

# CHCS

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## Resource Paper

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### **Minnesota Disability Health Options: Expanding Coverage for Adults with Physical Disabilities**

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### Online Resources

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

- **Resource Paper: Designing a Program Evaluation for a Multi-Organizational Intervention: The Minnesota Disability Health Options Project** – This paper outlines how a comprehensive evaluation was designed for the MnDHO program.
- **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.
- **Minnesota Disability Health Options Project Evaluation Plan** – This document provides the full evaluation plan for the Minnesota Disability Health Options Project.

*I have been living with my disability for more than 20 years. As my multiple sclerosis progressed, I've needed increasing services and supports. The health care system is like a very large, black room... most everything I need is there, but you can't find what I need, or get it when needed.*

*Then, I developed a skin breakdown. I couldn't see it, and my attendants didn't notice it for a while. After it progressed, I called my home care nurse and she came out several days later. She then came out a few times a week and scrubbed it with a toothbrush. It only became worse. I had my doctor look at it, and he immediately sent me to the hospital for surgery. After weeks in the hospital, I was moved to a nursing home where I was on bed rest for nine months. I still had my condominium, but didn't know how to put the pieces together to move back home.*

*After enrolling in AXIS, Patty, my health coordinator, pulled my family and friends together and made a plan. She authorized everything I needed, including modifications to my home, and I returned home within 45 days. A few months later, I had another skin breakdown. I called Patty, and she came out that day. She had a skin care nurse out to my home the next day. I was fully healed within a few weeks, and didn't even need a full day of bed rest.*

*-- Ron, AXIS Healthcare Member*

## **Overview**

Ron's story illustrates the value and success of Minnesota Disability Health Options (MnDHO), a specialized managed health care program for working-age Medicaid-eligible individuals (with or without Medicare) with physical disabilities who reside in Minneapolis-St. Paul. MnDHO, a voluntary program, integrates delivery of all Medicaid and Medicare services except for prescription medications. Since the program began in September 2001, over 200 people have enrolled. Slightly more than 50 percent are dual Medicare/Medicaid beneficiaries.

The Minnesota Department of Human Services (DHS) administers the MnDHO program and pays Medicaid capitation to UCare Minnesota, a nonprofit health plan. UCare Minnesota contracts with AXIS Healthcare to provide care coordination, provider relations, and member services for the target population of Medicaid adults with physical disabilities. The key feature of MnDHO is the health care coordination and support provided by AXIS.

Focus groups and surveys of MnDHO enrollees document that the program is improving the overall wellbeing of Medicaid adults with physical disabilities. Almost all people surveyed report they are involved as much as they want to be in their own health care decision-making, compared to less than half prior to enrollment. Interviews and focus groups at the end of the first year show that enrollees' quality of life is much better, with enrollees able to focus their attention on non-health related concerns. Preliminary outcomes data show promising results:

- Hospitalizations have been more than halved, to 100 hospitalizations/1,000 members.
- Hospital length of stay has been reduced by more than 60 percent.
- Ninety percent of members report satisfaction with their health care services, as compared with 10 percent satisfaction prior to enrollment.
- Eighty-five percent of members reported receiving help managing their health care services, as compared with five percent receiving help prior to enrollment.

At the same time, it is not yet known if savings in health care costs adequately offset the expenses of care coordination and health plan administration.

This paper describes Minnesota's previous efforts to enroll this vulnerable population in managed care prior to MnDHO, the current program, the design of its evaluation, and preliminary findings after the first year of operation.

## **Programs for Medicaid Beneficiaries with Disabilities in Minnesota**

Medicaid beneficiaries in Minnesota with physical disabilities have little access to coordinated care and integrated services. Most beneficiaries with physical disabilities receive no case management, unlike people with developmental disabilities (mental retardation) or behavioral disabilities (mental illness). Most enrollees must self-manage multiple health care appointments and providers. Providers often lack pertinent experience, disability expertise, and interest in serving this complex population. Consequently, many Medicaid beneficiaries with physical disabilities encounter fragmented specialty care and too little primary care. They often lack access to basic non-medical services and equipment that could help them remain independent and living in the community.

Since 1985, Minnesota has piloted various managed care alternatives for adults with disabilities. MnDHO is Minnesota's third attempt to develop Medicaid managed care for this population. The lessons of the first two efforts helped Minnesota DHS develop the MnDHO program. By understanding the modest success and ultimate failures of the prior programs, other states may be able to identify potential pitfalls as they develop their own health care service options for people with disabilities.

### **Prepaid Medical Assistance Program and Minnesota Senior Health Options**

In 1985, Minnesota began enrolling Medicaid-eligible children, working-age adults, and elders age 65 and over in a prepaid capitated health care program known as the Prepaid Medical Assistance Program (PMAP). PMAP included people with physical or behavioral disabilities, but not people with developmental disabilities. After the first year, the largest PMAP provider dropped their contract for people with disabilities. The state decided to return people with disabilities to fee-for-service rather than to disrupt

their health care again. For the next 10 years, people with disabilities were carved out of PMAP.

In 1997, Minnesota developed an optional program for PMAP elders called Minnesota Senior Health Options (MSHO). MSHO combines Medicaid and Medicare financing to provide health and support services including care coordination, acute care, hospitalization, 180 days of nursing home care, home- and community-based services, and any alternative services the health plan may choose to offer.

### **Demonstration Project for People with Disabilities**

In 1997, Minnesota offered no managed care option, like MSHO, for Medicaid enrollees with disabilities under age 65.<sup>1</sup> The state recognized that a prepaid approach could improve services for this population, and potentially slow cost increases. In the mid-1990s, one urban and several rural counties expressed an interest in developing managed care programs for adults with disabilities.

Initially, DHS envisioned competitive health plan bidding for state contracts to provide Medicaid services to all people with disabilities in specific counties. However, the Demonstration Project for People with Disabilities (DPPD) legislation ultimately provided for counties to purchase and take on the full risk for most Medicaid funds. DHS received a planning grant from The Robert Wood Johnson Foundation, administered by the Center for Health Care Strategies, to design and implement the DPPD.

Two small rural areas – Olmsted County and the Southern Minnesota Health Initiative (Blue Earth, Freeborn, and Sibley counties), and one urban county (Hennepin County) – agreed tentatively to serve all disability populations with mandatory enrollment. The state published a Request for Proposals in September 1999 that specified the details of the DPPD. Leading Medicaid policy analysts pronounced the Request for Proposals an “extraordinarily comprehensive” document that “offers a real vision regarding how to adapt managed care to the needs of individuals with physical, developmental, and mental disabilities.” They added, however, that the document creates “enormous financial risk for counties and their partners.”

The DPPD model ultimately foundered. Despite their initial insistence on taking on the risk in place of health plans, counties were not prepared to take on all financial risk for health services within the final DPPD legislative parameters. Mandatory payment discounts built into the legislation coupled with detailed legislative requirements and expectations of advocates further increased the perception of risk for the counties and several county boards ultimately balked at participation. Other obstacles included the

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<sup>1</sup> Some people with disabilities were eligible for Minnesota’s three small waiver programs: Traumatic Brain Injury Waiver, for people with traumatic brain injuries; Community Alternatives for Disabled Individuals, for individuals needing nursing facility level of care; and Community Alternative Care, for individuals needing hospital level care.

difficulties inherent in starting a managed health plan from scratch since the counties lacked the managed care infrastructures needed to manage risk.

### **Benefits of the DPPD Experience**

The DPPD was not a complete failure. The *process* of developing a publicly financed managed care program for adults with disabilities led to some positive outcomes. The pilot sites reported increased understanding of the county's Medicaid-eligible population and health care access gaps. Coordination among county agencies and health plans improved, and collaboration increased with consumers, advocacy organizations, and local providers.

Two DPPD counties established the South Country Health Alliance, a county-run Medicaid managed care program in nine counties. As of late 2003, South Country enrolls Medicaid eligible individuals who do not have disabilities, but they plan to enroll people with disabilities in the future.

Finally, DHS shifted from the idea of a single program for all people with disabilities to voluntary programs tailored for specific populations.

### **AXIS Healthcare**

The unmet needs of Medicaid enrollees with physical disabilities encouraged the Sister Kenny Institute (SKI) – an inpatient rehabilitation hospital in the Twin Cities – and the Courage Center – a community-based rehabilitation center in Minneapolis – to propose a prepaid managed care program designed by and for persons with physical disabilities. The Boards of Directors at SKI and the Courage Center established AXIS Healthcare in 1997. AXIS held focus groups to identify the features of an ideal coordinated health care program for working-age adults with physical disabilities.

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 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.

AXIS established a pilot care management program to develop the model and further engage both consumers and providers. In the pilot, AXIS provided care management on a voluntary basis with no financial risk or formal authority, other than the request of the consumer for help in navigating the health care system. More than 40 individuals with physical disabilities learned about the pilot through word-of-mouth and asked to participate. This strategy was extremely useful, establishing AXIS' reputation in the

disability community and among their providers. The pilot also helped AXIS and UCare refine the care management process.

## Minnesota Disability Health Options

DHS seized the opportunity to work with UCare Minnesota and AXIS Healthcare in developing a new program that incorporated the best features and lessons learned from prior experience. This new program was named Minnesota Disability Health Options.

One key lesson learned from the success of MSHO (and a significant failure of the DPPD) is the importance of merging Medicare services and financing for dual eligibles to create an integrated and comprehensive program. DHS began discussions with the Centers for Medicare and Medicaid Services (CMS) in 1998 about incorporating Medicare beneficiaries under the age of 65 who had physical disabilities under the Medicare payment demonstration waiver granted to MSHO. The state sought CMS approval for MnDHO as a voluntary enrollment program. DHS obtained three waivers from CMS in 2001: 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.

DHS partnered directly with the health plan and involved UCare throughout the development process. AXIS Healthcare facilitated meetings so DHS could maintain close involvement with consumers while developing MnDHO and specifying its implementation. DHS worked under the MSHO section of the state's broad and flexible Medicaid managed care statute rather than under the more detailed and prescriptive DPPD statute.

The state launched MnDHO in September 2001 as a public-private partnership with UCare Minnesota and AXIS Healthcare. As of June 2003, MnDHO enrolled more than 200 adults with physical disabilities.

## Minnesota Disability Health Options – Nuts and Bolts

Minnesota DHS, UCare Minnesota, and AXIS function as the MnDHO collaborative. The collaborative vision of MnDHO service delivery embodies six principles:

- **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.
- **Enrollee Self-Direction.** The managed care system strives to include a maximum level of enrollee choice and self-direction.
- **Integrated Service Coordination.** The AXIS Health Coordinator works with the member as a partner in developing a comprehensive care plan and in planning service needs. The health coordinator facilitates provision of these services for the enrollee.

- **Disability Competence.** The managed care system includes disability literate providers, those with disability expertise and experience, and the provider network is capable of facilitating the service access needs particular to people with physical disabilities.
- **Accessibility.** Each provider and the provider network 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 member’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 member to gain access to the service site.
- **Independent Living.** The managed care system supports individuals who desire to live independently in the community with necessary clinical and social supports.

## Enrollment

MnDHO is a voluntary program for working-age Medicaid-eligible people with physical disabilities, with or without Medicare. Individuals enroll in “UCare Complete,” UCare Minnesota’s name for their MnDHO product. UCare Complete features a disability-literate primary care network of five clinics and a large specialist network. UCare Minnesota delegates care coordination, utilization management, and portions of provider relations and member services to AXIS Healthcare. UCare Minnesota and AXIS share financial risk for the capitation.

## Case Management

The heart of MnDHO is holistic health care, which is evident from the time a person first enrolls in the program. Upon enrollment, a health coordinator from AXIS Healthcare conducts a comprehensive physiological and psychosocial assessment. To build a cohesive relationship, the health coordinator collects information on everything from current prescriptions to dental needs to the names of pets. The AXIS health coordinator collaborates with the enrollee to identify health care needs and prioritize services. The enrollee also establishes health-related goals, as well as higher-level goals that become possible once a positive state of health is achieved. All information on enrollees’ needs, goals, and service utilization are maintained in an electronic relational database.

After 18 months of operation, the case load for AXIS personnel is:

- One Member Services staff: 75 enrollees
- One Health Coordinator (medically-related care): 35 enrollees
- One Resource Coordinator (housing, financial, health education): 90 enrollees



## **Financing**

MnDHO's base capitation rate is constructed from Minnesota's average Medicaid expenditures for beneficiaries with physical disabilities. If the particular UCare Complete enrollee also is a Medicare beneficiary, UCare gets an additional capitation of the Medicare+Choice payment for the county in which the beneficiary resides, adjusted by the PACE risk adjuster. Medicaid payments range from \$437 to \$19,611 per member per month, depending on the individual's risk classification.

## **Quality Improvement and Medical Management**

Ongoing quality improvement is a high priority. The AXIS management, Medical Director, and UCare's Medical Director hold monthly medical management meetings to monitor hospitalizations, urgent interventions, alternative benefits, and other clinical issues pertinent to achieving the MnDHO's identified outcomes. They also review practice patterns and identify opportunities for improvement.

AXIS and UCare staff review all hospitalizations to identify breakdowns in ambulatory care. After a year of experience, they have estimated that 40 percent of hospitalizations were for three conditions (urinary tract infections, bowel impaction, or upper respiratory complications), many of which were potentially preventable. In response, AXIS developed an urgent intervention model for these three conditions and encourages member reliance on the 24-hour availability of AXIS health coordination support. These preventive and urgent intervention strategies appear to be effective as demonstrated by the significant reduction in hospital utilization.

A preliminary longitudinal analysis of pre- and post-enrollment hospitalizations demonstrated that members' average inpatient length of stay was reduced by more than two-thirds when compared to prior utilization patterns. While this analysis is based on a small subset of individuals for whom pre-and post-enrollment utilization data are available, it underscores the potential cost to state Medicaid programs of preventable hospital use by adults with physical disabilities that can be reduced through integrated care coordination.

## **Consumer Acceptance and Enrollee Characteristics**

Figure 1 presents the monthly enrollment and cumulative growth. The chart shows that enrollment is steady at about six to 15 new members each month. MnDHO exceeded 100 people within its first year and 175 in the first 18 months. Slightly more than 50 percent are dual Medicaid/Medicare enrollees. Figure 2 shows the racial/ethnic distribution.

Figure 1: MnDHO Enrollment Trajectory

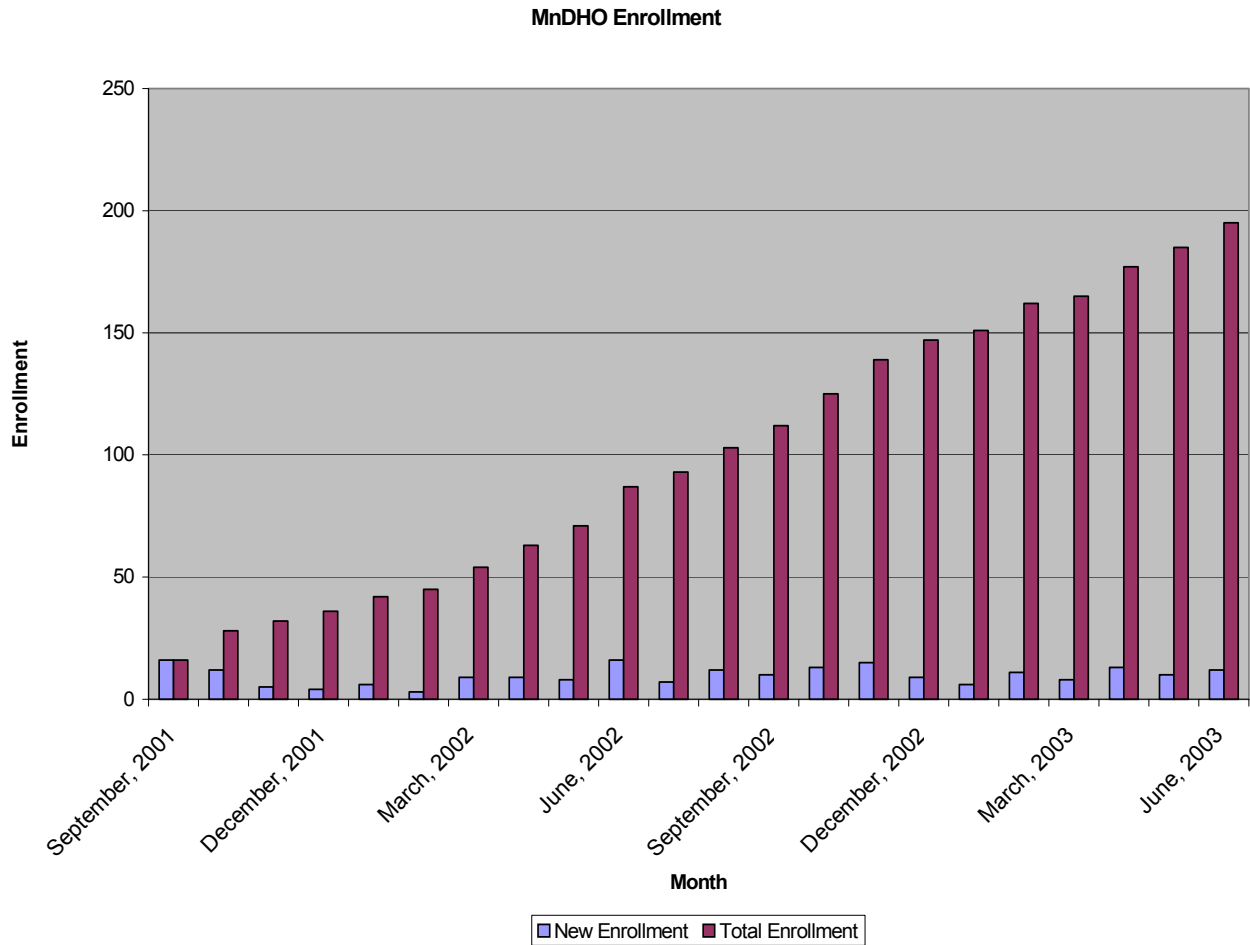
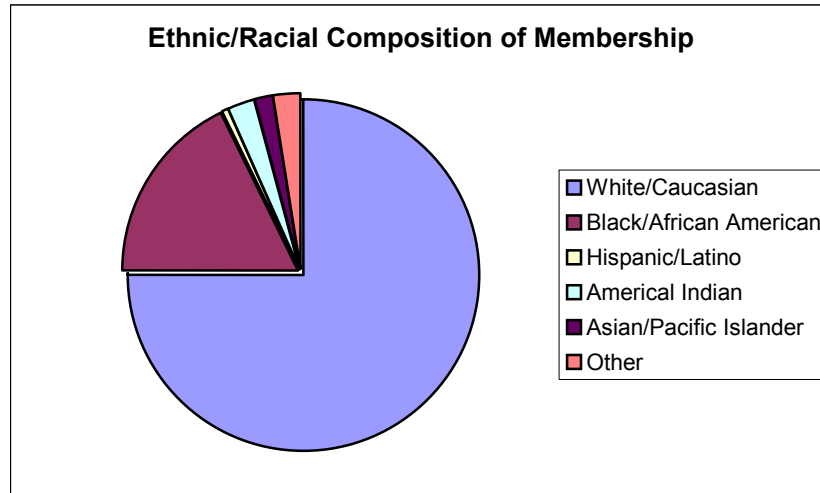


Figure 2: Racial / Ethnic Distribution of MnDHO Membership



UCare Minnesota is allowed to market to prospective enrollees in a manner similar to the process used for Medicare+Choice plans. All enrollee materials must be approved by the state and CMS. In the first year of operation, DHS sent a letter to every known Medicaid beneficiary eligible for the program (approximately 2,000 letters). This resulted in six to eight inquiries each month. Nursing home enrollees usually hear about MnDHO through social service staff or word-of-mouth. After 18 months of operation, provider groups overcame their early skepticism and started to refer patients to MnDHO.

Involuntary disenrollment is about five percent and is comprised of people who are no longer Medicaid eligible or move out of the service area. Voluntary disenrollment, which is sometimes viewed as a proxy for quality of care because people can “vote with their feet,” is less than four percent. This compares to rates of 20 percent or higher in commercial health plans for people without disabilities. Many of the voluntary disenrollments have been among people with significant substance abuse or mental health problems who wanted to remain independent of health coordination and returned to the anonymity of PMAP’s fee-for-service system.

The resource needs of new enrollees has changed over time. The initial enrollees had complex medical issues, while the program later attracted more individuals with dual diagnoses of physical and mental health. Enrollees in the first six months were most concerned about getting access to care and other medically-related issues. Later enrollees were more concerned with chronic pain and housing or other socially-related needs. For these enrollees, there were fewer opportunities for physical medicine cost savings to offset the cost of coordinating social, mental, and physical health services and medications.

## Telling the Story

O.C., an African American woman in her 50s, resided in a nursing home in the Twin Cities area. She had 22 known hospitalizations in the last five years under a wide range of diagnoses including: 1) anorexia; 2) nerve damage from diabetes; 3) pneumonia; 4) low potassium levels; 5) lupus; 6) skin ulcers; 7) kidney disease; 8) urinary tract infection; 9) depression; 10) digestive disorders; 11) bulimia; and 12) a broken arm. A state Mental Health Case Manager from her county followed her.

Under fee-for-service Medicaid, O.C. received good health care for the condition that required the hospitalization, but there was no focus on her overall health or on preventing future hospitalizations. At a weight of 53 pounds, a court ordered O.C. placed in a nursing home.

O.C. enrolled in MnDHO in late 2002, stating she wanted help getting out of the nursing home. At enrollment, she was receiving adequate custodial care but minimal medical management. AXIS immediately referred her to a psychiatrist for evaluation and medication management, and to a psychologist specializing in eating disorders for assessment and ongoing support. These initial assessments determined that O.C. had recurring major depression and generalized anxiety. Remarkably, even though she had been diagnosed with anorexia and bulimia in previous hospitalizations, the psychologist determined that O.C. “does not meet criteria for any eating disorder. She denies any drive for thinness... she denies any fear of weight gain...she believes that her current low-weightedness is a result of difficulties with mood and anxiety management which she has somatized.”

With the support of the psychologist, O.C. and her AXIS coordinators developed a plan to transition her out of the nursing home. She obtained an apartment in a building where her sister also resides. Her services include counseling and weekly weights, bi-weekly skilled nurse visits, and bi-weekly homemaker services. This plan has been supported by her Mental Health Case Manager, and endorsed by the Court. After several months in the community, O.C. has gained more than 20 pounds and is able to walk with the use of a rolling walker.

AXIS also arranged for her to see specialists to address her other medical conditions. A nephrologist determined O.C.’s kidneys are functioning at five percent of capacity and recommended dialysis. Following three months of treatment, her kidneys were functioning sufficiently enough to discontinue the dialysis.

O.C.’s story illustrates consequences of crisis management for individuals with physical and mental co-impairments. Her undetected kidney problems were misdiagnosed as psychiatric problems. She fell into a downward spiral of deteriorating health and increasing costs to Minnesota Medicaid, culminating in court-ordered placement in a nursing home when she desperately wanted to stay in her community. With the help of her care coordinator and an integrated service program, she has regained the physical and mental energy to live independently.

## Evaluation

An important part of MnDHO is a prospectively designed evaluation. This section sketches the design, funding, and preliminary findings from ongoing projects.

### Design

Program evaluations can cost a great deal of money, particularly if the evaluation is an afterthought. Often key pieces of data are missing, baseline information is not collected, or people implementing the program have moved on and are not available for a process audit.

The Center for Health Care Strategies allowed DHS to apply unused DPPD demonstration project funds to an evaluation of the first year of MnDHO. DHS capitalized on the interest of several researchers who had funds to evaluate different aspects of innovative health plans for adults with disabilities. Table 1 lists the organizations that have a stake in the evaluation and the funding sources:

**Table 1: Evaluation Stakeholders**

<i>Organization</i>	<i>Objective</i>	<i>Funding</i>
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; Demonstration grant from Center for Health Care Strategies.
Minnesota Department of Human Services	Fulfill statutory obligations to Medicaid beneficiaries and to provide cost-effective care.	Center for Health Care Strategies.
NRH-Center for Health & Disability Research	Real-world application of managed care assessment tool.	National Institute on Disability and Rehabilitation Research RRTC on Managed Care and Disability.
UCare Minnesota	Real-time business and clinical process redesign.	Revenue from operations.
University of Minnesota's Institute on Community Integration	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 health care, then comparing outcomes with a control group.	National Institute on Disability and Rehabilitation Research field initiated research project.
CMS	Quality of care for dual beneficiaries.	None.

All stakeholders agreed to form an Evaluation Consortium. Over a period of several months, the Consortium agreed on the goals outlined below.

- To create and maintain **satisfaction** with MnDHO for:
  - a. Consumers
  - b. Health Plans
  - c. Providers
  - d. State and CMS
  
- To promote the overall **well-being** of enrollees through the following:
  - a. Services that promote optimal health outcomes.
  - b. Prevention of health complications secondary to a person's disability.
  - c. Increase in the delivery of preventive services, such as screenings and immunizations.
  - d. Improvement or maintenance of functioning, appropriate to an enrollee's health status and disability.
  - e. Testing the effectiveness of various clinical interventions.
  - f. Continuous monitoring and improvement in meeting the access needs of enrollees.
  - g. Increase in enrollee capacity for independent living.
  - h. Foster and maintain optimal enrollee involvement in care delivery.
  - i. Inclusion of the enrollee's social and emotional needs in the service delivery process.
  
- To meet the following **cost and utilization** goals:
  - a. To ascertain changes in utilization and cost patterns within this model.
  - 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.
  - c. To determine the effectiveness of the DPS risk adjustment system for this model.

The Consortium tied measures to each goal to ensure effective monitoring and to ensure that it could conduct a comprehensive analysis at the end of the three-year demonstration period. The Consortium divided the evaluation plan into domains: consumer satisfaction, provider/health plan satisfaction, quality of care, utilization and patterns of care, and costs and rate setting. As the Consortium identified and assessed candidate measures, it also articulated specific hypotheses. It then determined the data that would be needed to test the hypotheses, how the data would be collected (e.g., survey or plan operational data), which consortium member would collect specific data points and be responsible for the cost, and timing of data collection.

The Consortium applied four criteria to each candidate measure:

**Use existing data to minimize costs.** Health plans 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, health plans 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 UCare by selecting a subset of already reported measures, rather than creating new ones.

**Avoid asking respondents to provide duplicate information.** The Consortium did not want to ask study participants to provide demographic or medical information that was already available elsewhere. The members of the Evaluation Consortium signed data sharing agreements. UCare Minnesota agreed to submit a full set of encounter data claims to DHS.

**Avoid asking respondents to recall events when solid documentation is available.** For example, the Consortium 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 health coordinators.

**Minimize respondent burden.** The Consortium was concerned that multiple 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 only interviewed during one month of the year.

The Consortium developed an “Evaluation Grid” that ties each measure to a testable hypothesis, describes the source of each data point (e.g., survey or annual comprehensive assessment), who has “ownership” of the data, and how and when data will be collected.

Once the evaluation was launched, the Consortium continued to hold monthly meetings to keep participants 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 the inner workings of MnDHO.

The Consortium facilitates collaboration on the details of human study participant protections, data sharing, and data management. Consortium members constructed several “firewalls” both to blind the researchers and maintain impartiality during data analysis, and to protect the confidentiality of the study participants. One lesson learned is that, no matter how straightforward the recruitment and informed consent package is designed, people feel intimidated by lengthy documents, particularly the MnDHO population, which finds it physically challenging to sign their name, to page through documents, and to mail documents. It is best to assign one research assistant to visit each potential recruit and walk him or her 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.

## Findings

The evaluation incorporates quantitative, qualitative, and financial analyses. Initial analyses of survey and focus group data collected by the National Rehabilitation Hospital Center for Health and Disability Research (NRH-CHDR) provide an early look at the extent to which the MnDHO is meeting its overall goals.

### Longitudinal Survey of Enrollees

With funding from the National Institute on Disability and Rehabilitation Research<sup>2</sup> and the Minnesota Department of Human Services,<sup>3</sup> researchers from the NRH-CHDR constructed the Longitudinal Survey. The items in the Baseline and Longitudinal Surveys are derived from the Adult Core Questionnaires and the Adult Supplemental Questionnaires of the Consumer Assessment of Health Plans Surveys (CAHPS).<sup>4</sup> NRH-CHDR supplemented the CAHPS surveys using input from health care consumers with physical disabilities in Houston, Philadelphia, and Washington DC,<sup>5</sup> and in Minneapolis – St. Paul.

Upon enrollment, survey participants are asked a series of questions about their pre-MnDHO experience in the fee-for-service Medicaid program. One year following enrollment, participants are asked the same set of questions. As of May 2003, 88 MnDHO enrollees were recruited to participate in this survey and 35 had completed the one-year follow-up interview. Preliminary findings described herein come from responses from these first 35 participants.

In the fall of 2002, NRH-CHDR researchers also conducted two focus groups with MnDHO enrollees and two focus groups with MnDHO eligibles. NRH-CHDR asked focus group participants to provide descriptions of their experience in the MnDHO and fee-for-service programs.

### Overall Satisfaction

- Eighty-nine percent of respondents reported higher overall satisfaction rates with their health care in the year after they enrolled in the MnDHO program, relative to the year before.
- Two-thirds (66 percent) of respondents reported higher overall satisfaction with their primary care doctors in the year after they enrolled in the MnDHO program, relative to the year before. An additional 16 percent had the same satisfaction levels before and after enrollment. This specific finding suggests that AXIS and UCare

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<sup>2</sup> National Institute on Disability and Rehabilitation Research Grant # H133B70003.

<sup>3</sup> Contract # A35138.

<sup>4</sup> <http://www.ahrq.gov/qual/cahpsix.htm>.

<sup>5</sup> O'Day B., Palsbo S. E., Dhont K., and Scheer J. "Health Plan Selection Criteria by People with Impaired Mobility." *Medical Care*, 2002; 40(9):732-742.



Complete have constructed a strong, appropriate provider panel for adults with physical disabilities. The following quote from a focus group with MnDHO enrollees underscores this point:

*[AXIS] knows the [doctors] that deal in disabilities, so they kind of direct us to go to those if they're available...Because on our own, I don't think we would know which ones, unless we went to them all.*

## **Experiences with Health Care Coordination**

The following results indicate MnDHO is achieving its aim of effective coordination of enrollees' health services.

- Eighty percent of survey respondents reported that someone helped them manage health care services they received from a wide variety of sources only after they enrolled in the MnDHO program. An additional 11 percent reported that they had care coordination both before and after they enrolled in MnDHO.
- Only 11 percent of respondents stated that someone had talked to them about their health needs and created a plan for treatment and services during the year prior to MnDHO enrollment. After enrolling in MnDHO, 83 percent of respondents indicated that someone had met with them to determine their needs, and to create a plan for treatment and services.
- More than three quarters (80 percent) of survey respondents felt more comfortable with their ability to get the health services they needed after enrolling in the MnDHO program. No respondents reported feeling less comfortable after enrolling in the program.
- About three-quarters (74 percent) of survey respondents reported that they did not talk to staff (Medicaid or AXIS staff) about their health care questions and concerns, until after they had enrolled in MnDHO.
- In the year following MnDHO enrollment, about 94 percent of respondents indicated that AXIS staff was available to answer their questions on how to get health care services that they needed. Sixty-five percent of respondents reported that Medicaid staff was not available to answer their questions prior to their enrollment in MnDHO.

These findings on health care coordination reflect a lack of care coordination in the fee-for-service Medicaid program and widespread positive experiences with care coordination after enrolling in MnDHO. The following quote from a family member of a Medicaid fee-for-service client summarizes the experience of most of the focus group participants who were receiving services through the traditional system:

*I think there's a need for an intermediary between the individual and the various agencies, to protect their interest, to deal directly with Medicaid or whoever. In many, many cases, the individual simply does not have the ability to do it, nor do they have a family member to do it. They're out there attempting to do it by themselves. There are communication problems, there are depression problems, or other kinds of problems. Left up to the individual, they're fighting a no-win battle. They need competent representation and they don't seem to get it.*

This perception contrasts well with the perceptions of MnDHO enrollees, summarized by the following quotes from MnDHO focus group participants:

*...[M]y health care coordinator is always willing to help me out or go to bat for me if I need something, services or DME. I've had real good experiences with my health care coordinators.*

*It was so neat that somebody who knows you can give you the authorization. Whereas in Medicaid [fee-for-service], people never know who you are and they've never been to your house. They'll tell you either yes or no if you need something. They don't check it out.*

## **Self-Direction in Health Care**

Initial survey results suggest that self-direction in health care issues is substantially enhanced in the MnDHO program.

- Almost all (94 percent) survey respondents report being involved as much as they wanted in health care decision-making during the year following MnDHO enrollment. About 44 percent felt that they were not adequately involved in making decisions about their health care until they enrolled in the MnDHO program.
- Ninety-one percent of respondents noted that their health care providers offered them choices in the year following MnDHO enrollment. More than one third of respondents (38 percent) indicated that health care choices were given by providers only after they had enrolled in MnDHO. Fifty-five percent reported that they were given choices both before and after enrollment.

While some focus group participants from the traditional Medicaid program expressed general satisfaction with their level of involvement in health care decision making, focus group participants from the MnDHO program were all satisfied with their ability to be involved in the health care decisions that affect their lives. The following quote from a MnDHO enrollee illustrates this generally high level of satisfaction:

*My health care coordinator, she always involves me. It is our lives. They can give us all the information, but ultimately it comes down to us, what we want to do, and yeah, having them help us is great, but it comes to us making the final decision. They're there to help us with that decision. Some of these things are life changing... It's not something we take lightly, and the health care coordinators are always there to give you the pros and cons. Here's what if this happens, and if this happens. They try to help us make more educated decisions.*

## **An Emerging Recipe for Managed Care Programs for People with Disabilities**

Through MnDHO's experiences, the following elements have emerged as essential ingredients for a successful state-sponsored managed care program for people with disabilities:

- **Integration of health care and long-term care.** Mental health, acute care, and long-term care are complementary services for the population of individuals with physical disabilities. Despite separate funding streams and separate mechanisms for management and oversight at the state and local level, these services are intertwined and closely connected in the lives of individuals with disabilities. The strongest health care delivery system will be undermined by a long-term care delivery system that does not meet the needs of enrollees. The provision of case management across the continuum from acute to community setting enables appropriate utilization of resources, while minimizing cost shifting among programs and settings of care. The savings reaped from preventive services and avoidance of extended acute care can finance case management and support community services.
- **Consumer involvement.** The MnDHO program benefited greatly from extensive consumer involvement at all stages of product development. The Minnesota DHS and AXIS Healthcare both have consumer advisory boards that meet regularly to discuss program issues and provide insights to guide programmatic changes.
- **Dedication to providing high-quality services.** DHS, UCare, and AXIS Healthcare share a common goal of providing high-quality, coordinated health care services for people with disabilities, with the ultimate aim of enhancing independence and community integration among enrollees. This common goal is the foundation of the collaborative, trusting relationship that exists between each of these crucial organizations.
- **Sophisticated and evolving rate-setting methodology.** A sophisticated and detailed rate setting system must be created and maintained for a voluntary managed care system for people with disabilities to be financially viable. This system must fairly compensate participating health plans, and must be flexible and sensitive enough to respond to changes in the voluntary pool of enrollees. One important lesson learned

is that Medicaid acute care costs and long-term care costs are driven by very separate cost profiles. Therefore it was important to use different methods for adjusting payments for each of these sets of costs.

Risk adjustment methodologies for complex Medicaid populations are still in the developmental and testing stages. While the current rate cell methodology used in MnDHO is quite sensitive to long-term care needs, the Medicaid acute care costs are adjusted more minimally. Therefore DHS had intended to implement the Disability Payment System-Chronic (DPS-C) and obtained research support to develop DPS-C weights specifically for people with physical disabilities in Minnesota. Analysis of the final design indicated that DPS-C would adequately reflect acute care costs for Medicaid acute care expenditures for various key sub groups of people with physical disabilities. However, DHS, UCare, and AXIS mutually decided not to use DPS-C at the present time, because the current multi-rate cell methodology responds more quickly to changes in the mix of enrollees than a diagnostic model, which must by design include a long claims lag. As the program grows and has a larger enrollment, implementation of DPS-C will be reconsidered.

- **Disability literacy.** UCare and AXIS Healthcare have worked hard to build a provider panel that is knowledgeable about the health care needs of individuals with disabilities. The benefits of a strong and knowledgeable panel of providers have outweighed the expenditure of time and resources that is required by AXIS and UCare to research and negotiate an increasing number of provider contracts.
- **Track enrollees' health care experience in real-time.** AXIS created a relational database that allows health coordinators to track every need for, and use of services by enrollees, as well as the context in which those needs arise. This allows AXIS health coordinators to make knowledgeable and individualized service recommendations and decisions.
- **Strong relationship with CMS.** Two years before the implementation of MnDHO, the Minnesota DHS built and strengthened its relationship with CMS through the process of negotiating waivers for Medicare payment and long-term care services. Medicare-covered benefits and services are vital parts of the equation for dual eligibles.
- **Concurrent outside evaluation.** Some of the key components of successful health care collaboratives and partnerships are having a shared mission and processes to monitor progress toward reaching that mission.<sup>6,7</sup> Accountability to all stakeholders in chronic care also is important.<sup>8</sup> The monthly MnDHO Evaluation Consortium

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<sup>6</sup> Mitchell S. M. and Shortell S. M. "The Governance and Management of Effective Community Health Partnerships: A Typology for Research, Policy, and Practice." *The Milbank Quarterly*, 2000; 78(2):241-289.

<sup>7</sup> Palsbo S. E., Kroll T., and McNeil M. "Addressing Chronic Conditions Through Community Partnerships: A Formative Evaluation of *Taking on Diabetes*." A Report to The Commonwealth Fund, February 2002.

<sup>8</sup> Wagner E. H., Glasgow R. E., Davis C., Bonomi A. E., Provost L., McCulloch D., Carver P., and Sixtra C. "Quality Improvement in Chronic Illness Care: A Collaborative Approach." *Journal of Quality Improvement*, 2001; 27:63-80.

meetings facilitate continuous quality improvement and stakeholder responsiveness. A vast amount of information is being collected at a relatively small incremental cost to enrollees, the health plan, and the state.

### **Comparing Mandatory and Voluntary Enrollment Provisions**

Minnesota's experience illuminates advantages and disadvantages associated with mandatory versus voluntary enrollment into managed care programs. An advantage of mandatory enrollment is that the health plan knows the number and characteristics of enrollees in advance, allowing for more targeted planning and rate setting. Large numbers also allow the state and associated health plans to spread the random and systematic risk of utilization. Finally, the unit cost of marketing, enrollment/disenrollment, and health plan administration will be reduced when it is spread over more people.

There also are advantages associated with voluntary enrollment. When enrollment is voluntary, consumers and their advocates feel they have a "safety valve" because they can opt-out back into the system they know if the new one is not a good fit for them. Voluntary enrollment allows for stronger partnerships to be built between consumers and program administrators, since individuals with a strong desire to be involved are most likely to enroll – leading to a greater willingness to work with the health plan and care coordinators to maximize health. With voluntary enrollment, there also is strong incentive for the health plan to design a program that will attract enrollees. With smaller, voluntary programs, the health plan tends to have greater flexibility to offer services in creative ways.

The Minnesota experience suggests that the administrative burden associated with voluntary enrollment (rate-setting for an unknown enrollee population, relatively unstable risk-sharing, marketing, and enrollment and disenrollment processes) can be overshadowed by the advantages of voluntary enrollment. MnDHO, UCare, and AXIS have been able to achieve a great deal of buy-in through direct consumer involvement in program monitoring and maintenance. UCare and AXIS Healthcare have the flexibility to create individualized health care delivery programs that aim to maximize health, independence, and enrollee satisfaction.

## **Conclusion**

The early successes of MnDHO suggest that a state can successfully work with prepaid managed care plans to develop tailored programs that enhance the physical and mental well-being of adults with physical disabilities. Expert, proactive care coordination is a key component to providing Medicaid-covered services (and Medicare, when applicable) in the least restrictive setting. By empowering people with disabilities to live in the community, MnDHO could be a model for helping states to comply with the *Olmstead v LC U.S. Supreme Court* decision.

It is too early to tell if the extra cost of case management, flexible benefits, and assembly of disability literate providers results in net savings to state Medicaid programs. But it is clear that at least some hospitalizations can be shortened or avoided altogether when

people with disabilities take an active role in setting their own health management goals and form a partnership with a care coordinator.

One unanticipated and exciting development is that two AXIS enrollees are extending the collaborative health coordination model to personal care assistance. They partnered with former personal care assistants to establish and manage the People Enhancing People organization. Their objective is to increase the availability of consumer directed personal care services. This project received a large grant from the state. People Enhancing People is working to improve the process of personal care assistance using strategies such as scholarships, health insurance, and an on-call pool for backup.

Through its innovative design and initial successes, the MnDHO experiment is being watched closely in Minnesota. Less than two years into its implementation, some providers are expressing interest in creating a MnDHO-type model for other underserved populations with complex needs. Plus, DHS is exploring expansion of this targeted, voluntary model to the population of people with developmental disabilities.