

CHCS

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Resource Paper

Measuring the Effectiveness of Managed Care for Adults with Disabilities

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I. Executive Summary

Coordinated care organizations (CCO) are an emerging person-centered health delivery system for community-based Medicaid adults with disabilities or complex chronic disease. This report develops recommendations on how states can support CCOs. The recommendations are drawn from visits to seven pilot programs:

- Access II Care of Western North Carolina – Asheville, NC
- AXIS Healthcare – Minneapolis, MN
- Commonwealth Care Alliance – Boston, MA
- Independence Care System, New York, NY
- Vermont Medical Home Project, Montpelier & Burlington, VT
- Community Health Partnership, Eau Claire, WI
- Community Living Alliance, Madison, WI

This report reviews the challenges the CCOs encounter in measuring quality and offers a comprehensive approach for developing a relevant and actionable measurement set. The proposed approach presents a way for CCOs, their staff, and state Medicaid agencies to benchmark CCO achievements and to identify areas needing improvement.

Challenges to Measuring Quality

Measuring quality within and across CCOs poses multiple challenges:

- Some CCOs lack access to Medicaid databases, which limits the CCO's ability to monitor utilization and costs.
- The populations served and the scope of benefits and services offered by CCOs vary across the programs.
- Levels of quality management and improvement expertise vary among the states and the CCOs.
- Different stakeholders in these projects focus on different measures (states are largely interested in cost benefits, while providers are interested in timely access and quality processes).
- Consumer-based quality of life outcomes, such as improvements in participants' lives and the benefits to the community, are absent.
- Intensity of care coordination varies widely within and among the different populations of persons with disabilities.
- Financial and technological resources to collect, clean, and evaluate data are limited.
- Few well-defined, evidence-based outcomes measures exist for clinical care and rehabilitation for persons with disabilities.
- Statistical comparisons are difficult due to the small numbers of people with the same disease or condition who participate in these programs.

Proposed Comprehensive Quality Management System

Based on our evaluations, we recommend the following approach to measuring the quality of care and outcomes for coordinated care organizations:

- 1. Define a coordinated, collaborative system of clinical, organizational, and consumer outcomes quality indicators and measures, initially using accepted measurement sets established by recognized leaders (HEDIS, NCQA, CMS, American Diabetes Association, Veterans Administration, JCAHO, etc.).
Measures should include:
 - Preventive care measures;
 - Community integration and quality of life measures;
 - Measures for the prevention of prevalent secondary conditions;
 - Measures specific for persons with physical disabilities;
 - Measures for persons with severe and persistent mental illness; and
 - Utilization and cost measures.
- 2. Collaborate on multiple site quality improvement projects.
- 3. Establish a CCO Research Consortium.

II. Introduction

Coordinated care organizations (CCOs) are an emerging type of comprehensive managed care program for Medicaid adults with disabilities and complex chronic disease. In 2004, we visited seven CCOs in six states:

- Access II Care of Western North Carolina, Asheville, NC
- AXIS Health Plan, Minneapolis, MN
- Commonwealth Care Alliance, Boston, MA
- Independence Care System, New York, NY
- Vermont Medical Home Project, Montpelier and Burlington, VT
- Community Health Partnership, Eau Claire, WI
- Community Living Alliance, Madison, WI

These seven programs extend managed care processes to the integration of health and social services for Medicaid beneficiaries with disabilities or complex chronic disease. Preliminary qualitative research suggests CCOs are improving health, quality of life, and satisfaction for participants. However, definitive outcomes measures are mostly absent. This frustrates CCOs' ability to manage the quality of their services and to document success. Moreover, the CCOs have not identified a set of salient indicators that reflect CCO mission and goals. Notably missing are indicators of community participation.

This report suggests a comprehensive approach for measuring quality of care and services coordinated by CCOs. We sought to answer two major questions: What are these CCOs doing that makes a difference? What outcomes of their efforts make a difference to the individual, the community, and the state?

Background: Overview of the CCOs

While these seven CCOs share a similar goal (improve the health and life of persons with disabilities and/or chronic disease living in the community), they differ in many ways. The variations address their organizational structures, the specific populations they serve, the care coordination models in use, and the financing mechanisms. These differences impact the need to monitor certain quality measures and their capabilities for doing so. A brief overview of the programs provides the basis for understanding why certain measures may or may not apply to a specific program.

Access II Care of Western North Carolina. Access II Care, one of 13 independent networks in a statewide program, provides health care for 25,000 Medicaid participants in rural North Carolina under a primary care case management (PCCM) model. 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; provider reimbursement for services occurs on a fee-for-service basis. Mental health services are carved out and not managed as part of primary care provider (PCP) practices.

Access II care coordination occurs both centrally and at the individual level. Central care coordination has two aspects. The first is a collaborative regional council of medical and mental health providers that integrates individual consumer services into a united, comprehensive plan.

The second central care coordination activity is to supply PCP offices with individual and comparative information on multiple quality indicators using a sophisticated, web-based system developed by the North Carolina Foundation for Advanced Health Programs, a state sponsored, nonprofit community health demonstrations entity. The web-based system integrates Medicaid enrollees' demographic and encounter data, as well as cost information as a basis for physician reports. The measures addressed are both general and disease-specific, addressing selected disease conditions. General measures reported include composite patient utilization data and associated costs (outpatient, inpatient, emergency department, mental health, labs, and x-rays); and selected disease-specific measures related to diabetes (case counts, case rates, eye exams, lipid tests, and HbA1c tests) and asthma (case counts, case rates, asthma-related emergency visits and hospitalizations). Access II staff compile the reports, distribute them to the physicians, assist in report interpretation, and collaborate with each practice to conduct quality improvement initiatives.

The second major care coordination activity occurs at the individual level. Access II nurse care managers are located in individual physician offices, serving as care managers for targeted populations. The target population of interest to this report is children with special needs who have diabetes and asthma. In short, they coordinate services using a disease management model, focusing on supplying the child and family with tools and aids to improve health. No quality measures addressing care coordination processes and outcomes at this individual level are specified.

AXIS Healthcare, Minneapolis, Minnesota. AXIS is an independent, not-for-profit organization, subcontracted to UCare Minnesota (a Medicaid health maintenance organization) to provide care coordination for physically disabled members. AXIS bills UCare Minnesota on a fee-for-service basis for care coordination encounters. UCare processes all provider claims, reimbursed under risk-adjusted capitation from Minnesota's Department of Human Services (MDHS) and CMS to provide all Medicaid and Medicare covered services; the exception is pharmacy, which is carved out.

Care coordination at AXIS works to improve access through utilization supports instead of utilization controls. The care coordination staff includes registered nurses (RNs) as health coordinators and social workers as resource coordinators. The RNs function independently to coordinate care and services using, as needed, the expertise of social workers. Care coordination occurs as a telephone model; home visits are not conducted as the organization bylaws state it is not a provider.

AXIS chose to have programmatic outcomes in the first three years of operation evaluated by an external reviewer while they developed their own internal quality management program. 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 the development of their electronic information database led to expanded developments in quality improvement monitoring.

Commonwealth Care Alliance, Inc., Boston, Massachusetts. Commonwealth Care Alliance (CCA), incorporated as a not-for-profit organization in March 2003, is a prepaid health plan providing all Medicaid and Medicare benefits to eligible enrollees in Massachusetts. 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.
-
- Related to this project, CCA contracted with the Community Healthcare Group (CHG), a nonprofit clinical group practice housed at Brightwood Health Center in Springfield, Massachusetts, to provide care coordination services for individuals (between 18-65 years) who have disabilities and/or chronic disease. CCA provides CHG administrative and management services (e.g., information system support, human resources, etc.), freeing CHG and the Brightwood medical staff to focus on providing health and psychosocial care, integrated by care coordination services.
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- The Massachusetts Department of Medical Assistance program, MassHealth, reimburses Brightwood physicians for medical and psychosocial care on a fee-for-service basis, and CCA for care coordination services under a cost reimbursement arrangement. (Care coordination services exist currently as a Medicaid demonstration program). MassHealth recently received a waiver from CMS to allow several contractors, including CCA, to enroll dual eligibles and integrate Medicare and Medicaid financing.

CHG care coordination staffing includes a physician, program managers, two care coordination teams, and a behavioral health team. Each care coordination team is comprised of two advanced nurse practitioners (APNs), a registered nurse (RN), and a certified medical assistant (CMA). The CHG behavioral health team consists of a behavioral health counselor and social workers who treat members directly, as well as collaborate with the care coordination teams.

The financing mechanisms preclude CCA from accessing Medicaid claims data, limiting their ability to monitor utilization and associated costs. To compensate, they are in the process of developing an electronic encounter system that is labor intensive for care coordinators, but provides beginning capabilities to capture and measure quality processes and outcomes.

Independence Care System, New York, New York. Independence Care System (ICS), a nonprofit organization in downtown Manhattan, coordinates only health and social services for 600 Medicaid adults with physical disabilities, as NY Medicaid reimburses

acute and primary medical care outside the auspices of long-term care organizations. ICS is capitated by the New York state Medicaid program only for a narrow subset of Medicaid services: long-term care, transportation, pharmacy (except HIV/AIDS medications), rehabilitation therapies, and durable medical equipment. RNs and social workers, working in teams comprised of both types of professionals, coordinate the services that are capitated while referring participants to other appropriate care systems for treatment outside their purview.

The allowable benefit structure and the reimbursement system limit the capability of ICS to monitor the quality of the full range of care and services their population needs and uses. Rather, they develop quality measures from the “bottom up,” conducting studies and reporting on measures unique to the members’ problems and needs (e.g. pressure ulcers). ICS is developing outcome measures that demonstrate the impact of ICS services on quality of life care. ICS is 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.

Vermont Medical Home Project, Montpelier and Burlington, Vermont. As a demonstration project, the state’s Medicaid agency, Office of Vermont Health Access (OVHA), applied the statewide primary care case management model (PCCM) concept of the medical home to adults with severe and persistent mental illness (SPMI). Even more pointedly, the project focused on adults with severe and persistent mental illness (SPMI) who have diabetes as a secondary condition. In analyzing state Medicaid claims data, it became apparent that many Vermonters with SPMI diagnoses and on new psychotropic medications were gaining significant amounts of weight, developing Type II diabetes as a secondary condition. For many individuals, the experience of living with SPMI created a major barrier to successful self-management of diabetes.

This SPMI program is funded by a CHCS grant and matching CMS and Medicaid funds that largely subsidize the costs of care coordinator salaries. Two registered nurses, certified diabetic educators, serve as the locus for overall care and service coordination for the target population in a PCCM provider fee-for-service milieu. These nurses each work as personal care partners with approximately 50 SPMI participants, also serving as significant bridges of communication between behavioral health and primary care providers.

Due to the demonstration status of the program, quality measures reported are largely measures already in the Vermont state system (e.g., HbA1c levels). Accompanying these measures are high satisfaction levels, anecdotally reported, among participants, as well as among the medical and behavioral health providers.

Wisconsin Partnership Program (WPP). 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 frail elderly and people with disabilities, combining services traditionally provided by Medicare, Medicaid, and home and community-based waiver programs.

The WPP contracts with four community-based organizations located in different geographical regions of Wisconsin. Over time, each site will be able to serve 600 members. Community Health Partnerships (CHP) in Eau Claire, and Community Living Alliance (CLA) in Madison are the two WPP organizations that serve persons with disabilities. They are separate organizations with unique characteristics but share many similar operational features as they both belong to the WPP.

- **Community Health Partnerships, Eau Claire, Wisconsin.** Community Health Partnerships, Inc. (CHP) in west central Wisconsin, incorporated as a 501(c)(3) in 1998, provides comprehensive benefits, i.e., medical and behavioral health care, long-term support services, and care coordination, for both the frail elderly and working age adults with disabilities. In 2004, CHP was the only program in WPP serving both the elderly and adults with physical disabilities between 18-65 years. All participants are certified at the state's nursing home level of care. CHP is capitated for its members by both Medicare and Medicaid, and plans to obtain an independent HMO license in 2005.

CHP approaches care coordination and quality and information management as core competencies. CHP staff, advanced practice nurses (APNs), registered nurses (RNs), and social workers, provide both care coordination and direct medical and health services in the home to its members, working in multidisciplinary teams. Teams are composed of six members: one APN, two RNs, two social workers, and one technical assistant, based centrally in pods where they have close contact with each other, facilitating timely communication.

CHP's quality improvement plan is the core of its quality program with clearly articulated goals that address services, processes, and outcomes. The plan 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 BCAP (Identification, Stratification, Outreach, and Intervention) methodologies.^{1,2}

To manage quality information, CHP has developed a competent information system. They use their claims data to populate an internally-developed relational database that also houses cost, utilization, diagnostic, and demographic information, and serves as the foundation for state-required reports. Further, CHP also constructed an electronic care coordination documentation system used by the care coordinators to record

¹ G. Langley, K. Nolan, T. Nolan, C. Norman, and L. Provost. *The Improvement Guide: A Practical Approach to Enhancing Organizational Performance*. Jossey-Bass, 1996.

² K.L. Brodsky and R. J. Baron. "A 'Best Practices' Strategy to Improve Quality in Medicaid Managed Care Plans." *Journal of Urban Health*, December 2000; 77:592-602.

health care events and evaluations on which the state periodically conducts medical chart reviews.

- **Community Living Alliance, Madison, Wisconsin.** Like CHP, CLA plans for HMO licensure in 2005, is capitated, holding both Medicare and Medicaid contracts with about 60 percent of members as dual eligibles. CLA has a separate funding stream for pharmaceuticals and for mental health services. As public mental health services are provided through Dane County, CLA has contracted with the county as one of their mental health and substance abuse providers.

Eleven teams provide care coordination services for about 300 members with physical disabilities and chronic disease. Each team, staffed by a nurse practitioner (APN), a registered nurse, a social worker and a team coordinator, work together in a pod office arrangement, interfacing with members on the telephone, as well as in home visits.

CLA's quality system is similar to CHP's, as they imported and adapted CHP's information system. Further, all quality coordinators in the WPP meet monthly to coordinate monitoring efforts and engage in joint quality improvement activities.

Each program had unique and diverse characteristics, but both realized improvements in participants' health and experienced programmatic successes. Quality management among all seven programs occurred with varying degrees of competency, affected largely by capabilities for accessing Medicaid databases and their own quality management expertise, a not surprising circumstance given the relatively young status of the programs, different financing mechanisms, and disparate state regulations.

Overview: Quality Management and Outcomes among the CCOs

While each state (except Vermont) required each CCO to have a quality assurance and quality improvement program, the states did not dictate what those should be. Each CCO (except Vermont) 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 to their internal staffs.

Vermont reports quality efforts and outcomes to participating providers and to CHCS as a pilot demonstration. The table below (Exhibit 1) compares the various quality management structures and activities across the programs.

Exhibit 1

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

A2C=Access II Care of Western North Carolina, Asheville, NC

AXIS = AXIS Healthcare, Minneapolis, MN

CCA=Commonwealth Care Alliance, Boston, MA

CLA=Community Living Alliance, Madison WI

ICS=Independence Care System, New York, NY

VT=Vermont Medical Home Project

CHP=Community Health Partners, Eau Claire, WI

Each CCO selected outcome measures that fit the CCO's unique target population. For example, CCOs intervening in diabetes monitor blood sugar levels, eye exams, or HbA1c 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 significantly affected by the CCO's ability to monitor claims. For example, the two Wisconsin programs with access to state Medicaid data have collaborated and identified some common measures, enabling them to benchmark their performance against each other. Further, the state of Wisconsin is conducting its own independent analysis of a matched group of non-participants to compare utilization and cost outcomes.

Similarly, Access II WNC, with the right to use North Carolina's Medicaid data, 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 Medical Home Project and the CCA program in Massachusetts, without direct access to Medicaid data, are still establishing the quality utilization

monitoring processes. Vermont plans to use state-level analysis to compare participants' utilization of benefits 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 CCO is monitoring quality in some manner.
- There are few shared measures across CCOs, 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.

It was evident to us after completing our evaluations of the programs, that a comprehensive approach to quality management would support CCO programs, sponsoring Medicaid agencies, and most importantly the consumers. Realistically, challenges for comprehensive programs exist, but opportunities for improvements exist, as well.

Challenges

One of our project tasks was to develop a protocol to generate empirical measures of the effectiveness of CCOs. The task was complicated by the following circumstances:

- Different stakeholders are interested in different measures. For example, people with disabilities and physicians put a premium on timely access, while payers are most interested in total costs and cost savings.
- The scope of services differs across CCOs, making it difficult to find comparisons that are relevant across differing organizational models and populations.
- Accurate, timely, and relevant data on cost and utilization vary widely across CCOs, with some CCOs processing all their own claims (WI, NC, VT), and others receiving rolled-up information (MA, MN), or no information (NY).
- Coordinating the needs and wants of the individuals being served varies widely, with some people needing intensive coordination, and others just a little. This suggests that direct measures of the volume of care (e.g., hours of care coordination) may be misleading, since more care is not necessarily better.
- Financial resources to collect, clean, and evaluate data are limited.
- There are few well-defined, evidence-based outcomes measures for rehabilitation and clinical care that are widely used for people with disabilities, making external comparisons difficult.

Strategy

We believe that the best strategic approach for CCOs is to *identify measures appropriate to their target population from measures that are already used by MCOs, the Veterans Administration, and/or Medicaid and Medicare programs*. The reason for recommending the use of existing measures is that it allows multiple benefits:

1. **Comparisons external to CCOs:** It increases the likelihood that the CCO can be compared against a group of people not in “coordinated care”, or against people in different organizational models for chronic care or frail elderly.
2. **Comparisons between CCOs:** The CCOs would be confident that differences in numbers are not an artifact of computing numbers differently.
3. **Acceptability:** Existing measures have some currency as being “appropriate”.
4. **Cost:** It may be possible for CCOs to purchase computer programs from a HEDIS certified vendor or to use programs it already owns to generate the measures, saving the CCO time and the effort of writing it themselves.

Resources

Researchers have already identified measurement domains for CCOs and compiled candidate measures. We categorized these into five sources.

1. Materials supporting implementation of the State Children's Health Insurance Program (SCHIP) for children with special needs. This generated several proposed indicators and survey tools (Shofaer et al. 1998; National Health Law Program; FACCT).
2. Service delivery rates selected by private sector quality monitoring organizations and state/federal regulators. These compare clinical outcomes across managed care organizations (MCOs) and nursing homes by comparing service delivery rates for closely-defined populations. The organizations and regulators also survey the target population to measure their perception of quality and to gather information that is not tracked through claims processing systems or routinely documented in medical charts. Among the most relevant organizations for CCOs to turn to are the National Committee for Quality Assurance (NCQA), the Commission on Accreditation of Rehabilitation Facilities (CARF), and the Nursing Home Quality Initiative of the Center for Medicare and Medicaid Services (CMS).³
3. Collaborations of private and public health organizations have developed evidence-based outcomes measures for a few highly prevalent and costly chronic conditions including asthma,⁴ diabetes,⁵ and heart disease.⁶ The 2003 National Healthcare Quality Report lists specific indicators and national values for effectiveness measures of care programs managing asthma, cancer, end stage renal disease, diabetes, heart

³ <http://www.hce.org/Medicare/mcareNHQI.html>.

⁴ <http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5206a1.htm>.

⁵ <http://www.ncqa.org/dprp/dqip2.htm>.

⁶ <http://www.qualitytools.ahrq.gov/qualityreport/browse/browse.aspx?id=98>.

disease, HIV/AIDS, maternal and child health, mental health, respiratory diseases, nursing home and home health, safety, timeliness, and patient centeredness.

3. The Disability-Appropriate Care Model,⁷ an adaptation of the Chronic Care Model^{8,9} developed by Ed Wagner, MD and colleagues.¹⁰
4. Previous research supported by the Center for Health Care Strategies to improve the quality of publicly financed health care.^{11,12,13}

III. Measurement Selection Criteria

Criteria for measuring quality indicators include those that are general and those that are specific to populations with disabilities.

General Criteria. Most quality indicators include the following five criteria for selecting good measures:

1. Relevant to various stakeholders;
2. Scientifically strong (derive from comparable data sources, and there is published information on the impact of risk adjustment);
3. Feasible (good precision, not too expensive to collect, can be collected quickly);
4. Differentiate among delivery systems with respect to their performance;
5. Stimulate continuous quality improvement.

Additional Criteria. When applying these criteria to selecting clinical measures for CCOs, we suggest four additional criteria:

1. Look at outcomes for life situations, medical conditions, functionality or episodes of care where we expect care coordination to have an impact.
2. The conditions should occur frequently in the population outside CCOs, to facilitate external comparisons, as well as before-and-after comparisons.
3. Measures should be “scalable” — that is, allow the CCOs of very different sizes to compare themselves to each other, as well as internal comparisons from year to year during times of rapid expansion.
4. Some measures should serve as indicators of CCO system breakdowns in institutional and ambulatory care, e.g. avoidable adverse events.

⁷ S. Palsbo and J. Kailes. Making Health Services Disability-Appropriate: Disability and the Chronic Care Model. *Disability Studies Quarterly*, 2006 (in press).

⁸ <http://www.improvingchroniccare.org/change/model/components.html>.

⁹ E.H. Wagner. “Chronic Disease Management: What Will it Take to Improve Care for Chronic Illness?” *Effective Clinical Practice*, 1998;1:2-4.

¹⁰ ICIC is a national program supported by The Robert Wood Johnson Foundation with direction and technical assistance provided by Group Health Cooperative's MacColl Institute for Healthcare Innovation.

¹¹ E. Wehr. *Basic Elements of Care Coordination for People with Special Health Care Needs in Medicaid Managed Care*. Center for Health Care Strategies, February 2000.

¹² M.L. Rosenbach and C.G. Young. *Care Coordination in Medicaid Managed Care: A Primer for States, Managed Care Organizations, Providers, and Advocates*. Center for Health Care Strategies, July 2000.

¹³ S. Palsbo, P. Beatty, P. Parker, C. Duff. *Designing a Program Evaluation for a Multi-Organizational Intervention: The Minnesota Disability Health Options Project*. Center for Health Care Strategies, January 2004.

IV. Statistical Reliability with Small Medicaid Enrollment

The small numbers of people with similar conditions participating in most CCOs challenge capabilities to establish statistically reliable samples. Several CCOs we visited enroll as few as a dozen people with similar medical diagnoses, e.g., a dozen people with multiple sclerosis, another dozen with spinal cord injury, a third dozen with cerebral palsy. These small numbers raise questions about statistical credibility when calculating measures from population samples. Another complication is that the numerical distribution of key indicators, including cost and utilization, do not form a bell-shaped curve. CCOs are targeted to enrolling the highest resource users—that is, the people in the Medicaid cost distribution’s right side. This characteristic violates the assumptions underlying many statistical calculations. Moreover, when CCO enrollment is voluntary, selection bias becomes a concern.

One solution is to simply gather information on 100 percent of the study population. Given the small enrollment in start-up CCOs, this could be very affordable, particularly if data collection is incorporated into the usual course of care management. For example, data collected by survey could be incorporated as part of the annual assessment.

V. Recommended Clinical and System Measures for Each CCO Site

This section presents measures and widely-used indicators of those measures. All measures meet the nine criteria listed in Section III. We also indicate the study sites that would be likely to find these measures appropriate. Exhibit 2 (next page) is based on the Disability-Appropriate Care Model.

Exhibit 2
Framework for CCO Measures*

CCM Framework	CCM Measure	Challenges and comments
Community Resources and Policies	<ol style="list-style-type: none"> 1. Encourage CCO participants to participate in effective community programs. 2. Form partnerships with community organizations to support and develop interventions that fill gaps in needed services. 3. Advocate for policies to improve patient care. 	<p>CCOs reported to us that community organizations such as local chapters of the American Lung Association may not be accessible to CCO participants. For example, meetings may not be building accessible; materials may not accessible in alternative formats; materials may not be cognitively accessible; materials treat a single condition and not always relevant to people with multiple co-impairments.</p> <p>All CCO study sites are heavily involved in advocacy, and that is their raison d'être.</p>
Health System Organization of Care	<ol style="list-style-type: none"> 1. Visibly support improvement at all levels of the organization, beginning with the senior leader. 2. Promote effective improvement strategies aimed at comprehensive system change. 3. Encourage open and systematic handling of errors and quality problems to improve care. 4. Provide incentives based on quality of care. 5. Develop agreements that facilitate care coordination within and across organizations. 	
Self-Management Support	<ol style="list-style-type: none"> 1. Emphasize the participant's central role in managing their health. 2. Use effective self-management support strategies that include assessment, goal-setting, action planning, problem-solving and follow-up. 3. Organize internal and community resources to provide ongoing self-management support to patients. 	<p>This is a key activity of CCOs. CCOs told us that many lower-income and lower-educated participants need extensive support. The participants have never learned how to set middle- and long-term goals. Many of them have been told, repeatedly, that they can't do anything themselves.</p> <p>Some participants may not be able to afford to make productive changes. For example, it is much cheaper to eat a high carbohydrate diet (boxes of macaroni and cheese) than it is to eat fresh fruit and vegetables.</p>
Delivery System Design	<ol style="list-style-type: none"> 1. Use planned interactions to support evidence-based care. 2. Provide clinical and social case management services for complex participants. 3. Ensure regular follow-up by the care team. 4. Give care that participants understand and that fits with their cultural background and functional abilities. 	<p>Resources for evidence-based care for populations with disabilities are limited.</p> <p>Providers may have narrow conceptions of culturally-sensitive care.</p>

*(Adapted from the Disability Appropriate Care Model.)

Exhibit 2 (cont'd)

CCM Framework	CCM Measure	Challenges and comments
Decision Support	<ol style="list-style-type: none"> 1. Embed evidence-based guidelines into daily clinical practice. 2. Share evidence-based guidelines and information with patients to encourage their participation. 3. Use proven provider education methods. 4. Integrate specialist expertise & primary care. 	Evidence-based medicine for many CCO populations is limited.
Clinical Information Systems	<ol style="list-style-type: none"> 1. Provide timely reminders for providers and participants. 2. Identify relevant subpopulations for proactive care. 3. Facilitate individual care planning. 4. Share information with patients and providers to coordinate care. 5. Monitor performance of practice team and care system. 	<p>CCOs told us that, even with reminders, many participants find it difficult to show up for appointments. Difficulties arise from failures of the transportation service, chronic forgetfulness by the participant, or even deliberate decisions by the participant to not go to the doctor.</p> <p>Some CCOs developed a participant-carried Service Journal or Walking Medical Record to facilitate information sharing.</p>
Informed, Active Patient; Prepared Proactive Practice Team	<ol style="list-style-type: none"> 1. Active role in self-management. 2. Providers feel prepared and supportive. 	Practice teams need to identify and define the specific measures for “self-management.” Expectations for self-management should be communicated to the patient.

Improving the Outcomes of Care

Following the recommendation of Sofaer et al.,¹⁴ we propose performance measures that reflect outcomes: “that is, whether people get better and how quickly; whether their conditions are managed effectively even if they cannot be cured; whether their functioning and quality of life are maintained to the extent possible; and whether and when they die...[and]... the degree to which patients or plan members are satisfied with the care they receive.” The CCOs should track demonstrated improvement in satisfaction using survey instruments nationally recognized as valid and reliable, the health outcomes resulting from support services, improved functional status, and quality of life. To Sofaer’s recommendations, we add improved social outcomes.

¹⁴ S. Sofaer, S.F. Woolley, K.A. Kenney, B. Kreling, D. Mauery. “Meeting the Challenge of Serving People with Disabilities: A Resource Guide for Assessing the Performance of Managed Care Organizations.” Report to ASPE. July 1998. <http://aspe.hhs.gov/DALTCP/REPORT/RESOURCE.HTM>.

Recommended Measures for All CCOs – Preventive Care

Preventive care schedules have been established for medically vulnerable populations by the Centers for Disease Control and Prevention, the American College of Physicians, and the U.S. Preventive Service Task Force. In addition, Healthy People 2010 has identified preventive care targets specifically for people with disabilities. We propose the following preventive care measures shown in Exhibit 3:

**Exhibit 3
Nationally-Used Preventive Care Measures**

Preventive Care Indicator	Measure	A2C	AXIS	CCA	CLA	CHP	ICS	VT
Annual comprehensive health Assessment	% participants	X	X	X	X	X	X	X
Blood pressure, pulse, temperature, height, weight	% participants {Need to establish appropriate frequency, as every encounter may not be feasible}	X	X	X	X	X	X	X
Annual Chlamydia	% sexually active participants	X	X	X	X	X	X	X
Annual digital rectal exam to screen for colorectal cancer	% of participants	X	X	X	X	X	X	X
Baseline electrocardiogram, and sequential ones as appropriate	% of participants	X	X	X	X	X	X	X
Bi-annual or annual vision and hearing	% of participants	X	X	X	X	X	X	X
Sigmoidoscopy every 5 years	% of participants	X	X	X	X	X	X	X
Annual skin exam	% of participants	X	X	X	X	X	X	X
Annual stool blood test	% of participants	X	X	X	X	X	X	X
Annual tuberculosis test	% of participants	X	X	X	X	X	X	X
Discuss tobacco use, smoking cessation, use of seat belts	% of participants	X	X	X	X	X	X	X
Annual depression screen (more often may be appropriate)	% of participants	X	X	X	X	X	X	X
Annual lab work for: blood sugar, cholesterol, LDL, HDL, triglycerides; kidney function test; complete blood count; Hepatitis C; HIV.	% of participants	X	X	X	X	X	X	X
Bone mineral density(at least once to determine risk)	% of men, % of women	X	X	X	X	X	X	X
Men: Annual rectal exam to screen for prostate cancer	% of men	X	X	X	X	X	X	X
Men: PSA	% of men Note that there are problems with the test for men for SCI, as lab results may be misleading	X	X	X	X	X	X	X
Women: Annual breast exam	% of women See HEDIS	X	X	X	X	X	X	X
Women: Mammogram	% of women (HEDIS)	X	X	X	X	X	X	X

Exhibit 3 (cont'd)

Preventive Care Indicator	Measure	A2C	AXIS	CCA	CLA	CHP	ICS	VT
Women: PAP test/pelvic exam	% of women See HEDIS	X	X	X	X	X	X	X
Antidepressant Medication Management	See HEDIS	X	X	X	X	X	X	X
Cholesterol Management After Acute Cardiovascular Events	See HEDIS	X	X	X	X	X	X	X
Women: Thyroid (lab test) every 5 years	% of women	X	X	X	X	X	X	X
Immunizations for Hepatitis A, Hepatitis B, Influenza, Tetanus-Diphtheria, Pneumococcal Disease, MMR, Varicella (chicken pox)	% of participants See HEDIS	X	X	X	X	X	X	X

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Community Integration: Recommended Measures for All CCOs

These measures are drawn from work done by A.F. Lehman,^{15,16} CARF,¹⁷ SAMSA, and the United States Psychiatric Rehabilitation Association’s (USPRA) IAPSRs Toolkit.¹⁸ While USPRA’s measures are targeted to measuring the quality of community readjustment for people with psychiatric disabilities, our interviews at the CCOs geared to people with physical disabilities lead us to recommend these measures for all CCOs (Exhibit 4).

¹⁵ A.F. Lehman, “The Well-Being of Chronic Mental Patients: Assessing their Quality of Life.” *Archives of General Psychiatry*, 1983, 40, 369 -373.

¹⁶ A.F. Lehman. “The Effects of Psychiatric Symptoms on Quality of Life Assessments Among the Chronic Mentally Ill.” *Evaluation and Program Planning*, 1983, 6, 143-151.

¹⁷ D. Wilkerson, D. Shen, M. Duhaime. “Performance Indicators for Rehabilitation Programs. Version 1.1 Working Paper for Comment. Commission on Accreditation of Rehabilitation Facilities, August 1998.

¹⁸ P. Arns, E.S. Rogers, J. Cook, C. Mowbray & Members of the IAPSRs Research Committee. “The IAPSRs Toolkit: Development, Utility, and Relation to Other Performance Measurement Systems.” *Psychiatric Rehabilitation Journal*, Summer 2001, 25:42-53.

Exhibit 4
Community Integration Measures

Community Integration Indicator	Measure	A2C	AXIS	CCA	CLA	CHP	ICS	VT
Program Responsiveness to Consumer Needs	% of participants reporting involvement in planning, design, delivery, and evaluation of services	X	X	X	X	X	X	X
Client-driven Services and Support	% of participants reporting active participation in treatment decisions; % of participants reporting they receive information to make informed choices	X	X	X	X	X	X	X
Personal Dignity	% of participants reporting staff members are sensitive to their disability, cultural, ethnic, and linguistic backgrounds; degree to which accommodations are made; degree to which consumers believe they are respected by staff members	X	X	X	X	X	X	X
Community Tenure	Length of time living in community; length of time in jail	X	X	X	X	X	X	X
Employment Status	% of participants reporting any work-type activity	X	X	X	X	X	X	X
Living Status	% of participants reporting increased independence in living arrangements, and living in environment of their choosing	X	X	X	X	X	X	X
Quality of Relationship	Participant satisfaction with personal relationships	X	X	X	X	X	X	X
Service Status	% of participants who need non-medical services report they are getting those services	X	X	X	X	X	X	X
Health Status	% of participants reporting positive changes in the problems for which they sought help	X	X	X	X	X	X	X
Psychological Well-being	% of participants reporting they feel good about themselves	X	X	X	X	X	X	X
Substance Abuse	Number of days drinking/drug abuse in a defined time period	X	X	X	X	X	X	X
Personal Safety	% of participants reporting they feel safe	X	X	X	X	X	X	X
Self-efficacy	% of participants reporting they can manage their daily life	X	X	X	X	X	X	X
Financial Well-being	People moving off SSI because they have stabilized and gained a job	X	X	X	X	X	X	X
Self-advocacy	% of participants reporting realistic opportunities for making informed choices (e.g., use of free time)	X	X	X	X	X	X	X

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While the above indicators provide starting definitions to measure functionality and community integration, collecting the data may prove cumbersome – many of the indicators would most likely be measured through consumer responses to surveys or interviews during annual assessments. A possible future endeavor would be to review the indicators that the programs already measure, evaluating if any are usable as proxies for the community integration indicators listed above.

Recommended Measures for Highly Prevalent Conditions

During our site visits, CCO staff consistently mentioned three chronic conditions as highly prevalent secondary diagnoses to the primary disabling condition: diabetes, asthma, and depression. The following measurement sets are a good place to start (Exhibit 5):

Exhibit 5
Widely-Used Quality Measures for Prevalent Secondary Conditions

Chronic Conditions	Measurement Set	A2C	AXIS	CCA	CLA	CHP	ICS	VT
Asthma	% of participants with an asthma action plan (AAP); % of participants and physicians complying with the national asthma guidelines ¹⁹	X	X	X	X	X	X	X
Depression	Clinical practice guideline for the management of major depressive disorder in adults. Sponsored by the Veterans Health Administration	X	X	X	X	X	X	X
Diabetes	Diabetes Quality Improvement Program (DQIP). Sponsored by the American Diabetes Association, NCQA, CMS, Veterans Health Administration	X	X	X	X	X	X	X
Overweight and Obesity	% of participants with BMI's over the CDC recommended guidelines addressing overweight and obesity	X	X	X	X	X	X	X

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¹⁹ <http://www.nhlbi.nih.gov/guidelines/asthma/execsumm.pdf>

Additional Measures for Adults with Physical Disabilities

The CCOs targeted to adults with physical disabilities, especially participants requiring wheelchairs, showed remarkable agreement on supplementary quality indicators of avoidable complications (see Exhibit 6). These complications that often endanger the individual's health and life are high cost, highly prevalent conditions that can largely be prevented through care coordination and self-management. While the Nursing Home Quality Initiative at CMS measures the percent of residents with pressure sores, this measure alone does not provide enough specificity for quality management of pressure ulcers by CCOs targeting persons with physical disabilities.

Exhibit 6
Supplemental Measures for People with Physical Disabilities

Avoidable Complications Indicator	Measure	A2C	AXIS	CCA	CLA	CHP	ICS	VT
Bowel Impaction	Incidence		X		X	X	X	
Urinary Tract Infections	Incidence of participants with catheters		X		X	X	X	
Pressure Ulcers	Incidence and duration at each stage; % detected for the first time at each Stage I-IV; Average length of time for PU healing; % of participants screened for PU risk; % in high risk with annual Braden score		X		X	X	X	
Autonomic Dysreflexia	Management complying with Paralyzed Veterans Association guidelines		X		X	X	X	

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Measures for Adults with Severe and Persistent Mental Illness

The Vermont Medical Home Project targeted coordinating care for adults with severe and persistent mental illness who had diabetes as a secondary, complicating condition. These types of programs need to measure indicators of quality mental health care and outcomes, as well as indicators measuring success in coordinating care for the medical conditions.

The measures in Exhibit 7 are based on the behavioral health indicators in HEDIS.

Exhibit 7
Supplemental Measures for People with Severe and Persistent Mental Illness

Mental health management indicators	Measure	A2C	AXIS	CCA	CLA	CHP	ICS	VT
Inpatient hospitalizations and re-hospitalizations	HEDIS measures			X	X	X		X
Hospital readmissions within 7 days of discharge, Within 30 days of discharge	HEDIS measures			X	X	X		X
ECHO* measures ²⁰	51-63 questions about treatment and counseling services; included in HEDIS in 2002. <ul style="list-style-type: none"> • Getting care quickly • Communication with clinicians • Information provided by clinicians on medication side effects • Family involvement in care • Information about self-help groups and treatment • Cultural competency • Perceived improvement in functioning • Patient rights • Health plan or MBHO administrative services 			X				X

* ECHO=Experience of Care and Health Outcomes Survey
 AXIS = AXIS Healthcare, Minneapolis, MN
 ICS=Independence Care System, New York, NY
 A2C=Access 2 Care of Western North Carolina, Asheville, NC
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To these established measures of quality in mental health, we suggest adding other types of established, measurable standards. For example, the Joint Commission on Accreditation of Health Care Organization²¹ standards for behavioral health call for defining and monitoring of sentinel events and informing participants of their citizenship privileges, among others. In short, CCOs dealing with the SPMI population would

²⁰ <http://www.hcp.med.harvard.edu/echo/home.html>

²¹ JCAHO (2004). Comprehensive Accreditation Manual for Behavioral Health Care.

understand the quality of their care and its outcomes based on a variety of measures specific to their specialty, as well as indicators specific to a secondary medical condition.

Cost and Utilization Measures for CCOs

CCOs have three options in defining comparison groups for cost and utilization:

1. Internal, year-to-year comparisons, with each participant serving as his or her own control;
2. External comparisons inside the state to other Medicaid beneficiaries; or
3. External comparisons outside the state to other CCOs targeting similar populations.

Advocates and Medicaid program managers will probably be most interested in the second, within state comparisons. They will be particularly interested in documenting savings to Medicaid through the use of comprehensive care and service coordination. We recommend that states take a global perspective, and compute costs across all publicly funded programs that touch the CCO participants, an often daunting objective given separate, discrete databases for the different types of care.

We also recommend that costs be aggregated across 18-24 month periods when observing comparative data due to the nature of changing circumstances with these populations. All CCOs related that the most expensive time period is the first six to eight months after enrollment, when the care coordinator is addressing a backlog of unmet needs and working with the participant to get them medically and psychologically stabilized. It takes another six to eight months for expenditures to drift down to the “average” amount. During the second year, the CCOs start to see more stable expenditures with the occasional acute episode.

Our third recommendation is that the CCOs include their own costs of doing business. If they want to become financially self-sustaining, they need to document to the state Medicaid program that the total amount of money spent on participants is less than the amount of money the state spends for non-participating beneficiaries. For example, states and the CCOs need to know if it is less expensive for the state to pay for CCO services and have a person live in the community, than to keep the beneficiary in a nursing home. If the state is convinced they save money in the long run, then the state will have a strong interest in supporting the growth of CCOs.

That said, there are many difficulties when trying to compare costs and utilization for CCO participants to non-participating beneficiaries. These include:

- Problems identifying comparison groups of non-participating beneficiaries, particularly if there is no information on functional or cognitive status;
- Problems merging data across different vendors, e.g. pharmacy vendors, dentists, mental health providers, medical suppliers, and clinicians;
- Problems tracking utilization if the CCO or non-participating beneficiaries are in capitated programs;

- Problems identifying the primary diagnosis to create subpopulations for comparisons (the primary diagnosis may be missing, especially when the beneficiary is being seen for a co-existing condition, e.g. being treated for depression secondary to multiple sclerosis);
- Incomplete data for risk adjustment algorithms;
- Turnover in Medicaid eligibility in the non-participating comparison group;
- Lack of standard utilization figures for small numbers of people with disabilities (e.g. costs per person, or costs per fifty, or a hundred participants).

Keeping in mind our measurement selection criteria in Section III, we recommend the following cost and utilization measures in Exhibit 8:

Exhibit 8 Cost and Utilization Measures

Cost and utilization	Measure	A2C	AXIS	CCA	CLA	CHP	ICS	VT
Care/Case Management, including Participant Education	Number and hours of contact per month, stratified by service intensity	X	X	X	X	X	X	X
Dental Care	Cost	N/A	X	N/A	X	X	N/A	N/A
Durable Medical Equipment	Cost; utilization; repairs (HCPCS coding)	X	X	N/A	X	X	X	N/A
Hospital Admissions	Cost; # of admissions; length of stay	X	X	N/A	X	X	N/A	X
Medical Encounters	Cost; utilization by primary care & specialty	X	X	X	X	X	X	X
Medical Supplies	Cost	X	X	N/A	X	X	X	
Mental Health Encounters	Cost; utilization by provider type	X	X	X	X	X	X	X
Missed Appointments	% of appointments that participant misses	X	X	X	X	X	X	X
Nursing Home	Cost; admissions; length of stay; discharge destination	N/A	X	N/A	X	X	N/A	N/A
Personal Care Assistance	Cost; hours	N/A	X	N/A	X	X	X	N/A
Pharmacy	Cost; prompt refills; evidence-based and appropriate medication management	X	X	X	X	X	X	X

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VI. Recommended Data Sources

The Minnesota Disability Health Options Evaluation Plan²² illustrates how CCOs can collect a large quantity of cost and utilization data in the course of normal business operations. This helps minimize costs. CCOs and states will probably collect data to compute quality measures from the following sources:

- Medicaid administrative data (eligibility files, processed claims for fee-for-service benefits);
- CCO data (health assessments, functional status); and
- Participant surveys.

With regard to participant surveys, our advice to CCOs is to follow the same strategy as we used in selecting measures: *identify survey instruments appropriate to their target population from tools that are already used by MCOs, the Veterans Administration, and/or Medicaid and Medicare programs.* These are:

- ECHO or the Behavioral CAHPS;
- Medicaid CAHPS;
- Forthcoming CAHPS for People with Mobility Impairment;
- Lehman Quality of Life Scale (includes questions on housing, income, community involvement, self-efficacy); and
- AXIS Longitudinal Survey (questions on access, care coordination).

VII. Recommendations for Next Steps

Recommendations for advancing to new levels of quality measures for persons with disabilities and chronic disease fall into three major categories: develop common data sets, develop multi-site quality improvement initiatives, and establish a research consortium to share findings and mediate statistical challenges.

1. Identify a common data set to answer common questions.

We recommend that interested CCOs join together to agree on common *clinical, social, and service* outcomes measurements specifically relevant to the vulnerable populations they serve, similar to the effort that culminated in the Medicaid HEDIS. Concurrent with comparing results on established quality indicators, the CCOs should focus on measures that are not likely to be addressed by NCQA, but are specific to conditions common in their service population, such as measures for urinary tract infections (UTI), pressure ulcer prevention, and the management of depression and substance abuse. The CCOs should work with professional organizations not commonly associated with care coordination at the present time, such as the organization of psychiatric rehabilitation professionals to further advance their abilities to define relevant outcomes. This would

²² Minnesota Department of Human Services. *Minnesota Disability Health Options Project Evaluation Plan*. Center for Health Care Strategies, January 2004.

enable them to select indicators of functionality and community integration that measure these types of outcomes for persons with mental illness, but may also apply to persons with physical disabilities. Identifying relevant measures of quality is a challenge, but there are others, as well.

Consolidating data collection and analytic methodologies are needed to bring a more robust feature to CCO quality measurement and reporting. For example, agreeing on common data collection protocols, including CPT codes to record hours of care coordination by provider type (nurse, resource person, doctor), survey tools, or in-person assessments, would achieve increased understanding of what is required and by which provider to meet the participants' needs.

Additionally, creating a standard stratification method that combines measures of resource use and care coordination time and function would add more specific understanding. With a standardized stratification method, reviewers and organizational managers can document and track what specific services the care coordinators provide. Further, CCOs would be able to classify the participants into similar intensity groups for more appropriate care coordinator caseload allocation.

In addition to the benefits of reaching agreement about common measures and data collection methods, CCOs quality management efforts would benefit greatly by their investing in similar information management systems. Among the programs we visited, the North Carolina Foundation for Advanced Health Programs has the greatest in-depth information management and processing technology, and Community Health Partners in Eau Claire, Wisconsin has the best user interface for CCO operations. Other CCOs adopting the same or similar systems would foster uniform data collection for comparative reporting.

2. Develop a multiple-site quality improvement project.

A common collaborative quality improvement effort among CCOs that share similar or comparable target populations would bring insights into best practices for coordinating care for persons with specific disabilities. This type of collaborative effort would benefit from initially using tools and methodologies that the CCOs have developed separately. For example, ICS in New York City has a survey on the process of care for people with multiple sclerosis that AXIS and the two Wisconsin sites might find useful. Vermont's project on improving diabetes management secondary to severe and persistent mental illness could be shared with CCA in Massachusetts and Access II Care in Asheville. These programs have independently developed quality initiatives that, if shared among similar CCOs, would more quickly advance the quest for care and outcomes improvements.

3. Establish a research consortium to overcome the “small numbers” problem.

A formal research consortium of CCOs, similar to the HMO Research Network,²³ would advance the quest even further. The consortium of CCOs would work together to apply for research funding to establish specific, evidence-based knowledge about coordinating care for persons with disabilities and chronic disease. For example, evidence is needed to evaluate new health care interventions for adults of working age with disabilities, conduct clinical trials of new pharmaceutical interventions for conditions with small prevalence, or compare care coordination models for organizational effectiveness and improved client outcomes.

VIII. Summary and Conclusions

Costs of care for people with severe disabilities are significant and are a major focus for federal and state governments. A number of states are evaluating pilot programs that coordinate multiple public programs across medical and social services.

Coordinated care organizations are emerging as all-inclusive managed care programs for Medicaid adults with disabilities. CCOs make a difference for their participants because they approach the individual holistically, coordinating not only health services but the multiple support services needed to keep these individuals independent and productive in their community. CCO services are significantly assisting their participants who express high levels of satisfaction, but the CCOs face challenges in devising comprehensive quality management programs and systems. While, in general, they currently monitor measures of utilization and care processes of selected diseases (diabetes and asthma), measures indicating outcomes, in terms of improvements in participants’ lives and health, are absent. Further, they are without means to compare their outcomes against each other or against other populations. Without salient measures and comparative systems, CCOs are limited in demonstrating how they make a difference in the lives of their participants and in benefiting the community.

We have recommended initial sets of indicators and ways for states and health care organizations to begin documenting and measuring indicators that define their unique contribution and ability to make a difference in the lives of persons with disabilities and the communities in which they reside. However, the journey of measuring quality for persons with disabilities has only begun. Those funding and providing health services for this population have within their reach the capability for proving they make a difference; a positive, cost-effective difference in the health and lives of this vulnerable population. The challenges are significant but achievable: unifying their efforts, building common data sets, using common data collection protocols and analytic strategies, and building similar information systems for comparative reporting.

²³ HMO Research Network: <http://hmoresearchnetwork.org/about.htm>