CHCS

Center for
Health Care Strategies, Inc.

Resource Paper

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*Disability Care Coordination
Organizations – The Experience of
Medicaid Managed Care
Programs for People with
Disabilities*

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Table of Acronyms

APN = advance nurse practitioner (a nurse licensed to provide some medical care and write prescriptions)
AXIS = AXIS Healthcare (located in Minneapolis. AXIS is not an acronym, but is always uppercase)
BSN = bachelor of science in nursing (an RN with two more years of college training)
CCA = Commonwealth Care Alliance (private corporation in Massachusetts that contracts with Massachusetts Medicaid)
DCCO = Disability Care Coordination Organization
CHG = Community Healthcare Group (group practice of physicians located at the Brightwood Health Center in Springfield, Massachusetts)
CHP = Community Health Partners (holds a WPP contract for Medicaid elderly and disabled in Eau Claire, Wisconsin)
CIL = Centers for Independent Living (funded by the U.S. Department of Education to help people with disabilities live independently)
CLA = Community Living Alliance (holds a WPP contract for Medicaid disabled in Madison, Wisconsin)
CMA = certified medical assistant
CMS = Centers for Medicare and Medicaid Services (federal agency that administers Medicare and Medicaid)
CPT = current procedural terminology (unique, 5 digit codes copyrighted by the American Medical Association, assigned to every medical procedure)
CSHCN = children with special health care needs
DME = durable medical equipment
FTE = full time equivalent
HMO = health maintenance organization
ICS = Independence Care System (partially capitated managed care program in New York City)
ISP = individual service plan (used by all DCCOs to operationalize person-centered care)
IT = information technology
MCO = managed care organization
MDHS = Minnesota Department of Human Services (Minnesota's Medicaid agency)
MnDHO = Minnesota Disability Health Options (demonstration managed care program funded by Minnesota Medicaid targeted to people with disabilities)
MIS = management information system
OASIS = Outcome and Assessment Information Set data set that CMS uses in home health agencies to monitor quality
OT = occupational therapist
OVHA = Office of Vermont Health Access (Vermont's state Medicaid agency)
PACE = Program of All-Inclusive Care for the Elderly (a Medicare/Medicare program that allows frail elderly needing skilled nursing services to receive those services in the community instead of a nursing home)
PCA = personal care assistant (provides non-medical services in a person's home)
PCCM = primary care case management
PCPM = primary care population management (North Carolina's approach)
PT = physical therapist
PLA = personal living assistant (provides non-medical services in a person's home)
QI = quality improvement
RN = registered nurse (a two-year degree)
SCO = Senior Care Options (demonstration managed care program funded by Massachusetts Medicaid and CMS, targeted to elderly)
SPMI = severe and persistent mental illness
WNC = Western North Carolina (generally, the mountainous part of the state)
WPP = Wisconsin Partnership Program (demonstration managed care program funded by Wisconsin Medicaid targeted to elderly and people with disabilities)

I. Executive Summary

One of the greatest challenges facing every state Medicaid program is devising an appropriate and effective delivery system for its most resource-intensive beneficiaries. Children and adults with disabilities consume a disproportionately high quantity of Medicaid services, and their annual costs are increasing at the highest rate of all beneficiary groups.

One way for states to make their Medicaid expenses more predictable is capitation. Most states have turned to fully or partially capitated arrangements for Medicaid beneficiaries, and today, approximately 80 percent of beneficiaries are in capitated programs. Disabled beneficiaries are usually exempted from capitation and managed care because of fears of under-treatment, restricted access to services and providers, and poor quality.

Bucking this trend are several pilot programs. Most of them have strong roots in working with people with disabilities. The programs are taking the best attributes of managed care and reconfiguring them to improve the lives of Medicaid beneficiaries with disabilities. We visited seven pilot programs during 2004. This paper synthesizes the programs' key components and describes the challenges they face in documenting their effectiveness to advocates and regulatory agencies. A companion paper presents a strategy to report comparative measures of program outcomes.

Findings

Following are our key findings:

Findings on Mission

- The primary mission of each program is to coordinate publicly funded medical and social services. They blend attributes of social services agencies and health care agencies. We refer to these new entities as: Disability Care Coordination Organizations (DCCOs).

Findings on Scope of Coordinated Services

- Medicaid beneficiaries in DCCOs have most or all of their benefits coordinated by the DCCO.
- DCCOs targeting people with physical disabilities coordinate DME, transportation, and personal care assistance; they may also provide non-Medicaid supplements to these services (e.g., in-home wheelchair repair).
- Capitated DCCOs offer supplemental benefits, funded out of cost savings.
- PCCM and fee-for-service models are unable to offer supplemental benefits.

Findings on Care Coordination Process and Key Functions

- Engage participants in writing a self-directed, patient-centered plan of care.
- Collaborate with other agencies, providers, and vendors to meet participants' needs.
- Organize and disseminate information across all agencies and providers.

- Communicate proactively with each participant on a regular basis, timed to meet participants' needs.
- Attend clinical visits when needed.
- Available to participants 24/7.

Findings on Organizational Structure

- Organizational structures range from being a specialty service provider to a full-fledged HMO.
- The DCCO is a flexible, robust approach to support independent living in the community, and person-centered and consumer-directed care, across a variety of disabling conditions.
- Care coordination models reflect the community environment and populace they serve.
- Three "core competencies" are: service coordination, patient education, and quality improvement.

Findings on Staffing Configuration

- Caseloads range from 20-75 participants per care coordinator.
- Some DCCOs stratify their participants by resource need to distribute the coordination burden equitably across the coordinator structure.
- Most DCCOs invest significant time and resources to develop productive teams and interdisciplinary cognizance between nurses and social workers.
- DCCOs using combined nurse-social worker teams house the teams at the corporate office, providing dedicated physical space for each team.
- DCCOs embedding nurse coordinators in physician offices link them with the expertise of social workers.
- DCCOs in states with advanced practice nurses are evolving models that best utilize their education and training in the comprehensive care coordination process.
- DCCOs targeting persons with physical disabilities must address mental health issues and develop expertise among care coordinators for dealing with these concerns.

Findings on Information Systems

- DCCOs are internally developing separate and distinct information management systems for the care coordination of their complex populations.
- Extensive relational databases are needed for effective care coordination of complex populations.

Findings on Quality Management

- There are few shared measures across DCCOs, partly because they target different types of disability clusters.
- The sophistication of quality measurement and reporting (number of measures, process to select measures, input of data to create measures) varies widely across sites.

Findings on Financing of Care Coordination Processes

- Capitated entities have the most freedom to allocate resources to provide person-centered health care.
- DCCOs that charge fee-for-service for coordination services may eventually become self-sustaining businesses rather than relying on grants.
- Blended financing models (some services capitated, some fee-for-service) are common.

Findings on Origins/Catalysts

- DCCO established effective partnerships between two or more sectors (state Medicaid program, community development agency, providers, or consumer advocates).
- Involving Centers for Independent Living (CILs) is an efficient strategy to obtain organized consumer input into the design and start-up of DCCOs, even though they may play a smaller role once the program is launched.

Outcomes

- Preliminary evidence indicates care coordination reduces hospitalizations and emergency room use, and improves access to primary, preventive, and specialty care.
- Quality of life improves for participants according to self-reported data.
- Satisfaction with Medicaid is increased for participants, providers, and coordinators over fee-for-service Medicaid.
- Internal DCCO data on clinical outcomes show they are improving the quality of life and health of many participants.

Recommendations for States

States designing and implementing managed care programs for adults with disabilities should consider the following:

1. Ensure that DCCOs are grounded in the infrastructure of the community served.
2. Develop mechanisms for formal input by beneficiaries into governance.
3. Fully capitate, if possible; if not, they should at least partially capitate and ensure that DCCOs can financially benefit from care coordination savings.
4. Allow DCCOs to compile all data on carved-out services, such as mental health or pharmacy expenditures.
5. Ensure that DCCOs have a sophisticated management information system.
6. Track quality of life outcomes, in addition to satisfaction, clinical, utilization, and financial outcomes.
7. Track utilization and pay for care coordination services.

II. Introduction

People with disabilities comprise 17 percent of the Medicaid beneficiaries, but utilize nearly 40 percent of the expenditures, due largely to the intensive use of acute and long-term care services.[1] During the 1990s, many states mandated managed care for Medicaid beneficiaries in an attempt to control costs. By year 2000, 36 states enrolled their disabled beneficiaries in managed care.[2] However, it was apparent that MCOs were having trouble providing high quality care to people with disabilities, and many states subsequently waived the mandatory managed care enrollment requirement for people with disabilities.

Despite these problems in transitioning people with disabilities into managed care, many still believe that accountable health systems with many of the attributes of MCOs offer an excellent opportunity for people with disabilities to receive person-centered care in the right place at the right time.[3,4]

The Center for Health Care Strategies (CHCS) has awarded several planning and start-up grants for development and implementation of managed care coordination programs for disabled Medicaid beneficiaries of working age.

This report describes seven programs in six states, all but one a recipient of CHCS funding. First, we examine the governance, financing, benefits and services provided, operational structure, care coordination activities, and quality programs. Second, we describe similarities and differences. Last, we make several recommendations for states and advocates who wish to develop similar programs.

These programs are an emerging type of new service delivery organization that integrates health, social, and life services for people with disabilities. We refer to them as *Disability Care Coordination Organizations* (DCCOs) to distinguish them from managed care organizations (MCOs) and case management programs that focus strictly on health care services. We also use the term *participants*, rather than "members" or "enrollees," as another distinction from MCOs or primary care management programs.

Methods

We collected information during structured telephone interviews with senior managers at each venue, followed by site visits from March 2004 through October 2004. The site visits included attendance at staff or team meetings and semi-structured interviews with managers, care coordinators, providers, members of boards of directors, and participants. Topics included governance, financing, information systems, quality improvement programs and processes, description of the target and enrolled population, care coordination activities, staffing, relations with the state's Medicaid agency, operational challenges, lessons learned, and recommendations

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[1] Kaiser Commission on Medicaid Facts, 2001.

[2] Ibid.

[3] N. Highsmith and S. Somers. "Adults with Disabilities in Medi-Cal Managed Care: Lessons from Other States." *Medi-Cal Policy Institute*, September 2003.

[4] J. Sutton and G. DeJong. "Managed Care for People with Disabilities: Framing the Issues." *Archives of Physical Medicine and Rehabilitation*, 1998; 79:1312-6.

for other organizations. Each DCCO also shared salient organizational materials such as annual reports, mission/vision/goal statements, organizational charts, and health education materials.

Each site had the opportunity to review our written description of their program for accuracy. However, the conclusions and recommendations are our own and do not necessarily reflect the position of any of the sites.

Program Descriptions

The seven sites vary in target population, financing, organizational setting, and organizational maturity. They serve as examples of how care coordination is being operationalized across a broad range of Medicaid climates. The next pages provide a brief description of each site and unique characteristics. We also highlight their quality assurance programs.

ACCESS II Care of Western NC, Asheville, North Carolina

Access II Care of Western North Carolina (WNC) provides health care for 25,000 Medicaid beneficiaries in rural North Carolina under a primary care case management (PCCM) model. Established in 1998, it serves Asheville (Buncombe County) and six rural counties. Access II Care uses DCCO strategies as part of its population approach to primary care services.

Access II Care is a statewide program operating under two auspices: the North Carolina Office of Research Demonstrations and Rural Health Development (an office of the North Carolina Department of Health and Human Services) and the North Carolina Foundation for Advanced Health Programs, a nonprofit community health demonstrations entity. Access II Care of WNC is one of 13 networks operating in 2004 in "Community Care of North Carolina." Each network is an independent not-for-profit corporation, comprised of primary care physician practices that contract with the state Medicaid managed care program, Carolina Access.

Program Overview

The Access II Care organization governs and manages the three interactive program components: a council of state agencies, a physician-focused quality assurance and improvement system, and care coordination. These components collaboratively interface with each other in order to improve access to care, coordinate health care services, enhance member outcomes of care, and eliminate inappropriate costs.

Council of State Agencies. The first program component is a council comprised of representatives from nine public agencies that provide services to Medicaid children with special needs in the Asheville area, beneficiaries with complex health conditions, and high-risk enrollees, especially those with diabetes and/or asthma. This council of state agencies operates collegially to eliminate fragmented and duplicative services, and was the body that forged the vision and mission of the care coordination initiative.

Physician Quality Improvement System. A second Access II program component supports the Community Care physicians in utilizing quality reports to improve the management of Medicaid enrollees with diabetes and asthma. The physician network utilizes a web-based system,

developed by the North Carolina Foundation for Advanced Health Programs, that houses Medicaid enrollees' demographic and encounter data as basis for reports. The Access II staff compiles the reports and distributes them to the physicians. The staff interprets the reports to individuals representing each network practice. The staff and network collaborate with all member group practices to devise improvement strategies.

Care Coordination. The third program component coordinates care for high cost Medicaid subpopulations with diabetes and asthma. Case managers conduct care coordination activities from offices at Access II Care and in physician clinics. Significant outcomes of this initiative include: development of uniform standards for the care of diabetes and asthma, standard forms to assess and document care, implementation of quality improvement strategies, and development of tools to assist enrollees with self-management practices.

Unique Program Features

Access II Care of WNC has multiple unique aspects that can serve as best practice models for other states, communities, and providers. The program's primary care coordination model demonstrates how web-based technology — combined with collaboration among community public agencies and clinical systems — can enrich provider practices and improve participant health.

PCCM Model. Access II Care functions under the North Carolina PCCM system of reimbursement as opposed to a capitated, centralized care coordination system. As such, the program offers a successful role model for other PCCM systems that strive to reduce costs, limit fragmentation and duplication of services, integrate physicians into the quality improvement culture, and enhance participants' abilities to manage their chronic diseases.

Care Coordination at Two Levels. Coordinating care both at the community and individual levels is a unique contribution to the care coordination movement. Coordination at the community level, occurring through the collaborative council, is distinctive in that *all the public agencies that interact with the beneficiary* together decide on the integrated coordination plan. Proactive care coordination at the community level is one of the largest initiatives of the collaborative.

The second level of care coordination occurs at the individual case manager-participant level, operating somewhat differently from other sites we visited. While the case managers are housed in the physician office practices and collaborate interdependently with the physicians and office staff, they function independently in the case management role as opposed to a central team of care coordinators. They monitor approximately 3,000 participants assigned to their medical group for high risk indicators, while coordinating care on an individual basis for special needs children and children with diabetes or asthma.

Information Systems. A seminal and key operational component is the web-based case coordination system developed by the NC Foundation for Advanced Health Care Programs. The system serves as a longitudinal record of case management interventions, clinical outcome and process measures, and as a repository of service delivery information. The web-based tool allows the community networks to query the database on diagnoses, procedures, current and past

utilization, and all state-paid costs at the individual and family level. This information system is the linchpin in the community network physicians' ability to conduct primary care population management (PCPM) for participants with specific diseases or chronic conditions.

Quality Improvement Program

Quality improvement efforts are fundamental in each of Access II Care's three program components, although conducted with varying levels of sophistication.

Community Level Quality Improvement. First, at the community level, the collaborative council of public agencies serves as the decision catalyst for improving systems across the region. Together, council members have defined case management, established an operating protocol for the case management system, identified the need to use a traveling medical record for provider encounters, spurred the development of the web-based documentation system, and specified the case management claims codes that determine which agencies/providers are engaged in the delivery of case management services.

Provider Quality Improvement. At the provider level, Access II Care employs a nurse dedicated to quality improvement who provides onsite support to physicians, tracks progress towards state-mandated projects on asthma, diabetes, and pharmacy management, and supplies technical support through data queries, analyses, and report generation at the network and practice level. Physician groups use the reports for continuous quality improvement and to identify areas for clinical process redesign.

Care Coordination at the Participant Level. The quality of the case management system at the individual participant level is more difficult to capture as data are not always formally collected and reported. Largely, quality in the case management system is addressed through peer review and continuing education of the case managers. Further, while the core of the case management is the committed relationship between the case manager and the participant, there is a paucity of data about the processes and outcomes of case management's professional practice. Anecdotal evidence is available. For example, during a participant interview, one mother was clearly pleased with the efforts of the case manager with her family, stating that she (the mother) was now able to manage her child's care much more effectively due to the support and information supplied by the nurse. However more objective data are needed; polling provider and participant patient satisfaction levels may serve as more reliable documentation of the value of individual care coordination, while other applicable measures are identified from data in the web-based system.

AXIS Healthcare, Minneapolis, Minnesota

AXIS Healthcare was founded in 2000 by the Sister Kenny Rehabilitation Institute and the Courage Center, a nonprofit rehabilitation and resource center for people with disabilities. The genesis of AXIS was a belief that managed care delivery systems, with their integrated financing and benefits, had unrealized potential to improve the health of people with disabilities. Both founding organizations worked closely with adults with physical disabilities to design AXIS' services.

Simultaneously, Minnesota's Department of Human Services (MDHS) wanted to extend the successes of its program of coordinated care for frail elders to people with disabilities. In 2001, the state opened the Minnesota Disability Health Options (MnDHO) program to Medicaid adults age 18-64, with physical disabilities, who resided in the Twin Cities area.[5] The state identified a willing HMO partner, UCare Minnesota. AXIS Healthcare is a subcontractor to UCare Minnesota.

Program Overview

At the time of our visit in 2004, UCare Minnesota was the only HMO contracting with the state to enroll MnDHO participants. UCare Minnesota also contracts with CMS as a Medicare+Choice provider, so dual eligibles may enroll in MnDHO. MnDHO enrolls approximately 300 Medicaid beneficiaries, of which 60 percent are dual eligibles. All participants enroll in UCare Minnesota's "UCare Complete" product, receiving care and services from UCare's contracted provider network. UCare subcontracts with AXIS Healthcare to coordinate health and social services, administer member services, and authorize all referrals for UCare Complete enrollees.

Program Participants. The target population is adults of working age with limited physical function as their primary disability. The most frequently reported impairments are related to spinal cord injury, multiple sclerosis, or cerebral palsy. Most MnDHO enrollees are certified at the nursing home level of care.

Members range in age from 18-68, with an average age in the mid-40s. The enrollees mirror the racial/ethnic distribution of the Twin Cities: predominantly Caucasian, with some Hmong, Native Americans, and African Americans.

Financing. AXIS has two funding streams: a fee-for-service stream, and a capitation stream. The first stream is straightforward: AXIS bills UCare Minnesota on a fee-for-service basis for care coordination encounters.

The second stream is more complex. UCare Minnesota receives risk-adjusted capitation from MDHS and CMS to provide all Medicaid and Medicare covered services except pharmacy. Since AXIS is not licensed as a health insurer or provider, it cannot legally take on the insurance risk itself. UCare retains the insurance risk, but delegates the responsibility for managing the capitation to AXIS Healthcare. UCare processes all payments to providers.

Care Coordination. Care coordination at AXIS works to improve access through utilization supports instead of utilization controls. The care coordination staff includes registered nurses as health coordinators, social workers as resource coordinators, member services staff, and one registered nurse who conducts all assessments. At the time of the site visit, there were 12 health coordinators and four resource coordinators.

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[5] "Minnesota Disability Health Options: Expanding Coverage for Adults with Physical Disabilities," CHCS Resource Paper. October 2003.

Unique Program Features

AXIS' unique features address care coordination staffing and interactions and their commitment to a formal external program evaluation.

Care Coordination Staffing and Services. Care coordination focuses on patient education and service coordination and does not include providing nursing services directly. This was a deliberate decision by the Board of Directors as AXIS was being developed; they identified the AXIS model of care coordination as managing medical and health care, not providing care itself. Limiting the services in this way enabled AXIS to start with a much smaller financial outlay than organizations that have to meet insurance reserve requirements and pay malpractice premiums.

Their model of care coordination directly impacted the types and skill sets of the nurses AXIS hired. Unlike the sites in Wisconsin and Massachusetts, AXIS did not employ advanced practice nurses. While their registered nurses were largely educated at the bachelor's level, they were less likely to have extensive medical/surgical backgrounds, and more likely to come from public health backgrounds.

Health coordinators are registered nurses and conduct the care coordination activities, carrying a caseload each of 35 enrollees. In contrast, resource coordinators function as a resource pool for care coordination. Each resource coordinator has unique expertise, such as "the wheelchair expert" or "the housing expert" or "the PCA expert." Unlike most other sites we visited, the health coordinators and resource coordinators do not function in teams. Rather, they conduct their functions separately, but meet weekly to coordinate efforts around the needs of specific participants.

Member services staff form an administrative pool that works closely with participants, the provider network, health coordinators, and resource coordinators. Member services employees spend 80 percent of their time on the phone with members, providers, and vendors making appointments, arranging transportation for health visits, and organizing schedules for the coordinators, clinics, providers, and clients.

Program evaluation. Another unique programmatic feature employed by AXIS was commissioning an external program evaluation during the three-year start-up phase (2001-2004). This evaluation will give the AXIS Board of Directors and senior management an unbiased and scientifically rigorous audit of care coordination outcomes at the end of the start-up period. The evaluation will be presented to the board and the disability community.

Quality Improvement Program

The Quality Improvement program at AXIS evolved as the organization matured and the staff gained expertise. Initially, they largely monitored utilization and developed interventions that would improve care coordination practices and enrollees' outcomes. For example, each month the medical directors of AXIS and UCare reviewed hospitalizations, urgent interventions, and the approval and use of alternative services. A closer scrutiny of hospitalizations revealed opportunities for quality improvement: 40 percent of hospitalizations involved three largely preventable conditions: urinary tract infections, bowel impaction, and upper respiratory complications. In response, AXIS developed education materials to help members identify potential problems earlier and utilize the 24-hour hotline to report problems more quickly. Subsequently, AXIS also developed urgent clinical intervention pathways for these three conditions.

As part of the external evaluation, AXIS monitored and evaluated members' satisfaction levels and their integration into program goals and services at six months and on an annual basis. These initial efforts and their information database led to expanded developments in quality improvement efforts.

AXIS continues to formalize the quality program, recently hiring a full-time quality improvement director to expand the program. AXIS is beginning to identify measures that will allow monitoring a wider range of concerns, such as enrollees' psychosocial status and compliance with prescription medication regimens. Further, AXIS is addressing a major problem experienced by wheelchair-bound individuals – pressure ulcers. AXIS was awarded a grant from CHCS to design and implement a quality initiative for pressure ulcer prevention, detection, and management.

Information Management System. AXIS built a large relational database to manage care and social service coordination activities. The database includes the state's annual long-term care eligibility screener, contact information, and supplemental psychosocial-medical information that the health and resource coordinators require.

Commonwealth Care Alliance, Inc., Boston, Massachusetts

Commonwealth Care Alliance (CCA), incorporated as a nonprofit organization in March 2003, is a prepaid health plan providing all Medicaid and Medicare benefits to eligible enrollees in Massachusetts. This population includes individuals with physical and cognitive disabilities, children with special health care needs, elders, those with AIDS, and others with a mix of serious mental health issues and chronic illnesses. CCA evolved from one of the first care coordination programs for people with physical disabilities in the country.

CCA is an umbrella organization providing administrative services for contracted providers under three major programs:
- Elders under the Senior Care Options Program (SCO);
- Individuals between 18-65 years with disabilities and/or chronic illnesses; and
- Children with special health care needs (CSHCN), a program in development.

We visited one CCA provider site, Brightwood Health Center in Springfield, Massachusetts. Brightwood is a federally qualified community health center owned by Baystate Medical Center. Brightwood houses the Community Healthcare Group (CHG), a nonprofit clinical group practice incorporated as a clinical affiliate of CCA. A team of diverse health professionals, they provide a full spectrum of care services and care coordination for SCO participants and for working age adults with disabilities and/or chronic diseases. This report focuses on the latter program.

Program Overview

Commonwealth Care Alliance supplies a full spectrum of administrative services to its medical providers. Each primary care site is the "clinical effector arm" while CCA is the "administrator arm." This organizational model frees providers to focus care delivery without being burdened by administrative necessities. In Springfield, CCA supplies managed care administrative services including quality improvement, some member services, information technology (e-mail, member information, online care coordination forms, etc.), budgeting, and finance. The CHG group practice reports to both Baystate Medical Center and CCA.

Program Participants. At the time of our visit in fall of 2004, about 400 individuals of working age with disabilities and/or chronic care participated in the DCCO.

Brightwood Health Center is located in a predominantly Hispanic community, comprised mainly of immigrants from Puerto Rico (80 percent). The community of 11,000 is geographically isolated from the rest of Springfield by the Connecticut River, an industrial park, and the non-residential downtown section. Brightwood contains the poorest census tract in the state, with a median family income of $7,000. While the low-income housing and grounds are attractive and well maintained, the residents live with the issues commonly associated with poverty. Racism, substance abuse, police brutality, and excessive school dropout rates (only 40 percent of the children who start school actually graduate) are endemic. Fifteen percent of the community is incarcerated in any given year. Additionally, this population is at the epicenter of the AIDS epidemic in western Massachusetts, having 45 percent of the area's HIV/AIDS population. Despite their poverty and its concomitant problems, the Brightwood community maintains a population of longtime residents and stable family groups who remain because of the excellent housing and their connections to the community.

Financing. CCA originally planned to capitate the CHG physicians. This plan ran afoul of well-intentioned legislation to carve out capitated managed care for people with disabilities. In the interim, MassHealth was able to arrange fee-for-service payments under an existing behavioral health cost contract at Brightwood Health Center. Physicians and care coordinators told us that they found the fee-for-service preauthorizations and reviews much more burdensome than the Medicaid capitation model to which they were accustomed.

Currently, the care coordination services are provided as a demonstration program of the Massachusetts Department of Medical Assistance (Medicaid), receiving funds through MassHealth under a cost reimbursement arrangement. MassHealth recently received a waiver from CMS to allow several contractors, including CCA, to enroll dual eligibles and integrate Medicare and Medicaid financing. All parties intend to return to capitation as soon as possible.

Care Coordination. CHG has four leadership positions, including chief medical officer, program manager, clinical support manager, and an assistant. Twelve clinical positions are assigned among two care coordination teams and a behavioral health team that works with both care coordination teams. Each care coordination team is comprised of two advanced nurse practitioners (APNs) – one of whom is the designated team leader – a registered nurse (RN), and a certified medical assistant (CMA). Each team member has a caseload between 50-65 members. The care coordinators provide comprehensive medical and psychosocial support, with the ultimate goal being self-directed care and community integration. The CHG behavioral health team consists of a behavioral health specialist, who holds a doctoral degree, and social workers, all of whom collaborate with the care coordination teams, as well as treat members directly.

Unique Program Features

The notable features of the program are its intimate involvement in all aspects of community life, the longstanding commitment of the governance stakeholders to develop cost-effective models of care coordination for persons with disabilities and chronic disease, and the evolving model of care coordination teams.

Community Involvement. Brightwood Health Center has existed in the community for several decades. The staff is closely involved with all aspects of community life. Brightwood is a member of the health committee of the New North Citizens Council, a group of elected individuals who live in the community; in many ways Brightwood staff consider the center "governed" by the New North Citizens Council. In addition, health center representatives meet monthly with representatives of 13 organizations involved in the welfare of the community. This "campus committee" exchanges information and plans for community activities in a coordinated way. Together they organize and employ an outreach network to the 11,000 people living in the community. The outreach program encourages participation in community life to improve health, education, safety, and the economy. Brightwood staff have been particularly effective in identifying persons who are eligible for state and local health programs, reducing the community's uninsured from 16 percent to 8 percent since 2001.

Governing Stakeholders. CCA's governance system is the result of long-term relationship-building and collaboration among multiple stakeholders including the state Medicaid agency, advocacy groups (Health Care For All, Community Catalyst, Boston Center for Independent Living), and the work, vision, and commitment of Robert J. Master, MD, President and Chief Executive Officer of CCA. Dr. Master has spearheaded ongoing efforts to improve health care for disabled individuals for over 20 years and was the first physician to develop a self-sustaining business and organizational model using advance practice nurses for high-cost adults. Over the past 12 years, all partners have been focused and active advocates for vulnerable populations. With creative ingenuity, they financed, developed, and refined pilot programs of prepaid systems of care and care coordination that now serve as templates for similar arrangements in other states.

Care Coordination Structure and Function. The CCA/CHG approach to care coordination grew out of the need to address the HIV/AIDS, substance abuse, and mental illness endemic in

the community, as well as the needs of adults with physical disabilities. Each care coordination team is staffed with nursing personnel, including advance nurse practitioners (ANPs), RNs, and certified medical assistants (CMAs). A separate behavioral team provides direct mental health services for participants and also works in partnership with the care coordinators. This structure and function is unique among all the programs we visited.

Quality Improvement Program

Under the current cost reimbursement structure through the Medicaid contractor, CCA does not have access to participants' utilization and claims information. This limits CCA's ability to monitor quality. To address this gap, CCA and the CHG staff have developed an encounter system as part of their information system where the CHG staff enters the information from care coordination forms, e.g., an assessment tool, plan of care instrument, disease-specific worksheets, and chart review checklists. While this is the start of capabilities to track utilization and outcomes, the process is labor and time intensive. CCA is developing a quality management reporting system with an outside vendor for future use.

CCA also developed nine measures for CHG to monitor in 2004. These are largely process indicators covering clinical and care coordination activities: quarterly testing of HIV patients for their CD4 counts and viral load, the quarterly monitoring of updates to individual service (care) plans (ISPs), the care coordination process indicating appropriateness of treatment, patient satisfaction levels, selected preventive health measures (e.g., number of mammograms performed), integration of PCP and care coordinator interactions with the behavioral specialist about post hospitalization treatment for individuals with depressive disorders, and evidence of communication and action between the CHG staff and the department of medical assistance regarding the approval and denial of claims.

Independence Care System – New York City, New York

Independence Care System (ICS) is a nonprofit organization in downtown Manhattan. ICS coordinates comprehensive health and social services for Medicaid adults with physical disabilities in New York City, but is financially accountable for only a few of the services it coordinates. ICS is remarkable for demonstrating the incremental advantages of comprehensive service coordination outside of clinical and institutional encounters, and may be the easiest DCCO model for advocates and states to replicate quickly.

Program Overview

The scope of ICS's activities falls between AXIS Healthcare and Community Living Alliance (CLA) in Madison, Wisconsin. Like AXIS, ICS identifies disability-literate providers for its members, coordinates medical and social services, and monitors the quality of care provided to its members. Like CLA, ICS has developed a training program for home care aides. Unlike CLA, ICS does not employ PCAs.

Program Participants. ICS enrolled more than 570 participants in July 2004. Most were African American and Latino adults age 30-50, with 10 percent over age 65. About 60 percent are women, and 40 percent are dual eligibles. About 20 percent have a primary diagnosis of

spinal cord injury, 20 percent multiple sclerosis, and 12 percent cerebral palsy. Many participants have psychiatric comorbidities, substance abuse concerns, and impaired cognition. About 80 percent of ICS participants use home care aide services and the balance use personal care assistants. About 25 percent to 30 percent require 12-24 hours of home assistance, daily.

Financing. Unlike the Minnesota, Massachusetts, or Wisconsin programs for adults with physical disabilities, ICS is not financially at risk for the majority of the services it is coordinating. ICS is capitated by the New York state Medicaid program for a narrow subset of Medicaid services: long-term care, transportation, pharmacy (except HIV/AIDS medications), rehabilitation therapies, and durable medical equipment. There are two ramifications. First, ICS does not financially benefit from reduced hospitalizations or institutionalization costs that are the outcome of proactive care coordination. Instead, the financial savings accrue directly to the New York Medicaid. Since ICS can't capture those dollars, it is difficult to financially sustain the expenses of the care coordination process and ICS' operating costs.

Second, like CCA in Massachusetts, ICS cannot track their members' use of services. This creates a challenge for ICS to monitor quality of care measures such as preventive screenings, and to measure the impact of care coordination services. For example, ICS has an aggressive intervention program to fit wheelchairs to each member who needs one. This includes regular electronic pressure mapping for people at the greatest risk of pressure ulcers. Since the mapping and fitting is performed by a physical therapist, it comes under ICS' capitation rate. However, ICS does not capture the savings from prevented hospitalizations or pressure ulcer complications.

Care Coordination Structure and Function. ICS employs 20 care managers, with an average caseload of 25 participants per manager. ICS classifies members during the intake process into three levels according to their use of resources to assure appropriate care coordinator assignments and evenly distributed caseloads. Exhibit 1 illustrates the member classification system in terms of resource intensity levels, characteristics of member capabilities, and staffing requirements.

Exhibit 1
ICS Member Classification System

Resource Intensity Level	Staffing Requirements	Characteristics: Member Capabilities
Low	1 nurse, 2 social workers	Clinically stable, can advocate for themselves, but sometimes need transportation, socialization, or vocational assistance.
Medium	2 nurses, 2 social workers	Need contact about once per week.
High	2 nurses, 2 social workers	Unstable, on many medications and supplies. Degenerative conditions. See several physicians. Socialization is low. Overwhelmed by medical conditions.

Care managers work with participants to help them distinguish between *needs* and *wants*. They also work with participants to develop personal goals and learn how to make choices. For many lower-income participants, this is a novel situation because they have not been in a position to have a choice or to do long-range planning. *"Our members are not used to having choices, and they're not used to having someone with the mission of ICS — that they become independent, that they make their own choices, that they are the director, they are the consumer."* We heard similar statements expressed by care coordinators at other DCCO sites.

Unique Program Features

Unique features of ICS include its origin, its approach to wheelchair acquisition and maintenance, and its ability to open opportunities for increased socialization.

Origins. At the time it was conceptualized, people with physical disabilities had only two sources of living assistance and nursing services: institutionalization or a home health agency. The Paraprofessional Healthcare Institute is an employee-owned and directed cooperative in New York City that provides home care services to people with disabilities. It seemed a natural step to try to develop a consumer-directed company. ICS was created to fulfill that role and also to provide a mechanism for consumer-directed medical services.

Focus groups conceptualizing the planned ICS services repeatedly cited problems with transportation, timely wheelchair repair, and lack of opportunities for socialization. Consequently, ICS directly contracts with accessible van services and livery companies to transport members who can't use public transportation. ICS is trying to use its market power to negotiate safety standards, such as tie-downs for wheelchairs, and to improve reliability and customer service.

Wheelchair Maintenance and Socialization Opportunities. The consumer input also culminated in two discrete services that are not available in fee-for-service Medicaid: wheelchair repair and social participation.

- **Wheelchair repair**. ICS has eliminated the usual 6-12 month delay for obtaining wheelchairs. Wheelchairs are not issued without a home visit to ensure the equipment can fit through hallways and into elevators. ICS also provides prompt wheelchair repair service that allows participants to stay mobile. Most repairs are done within the person's home; otherwise, they are repaired at the ICS repair shop and returned within 48 hours. Participants can take a wheelchair care and maintenance class and have access to the ICS repair shop to perform preventative maintenance, such as lubrication, monitoring battery capacity, and tightening bolts.

- **Social participation**. ICS builds opportunities for social participation and recreation for its participants. ICS rents space that is dedicated for meetings, such as Weight Watchers and Artists on Wheels, which also includes a small kitchen. The participants produce a newsletter and started a writers' group.

Even though ICS is not financially responsible for major medical services, the care coordination, transportation services, and wheelchair fitting and repair are making improvements in members' quality of life. These improvements are anecdotal and have not been externally evaluated.

Quality Improvement Program

ICS has a focused approach to quality improvement. Typical measures such as reductions in hospitalizations cannot be computed since ICS is not financially accountable for medical care and does not have to submit Medicaid claims data.

Program-specific Measures. ICS approaches quality management from a unique perspective. They develop quality measures from the "bottom up," conducting studies and reporting on measures unique to the members' problems and needs. ICS is developing outcome measures that demonstrate the impact of ICS on quality of life and care — identifying measures that have reliable data input from within the program's covered services, such as financial reports and clinical studies related to member concerns.

Member-focused Quality Measures. Since 70 percent of ICS members use mobility devices (mostly wheelchairs), ICS identified pressure ulcer prevention and intervention as a key indicator of effective care coordination. The quarterly nursing assessment includes the Braden Scale for prevention and early detection. The assessment scores are tracked in a database created for this purpose. Further, ICS contracts with a physical therapist who is an expert on 3-D pressure mapping. She maps anyone who is at high or moderate risk. Finally, the nurse care managers develop appropriate interventions for each individual at high or moderate risk, including purchase of new beds; new or modified wheelchair cushions; member education; modifications of bowel and bladder routine;, and assessment/modification of diet.

ICS also selects at least one project for an annual, focused quality improvement project with the New York state peer review organization. The 2004 project focused on people with multiple sclerosis.

Performance Improvement Committee. The Performance Improvement Committee, chaired by the medical director, meets quarterly. They review enrollment, disenrollment, reasons for disenrollment and complaints. They also review quality process measures of care coordination, e.g., the results of a care plan audits, verifying that the OASIS assessment and Braden Scale, as well as new assessments were completed. The committee also evaluates progress reports on the special studies.

Vermont Medical Home Project, Montpelier and Burlington, Vermont

Medicaid beneficiaries in Vermont may enroll in a primary care coordination model (PCCM) known as "PC Plus," a program centered on precepts of the Medical Home model. PC Plus has two components. The first component supports the capacity of selected primary care practices in community health centers to serve low-income people with various levels of physical and/or psychiatric disabilities. The second component more pointedly focuses on a specific population — adults with severe and persistent mental illness (SPMI) who have diabetes.

SPMI Focus. This report focuses on the second group. The state's Medicaid agency, Office of Vermont Health Access (OVHA), conceived the idea of applying the Medical Home model for children with special needs[6] to adults with severe and persistent mental illness (SPMI). In Vermont, a diabetes nurse-educator serves as the locus for state-funded service coordination and overall care management, operating in a fee-for-service milieu. Two nurses work with approximately 50 participants.

Program Overview

The program was developed by a collaboration of the OVHA, the Vermont Center for Independent Living, and the Vermont Psychiatric Survivors organization. They observed that many Vermonters with severe and persistent mental illness (SPMI) on new psychotropic medications were gaining a significant amount of weight and developing Type II diabetes as a secondary condition, thereby increasing costs to the state Medicaid program and decreasing quality of life for the affected individuals. For many individuals, the experience of living with SPMI created a major barrier to successful self-management of diabetes.

Community mental health centers offer Vermonters an innovative recovery program. The Vermont Psychiatric Survivors hoped that the behavioral self-modification techniques used in the program could also be applied to diabetes management. Since the participants are usually comfortable coming to the centers, but very uncomfortable going to medical clinics, OVHA decided to embed the nurse-educators at the mental health centers.[7]

Care Coordination Structure and Function. The Medical Home project for SPMI has two components – one focused on linking community providers, the second centered on direct care coordination services for SPMI participants.

The objective of the first component is to integrate medical and behavioral health care in the community. The nurse care partners employed by the OVHA serve as the physical bridge, spending half of each week at offices in both the neighborhood health center and the community mental health center. The challenges the nurses face are building relationships and personal credibility with the mental health workers, educating mental health workers about project goals and resources that the nurses bring to the table, and developing a successful recruitment process for the mental health workers to steer candidates to the care partners.

The objective of the second component is to direct care coordination services and diabetes education for participants. The nurses, who had not previously worked with psychiatric patients, had to modify their personal expectations on realistic goals for the participants, and think in terms of "harm reduction" instead of "harm elimination." Each nurse care partner works with clients to learn about healthy behaviors and self-management. This is especially challenging for participants over age 40, because they've been told their entire lives that they can't make

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[6] G.S. Liptak and G.M.Revell. "Community Physician's Role in Case Management of Children with Chronic Illnesses." *Pediatrics*, 1989; 84:465-471.

[7] K. Strosahl. "Integrating Behavioral Health and Primary Care Services: the Primary Mental Health Care Model." In: A. Blount, (Ed.). *Integrated Primary Care: The Future of Medical and Mental Health Collaboration.* New York: W.W. Norton & Company, Inc., 1998.

decisions, are not self-efficacious, and have no control. The care partner sees most participants weekly or bi-weekly, usually in individual settings or a group home. She can discuss nutrition and cooking at the kitchen table while taking blood pressure readings. Many participants do not venture out of their home, so the care partner drives clients to malls or parks and walks with them. The nurses also accompany clients to at least one health care appointment, if clients are willing.

Unique Program Features

The most unique feature of the Vermont Medical Home Project is that it combines and applies a variety of new philosophical approaches and conceptual models to SMPI treatment and recovery, including the Chronic Care Model,[8] the Strosahl model for mental health in primary care practice,[9] the concept of the Medical Home,[10] the Flinders Model,[11] and Mary Ellen Copeland's Wellness Recovery approaches.[12]

Provider Communication Links. While the program was too new for us to document outcomes at the patient level, the nurse educators' dual presence at health and mental health centers have already had a profound, positive impact on community providers. The psychiatric providers reported that they have changed the way they practice: they now address aspects of their patients' general health, monitoring basic medical information such as weight, pulse, and blood pressure. They reported consistent two way communication between mental health providers and general practitioners. Both physical and mental health providers told us they are seeking ways to share relevant patient information without compromising state privacy laws. The nurses bridge the professional silos and open lines of communication and coordination. This situation makes the providers more confident that the patients' physical and mental health will improve.

The project staff's future vision includes integrating the medical problem list with the mental health problem list, so the care partner can coordinate care across the spectrum. They believe this will bring multiple advances: improved access to care, and more comprehensive treatment approaches. They also believe that medical and behavioral providers will gain a more holistic view of an individual's health problems, and not assume that physical symptoms are psychosomatic or imagined, or ignore physical problems in mentally ill persons.

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[8] The Chronic Care Model was developed by Ed Wagner, MD, MPH, Director of the MacColl Institute for Healthcare Innovation, Group Health Cooperative of Puget Sound, and colleagues with support from the Robert Wood Johnson Foundation http://www.improvingchroniccare.org/change/model/components.html

[9] http://www.centerforhealthyaging.com/NatPsychArticles/May_June_2001.htm

[10] American Academy of Pediatrics http://www.medicalhomeinfo.org/training/

[11] Flinders Human Behaviour & Health Research Unit, Flinders University, Adelaide, Australia

[12] http://www.mentalhealthrecovery.com/

Quality Improvement Program

Specific quality measures for the project are not yet available for this pilot project. As proxy measures, the Care Partners are tracking indicators of good disease management and improved access to care, such as HgA1c levels in persons with diabetes or peak flow meter readings for clients with COPD or asthma.

OVHA plans to mine its claims data to measure changes in standard physician and hospital utilization data for program participants. OVHA is also working with the primary care sites to assign CPT codes to different types of care coordination encounters such as care plan oversight, team conferences, and phone calls related to client encounters. Ultimately, OVHA would like to look at the relationships between the volume of care coordination services and medical costs. OVHA feels that all sites need continued training and assistance on quality improvement methodologies, including the continued formalization of site-specific aims and measures.

To promote the project's viability and sustainability, OVHA convened a summit for multiple stakeholders in September 2004. The summit's purpose was to evaluate progress to-date, identify what was needed to expand the program, consider changes that would achieve greater effectiveness, specify hurdles, and develop an action plan. The greatest challenge will be creating a marketing package to persuade state legislators and funding agencies to continue the intervention.

Wisconsin Partnership Program

The last two sites we visited are organizations participating in the Wisconsin Partnership Program (WPP). WPP, operated by the state's Medicaid agency, the Department of Health and Family Services (DHFS), is an integrated health and long-term care program for the frail elderly and people with disabilities, combining services traditionally provided by Medicare, Medicaid, and home and community-based waiver programs. The WPP contracts with several community-based organizations located in different regions of Wisconsin. Over time, each site will be able to serve 600 members.[13]

We visited two of the four existing WPP sites that serve adults with physical disabilities: Community Health Partnerships (CHP) in Eau Claire, and Community Living Alliance (CLA) in Madison. While both are unique organizations, they have many similar operational features, as they both belong to the WPP.

Community Health Partnership, Eau Claire, Wisconsin

Community Health Partnership, Inc. (CHP), incorporated as a 501(c)(3) in 1998, provides health care, long-term support services, and care coordination for both the frail elderly and working age adults with disabilities in west central Wisconsin. In 2004, CHP was the only program in WPP serving both the elderly and adults with physical disabilities between 18-65 years.

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[13] http://www.dhfs.state.wi.us/wipartnership/

Program Overview

CHP's service area is both urban and rural, covering three counties: Dunn, Eau Claire, and Chippewa — an area of 2,500 square miles. Distances and the rural nature of much of the service area impart some challenges to timely access to services.

Benefits and Services. CHP participants receive a variety of benefits and services that include the standard Medicare, Medicaid, and/or PACE benefits, including care coordination, as well as additional individualized benefits. However, a CHP core practice is person-centered care, reflected by the ability to supply additional benefits and services that meet each participant's unique needs.

Finances. CHP is capitated under Medicare and Medicaid. In the planning and start-up stages, CHP received funding from the Wisconsin Department of Health and Family Services and the Robert Wood Johnson Foundation. This enabled CHP to meet initial risk reserve requirements and administrative costs. CHP now bears 100 percent of the financial risk. CHP receives a capitated amount from the state for each member enrolled, using a formula based on 95 percent of area nursing home costs; additional factors are included in the capitation rates such as level of care, age, sex, and a ratio of nursing home versus community living situations. CHP obtained an HMO license in 2005.

Member population. CHP membership totaled 550 in mid-2004, all certified at the nursing home level of care, though only 7 percent of the CHP members reside in nursing homes. The elderly population (age 65 years and over) comprised 63 percent of the membership while adults with disabilities (age 18-64 years) totaled 37 percent. Enrollment figures for both groups have increased at an average rate of 25 percent per year. Approximately 85 percent of all CHP members are dually eligible for Medicaid and Medicare, including 55 percent of the participants with physical disabilities. Like AXIS Healthcare and ICS in New York, CHP has enrolled about two members per month directly from nursing homes over the past three years, and assisted them with moving back into the community.

The racial distribution mirrors local demographics and is largely Caucasian. The most significant minority population, Hmong (Cambodian), presents service delivery challenges occasionally because of language barriers and different cultural practices.

Providers. CHP contracts with a large diverse network of provider types: three health care systems (Mayo Health System, Marshfield Clinic, and a group of independent providers who have formed an alliance), 130 primary care physicians in 24 clinics, five hospitals, three county human services departments, 22 nursing homes, four home health agencies, 19 community residential facilities, six transportation vendors, and three adult day care providers.

Care Coordination. CHP staff RNs and APNs provide both care coordination and direct medical and health services to its members. Ten teams provide care coordination services, with an average of 60 members assigned to a team. Teams are composed of six members: one nurse practitioner, two RNs, two social workers, and one technical assistant. The team members work in pods where they have close contact with each other, facilitating timely communication.

The Individual Service Plan (ISP) is central to providing consistent care for CHP members. The ISP serves as the framework for identifying each member's unique needs, and outlines the benefits and services required to meet needs and maintain independence. Each team meets weekly to confer about the members assigned to the team, provide updates, and highlight progress.

Unique Features of the Program

Community Health Partnership's three unique features are the leadership style of its executives and staff, the organization's culture of quality improvement, and the innovative information management system.

Leadership. The leadership of CHP ascribes to the precepts of Servant Leadership.[14] Executives, managers and staff function in open, supportive relationships that have created a culture of collegiality and team work.

Quality Culture. Quality management, quality assurance, and quality improvement are embedded in the culture of CHP. Quality of care is approached openly and discussed regularly among the managers and the staff. The focus on quality starts at the top, specifically listed as one of CHP's goals.

Staff immersion in quality was evident during our 2004 site visit. In addition to following the formal quality program, the care coordination staff had conducted 28 individual independent quality studies. Posters describing each study were prominently displayed in meeting and conference rooms, attesting to the staff's enthusiasm, creativity, and efforts to improve organizational life and the members' health.

This culture of quality is shared with the other three WPP organizations. The CHP Quality Improvement Coordinator meets regularly with coordinators from other WPP sites, and they standardize their outcomes reporting. They hope to begin valid comparisons among themselves, as well as to other managed care organizations. Another focus for this group is to regulate the review and evaluation of nursing homes where their members reside, standardizing their assessment of nursing home performance and quality.

Information Management System. CHP approaches claims processing, care coordination, and information management as core competencies. They use the claims data to populate an internally developed large relational database that houses cost, utilization, diagnostic, and demographic information. This database is the foundation for state-required reports including costs, utilization, hospital admissions, emergency room use, nursing home days, and overall medical expenditures and expenses for 13 specific prescriptions including insulin, diuretics, Lipitor, and protease inhibitors.

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[14] R.K. Greenleaf. *The Servant as Leader*. 1970. Reprinted in 1991 by The Robert K. Greenleaf Center, Inc., Indianapolis IN.

CHP also constructed an electronic care coordination documentation system used by the care coordinators to record health care events and evaluations. The state periodically does a medical chart review of CHP's electronic documentation.

CHP employs a Visual Basic 6 programmer who writes user-friendly interfaces for managers and care coordinators to retrieve and explore information in the data warehouse. CHP is moving towards a consolidated information system that will integrate inventory, financial, and care coordination reporting capabilities. Both CLA in Madison and ICS in New York City have adopted CHP's interface.

Quality Improvement Program

The organizational Quality Improvement Plan is the core of the quality program. It focuses on improving the performance of clinical and support activities, ultimately aimed at enriching member care and services. The plan has clearly articulated goals and addresses services, processes and outcomes. It aligns with the state's plan for quality improvement and uses standard clinical process improvement methodologies including the PDSA (Plan, Do, Study, Act) cycle and the BCAP (Identification, Stratification, Outreach, and Intervention) methodologies. Quality improvement is well rooted in theory, similar to the leadership styles.

Operationally, processes and outcomes of care coordination are monitored by, and reported to, the staff on a monthly basis. CHP has an active quality improvement committee with representatives from the quality and information technology departments, clinical teams, office staff, and daily living assistants, and anticipate a consumer will be included in the near future. The purpose of this committee is to monitor initiatives and share outcomes throughout the organization.

Community Living Alliance, Madison, Wisconsin

Community Living Alliance (CLA) in the city of Madison is another WPP organization. CLA, similar to ICS in New York, grew out of a community development agency and a strongly articulated need by adults with physical disabilities for personal care assistance. CLA operates largely in an urban area, similar to ICS and AXIS Healthcare, but includes some rural areas, as well. CLA operates similarly to its WPP partner, CHP, in that it is a health care payer, as well as a care coordinator of medical, health, and psychosocial services.

Program Overview

Benefits. CLA coordinates the members' medical and mental health care and provides nursing and personal care assistance. Members receive all Medicaid and Medicare covered benefits as well as additional person-centered benefits. Most services are provided in members' homes.

Financing. Like CHP and UCare Minnesota, CLA is capitated and holds both Medicare and Medicaid contracts. About 60 percent of members are dual eligibles. The capitation is risk-adjusted. In 2005, it became a fully licensed HMO.

CLA has a separate funding stream for pharmaceuticals and mental health services. Because public mental health services are provided through the county, CLA has contracted with the county as one of their mental health and substance abuse providers.

Target population. In 2004, the CLA membership totaled 694 individuals, including 290 members with physical disabilities and multiple co-morbidities in the Wisconsin Partnership Program. Twenty-five percent of CLA members are racial/cultural minorities, largely African American. CLA differs from CHP in Eau Claire in that it only serves individuals with physical disabilities age 18-64 years, whereas CHP also serves the frail elderly.

By program design, individuals with primary mental health disorders are excluded from the membership. However, CLA discovered that 60 percent of the WPP target population had diagnoses of mental health problems and substance abuse. Consequently, all care coordinators are given in-service training on mental health conditions. In 2004, CLA formed two specialized teams with mental health and substance abuse experience for members needing these services.

Voluntary disenrollment is minimal. Involuntary disenrollment includes death, functional and financial ineligibility, or moving out of the service area. Members who improve their health may lose eligibility because they no longer meet a nursing home level of care. This causes problems because the participants lose care coordination services until they deteriorate enough to regain eligibility. CLA is exploring the possibility of providing their services to the SSI population to prevent interruptions in care coordination.

Care Coordination Structure and Functions. Like CHP, UCare Minnesota, and CCA in Massachusetts, CLA contracts with a diverse network of provider types: primary care physicians, specialists, hospitals, clinics, durable medical equipment (DME) suppliers, transportation providers, and pharmacies. CLA offers seminars for physicians to develop their disability literacy. About 90 percent of the provider panel attended a seminar on the mental health aspects of people with physical disabilities.

About 66 people work in the WPP care coordination program. Eleven teams provide care coordination services, each team having an average caseload of 32 members. Each team includes a 0.5 FTE nurse practitioner, a registered nurse (90 percent have a BSN), a social worker, and a 0.5 FTE team coordinator. Nurse practitioners serve as the major conduit of communication and information sharing between primary care physicians and the team; physicians value the doctor-nurse practitioner collaboration because of the accountability and follow-through. Social workers provide counseling and access to psychosocial services, and the RNs focus on health education, home visits, and maintaining continuity of care. Each team reports to a supervisory team of a registered nurse and a social worker. The team members work together in a pod office arrangement to ease communication and collaboration. Additionally, the teams share the services of three RNs who coordinate personal care services.

Unique Program Features

The unique features of CLA are its governance system, the extensive, formal personal care assistance program, and the manner in which CLA manages durable medical equipment and medical supplies.

Governance. Governance of the CLA organization includes the state, the organizational board of directors, the staff, and program participants. CLA is first a membership organization, encouraging members to participate in governance and contribute their ideas and opinions about how CLA can better serve the community.

Members serve on focus groups, the board, and the committees. CLA's bylaws regarding the board of directors, like those of CHP, require that at least half of the board be CLA members. Of the 15-member Board, 70 percent have a disability, and another 15 percent know someone with a disability.

The Board adopted a conceptual approach to governance based on the work of John Carver,[15] articulating a very clear vision about its role in governing CLA. Board responsibilities include:

- Representing the interests of the members;
- Strategic planning;
- Establishing and monitoring organizational goals;
- Hiring, monitoring, and evaluating the executive director.

Personal Care Assistance Program. Like ICS in New York, CLA commits to maintaining a well-trained core of staff to provide personal care assistance. However, while ICS contracts with a corporate partner to provide these services, CLA sponsors and operates a large personal care program within the organization. The director, himself a quadriplegic, is a role model for members.

CLA employs and trains over 700 full and part-time personal living assistants (PLAs) to support members with personal care assistance in their homes. All PLAs are trained on a continual, consistent basis by the health professional staff; over two-thirds of the PLAs are family members.

Medical Supply and DME Management System. A unique CLA cost-management innovation is the management system for durable medical equipment (DME) and medical supplies. CLA staff includes two physical therapists (PTs) and an occupational therapist (OT) who work in partnership with the care coordination teams. The PTs and the OT assess the home environment and the patient to define the need for adaptive aids. The medical supply staff orders the equipment and confers with the care coordination team. A standing resource allocation committee (the "RAC") develops health and safety guidelines for providing equipment not traditionally covered by Medicare or Medicaid, such as an air conditioner.

CLA has used its market power to negotiate favorable contracts with vendors for both purchase and maintenance of equipment and medical supplies. Through bulk purchasing, CLA is sometimes able to pay less than the Medicaid rate. CLA employs a medical supply manager and an assistant to manage the program. For 80 of the 280 partnership members (27 percent), the medical supply manager prepares one month's worth of supplies for each member, packages

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[15] J. Carver. *Boards That Make a Difference: A New Design for Leadership in Nonprofit and Public Organizations*, 2nd edition. San Francisco: Jossey-Bass Inc., 1997.

them together, and then has them delivered to the individual's home. Members with less predictable needs call up and have a package mailed to them, or the PLA will pick up the supplies when attending, training, or turning in a timesheet at the CLA office.

Quality Improvement Program

The Quality Improvement program began in response to the state's requirement that each WPP conduct two studies annually. The QI program has evolved over the past six years to encompass organizational concerns such as ongoing member satisfaction, provider and staff credentialing, competencies and availability, as well as the traditional reporting of complaints, appeals, and benefit utilization (e.g. hospital, emergency department, residential care, DME/supplies, and personal care). Additionally, there are multiple quality improvement projects with a focus in 2004 on managing diabetes, obesity, and wound care.

CLA's active QI Committee includes the director of the quality department (who is a leader with other WPP organizations in developing quality improvement across the state), a data analyst, two social workers, two registered nurses, a nurse practitioner, the medical director, the compliance manager, a representative from provider relations, and the building receptionist, who is the first line "ambassador" for CLA and hears many of the member complaints and compliments.

CLA is testing some quality measures that will give them actionable information and also measure its performance: number of contacts, documentation, peer review of charts for content and follow-through. CLA has a "Basic Pathway" which includes a quarterly (first enrollment year) or semi-annual psychosocial interview with the participant to ensure that all issues are being addressed, not just the crisis of the moment.

Information Systems. CLA's information system, adapted from the CHP system, is comprehensive. It includes an electronic medical record interface with the University of Wisconsin. This enables the nurse practitioners to review hospital medical records in real-time, such as lab results and hospital-based office visit information. CLA sees this ability as "indispensable" as it also permits the medical director to monitor the quality of medical charting on participants in the hospital.

CLA uses an internally developed system, visualPrime, to house and manage claims information, case management documentation, as well as health record documentation. Modules include members' assessments, encounters with care managers and providers, health information (e.g. diagnoses, medications, orders, lab results) and prior service authorizations. The case management system integrates all member information into the plan of care, the centralizing document for coordinating member services.

III. Findings

The previous chapter illustrates the broad array of the pilot DCCOs. While no two are exactly alike, similar characteristics are shared across the programs. In this chapter, we organize most of the information into matrices. Each matrix is accompanied with a narrative description of our observations and one or more key findings. We first address the targeted populations, the services arranged by the DCCOs, the process DCCOs used to provide those services, the

organizational structure and staffing of the coordinators, and the information systems they use. We then touch on the engines that keep the DCCOs information systems and finances running. Finally, we compare the origins and catalysts of the DCCOs and show how these impact the DCCO governance.

Participants' Characteristics

All sites we visited target very specific populations, such as "adults with physical disabilities" or "low-income adults with severe and persistent mental illness." This keeps the DCCO focused on closely related functional types of disability (mental illness or physical disability) (Exhibit 2). The focus may reflect that most programs are still in start-up stages.

Exhibit 2
Service Populations by Program

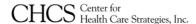|	Adults with physical disabilities	Adults with behavioral disabilities	Adults with complex medical and health needs	Children/families with chronic conditions/ complex social needs
A2C				X
AXIS	X		X	
CCA	X	X	X	
CHP	X		X	
CLA	X		X	
ICS	X			
VT		X	X	X

A2C=Access II Care of Western North Carolina, Asheville NC
AXIS=AXIS Healthcare, Minneapolis, MN
CA=Commonwealth Care Alliance, MA

CHP=Community Health Partners, Eau Claire, WI
CLA=Community Living Alliance, Madison WI
ICS=Independence Care System, New York City, NY
VT=Vermont Medical Home Project

Benefits and Services

All participants are eligible for all benefits and services covered by Medicaid in their state. However, DCCOs vary in the specific benefits they coordinate and for which they are financially at risk (Exhibit 3). Capitated DCCOs fund their operations within the specified rate and are able to offer supplemental benefits and services that facilitate independent living, such as additional hours of personal care assistance and home renovations to accommodate wheelchairs. Some fee-for-service DCCOs bill care coordination services directly to the Medicaid entity or have care coordination subsidized by grant funds. These programs are unable to offer additional, need-specific services outside the state's scheduled Medicaid benefit package.

Exhibit 3
Benefits and Services Coordinated by the DCCOs

	A2C	AXIS	CCA	CHP	CLA	ICS	VT
Care coordination	X	X	X	X	X	X	X
Mental health/behavioral treatment services		X	X	X	X	X	X

	A2C	AXIS	CCA	CHP	CLA	ICS	VT
Acute care	X	X	X	X	X		
Long-term care including nursing home care		X	X	X	X	X	
Home health care		X	X	X	X	X	X
Outpatient care	X	X	X	X	X		X
Durable medical equipment		X	X	X	X	X	
Medical supplies		X	X	X	X	X	
Transportation		X	X	X	X	X	X
Medication management			X	X	X	X	X
Adult day care				X	X		
Supplemental benefits		X		X	X	X	

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ICS=Independence Care System, New York City, NY
VT=Vermont Medical Home Project

Findings on Scope of Coordinated Services
- Medicaid beneficiaries in DCCOs have most or all of their benefits coordinated by the DCCO.
- DCCOs targeting people with physical disabilities coordinate DME, transportation, and personal care assistance; they may also provide non-Medicaid supplements to these services (e.g., in-home wheelchair repair).
- Capitated DCCOs offer supplemental benefits, funded through cost savings.
- PCCM and fee-for-service models are unable to offer supplemental benefits.

Care Coordination Process

Patient-centered, self-directed comprehensive service coordination is the hallmark of DCCOs, and the process is remarkably similar regardless of the target population. All sites conduct a comprehensive intake assessment within a few weeks of enrollment, concurrently engaging the participant in an orientation process that establishes the participant-DCCO partnership. The medical and psychosocial assessment identifies service needs. The DCCO engages the participant in setting priorities and devising an individualized service plan. Most sites electronically record the intake psychosocial information into the care coordination database. The participant is assigned a personal care coordinator or coordination team who serve as the primary partner and liaison between the participant, providers, and the DCCO.

Self-direction and patient-centered plans. The chief mechanism DCCOs use to engage participants in self-directed care is the individualized patient-centered service plan. Most sites try to have the plan in place within one month of enrollment. Sites vary in how frequently the plans are updated (ranging from quarterly to annually); but all sites adjust the plan as goals are achieved or when new services are needed.

Most sites find that many participants are unfamiliar with setting long-range goals or making decisions. Several coordinators believe this is a consequence of poverty rather than disability. Thus, care coordinators may invest a large percentage of their time with new participants in basic instruction about decision-making and planning.

Care coordinators at all sites also reported similar challenges in fostering behavioral change among their clients, such as controlling diabetes or substance abuse. The coordinators invest heavily in patient education and coaching to get participants "ready to change." Most new care coordinators scaled back their initial expectations from solving all problems at once to a pace that is comfortable for the participant. For example, several venues employ harm reduction as long-term goals, rather than harm elimination (e.g., reduce the number of alcoholic drinks rather than total abstinence).

Despite the emphasis on self-direction, all DCCOs have learned that some participants are not interested in having an active role in their health planning. One coordinator said these participants suffer "fear and fatigue" from repeated battles with the health care and social service system. It may take a much longer time to build trust, interest, and competence in self-direction among these individuals.

Health Visit Support. Another feature all DCCOs share is the practice of having care coordinators accompany participants on physician visits, serving as an educational conduit between participants and providers. Both participants and physicians report that many encounters are much more productive when a care coordinator attends. The coordinator serves as an objective and informed intermediary, as well as an expert informational resource about available community resources. The coordinator, knowledgeable about all aspects of the participant's life, knows the best questions to ask, interprets the responses in ways the participant can understand, and assists the participant to follow through on the physician's instructions, such as filling prescriptions or making appointments with specialists. Eventually, many participants and physicians learn how to interact more effectively with each other and the coordinator does not need to be present. Other participants, particularly people with cognitive impairments, always have a care coordinator present.

Organize Information. Most sites help their participants gain control over their lives by shouldering the burden of scheduling appointments and arranging for reliable transportation services. The care coordinators corral all of the physician orders and diagnostic testing values, often electronically. Some DCCOs help the participants learn organization skills by issuing a binder to hold paper copies of appointment schedules, contact information, and physician orders.

Bridge Community Resources. Care coordinators work with multiple social service agencies, particularly housing. Most sites also work frequently with public transportation and adult foster care services. Several sites were able to deinstitutionalize participants by helping family members or friends obtain state licenses to provide home care services as PCAs or foster homes.

Constant communication. All care coordinators proactively communicate with participants on a regular schedule. The schedule is adjusted to meet the participants' needs, with some having daily contact and others contacted once a month. Care coordinators told us the proactive outreach is crucial in detecting social or medical problems before they prompt a crisis. Most DCCOs issue a cell phone to each care coordinator, and most care coordinators are available around the clock to their patients.

Findings on the Care Coordination Process

Care coordination includes the following key functions:

- Engage the participants in writing a self-directed, patient-centered plan of care.
- Collaborate with other agencies, providers, and vendors to meet participants' needs.
- Organize and disseminate information across all agencies and providers.
- Communicate proactively with each participant on a regular basis, timed to meet the participant's needs.
- Attend clinical visits when needed.
- Be available 24/7.

Organizational Structure

Exhibit 4 shows how each DCCO assembles resources to execute service coordination. All DCCOs have service coordinators and patient educators on staff. All have in-house quality improvement programs and an information system to support the care coordination process through real-time monitoring of utilization and service needs. All but one DCCO also uses nurses in surveillance and treatment roles. We conclude that these are core functions of the coordination programs.

These core functions operate under a variety of corporate structures. The two Wisconsin DCCOs and ICS are the most like HMOs, including processing their own claims and providing nursing care. In fact, the two Wisconsin organizations will obtain HMO licenses during 2005.

At the other end of the spectrum are the Vermont and Asheville projects, which are similar to having an external consulting provider. AXIS Healthcare is a stand-alone corporation that sells its specialty case management services to an HMO. CCA in Massachusetts is a stand-alone corporation that is directly capitated by the state and outsources most services including providers, claims payment, and software/IT.

Exhibit 4
Delivery System Elements

	A2C	AXIS	CCA	CLA	CHP	ICS	VT

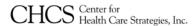|	A2C	AXIS	CCA	CLA	CHP	ICS	VT
Organization Type	Contracted by physician network for specialized services	Contracted by HMO for specialized services	Partners with community health centers for add-on services	HMO	HMO	Abbreviated HMO	Partners with community health & mental health centers for add-on services
Service coordinators	On staff	On staff	On staff	On staff	On staff	On staff	On staff
Quality improvement	In-house	In-house	In-house	In-house	In-house	In-house	In-house
Claims processing	Outsourced to state	Done by HMO	Outsourced to developer in a joint venture	Out-sourced	In-house	In-house (only the services for which it is capitated)	Performed at the state level
Provide nursing care	Yes	No	Yes	Yes	Yes	Yes	Yes
Patient educators	In-house	In-house	In-house	In-house	In-house	In-house	In-house
Medical care arrangements	Contract with Medicaid providers	Conducted by HMO	Contract with Medicaid providers	Contract with Medicaid providers	Contract with Medicaid providers	None, refer participants to willing providers	Contract with Medicaid providers
Information systems for care coordination	In-house	In-house	In-house (partnership to develop)	In-house	In-house	In-house	Pen-and-paper

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Findings on Organizational Structure

- Organizational structures range from being a specialty service provider to a full-fledged HMO.
- The DCCO is a flexible, robust approach to support independent living in the community, person-centered care and consumer-directed care, across a variety of disabling conditions.
- Care coordination models reflect the community environment and populace they serve.
- Three "core competencies" are: service coordination; patient education; and quality improvement.

Staffing Configuration

Each DCCO developed its own staffing configuration (Exhibit 5). The only shared feature is the employment of both social workers and nurses within the organization. However, the interaction of social workers and nurses varies, with some sites configuring them into interdisciplinary teams, and other sites keeping them independent.

Exhibit 5
Comparison of Care Coordination Structures

	Title	Practice	Caseload	Professional Discipline
A2C	Case Manager	Independent	1:3,000 to monitor; 1:75-100 medium-high risk; 1:350-400 low risk	RN, SW, health educators, substance abuse counselors
CHP	Care Coordinator	Team	1:20	APN, RN, SW
CLA	Care Coordinator	Team	1:32	APN, RN, SW
AXIS	Health Coordinator	Independent	1:25	RN, SW
ICS	Care Manager	Team	1:30	RN, SW
CCA	Care Coordinator	Team	1:50-65	APN, RN, CMA, MH/SA counselor
VT	Care Partner	Independent	1:20	RN, SW

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Titles

All sites carefully considered which title to use for the staff coordinating care. Access II Care uses "Case Manager," while ICS uses "Care Manager." The two Wisconsin programs and CCA use the term "Care Coordinators" because their members did not want to be "managed." AXIS Healthcare chose "Health Coordinator" and "Resource Coordinator" for similar reasons, and also to denote the different functions and organizational arrangement of staff. Vermont chose "Care Partner" to emphasize the active partnership of participants with providers in the treatment and recovery from mental illness.

Team Models of Service Coordination

Five of the programs adhere to the team model of care coordination. Teams exist in two configurations: interdisciplinary and collaborative. Team composition depends on the DCCO's mission, benefits structure, and target population.

Interdisciplinary. Interdisciplinary teams consist of nurses and social workers functioning together on the same team. The two Wisconsin plans, geared to adults with physical disabilities, have teams of one advanced practice nurse (APN), two RNs, a social worker, and a medical assistant. ICS in New York has teams comprised of RNs and social workers. Interdisciplinary team members generally share a room or office pod, facilitating the sharing of information and expertise in meeting participants' needs. Occasionally, this arrangement conflicts with privacy issues when conversing with participants; in such cases, the coordinators move to a place that ensures confidentiality.

Collaborative Teams. Collaborative teams are separate teams of nurses and social workers who work in partnership to meet participants' needs, such as those in Massachusetts and Minnesota, and, to a degree, in Vermont and North Carolina. In Massachusetts, care coordination teams are composed of different types of professional nursing personnel – two APNs, an RN and a certified nursing assistant. The CHG behavioral health team, lead by a counselor prepared at the doctoral level and comprised of social workers experienced in mental health and substance abuse rehabilitation, provide direct services to participants, as well as collaborate with the CHG care coordination teams.

All sites had to invest time and effort in creating functional, productive teams whose configurations continue to evolve in response to the search for the most effective structures. Nurses and social workers, in their separate disciplines, have distinct expertise and skills which bring value to DCCOs and their participants. However, professional education instills professional boundaries that can cause challenges in inter-professional relationships. The DCCOs try to overcome these constraints by training staff in group collaboration and communication.

Independent Practice Models of Care Coordination

Three of the programs have models where the care coordinator functions autonomously, yet is linked to other professional resources within the organization. Two DCCOs embed nurse coordinators in physician offices (Vermont and Access II Care). They function as liaisons between different types of teams with dual reporting responsibilities. Vermont's Care Partners are based one-half of their time in the community mental health center collaborating with the behavioral health staff; the other half at their neighborhood health center office collaborating with the medical providers. They independently partner with participants in planning and coordinating care and health education. Organizationally, they report to supervisors at both sites.

Access II Care coordinators function somewhat differently. The Case Managers are located full-time in a physician group practice office, where they interact with the office team and independently serve program enrollees. Case Managers report organizationally to both the Access II Care director and to their physician group.

AXIS Healthcare puts nurses and social workers into separate departments of care coordination services – nursing and social work. Nurses, the health coordinators, coordinate care and services independently for their assigned caseload. Social workers, the resource coordinators, are organized into pools. They have specialized areas of knowledge, e.g., "wheelchair expert" or the "housing expert," which the health coordinators draw upon as needed.

Advanced Practice Nurses

Several sites are located in states that license advance practice nurses (APNs) to prescribe or renew some medications, conduct medical assessments, and stipulate therapeutic regimens – expertise that complements and extends primary care medicine. Several programs capitalize on these capabilities. In Massachusetts, CCA uses APNs as team leaders and primary care providers. In Wisconsin, CHP and CLA are using APNs as part of an urgent care resource pool for teams, and as primary communication conduits with physician providers. All three sites are still experimenting with different arrangements of linking APNs to community physicians.

Mental Health Services

Mental health concerns are significant in populations with disabilities. Mental health issues including substance abuse, anxiety, and depression exist as comorbidities in 50 percent to 60 percent of their participant population. All four organizations targeted to people with physical disabilities learned through experience that they had to address mental health needs. AXIS contracts with an external mental health consultant to advise on cases. Both the Wisconsin programs include social workers on the care coordination teams. The WPP program director in CLA, Madison WI, is a psychiatric RN with executive administrative experience in psychiatric hospitals, and provides in-service training sessions on mental health treatment to both staff and community physicians. Further, CLA recently established two behavioral health teams. The CHG physicians in Springfield, Massachusetts draw upon their staff psychologist, who leads the behavioral health team of social workers in treating patients and collaborating with the care coordination teams.

Findings on Staffing Configuration

- Nurse coordinators are either teamed with social workers or collaborate with them independently.
- Caseloads range from 20-75 participants per care coordinator.
- Some DCCOs stratify their participants by resource need to distribute the coordination burden equitably across the coordinator structure.
- Most DCCOs invest significant time and resources to develop productive teams

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and interdisciplinary cognizance between nurses and social workers.

- DCCOs, using combined nurse-social worker teams, house the teams at the corporate office, providing dedicated physical space for each team.
- DCCOs embedding nurse coordinators in physician offices link them in some manner with the expertise of social workers.
- DCCOs in states with advanced practice nurses are evolving models that best utilize their education and training in the comprehensive care coordination process.
- DCCOs targeting persons with physical disabilities must address population mental health issues and develop expertise among the care coordinators for dealing with these concerns.

Information Management for Quality Improvement and Care Coordination Activities

With the exception of Vermont, all DCCOs are building their own management information systems (IS) in relational databases to coordinate care. The IS maintains medical and social information on each participant, which the coordinators use to track needs and progress toward participants' goals. The databases allow DCCO management to stratify their participants into high, medium, or low resource users. Many sites also use their database to identify quality improvement projects and to monitor progress toward meeting quality improvement goals. CHP in Eau Claire sold their homegrown IS to CLA in Madison and ICS in New York.

Currently, the most sophisticated reporting systems are located in Asheville and Wisconsin. Access II Care has a highly developed information management system built by the North Carolina Foundation for Advanced Programs. This includes an Internet interface that allows all agencies to review demographic and care coordination services. Access II Care produces utilization information and helps physicians develop actionable reports for clinical process improvement.

AXIS Healthcare has an intermediate system, mostly populated with the assessment data and care coordination activities, and a monthly summary feed from UCare Minnesota HMO on claims it has processed. CCA in Massachusetts has outsourced the development of a care coordination system to a development partner; in the meantime, it has developed a database from the Brightwood Community Health Center encounter data that provides information on quality, but is time and labor intensive for the care coordinators.

Findings on Information Systems
- DCCOs are internally developing separate and distinct information management systems for the care coordination of their complex populations.
- Extensive relational databases are needed for effective care coordination of complex populations.

Quality Management and Outcomes

While states require that DCCOs have a quality assurance and quality improvement program, they do not dictate what those should be. Each DCCO has a dedicated quality assurance director, a written quality improvement plan, quality management committees, internal improvement initiatives, and formal reporting requirements to the state, their sponsoring agency, and their internal staffs. Vermont reports quality efforts and outcomes to participating providers and to CHCS as a pilot demonstration. Exhibit 6 compares the various quality management structures and activities across the programs.

Exhibit 6
Comparison of Quality Management Structures

	A2C	AXIS	CCA	CHP	CLA	ICS	VT
Quality Department	X	X	X	X	X	X	
Quality Committee	X	X	X	X	X	X	
Quality Improvement Plan	X		X	X	X	X	
Conduct internal quality initiatives	X		X	X	X	X	
Conduct studies of the population		X	X	X	X	X	
State required reports	X	X		X	X	X	X
Communicate quality outcomes to staff	X	X	X	X	X	X	X
Partner with other health care providers to develop quality improvements	X		X	X	X		X

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Each DCCO has selected outcome measures that fit the DCCO's target population. DCCOs intervening in diabetes are monitoring blood sugar levels. One of Access II Care's interventions targets asthma management, so they monitor peak flow readings and the presence of asthma action plans. ICS is focusing on pressure ulcer prevention and the process of multiple sclerosis care in ambulatory clinics.

The quality measurement process varies widely and is driven by DCCO's ability to monitor claims. For example, the two Wisconsin programs have collaborated and identified common measures so they can benchmark their performance against each other. Wisconsin is conducting its own analysis of a matched group of non-participants to compare utilization and cost outcomes.

Similarly, North Carolina has developed a very detailed quality reporting mechanism that provides real-time, actionable information back to provider groups. The physicians can look at their group's performance over time, and also see how they are doing compared to other groups in the network or around the state.

In contrast, the Vermont and CCA program in Massachusetts are still establishing the processes. Vermont plans to use state-level analysis to compare participants' utilization against non-participants.

AXIS Healthcare chose to focus on an external program evaluation and quarterly satisfaction with health plan processes. Like ICS, AXIS is creating specific quality measures to monitor the results of an intervention targeted to pressure ulcer prevention.

Findings on Quality Management

- Each DCCO is monitoring quality in some manner.
- There are few shared measures across DCCOs, partly because they target different populations.
- The sophistication of quality measurement and reporting (number of measures, process to select measures, input of data to create the measures) varies widely across the sites.

Finances

One of the most striking differences across the seven sites we visited is how the coordination services are financed (Exhibit 7). There are four approaches: capitation, monthly management fee, fee-for-service billing or cost allocation, or grants. Some DCCOs employ a combination of approaches.

Exhibit 7
Financing Approach

A2C	Fee-for-service for allied agency case management; monthly capitation fee for medical case management ($1 pmpm Carolina Access case management; $2.50 pmpm community case management from Rural Health office)
AXIS	Partial capitation (pharmacy carve out); cost reimbursement for care coordination
CCA	Cost reimbursement
CHP	Full capitation
CLA	Capitation
ICS	Full capitation for some services (clinical carve out); grants
VT	Grants

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Capitation. In New York, Minnesota and Wisconsin (and eventually Massachusetts), the state Medicaid programs pay a risk-adjusted capitation rate to the DCCOs. The DCCOs fund coordination through savings achieved in shorter hospital stays, deinstitutionalization, and medical stabilization/early interventions. Under capitation, the financial incentives are clearly aligned with maximizing the participants' health and function. Decision-making authority for benefits or services outside the defined Medicaid benefit package resides at the DCCO. This gives the DCCO the freedom to make rapid decisions on how best to allocate its budget. One of the challenges to sustainability faced by ICS — since it is not capitated for inpatient care or medical visits — is that savings resulting from care coordination accrue mostly to the state of New York, and not to ICS.

Monthly Management Fee. The PCCM programs in North Carolina and Vermont pay providers a modest management fee per person per month. The Community Care networks in North Carolina pool their management fees to fund the care coordination program. In this financing model, the financial incentives are comparatively cloudy since savings are realized at the county or state level rather than the organizational level.

Fee-for-service/cost reimbursement. The DCCO at Brightwood Health Center in Massachusetts and some agencies in North Carolina bill the Medicaid program for care coordination services or apportion actual costs to this function.

Grants. ICS in New York and the Vermont Medical Home Care Partners are funded through foundation grants.

Findings on Financing of Care Coordination Processes

- Capitated entities have the most freedom to allocate resources to provide person-centered health care.
- DCCOs that charge fee-for-service for coordination services may eventually become self-sustaining businesses rather than relying on grants.
- Blended financing models are common.

Origins/Catalysts

Each DCCO's formation was catalyzed by different combinations of partnerships from the political, social, medical, and/or consumer sectors (Exhibit 8).
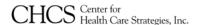
Exhibit 8
Comparison of Originating Founding Partners

	A2C	AXIS	CCA	CHP	CLA	ICS	VT
Political Partners	Medicaid North Carolina Foundation for Advanced Health Programs	Medicaid	Medicaid	Medicaid	Medicaid		Medicaid
Community Development Partners			Health Care For All Community Catalyst			New York Fund United Hospital Fund	Community and Economic Development Office of Burlington
Provider Partners	Community Care Network of Asheville	Sister Kenny Rehabili-tation Hospital Courage Center	Brightwood Community Health Center			Paraprofessional Healthcare Institute	Community Mental Health Centers Neighbor-hood Health Centers
Consumer Partners			Boston CIL	CIL for Western Wisconsin	Access to Indepen-dence CIL	Bronx, Harlem and Manhattan CILs	Vermont CIL Vermont Psychiatric Survivors

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Political. In all the states except New York, the state Medicaid agencies either initiated or played an important role in bringing key stakeholders to the table during design and early implementation. The agencies obtained waivers from CMS, worked with their legislatures to get funding authorized, analyzed data for rate setting and actuarial projections, helped inform beneficiaries about the program, and ensured beneficiary protection. All of these states continue to partner with the DCCOs on program operations.

New York's Medicaid program has not provided any of this type of assistance to ICS, and ICS does not view the state as a partner. Consequently, ICS believes that it is missing many opportunities to coordinate Medicaid services and improve outcomes.

Social. Local community development organizations were key players in the founding of CLA in Madison, CCA in Massachusetts, ICS in New York City, and the participating community health center in Burlington, Vermont. Community development organizations continue to be involved with these DCCOs as collaborators or on the Board of Directors. The discipline of community development focuses on creating opportunities for human interactions that form the building blocks of society. These include creating job opportunities through micro-economic development, developing leadership within the communities to create positive changes, making decisions on land-use planning by communities, improving high school graduation rates and successful rehabilitation of incarcerated residents, building affordable and accessible housing and shelters, and providing health services for all.

Medical. Providers of medical services were highly instrumental catalysts in the start-up of some DCCOs. Community mental health centers were key players in Vermont's program. Neighborhood Health Plan in Boston played a major role in advocating for the establishment of CCA, as were private group practices and individual physicians. The Community Care Network in Asheville was founded by physicians, who also play a major role in the governance and operational success of Access II. An inpatient rehabilitation hospital in the Twin Cities, the Sister Kenny Institute (SKI), and the Courage Center, a community-based rehabilitation center in Minneapolis, established AXIS Healthcare.

Consumers. Consumer advocacy groups, particularly the local Centers for Independent Living (CILs), played a major role in most of the programs' startup, with the exception of Asheville. (The Asheville program has a focus centered on chronic disease rather than physical disabilities). The CILs' role ranged from being founding partners in Wisconsin, New York, and Boston, to serving as substantial consumer advisors during the planning stage in Vermont and Minneapolis.

It is worth noting that the Wisconsin and New York City CILs dropped out of active participation as the DCCOs began providing services. In Wisconsin, neither CIL viewed the provision of health care as a core competency. In NYC, the CIL directors in Harlem, Manhattan, and the Bronx experienced a turnover in the organizational champions, so the initial alliances dissolved.

Findings on Origins/Catalysts

- DCCO established effective partnerships between two or more sectors (state Medicaid program, community development agency, providers, or consumer advocates).
- An efficient strategy to obtain organized consumer input into the design and start-up of DCCOs is to involve Centers for Independent Living (CILs), even though they may play a smaller role once the program is launched.

Governance

DCCO governance builds on the partnerships established in the planning and launching phases, i.e. relationships among state and local community groups. Governance resides within each board of directors or — in the case of Vermont — within the sponsoring Medicaid agency. However, the boards seek and prize alliances that link them with local community advocates, providers, consumers, as well as with the state's Medicaid program office. In addition to the established boards and member advisory groups, key external organizations have input into the strategic direction and operations of the DCCOs. We call these the "governing partners" (Exhibit 9).

Exhibit 9
Governing Partners

Access II Care WNC	• Board of Directors – 12 members (four physicians from each of three geographic Carolina Care network clusters) • North Carolina Foundation for Advanced Health Programs • N.C. Medicaid (Department of Medical Assistance)
AXIS Healthcare	• Board of Directors – 12 members representing the two founding provider organizations • UCare Minnesota • Member Advisory Committee • Minnesota Medicaid (Department of Human Services)
Commonwealth Care Alliance	• Board of Directors – 12 members representing the four founding organizations, consumers, legal, finance, and two representatives with links to Brightwood Health Center and the New North Citizens Council in Springfield, MA • Massachusetts Medicaid (MassHealth)
Independence Care System	• Board of Directors – 9 members representing long-term care partners, advocates, financial institutions, and one slot for a public representative • ICS membership advisory group
Office of Vermont Health Access	• Vermont Medicaid (Office of Vermont Health Access) • Department of Developmental and Mental Health Services • Pilot Community Mental Health Centers • Pilot primary care centers • Vermont Center for Independent Living • Vermont Psychiatric Survivors
Community Health	• Board of Directors – at least 51 percent of people with physical disabilities

Partnerships (WPP)	• Member Advisory Council • Wisconsin Medicaid (Wisconsin Partnership Program)
Community Living Alliance (WPP)	• Board of Directors – at least 51% of people with physical disabilities • Member Advisory Council • Wisconsin Medicaid (Wisconsin Partnership Program)

States' role. The demonstration programs in Massachusetts, Wisconsin, North Carolina, Vermont, and Minnesota benefit from strong support by the state Medicaid agency. Champions within the agency have been able to secure and maintain funding during formative time periods. Several states (Minnesota, Massachusetts, and Wisconsin) obtained CMS waivers.

Boards' role. Except Access II Care, all boards include persons with disabilities or advocacy organizations in the governing system. The two Wisconsin programs and CCA in Massachusetts include a very large percentage of people with disabilities on their boards. AXIS in Minnesota and ICS in New York rely heavily on direct member participation in advisory committees. Vermont's initiative has a strong alliance with the Center for Independent Living. The Board of Access II Care is its primary constituency, the Community Care Network of physicians.

Findings on Governing Partners

- Strong state Medicaid agency support is critical for a successful start-up and expansion.
- Boards tend to reflect the composition of the founding financial stakeholders.
- All programs directly tap into the voice of the consumer through board representation or member advisory committees.

IV. Outcomes and Recommendations

Our findings suggest that Disability Care Coordination Organizations strike the right balance for Medicaid participants with complex health needs and for Medicaid programs that need to spend limited resources wisely. DCCOs are templates of best practices, allocating the most fitting public and community resources — In the right amount, at the right time, in the way the beneficiary wants — to each participant through person-centered planning, purposeful resource allocation, health education, and focused quality improvement initiatives. Even more tantalizing is local evidence that the incremental cost of care coordination leads directly to net reductions in Medicaid expenditures through timely interventions and new linkages across providers.

Outcomes

We looked for evidence of financial, clinical, satisfaction, and quality of life outcomes. Most current evidence is anecdotal, but some formal evaluations were published in 2005.

Finance and Utilization

All sites monitor hospitalizations and emergency room use. They each report major declines in acute care and emergency room admissions. They also report increases in improved access to outpatient services, which is not surprising since the care coordinators are facilitating appointments for primary, preventive and specialty care, transportation to the appointments, and sometimes accompanying the participants to appointments. Most sites believe that the average per member per month expenditures increase for the initial enrollment months, since there is a large backlog of unmet needs. As time goes on, individual expenditures taper off as each person is medically and socially stabilized.

At the time of our site visits, it was not yet determined if the DCCOs reduce average expenditures over the long run. Preliminary reports on the programs in Wisconsin, Minnesota, and Massachusetts suggest reductions in Medicaid expenditures for beneficiaries after enrollment.

Quality of Life

Participants uniformly told us that their quality of life was immeasurably improved. Some had concrete ideas on ways the DCCOs could do an even better job to deliver more services within financial constraints. The participants in DCCOs that offer socialization programs (New York, CLA in Madison, and AXIS) said they really enjoy those opportunities and view them as an important member benefit.

Many beneficiaries enjoy improved relationships with family members. They have extended their network of friends and engage in activities (swimming, wheelchair sports, shopping, graduate school) that they formerly thought impossible.

Satisfaction

We interviewed participants, physicians, and coordinators at each site to ascertain how they viewed the care coordination program and their satisfaction with the services and outcomes. Most sites arranged interviews for us, sometimes at the participants' home (CCA, CHP) and other times at the organization's office or clinic (AXIS, Access II Care, Vermont). In Madison, we attended CLA's annual member meeting and picnic, and spoke to many participants at random.

Participant satisfaction. The verbal and written testimony of program participants attest to the positive, beneficial changes that comprehensive care coordination has made in their lives. Participants value being treated with respect and receiving personalized care. They praise the coordinators' ability to resolve problems quickly. Some participants were unaware of specific services they needed, such as a mentally ill gentleman with stomach pains who didn't know he had an ulcer. Others were unaware of their entitlement to specific services, income supports, or

adaptive equipment, such as slant boards to assist with bed transfers. Most participants mentioned their appreciation of being able to call one person to resolve any problem. Several people also offered self-actualization statements, such as, "Now I am in control of my health, instead of my health controlling me." All participants would recommend their DCCO to a friend.

Several DCCOs use in-house survey instruments to survey participant satisfaction. Instruments vary widely in content, frequency of administration, and testing for internal reliability or validity. The DCCOs reported to us that the surveys indicate high satisfaction. While this may be partly attributed to voluntary disenrollment of dissatisfied members, the voluntary disenrollment rate is about 1 percent, leading us to conclude that satisfaction is, truly, very high.

Physician satisfaction. We spoke with one to three participating physicians at each site. With one exception, physicians placed a high value on their relationships with the DCCO nurses. The physicians told us that they had more confidence their patients would comply with prescribed medications, therapies, and appointments. They also are relieved that they can refer their patients to a single resource (the coordinator) to deliver social and medical resources. Physicians appreciated having a single individual (the coordinator) who knew everything going on with the patient; in effect, the coordinator is a walking comprehensive medical record. One physician viewed the DCCO nurses as intrusive and did not believe they added any value.

It appeared to us that the physicians housing coordinators in their practice were most enthusiastic, though this may reflect some selection bias towards acceptance of the DCCO concept.

Coordinator satisfaction. We spoke with varying numbers of coordinators, including both nurses and social workers. Most of them had been in practice for five or more years and had prior experience working with people with disabilities. They joined the DCCO in the belief that there is a better way to arrange care. Some also were attracted by the autonomy and authority vested in the coordinators. All coordinators found the job very challenging and highly rewarding.

Clinical Results

Sites are beginning to see improved clinical outcomes under their focused quality improvement programs. Some of these include: reductions in blood sugar and increased exercise for the DCCOs targeting diabetes; improved compliance with recommended preventive care screenings (all sites); and improved detection of pressure ulcers at early stages for DCCOs targeting adults with physical disabilities. Access II Care probably has the best public documentation of clinical improvements. Minnesota, Wisconsin, and Massachusetts released clinical results in 2005.

Recommendations for States

We have seven recommendations for states to consider as they design and implement DCCOs for adults with disabilities. These recommendations are drawn from our observations during the sites visits, as well as specific suggestions from the Medicaid beneficiaries, coordinators, and physicians we interviewed.

1. Ensure that DCCOs are grounded in the infrastructure of the community served.
Identify existing providers and resources, such as community development programs, physicians treating people with disabilities, neighborhood health centers, community mental health centers, Centers for Independent Learning, disability advocates, and Medicaid beneficiaries. Incorporate their perspectives into DCCO design.

2. Develop mechanisms for formal input by beneficiaries into governance. This will ground the DCCO in the needs of the target population and service providers. Since these needs fluctuate, DCCOs and states should maintain lines of open communication with constituencies. States should also assist the governing boards in selecting a governing philosophy. Formal or informal governance structures that link state agencies, advocates, providers, and consumers will foster accountability, communication, and commitment. States should nurture partnerships at the state and local levels, build trust, and cement stakeholder alliances.

3. Capitate the DCCOs for all services, if possible; if not, states should at least partially capitate and ensure that DCCOs can financially benefit from care coordination savings. If possible, states should also allow DCCOs to integrate Medicare and Medicaid financing and services. States should also ensure that DCCOs capture financial savings from reduced hospitalizations and emergency room use. This is key to becoming a self-sustaining business operation.

4. Allow DCCOs to compile all data on carved-out services, especially mental health and pharmacy expenditures. Several DCCOs mentioned the importance of being able to combine mental health and physical health information. Real-time information about participants allows

coordinators to integrate all dimensions of the participants' lives and to set priorities, particularly when social services are more critical than medical services. Access II Care is the best in class of secure information-sharing across agencies. It ensures confidentiality, while allowing timely inter-agency data sharing.

5. Ensure that DCCOs have a sophisticated management information system. The information system is the glue that holds the care coordination process together. Care coordinators track a vast quantity of information about each Medicaid beneficiary and need to be able to retrieve the information efficiently. Data entered into the information system serves as the foundation of the clinical management system and outcomes reporting. Community Health Partners, in Eau Clair, is a best-in-class example.

6. Track quality of life outcomes, in addition to clinical, satisfaction, utilization, and financial outcomes. Participants spoke to us of enlarged social networks, enhanced productivity, and improved mental and physical health, even when enrolled in programs geared solely to mental or physical health. Several were engaged in volunteering their time and talents back to their communities; others had landed a job and planned to move off welfare.

7. Track utilization and pay for care coordination services. States should define care coordination services by all public agencies, and reimburse for those services. This will allow states to track what types of services are being provided, who is providing them, who is receiving them, and how much is spent. Armed with this information, states will be able to make more informed decisions on the financial implications of establishing and maintaining DCCOs.