# North Dakota Real Choice Rebalancing Grant

Choice and Self-Directed Community Resource Delivery
for the Elderly and People with Disabilities

# A Summary of Studies & Reports Related to North Dakota's Aging Population and People with Disabilities

This summary of studies and reports was developed by the North Dakota Real Choice Rebalancing Grant staff and was intended to be used as a resource guide for various Real Choice Rebalancing Grant activities.


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## Preface

This document summarizes significant contributions of the information gathered over the last 20 years about continuum of care services (i.e. home and community based services (HCBS) and nursing facility services) in North Dakota (ND). Beginning with a summary of the *Long Term Care: Issues and Recommendations, 1987 ND Interagency Task Force on Long Term Care* report, also referred to as the *Drayton Study* and concluding with summaries of current reports written in 2006.

Following the 1987 *Drayton Study*, three North Dakota legislative interim committees (1996, 1998, and 2000) were assigned the task of also studying long term care or continuum of care services. In July 1999, the Supreme Court issued the Olmstead decision. The Supreme Court's decision in that case clearly challenges Federal, State, and Local governments to develop more opportunities for individuals with disabilities through more accessible systems of cost-effective community-based services. (Centers for Medicare and Medicaid Services website: www.cms.hhs.gov/olmstead/default.asp). The Olmstead decision interpreted Title II of the Americans with Disabilities Act (ADA) to require states to administer their services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities. This applies to all qualified individuals with disabilities regardless of age. These services, programs, and activities include what are often called long term care services (i.e. nursing home and HCBS).

Since the Olmstead decision, many states, including ND, began to take a closer look at their systems of long term care for persons with disabilities, including those who are aging. This prompted the creation of ND's Olmstead Commission/Workgroup and its statewide public forums, and resulted in the report titled *White Paper: November 6, 2000* that gave recommendations for ND's long term care system. Since the publication of the *White Paper,* there have been several more recent studies which have looked at various components of the long term care system in ND.

The wealth of information included in this summary and in the full reports, provides a detailed picture of North Dakota's continuum of care system. This information is available to assist ND in the development, design, and implementation of a continuum of care system, its programs, and services that are provided, in the most integrated setting appropriate to the needs of qualified individuals with disabilities and provide choice and self-directed community resource delivery for the elderly and people with disabilities in ND.

## Timeline of Reports

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| **1987** | Long Term Care: Issues and Recommendations, 1987 ND Interagency Task Force on Long Term Care |
| **1996** | Report of the Task Force on Long term Care Planning 1996 |
| **1998** | Report of the Task Force on Long term Care Planning 1998 |
| **2000** | Report of the Task Force on Long term Care Planning 2000 |
| | White Paper: Olmstead Workgroup November 6, 2000 |
| | Report of the ND Governor's Task Force on Long term Care Planning Expanded Case Management, June 30, 2000 |
| **2002** | Needs Assessment of Long Term Care, North Dakota: 2002, Initial Report & Policy Recommendations, November 2002 |
| | Cost Containment Alternatives for ND Medicaid, November 1, 2002 |
| **2003** | Informal Caregivers: 2002 Outreach Survey, 2003 |
| | Community of Care Baseline Survey, 2003 |
| | National Family Caregiver Support Program: ND American Indian Caregivers, June 2003 |
| **2004** | 2004 AARP ND Member Survey: Support Services, June 2004 |
| | Senate Bill 2330 Workgroup Final Report, December 2004 |
| **2005** | Community of Care Olmstead Grant, August 2003 - 2005 Final Report |
| | Final Report Real Choice Systems Change Grant Cultural Model, May 05-06 |
| **2006** | Home and Community Based Services Planning Project Survey Results, June 2006 |
| | North Dakota Real Choice Systems Change Grant-Rebalancing Initiative: Focus Groups and Personal Interviews- Research Report One, June 2006 |
| | North Dakota Real Choice Systems Change Grant-Rebalancing Initiative: Hospital Discharge Planner Questionnaire – Research Report Two, August 2006 |
| | Resident and Family Satisfaction Survey Summary, prepared for the ND Long Term Care Association, December 2006 |
| | North Dakota Real Choice Systems Change Grant- Rebalancing Initiative: North Dakota Consumers of Continuum of Care Services Questionnaire – Research Report Three, December 2006 |
| | Final Olmstead Plan and Recommendations **(Pending)** |

| | **North Dakota Long Term Care: Issues and Recommendations, 1987**<br>**By**: Interagency Task Force on Long Term Care<br>**Targeted Population:** Elderly and people with disabilities |
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| Summary of Information | The ND Interagency Task Force on Long Term Care, which includes the Governor's Office, Department of Human Services, and Department of Health, conducted a study in Drayton, ND in 1986. This study established the need to look at the structural, functional, financial and social concerns regarding the long term care delivery system in ND and how it affects the needs of the aging population in our state. The report is not directly about the Drayton Study, but about the issues that the nation and ND is facing in regard to long term care.<br>The Task Force gave the following recommendations:<br>1. State policy be implemented to include: a) A balanced continuum of long term care services, b) The functional limitations and needs of the elderly will serve as the principal criterion for the use of long term care services or the development of additional long term care services, c) The financial and organizational structure of the long term care delivery system will be designed to assist older adults in obtaining appropriate long term care services, d) Access to appropriate long term care services for older adults will be improved through provided a central point of entry, e) Institutional services will be considered "alternative" services within the continuum of long term cares services, f) Families, as the principle caregivers to older adults, will be supported, and g) ND's certificate of need law will continue as a function of the State Health Council and the Council will make necessary changes in its review process that will further the development of a balanced continuum of long term cares services in ND.<br>2. Single point of entry to the system of long term care be recognized and used, and that a system of case management be established and used.<br>3. Federal and state dollars for long term care services be pooled in state government and dispersed on the basis of the functional needs of clients.<br>4. The Department of Health and DHS continue the ongoing consolidation of the inspection of care function with the certification survey for ICF/MRs.<br>5. Based upon the demonstrated efficiencies expected to be achieved under the ICF/MR consolidation pilot project, the task force recommends that the Department of Health and DHS consolidate the inspection of care, certification and licensure functions for all long term care facilities.<br>6. Consolidation of inspection of care with the certifications survey process should accompany the consolidation of authority for imposing graduated economic sanctions on those facilities that fail to meet the quality compliance standards.<br>7. The State Health Council, with the assistance of the Department of Health and DHS, should recommend to ND's Congressional delegation a series of changes in federal nursing requirements that would permit the state to reduce the burden of regulation for long term care facilities.<br>8. Passage of legislation to improve access to HCBS by a) Requiring all HCBS that are financed by the state be available in each county, b) Apply economic assistance on a sliding fee scale, c) extend eligibility standards through assessments of functional impairment rather than the likelihood of institutionalization, d) A system of case management within the communities and pre-admission assessment of all applicants for nursing home care.<br>9. Enact a bill that 1) Directs the DHS to develop a case-mix reimbursement system for nursing homes which will a) provide that the rates determined will be adequate to support the basic services, b) Assures that payment system will provide incentives for service to "heavy care patients", c) Require the payment system incorporate positive economic incentives for the efficient operation of nursing homes. 2) Provides that the rate of payment for the basic services required participation in the Medicaid program will apply to all residents equally.<br>10. The Health Department, the DHS, the Governor's Office and the Office of Management and Budget recommend an appropriated level of state funding of the health planning/certificate of need programs for the 1987-1989 biennium. |

| | **ND Report of the Task Force on Long Term Care Planning, 1996**<br>**By**: ND Department of Health and ND Department of Human Services<br>**Targeted Population:** Native Americans, aging population, people with disabilities, veterans |
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| Summary of Information | The Task Force gave the following recommendations:<br>1. Services inventory, distribution and alternatives<br>o Service Inventory-Institutional Care: Economic incentives be established to encourage reduction of nursing facility bed capacity to 60 beds per thousand population over age 65 for all planning regions by the year 2002.<br>o Hospital Swing Beds: Case management be available to all clients prior to admission to a swing bed.<br>o Veterans' Service Capacity: A continuing study to quantify the veteran population in need of the services offered by the ND Veterans Home basic care facility in Lisbon and options for addressing this need.<br>o Alzheimer's and Related Dementia (ARD): Existing institutional service capacity be re-focused or re-tailored to meet the needs of this population. Greater emphasis on social services may be more appropriate for clients without significant complicating medical conditions.<br>o Definitions of Services and Housing Components: Consider establishing a pilot project in one planning region of ND, involving the pooling of service dollars to the maximum extent permitted by law, with innovative service delivery experiments initiated under the Alternative Services Program (NDCC 23-01-04.3).<br>o Native American Long-Term Care Access: Continue studying Native American long term care needs and access to appropriate services appears to be indicated. Of particular interest is the functional relationship between various state subdivision service units and the individual reservation service systems.<br>o Isolated Rural Elderly: The HCBS system can be highly effective when a QSP can be located in close proximity to the client. Because of distance between QSPs and clients, in most cases, service delivery in the very rural areas tends to be more expensive. QSPs are limited in rural areas. These factors contribute to rural elders facing relocation to access services or going without needed services. To enhance provider availability include expanding available training for QSPs, expand case management to facilitate better arrangement of services, and enhancement of reimbursement for QSPs.<br>o Home and Community Based Service Provider Availability: QSPs are most frequently recruited by word of mouth by clients, family members, and other QSPs. Larger counties and agencies seem to achieve greater results in locating providers to fill the demand. Frequent turnover tends to be greater in rural areas due to over booking of QSPs resulting in burnout and lack of training opportunity.<br>o Training of Qualified Service Providers: Continued study of the means of expanding service availability, including options for training additional QSPs.<br>o Geropsychiatric Service Adequacy: Continued monitoring of this issue, with no further action recommended pending the completion of studies by the State Hospital.<br>o Pooling of Service Reimbursement Sources: The pooling of service reimbursement payment sources. The object of such pooling is increased flexibility or portability of service payments to allow payment to flow to a broadened array of housing options. These services should be rendered pursuant to a service plan developed in an effort coordinated by a case manager and involving the client, the client's family, and the care providers (both formal and informal).<br>o Payment system to ensure that appropriate incentives are developed and adequate time is available for nursing facilities to change to a different payment process.<br>2. Financing of long-term care<br>o Nursing Facility payment Policy: In order to change the emphasis on institutional long term care, the payment system must undergo a change that will encourage nursing facilities to consider reducing the number of nursing facility beds currently in use and provide incentives to deliver alternative HCBS for the elderly and people with disabilities in our state. With the realization that any major change in the delivery system for long term care could create financial and other problems for nursing facilities. For that reason, it will be necessary to carefully plan for changes in the payment system to ensure that appropriate incentives are developed and that adequate time is available for nursing facilities to change to a different payment process.<br>o Nursing Facility Bed Capacity: Current payment policy motivates nursing facilities to keep high occupancy rate in order to maximize reimbursement. This is counter-active to the goal of providing service in the least restrictive, most cost effective environment possible. If the number of nursing facility beds remains unchanged, it will be very difficult to divert funds to HCBS. Funds will need to be appropriated to maintain these beds while a t the same time try to provide additional funding for alternative service. A specific recommendation regarding the goal for reduction of current licensed bed capacity is include in the report from the Inventory, Distribution and Alternatives Committee. |

ND Report of theTask Force on Long Term Care 1996 continued

- Long Term Care Insurance: Promote the purchase of long term care insurance in order to reduce reliance on the Medicaid Program for payment of long term care services. If successful, it should result in increasing the percentage of nursing facility revenues received from the insurance industry and should result in reducing the growth of Medicaid expenditures in the long term.
- Managed Care: May play a role in the delivery of long term care services that could result in the development of alternative care in a cost-efficient manner. However, due to limited experience and knowledge of the effects of managed care on long term care services, this issue must be approached cautiously and systematically.
- Transfer of Assets: It is recognized that it is prudent to plan for the orderly transition of assets, but such planning does not necessarily mean that individuals should impoverish themselves in order to qualify for a program that was originally designed to meet the needs of America's poorest citizens. The committee believes that a formalized educational effort is needed to discourage this activity.
- Spousal Impoverishment: Provisions do not apply to individuals who are receiving HCBS. This restriction may discourage married couples from choosing HCBS as an alternative to nursing facility care. In addition, this may deter individuals from returning home from a nursing facility because the spouse would lose the asset exemption and the family would no longer qualify for Medicaid coverage.

3. Case Management:
    - Case Management Definition: Amend all applicable administrative codes, policies and procedures, rules, handbooks, and other written materials to include and operationalize the revised definition of case management. Amending additional ND Century Code references to case management may also be required, based on input from legal staff.
    - Access & Standards: Statewide implementation of the expanded case management system based on the finding of the pilot project(s).
    - Client Assessment: Implementation of a uniform computerized assessment document with the ability to transfer client information to each agency involved with the client that is accepted and used by a variety of agencies.
    - Cost of Case Management: Implementation of an expanded, automated, comprehensive, case management system that would include the ability to tap or "broker" a number of funding sources to pay for clients' service needs in a cost-effective manner, in the least restrictive environment.

**Report of the Task Force on Long term Care Planning, June 1998**
**By:** ND Department of Health and Department of Human Services
**Targeted Population:** residential providers, geropsychiatric providers, long term care providers

Summary of Information

The Task Force gave the following recommendations:

1. Basic Care Rate Equalization and Rate: Repeal basic care rate equalization.
2. Long term Care Financing and Incentives: a) Amend the definition of a private pay resident to include managed care entities as payers exempt from rate equalization, b) Consider incentives package to reduce bed capacity and provide alternative long term care to elderly, c) Study the use and effectiveness of the Senior Mill Levy match Funds as described under NDCC 57-15-56 to determine whether the program should be expanded as a means of enhancing in-home and community-based services availability.
3. Alternative Services: Enact enabling legislation that would direct the DHS and Department of Health, the long term care industry and consumer to develop the rules, policies and procedures necessary to implement the proposed changes in the current delivery system for alternative long term care service.
4. Case Management: a) Require that individuals eligible for Medicaid must, prior to entering a nursing facility or accessing other long term care services, obtain preadmission needs assessment to determine the type of services necessary to maintain each individual and what long term care alternatives, if any, could meet those care needs, b) Authorize DHS to implement a Targeted Case Management Program for the elderly and people with disabilities at risk of entering a nursing facility or needing other long term care services including the necessary general fund and federal spending authority to operate the service in the next biennium, c) Consider monitoring the results of this program to determine if the above policy should be extended to all individuals wishing to enter nursing facilities.
5. Moratorium on Nursing Facility and Basic Care Beds: a) Continue the current moratorium that prohibits an increase in the nursing facility bed capacity and basic care facility bed capacity in accordance with current law, b) Allow for an exception to the basic care facility moratorium that will permit the addition of one basic care facility specifically designed to meet the care needs of the TBI population not to exceed the greater of 10 beds or the number o available slots permitted in the waiver.
6. Pilot Projects: a) Authorize DHS to continue three approved ARD pilot projects into the 1999-2001 biennium, b) Require DHS to monitor the progress of the projects and prepare a final report for the legislature that provides conclusions and recommendations regarding the future of these pilot projects.
7. Funding Sources: Consider any restructuring of the DHS based on the ongoing study of the Department that was commissioned specifically for this purpose.
8. Swing Bed Facilities: Consider studying the swing bed process to determine if any changes are necessary in the current requirements for providing services to swing bed residents, including the need for a standard assessment process and whether any limits such as length of stay or number of available swing beds should be implemented.
9. Geropsychiatric Services: a) Consider a legislative study resolution to explore expansion of psychiatric and geropsychiatric training for general practice and family practice physicians at the UND School of Medicine, b) Provide a legislated exception to the case-mix system to allow establishment of a 14-bed geropsychiatric unit to serve clients that are elderly or physically disabled and severely mentally ill.
10. Expanded Case Management: The DHS will continue to monitor the progress of the pilot projects and prepare a final report on the results no later than June 30, 2000. Continued funding of these projects is planned to come from within the DHS budget.
11. Service Availability: A better understanding of the current services delivery system regarding private formal and voluntary informal services, as well as public and formal services including regional human service centers, county social services, service payments for elderly and disabled (SPED), expanded SPED programs, older Americans act Title III and Title IV services, and medical assistance, b) conduct the necessary assessment to determine the extent of the current and future service delivery systems for North Dakotans age 60 and older and fro persons with physical disabilities age 18 through 59 in ND.
12. Training of In-Home Care Providers: a) The DHS should coordinate with the State Board for Vocational and Technical Education to establish a statewide model curriculum of in-home care certification/competency, b) The Task Force on Long Term Care Planning should investigate the impact of a formalized in-home care training program on service availability and quality service delivery, c) In order to attract and retain in-home care providers, competitive reimbursement rates must be established. A market analysis should be commissioned to determine the financial resources needed to support the in-home care provider system.
13. Protection of Vulnerable Adults: Introduce legislation that amends the ND Century Code Chapter 50.25.3 to require implementation of the vulnerable adult protective service statute. The legislation should permit assignment within existing administrative structure with clear direction for cooperation and collaboration with other existing programs that serve adults in ND.

| | **Report of the Task Force on Long term Care Planning, June 2000**<br>**By:** North Dakota Department of Health and North Dakota Department of Human Services<br>**Targeted Population:** elderly, people with disabilities, and Native Americans |
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| Summary of Information | 1. Nursing Facility Rate Equalization<br>o Rate equalization should be continued and funding should be consistent, fair and periodically reviewed.<br>2. Basic Care and Assisted Living<br>o The following recommendations regarding assisted living and basic care should be implemented together: a) Retain basic care as it is currently defined and regulated. b) Require the Department of Human Services to register assisted living facilities and charge a registration fee. c) Require mandatory registration of assisted living facilities that meet the modified definition of the current definition, which would include meeting food and lodging licensing requirements under NDCC 23-09 if appropriate. d) Amend NDCC 23-09 as appropriate to allow the Department of Health to license assisted living facilities under the food and lodging regulations. e) Have the Department of Human Services receive complaints related to assisted living and forward them to the appropriate agency for investigation. f) Exclusive of units in nursing facilities, Alzheimer's (memory care or special needs) facilities and other pilot project facilities must be licensed and operated as basic care facilities.<br>o Establish a rent subsidy program for assisted living. Rent should be subsidized to a maximum of $750. Thirty percent of the medically needy income level should be applied to rent when determining the rent subsidy. A maximum of $2.5 million not to exceed the amount of general fund dollars saved if the personal care option is added to the state plan and provided in basic care facilities. (See Exhibit 7 for Fiscal Impact Projections for the 2001-2003 Biennium)<br>o Establish a licensing fee for basic care facilities.<br>o Repeal the moratorium on basic care beds.<br>3. Personal Care Services<br>o The State should add the Medicaid personal care service option to the State Plan.<br>o Limit the personal care service option to certain provider types, such as basic care or assisted living.<br>4. Senior Mill Levy Match<br>o The Task Force on Long Term Care Planning recognizes the importance of this funding source in the overall provision of services to the senior citizens of our state and recommends the legislature restore the Senior Mill Levy Match to a dollar-for-dollar match as included in the original appropriation.<br>5. Native American Long Term Care Needs<br>o The unmet transportation needs of tribal elders be jointly addressed by local Tribal officials, the Department of Transportation, the Aging Service Division and Medical Services Division of the Department of Human Services, and the Regional office of the Administration on Aging.<br>o The Indian Affairs Commission take the lead to facilitate development of elder councils on each reservation, to serve as a liaison to the Tribal Council and as an advocate for older persons.<br>o Inter-agency communication at the local level be strengthened, and inter-agency meetings be held for the purpose of sharing information and addressing unmet needs of tribal elders.<br>o Issues and needs identified as specific to either the federal government or the tribal government will be brought to their attention by the Task Force on Long Term Care Planning.<br>o The Governor's Committee on Aging be expanded to include a representative from each of the Tribal Nations (possibly as a sub-group), rather than the current one representative. The role of the Governor's Committee be examined and strengthened to include greater authority in the areas of public policy and planning.<br>o Public education efforts be increased, through workshops and other methods, to create greater awareness of the following: Senior Health Insurance Counseling Program; Older Americans Act outreach services; Home Extension Services; In Home and Community Based Services; Indian Health Service programs; Medicaid and Medicare; Public Health; County and Tribal Social Service programs, and others.<br>o A template be developed outlining the structure and funding sources of various health services available to Tribal members. The template could be used as an educational document for higher education, the Legislature, and the public.<br>o A request be sent to the Administration on Aging asking that additional resources be allocated to provide technical assistance and training to Title VI Older Americans Act service providers.<br>o Diabetes Education efforts need to be coordinated among the various agencies and organizations dealing with diabetes to better serve the affected population.<br>o Appropriate state agencies work with the Tribal Governments and agencies regarding a continuum of living arrangements, including tribal and public housing, assisted living and congregate living, nursing home and basic care services (including discussion on the moratorium on nursing homes) to ensure the safety, comfort, and preferences of the elders.<br>o A follow-up meeting be held on each Reservation and Indian Service Area to discuss how the long-term care needs of Tribal elders, brought forward during the input meetings, have been addressed. |

Report of the ND Task Force on Long Term Care, June 2000 continued

6. Care Coordination/Case Management
    - An optional Targeted Case Management service be added to the Medicaid State Plan for Medicaid eligible recipients who are elderly or persons with physical disabilities at risk of long-term care services including but not limited to SPED and Expanded SPED eligible recipients. (SPED – Service Payments for Elderly and Disabled)
    - Statewide funding for expanded case management.
    - As a matter of public policy, Information and Assistance/Referral should be available under case management service to older persons and persons with physical disabilities.
    - Funding from public/private resources be obtained to pay for a statewide education campaign geared to discharge health professionals, and the general public regarding service options and life planning for older persons and persons with physical disabilities. To accomplish this recommendation, a steering committee composed of the ND Long Term Care Association, ND Health Care Association, ND Department of Human Services, and the ND Health Department needs to take the lead in this education effort.
    - Core case management components for the elderly and persons with physical disabilities be consistent with the ND Department of Human Services Case Management Workgroup recommendations.
    - No formal mandatory pre-admission assessment; except for federally required pre-admission screening and resident review (PASRR). Emphasis will be placed on Information and Assistance/Referral, outreach, case management, and public education to address many of the same concerns as pre-admission assessment had previously intended to cover.
    - The Governor's Committee on Aging take the lead to facilitate agencies to coordinate and collaborate with each other in service delivery to common clients.
    - Case Management service be housed within the geographical area of the client and be provided by a neutral party who knows the core components of case management, knows the community resources and has the ability to network with those resources. A licensed social worker currently performs this function under current HCBS state statute funding sources within the County Social Service Board service delivery structure. It is recommended that this established practice continue. It is further recommended that this method be reviewed in the future.
7. Swing Bed Facilities
    - Do not mandate the use of the Minimum Data Set (MDS) by all hospitals providing swing bed services.
    - The North Dakota Long Term Care Association, the North Dakota Healthcare Association, and the Department of Health work together to provide training to hospitals with swing bed service related to federal Medicare Conditions of Participation and Quality of Care issues.
    - The swing bed occupancy survey be repeated in January 2001. If the Task Force on Long Term Care is not reconstituted, the report should go to the State Health Council.

## North Dakota Department of Human Services
## White Paper: Olmstead Workgroup November 6, 2000

**By:** ND Department of Human Services

**Targeted Population:** mental health, elderly, developmental disabilities, and physical disabilities

Summary of Information

An internal workgroup was formed within the DHS to review the Olmstead Decision and make recommendations on any further action. The workgroup conducted regional meetings and surveys to gather information from consumers, families, advocates, and providers. This study is broken into the following categories: Legal Background, Institutional-Based Services, Community-Based Services, Survey Results, and Recommendations.

The following are recommendations given:

1. Request to the Governor to appoint a commission to provide the North Dakota definitions inherent to the Olmstead decision and to develop a comprehensive State Plan. This commission would consist of a representative from the Governor's Office, legislators, family members, consumers, advocates, providers, and State agency heads. Federal agencies will be available for consultation as appropriate (See Appendix II – Letter of Support).
2. The Department of Human Services should schedule regular information/discussion sessions with regional stakeholders surrounding community-based services for persons with disabilities.
3. The Department of Human Services should take the lead to develop a pre-assessment screening process that must be completed prior to admission to a nursing facility. This screening process would determine care needs and identify where the services necessary to meet those needs could be obtained. This would help to ensure that persons in need of long-term care services and their families can make informed decisions regarding where they wish to obtain needed services.
4. The Department should continue to encourage and support the development of alternatives to nursing facility services.

| | **Report of the North Dakota Governor's Task Force On Long Term Care Planning Expanded Case Management (ECM) June 30, 2000**<br>**By:** Governor's Task Force on Long Term Care Planning<br>**Targeted Population**: Individuals in need of long term care services and their families |
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| Summary of Information | ECM Pilot Projects were administered in three different areas of ND. These are the recommendations based on the findings gained during the pilot project effort of ECM.<br>1. Access to Services: a) For urban areas referrals from hospitals has generated the greatest single referral source to ECM. In rural areas, word of mouth and public health nursing have provided for the greatest single referral sources to ECM. Although limited numbers of contacts to ECM have actually come from the various methods tested to generate self-referrals, it has been determined critical that routine and regular 'advertising' is required to assure the general public is continuously made aware of the availability of a service like ECM for purposes of long term care service access, planning, and implementation. b) ECM service is not generally perceived to be an emergency response service delivery system. Therefore, 24-hour access to ECM can be adequately served through the availability of a voicemail system that is accessible 24 hours a day, 365 days per year. The entity providing a service like ECM will have an established procedure for routinely and regularly responding to after hours, weekend, and holiday ECM inquires. c) The concept of "one-stop" access to answers, solutions, and guidance to all your needs is currently being promoted by many different types of businesses and organizations. Through appropriate public education ECM can serve the general public as a "one-stop" FIRST contact for accessing long term care services. Critical to the success of "one-stop" concept will be the establishment of a publicly recognized entity within each community or county that people will know to contact for their long term care questions.<br>2. Interagency Collaboration and Coordination: The ECM pilots have concluded it is essential to the success of a service like ECM to establish formal interagency collaborative and coordination agreements. Without such agreements, it is very difficult to fully give credence to a person in need of long term care service(s), the least intrusive and most uniformly consistent access to their choices within the long-term care service delivery system.<br>3. Affect on Demographics of Institutional Persons: Individuals in need of long term care service(s) and their families have consistently requested the opportunity to remain in their own home and community for as long as reasonably possible. A publicly recognized service like ECM can make this a reality for a certain percentage of the population requiring long-term care service(s).<br>4. Screening for Every Person to Measure Nursing Home Eligibility: ECM pilot results are consistent with national studies which have concluded that very few people in the general public actually require nursing home care. However there continues to be the general public perception that all older people, who require long term care service(s) must be in a nursing home to receive such support care. It is essential that public education efforts be made to inform the general public of the availability of options to meet their long-term care needs.<br>5. Client Satisfaction: The overwhelming satisfaction survey results suggest strong support for a service like ECM in both the rural and urban counties.<br>6. Additional Persons Served: The rural ECM pilot has identified between 1 and 5 "additional persons served" during the course of their quarterly reporting periods. The urban ECM pilot has averaged between 25 and 30 "additional persons served" during their quarterly reporting periods.<br>7. Impact on Other Agencies in the Community: It is essential that well-established lines of communication be established with community resources. Positive reflective contact results in substantial trust and a continued service support base for persons seeking long term care services.<br>8. Single Computer Intake (Assessment) Instrument: The computerized ASIF document is a valuable generic tool for use in the provision of a service like ECM. The use of the ASIF instrument should continue and be improved over time based on actual use and experience by providers. It is not feasible, at this time, to expect to require all agencies/organizations of common clients to use exclusively the ASIF instrument. However, whenever and wherever possible information captured by more than one agency/organization on a common client should not have to be repeatedly captured from the client by numerous different provider representatives. This lends to the potential for considerable confusion and unnecessary repetition for the client.<br>9. Termination of Expanded Case Management Service: Terminations are appropriate under the following circumstances: a) upon request of the client, b) death of the client, c) after the client has entered an institutional setting and there is not probability of discharge, d) at such time when it has been concluded that the case is determined "stable" and there is no anticipation of immediate additional long term care service intervention required, and e) the client moved out of the service area. |

Summary of Information

Report of the North Dakota Governor's Task Force On Long Term Care Planning Expanded Case Management June 30, 2000 (continued)

10. Initial Referral Impact on Client: The findings under this category conclude it is preferable to reach or have initial contact with the client in their home setting with a high preference that the contact is well ahead of the time when critical or crisis type intervention for long term care is required.
11. Client's Right to Self-Determination and Least Restrictive Environment: It has been well documented through the ECM pilots that it is critical for individuals to have the opportunity to learn of ALL options and choices available to them for their specific situation. In addition it is critical that each individual be allowed to make their own decision without undue influence of others. As a society, we tend to want to "over protect people", thus reducing one's ultimate preference of reasonable choice.
12. Barriers: Uniform efforts must be taken to educate the general public about the importance of planning and learning about long term care options and services in North Dakota. The education needs to start at a very young age and most certainly well before an individual or loved one faces a crisis scenario often forcing a more restrictive service delivery option than is actually required to meet the client care needs.
13. Other Report Recommendations and Considerations: a) Avenues must be sought to assure that Information & Assistance/Referral (I & A/R) Service is included in reimbursement sources for case management service or that I & A/R is a recognized "stand alone" service advertised and readily available to the general public via toll free telephone number and/or the internet. b) Public education efforts must be supported and offered regularly at strategic geographical locations throughout the state. c) Public education efforts must be supported and offered regularly at strategic geographical locations throughout the state to encourage persons with personal financial means to prepare to "invest" in planning and utilization of their resources for long term care needs.

## Needs Assessment Of Long Term Care, North Dakota: 2002, Initial Report & Policy Recommendations, November 2002

**By:** ND State Data Center, NDSU and Center for Rural Health, UND

**Targeted Population:** Residents in ND aged 50 and older

Summary of Information

4 different needs assessments in regards to the issues of long term care were conducted and they include: 1) Current and Future Elderly Population, 2) Elderly Needs Profile, 3) Availability and Demand for Elderly Services, and 4) Survey of Long Term Care (LTC) Administrators. These are the recommendations based on the findings gained during the 2002 ND Needs Assessment of Long Term Care:

1. Priority needs to be given to legislative efforts in the form of program initiatives and tax incentives for HCBS. Elderly who are in greatest need for services reside in the state's rural areas and small communities. These areas lack facilities, resources, and professional staff. The communities need to be empowered to take a more active role in caregiving. Program initiatives and tax incentives that create or enhance the care of elderly in the home or through community-based efforts will reduce the demand for institutional care and, in turn, the financial burden on the state.
2. The state has a very tight labor market with very limited labor available to serve the health and caregiving needs of communities. This is especially true in the rural areas of the state. In addition, statewide wages are low compared to regional averages. Therefore, legislative action needs to be taken to elevate economic development and employee training. Specific attention should be given to youth retention programs, public-private partnerships that advance apprenticeship training, and innovative skills training for those switching careers especially in rural areas. In addition, priority should be given to support and advancement of tele-medicine and distance-service delivery systems.
3. Research indicates that significant cost savings in elderly care can be gained through enhanced support of family caregiving. In 1998, the amount of Long Term Care (LTC) provided by informal caregivers in the U.S. was estimated to have a market value of $196 billion. In contrast, cost for home health was estimated at $32 billion and the cost for nursing home care was approximately $83 billion. The savings to the state for having an effective informal care system are obvious and compelling. Therefore, the legislature should sponsor a statewide informal caregivers system. Currently, an active informal caregiving program is being facilitated through the Aging Services Division of the Department of Human Services. Legislative support of this effort along with a challenge to create an integrated system will greatly advance informal caregiving in North Dakota.
4. Elderly care costs can be reduced through increased health promotion and wellness. Therefore, the state should direct its energies and resources into enhancing such programs through education and prevention efforts.

**Cost Containment Alternatives for ND Medicaid, November 1, 2002**

**By:** David Ricks, Peterson Consulting

**Targeted Purpose:** Identify initiatives that can help to achieve the DHS's goal of approximately $17 million in total annual savings (approximately $6 million in state funds).

Summary of Information

ND, like most states, is facing budget difficulties because of decreased revenues and increased demand for services in the current recession. Despite many efforts to control expenditures, Medicaid costs continue to increase. The reasons for increasing costs include: 1) Increases in the number of eligible persons, 2) Increases in utilization of services, and 3) Increases in the costs of services. Some of the findings from this study include:

1. ND spends much more than most states on institutional services, especially nursing homes and institutions for the developmentally disabled.
2. Expenditures are higher partly because ND has more elderly people in its population.
3. However, elderly ND residents are also more likely to enter nursing homes than are elderly residents of other states.
4. ND also pays higher daily rates to nursing homes than other states.
5. ND spends a great deal for one state facility for the developmentally disabled.
6. Opportunities for savings included: restructuring institutional reimbursement, expanding managed care, strengthening the managed care enrollment process, and expanding alternatives to nursing home care. The savings from these actions would not be as great as those from changing institutional reimbursement.
7. Overall, the Medicaid program faces extraordinary challenges. If funding for nursing homes and ICF-MRs is to be maintained at present levels, then the savings must come from other services, and mostly cutting fees.

**Informal Caregivers: 2002 Outreach Survey, May 2003**

**By:** ND State Data Center @ NDSU

**Targeted Population:** Residents in ND who serve as informal caregivers

(Outreach Survey was conducted face to face and by phone)

Summary of Information

1. Broad Policy Recommendations:
   - A sustainable initiative should be established that monitors the changing demand for caregiving in the state.
   - Priority needs to be given to providing support services that will enhance the abilities of current and potential informal caregivers.
   - Significant cost savings in elder care can be gained through enhanced support of family caregiving. Therefore, public and private incentive programs should be vigorously explored. peers, services, and health care professionals easy 24-hour access
2. Research Support of Policy Initiatives:
   - Volunteer Services: The legislature should promote community-based programs that tap the professional and volunteer services of local residents to assist in elderly caregiving.
   - Equipment Stipends: The legislature should fund equipment stipends which allow elderly or caregivers to purchase equipment that facilitates independence. These stipends promote caregiving by easing its financial burden. Greater use of informal caregivers reduces the long-term care cost both to the family and to the state. In addition, subsidies such as equipment stipends will assist middle-income families who are the hardest hit financially. These families cannot afford nursing home care or home health care, nor do they qualify for Medicaid or other public health programs because their incomes are too high.
   - Distance Education: North Dakota should focus resources on advancing distance education as a way to assist rural communities in providing support services to caregivers.
   - Incentives: The legislature should fund caregiver incentive programs.
   - On-line Computer Assistance: There should be ongoing support for an on-line resource assistance website for caregiving.

**Community of Care Baseline Survey: 2003**

**By:** Richard Rathge, Director, Jordyn Nikle, and Ramona Danielson - North Dakota State Data Center-North Dakota State University

**Target Population**: residents of rural Cass County.

Summary of Information

This study was designed to evaluate the knowledge and attitudes pertaining to the services, funding and perceptions of community responsibility for the care of seniors and people with disabilities located in rural Cass County. Below is a summary of the findings gained during the Community of Care Baseline Survey:

1. Level of Knowledge:
   - A majority of respondents do have at least some knowledge about senior and disabled services such as housing, outreach, wellness/health promotion, ambulatory care, home care, acute care, and extended care. Knowledge of all services are higher among respondents who are older. Respondents indicate higher levels of knowledge about housing, outreach, and funding options if they care for a disabled person or a senior.
   - Respondents who indicate no concern for their long-term care were more likely to indicate no current knowledge about the services of outreach, wellness/health promotion, ambulatory care, and acute care.
   - However, 40 percent of respondents have no current knowledge about funding options for services for seniors and disabled persons.
   - The top four funding options the majority of respondents perceive as important for most senior and disabled services are government aid, private assets, insurance, and social services.
   - At least one in five respondents are unsure whether acute care, ambulatory care, outreach, and wellness/health promotion services are available in rural Cass County.
   - More than three-fourths of respondents consider services offered in urban Cass County, namely Fargo and West Fargo, as feasible and convenient.
2. Perceptions of Care:
   - Nearly two-thirds of respondents are concerned about the long-term care of family and friends. On a scale of one to five, with five being "very concerned," the average level of concern respondents have about the long-term care of others is 3.79, indicating much concern. Respondents indicate less concern about their own long-term care with a mean of 3.10, which still suggests a moderate amount of concern.
   - The majority of respondents who are concerned for the long-term care of others are between the ages of 20 to 69 years of age. The majority of respondents with an income of less than $20,000 indicate they are not concerned about others' long-term care.
   - Concerning their own long-term care, respondents are less likely to be concerned if they are between the ages of 20 to 29, while those 50 to 79 indicate higher concern.
   - More than half of respondents indicate that when the time comes they would like their long-term care needs to be met by professional home care. One in five respondents also prefers an informal means of caregiving. Approximately16 percent indicate a nursing home.
   - Forty percent of respondents indicate ensuring access to services for seniors and disabled persons to be a community responsibility, one-third believe it to be a private responsibility, and one in five respondents perceives it to be both.
   - Approximately 71 percent of respondents perceive that rural communities in their area are at least somewhat willing to embrace a shared responsibility concept of senior and disabled care.
3. Characteristics of Rural Residents:
   - Approximately 83 percent of respondents spend some time participating in community activities. One in five spends 11 hours or more each month. Of those who do not participate, almost half of respondents indicate an annual household income of less than $20,000.
   - Nearly two-thirds of respondents indicate they have lived in rural Cass County for more than 15years, and 85 percent say they do not plan to move out of rural Cass County in the next five years.
   - Thirteen percent of respondents care for a senior or disabled person and 41 percent are responsible for a child under the age of 18.One-third of respondents report an annual household income between $30,001 and $60,000.
   - One-fourth of respondents did not report their income. Income varied by respondents' age, with those 30to 59 years of age indicating a household income of more than $40,000 per year. One-third of respondents 60 years of age and older indicate less than $20,000 per year.
   - Respondents are fairly evenly distributed by age. Half of respondents are 50 years or older and half are younger than 50 years of age.
   - Two-thirds of respondents are female.

| | National Family Caregiver Support Program: ND American Indian Caregivers, June 2003<br>**By:** Center for Rural Health, UND School of Medicine & Health Services<br>**Targeted Population:** Five reservations in ND, caregivers from the ND American Indian population |
|---|---|

**Summary of Information**

The following is a summary of finding as a result from North Dakota Native Americans as informal caregivers (those who serve as informal caregivers to individuals 60 years of age or older) survey.

1. Characteristics of Caregivers:
   - 25% retired
   - 33% work full-time
   - 69% female
   - 61% married
2. Intensity of Care:
   - The intensity of care is relatively low because of the age of the American Indian elders
   - Care is of short duration but is very time consuming.
3. Caregiver burden:
   - Low sense of burden – 13 items all scored below 2.0 on a 5 point scale where 5 indicated serious difficulty.
   - Highest concern reflected conflict between a sense of duty to provide care and accepting help.
   - Conclusion- Burden is not a major problem
4. Support from other caregivers:
   - 41% of the American Indian respondents had other caregivers compared to 51 % in the general population.
   - The cultural value of familism on reservations appears to assure informal care when needed, but does not extend to supporting the caregivers, especially for grandparent caregivers.
5. Availability of formal services
   - For Recipient of Care: a) Almost all services are less available to Indian elders than to the general population. b) Over half of the services were available to less than 50% of the Indian respondents.
   - For Caregivers: a) Caregiver education is more readily available to reservation respondents than others, but recall that informal care is the main local option. b) Respite care is less available. c) Information about services and assistance in accessing services were low reflecting the low volume of services locally available.
6. What they want- top priorities.
   - For recipients: a) visiting nurses, b) homemaker services, and c) outreach
   - For Caregivers: a) information, b) Caregiver training, and c) assistance in accessing services.
7. Use of Available Services.
   - Recipient Services: a) when services were available, Indian caregivers used them at high rates.
   - Caregiver Services: a) A1 ratings were at the positive end of a 5 point rating scale and b) Services were not rated as highly by American Indian caregivers when compared to the general population.
8. Services caregivers provide
   - They do it all! Especially socio-emotional support, household tasks and transportation
   - Legal assistance and help getting other family involved were lowest
9. Most valued information
   - Information generally was less valued by ND's American Indian respondents and services not locally available.
   - Top Categories: a) Information about conditions, b) Counseling/support programs, c) Financial support, and d) assistance in dealing with agencies.
10. The Impact on caregivers
    - Relatively low impacts were observed among American Indian caregivers, probably as a result of the relatively young ages of the caregivers and recipients.
    - Dementia is less of a problem in this population.
    - Work conflicts are the most common impacts.

| | 2004 AARP ND Member Survey: Support Services, June 2004<br>**By:** David Cicero<br>**Targeted Population:** ND AARP members |
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**Summary of Information**

The purpose of the survey was to gather information from members regarding their personal concerns, views of AARP's role and activities at the state level, opinions of ND legislative issues, ideas concerning Social Security and unemployment benefits, and experiences with support services.

- 4 in 10 ND members have used support services or a family member or friend who has in the past 5 years.
- Of these, half lived at home while receiving visits from health professionals and the other half lived in a nursing home.
- 1 out of 7 indicated it is not easy to find needed support services.
- Information about personal care services was received from Health and Human Services and Senior Service providers.
- Half of the members are extremely concerned with having choices in long term care.
- More than 3 out of 4 members think it is very important to provide funding to make support services widely available, even if it means increasing taxes.

**Senate Bill 2330 Workgroup Final Report, December 2004**

**By:** Senate Workgroup of the ND Disabilities Advocacy Consortium

**Targeted Population:** elderly and people with disabilities

Summary of Information

1. Identify specific barriers to nursing homes providing home and community based services and pursue demonstration grants to eliminate the barriers. Action Steps:
   a) #1 barrier is an adequate payment system for individuals and agencies. The cost of providing services out of a facility is prohibitive for the current rate of reimbursement. b) Pilot projects to promote nursing facilities to expand their Mission to serve and care for individuals in need of support and health services wishing to remain at home are proposed as a joint effort between the North Dakota Long Term Care Association and the Department of Human Services. Pilot project concepts have been submitted by 3 facilities. A funding source for the pilot projects is being explored. c) The Department of Human Services/Aging Services Division, North Dakota Long Term Care Association, and North Dakota Association for Home Care should meet to further clarify whether home care health services are available statewide, or whether new providers would create duplication.
2. Identify legal barriers to "the money following the client". Action Steps: a) SB 2330 states "The individuals medical assistance funds must. Follow the individuals for whichever service option the individual selects". Because nursing home rates are set based on costs, a client moving out of a nursing home does not necessarily mean a savings has occurred and funds are available to be transferred. If there isn't a direct reduction to the nursing facility's costs (property costs, staff, etc?), when a resident moves out of the nursing home, the costs are included when calculating future rates for the nursing home and passed on to other residents through increased rates. b) The growth of the budget for institutional care could potentially be curbed through enhancement of home and community based services.
3. Explore the pros and cons of submitting an 1115 or 1915 Independence Plus Medicaid Waiver or modifying existing waivers and the experiences of other states. Research the needs of special population groups; who are underserved or unserved. (examples: younger persons not fitting aged & disabled waiver; T.B.I.;D.D. but not M.R.; behavioral issues; Native Americans. Action Steps
   a) Have developed a research document that will be distributed to Various social services types of agencies. The response was minimal.
   b) The Aging Services Division has researched Medicaid Waivers in other states and solicited input from agencies and individuals regarding a "Dream Waiver". Expansion of Waivers in North Dakota will be pursued and may focus on the following:
      - Limited funding for transitioning from institutional to in-home;
      - Include QSP rate increase and broaden the labor pool;
      - Single Entry Point integration
      - Consumer Choice and Consumer Direction
      - Service availability 24/7 with right to case mix
      - Socialization or therapeutic recreation services
      - Review of Robin's list of other State's Waivered services & include if applicable
   c) Develop a system that allows for a medical/social mix of services for persons with complex medical need;
   d) Review the Nurse Practice Act (to allow greater access to medication administration, similar to DD) while considering consumer safety and provider reimbursement. Review Nurse Delegation. In process of review by a subgroup of the SB2330 work group.
   e) Review the $2400 (current) cap on the Medicaid Waiver,
   f) Involve stakeholders in the expansion of the Waivers while considering mutual planning between various groups to evaluate group composition and avoid duplication of representation when the reviewing changes or when applying for waivers.
   g) Communicate with the Olmstead Commission
4. Pursue funding through the Real Choice Systems Change grants and New Freedom Initiative grant opportunities. Action steps:
   a) A grant for $323,067 for a Real Systems Change Grant: "Money Follows the Person, Rebalancing Initiative" in July 2003. The request was not funded. There were 146 proposals submitted and 9 requests were funded. In the request for proposals that were released by CMS in 2004, this category was not listed, therefore no proposal was developed. A weekly Internet search was made to review for federal grants available for this purpose. To date, none has been found.
   b) A second grant application for a Real Choice Systems Change Grant Rebalancing Initiative was submitted to CMS in July, 2004. The grant was funded by CMS in the amount of $315,000 for a 3 year time period beginning 9/30/2004. The grant application was a partnership between AARP, DHS, and the North Dakota Disabilities Advocacy Consortium.
5. Develop a prototype for counties to organize "Aging Services Coordinating Committees" Action steps:
   Cass County has had two meetings. Various agencies discussed their roles, shared plans, brain stormed about strategic planning, and did work in smaller groups. Bottineau County had 32 agencies appear for their initial meeting. The respective directors are asked to report on this model.

| | **Community of Care Olmstead Grant August 2003/2005 Final Report**<br>**By:** Good Samaritan Society and North Dakota Department of Human Services<br>**Targeted Population:** elderly and people with disabilities in rural Cass County |
|---|---|
| Summary of Information | *Major accomplishments:*<br>Outcome Objective 1 – Facilitate access and awareness of existing formal and informal support<br>o The utilization of the Resource Center by community members and presentations to local civic groups has fostered increased awareness and education of long-term care services and support.<br>Outcome Objective 2 – Develop new and enhance existing needed formal and informal support services.<br>o New services include the Resource Center (Resource Library and Care Coordination), Volunteer Program, and Caregiver Support Program.<br>o Expanded services include the Care Companion Program, the Bereavement Program and BeFriender Ministry program.<br>o The development and enhancement of these services have assisted in increased access to needed services.<br>Outcome Objective 3 – Mobilize formal and informal organizations to work together in new and innovative ways to support needs of elderly/people with disabilities in the community.<br>o Community of Care has worked to increase the awareness of the needs of rural elderly/people with disabilities through developing and implementing a communication plan to reach a variety of audiences.<br>o Community of Care has established numerous new relationships and partnerships with local health and human service providers, churches, businesses, etc. for the purpose of promoting collaboration in meeting the needs of the elderly and persons with disabilities.<br>Outcome Objective 4 – Integrate private and public long-term care funding.<br>o Preoperational work has been done on the feasibility of either a rural PACE program or a social cooperative as potential components of a permanent community-based model of care as the intent of this objective is to further research appropriate funding mechanisms in Phase II.<br>*Unsuccessful initiatives*:<br>o The case management system, as defined in the grant application, is not fully developed to the level anticipated for several reasons. First, the Steering Committee planning process identified other issues as more critical than the case management system. Second, the planning activities and other service development work required the majority of time delineated in the Olmstead grant. Third, staff understanding of care coordination has changed and matured throughout the grant process and will be fully developed in Phase II of the project.<br>*Lessons learned:*<br>o The long-term care system is truly fragmented and difficult to navigate, even for professionals.<br>o Home and community-based services (HCBS) and institutional based professionals seem to all operate in silos and both of these groups are unaware of the value of integrating those services and collaborating with each other.<br>o Many good projects, initiatives, and/or activities are taking place through the state and region, but there is not a system in place to disseminate the information to interested parties.<br>o Community members are concerned about the welfare of their senior citizens and are willing to work to improve their quality of life, but they need a local leader to organize their efforts.<br>o Building community awareness and local ownership is critical to the success of a rural program.<br>o Many elders and people with disabilities whom are living in the community lack the information and ability to advocate for themselves, especially in times of crisis. A care management model that encompasses health care and an interdisciplinary team seems to be an effective solution to improving both the quality of care and the quality of life for the frail elderly or those with long-term health care needs.<br>o The need for information on long-term care issues is great. People do not seek out information until a traumatic event has occurred. They need immediate access to current and accurate information. Individuals prefer personal assistance rather than navigating through vast amounts of information on their own. |

**Final Report Real Choices Systems Change Grant Cultural Model**
**May - June 2004**

**By:** North Dakota Olmstead Commission
**Targeted Population:** American Indian elders and Native Americans with disabilities

Summary of Information

*Major accomplishments:*

- Good engagement from all tribal communities.
- The project was able to secure sincere and committed involvement of service providers from all communities and the state.
- Each tribal community now has plans focused on a continuum of care for their consumers.
- Project facilitated the movement toward the formation of an elder association on the Turtle Mountain reservation.
- Awareness that the way American Indian elders and people with disabilities receive services should be different.

*Unsuccessful initiatives:*

Initiative 1- To Expand HCBS Case Management to Tribal Entities: The need fro reservation-based HCBS case management became evident as information was gathered through focus groups. Initial focus group findings from all 5 tribal areas became available in year one. The Steering Committee drafted a bill which was submitted to the 59th Legislative Assembly. The bill would have allowed the ND DHS to contract with the Tribal entities to fulfill HCBS, presently performed by County Social Service agencies. The bill eventually became a part of a larger State-Tribal Relations Committee.

- The State-Tribal Relations Committee is to be comprised of legislators or their designees. A citizens' committee component is to be comprised of tribal chairpersons or designees, and the director of the ND Indian Affairs Commission or designee. The State-Tribal Relations Committee will examine this issue, among others, throughout the 2005-2007 interim. While not un-successful, HB 1524 will allow for further and continued dialogue between legislators, tribal leaders, consumers and providers prior to the next legislative assembly.

Initiative 2 – To Engage Certain Groups did not materialize: Greater involvement was desired. However, timing of invitations sent county social services representatives to attend meetings was too short, and while responses were sent, few attended. The project was unable to identify a core of American Indians with disabilities to attend and participate. While there was attendance by several individuals with disabilities, the project had to rely on the Tribal Vocational Rehabilitation V1-21 directors for recommendations, and for stakeholders with disabilities feedback.

*Lessons learned:*

- Program literature needs to be geared to various levels of literacy, and focused on age-related needs, e.g. larger print, use of native language where appropriate, geared toward non-English speaking consumers, non use of acronyms, more culturally-specific graphic images, and use of graphics in the place of text.
- The message needs to be consistent.
- Be prepared to offer financial accommodations and other social supports to encourage attendance, such as transportation assistance or reimburse expenses to attend meetings.
- Be mindful of the schedules of the elders, when do they prefer to meet and how long can they meet.
- Gear the transmission of information toward more traditional methods of teaching older learners, e.g. use of easy to read language, more visual graphics versus text, use of observation, anecdotal information, etc.
- Support by policy makers, legislators and agencies are crucial to effect systems change.
- The support of the Governor and Tribal leadership is also crucial to effect change.
- Importance of creating opportunities to establish personal interactions and relationships between consumers and providers.
- Take into consideration community norms of experience and protocols when planning work in Native communities.
- Consumers and mid-level providers were missed in the planning. Counties came late to the dialogue and should have been engaged sooner.
- Notices for meetings and other communications needed to be more timely.
- The process facilitated greater personal interaction and cultural understanding.
- Cultural nuances became evident through interaction – such as the use of humor, ability of making light fun of each other, teasing each other, important protocol for relationship building. These may need to be identified or explained to capture their importance.
- Incorporating cultural values into meetings such as starting and ending with a prayer (usually requested of an elder) and serving of food are important social protocols.
- Small groups should choose their own spokespersons.

Final Report Real Choice Systems Change Grant Cultural Model continued

*Lessons Learned about Tribal Communities:* When proposing to work with Tribal Communities, it is important to:

- Recognize that each community is different and that one size does not fit all.
- Recognize that each community may be at a different stage of development with more or t less of the following resources: Human Resources, skills, intellectual property, experience and expertise and more programs and individuals within programs to support people with disabilities and the elderly; fiscal resources- i.e. funded programs from which to draw upon, i.e. Meals-On-Wheels, Elder protection teams, Community Health Representative Programs, for profit, and private-sector providers to build a continuum of care.
- Physical infrastructures, e.g. hospitals versus clinics, congregate elder facilities, assisted living centers and nursing homes within close proximity to the reservation. Some had less and some had none.
- Policy infrastructure developed, e.g. tribal regulatory laws, Elder abuse codes.

## Home and Community Based Services Planning Project Survey Results, June 2006

**By:** Elizabeth Cunningham, North Dakota Department of Human Services

**Targeted Population:** Elderly and people with disabilities

### Summary of Information

Periodically, the North Dakota Department of Human Services, Medical Services Division conducts a Home and Community Based Services Planning Project survey in order to plan for services that will assist older persons and persons with disabilities to remain at home. The survey consisted of twenty-four questions, each referring to a different type of task or service that the respondents felt would be important for them to remain in their own homes.

- The majority of respondents to the survey fell into the "Consumer" category, with 72%.
- Five respondents reported that they were both a Provider and Advocate, while six reported being both a Consumer and Advocate.
- Approximately half of all respondents (52.5%) were between 65 and 84 years old, the highest percentage of any age group.
- There were no respondents under the age of 18.
- The ten out of twenty-four questions that received the highest percentage of responses were Homemaker with 76.5%, Home Delivered Meals with 73.7%, Medical Transportation with 71.3%, Lifeline/Call System with 62.1%, Chore Services with 61.3%, Non-medical Transportation with 60.0%, Personal Care with 48.9%, General transportation with 48.1%, Medication Management and Administration with 41.7%, and Meal Preparation with 35.9%.
- The question that received the lowest percentage was Supported Employment with 12.2%.

**North Dakota Real Choice Systems Change Grant – Rebalancing Initiative: Focus Groups and Personal Interviews - Research Report One, June 2006**

**By:** Amy B. Armstrong, North Dakota Center for Persons with Disabilities

**Targeted Population:** Consumers of continuum of care services, family members of continuum of care services, and providers of continuum of care services

Summary of Information

This research was conducted to identify current perceptions, patterns, themes, and suggestions for improving the choice and self-direction, quality and access to long term care supports, (i.e. home and community based services and nursing home care) for the elderly and persons with disabilities, as well as to identify ways to develop a mechanism to balance state resources for services, and to identify elements for the design and structure of a single point of entry mechanism for all long term care supports for the elderly and people with disabilities in North Dakota. Based on the results of this research the following conclusions and recommendations have been identified:

1. The current 2005-2007 biennium funding for long term care services (i.e. continuum of care services) includes $343,013,040 appropriated to nursing homes and $37,697,922 appropriated to home and community based services. Since 1999, funding for nursing home services has increased by approximately $90,600,000 while funding for HCBS has only increased by approximately $16,700,000. This funding does not reflect the needs and preferences identified by the focus group participants for additional home and community based service options and the importance of the opportunity for consumers to remain in their own homes. It is important to note that data from all five groups (including providers) supports the desire of people to remain in their homes. There must be a concerted effort to implement change that will help to balance the funding for providing continuum of care services. Without such change, a certain crisis in providing care for North Dakota's growing population of aging citizens may occur.
2. In order to implement systems change in North Dakota, Medicaid and state funded services, the people using those services, and also those who are privately paying for continuum of care services need to be considered. This is necessary to build a proactive and fiscally responsible system that wisely spends and appropriately uses its funds for the services that North Dakotans prefer, and those services that are most effective at helping people maintain independence and self reliance.
3. There needs to be support and funding for pilot projects for a single point of entry (SPE) concept, which can serve as an effective tool and step to improving choice and access to continuum of care services. The SPE projects should focus specifically upon the need for a consistent "go to" person, financial and functional assessment, case management type services, access to comprehensive timely information about services, access to increased HCBS options including access in rural communities, and availability to various income populations.
4. The shortage of workers available to provide continuum of care services and particularly home and community based services should be addressed. A system that will support and equitably reimburse providers of home and community based services, both individuals and agencies should be funded.
5. The need for unbiased functional and financial assessment and case management services should be addressed in order to ensure consumers have access to choices and services that are most appropriate to their needs. Exploration of how other states have used the idea of different levels of case management, such as options counselors and care coordinators, and streamlined assessment processes should occur.
6. Federal and state initiatives that allow flexible use of funds to pay for the services that consumers choose, such as Money Follows the Person, Cash and Counseling, home and community based services in the Medicaid State Plan, and items of the Deficit Reduction Act should be explored and implemented when appropriate.

**North Dakota Real Choice Systems Change Grant – Rebalancing Initiative: Hospital Discharge Planner Questionnaire - Research Report Two, September 2006**

**By:** Amy B. Armstrong and Kylene Kraft, North Dakota Center for Persons with Disabilities

**Targeted Population:** ND hospital discharge planners/social workers (HDP)

Summary of Information

RCR Grant gathered input from HDPs regarding their awareness of and recommendations for improving choice and access to all types of continuum of care services. Based on the results of this research the following conclusions and recommendations have been identified:

1. HDPs, physicians, hospitals and clinics should be targeted with training and on-going education and updates regarding locally available options for continuum of care services for the elderly and people with disabilities.
2. Resources should be provided to HDPs to help them save time, stream line the discharge planning process, and effectively provide an array of appropriate options for patients and their families.
3. Develop a SPE that may be accessed by HDPs, physicians, families and patients and to be used as a tool to provide a full array of continuum of care options for patients. The SPE should have available a streamlined assessment process, eligibility assistance, case management, benefit and financial information, and service availability information. This system should provide up-to-date information about long term care support services and be a user friendly place that can be accessed daily.
4. The SPE should be strategically targeted and marketed to HDPs, physicians and hospital and clinic staff. The SPE should be marketed as a resource tool to assist HDPs, physicians, families, and consumers to help individuals stay as independent as possible.
5. Availability, resources, support, and marketing for a variety of continuum of care services should be expanded emphasizing HCBS. Resources, support, and marketing should focus on HCBS with particular attention to those indicated by HDPs as lacking such as: Adult Day Care, Adult Family Foster Care, Family Home Care, Senior Companion Program, Personal Care Services, and others. Expansion of HCBS services and marketing of them will work to increase usage and decrease reliance on institutional forms of care.
6. Pressure felt by HDPs to fill nursing home beds should be eliminated, especially in rural/frontier communities. A continuum of care system should be in place to ensure that HDPs are able to focus discharge planning on the consumer and his/her needs.

**Resident and Family Satisfaction Survey Summary**
**Prepared for the ND Long Term Care Association, December 2006**

**By:** InnerView Management Intelligence for Healthcare

**Targeted Population:** Resident, families and caregivers of nursing facility residents.

Summary of Information

The purpose of the surveys is twofold: (1) to assess the level of satisfaction among residents and their family/caregivers; and (2) to collect information about family/caregiver decisions related to the placement of current residents in nursing homes or in alternative community settings.

**Conclusions**

1. Long-term care services should be provided in the least restrictive environment within the constraints imposed by current public payment systems.
2. It is widely acknowledged that 80% of long-term care services in the United States is provided informally by unpaid caregivers.
3. A major challenge to discharging current nursing home residents will be finding family/caregivers or others who are willing and able to take on additional caregiving responsibilities. This challenge is especially acute after nursing home placement has occurred because family/caregivers have already made an adjustment to their new role as a caregiver for a relative in the nursing home.
4. A potentially greater challenge exists for nursing home residents who have lived in a facility for more than a few months.
5. Except for those residents who are discharged after a successful rehabilitative short stay, few long-stayers are likely to have the social, psychological or economic resources necessary to make an easy transition back into the community setting.
6. As residents grow older and more frail, the stress of relocation becomes a significant concern. Research shows that relocating older persons increases their risk of morbidity and mortality.
7. The risk of death or injury increases when an individual has less control over the decision to relocate or the relocation is involuntary.

**Recommendations**

1. The decision to relocate a current nursing home resident to an "alternative" setting should be based on voluntary and fully informed consent from the resident. This decision should be made in full consultation with the resident's family/caregivers or other responsible party.

| | **North Dakota Real Choice Systems Change Grant – Rebalancing Initiative: Consumers of Continuum of Care Services Questionnaire Report - Research Report Three, December 2006**<br>**By:** Amy B. Armstrong and Kylene Kraft, North Dakota Center for Persons with Disabilities<br>**Targeted Population:** ND consumers of continuum of care services |
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| Summary of Information | The intent of the questionnaire was to gain information from consumers regarding what continuum of care services they are using, what services are needed, barriers encountered, how they are paying for services and choice of services given. Data was also gathered regarding how consumers learn about available continuum of care services and suggestions to guide the development of a **single point of entry (SPE)** system, also called an **Aging and Disability Resource Center (ADRC)**. Based on the results of this research the following conclusions and recommendations have been identified:<br>1. Due to lack of consistent knowledge and awareness of continuum of care services, particularly HCBS options; a public information and education campaign should occur targeting consumers and family members. This public information effort should also incorporate education about planning ahead for future care needs. All areas of the state are in need of this type of outreach; however, particular efforts should be made in rural and frontier communities.<br>2. Potential barriers to accessing continuum of care services; such as lack of funding, transportation, knowledge of and access to needed services, should be addressed and efforts should be made to remove or minimize those barriers. This report may be used to assist the RCR steering committee, policy makers, legislators, and various provider groups in further identifying potential barriers and making efforts to remove these barriers.<br>3. Efforts should be made to build on and support community resources, volunteers, and informal caregivers to expand HCBS availability in ND especially in smaller communities where formal resources might be limited.<br>4. Educate and provide support to adults with disabilities, seniors, and their families about ways to pay for continuum of care services, focus on education about long-term care insurance and wise use of private funds to help ease the burden on Medicaid and other state funds.<br>5. Regardless of the source of funds for continuum of care services (e.g. private pay, private insurance, Medicaid, Medicare, and other state funds), it is important to look at all of these areas collectively in order to implement systems change in ND. This is necessary to build a proactive and fiscally responsible long-term support system that wisely spends and appropriately uses funds fro the services that North Dakotans prefer and those services that are most effective at helping people maintain independence and self-reliance.<br>6. Support for the implementation and funding of a SPE also called an Aging and Disability Resource Center (ADRC), should occur in order to develop a streamlined, user friendly system for seniors, adults with disabilities, and their families to access continuum of care services. This system should provide a consistent person to provide the face-to-face contact that many consumers prefer, print materials, and information in other forms such as internet access to be accessible to many populations. The SPE/ADRC should be accessible to all income populations and provide access to comprehensive, timely information about services, financial and functional assessments, and case management type services. |

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