based residential care to individuals who, because of impaired capacity for independent living, require health, social, or personal care services but not 24-hour-a-day medical or nursing services.

**Medicaid waiver for the aged and disabled** - Provides in-home and community-based care to individuals who otherwise would require nursing home care and who are Medicaid-eligible. Services available include:

1. Adult day care.
2. Adult foster care.
3. Adult/traumatic brain-injured residential.
4. Chore services.
5. Emergency response system.
6. Environmental modification.
7. Case management.
8. Homemaker services.
9. Transportation (nonmedical).
10. Respite care.
11. Specialized equipment/supplies.
12. Supported employment.
13. Transitional care.
14. Nurse management.
15. Attendant care service.

**Service payments for elderly and disabled (SPED)** - Provides in-home and community-based care to individuals who are impaired in at least four activities of daily living (examples include toileting, transferring, eating, etc.) or at least five instrumental activities of daily living (examples include meal preparation, housework, laundry, medication assistance, etc.). Services available include:

1. Adult day care.
2. Adult foster care.

3. Chore services.
4. Emergency response system.
5. Environmental modification.
6. Family home care.
7. Case management.
8. Homemaker services.
9. Respite care.
10. Personal care.

**Personal care services** - Provides in-home care to individuals who are impaired in at least one activity of daily living (examples include toileting, transferring, eating, etc.) or in at least three of the four following instrumental activities of daily living--meal preparation, housework, laundry, and medication assistance. The individual must be Medicaid-eligible to receive personal care services. These services include assistance with bathing, dressing, toileting, transferring, eating, mobility, and incontinence care and also assistance with meal preparation, housework, laundry, and medication assistance.

**Expanded SPED** - Provides in-home and community-based care to individuals who are not severely impaired in activities of daily living (examples include toileting, transferring, eating, etc.) but who are impaired in at least three of the four following activities of daily living--meal preparation, housework, laundry, and medication assistance, or who have health, welfare, or safety needs, including requiring supervision or a structured environment. This program is an alternative to basic care. The individual must be Medicaid-eligible to receive services under this program. Services include:

1. Adult day care.
2. Adult foster care.
3. Chore services.
4. Emergency response system.
5. Environmental modification.
6. Family home care.
7. Case management.
8. Homemaker services.
9. Respite care.

### **Nursing Facility Payment System**

The committee learned North Dakota's nursing facility payment system has been in place since 1990 and requires equalized rates, which means nursing facilities may not charge private pay residents a higher rate than individuals whose care is paid for through the Medicaid program. Nursing facilities may, however, charge higher rates for private occupancy rooms.

The North Dakota nursing facility payment system consists of 34 classifications. Classifications are based on the resident assessment instrument (minimum data set) required in all nursing facilities. The rates for each classification vary by facility based on each facility's historical costs. Residents in higher classifications pay more than residents in lower classifications at the same facility.

Facility rates change annually on January 1 and may change throughout the year due to audits or special circumstances. Revenue received by a facility changes throughout the year based on the classifications of the residents receiving services. Each resident is reviewed

within 14 days of admission or reentry from a hospital and every three months subsequently. A resident's classification may change only at the scheduled three-month interval or if hospitalization occurs. Private pay resident classification evaluations may be done more frequently than those individuals on Medicaid. The facility is required to give 30-day notice to its residents whenever the facility's rates change. If an individual's classification changes, no notice is required and the rate is retroactive to the effective date of the classification. The department's policy is that Medicaid pays for up to 15 leave days for each hospital admission.

### **Nursing Care and Basic Care Bed Moratorium**

The committee learned Senate Bill No. 2109 (2007) continues through July 31, 2009, the moratorium on the expansion of nursing facility bed capacity above the state's gross licensed capacity of 6,383 beds. The provisions allow, not more than once in a 12-month period, a nursing facility to convert licensed nursing facility bed capacity to basic care bed capacity and a basic care facility to convert basic care bed capacity back to nursing facility bed capacity. The 2007 Legislative Assembly provided an exception to the moratorium on expansion of long-term care bed capacity and allowed the Veterans Home to convert 14 basic care beds to skilled care beds. The new Veterans Home facility will be authorized 52 skilled care beds and 98 basic care beds. Senate Bill No. 2109 also continues through July 31, 2009, the moratorium on basic care bed capacity. The bill provides that except for a nursing facility that is converting nursing facility bed capacity to basic care or unless the applicant demonstrates to the State Department of Health and the Department of Human Services that a need for additional basic care bed capacity exists, the department may not issue a license for additional basic care bed capacity above the state's gross licensed capacity of 1,527 beds.

North Dakota Century Code Section 23-16-01.1 allows nursing facilities to transfer beds from one facility to another, and Section 23-09.3-01.1 allows basic care facilities to transfer beds from one facility to another. Under both sections, the facility receiving the beds has 48 months in which to license the beds.

### **Capacity and Geographic Boundaries for Determining Capacity**

The committee learned the average for nursing facility beds in North Dakota has been reduced from 89 beds per 1,000 elderly individuals in 1996 to 65.3 nursing facility beds per 1,000 elderly individuals in 2007. The national average is 49 nursing facility beds per 1,000 elderly individuals. Regarding basic care beds, the committee learned North Dakota has an average of 17.25 basic care beds per 1,000 elderly individuals in the state. The average occupancy percentage is 94 percent for nursing homes, 86 percent for basic care facilities, and 92 percent for assisted living facilities.

The committee learned the reduction in nursing home beds per 1,000 elderly individuals has occurred because of the moratorium in place, the 2001 state bed buyout

program, and an increase in elderly population. The committee learned that demand for nursing facility beds is increasing in urban centers and decreasing in rural areas of North Dakota.

Nursing facilities are allowed to transfer or sell beds to other facilities. The demand for nursing home services is the greatest in Bismarck, Minot, Fargo, and Grand Forks. It is anticipated that by 2010, over 300 nursing facility beds and over 180 basic care beds will move from rural to urban North Dakota. The market price for a nursing facility bed in 2008 varies from \$12,000 to \$20,000. The cost of purchasing a bed is not an allowable cost for payment purposes. If the moratorium were allowed to expire, the committee learned that urban areas would experience unprecedented growth in the number of beds resulting in more Medicaid funds being spent for institutional care and available rural nursing home beds would have minimal value. The committee learned that other states with a high number of nursing home beds per 1,000 elderly individuals also have nursing home bed moratoriums. Of the 14 states that responded to a survey by the American Health Care Association, 4 states had a moratorium and a certificate of need process in place, 2 states had only a moratorium, 7 states had only a certificate of need process, and 1 state had neither a moratorium nor a certificate of need process.

The committee received information from the State Department of Health regarding the number of beds transferred between facilities and the conversion of beds from skilled care to basic care and from basic care to skilled care during the 2007-09 biennium. The number of licensed basic care beds increased from 1,515 in July 2007 to 1,592 as of May 15, 2008. The number of licensed skilled nursing facility beds decreased from 6,380 in July 2007 to 6,279 as of May 15, 2008, a reduction of 101 beds.

### **Home and Community-Based Services**

The committee received a report from representatives of the Real Choice Systems Change Grant - Rebalancing Initiative project on home and community-based services in North Dakota. It is estimated that by 2020 the state will have an estimated 150,000 individuals over the age of 65 and 24,300 individuals over the age of 85. The committee reviewed the initiative's report, *At a Crossroad, North Dakota Home and Community Based Services - An Overview and Recommendations*, which contains information taken from surveys, data analysis, and discussion groups and includes the following recommendations:

1. Each individual needing long-term continuum of care services should receive adequate information to make informed decisions regarding how to access available services through the implementation of assessment and screening tools using a coordinated single point of entry or "no wrong door" process.
2. Increase medically needy income levels to at least match the amount received by individuals that receive supplemental security income and

permit more access to SPED funding for individuals who would otherwise have a high recipient liability through the Medicaid program.

3. Provide incentives to develop affordable, accessible housing with services for low- and moderate-income elderly and people with disabilities and housing subsidies for affordable, accessible housing with services to low- and moderate-income elderly and people with disabilities.
4. Maintain the necessary flexibility in long-term continuum of care programs and services to ensure that consumers receive the needed services to remain in their communities.
5. Provide additional ongoing funding in order to attract and retain an adequate number of qualified service providers (QSPs) to meet current and future needs.
6. Create a task force that will make recommendations on how best to encourage individuals and agencies to become QSPs by improving recruitment, retention, training, and recognition for this important group of providers.

The committee received information from the Department of Human Services regarding various services available within North Dakota's long-term care continuum, including information on eligibility criteria and service limits. As of May 2007, 1,411 individuals were being served in the SPED program, 114 individuals in expanded SPED, 249 individuals through home and community-based waiver services, and 594 individuals under the Medicaid personal care option.

The committee learned the Department of Human Services began serving individuals who are technology-dependent through a home and community-based waiver and that the Interagency Program for Assistive Technology provides assistive technology devices that allow residents to continue living at home. The committee also learned four new services, approved during the 2007 legislative session, were added to the home and community-based waiver, including family home care for spouses, home-delivered meals, nurse management, and adult foster care.

The committee learned that in May 2007 the Department of Human Services was awarded an \$8.9 million federal grant for a money-follows-the-client demonstration project. The five-year initiative will assist 110 individuals, including 80 individuals currently in nursing homes and 30 individuals in developmental disability placements, to transition from an institutional setting to a home or community-based setting. It is anticipated 25 percent of all residents admitted to a nursing facility return to their own homes and one-third return home or to a lower level of care, such as basic care, assisted living, adult foster care, or to the home of a family member.

The committee received information on the Program of All-Inclusive Care for the Elderly. The program is a five-year project to help the poor who screen in need of nursing facility care to remain at home with day support,

care, and services. Northland Healthcare Alliance is the recipient of the Program of All-Inclusive Care for the Elderly planning grant. The program has met the Department of Human Services' requirements and has been accepting participants. Participants must be at least 55 years old, live in a Program of All-Inclusive Care for the Elderly service area, and be certified as eligible for nursing home care by the appropriate state agency. An interdisciplinary team, consisting of professional and paraprofessional staff, assesses participants' needs, develops care plans, and delivers all services, including acute care services and, when necessary, nursing facility services. The first urban program will be in Bismarck and the first rural program will be in Dickinson. The Program of All-Inclusive Care for the Elderly could provide services anywhere in North Dakota as long as medical and nursing services, occupational therapy, physical therapy, and dietician services are available. Use of telemedicine could allow services to be available in underserved areas. The program does not limit the number of participants and it is estimated 5 percent of individuals over the age of 65 may meet eligibility requirements. It is estimated 550 individuals are eligible in Burleigh and Morton Counties and 150 are eligible in Stark County. The Program of All-Inclusive Care for the Elderly providers receive monthly Medicare and Medicaid capitation payments for each eligible enrollee and assume full financial risk for participants' care without limits on amount, duration, or scope of services.

The committee learned the North Dakota Senior Service Providers, representing the agencies that provide Older Americans Act services, such as home-delivered and congregate meals, health services, outreach, and legal assistance to persons aged 60 and older, served 30,804 different older adults statewide from October 2005 to September 2006. During the same period, providers delivered 521,481 meals to 6,195 older adults.

### **Identifying Areas of the State Needing Additional Nursing Home Beds**

The committee received population projections to 2020 by age category and by human service region and compared the projected elderly population in North Dakota by location to capacity of services available in these locations. The committee received information from the Department of Human Services, the State Department of Health, and the North Dakota Long Term Care Association on the long-term care service capacity in North Dakota and the number of residents accessing those services in 2007 as well as information on the potential number of residents that may be accessing long-term care services in 2020. The following schedule summarizes information received by the committee regarding the number of facilities, beds, and QSPs providing services to residents and service recipients and the potential number of residents and recipients that may be receiving these services in 2020 based on the percentage of the population currently receiving services:

Region	Number of Facilities/ Providers 2007	Licensed Beds/Units 2007	Number of Residents/ Recipients 2006/2007	Potential Number of Residents/ Recipients 2020
<b>Nursing home services</b>				
Region 1	4	301	248	321
Region 2	10	813	822	1,145
Region 3	8	480	437	617
Region 4	11	829	761	1,035
Region 5	16	1,264	1,327	2,161
Region 6	12	999	1,033	1,446
Region 7	16	1,198	1,263	1,930
Region 8	6	496	467	634
Total	83	6,380	6,358	9,289
<b>Basic care services</b>				
Region 1	4	131	106	130
Region 2	6	227	181	237
Region 3	6	120	101	137
Region 4	4	150	122	160
Region 5	12	345	263	420
Region 6	8	225	195	253
Region 7	11	281	261	381
Region 8	5	95	88	113
Total	56	1,574	1,317	1,831
<b>Assisted living services</b>				
Region 1	3	71	66	81
Region 2	11	488	452	594
Region 3	4	112	104	141
Region 4	7	283	263	346
Region 5	12	597	554	884
Region 6	10	167	156	203
Region 7	6	204	189	275
Region 8	6	150	139	180
Total	59	2,072	1,923	2,704
<b>Home and community-based services</b>				
Region 1	83		72	83
Region 2	311		382	467
Region 3	346		307	391
Region 4	259		246	296
Region 5	291		539	804
Region 6	133		217	266
Region 7	284		416	565
Region 8	151		306	376
Total	1,858		2,485	3,248

The committee learned the Department of Human Services is in the process of developing an Aging 2020 project. The committee received information regarding an outline of the department's Aging 2020 project. The Aging 2020 project has two goals:

1. To identify, compile, and analyze past and current administrative data as well as census data to show the current status of programs administered by the state.
2. To produce comprehensive data documentation for state government policy and program professionals about the intergenerational dynamics of the emerging issues related to eligibility programs and services delivery.

The project will be completed in three phases over the course of three years and will coordinate with other departments and advisory groups, including the Department of Commerce, the State Department of Health, the Department of Transportation, the Olmstead

Commission, and the Governor's Committee on Aging. A preliminary planning document is anticipated to be available in July 2010.

### Access

The committee learned the Aging Services Division of the Department of Human Services has provided aging-related information and assistance for at least 20 years and has offered a nationwide toll-free number for approximately 15 years. Website and e-mail availability in recent years have enhanced access for consumers. The Aging Services Division has coordinated access to information with Mental Health America of North Dakota and with the FirstLink Hotline of Fargo.

The committee learned the Rural Assistance Center, at the University of North Dakota School of Medicine and Health Sciences Center for Rural Health is a federally funded initiative. In 2002 the Rural Task Force of the United States Department of Health and Human Services implemented a single coordinated point of contact for all Department of Health and Human Services programs that affect rural communities across the nation. Information is organized by state and the North Dakota page features links to specific tools available in North Dakota such as 2-1-1 North Dakota and the Aging and Disability Resource-LINK.

The committee learned in February 2004 the Public Service Commission designated Mental Health America of North Dakota as the 2-1-1 program in North Dakota. The 2-1-1 program is a confidential community information and crisis service available 24 hours a day 7 days a week. The 2-1-1 program contains a database of thousands of human service providers, programs, and community services and can assist local governments that do not have the funds to establish a comprehensive information and referral system.

The committee learned telemedicine began in 1995, funded by grants that provided for T-1 line connections to hospitals, clinics, and a few nursing homes. Later, homeland security grants were received to create a video-capable network connecting all the hospitals in the state that could be used during a disaster. This video-capable network could be used to conduct clinical consultations, education activities, and administrative meetings over the hospital connections, leaving funds available from the earlier grant to be used to connect to additional nursing home networks. Early telemedicine regulations did not include nursing homes as sites of service so residents had to be transported to a clinic or hospital for telemedicine appointments. A recently approved change in Medicare regulations identifies nursing homes as Medicare sites of service for telemedicine services beginning January 1, 2009.

The committee learned 2006 amendments to the federal Older Americans Act require the Assistant Secretary for Aging to implement aging and disability resource centers in all states. These centers are to:

1. Serve as visible and trusted sources of information on the full range of long-term care options.

2. Provide personalized and consumer-friendly assistance to empower individuals to make informed decisions about their care options.
3. Provide coordinated and streamlined access to all publicly supported long-term care options so consumers can obtain the care they need through a single intake, assessment, and eligibility determination process.
4. Help individuals plan ahead for their future long-term care needs.
5. Assist in understanding and accessing prescription drug and preventive health benefits.

Aging and disability resource centers have been established in 43 states. North Dakota is one of the seven remaining states without a center. The 2007 Legislative Assembly provided an appropriation of \$840,000, of which \$40,000 is from the general fund, for establishing a center in North Dakota if federal funds are available. The department has applied for a Real Choice Systems Change grant and an Aging and Disability Resource Center grant, which may provide up to \$800,000 for establishment of a center with an anticipated 5 percent matching requirement.

### Workforce

The committee learned staffing is a continuing challenge for long-term care facilities. Nursing facilities are experiencing difficulties recruiting and retaining staff, especially in rural areas.

The committee learned the North Dakota Medicaid Infrastructure Grant project included a survey of North Dakota individual and agency QSPs. Survey responses indicated the following:

- Less than 10 percent of QSP consumers are private pay.
- Time, travel, and reimbursement were most often noted as barriers preventing the QSP from providing additional requested services.
- Changes needed to allow QSPs to improve their services include less paperwork, increased reimbursement, access to health insurance and benefits, training, travel and mileage reimbursement, flexibility in services and time limits, more respite care, and more training opportunities.

The committee learned the North Dakota Association for Home Care recently surveyed its members and found that personal care services are being limited by many agencies as a result of the cost of travel to rural areas of the state. While the average reported cost to provide QSP services in 2008 is \$27.75 per hour, the reimbursement payment is \$19.64 per hour. Qualified service providers may charge private pay individuals a higher rate to subsidize the low reimbursement rate and at times will decline to provide services under the state program and instead choose to provide services to Medicare home health and hospice patients which provide a higher payment level.

The committee learned the North Dakota Nursing Education Consortium was established in 2007 pursuant to Senate Bill No. 2379 to address common concerns in nursing education which produce obstacles in meeting

the state's current and future nursing needs, with a focus on the specific needs of rural communities. The consortium has developed the following action plan relating to the focus on nursing needs of rural communities:

1. Develop "grow-your-own" resources;
2. Develop additional rural clinical sites;
3. Enhance school nurse resources; and
4. Increase simulation laboratory availability for rural students.

### Reimbursement and Payment Incentives

The committee reviewed reports from the Department of Human Services relating to the level of spending, utilization, and cost of long-term care services and programs for the 2005-07 and 2007-09 bienniums.

The committee learned the 2007 Legislative Assembly provided funding to:

1. Allow a 4 percent inflationary increase for the first year of the biennium and a 5 percent increase for the second year for all department service providers.
2. Rebase nursing home rates effective January 1, 2009.
3. Pay QSPs using a fee-for-service method based on 15-minute units of service.

The following schedule compares actual long-term care services utilization and spending for the 2005-07 biennium to appropriated amounts for the 2007-09 biennium:

<b>2005-07 Biennium Actual Expenditures</b>	<b>Total</b>	<b>General</b>	<b>Other</b>	<b>Units</b>
Nursing homes	\$322,520,167	\$110,618,033	\$211,902,134	3,684
Basic care	12,057,997	4,833,310	7,224,687	452
Home and community-based services	29,986,904	15,837,627	14,149,277	
Developmental disabilities community-based care	214,341,903	73,024,306	141,317,597	
<b>Total</b>	<b>\$578,906,971</b>	<b>\$204,313,276</b>	<b>\$374,593,695</b>	
<b>2007-09 Biennium Appropriation</b>	<b>Total</b>	<b>General</b>	<b>Other</b>	<b>Units</b>
Nursing homes	\$371,475,215	\$133,318,915	\$238,156,300	3,494
Basic care	14,083,121	6,097,305	7,985,816	458
Home and community-based services <sup>1</sup>	39,798,605	21,954,683	17,843,922	
Developmental disabilities community-based care	274,423,470	95,952,600	178,470,870	
<b>Total</b>	<b>\$699,780,411</b>	<b>\$257,323,503</b>	<b>\$442,456,908</b>	

<sup>1</sup>Includes appropriation for medical waiver for medically fragile children (Senate Bill No. 2326 (2007)).

The committee learned revised estimates of expenditures for nursing homes for the 2007-09 biennium are projected to total \$355.2 million, approximately \$16.3 million less than the appropriated amount of \$371.5 million. Of the variance, \$4.5 million is

from the general fund. Basic care costs are projected to be \$14,500,000, \$400,000 more than the appropriation of \$14,100,000. Nursing home beds are projected to be 3,332, which is 162 less than budgeted, and basic care beds, projected to be 406, are 52 beds less than the 458 beds anticipated. Home and community-based services expenditures are projected to total \$39,500,000, \$300,000 less than the \$39,800,000 appropriated.

The committee received information on nursing home facility-related costs compared to service-related costs. Direct costs include nursing and therapy; other direct costs include laundry, activities, and social services; and indirect costs include administration, chaplain, pharmacy, housekeeping, and medical records. As of June 2007 approximately 58 percent of the average daily costs related to direct costs, while approximately 25 percent related to indirect costs. The remaining 17 percent consisted of property, food, and other direct costs. The committee learned that the average daily per bed cost of a nursing facility has increased from \$97.68 in 1998 to \$165.59 in 2007. The current average daily per bed cost for basic care facilities and assisted living facilities in North Dakota is \$78 and \$100, respectively.

The committee also received a report containing information regarding Medicaid long-term care spending by state.

### **Other Testimony and Reports**

#### **Long-Term Care Insurance Partnership Program**

The committee received information from the Insurance Department regarding the Long-Term Care Insurance Partnership Program, including the number of approved policies and sales. The committee learned the Long-Term Care Insurance Partnership Program authorized by Senate Bill No. 2124 (2007) provides that for long-term care insurance policies certified by the Insurance Department as meeting the consumer protection provisions of the 2003 Long-Term Care Insurance Model Act, benefit amounts paid under the insurance policy will increase the asset limit used in determining eligibility for Medicaid benefits. The Insurance Department has certified 17 companies offering 42 products as eligible for the Long-Term Care Insurance Partnership Program in North Dakota.

#### **Notice of Transfer or Discharge**

The committee learned before a nursing facility may transfer or discharge a resident, the facility must, as required by administrative rules, notify the resident and, if known, a family member or legal representative of the resident in writing and in language and in a manner they understand at least 30 days prior to the move. Basic care facility residents must also be provided with 30 days' notice of transfer or discharge, but the notice does not need to be in writing.

#### **Legal Representation of Financially Exploited Elderly**

The committee heard testimony regarding the possibility of the state appointing an attorney to represent elderly individuals who are being financially exploited by family members or others and on services

currently provided by the Department of Human Services. Regarding the provision of legal services to elderly individuals, the department's Aging Services Division has contracted with Legal Services of North Dakota for over 25 years. The services provided under this contract are required under Title III of the Older Americans Act and are available to persons over age 60. The services are targeted to low-income, rural, minority, and socially isolated persons. Legal Services of North Dakota provides legal assistance to older individuals in the areas of abuse, age discrimination, defending guardianships, health care, housing, income, long-term care, neglect, nutrition, protective services, and utilities.

Vulnerable Adult Protective Services is a program within the Department of Human Services that works to prevent further abuse, neglect, or exploitation of vulnerable adults and promotes self-care and independence for vulnerable adults. North Dakota Century Code Section 50-25.2-03 authorizes the department to provide adult protective services if the vulnerable adult consents to and accepts the services. The department may also pursue other means to protect those that cannot give consent. The committee learned 10 percent of referrals to Vulnerable Adult Protective Services relate to financial exploitation.

The committee learned the Protection and Advocacy Project has been involved in financial exploitation cases for people with developmental disabilities and serious mental illness. The Protection and Advocacy Project reported it could expand its services by either:

1. Using additional resources to provide direct legal services to remedy exploitation for people who need long-term care but do not have developmental disabilities or mental illness;
2. Administering additional resources to contract with private attorneys to provide these services; or
3. Assisting another agency in developing this type of program.

#### **North Dakota Health Information Technology Steering Committee**

The committee learned the North Dakota Health Information Technology Steering Committee was created pursuant to House Bill No. 1021 (2007) to facilitate the adoption and use of health information technology and exchange to improve health care quality, patient safety, and overall efficiency of health care and public health services in North Dakota. The steering committee has completed a survey of all the hospitals in the state and is compiling the data. The steering committee is currently conducting surveys of the long-term care facilities, clinics, local public health units, and workforce in the state to determine the effects of using technology. Support for North Dakota health information technology projects has totaled \$10.3 million over the past 10 years, including \$1.1 million of nonfederal funds. The committee learned that lack of financial resources and well-trained information technology staff are common barriers to the adoption of health information technology in rural North Dakota facilities.

## **Olmstead Commission**

The committee received information on the Olmstead Commission regarding outcomes of long-term care-related pilot projects, other activities and findings, and recommendations of the commission. The commission was involved in the following six pilot projects:

1. The Evangelical Lutheran Good Samaritan Society - Simplified Access to Services Model - \$175,000 - This project was implemented in Arthur. The project involved developing informal and family support services to enable residents of the long-term care facility in Arthur to leave the building regularly to participate in community activities. The project also established a coordinating entity to assess needs and coordinate informal support systems to help people delay or avoid nursing home placement. This project is continuing. The project has resulted in the development of a one-stop resource center for community members as well as the provision of technical assistance, education, and support services.
2. Western Sunrise, Inc. - Living in Place Model - \$55,000 - This project involved the creation of a system of domestic peer bridging and counseling for those with severe and persistent mental health issues throughout Region 1--Williston. The results of the project indicate consumers, families, and providers discussed service delivery and agreed that consumers need to be better-informed and more involved in discussions and decisions. This project is continuing and also is to be implemented in the north central human service region--Minot.
3. Knife River Care Center - Living in Place Model - \$50,000 - This project focused on allowing residents to make more decisions regarding their care. The results indicated that residents had a greater satisfaction and interest in services and activities. This project is also continuing.
4. Independence, Inc. - Living in Place Model - \$134,000 - This project created information awareness for persons with disabilities and their families. A brochure and brief video were produced and assisted persons with physical disabilities to become aware of assistive technology service options outside of institutionalization. This project resulted in consumers, family members, and local providers discovering service accessibility and availability strengths and barriers. Transportation remains a great barrier in rural areas for persons with disabilities.
5. Mental Health America of North Dakota - Services Model (2-1-1 Line) - \$170,000 - This project implemented an information and referral service for all North Dakota citizens by making available the current 2-1-1 information line to persons with questions about service delivery for persons with disabilities. This project helped

meet the rural communications need regarding services and service delivery of long-term care.

6. Indian Affairs Commission - Cultural Model - \$85,000 - The first phase of this project included focus groups on each of the reservations and Indian service areas in partnership with the Native American Training Institute to identify gaps in service delivery. Although services exist, this project determined that many American Indians are not aware of them.

The committee learned the commission will continue to monitor the pilot projects.

## **Recommendations**

The committee recommends Senate Bill No. 2044 to extend the moratorium on the state's licensed basic care beds and the state's licensed nursing facility beds from July 31, 2009, to July 31, 2013.

The committee recommends Senate Bill No. 2045 to require at least a 30-day written advance notice of any transfer or discharge from a nursing home, swing-bed hospital, basic care, or assisted living facility.

## **DEMENTIA-RELATED SERVICES STUDY**

House Concurrent Resolution No. 3022 (2007) directed a study of the availability of and future need for dementia-related services, as well as funding for programs for individuals with dementias.

## **Background Information**

### **Previous Studies**

The committee learned the 1995-96 Budget Committee on Home and Community Care studied the continuum of care for North Dakotans with Alzheimer's and related dementias and the needs of caregivers and families of patients with Alzheimer's and related dementias. The committee recommended House Bill No. 1037, which required the Department of Human Services to establish pilot projects to meet the service needs of the Alzheimer's and related dementia population.

The 1997-98 Budget Committee on Long-Term Care monitored the implementation of the Alzheimer's and related dementia population projects. Due to delays in the startup of the pilot projects, it was not possible to fully evaluate the effectiveness of the pilot projects during the 1997-99 biennium. The committee recommended Senate Bill No. 2034, which authorized the Department of Human Services to continue the approved Alzheimer's and related dementia population pilot projects into the 1999-2001 biennium and required the department to monitor and report on the progress of the pilot projects.

The 1999-2000 interim Budget Committee on Institutional Services received the final report from the Department of Human Services on the progress of the Alzheimer's and related dementia pilot projects. The committee learned that, based on the department's review of the Baptist Home in Kenmare and with the approval of three additional units, the Alzheimer's and related dementia pilot project accomplished the goal set forth in the original legislation. The report indicates the



facility in Kenmare provided appropriate and adequate care to its residents with Alzheimer's and related dementias. The payment rate was \$15.05 per day less than the services of a similar nature in a nursing facility.

### **Issues Relating to Dementia**

The committee learned, according to national estimates, North Dakota has 16,000 individuals diagnosed with dementia, including Alzheimer's, which is the most common form of dementia. By 2010 the number is expected to increase to 18,000. Approximately 10 percent of individuals diagnosed with Alzheimer's have early onset of the disease which is before age 65. The committee learned that about 50 percent of nursing home residents have some type of dementia. Thirty percent of the victims of abuse, neglect, self-neglect, and exploitation assisted by adult protective services have dementia.

The committee learned that in 2000 Medicare spent nearly three times as much, on average, for people with Alzheimer's and other dementias as for beneficiaries without dementias. Estimated nursing home and other costs for Alzheimer's and dementia patients for calendar year 2007 totaled \$104 million in North Dakota.

The committee learned 70 percent of individuals with Alzheimer's and other dementias live at home where they are cared for by family and friends. Information on caregivers and the economic value of caregiving by state in 2006 indicated the total annual economic value of caregivers in North Dakota was estimated at \$550 million and nationally it was \$350 billion.

The committee learned county social services are often unable to provide assistance to individuals with dementia because they exceed certain income levels or are below certain age requirements. In addition, some individuals choose not to seek assistance because of the perceived stigma attached to the disease.

The committee learned the primary reasons individuals with dementia enter skilled nursing facilities are caregiver exhaustion and lack of resources.

### **Dementia Services Available**

The committee learned the Department of Human Services, in 2004, received a three-year federal Alzheimer's demonstration grant. The grant, \$261,150 for each year, was to expand the availability of diagnostic and support services for persons with Alzheimer's, their families, and caregivers as well as to improve the responsiveness of the home and community-based care system for persons with dementia. The Department of Human Services contracted with the Alzheimer's Association Minnesota-North Dakota Chapter; MeritCare Medical Group, Fargo; and St. Alexius Medical Center, Bismarck, to conduct the Alzheimer's demonstration grant and provide community education, dementia awareness training, family caregiver training, educational workshops, sessions at major state conferences, public information, memory loss screening clinics, Alzheimer's support groups, training and presentations for medical staff, focus groups for caregivers, and a symposium on dementia and management. In addition, Lake Region State College

developed an informational manual for training for family caregivers who are caring for someone with Alzheimer's or related dementias.

The committee learned the following services are available for individuals with dementia:

1. Skilled nursing facilities - Some facilities have designated memory care units; however, the number is not adequate.
2. Assisted living/basic care facilities.
3. In-home care providers.
4. Adult day care programs.
5. Adult foster care.
6. Medical professionals.
7. Support groups.
8. Care consultation/geriatric case managers.

### **Skilled Nursing Facilities**

The committee learned every nursing facility in North Dakota provides care and services to individuals with dementia. Of the 83 licensed nursing facilities, 25 have special care units for those who have a diagnosis of Alzheimer's or a related dementia. Special care units have a restricting device to keep residents with a dementia diagnosis in a specific area and to separate them from the residents in the remainder of the facility. As of May 2008 nursing facilities with special care units provided 456 beds and had a 94 percent occupancy rate from January through April 2008.

### **Assisted Living/Basic Care Facilities**

The committee learned that of the 59 licensed basic care facilities, 10 have special care units for individuals with Alzheimer's or a related dementia. As of May 2008 the basic care facilities with special care units provided 238 beds and had an 86 percent occupancy rate from January through April 2008. A limited number of facilities offer adult day care or respite care. The committee learned that few state or federal regulations relate to the creation and operation of specialized memory care units.

### **In-Home Care Providers/Adult Day Care Programs/Adult Foster Care/Medical Professionals/Support Groups/Care Consultation**

The committee learned in January 2002 the North Dakota Family Caregivers Support Program, provided for under the Older Americans Act, began offering support and services to individuals who are caring for someone in their home or community. There are no income eligibility limits in order to receive services, and services are provided at no cost to the caregiver. The program targets individuals who are lower income, socially isolated, and living in rural areas. From July 2006 through June 2007 the North Dakota Family Caregivers Support Program provided services to 272 family caregivers. Of the total, 141 family caregivers were caring for an individual with Alzheimer's or a related dementia.

The Department of Human Services provides other services for eligible individuals with dementias and their caregivers, including case management, personal care,

home-delivered meals, homemaker services, outreach, and respite care.

The committee learned counties provide home and community-based services, including:

- Case management;
- Personal care services;
- Adult day care;
- Adult family foster care; and
- Respite care.

In 47 of 53 counties, county social services are serving 316 individuals who have a diagnosis of Alzheimer's or dementia and 345 individuals with a significant memory loss.

The committee learned the Interagency Program for Assistive Technology provides assistive technology devices, which include wandering alerts, automated medication dispensers, Alert One telephone services, car battery interrupters, walkie-talkies, and invisible cabinet locks. These devices allow individuals with Alzheimer's and related dementias to remain in their homes longer, be safer, and reduce the burden of caregiving.

### **Suggested Changes**

The committee learned it is difficult to access dementia-related services for individuals under the age of 60 and assistance with legal-related services is generally available to older individuals but may not be available to those under age 65.

The committee learned several states are considering dementia-related legislation and some have developed state dementia plans.

The committee heard testimony from the Department of Human Services, Alzheimer's Association Minnesota-North Dakota Chapter, Burleigh County Home and Community-Based Services, AARP North Dakota, and individual caregivers regarding suggestions for improving dementia care services. Suggestions included providing the following:

1. More in-home support services for individuals with early onset Alzheimer's.
2. Access to senior meals programs for individuals under the age of 60 who have Alzheimer's and their caregivers.
3. Additional funding for new facilities and for upgrading existing facilities to care for individuals with dementia.
4. Additional training and support for caregivers.
5. Training for early detection by health care professionals and training standards for all staff involved with caring for individuals with dementia, including QSPs.
6. Financial, legal, housing, and life planning assistance.
7. More adult family foster care and day care services.
8. Medication certification for in-home care providers.
9. Nonmedical transportation to those who qualify for SPED and expanded SPED.
10. Expanded memory loss clinics.

11. A single point of entry to long-term care in North Dakota.
12. A coordinated care planning system to assist individuals in accessing services because a family's needs change as the disease progresses.
13. Easier access to funding for coordinated care planning on an ongoing basis.
14. Expanded family caregiver program services.
15. A statewide dementia coordinator position to develop and implement a coordinated care planning system.

The committee heard testimony expressing support for creating a statewide dementia coordinator position and extended care coordination from representatives of the Alzheimer's Association Minnesota-North Dakota Chapter, the Protection and Advocacy Project, and primary caregivers. The committee learned a 19-year study of the benefits of intervention and support showed nursing home placement was delayed 18 months for couples receiving care coordination and support. The 18-month delay could result in public and private health care cost-savings and improved physical and psychological health of the family caregiver.

### **Recommendations**

The committee recommends House Bill No. 1043 that:

- Directs the Department of Human Services to contract for a dementia care services program in each area of the state served by a regional human service center to provide personalized care consultation services, training, and education regarding dementia;
- Provides for a \$1.2 million general fund appropriation for the program; and
- Provides for a report to the Legislative Council regarding the outcomes of the program.

### **TRANSITION TO INDEPENDENCE PROGRAM STUDY**

Senate Concurrent Resolution No. 4005 (2007) directed a study of the feasibility and desirability of establishing a transition to independence program for young adults with mental illness.

### **Previous Studies**

The committee learned the 2003-04 Budget Committee on Government Services studied the needs of individuals with mental illness, drug and alcohol addictions, and physical and developmental disabilities, including individuals with multiple needs and how the state responds to those needs. The 2003-04 Budget Committee on Government Services reviewed information regarding a community-based system of care for persons with mental illness and substance abuse disorders.

### **Service Needs of Transition-Aged Youth**

The committee learned severe emotional disturbances is the term used to identify children under

the age of 18 who have been diagnosed with a severe behavioral, emotional, or mental health disorder that has been a major impairment in a child's level of functioning at home, school, or community for at least one year. The committee learned that in 2006 the number of students with severe emotional disturbances meeting the criteria of emotional disturbance in North Dakota schools aged 16 to 21 was 318 and aged 3 to 15 was 769.

The committee learned it is common to find youth with mental illness in the foster care or juvenile justice systems, and in 2006 the public mental health system provided services to 1,538 children and adolescents with serious emotional disturbances and 1,527 children and adolescents with emotional disturbances.

The committee learned of the 886 young adults with serious emotional disturbances who turned 18 years of age during the 2005-07 biennium, 33 percent continued to receive services at a regional human service center. It is not known if the remaining 67 percent continued to access services in the private mental health system or decided to discontinue services.

Statistics indicate that youth with mental illness reenter the corrections system at a higher rate than other youth. Youth with serious emotional disturbances are able to manage themselves within the high level of structure provided by correctional case management and correctional placement; however, once these services are no longer a part of their daily lives, some youth are not able to sustain their behavioral gains. The committee learned that these youth would benefit from intensive case management services that would continue further into their lives; however, the program would require a continuum of services to develop and support adequate treatment plans for these youth.

The committee learned the Department of Human Services has a state review team to address situations with extreme challenges to use the collective expertise and resources of multiple divisions and agencies to solve service challenges, but often the barriers are funding and levels of care. Most youth considered by this team are involved in the foster care or juvenile justice systems, have developmental disabilities, or are cognitively lower functioning and have mental health or substance abuse issues. The state does not have a multiagency transition program specifically for youth with mental illness.

The committee learned services are available for individuals with developmental disabilities or if the youth are in the foster care system; however, for youth that are not in these programs services are limited.

The committee learned there is confusion and lack of awareness primarily in the following three areas, especially for young adults between the ages of 18 and 21:

1. Identifying the youth and young adults who are at risk of homelessness, incarceration, substance abuse, suicide, dropping out of school, etc.
2. Developing a continuum of service plan specifically for transitioning youth with mental illness that addresses their medical condition and its relationship to their educational focus.

3. Providing services to youth prior to crisis or after hospitalization before returning to the family home.

The committee learned a study, involving University of Mary graduate students, to identify youth at risk identified approximately 13,000 youth in 2005 and 2006 who have been involved in the judicial system. By identifying youth involved in the judicial system, who also have a mental health diagnosis, services can be better structured. However, more detailed information on these youth has not been collected due to lack of funding and an inability to access additional information on these individuals.

The committee learned most psychiatric illnesses have their visible beginnings in childhood or adolescence and the suicide rate among age groups 10 to 19 and 20 to 24 per 100,000 in North Dakota generally exceeds the national rate. Nationally, over 60 percent of young adults with a serious mental illness are unable to complete high school. These adults are often unemployed, unable to participate in continuing education, and lack the skills necessary for establishing and maintaining supportive relationships and independent living. Transition-aged youth with serious mental illness have higher rates of substance abuse and enter adulthood three times more likely to be involved in criminal activity than those without an illness.

The committee learned the Chief Justice of the North Dakota Supreme Court convened a multidisciplinary group to discuss child welfare issues in North Dakota. Recommendations included transitional services when children return home or are aging out of foster care. The recommendation is that the Department of Human Services should support efforts to use federal IV-E funds for transitional services when children return home.

The committee learned the Department of Human Services has conducted statewide stakeholder meetings to discuss the strengths, needs, and gaps in transition services for young adults. Concerns expressed include housing, employment opportunities, resources, complexity of diagnoses, independence, and decisionmaking.

### **Current State Agency Programs Serving Youth Department of Human Services**

The committee received information on selected Department of Human Services programs benefiting transition-aged youth, including:

**Vocational rehabilitation services** - Vocational rehabilitation services are provided to youth with severe emotional disturbances by the Department of Human Services. Eligibility requirements for vocational rehabilitation services include:

1. A physical or mental impairment that has been documented by a professional.
2. The impairment results in an impediment to employment.
3. The individual requires vocational rehabilitation services to prepare for, enter into, engage in, or retain employment.

Vocational rehabilitation services generally begin at the age of 16; however, students may begin receiving

services as young as the age of 14 if complex factors are involved. The program seeks to have an individual plan for employment in place by the time the student graduates high school.

The committee received information from the Department of Human Services regarding the development of plans to improve the coordination and collaboration of children's transitional services in the state. The Vocational Rehabilitation Division has allocated funding for regional transition projects. The projects were offered to all schools, including 34 special education districts and all eight regional transition committees. The projects are to focus on students entering their senior year who were eligible for or referred to the Vocational Rehabilitation Division.

**Foster care independent living program** - The committee learned the Department of Human Services, under the Children and Family Services Division, administers the foster care independent living program for youth transitioning out of foster care. The program is the Chafee foster care independent living program. The program's purpose is to ensure that all youth aging out of the foster care system have the necessary support and services available to them to assist in making the transition from foster care to adulthood. The goal of the program is for all foster youth to reach the following outcomes by the age of 21:

1. Access to physical and mental health services.
2. Sufficient economic resources.
3. Safe and stable living arrangement.
4. Academic/educational/vocational goal attainment.
5. Connections to persons and community.
6. Avoidance of illegal or high-risk behaviors.
7. Postponement of parenthood.

The program serves foster care youth aged 16 and older who have been identified as likely to age out of foster care as well as former foster care youth up to the age of 23 who have aged out of foster care. The independent living program served 284 youth during the last federal fiscal year.

The program receives \$500,000 per year in federal Chafee grant funds requiring a 20 percent state match that is provided from the state general fund and eligible in-kind matching. The funding is used for regional independent living coordinator positions; direct financial assistance to youth for rent, utilities, food, clothes, etc.; youth groups; teen conferences; and program-related materials, equipment, supplies, etc.

The Department of Human Services also administers the federal Chafee education and training voucher program. This program provides funding to pay for the tuition, books, and room and board expenses of foster care youth to attend higher education institutions. This program receives \$115,000 per year in federal funds requiring a 20 percent state match. Approximately 31 foster care youth are served by this program each year.

The Department of Human Services' Mental Health and Substance Abuse Services Division provides therapeutic and support services to children with severe emotional disturbances and their families. Examples of

these services include individual, family, and group therapy; psychiatric services; psychological evaluations; care coordination; case aides; medication management; and residential and crisis services. The department contracts with private providers for some of these services while others are provided directly at the human service centers.

### **Department of Public Instruction**

The committee learned the federal Individuals With Disabilities Education Act requires that transition services be incorporated into each child's individualized education program plan no later than the first plan in effect by the time the student turns 16 years old. The individualized education program plan must include the transition services needed to assist the student in reaching the student's postsecondary goals. The Act requires involvement of multiple agencies and the coordination of services. The school must ensure participation of any agency that is likely to be responsible for providing or paying for transition services by inviting the participating agency to the individualized education program meeting.

### **Department of Corrections and Rehabilitation**

The committee learned transitional services are provided to youth who are at the Youth Correctional Center as well as in the custody of the Division of Juvenile Services. All case management provided to these youth is community-centered and involves other agencies and service providers. The center's role in planning for transition is to help youth develop the behavioral self-control necessary to reenter the community and remediate educational deficiencies. Juvenile corrections specialists provide wraparound case management services to ensure a case plan is in place when custody ends. The plan may include ongoing services for mental health, chemical health, or physical health services. Each case plan addresses living, work, and school arrangements.

### **Department of Career and Technical Education**

The committee learned the Department of Career and Technical Education provides some services to assist students who are receiving special education services. The level of service varies by school district across the state. The department uses a referral process to get additional assistance for these students and does not provide the services directly.

### **Collaborative Efforts**

The State Transition Steering Council includes members from each region of the state and from education, independent living, Job Service North Dakota, vocational rehabilitation, consumers, etc. Efforts have been made to establish regional interagency transition teams to identify and work on local issues. The level of progress of establishing these teams varies among the regions of the state. The Department of Human Services has allocated \$400,000 of its biennial vocational rehabilitation budget for regional transition projects.

The committee learned the Department of Human Services has cooperated with the Department of Public Instruction and other partners to develop the Transition Community of Practice Advisory Council. The department will be providing technical assistance to each of the eight regions. A Youth Advisory Council has been established, and a Youth Leadership Forum in the summer of 2009 will provide training for 20 youth with disabilities to better advocate for themselves. Strategies of the North Dakota Transition Program include interagency collaboration, professional development and technical assistance, and family training and empowerment. The Youth Advisory Council will advise the Department of Human Services, Mental Health and Substance Abuse Services Division, and other system partners on issues of concern to North Dakota's youth, including underage drinking, transition to adulthood, and overall health and well-being. Suicide prevention and substance abuse prevention were the two most important issues identified by the council. The department received a \$20,000 grant from the federal Substance Abuse and Mental Health Services Administration Center for Mental Health Services which it will use to establish a transition flex fund to assist youth aged 17 to 21 with expenses related to transition to adulthood and to supplement other sources of financial support for one-time requests for items, including clothing, food, rent deposits, and rent. A portion of the funding will also be used to reimburse youth and a parent or guardian to attend the council meetings.

The committee learned ND Youth, an advisory group of youth who are or have been in foster care, is working on educating others about foster care, dispelling myths related to youth in foster care, and helping to mentor each other. The group is developing a website to serve as a resource to all youth who are transitioning into adulthood and will include links to numerous transitioning resources.

### **Private Programs**

The committee received information regarding the in-home counseling program provided by The Village Family Service Center, Fargo. The center's intensive in-home family counseling therapy program focuses on providing services to families within the family setting and the program's success rate is up to 85 percent. Because services are limited in time and very intensive, some counselors are involved with as few as three families. The program challenges families to become responsible and to address issues affecting their children.

The committee received information from Youthworks, Bismarck and Fargo, an alternative to the formal human services delivery system that provides services on a voluntary basis regardless of ability to pay or other limiting eligibility requirements. Youthworks focuses on runaway, homeless, and at-risk youth and their families.

The committee learned the Anne Carlsen Center for Children plans to establish satellite offices across North Dakota over the next three years. The satellite offices

will provide therapy sessions, team meetings, and individual and group training and allow parents to keep their children closer to home. The average annual cost for the direct support at 16 hours per week is approximately \$18,000 compared to \$180,000 for the cost of institutional care. Children benefit from individual services and integration of these services into the community as they make the transition from youth to adulthood.

The committee received information on a skill enhancement training program and an anticipated pilot project, currently titled the Circle of Trust, both established by Fraser, Ltd., Fargo. The skill enhancement training program was established in 2004 to assist youth in developing the life skills necessary to become responsible adults. The program will be implemented to meet additional needs and as a complement to the skill enhancement training summer program. The committee heard testimony from Fraser, Ltd., regarding the Circle of Trust project, which is community-based and allows for individual communities to build services to meet needs. The project will be a partnership between Youthworks and Fraser, Ltd., allowing for more efficient use of space and resources. The project will build an alliance between community organizations and businesses to meet the needs of youth and young adults aged 12 to 21 and provide a seamless continuum of services with a focus on prevention programs, therapies, peer support, mentoring, independent living skill development, outreach to youth at risk, social skill activities, and service coordination. The project anticipates an annual budget of approximately \$450,000, of which \$225,000 may be requested from state funds.

### **Suggested Program Enhancements to Serve Transition-Aged Youth**

The committee received testimony from the North Dakota Federation of Families for Children's Mental Health, Fraser, Ltd., Youthworks, and parents of youth with learning disabilities, and the following enhancements were suggested:

1. Better coordinating transition planning involving agencies currently serving the youth and agencies that will be providing services in the future to ensure a seamless transition for the youth into adulthood.
2. Providing more education regarding transition needs.
3. Involving youth and their families to a greater extent in developing the policy regarding transition services.
4. Focusing resources on family-based care.
5. Implementing national and state model programs to provide a service continuum to assist youth transitioning to independence.
6. Collecting data to assist in identifying youth at risk of not receiving services, where service continuums are not adequate, what existing programs could be enhanced, and what additional transition services or programs are necessary.

7. Changing eligibility requirements to correct gaps in access to needed services.
8. Providing additional education, support, and independent living training for youth transitioning out of the child welfare system.
9. Offering more meaningful school-to-work experiences.
10. Increasing the collaboration between special education and vocational rehabilitation to serve students with learning disabilities, emotional disturbances, autism spectrum disorders, and other health impairments.
11. Increasing case management services, supportive services, and housing services for youth transitioning to adulthood.
12. Establishing a state health insurance plan to cover youth with disabilities after graduating from high school.
13. Offering programs to assist youth to identify the types of jobs available to them and required skills.
14. Expanding independent living training.
15. Adding transition-aged youth to the wraparound services currently available through county social services.
16. Lowering the starting age for services. Currently the typical transition age is from 16 to 21.
17. Adding more crisis or safe beds for at-risk youth.

The committee learned a study completed by the North Dakota Center for Persons with Disabilities concluded the following needs exist to better serve youth transiting to adulthood:

1. Services to families' homes;
2. In-home support to families;
3. Personal and community support; and
4. Alternative living supports.

The committee received information on other states' transitional services programs for youth with mental illness. The four primary components used to develop these programs are:

1. Youth and family voices.
2. Specialized care management.
3. Natural supports within the community.
4. Interagency partnerships.

The committee learned the most successful of these programs stress the effectiveness of collaboration and forming partnerships to coordinate services for youth as they transition to adulthood. The transition to independence model identifies seven key principles for transitioning youth, including:

1. Engage youth.
2. Tailor services.
3. Respect youth independence.
4. Ensure a safety net of support.
5. Strengthen competencies.
6. Help maintain focus on outcomes.
7. Involve young people, parents, and other community partners.

The committee learned that other key components of successful programs for youth transitioning to adulthood include:

1. Residential programs.

2. Peer mentoring.
3. Employment opportunities.
4. Outreach activities.

The committee heard testimony supporting the wraparound process of providing services because it meets the need for coordination and collaboration between the various system providers. The wraparound process is a planning process that brings together a team of people from the youth's and the family's life. A facilitator assists the youth and family team in coordinating the supports necessary to meet the unique needs of the youth and family.

## **Recommendations**

The committee recommends House Bill No. 1044 that directs the Department of Human Services to develop or contract for a program for services to transition-aged youth at risk. The bill identifies services to be a part of the program, including individualized assessments, coordinated services, self-advocacy training, vocational rehabilitation, in-home support, and independent living skills training. The bill provides for the use of a wraparound planning process and a transition-aged youth at risk pilot project. The bill appropriates \$700,000 from the general fund for the program and the pilot project.

## **OTHER RESPONSIBILITIES**

The committee was also assigned to:

1. Receive a report from the State Department of Health before August 1, 2008, regarding the status of the department's demonstration project involving life safety surveys for basic care facilities and long-term care facilities during and at the conclusion of construction or renovation projects that cost more than \$3 million and whether the program should be made permanent (House Bill No. 1004 (2007)).
2. Receive a report from the State Department of Health before August 1, 2008, regarding the impact of the implementation of the survey process for basic care facilities to identify and correct deficiencies (House Bill No. 1488 (2007)).

## **State Department of Health Life Safety Survey Demonstration Project Report**

Subdivision 4 of Section 12 of House Bill No. 1004 required the State Department of Health to report to the Legislative Council before August 1, 2008, regarding the status of the department's demonstration project involving life safety surveys for basic care facilities and long-term care facilities during and at the conclusion of construction or renovation projects that cost more than \$3 million and whether the program should be made permanent.

## **Background**

Section 12 of House Bill No. 1004, approved by the 2007 Legislative Assembly, provides that during the

2007-09 biennium the State Department of Health design and implement a demonstration project to provide a life safety survey process for basic care and long-term care facilities to assess, voluntarily, a construction project, a renovation project, or a construction and renovation project costing more than \$3 million. The department may charge a reasonable fee for the survey, the revenue of which is deposited into the State Department of Health's operating fund, to defray the food, lodging, and transportation expenses of the survey process. Subdivision 4 of Section 12 requires the department to report to the Legislative Council before August 1, 2008, regarding the status of the project, including the feasibility and desirability in making the program permanent and whether the department will be recommending any legislation to make the program permanent.

### **Report**

The State Department of Health reported it received three requests from facilities to participate in the demonstration project. Two requests have been approved and the third is under consideration. The department contracted with a Minnesota Department of Health survey staff member to conduct the demonstration project surveys. Survey results of the facilities' level of satisfaction with the demonstration project were good to excellent. Total demonstration project costs were \$3,918 and did not include the cost of plans review or administration of the demonstration project. The facilities reimbursed the department \$1,200 and the department provided the remaining \$2,718 from other areas of the department's budget. Since the demonstration project began, the department has dedicated approximately 250 hours to the development and implementation of the demonstration project, in addition to the time spent on surveys performed by a Life Safety Code surveyor under contract by the department. The demonstration project indicated the earlier onsite surveys resulted in fewer issues needing correction later which reduced cost and frustration on the part of both the industry and the department. The department is continuing to evaluate the demonstration project with regard to providing the onsite inspections to all construction and renovation projects without regard to size and provider type and charging a fee to the facilities for a portion of the cost.

The committee learned that federal regulations do not allow the department's life safety survey inspectors to conduct voluntary construction consultation services and also be involved in the federal certification process for the facility. To comply with the federal regulations the department suggested eliminating the voluntary component of the demonstration project and authorize the department to provide a number of inspections that lead to state licensure, and once licensed, the facility could seek federal certification.

The committee received information regarding the Knife River Care Center's experience of not having the benefit of being a part of the demonstration project. The inconsistencies between the inspectors and regional interpretations of rules caused unnecessary expenses

that added an estimated \$150,000 to the cost of the project for the facility.

The committee received information on the possibility of posting facility plans on the State Department of Health's website to provide additional information to facilities considering construction projects. The committee learned that due to restrictions relating to proprietary information and protections given to a copyright owner under the federal copyright law, the department may be prohibited from posting blueprints or floor plans on its website. The department is considering posting findings resulting from the Life Safety Code construction and renovation surveys and the initial licensure surveys on its website to provide additional information to facilities.

The committee learned the department will continue to work with the North Dakota Long Term Care Association to provide additional Life Safety Code training to architects and contractors across the state.

The committee heard testimony from nursing home administrators, a hospital administrator, and the North Dakota Long Term Care Association regarding the cost-savings of items identified during demonstration inspections and in support of making the demonstration project a permanent service of the State Department of Health, expanding the service to all health facilities licensed by the Division of Health Facilities of the State Department of Health, and removing the \$3 million minimum project requirement.

### **Recommendations**

The committee recommends Senate Bill No. 2046 to require the State Department of Health conduct surveys during construction or renovation projects of health facilities licensed by the State Department of Health. To provide this service, the department estimates the need for two full-time equivalent positions and funding of \$300,000, of which \$100,000 could be generated from fees and \$200,000 provided from the general fund.

### **State Department of Health Basic Care Survey Process Report**

Section 2 of House Bill No. 1488 required the State Department of Health to report to the Legislative Council before August 1, 2008, regarding the impact of implementation of a survey process for basic care facilities.

The State Department of Health reported on the impact of implementation of the basic care survey process. All Life Safety Code surveys have been completed on an announced basis and half of the health surveys have been completed on an unannounced basis. The announced and unannounced basic care survey process has not resulted in a significant change in the number of citations issued. The department provided information summarizing the Tier I and Tier II findings and the process utilized by the survey team. Tier I findings are isolated findings that have no more than a minimal potential for causing a negative impact on the residents and must be verified as corrected while the surveyor is onsite and prior to the exit conference, while Tier II findings are a pattern of findings of

noncompliance that have the potential for causing a negative impact or harm to the residents. Since implementation of the two-tiered survey process for identification of noncompliance, the department has conducted five announced and four unannounced health surveys resulting in 37 Tier I findings and 21 Tier II findings. Four Tier I findings were moved to Tier II because the facility was not found to be in compliance at the time of the revisit. Response from the providers and the surveyors to the two-tiered survey process has been positive and the department does not anticipate recommending any legislative changes to the survey process.

The committee heard testimony from the North Dakota Long Term Care Association in favor of continuing the two-tiered survey process, and the Protection and Advocacy Project suggested the committee consider discontinuing the announced survey process for basic care facilities since during the previous interim the pilot project results indicate that announced surveys resulted in fewer citations.

### **Recommendations**

The committee made no recommendations regarding the report on the impact of implementation of the survey process for basic care facilities.