

# CHCS

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## Resource Paper

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### **Designing a Program Evaluation for a Multi-Organizational Intervention: The Minnesota Disability Health Options Project**

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## **Online Resources**

Visit [www.chcs.org](http://www.chcs.org) for the following resources related to this paper:

- **Minnesota Disability Health Options Project Evaluation Plan** – This document provides the full evaluation plan for the Minnesota Disability Health Options Project.
- **AXIS Evaluation Follow-Up Survey** – This longitudinal survey instrument was used to evaluate enrollee satisfaction with AXIS compared with the fee-for-service system.
- **“How Are We Doing” Survey** – This 16-question quality improvement tool is given to all AXIS enrollees every six months to identify problems and respond quickly.
- **Resource Paper: Minnesota Disability Health Options: Expanding Coverage for Adults with Physical Disabilities** – This paper details the history behind the MnDHO program, how the program was developed and implemented, and initial evaluation results.

## Background

About 85 percent of the estimated 25 million people with disabilities under age 65 in the United States have health insurance. Two-thirds (65 percent) of these people are covered by private sector health plans.<sup>1</sup> Another 25 percent of persons with disabilities under age 65 are Medicare and/or Medicaid beneficiaries, constituting 7 million and 1.3 million people, respectively.<sup>2,3</sup> Most people with severe disabilities, complex medical and social needs, or multiple impairments fall into this category.

Most public and private sector health insurance is designed to meet acute health care needs. The focus on acute care creates benefit and service gaps for people with chronic or complex needs. In an effort to close that gap, many innovative programs have sprung up around the country since the mid-1980s. These programs are tailored to meet the needs of vulnerable populations such as the very poor,<sup>4,5</sup> the very old,<sup>6,7,8,9</sup> or people with chronic needs such as people with physical<sup>10,11,12</sup> or developmental<sup>13,14</sup> disabilities. The subject of our paper is the population of working age adults with physical disabilities.

Several organizations believe that comprehensive, organized, prepaid systems of care have the greatest potential to improve the health and life of people with disabilities.<sup>15,16</sup>

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<sup>1</sup> Meyer J.A. and Zeller P.J. "Profiles of the Disabled: Employment and Health Coverage." *Kaiser Commission on the Medicaid and Uninsured*, September 1999.

<sup>2</sup> Regenstien M. and Schroer C. "Medicaid Managed Care for Persons with Disabilities: State Profiles." The Henry J. Kaiser Family Foundation, 1999.

<sup>3</sup> National Academy for State Health Policy. *Directory of Risk-Based Programs Enrolling Elderly Persons or Persons with Disabilities*, 1999.

<sup>4</sup> Turner R. "Birth Weight Increased, Costs Cut with Medicaid Care-Coordination Plan." *Family Planning Perspectives*, 1992; 24(3):139-40.

<sup>5</sup> Master R.J. and Taniguchi C. "Medicare, Medicaid, and People with Disability." *Health Care Financing Review*, 1996; 18(2):91-7.

<sup>6</sup> Bailey M.L. Care Coordination in Managed Care. "Creating a Quality Continuum for High Risk Elderly Patients." *Nursing Case Management*, 1998; 3(4):172-80.

<sup>7</sup> Fischer L.R., Leutz W., Miller A., Von Sternberg T.L., and Ripley J.M. "The Closing of a Social HMO: A Case Study." *Journal of Aging & Social Policy*, 1998; 10(1):57-75.

<sup>8</sup> Hornung C.A., Brewer B.M., Stein M.D., Eleazer G.P., Brown T.E., and Byrd M.D. "The South Carolina Geriatric Rural Initiative Project: The Paraprofessional Geriatric Technician in Care Coordination." *Journal of the South Carolina Medical Association*, 1997; 93(7):248-54.

<sup>9</sup> Hammer B.J. "Improved Coordination of Care for Elderly Patients." *Geriatric Nursing*, 1996; 17(6):286-90.

<sup>10</sup> Ziring P.R., Brazdziunas D., Cooley W.C., Kastner T.A., Kummer M.E., Gonzalez de Pijem L., Quint RD, Ruppert E.S., Sandler A.D., Anderson W.C., Arango P., Burgan P., Garner C., McPherson M., Michaud L., Yeargin-Allsopp M, Johnson C.P., Wheeler L.S., Nackashi J., and Perrin J.M. "Care Coordination: Integrating Health and Related Systems of Care for Children with Special Health Care Needs." *Pediatrics*, 1999; 104(4 Pt 1):978-81.

<sup>11</sup> Appleton P.L., Boll V., Everett J.M., Kelly A.M., Meredith K.H., and Payne T.G. "Beyond Child Development Centres: Care Coordination for Children with Disabilities." *Child: Care, Health & Development*, 1997; 23(1):29-40.

<sup>12</sup> Berdes C. "Driving the System: Long-Term Care Coordination in Manitoba, Canada." *Journal of Case Management*, 1996; 5(4):168-72.

<sup>13</sup> Kastner T.A., Walsh K.K., and Criscione T. "Overview and Implications of Medicaid Managed Care for People with Developmental Disabilities." *Mental Retardation*, 1997; 35(4):257-69.

<sup>14</sup> Walsh K.K., Kastner T., and Criscione T. "Characteristics of Hospitalizations for People with Developmental Disabilities: Utilization, Costs, and Impact of Care Coordination." *American Journal of Mental Retardation*, 1997; 101(5):505-20.

<sup>15</sup> Sutton J. and DeJong G. "Managed Care and People with Disabilities: Framing the Issues." *Archives of Physical Medicine and Rehabilitation*, 1998; 79:1322-6.

<sup>17</sup> Typically, the systems are organized to coordinate both health care and social services.<sup>18,19,20,21</sup> The former Social Health Maintenance Organizations (SHMO) and the current Program of All-inclusive Care for the Elderly (PACE), which contract with the Centers for Medicare and Medicaid Services (CMS) to coordinate Medicare benefits, are perhaps the best known models.<sup>22,23,24</sup>

While most states enroll Medicaid beneficiaries with disabilities in managed care programs, three states have demonstrations that are similar to SHMO and PACE. These unique programs enroll beneficiaries of working age with disabilities. The first is the Community Medical Alliance located in Boston, which serves adult Medicaid beneficiaries with spinal cord injury or HIV/AIDS.<sup>25,26,27,28</sup> The second is the Wisconsin Partnership Program (WPP), a dual-eligible program that integrates community-based long-term care and acute care services for frail elders and adults with disabilities.<sup>29</sup> Two of the WPP sites are operational for people with disabilities: the Community Living Alliance in Madison, Wisconsin, and the Community Health Partnership, Inc. in Eau Claire. The third system is the AXIS Healthcare program, located in the Twin Cities of Minneapolis and St. Paul, Minnesota. This program serves adults with physical disabilities who are Medicaid beneficiaries, and incorporates Medicare benefits for dual beneficiaries.

All three programs offer voluntary enrollment and a strong voice for consumers. Because these programs are so new, people with disabilities and policy makers are very interested

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<sup>16</sup> Master R., Dreyfus T., Connors S., Tobias C., Zhou Z., and Kronick R. "The Community Medical Alliance: An Integrated System of Care in Greater Boston for People with Severe Disability and AIDS." *Managed Care Quarterly*, 1996; 4:26-37.

<sup>17</sup> Sandy L. and Gibson R. "Managed Care and Chronic Care: Challenges and Opportunities." *Managed Care Quarterly*, 1996; 4:5-11.

<sup>18</sup> Schillinger D., Bibbins-Domingo K., Vranizan K., Bacchetti P., Luce J.M., and Bindman A.B. "Effects of Primary Care Coordination on Public Hospital Patients." *Journal of General Internal Medicine*, 2000; 15(5):329-36.

<sup>19</sup> Campbell A. "Improvement of Patient Care through a Collaborative Approach to Patient Education and Triage." *Advances in Renal Replacement Therapy*, 1999; 6(4):347-50.

<sup>20</sup> Bennett P.J., Fosbinder D., and Williams M. "Care Coordination in an Academic Medical Center." *Nursing Case Management*, 1997; 2(2):75-82.

<sup>21</sup> Abrahams R., Macko P., and Grais M.J. "Across the Great Divide: Integrating Acute, Post-Acute and Long-Term Care." *Journal of Case Management*, 1992; 1(4):124-34.

<sup>22</sup> Boulton C. and Pacala J.T. "Integrating Healthcare for Older Populations." *American Journal of Managed Care*, January 1999; 5(1):45-52.

<sup>23</sup> Fischer L.R., Leutz W., Miller A., Von Sternberg T.L., and Ripley J.M. "The Closing of a Social HMO: A Case Study." *Journal of Aging and Social Policy*, 1998; 10(1):57-75.

<sup>24</sup> Schraeder C. and Britt T. "Case Management Issues in Rural Long-Term Care Models." *Journal of Applied Gerontology*, December 2001; 20(4):458-70.

<sup>25</sup> Master R., Dreyfus T., Connors S., Tobias C., Zhou Z., and Kronick R. "The Community Medical Alliance: An Integrated System of Care in Greater Boston for People with Severe Disability and AIDS." *Managed Care Quarterly*, 1996; 4:26-37.

<sup>26</sup> Master R.J. "Massachusetts Medicaid and the Community Medical Alliance: A New Approach to Contracting and Care Delivery for Medicaid-eligible Populations with AIDS and Severe Physical Disability." *American Journal of Managed Care*, June 25, 1998; 4 Suppl:SP90-8.

<sup>27</sup> Meyers A.R., Glover M., and Master R.J. "Primary Care for Persons with Disabilities. The Boston, Massachusetts Model Program." *American Journal of Physical Medicine & Rehabilitation*, May-Jun 1997; 76(3 Suppl):S37-42.

<sup>28</sup> Glover M., Master R.J., and Meyers A.R. "Boston's Community Medical Group and the Community Medical Alliance Health Plan." *American Rehabilitation*, 1996; 22(3):2-9, (21 bib).

<sup>29</sup> [www.dhfs.state.wi.us/WIpartnership/](http://www.dhfs.state.wi.us/WIpartnership/)

in how well the programs perform. A successful evaluation design will help potential plan sponsors, clinicians, and enrollees determine if these programs “work,” how they work, whether hiring care coordinators saves money in the short and long run, and if clinical outcomes and quality of life are improved.

Program evaluations can cost a great deal of money, particularly if the evaluation is an after-thought. Oftentimes, it turns out that key pieces of data are missing, baseline information was not collected, or people implementing the program have moved on and are not available for a process audit. At the worst, the retrospectively designed evaluation can result in misleading findings and erroneous decision-making.

Minnesota’s Department of Human Services (DHS), the state Medicaid agency, wanted to avoid these mistakes by designing a comprehensive program evaluation from the very start of its Minnesota Disability Health Options (MnDHO) project. This paper describes the process and presents the evaluation tools developed. We hope this will serve as a blueprint for other researchers and state regulatory agencies to prospectively construct their own evaluations at the time of program startup.

## **AXIS Healthcare**

AXIS Healthcare was founded in 1997 as a joint venture of the Sister Kenny Institute (SKI) (a free-standing rehabilitation hospital) and the Courage Center (a community-based rehabilitation center), both located in the Twin Cities. At a time when growing numbers of state Medicaid programs around the country were starting to require people with disabilities to participate in mandatory Medicaid managed care,<sup>30</sup> these two large providers came together to develop a comprehensive, integrated managed care program designed specifically by and for persons with disabilities. AXIS held several focus groups to identify the features of an ideal coordinated health care program for adults of working age. After developing a business plan, the Board of Directors at Sister Kenny Institute and the Courage Center established the AXIS joint venture and hired a Chief Executive Officer.

AXIS approached different health plans about their interest in partnering to provide a capitated program for enrollees with physical disabilities. One of these plans was UCare Minnesota, which is a PMAP and Minnesota Senior Health Options (MSHO) contractor, as well as a Medicare+Choice contractor. UCare also had been involved in the DPPD program and followed it closely. In 1997, AXIS and UCare approached DHS about a demonstration program to provide managed care for adult Medicaid beneficiaries with physical disabilities, modeled after MSHO.

Coincidentally, DHS had already begun an independent effort to develop a fully capitated program for people with disabilities. It began discussions with CMS in 1998 about adding people with disabilities to the MSHO program, which was operating under

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<sup>30</sup> Palsbo S.E. and Post R. “Implementing Risk Assessment and Risk Adjustment for People with Disabilities in State Programs: Six Case Studies.” *Managed Care Quarterly*, 2002.

a §1115 waiver. It took nearly two years to amend the Medicaid waivers from §1115 to §1915(a) and (c). In the meantime, the original Medicare waivers were about to expire and DHS had to extend them. DHS had to design the reimbursement rates, submit a revised waiver document (October 2000) and get new CMS approvals. CMS approved the Medicaid waiver in March 2001 and Medicare in October 2001. Enrollment began on September 1, 2001 with the Medicaid capitation, with the Medicare capitation effective November 1, 2001.

As noted above, DHS obtained approval in 2001 to establish the Minnesota Disability Health Options project, a §1915(a) state option, §1915(c) waiver amendments, and permission to add people with disabilities enrolled in MnDHO under the state's existing §402 Medicare payment demonstration waiver for MSHO. The MnDHO base capitation rate is constructed from Minnesota's average Medicaid expenditures for beneficiaries with disabilities. If the particular AXIS enrollee also is a Medicare beneficiary, the HMO gets a Medicare + Choice capitation payment from CMS based on demographic factors. For the community home nursing certifiable population the Medicare + Choice payment is adjusted by the PACE cost factor. Medicaid payments range from \$437 to \$19,611 per member per month, depending on the individual's risk classification.

The next step was to identify a partnering HMO. UCare Minnesota, an HMO with a long history of commitment to providing services to Medicare and Medicaid beneficiaries, agreed to be the health plan partner. UCare's experience included the development and five years operation of the MSHO project for the elderly. AXIS obtained a planning grant from the Center for Health Care Strategies and established a pilot program. The pilot provided an opportunity to develop and refine the specialty managed care model.

On September 1, 2002 AXIS Healthcare formally enrolled its first 16 clients. All clients were Medicaid beneficiaries, and most with Medicare. All voluntarily enrolled in "UCare Complete," the coordinated care product for adults with physical disabilities. UCare Minnesota delegates care coordination, utilization management, and portions of provider relations and member services to AXIS. UCare Minnesota and AXIS share financial risk for the capitation.

DHS, UCare Minnesota, and AXIS function as the MnDHO collaborative. The collaborative has a very concrete vision of the MnDHO service delivery, embodying six principles:

- a. **Holistic Focus.** The managed care system constantly and consistently focuses on the person being served within the context of his/her living situation, support system, and health status.
- b. **Enrollee Self-Direction.** The managed care system strives to include a maximum level of enrollee choice and self-direction.
- c. **Integrated Service Coordination.** The health plan care coordinator works with the enrollee as a partner in developing a comprehensive care plan and in

- planning service needs. The care coordinator facilitates provision of these services for the enrollee.
- d. **Disability Competence.** The managed care system includes providers with disability expertise and experience and the provider network as a whole is capable of facilitating the service access needs particular to people with physical disabilities.
  - e. **Accessibility.** Each provider and the provider network as a whole strives to continuously improve the access needs of people with physical disabilities in the following areas: (a) the number of appropriately trained staff to meet the enrollee's needs during the service session; (b) the physical plant of the service site; and (c) the availability and use of equipment and durable medical equipment needed by the enrollee to gain access to the service site.
  - f. **Independent Living.** The managed care system supports individuals who desire to live independently in the community with necessary clinical and social supports.

## Formation of the Evaluation Consortium

A key feature of AXIS is its strong mission commitment to consumer participation and responsibility for their own health.<sup>31</sup> Coincidentally, the Institute for Community Integration (ICI) at the University of Minnesota wanted to extend their work on the self-determination of persons with disabilities with an emphasis on person-centered planning as a means through which this outcome might be facilitated. The ICI submitted a joint proposal with AXIS and the Courage Center to the National Institutes for Disability and Rehabilitation Research (NIDRR). NIDRR awarded funds for a three-year study to evaluate the extent to which participation in the AXIS program facilitates self-determination in the health care arena and has a positive impact on the participants' quality of life.

Meanwhile, the National Rehabilitation Hospital Center for Health & Disability Research (NRH-CHDR) in Washington DC was concluding a five-year NIDRR grant investigating the impact of managed care on adults with physical disabilities.<sup>32,33,34</sup> NRH-CHDR developed a survey instrument to measure consumers' ratings of the quality of managed care programs.<sup>35</sup> NRH-CHDR was very interested in piloting the tool in order to measure its psychometric properties.

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<sup>31</sup> Stanton M.W. "Expanding Patient Centered Care to Empower Patients and Assist Providers." Research in Action No. 5, Agency for Health Care Research and Quality. AHRQ Publication No. 02-0024. May 2002. [www.ahrq.gov/qual/ptcareria.htm](http://www.ahrq.gov/qual/ptcareria.htm).

<sup>32</sup> Scheer J., Kroll T., Neri M.T., and Beatty P. "Access Barriers for Persons with Disabilities: The Consumers' Perspective." *Journal of Disability Policy Studies*, 2002.

<sup>33</sup> Neri M.T. and Kroll T. "Understanding the Consequences of Access Barriers to Health Care: Experiences of Adults with Disabilities." *Disability and Rehabilitation*, 2002; 25(2):85-96.

<sup>34</sup> DeJong G., Palsbo S.E., Beatty P.W., Jones G.C., Kroll T., and Neri M. "The Organization and Financing of Health Services for Persons with Disabilities." *Milbank Quarterly*, 2002; 80(2):261-301.

<sup>35</sup> O'Day B., Palsbo S.E., Dhont K., and Sheer J. "Health Plan Selection Criteria by People with Impaired Mobility." *Medical Care*, 2002; 40:732-742.

Additionally, CHCS awarded AXIS a three-year model demonstration grant. Besides funding the implementation of the new project, funds were allocated to support a comprehensive evaluation of MnDHO. Thus, there were three multi-year research projects assessing the impacts of the AXIS model and the MnDHO project as a whole.

Other stakeholders were keenly interested in assessing the program. Table 1 shows the groups, their objectives, and funding sources.

**Table 1. MnDHO Stakeholder Groups**

Organization	Objective	Funding
Consumers with physical disabilities on Medicaid	Improved health care services and community integration.	None.
AXIS Healthcare	Real-time business and clinical process redesign.	Financial startup funds from SKI and Courage Center; revenue from operations.
Minnesota Department of Human Services	Fulfill statutory obligations to Medicaid beneficiaries to provide cost-effective care.	Robert Wood Johnson Foundation/Center for Health Care Strategies (with funds remaining from a previous grant).
NRH-Center for Health & Disability Research	Real-world application of managed care assessment tool.	NIDRR RRTC on Managed Care and Disability.
UCare Minnesota	Real-time business and clinical process redesign.	Revenue from operations.
University of Minnesota	Evaluation of the impact of coordinated health care on a variety of psychological outcomes for adults with physical disabilities. Teaching people with physical disabilities to be proactive in taking charge of their own healthcare; then comparing outcomes with a control group.	NIDRR field initiated research project.
CMS	Quality of care for dual beneficiaries.	None.

All parties focused their sights on AXIS. The CEO quickly realized that the AXIS enrollees could be bombarded with surveys and questionnaires. UCare Minnesota was concerned about the cost and time of submitting extensive extra data for evaluation purposes, and Minnesota was facing the prospect of state budget cutbacks. The AXIS CEO provided a venue for a common meeting ground of the stakeholders. NRH-CHDR suggested that the research investigators work together under the auspices of an Evaluation Consortium. Everyone agreed with this proposal, and NRH-CHDR functions as the facilitator of the Evaluation Consortium.



## Consortium Strengths

The Consortium met in person several times over a period of six months. The face-to-face meetings allowed members to get to know each other and to build trust and mutual respect. The group operates as a partnership; for example, there is no official chairperson. Occasionally, we appoint a small task force to work out operational issues and options, which are reported back to the full Consortium for action. One early task force worked out the overall Evaluation Grid<sup>36</sup>, and another worked out the details of sharing data while protecting the privacy of the enrollees. As facilitator, NRH-CHDR convenes monthly conference calls, proposes the agenda, and prepares minutes.

While the initial purpose of the Consortium was to coordinate all data collection efforts, over time the Consortium has evolved to an integrated, collegial, and interdisciplinary group of researchers and practitioners. We still discuss logistical issues, but there is more brainstorming on creative problem solving and ad hoc, instantaneous peer review. This paper is the first of several papers that will likely be coauthored by the entire Consortium.

In addition, the monthly telephone meetings have been extremely helpful for the independent evaluators. The meetings keep us abreast of enrollment progress, provide an opportunity to record the “burning issues” of the moment that would otherwise be forgotten or lost when doing a retrospective process audit, and imbue the researchers with a solid grounding in what MnDHO is all about. The meeting minutes will provide important documentation of the evolution of the MnDHO project and evaluation process in years to come.

## Evaluation Design

There are no articles in the peer-reviewed literature that address disability-specific quality measures. The Center for Policy Research recently completed two small federal contracts that considered how to assess the performance of managed care organizations for people with disabilities.<sup>37,38</sup> These two studies inventoried all measurement domains and indicators that might be suitable for people with disabilities. They also suggest a framework for selecting specific measures. Among their recommendations is that some measure of “care coordination” be included.

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<sup>36</sup> Visit [www.chcs.org](http://www.chcs.org) for Appendix 1: Minnesota Department of Human Services, Minnesota Disability Health Options Project, Evaluation Plan.

<sup>37</sup> Sofaer S., Woolley S.F., Kenney K.A., Kreling B., and Mauery D.R. “Meeting the Challenge of Serving People with Disabilities: A Resource Guide for Assessing the Performance of Managed Care Organizations.” Office of the Assistant Secretary for Planning and Evaluation, US Department of Education, July 1998; 70 pp.

<sup>38</sup> Kreling B. and Sofaer S. “Defining and Measuring Care Coordination for People with Disabilities in Medicaid Managed Care: Report on a Measurement Set.” Submitted to the Office of the Assistant Secretary for Planning and Evaluation, US Department of Health and Human Services and Center for Health Care Strategies, June 15, 2001.

However, evaluation objectives are not only to measure quality, but to ensure that the MnDHO project stays on track to accomplish its goals. The stakeholders articulated these goals at a series of community forums hosted by the Courage Center and facilitated by DHS, AXIS, and NRH-CHDR. The consumers reached a consensus on project goal #2: “To promote the overall well being of enrollees” through the nine aims shown in Table 2.

The list of goals is the foundation of the evaluation framework. The next section describes how we tied measures to each goal to ensure that everything that needed to be tracked will be monitored, and to ensure that we could do a comprehensive retrospective analysis at the end of the three-year demonstration period.

**Table 2. MnDHO Project Goals**

<ol style="list-style-type: none"> <li>1. To create and maintain <b>satisfaction</b> with MnDHO for: <ol style="list-style-type: none"> <li>a. Consumers</li> <li>b. Health Plans</li> <li>c. Providers</li> <li>d. State and CMS</li> </ol> </li> <li>2. To promote the overall <b>well being</b> of enrollees through the following: <ol style="list-style-type: none"> <li>a. Services which promote optimal health outcomes.</li> <li>b. Prevention of health complications secondary to a person’s disability.</li> <li>c. Increase in the delivery of preventative services, such as screenings and immunizations.</li> <li>d. Improvement or maintenance of functioning, appropriate to an enrollee’s health status and disability.</li> <li>e. Testing the effectiveness of various clinical interventions.</li> <li>f. Continuous monitoring and improvement in meeting the access needs of enrollees.</li> <li>g. Increase in enrollee capacity for independent living.</li> <li>h. Foster and maintain optimal enrollee involvement in care delivery.</li> <li>i. Inclusion of the enrollee’s social and emotional needs in the service delivery process.</li> </ol> </li> <li>3. To meet the following <b>cost and utilization</b> goals: <ol style="list-style-type: none"> <li>a. To ascertain changes in utilization and cost patterns through this model.</li> <li>b. To provide quality health care and support services for no more than the funding levels which would be available in the fee-for-service system.</li> <li>c. To determine the effectiveness of the DPS risk adjustment system for this model.</li> </ol> </li> </ol>
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We divided the evaluation plan into four domains: consumer satisfaction (goal 1a), provider/health plan satisfaction (goals 1b and 1c), quality of care (goal 2), Utilization and patterns of care (goal 3a), and costs and rate setting (goals 3b and 3c). As we started to identify and assess candidate measures, we also articulated specific hypotheses. We then determined what data we will need to test the hypotheses, how the data will be collected (e.g., survey or plan operational data), which consortium member will collect it, timing of data collection, and who is responsible for the cost.

The Consortium applied the following four criteria to each candidate measure.

1. **Use existing data to minimize costs.** HMOs already assemble and report a large amount of data to external agencies. This includes financial data for state insurance reporting; HEDIS® utilization, quality, and financial measures for businesses; and state Medicaid and federal Medicare reporting. In addition, HMOs assemble a large amount of medical claims information for internal monitoring and actuarial analysis. *The Evaluation Consortium decided to stretch its limited funding and to minimize the reporting burden on the HMO by selecting a subset of already reported measures, rather than creating new ones.*
2. **Avoid asking respondents to provide duplicate information.** We did not want to constantly ask study participants to provide demographic or medical information that was already collected by one of the Consortium partners. *The Evaluation Consortium signed data sharing agreements. UCare Minnesota agreed to submit a full set of encounter data claims to DHS.*
3. **Avoid asking respondents to recall events when solid documentation is available.** For example, we did not want someone to estimate how many physician encounters they had in the prior year, when actual information was available in the electronic medical logbook maintained by AXIS Care Coordinators. *The Evaluation Consortium minimizes recall questions, except when we want to compare perceptions against actual events.*
4. **Minimize respondent burden.** We were very concerned that competing surveys could lead to cross-contamination, respondent burn-out, and loss to follow-up. *The Evaluation Consortium agreed to a specific schedule of surveys, so study participants are being interviewed only one month of the year.*

Appendix 1 contains the entire Evaluation Plan. We describe the first domain, Consumer Satisfaction, in detail because it is a good illustration of the collaborative Evaluation Consortium process.

## **Consumer Satisfaction**

Our working hypothesis is that consumer satisfaction will be high, since consumers had substantial input into the development of the AXIS program. The Consortium agreed that we wanted to measure satisfaction using both quantitative and qualitative methods. Table 3 is a partial excerpt from Appendix 1.

**Table 3. Satisfaction Measures**

Outcome Measure	Methods/ Data Sources	Frequency Timing
1. Enrollee satisfaction with AXIS compared with the fee-for-service system. ( <i>Quantitative portion</i> )	Longitudinal survey	<ul style="list-style-type: none"> <li>Baseline</li> <li>12- and 24-months post enrollment (if enrolled in AXIS that long).</li> </ul>
2. Enrollee satisfaction with AXIS compared to their prior fee-for-service system. ( <i>Qualitative portion; supplements quantitative survey</i> )	<ul style="list-style-type: none"> <li>Baseline</li> <li>MDHS focus groups</li> </ul>	<i>Baseline already established by AXIS at March 1, 2001 Forum.</i>
3. Enrollee satisfaction with AXIS compared with the fee-for-service system. ( <i>Qualitative portion across delivery systems</i> )	3-6 individual, in-depth interviews/case studies of MnDHO and 3-6 comparable fee-for-service (ffs) clients (matched by condition) to compare ffs versus MnDHO during same time period.	Once, 1 year post enrollment.
4. Reasons for disenrollment	<ul style="list-style-type: none"> <li>MSHO disenrollment survey</li> <li>Mail and phone</li> </ul>	Ongoing collection, with annual reviews and summary narrative by DHS at end of demonstration.
5. Grievance, appeals, & UCare written complaints	Existing MSHO health plan reporting protocol.	Ongoing collection, with annual reviews by DHS and summary narrative by DHS at end of demonstration.
6. Informal AXIS survey- "How are we doing?" questionnaire.	Short operationally-oriented, cross-sectional questionnaire. (Simple 10 questions, Firewall with health coordinator)	<ul style="list-style-type: none"> <li>Every six months, post-enrollment</li> <li>Everyone for the first 16 months, then cross-sectional</li> <li>Summary analysis at end of demonstration.</li> </ul>

\*DHS collects case illustrations from care system or health plan.

The first thing to notice in Table 3 is that the Consortium is using a variety of methods to measure satisfaction: qualitative focus groups and in-depth case interviews; a longitudinal survey; the state disenrollment survey; and a periodic questionnaire. Our strategy is to collect data on how people's satisfaction varies with the length of time they are enrolled, as well as with modifications in the AXIS procedures. The qualitative

interviews and case studies will help us gain in-depth understanding and context of the longitudinal findings, and also will be part of our fee-for-service comparison.

The *content* of the longitudinal survey is based on the consumer stakeholder forum held in March 2001, and on studies of the CAHPS instrument. O'Day and colleagues at NRH-CHDR<sup>39</sup> evaluated the CAHPS instrument for adults of working age with multiple sclerosis, cerebral palsy, rheumatoid arthritis, or spinal cord injury. This study found that the CAHPS instrument cover most of the areas of interest to adults with mobility impairments who have a choice of health plans, but there are also several gaps.

One study of particular relevance to this project is cognitive testing of the CAHPS on a population of frail, low-income adults receiving home care in Connecticut.<sup>40</sup> Gruman and her colleagues found that the Medicare CAHPS is too long for most elders, and too complex for cognitively impaired elders. In addition, the Medicaid and Medicare CAHPS failed to address the breadth of services viewed as important to dually eligible beneficiaries, including experience in accessing support services.

Another line of research evaluated the application of CAHPS for special populations, including the impact of adjusting for age, health, education, and function.<sup>41</sup> CAHPS reports also are being used to explore differential access by race/ethnicity and primary language.<sup>42,43</sup>

NRH-CHDR combined all these research findings with the Consumer Forum input and developed the AXIS Longitudinal Survey Instrument.<sup>44</sup> It is similar to CAHPS and fills in the gaps by adding questions on transportation and personal care attendant services. The survey also asks questions about the added services provided by AXIS and the goals of the MnDHO program, including questions on care coordination, dental care, access to alternative care such as massage and acupuncture, and self-directed care. NRH-CHDR is using the first-year's responses to validate the survey instrument.

The Consortium gave a great deal of thought to the *timing* of the longitudinal surveys. Normally, we would use an annual, cross-sectional design. However, since this is a start-up program, we could not project how many people would be enrolled after one year of plan operation. Also, we were concerned that the length of time since enrollment would vary from as short as one month to as long as one year if we did a cross-sectional design.

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<sup>39</sup> O'Day, B. et al, op. cit.

<sup>40</sup> Gruman C., Curry L., and Porter M. Summary of the Pilot Test of a Consumer Survey Among Participants of the Connecticut Home Care for Elders Program. New England Dual Eligibility Coordination Center, March, 2000; 42 pp.

<sup>41</sup> Elliott M.N., Swartz R., Adams J., Spritzer K.L., and Hays R.D. Case-Mix Adjustment of the National CAHPS Benchmarking Data 1.0: A Violation of Model Assumptions?" *Health Services Research*, July 2001; 36(3):555-73.

<sup>42</sup> Weech-Maldonado R., Morales L.S., Spritzer K., Elliott M., and Hays R.D. "Racial and Ethnic Differences in Parents' Assessments of Pediatric Care in Medicaid Managed Care." *Health Services Research*, July 2001; 36(3):575-94.

<sup>43</sup> Morales L.S., Elliott M.N., Weech-Maldonado R., Spritzer K.L., and Hays R.D. "Differences in CAHPS Adult Survey Reports and Ratings by Race and Ethnicity: An Analysis of the National CAHPS Benchmarking Data 1.0. *Health Services Research*, July 2001; 36(3):595-617.

<sup>44</sup> Visit [www.chcs.org](http://www.chcs.org) for Appendix 2: Evaluation Follow-up Survey.

Therefore, we selected longitudinal administration upon the anniversary of each study participant's enrollment.

The AXIS CEO was concerned about the delayed feedback that he would obtain on AXIS operations if he relied on successful recruitment to the longitudinal survey study. He certainly did not want to learn about a problem 18 months after it first created a difficulty for someone. To address this issue, NRH-CHDR collaborated with the CEO in creating a "How are we Doing?" cross-sectional questionnaire.<sup>45</sup> This is a 16-question quality improvement tool that AXIS administers to all enrollees every six months. Results alert AXIS management to problems that need to be addressed immediately.

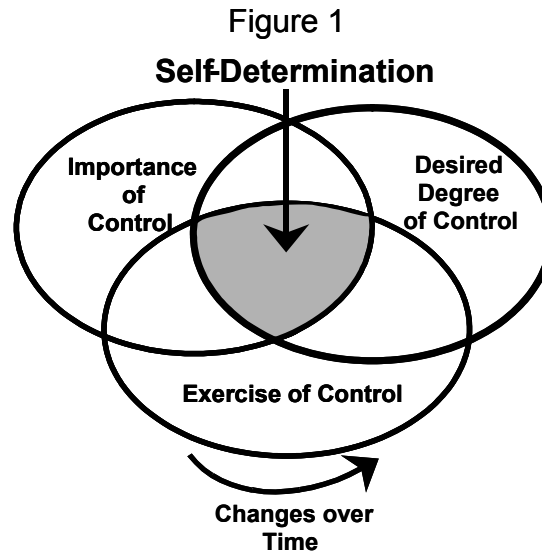
We do not ask health status on the longitudinal survey. Instead, we will tie responses directly to the clinical health status at the time of the survey. These clinical measures are part of an exhaustive medical and social history taken by the AXIS health coordinator upon enrollment and at least annually thereafter. The health history is maintained in an Access database and updated as needed. Variables in the database include the primary care physician, plans for therapy, orders for medications and supplies, age at onset of disability, functional and cognitive abilities, and other information that will allow us to risk adjust survey responses, costs, and utilization information. The clinical database also will help us conduct a retrospective analysis of how the money flowed to different types of services and equipment.

## **Self-determination and Person-Centered Health Care Planning**

The second principle of the MnDHO service delivery vision is "Enrollee self-direction: The managed care system strives to include a maximum level of enrollee choice and self-direction." Self-determination entails individuals exercising the degree of control they desire over those areas of life that are important to them. A tripartite model, as shown in Figure 1, takes into account the fact that self-determination simultaneously involves: (a) the degree to which individuals *exercise personal control* over various areas of their lives, (b) the level of control they *desire* to exercise in each area, and (c) the degree to which they regard these areas *important*. Self-determination can be viewed as the intersection of these three elements where there is a high level of concordance between the level of control exercised, and the amount of control desired, in areas of life that are important to the person.

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<sup>45</sup> Visit [www.chcs.org](http://www.chcs.org) for Appendix 3: "How Are We Doing" questionnaire.



Individuals with disabilities, like most persons, typically perceive their role in health care as passive recipients of services despite the fact that the Patient Self-Determination Act<sup>46</sup> went into effect almost a decade ago. Study results demonstrate that although most individuals have a high desire for information prior to health care related decision-making, they often are provided with only the most basic facts related to treatment decisions.<sup>47,48</sup> Just as important, it has been found that when health care related decision-making is differentiated from problem-solving, most consumers (48-83 percent) have a strong desire to be involved in either independent or collaborative decision-making with health care professionals.<sup>49,50,51</sup> Respect for consumer involvement is critical given that physicians have been found to be notoriously poor predictors of patients' preferences for treatment,<sup>52,53</sup> a tendency that does not improve with professional experience or duration of physician-patient relationship.<sup>54</sup> Additionally, studies indicate that consumer involvement in decision-making is related to satisfaction with health care,<sup>55</sup> associated

<sup>46</sup> Patient Self-Determination Act (IPSDA), 42 USC ~ 1395cc and 1396A supp, 1991).

<sup>47</sup> Deber R.B, Kraetschmer N., and Irvine J. "What Role do Patients Wish to Play in Treatment Decision Making?" *Archives of Internal Medicine*, 1996; 156:414-420.

<sup>48</sup> Nease R. and Brooks W.B. "Patient Desire for Information and Decision Making in Health Care Decisions: The Autonomy Preference Index and the Health Opinion Survey." *Journal of General Internal Medicine*, 1995; 10: 593-600.

<sup>49</sup> Deber, et al. "What Role Do Patients Wish to Play in Treatment Decision Making?" *Archives of Internal Medicine*, 1996; 156:414-420.

<sup>50</sup> Frosch D.L. and Kaplan R.M. "Shared Decision Making in Clinical Medicine: Past Research and Future Directions." *American Journal of Preventive Medicine*, 1999; 17(4):285-295.

<sup>51</sup> Mazur D.J. and Hickam D.H. "Patients' Preferences for Risk Disclosure and Role in Decision Making for Invasive Medical Procedures." *Journal of General Internal Medicine*, 1997; 12:114-117.

<sup>52</sup> Danis M., Gerrity M.S., Southerland L.I., and Patrick D.L. "A Comparison of Patient, Family, and Physician Assessments of the Value of Medical Intensive Care." *Critical Care Medicine*, 1988; 16:594-600.

<sup>53</sup> Ebell M.H., Doukas D.J., and Smith M.A. "The Do-Not-Resuscitate Order: A Comparison of Physician and Patient Preferences and Decision-Making." *American Journal of Medicine*, 1991; 91:255-260.

<sup>54</sup> Druely J.A., Ditto P.H., and Moore K.A. Physicians' Predictions of Elderly Outpatients' Preferences for Life-Sustaining Treatment." *Journal of Family Practice*, 1993; 37:469-475.

<sup>55</sup> Speeding E.J. and Rose D.N. "Building An Effective Doctor - Patient Relationship: From Patient Satisfaction to Patient Participation." *Social Science Medicine*, 1985; 21:115-120.

with compliance with treatment,<sup>56</sup> patients' beliefs that they can control their illness,<sup>57</sup> and health care outcomes.<sup>58,59</sup> In spite of these findings, however, most research suggests that patients view their role in the decision-making process as passive<sup>60</sup> and that physicians rarely engage in shared decision-making.<sup>61</sup>

As part of the AXIS program, health care professionals will receive training to enhance their collaboration skills. In addition, consumers will take part in a program designed to support them in becoming *care management partners*. The most extensive effort in this area, however, will involve the employment of person-centered health care planning to ensure that the health care plans of consumers are not only under their control but concordant with their vision for their life in the future.

Person-centered approaches to support planning have been developed to empower individuals with disabilities to take greater control over the supports they receive and enhance the quality of life they experience. These processes are based on the assumption that involvement of family and friends, individualization, flexibility, and collaboration are necessary for creating a desirable future. All such processes begin with the recruitment of family members, friends, and professionals who are significant in the individual's life. This group works together to share their knowledge, better understand the focus person, and envision a desirable future. Action plans, designed to make the individual's personal vision a reality, are then developed and implemented. Throughout the process, the circle continues to meet to ensure the plan developed is effectively implemented. This approach will make it possible to develop person-centered health care plans for all individuals and ensure that the supports developed are based on the individuals personal vision for the future.<sup>62,63,64</sup>

## Health Care Self-Determination

The outcomes span a wide range of issues including: (1) self-determination exercised by adults with physical disabilities on their health care services and supports, (2) stress faced as a result of having a physical disability, (3) impact of a physical disability on daily functioning, (4) degree to which one follows the recommendations of medical providers,

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<sup>56</sup> Hoogstraten J. and Albrecht G. "Satisfaction as a Determinant of Compliance." *Community Dent Oral Epidemiol*, 1998; 26:139-146.

<sup>57</sup> Van den Borne H.W. "The Patient from Receiver of Information to Informed Decision-Maker." *Patient Education and Counseling*, 1998; 34:89-102.

<sup>58</sup> Kaplan S.H., Greenfield S., and Gandek B. "Characteristics of Physicians with Participatory Decision-Making Styles." *Annals of Internal Medicine*, 1996; 124:497-504.

<sup>59</sup> Rost K.M., Flavin K.S., Cole K., and McGill J.B. "Change in Metabolic Control and Functional Status After Hospitalization: Impact of Patient Activation Intervention in Diabetic Patients." *Diabetes Care*, 1991; 14:881-889.

<sup>60</sup> Caress A.L. "Patient Roles in Decision-Making." *Nursing Times*, 1997; 93(31):45-48.

<sup>61</sup> Stevenson F.A., Barry C.A., Britten N., Barber N., and Bradley C.P. "Doctor-Patient Communication about Drugs: The Evidence for Shared Decision-Making." *Social Science Medicine*, 2000; 50:829-840.

<sup>62</sup> O'Brien C.L. and O'Brien J. "The Origins of Person-Centered Planning." In: Holburn S, Vietze PM, eds. *Person Centered Planning*. Paul H. Brooks Publishing, 2002: 3-27.

<sup>63</sup> Pearpoint J. and Forest M. "Person-centered Planning: MAPS and PATH." *Impact*, 1998; 11(2): 4-5.

<sup>64</sup> Sanderson H. "A Plan Is Not Enough." In: Holburn S, Vietze PM, eds. *Person Centered Planning*. Paul H. Brooks Publishing, 2002: 97-126.



(5) coping responses employed when faced with stressful circumstances, and (6) life satisfaction experienced.

Using an interview format, the health care self-determination of AXIS enrollees is being assessed as they enter the program and at one-year intervals thereafter for a three-year period using three scales specifically developed for this purpose: The Health Care Exercise of Control Scale (HECS),<sup>65</sup> The Health Care Decision-Making Preference Scale (HDMPS),<sup>66</sup> and The Health Care Importance Scale (HIS).<sup>67</sup> These scales were developed based on 10 years of research on the topic of self-determination undertaken with a wide variety of disability groups at the University of Minnesota's ICI. In addition to information provided by AXIS enrollees, ICI staff also will interview, during each of the last two years of the project, a comparison group of individuals who receive health care services through a traditional fee-for-service format.

The HECS is a 42-item scale in which respondents indicate who makes decisions in 10 different areas of health care (i.e., Choosing a Provider, Scheduling and Getting to Appointments, Decisions About Treatment, Communication About Health Care, Setting and Working Towards Health Care Goals, Taking Medication, Health at Home, Assistive Devices and Accommodations, and Gathering Health Care Information), and the relationship they have with persons other than themselves involved in decision-making processes (i.e., Significant Other, Health Care Professional, Extended Family, Insurance). The HIS is a 39-item scale in which individuals indicate the importance they place on a variety of aspects of managing their health care on a Likert type scale (1=Not very much to 3=Very much) in the same 10 areas of health care decision-making. The third scale that will be used to gain understanding of health care decision-making is the HDMPS, which is composed of the same 10 domains as the HECS and HIS. Using this scale, participants are asked to indicate whether they desire to make health care decisions by themselves, together with someone else, or have another person make the decision for them. All of these scales have been shown to have good internal consistency (HECS  $\alpha = .80 - .95$ , HIS  $\alpha = .70 - .90$ , and HDMPS  $\alpha = .73 - .89$ ) with high face validity among consumers, family members, and healthcare professionals.

## Nuts and Bolts

The Evaluation Consortium also serves as an infrastructure to facilitate collaboration on the nuts and bolts of human study participant protections, data sharing, and data management. We constructed several “firewalls” both to blind the researchers to maintain impartiality during data analysis, and to protect the confidentiality of the study participants.

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<sup>65</sup> Abery B.H., Elkin S.V., Lewis M., and Smith J.G. “Healthcare Exercise of Control Scale.” Institute on Community Integration. University of Minnesota, 2000.

<sup>66</sup> Abery B.H., Elkin S.V., Lewis M., and Smith J.G. “Healthcare Decision-Making Preference Scale.” Institute on Community Integration. University of Minnesota, 2000.

<sup>67</sup> Abery B.H., Elkin S.V., Lewis M., and Smith J.G. “Healthcare Importance Scale.” Institute on Community Integration. University of Minnesota, 2000.

The NRH-CHDR and University of Minnesota are collaborating on the logistics for each other's research projects. NRH-CHDR obtains the informed consent documents for both institutions and forwards the University's consent to them. The University helps arrange for translators when the NRH-CHDR survey needs to be administered in a language other than English. The University of Minnesota reduced the length of its survey through a data sharing agreement with NRH-CHDR. Finally, NRH-CHDR, University of Minnesota, and AXIS agreed on the timing of the surveys. Our goal is to maximize responses to both surveys and minimize confusion about which study is being conducted. We agreed to combine the two surveys and recruit the participants simultaneously. In the month following enrollment, AXIS contacts the member, explains the importance of the evaluation, and obtains their verbal consent to participate. Upon the consent, AXIS schedules an appointment for the first survey. The survey is administered in person; this person also collects the signed informed consent documents. When the ICI survey is completed, ICI notifies NRH-CHDR to administer the longitudinal survey by telephone. The longitudinal survey is conducted by a contractor with a disability whom we trained for this study.

One lesson we have learned is that the typical informed consent document is too long for many people with physical disabilities to manipulate. We have learned that it is best to assign one research assistant to visit each potential recruit and walk them through the informed consent document.

The recruitment protocols and informed consent documents are approved by the Institutional Review Boards of the University of Minnesota, MedStar Research Institute, and the DHS.

## **Limitations**

Since the survey instruments are new, we do not yet know the psychometric properties. These properties are important to know, since the population has more heterogeneous and intensive health care needs than people who are not enrolled in Medicare or Medicaid.

## Conclusion

The Evaluation Consortium will assess the value of this innovative managed care program, using a minimally intrusive, yet effective and efficient framework. Through careful coordination, the Evaluation Consortium is able to leverage limited funds beyond the initial scope of the awards. ICI is working with DHS to recruit a comparison group of individuals who are being served in the fee-for service system. ICI will survey these individuals using all instruments, including the longitudinal survey over the next two years. This data will be shared with everyone in the consortium. Unfortunately, we cannot track utilization and expenditures of a fee-for-service comparison group in “real time.” The Consortium is seeking additional funding to conduct a retrospective analysis of combined Medicare and Medicaid claims data.

## Appendix 1: Minnesota Department of Human Services Minnesota Disability Health Options Project Evaluation Plan – February, 2002

This evaluation plan is designed to determine if the following project goals, consistent with the MnDHO service delivery vision, have been met.

### MnDHO Vision

A **consumer-centered service delivery** model, which embodies the following principles:

- g. **Holistic Focus.** The managed care system constantly and consistently focuses on the person being served within the context of his/her living situation, support system, and health status.
- h. **Enrollee Self-Direction.** The managed care system strives to include a maximum level of enrollee choice and self-direction.
- i. **Integrated Service Coordination.** The health plan care coordinator works with the enrollee as partner in developing a comprehensive care plan and in planning service needs. The care coordinator facilitates provision of these services for the enrollee.
- j. **Disability Competence.** The managed care system includes providers with disability expertise and experience and the provider network as a whole is capable of facilitating the service access needs particular to people with physical disabilities.
- k. **Accessibility.** Each provider and the provider network as a whole strives to continuously improve the access needs of people with physical disabilities in the following areas: (a) the number of appropriately trained staff to meet the enrollee's needs during the service session; (b) the physical plant of the service site; and (c) the availability and use of equipment and durable medical equipment needed by the enrollee to gain access to the service site.
- l. **Independent Living.** The managed care system supports individuals who desire to live independently in the community with necessary clinical and social supports.

## Project Goals/Measurement Domains:

2. To create and maintain **satisfaction** with MnDHO for:
  - e. Consumers
  - f. Health Plans
  - g. Providers
  - h. State & HCFA
  
4. To promote the overall **well being** of enrollees through the following:
  - j. Services that promote optimal health outcomes.
  - k. Prevention of health complications secondary to a person's disability.
  - l. Increase in the delivery of preventative services, such as screenings and immunizations.
  - m. Improvement or maintenance of functioning, appropriate to an enrollee's health status and disability.
  - n. Testing the effectiveness of various clinical interventions.
  - o. Continuous monitoring and improvement in meeting the access needs of enrollees.
  - p. Increase in enrollee capacity for independent living.
  - q. Foster and maintain optimal enrollee involvement in care delivery.
  - r. Inclusion of the enrollee's social and emotional needs in the service delivery process.
  
5. To meet the following **cost and utilization** goals:
  - d. Ascertain changes in utilization and cost patterns through this model.
  - e. Provide quality health care and support services for no more than the funding levels which would be available in the fee-for-service system.
  - f. Determine the effectiveness of the DPS risk adjustment system for this model.

Consumer Satisfaction – Goal 1a.				
Satisfaction measures will help us monitor quality of care and case management programs and how well the program is setting and meeting consumer's expectations. We will employ existing and new quantitative tools, supplemented with qualitative, in-depth interviews. Surveys will cover: paperwork, care coordinators, DME, PCA, access, self direction, etc.				
Outcome Measure	Methods/ Data Sources	Frequency Timing	Who Collects	Who Analyzes
1. Enrollee satisfaction with AXIS compared with the fee-for-service system. ( <i>Quantitative portion</i> )	Longitudinal survey <sup>1</sup>	<ul style="list-style-type: none"> <li>Baseline</li> <li>12- and 24-months post enrollment (if enrolled in AXIS that long).</li> </ul>	CHDR on behalf of UCare/AXIS	CHDR
2. Enrollee satisfaction with AXIS compared to their prior fee-for-service system. ( <i>Qualitative portion; supplements quantitative survey</i> )	<ul style="list-style-type: none"> <li>Baseline</li> <li>DHS focus groups</li> </ul>	Baseline established by AXIS at March 1, 2001 Forum.	CHDR	CHDR
3. Enrollee satisfaction with AXIS compared with the fee-for-service system. ( <i>Qualitative portion across delivery systems</i> )	Three-six individual, in-depth interviews/case studies of MnDHO and three-six comparable ffs clients (matched by condition) to compare ffs versus MnDHO during same time period.	Once, one-year post enrollment	CHDR	CHDR
4. Reasons for disenrollment.	<ul style="list-style-type: none"> <li>MSHO disenrollment survey (<i>will adapt the MSHO survey tool</i>).</li> <li>Mail and phone</li> </ul>	Ongoing collection, with annual reviews and summary narrative by DHS at end of demonstration.	DHS	DHS

Consumer Satisfaction – Goal 1a.				
Satisfaction measures will help us monitor quality of care and case management programs and how well the program is setting and meeting consumer's expectations. We will employ existing and new quantitative tools, supplemented with qualitative, in-depth interviews. Surveys will cover: paperwork, care coordinators, DME, PCA, access, self direction, etc.				
Outcome Measure	Methods/ Data Sources	Frequency Timing	Who Collects	Who Analyzes
5. Grievance, appeals, & UCare written complaints.	Existing MSHO health plan reporting protocol.	Ongoing collection, with annual reviews by DHS and summary narrative by DHS at end of demonstration.	UCare	DHS
6. Informal AXIS survey- "How are we doing?" questionnaire.	Short operationally-oriented, cross-sectional questionnaire. <sup>2</sup> (Simple 10 questions, Firewall with health coordinator)	<ul style="list-style-type: none"> <li>• Every six months, post-enrollment.</li> <li>• Summary analysis at end of demonstration.</li> </ul>	AXIS	CHDR for summary

Provider/Health Plan Satisfaction- Pre and Post – Goals 1b & 1c				
To include perceptions of flexibility, hassle factor, role of the health coordinator, etc. <b>Survey participants</b> should include: care coordinators, Medical Directors, and key health plan staff.				
Outcome Measure	Methods/ Data Sources	Frequency Timing	Who Collects	Who Analyzes
1. UCare's financial experience with the product.	Qualitative interviews of senior health plan management.	Once, after nine months. (Summer 2002).	MDHS-HDWG	MDHS-HDWG
2. UCare perceives they are able to enhance the lives of patients/enrollees.				
3. UCare perceives that care coordinators help them to better serve enrollees.				
4. UCare feels they have the flexibility needed to serve enrollee needs.				
5. UCare is satisfied with the administration of the program.				
6. UCare generally feels that enrollees participate in care decisions and comply with care regimens.				



## Quality of Care – Goal 2

*The complete evaluation will combine information from multiple methods to assess “quality of care,” including process and realized outcomes. We will measure quality from the perspective of the enrollee and the clinician. Some of this information will be collected as part of the “satisfaction” measurement process.*

**Process** This measures the presence or absence of processes that we hypothesize should be “in place” to ensure high quality care for the enrollees.

Outcome	Measures	Methods/ Data Sources	Frequency	Who Collects	Who Analyzes
1. Enrollees have a personal physician & a care coordinator.	Enrollee is offered a choice of physicians, therapists and care coordinators and makes a choice within 15 days of enrollment. Otherwise, health plan assigns enrollee to physician.	<ul style="list-style-type: none"> <li>• Surveys</li> <li>• Focus groups</li> <li>• Randomly selected case record audit.</li> <li>• Comprehensive Assessment Tool</li> </ul>	Survey timelines	<ul style="list-style-type: none"> <li>• CHDR</li> <li>• DHS</li> </ul>	<ul style="list-style-type: none"> <li>• CHDR</li> <li>• DHS</li> </ul>
2. Facilitated access.	Written policies to facilitate access to specialists, DME, etc. Survey questions addressing this.	<ul style="list-style-type: none"> <li>• Surveys</li> <li>• Focus groups</li> <li>• Comprehensive Assessment Tool</li> </ul>	Survey timelines	<ul style="list-style-type: none"> <li>• CHDR</li> <li>• DHS</li> </ul>	<ul style="list-style-type: none"> <li>• CHDR</li> <li>• DHS</li> </ul>
3. Coordinated care management.	Development of written, holistic care plan within 30 days of enrollment, e.g. plan considers biomedical, psychosocial, behavioral health and quality of life issues. Cognitively appropriate plan is signed and dated by health coordinator and enrollee, w/ review by physician. Health plan reviews enrollee health status at least annually.	Longitudinal survey.	Survey timelines	CHDR	CHDR

## Quality of Care – Goal 2

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**Outcomes** *This measures how well the potential for quality care is realized. That is, are the structures and procedures in place being followed? Is the medical care clinically appropriate?*

4. New enrollees understand how to use the system	<ul style="list-style-type: none"> <li>Enrollee can answer questions on how to get services.</li> </ul>	<ul style="list-style-type: none"> <li>Focus groups</li> <li>AXIS informal survey</li> <li>longitudinal survey.</li> </ul>	Survey timelines	<ul style="list-style-type: none"> <li>DHS</li> <li>AXIS</li> <li>CHDR</li> </ul>	<ul style="list-style-type: none"> <li>DHS</li> <li>AXIS</li> <li>CHDR</li> </ul>
5. Enrollees have a personal physician.	<ul style="list-style-type: none"> <li>Initial visit with primary care provider within 30 days of enrollment (new, non-pilot enrollees, only).</li> <li>Enrollee reports</li> </ul>	<ul style="list-style-type: none"> <li>AXIS records</li> <li>Longitudinal survey- first 2 times</li> </ul>	Survey timelines	CHDR	CHDR
6. Self-directed care.	Enrollee capabilities, needs and preferences are considered in care planning.	<ul style="list-style-type: none"> <li>Focus groups</li> <li>LEEP experience</li> <li>AXIS Questionnaire</li> <li>Longitudinal survey</li> <li>AXIS records</li> </ul>	Survey timelines	<ul style="list-style-type: none"> <li>DHS</li> <li>AXIS</li> <li>AXIS</li> <li>CHRD</li> </ul>	<ul style="list-style-type: none"> <li>DHS</li> <li>AXIS</li> <li>AXIS</li> <li>CHRD</li> </ul>
7. Access to primary care, specialty care, DME, therapy, mental health services, etc.	<ul style="list-style-type: none"> <li>Perceived need for access.</li> <li>Match actual utilization for sub-sample of survey respondents.</li> </ul>	<ul style="list-style-type: none"> <li>Encounter data</li> <li>Utilization data<sup>3</sup></li> <li>Longitudinal survey</li> <li>AXIS records</li> </ul>	<ul style="list-style-type: none"> <li>Annual</li> <li>Survey timelines</li> </ul>	<ul style="list-style-type: none"> <li>UCare</li> <li>UCare</li> </ul>	<ul style="list-style-type: none"> <li>CHDR</li> <li>CHDR</li> </ul>

## Quality of Care – Goal 2

*The complete evaluation will combine information from multiple methods to assess “quality of care,” including process and realized outcomes. We will measure quality from the perspective of the enrollee and the clinician. Some of this information will be collected as part of the “satisfaction” measurement process.*

8. Enrollees are referred to patient education, support groups and skills training, if appropriate. Services may be provided within the health plan or through other community resources.	<ul style="list-style-type: none"> <li>• Actual access.</li> <li>• Perceived need for access.</li> </ul>	<ul style="list-style-type: none"> <li>• AXIS records</li> <li>• Enrollee surveys</li> <li>• Focus groups</li> </ul>	Annual	CHDR	CHDR
9. Clinical care.	<ul style="list-style-type: none"> <li>• Skin integrity (early detection and prevention of deterioration to Stage 3 or 4; testing of treatment protocol).</li> <li>• “Watch list” that bubbles up from actual incidence.</li> </ul>	<ul style="list-style-type: none"> <li>• AXIS records</li> <li>• Application of treatment protocol</li> <li>• Medical records</li> <li>• Medications</li> </ul>	<ul style="list-style-type: none"> <li>• Once a year</li> <li>• ID from Watch List.</li> </ul>	<ul style="list-style-type: none"> <li>• UCare – AXIS Contract 8.11</li> <li>• CHDR</li> </ul>	<ul style="list-style-type: none"> <li>• UCare-AXIS</li> <li>• CHDR</li> </ul>
10. Other issues	<ul style="list-style-type: none"> <li>• Chronic pain</li> <li>• Anxiety</li> <li>• Fatigue</li> <li>• Stress</li> <li>• Quality of home care</li> <li>• Transitions between settings</li> </ul>	<ul style="list-style-type: none"> <li>• Surveys</li> <li>• Medications</li> </ul>	Annual	CHDR	CHDR

## Quality of Care – Goal 2

*The complete evaluation will combine information from multiple methods to assess “quality of care,” including process and realized outcomes. We will measure quality from the perspective of the enrollee and the clinician. Some of this information will be collected as part of the “satisfaction” measurement process.*

11. Identified accessibility issues are tracked and addressed, including ADA compliance and best practices.	<ul style="list-style-type: none"> <li>• Process in place for feedback and improvement.</li> <li>• Improvements implemented at clinics.</li> </ul>	<ul style="list-style-type: none"> <li>• Focus groups</li> <li>• AXIS Questionnaire</li> <li>• UCare reporting</li> <li>• UCare/AXIS annual walk-through</li> </ul>	<ul style="list-style-type: none"> <li>• Survey timeline</li> <li>• Pre and post</li> </ul>	<ul style="list-style-type: none"> <li>• DHS</li> <li>• UCare-AXIS</li> </ul>	<ul style="list-style-type: none"> <li>• DHS</li> <li>• UCare-AXIS</li> </ul>
12. Hospitalization for preventable conditions.	All admissions will be tracked “real time” by AXIS and UCare.	<ul style="list-style-type: none"> <li>• Tracking system</li> </ul>	Monthly medical meetings	AXIS-UCare	AXIS-UCare
13. Life satisfaction & Community integration.	<ul style="list-style-type: none"> <li>• Recreation and leisure</li> <li>• Social participation</li> <li>• Personal contact</li> </ul>	ICI surveys	Baseline and annually thereafter	ICI	ICI

Utilization and Patterns of Care – Goal 3a					
Utilization data will help us learn how case coordination redistributes care across sites of service and provider types. In most cases, utilization measures are reported by rate cell.					
Nursing facility use					
Outcome	Measures	Methods/ Data Sources	Frequency	Who Collects	Who Analyzes
1. Numbers of previous NF residents appropriately being served in the community.	Numbers of enrollees by case mix residing in NFs at enrollment who are now being served in the community.	<ul style="list-style-type: none"> <li>Rate cell analysis</li> <li>Matched case illustrations (<i>DHS collects from care system or health plan</i>).</li> </ul>		DHS	DHS
2. NF admission rates. (From hospital and from community).	Admissions/1000 member months, compared with ffs experience.	<ul style="list-style-type: none"> <li>UCare reporting for AXIS</li> <li>DHS for ffs</li> </ul>	Semi-annual	<ul style="list-style-type: none"> <li>UCare</li> <li>DHS</li> </ul> <i>Contract 8.9.2</i>	DHS
3. NF length of stay (LOS).	Average LOS, compared with ffs experience.	<ul style="list-style-type: none"> <li>UCare reporting</li> <li>Encounter data</li> <li>Actuarial database</li> </ul>	Semi-annual	DHS	DHS
4. Change at person level.	Medical record or case files.	10 case studies. Same people as in 1a 3.	Once	UCare	CHDR

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<b>Emergency room</b>					
5. ER use rates.	ER visits/1000 enrollee months, compared with ffs experience.	<ul style="list-style-type: none"> <li>UCare reporting via HEDIS for AXIS enrollees.</li> <li>DHS for ffs.</li> </ul>	Semi-annual	<ul style="list-style-type: none"> <li>UCare</li> <li>DHS</li> </ul> Contract 8.9.5	<ul style="list-style-type: none"> <li>UCare</li> <li>DHS</li> </ul>
6. ER use type	<ul style="list-style-type: none"> <li>Diagnosis, procedures, disposition.</li> </ul>	Admission authorization processed by health coordinator.	Once, at end of two years	UCare	CHDR
<b>Acute care.</b>					
7. Hospital admissions rate.	Admissions /1000 enrollee months, compared with ffs experience.	<ul style="list-style-type: none"> <li>UCare reporting for AXIS enrollees</li> <li>DHS for ffs.</li> </ul>	Semi-annual	<ul style="list-style-type: none"> <li>UCare</li> <li>DHS</li> </ul> Contract 8.9.1 & 8.9.3	<ul style="list-style-type: none"> <li>UCare</li> <li>DHS</li> </ul>
8. Hospital LOS.	ALOS by DRG and rate cell.	<ul style="list-style-type: none"> <li>UCare reporting for AXIS enrollees</li> <li>DHS for ffs.</li> </ul>	Semi-annual	<ul style="list-style-type: none"> <li>UCare</li> <li>DHS</li> </ul> Contract 8.9.1 & 8.9.3	<ul style="list-style-type: none"> <li>UCare</li> <li>DHS</li> </ul>
9. Discharge disposition.	By DRG and rate cell.	<ul style="list-style-type: none"> <li>UCare reporting for AXIS enrollees</li> <li>DHS for ffs</li> </ul>	Semi-annual	<ul style="list-style-type: none"> <li>UCare</li> <li>DHS</li> </ul>	<ul style="list-style-type: none"> <li>UCare</li> <li>DHS</li> </ul>

Utilization and Patterns of Care – Goal 3a					
Utilization data will help us learn how case coordination redistributes care across sites of service and provider types. In most cases, utilization measures are reported by rate cell.					
<b>Inpatient Rehabilitation Facility.</b>					
10. Rehab admission rate.	Rates/1000.	<ul style="list-style-type: none"> <li>• UCare reporting for AXIS enrollees</li> <li>• DHS for ffs.</li> </ul>	Semi-annual	<ul style="list-style-type: none"> <li>• UCare</li> <li>• DHS</li> </ul>	<ul style="list-style-type: none"> <li>• UCare</li> <li>• DHS</li> </ul>
11. Rehab LOS.	ALOS by FIM (or equivalent) and rate cell.	<ul style="list-style-type: none"> <li>• UCare reporting for AXIS enrollees</li> <li>• DHS for ffs.</li> </ul>	Semi-annual	<ul style="list-style-type: none"> <li>• UCare</li> <li>• DHS</li> </ul>	<ul style="list-style-type: none"> <li>• UCare</li> <li>• DHS</li> </ul>
12. Discharge disposition	By FIM and rate cell.	<ul style="list-style-type: none"> <li>• UCare reporting for AXIS enrollees</li> <li>• DHS for ffs.</li> </ul>	Semi-annual	<ul style="list-style-type: none"> <li>• UCare</li> <li>• DHS</li> </ul>	<ul style="list-style-type: none"> <li>• UCare</li> <li>• DHS</li> </ul>
<b>Use of non-covered services.<sup>4</sup></b>					
13. Utilization of HCB waiver-like, alternative services, and assisted living.	<ul style="list-style-type: none"> <li>• List of alternative services provided &amp; frequency.</li> <li>• Differences in service patterns, compared with ffs experience.</li> </ul>	<ul style="list-style-type: none"> <li>• “Request for non-covered services form.”, AXIS</li> <li>• Matched case illustrations (include clients with previous ffs history)*</li> </ul>	<ul style="list-style-type: none"> <li>• Semi-annual</li> <li>• Once</li> </ul>	<ul style="list-style-type: none"> <li>• DHS for list</li> <li>• CHDR</li> </ul>	<ul style="list-style-type: none"> <li>• DHS for list.</li> <li>• CHDR</li> </ul>

Utilization and Patterns of Care – Goal 3a					
Utilization data will help us learn how case coordination redistributes care across sites of service and provider types. In most cases, utilization measures are reported by rate cell.					
<b>Ambulatory encounters.</b> <sup>5</sup>					
14. Primary care procedures	Visits/1000 member months, compared with ffs experience, by provider type and rate cell.	<ul style="list-style-type: none"> <li>• Encounter data on Dx and CPT-4 codes.</li> <li>• Selected HEDIS measures</li> <li>• State claims data.</li> </ul>		<ul style="list-style-type: none"> <li>• DHS</li> <li>• UCare</li> </ul>	<ul style="list-style-type: none"> <li>• DHS</li> <li>• UCare</li> </ul>
15. Specialty care services	Visits/1000 member months, compared with ffs experience, by provider type and rate cell.	<ul style="list-style-type: none"> <li>• Encounter data on Dx and CPT-4 codes.</li> <li>• Selected HEDIS measures</li> <li>• State claims data</li> </ul>	<ul style="list-style-type: none"> <li>• Semi-annual</li> <li>• Annual</li> <li>• MDHS</li> </ul>	<ul style="list-style-type: none"> <li>• DHS</li> <li>• UCare</li> <li>• MDHS</li> </ul>	<ul style="list-style-type: none"> <li>• DHS</li> <li>• UCare</li> <li>• MDHS</li> </ul>
16. Preventive care utilization	Possibilities: <ul style="list-style-type: none"> <li>• Flu shots</li> <li>• Cancer screenings</li> <li>• Cholesterol tests</li> <li>• Blood pressure checks</li> <li>• Urology</li> <li>• Bone density</li> </ul>	<ul style="list-style-type: none"> <li>• AXIS records.</li> <li>• Selected HEDIS measures (adult immuniz., depression med mgmt, diabetes care, cancer screens, hypert. &amp; cholest. screens).</li> </ul>	Annual	<ul style="list-style-type: none"> <li>• DHS</li> <li>• AXIS/UCare</li> <li>• UCare</li> </ul>	<ul style="list-style-type: none"> <li>• DHS</li> <li>• AXIS/UCare</li> <li>• UCare</li> </ul>
17. Utilization of PCA & other home care services	Differences in service patterns compared with home care clients on ffs	<ul style="list-style-type: none"> <li>• UCare reporting</li> <li>• Encounter data</li> <li>• Case illustrations*</li> </ul>	Semi-annual	<ul style="list-style-type: none"> <li>• UCare</li> <li>• DHS</li> </ul> <i>Contract 8.9. 4</i>	<ul style="list-style-type: none"> <li>• UCare</li> <li>• DHS</li> </ul>



Utilization and Patterns of Care – Goal 3a					
Utilization data will help us learn how case coordination redistributes care across sites of service and provider types. In most cases, utilization measures are reported by rate cell.					
18. Utilization of DME, RX, and rehab services (PT, OT, ST)	Differences in service patterns compared with ffs	<ul style="list-style-type: none"> <li>• UCare reporting</li> <li>• Encounter data</li> <li>• Case illustrations*</li> </ul>	Semi-annual	DHS	DHS

\*DHS collects case illustrations from care system or health plan.

#### Working Hypotheses:

1. Enrollees will have fewer long term stays in nursing facilities. Reductions in long term stays will come through a combination of self-directed care, home care and alternative services authorized by AXIS and UCare.
2. Emergency room use will be lower for enrollees. The greatest reductions will come from conditions that can be prevented by facilitating access to care in the outpatient setting, e.g. urinary tract infections, influenza, diabetic hypoglycemia.
3. Appropriate hospital admission rates will be the same, but length of stay will be shorter and discharge disposition will be to less resource intensive sites (such as the enrollee's home). Post-acute care services will be different than for ffs.
4. No difference in Rehab services for Medicare enrollees, since inpatient rehab will come under Medicare prospective payment in 2002. For Medicaid, we hypothesize that enrollees will be more likely to be discharged to home care.
5. The capitation mechanism will financially incent UCareComplete to provide services that are not typically covered by Medicaid or Medicare. These include the use of complementary therapies (e.g., acupuncture for pain; music therapy), exercise equipment (eg. a rowing machine to improve cardiovascular fitness), transportation assistance, or provision of personal assistants. Use of these non-covered services will contribute to a reduction in more expensive, traditionally covered services, such as hospitalizations.
6. Overall access to ambulatory care will be facilitated for people enrolled in AXIS compared to ffs. There will be more primary care visits, mental health visits, and therapists; there will be a similar number of visits for specialty care.

Cost and Rate Setting– Goals 3b & c						
Cost data will help us determine the cost-effectiveness of the program, and whether or not the program saves the state money.						
Outcome	Measures	Methods/ Data Sources	Frequency	Who Collects	Who Analyzes	
1. Service costs.	Compare with ffs equivalent, adjusted for case mix.	<ul style="list-style-type: none"> <li>• Encounter data*</li> <li>• DHS forecast</li> <li>• DPS results</li> <li>• Actuarial analysis.</li> </ul>	Annual	DHS	DHS	
2. Adequacy of DPS payments.	Compare health plan experience with base experience on DPS profiles.	<ul style="list-style-type: none"> <li>• Encounter data<sup>6</sup></li> <li>• MDH MnDHO database</li> <li>• Actuarial MnDHO database.</li> </ul>	Annual	DHS	DHS	

<sup>1</sup>Longitudinal Survey: We assume the “worse case scenario” that enrollment will be slow and sporadic. Since there will be a maximum of 200-300 enrollees in year one, CHDR recommends that the survey be administered at 0, 12 and 24 months of enrollment; that is, a longitudinal survey. Analyses will be restricted to longitudinal analysis. This survey will be “CAUCareS-like”, building on prior work done by CHDR, Connecticut, Minnesota, and DHHS/ASPE on tools that survey consumers to assess quality of care.

<sup>2</sup> The primary purpose of the questionnaire is to help UCare and AXIS management monitor effectiveness of orientation and education program and changing expectations as enrollees learn how to use the health plan. It also alerts plan management to things that need immediate corrections, rather than waiting until the annual survey. Questions will address: timely medical appointments; identifying the PCP and care manager; self-direction in plan and care (will coordinate with LEEP); understanding of how to access plan services, including how to file complaints and compliments. Some questions will be identical to the longitudinal survey. We will also include opportunities for open-ended responses.

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The secondary purpose is to track changes in individual perceptions of AXIS over time, to match up against disenrollment or grievances and appeals, etc. This will augment the picture we get from the annual survey and help us see if the experience varies by impairment type and origin type.

<sup>3</sup> Utilization data may be appropriate HEDIS measures.

<sup>4</sup> We will work with DHS, AXIS and UCare to develop a simple request/data collection form for each enrollee's health coordinator to fill out as services are arranged and requested, and that will comply with HIPAA. Claims data will not give enough detail.

<sup>5</sup> Screening will be a problem since screens are usually done every few years, and the demo won't be operating that long. I think "flu shots" are good, but we may have a problem documenting a comparison to ffs unless Minnesota docs are good at reporting that they gave the shots. We could also have the care manager ask the enrollee when was the last time they had a cancer screen, as part of the intake process, and then include it in the care management plan and see if it was actually done.

<sup>6</sup> Need to assure a consistent designation of costs on encounter data, especially for "alternative services", which cannot be assigned an MA price.