

RESEARCH BRIEF

**Comparative Effectiveness
of Care Coordination
for Adults with Disabilities**

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ISSUE AT A GLANCE

The notion that care coordination can improve outcomes for people with disabilities or complex health needs has existed for decades.¹ Beginning with On Lok and the National Long Term Care Demonstration,² policymakers and researchers have sought to establish a strong basis for this belief. To some extent, their efforts have paid off. There is substantial evidence that care coordination can, under certain circumstances, improve outcomes for people with chronic conditions (Peikes et al. 2009; Boulton et al. 2009). However, it has been difficult to replicate or scale up approaches that have shown promise in early, small studies (Boulton et al. 2009; Lipson and Au 2010). Moreover, several factors have stymied attempts to identify a generalizable program design with predictable benefits, including the complexity of such programs, differences in targeted populations, and variation in program organization, staffing, and context. The findings from systematic reviews of the literature on care coordination for adults with disabilities have been mixed (Ziguras and Stuart 2000; Marshall 2010; Liebel et al. 2009), and there is little detail on common, key elements.³

Policymakers and practitioners continue to gravitate toward care coordination, placing it at the center of new models of care such as accountable care organizations and medical homes. At the heart of these activities is a belief that coordination works, but pinning down what “it” is has been difficult.

In response to this trend, Mathematica has developed a conceptual framework to describe (1) the basic elements of care coordination and how they might vary according to the type or severity of a disability(ies), (2) the relationship to health and supportive services, and (3) expected results and outcomes. We then used this framework to conduct a systematic review of the literature on care coordination for people with disabilities, focusing on information about key program elements.

The review revealed major weaknesses in the literature, the most prominent being the absence of information on many basic elements of care coordination—even in rigorous studies. Going forward, our framework should help researchers identify a common set of elements to use in all descriptions and evaluations of care coordination programs. Policymakers, practitioners, and program developers can use the framework to form a checklist as they consider how to structure and operate care coordination programs to maximize the benefits for people with disabilities.

¹We use the term “care coordination,” although such programs are also known as case management and disease management programs.

²On Lok was the precursor to PACE (the Program for All-Inclusive Care for the Elderly), and the National Long Term Care Demonstration is also known as “Channeling.”

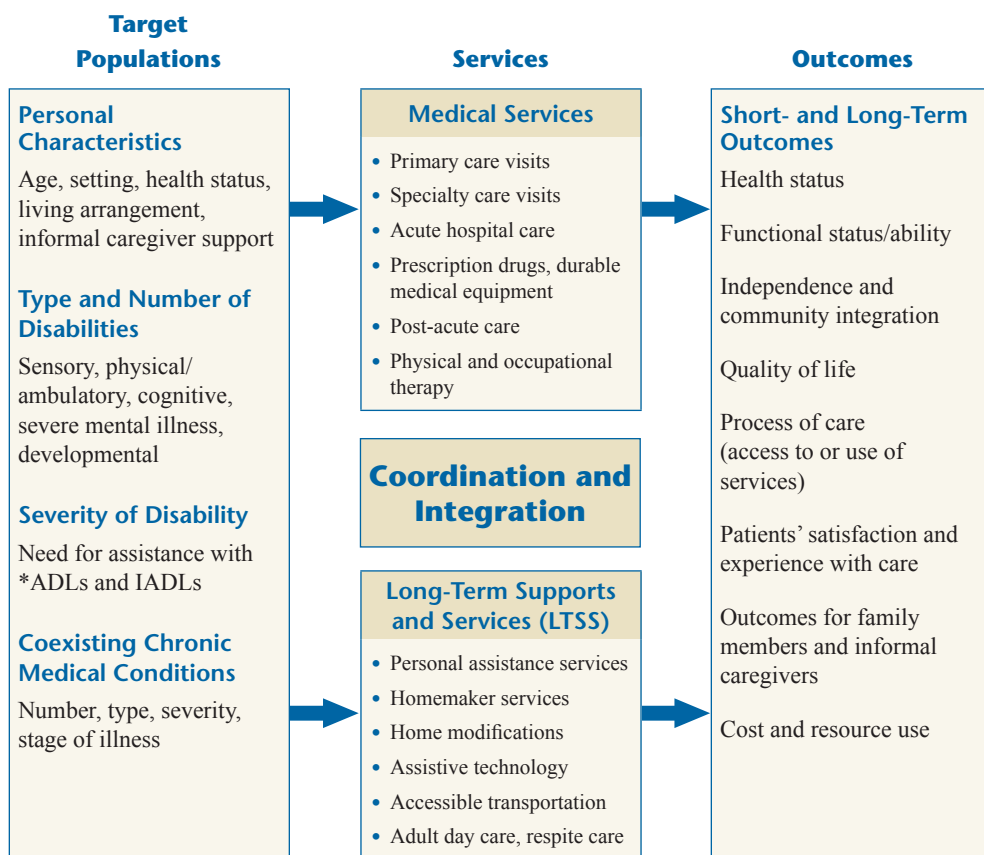
³A list of the reviews examined is available at http://www.mathematica-mpr.com/chce/review_au_0711.asp.

Developing a Conceptual Framework

Given the importance of a robust intervention typology that would be relevant to real world decision makers, we developed a conceptual framework, presented in three figures, that illustrates how care coordination programs work. Figure 1 illustrates the complexity of effective care coordination. A range of patient characteristics and circumstances (left side in the figure) determine patient needs for medical services and long term supports (middle). This mix of services, which can differ even for patients with similar disabilities, affects a number of outcomes (right side) in varying ways. Care coordination (in the center) is essential to matching the appropriate combination of services to the right patients and coordinating the delivery of those services to improve outcomes. The dimensions and features of different care coordination programs are presented in Figures 2 and 3. While this framework does not capture every type of care coordination model, nor specify every discrete pathway through which care coordination may affect outcomes, it highlights the importance of specifying (1) the characteristics of the population(s) served (Figure 1), (2) the types of services coordinated in the program (Figure 1), and (3) the dimensions and features of different care coordination programs (Figures 2 and 3).

Adults with disabilities are like all other people in their need for basic health care and their desire to be fully included in society. But their health and social care needs differ from the

Figure 1. General Framework of Populations, Services, and Outcomes



*ADLs = Activities of daily living ; IADLs=Instrumental ADLs

general populations' due to impairments in physical, cognitive, developmental, or sensory ability. Even individuals with similar disabling conditions can have very different needs and very different preferences for the type and intensity of services or supports they receive. For example, adults with physical disabilities may need help with all or just a few activities of daily living (ADLs), such as eating, bathing, dressing, or toileting. Adults with cognitive or developmental disability may need help with some or all instrumental activities of daily living (IADLs), such as managing household finances, getting outside the home, and shopping for groceries. Some adults with serious mental illness can follow treatment plans; others may need considerable support to do so. Adults with multiple disabilities and/or co-existing medical conditions may have more functional limitations, so they may have an even greater need for diverse services and care coordination. Anyone seeking to determine the comparative effectiveness of services for persons with disabilities, therefore, must avoid a "one-size-fits-all" approach.

There are many ways to classify the range of outcomes that matter most to people with disabilities. Our conceptual framework shows the range of outcomes commonly examined in the literature across eight domains: (1) health status; (2) functional status or ability; (3) independence and community integration; (4) quality of life; (5) process of care measures (including timely access to and use of needed services); (6) patient satisfaction and experience with care; (7) family and informal caregiver health and well-being; and (8) cost and resource utilization. Depending on their perspective and circumstances, individuals will value some of these outcomes more than others. For example, community-dwelling adults with disabilities may consider quality of life and integration in society to be the most important outcomes. For purchasers of services, cost and process of care outcomes may be most important. Because our systematic review of evidence on care coordination seeks to provide the information needed by different types of decision makers, our conceptual framework acknowledges the range of outcomes of interest to them.

Services to be coordinated. Within our conceptual framework (Figure 1), the outcomes of care desired by persons with disabilities are mediated by their receipt of medical care, which is intended to treat or prevent specific health conditions, and long-term supports and services (LTSS), which seek to facilitate functioning. Care coordination plays a key role in determining timely access to needed services. Meeting the needs of adults with different types of disabilities can be particularly challenging because they may require a variety of medical services and LTSS to maintain health and functioning. Yet the providers and systems that deliver these two types of services operate very differently and may not interact with one another (Leutz 2005). These realities increase the potential value of care coordination and also make its successful implementation challenging.

The medical services required by community-dwelling adults with disabilities fall along a continuum from general medical care, such as what might be provided during a physician office visit, to home hospice care during the waning days of life. Between these points, a person may receive outpatient services from a range of physician specialists; acute care inpatient services in hospitals; and an array of technological services (diagnostic tests and imaging) and therapies delivered in hospitals, physicians' offices, or specialized outpatient facilities (imaging centers, surgical centers, and rehabilitation centers, for example).

LTSS, by contrast, are designed to help individuals with disabilities maintain independence and functional status, and overcome limitations with daily activities. Examples include personal assistance services, assistive technology, home modifications, home care aides,

and respite programs that support informal and family caregivers. Other services, such as accessible transportation and adult day care, facilitate social participation in the community.

Features of care coordination. Care coordination is situated in the middle of the framework (Figure 1). The 2009 report of the Federal Coordinating Council for Comparative Effectiveness Research calls it “critical” in helping persons with disabilities “live independently in their communities with added years of quality life” (FCCER 2009). Yet in the medical, health services research, and disability literatures, the term “care coordination” does not have a single consistent meaning. A 2007 Agency for Healthcare Research and Quality (AHRQ) systematic review (which focused more on coordinating medical services than on addressing the specific needs of individuals with disabilities) defined care coordination as “the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient’s care to facilitate the appropriate delivery of health care services”; it went on to assert that “organizing care involves the marshalling of personnel and other resources needed to carry out all required care activities, and is often managed by the exchange of information among participants responsible for different aspects of care” (McDonald et al. 2007). As this AHRQ review notes, some models of care coordination focus mainly on the integration of medical services. Others, described more fully below, help populations with disabilities by coordinating different types of LTSS. Still others seek to integrate both medical care and LTSS for persons with disabilities. Our conceptual framework builds on the AHRQ report while emphasizing the potential need to integrate relevant medical services as well as social supports across multiple providers and settings in order to improve outcomes for community-dwelling adults with disabilities.

Figure 1 illustrates how various care coordination programs might differ depending on the target population, scope of services coordinated, and outcomes of interest. Figure 2 illustrates how, within these programs, specific elements and program features that affect the implementation and outcomes of care coordination may vary substantially. For any specific population targeted for care coordination, the programs may vary along several dimensions, including which services are to be coordinated, who coordinates or manages care (and whether they are part of an interdisciplinary team), how frequently and over what period

Figure 2. Dimensions and Features of Care Coordination Models



*Home and community-based services

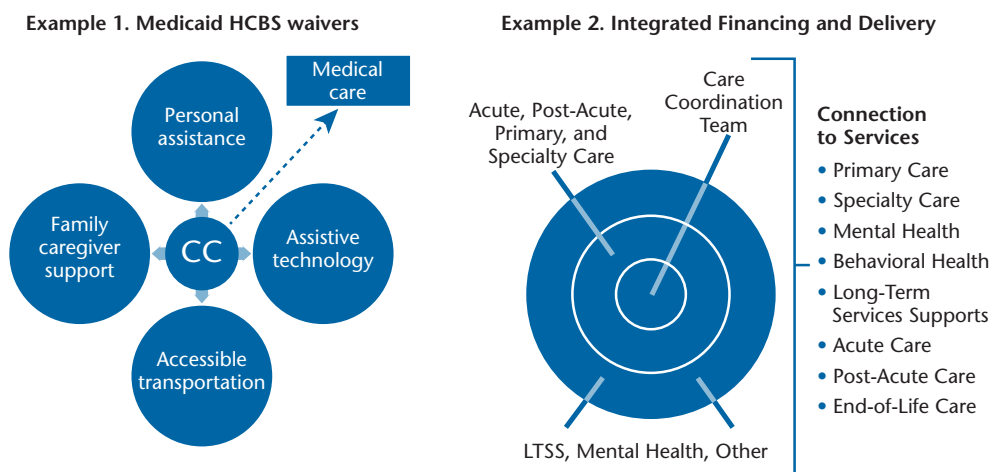
of time services are coordinated, and the extent and quality of information exchanged between providers and care coordinators, as well as the involvement of patients, family members, and other informal caregivers in decision-making.

Influence of organizational setting and financing context. The various organizational settings and financing contexts for services are potentially important mediating factors in determining how effectively care is coordinated. Indeed, the way in which medical, LTSS, and other services are organized and financed may be critical to achieving desired outcomes, by influencing the ease of service coordination and the number and quality of the services received (Figure 3).

Organizational settings for delivering services to adults with disabilities vary widely. They range from several individual health professionals operating independently in different organizations and agencies, to integrated systems in which interdisciplinary teams work closely together at the same site to assure that all needed care is provided. The number and type of health care organizations involved in an individual's care can determine the number and type of services recommended, as well as the ease or difficulty of connecting persons with disability to needed services. The organizational setting for care coordination can influence the number and type of professionals involved, as well as the resources available for needs assessment (and thus its scope and sophistication). It can also influence which professionals serve as case managers (physician, nurse, or social worker, for example) and whether care is coordinated by a team or an individual.

The financing of health care and LTSS under public or private insurance has a strong relationship with access to services, especially for adults with disabilities, since it influences both the timing and the scope of services available. For example, adults who qualify for Medicare can get coverage for medical services, prescription drugs, and devices deemed “reasonable and necessary for the diagnosis and treatment” of an illness or injury. But Medicare does not cover long-term home and community-based services (HCBS), and it provides limited coverage for services aimed at enhancing mobility, self-care, and independence, such as physical therapy and assistive technology (Field and Jette 2007). Depending on their income and assets, disabled individuals may or may not be eligible for Medicaid or other programs that cover benefits not included under Medicare, or that subsidize Medicare monthly premiums, deductibles, and copayments. If individuals must pay such costs themselves, they may not get all the services needed to assure good outcomes. If they qualify for two or more programs as “dual-eligibles” (for example, Medicare and private disability insurance, or Medicare and Medicaid), they may still experience problems in coordinating benefits to ensure timely access to services.

Various programs using available organizational and financing systems have emerged over the years to address the coordination (and provision) of medical and social services to adults with disability. For example, nearly every state Medicaid agency finances various forms of case management in HCBS waiver programs (Figure 3, example 1). In this model, the case manager exerts direct control over access to HCBS services and financing, but uses more modest “linking and referral” (shown as a dotted line) mechanisms to encourage appropriate medical care by physicians or other health professionals. At the other end of the spectrum are fully integrated models for the organization and financing of both care coordination and services (Figure 3, example 2). This model is exemplified by the Program of All-Inclusive Care for the Elderly (PACE), as well as by some state programs operating under federal waivers, which combine Medicaid and Medicare financing to pay managed care organizations

Figure 3. Organization and Financing of Care Coordination

at capitated rates for providing all medical and long-term care services for persons with disability. In between, other models of care coordination function in different organizational and financing contexts, and therefore use different approaches to coordinate subsets of benefits and services across financing sources and providers and agencies.

Implications for review of evidence on care coordination. The role of both the organization and financing of services in determining the outcomes of services and care coordination for adults with disabilities has implications for our systematic review of the literature. In assessing the relative effectiveness of care coordination approaches, we sought to compare those that operate under similar organizational and financing models in order to reduce the chance that outcomes were influenced by organizational structure, benefits and services covered under participants' financing sources, and reimbursement incentives in financing programs. Accordingly we analyzed care coordination effectiveness by organization and financing models: the categories were Medicaid Fee for Service (FFS), Medicaid Consumer Directed Cash Benefit, Integrated Medicaid and Medicare, Medicare capitation, private health care organizations, Veterans Affairs' programs, private foundations, and mixed-funding sources.

With respect to the relationship of specific features of care coordination to various outcomes, an earlier review of reviews revealed mixed findings. Despite widespread endorsement of care coordination as a strategy for improving the quality of care, increasing patient satisfaction, lowering costs, and improving health status, our "review of reviews" of programs for persons with disabilities showed that care coordination had limited effects. We also found very little information on the potentially important features of care coordination programs, even features that previous evaluations of care coordination deemed important [for example, greater in-person contact and more targeting to higher-risk patients (Peikes et al. 2009)]. Indeed, many of the systematic reviews we identified recommended that future studies be more specific about a number of features, including the study population, how the population was targeted, the scope of needs assessment, the professional training and qualifications of care coordinators, the integration of care coordinators with service providers, and the intensity (amount, frequency, and length) of contact between care coordinators and patients, and their caregivers. Our systematic review of original literature therefore focused specifically on evidence for how these key dimensions of care coordination influence program effectiveness.

What Did We Find?

We searched the published and the “grey” literature from 2000 to 2010 for primary studies on the effectiveness of care coordination programs for adults with disabilities. This review focused on care coordination programs aimed at optimizing independent living for community-dwelling adults with disabilities. We therefore excluded models used in institutions as well as broad-based interventions in which it is difficult to separate care coordination from other intervention components (for example, PACE). (See pages 14 to 15 for a description of our methods.)

Although the body of literature on care coordination is extensive, only a few evaluation studies address what works for whom. Specifically, our search criteria identified a total of 9,866 articles (after removing duplicates), but only 46 of those were judged to be evaluations that met our inclusion criteria. We excluded 9,289 articles during a title-level review and an additional 456 during an abstract-level review based on the criteria described in the methodology, because the studies were off-topic, did not include people with disabilities, did not include a community-dwelling population, were only about children, did not include any care coordination services, did not include outcomes of interest, or were not implemented in the U.S.⁴ We used a number of search terms to sufficiently capture our disability categories. However, the amount of articles excluded at title-level review suggests that additional fine-tuning of search terms may have reduced the number of articles requiring review.

We divided the 46 articles into groups based on type of disability and funding source. Seventeen articles addressed care coordination for people with severe and persistent mental illness (SPMI), 9 addressed individuals with cognitive impairment, 3 addressed people with physical impairment, and 17 addressed populations with multiple disabling conditions (Table 1).⁵ No studies that examined care coordination for people with developmental/intellectual impairments or sensory impairments met our inclusion criteria. The most common funding sources cited in the 46 articles were private health care organizations (10), Veterans Affairs (VA) (9), and Integrated Medicaid and Medicare (7). Eight studies were supported by a mix of funding (for example, a combination of both foundation and private health care organization resources). No intervention we reviewed was funded through the other funding mechanisms we sought to examine: Medicaid FFS, Medicaid Consumer Directed Cash Benefit, and Medicare capitation.

Only 19 of the 46 studies relevant to our review were designed such that the findings had moderate or high internal validity. Table 2 shows the limited evidence we found for various types of disabilities. While a number of the 19 evaluations reported favorable impacts on outcomes, the state of the literature cannot support definitive conclusions about which program features will yield the best outcomes for people with particular disabilities. The problem is twofold: the programs served several distinctly different types of patients through a variety of organizational and financing mechanisms (Table 1); and the information on specific features of the programs was frequently incomplete or the features themselves

⁴Additional details on our methodology can be found in the full report, which can be requested by emailing chce@mathematica-mpr.com.

⁵The full report includes a variety of tables that present information on studies by type of disability addressed (SPMI, cognitive impairment, physical impairment, and multiple disabling conditions). In each section, an initial table presents descriptive information on the studies reviewed; a second table provides information on care coordination dimensions; and a third table presents information on findings. The report can be requested by emailing chce@mathematica-mpr.com.

Table 1. Summary of Review Articles by Population and Funding Categories

	Medicaid: Managed Care Organization	Integrated Medicaid and Medicare	Medicare FFS	Foundation/ NIH	Private Health Care Organization	Veterans Affairs	State Department of Health/ Mental Health	Mixed Funding	Other	Total
SPMI	—	—	—	4	3	4	2	4	—	17
Cognitive Impairment	—	—	—	1	5	1	—	1	1	9
Physical Impairment	—	2	—	1	—	0	—	—	—	3
Multiple Disabling Conditions	1	5	1	—	2	4	—	3	1	17
Total	1	7	1	6	10	9	2	8	2	46

were inadequately documented (Table 3). We sought to abstract key elements of care coordination from our conceptual framework (Figure 2): needs assessment, coordinator experience/background, team composition, scope of services, and intensity of coordination. As shown in Table 3, many of these dimensions are not consistently reported.

Our systematic review found that the current literature cannot support identification of consistent patterns of effectiveness and lacks detail needed to understand the importance of care coordination dimensions for adults with disabilities. However, for policymakers searching for lessons they might readily apply to their current circumstances, we highlight those programs where evidence suggests a meaningful impact on one of three outcomes of broad interest: (1) independent living, as measured by reduced hospital admissions and nursing home use, (2) health status, and (3) quality of life. For each disability category, we highlight specific features of the few programs that demonstrated impact on such outcomes.⁶

Adults with serious and persistent mental illness. For care coordination programs directed to adults with SPMI, only one in seven programs demonstrated an outcome relevant to improved independence, in this case reduction in psychiatric hospital admissions and hospital days. This initiative, focused on clients with co-occurring SPMI and substance use disorders, was financed through state-funded mental health services (Mangrum et al. 2006). The intervention was provided to 123 clients at three sites, all of which established a dual-diagnosis treatment team providing care coordination and access to a range of mental health and substance abuse services (psychiatric services, individual therapy, and specialized groups tailored to client issues). The sites varied in the extent to which they established broader community networks with ancillary service providers; several other care coordination program details are not reported (for example, approach to needs assessment, intensity of contact, type of outreach).

Table 2. Limited Evidence Base

Target Condition	Number of Studies	Internally Valid Studies
SPMI	17	7
Cognitive Impairment	9	3
Physical Impairment	3	0
Multiple Disabling Conditions	17	9
Total	46	19

⁶Other outcomes are presented in the full report, which can be requested by emailing chce@mathematica-mpr.com.

Table 3. Selected Dimensions of Care Coordination Described in Literature

Dimension	SPMI (N=7)	Cognitive Impairment (N=3)	Multiple Disabling Conditions (N=9)
Needs Assessment	2	2	1
Coordinator Experience or Background	5	2	9
Team Composition	3	2	6
Scope of Services	5	2	6
Intensity of Coordination	3	1	5

Although no other studies judged to have at least moderate internal validity reported program benefits on independence for adults with SPMI, two models of care coordination that address both medical and psychiatric care showed moderate evidence (albeit with small samples) for improved health status or quality of life. Both studies were in the VA health care system. One program involved a multidisciplinary team providing primary care in a dedicated clinic adjacent to mental health services; the evaluation demonstrated improved physical health status (SF 36 subscale) for 59 veterans served by the intervention (Druss et al. 2001). In this program, registered nurses provided patient education and were liaisons with mental health providers and case management service providers, while physicians served as liaisons to the psychiatry service. The other promising program, a multicomponent bipolar disorder medical care model, demonstrated improved health-related quality of life for 27 veterans with bipolar disorder and cardiovascular risk factors at higher risk for repeated admission to hospitals or nursing facilities than veterans receiving usual care (Kilbourne et al. 2008). The program included a self-management component, educational sessions, and care coordination by a registered nurse. However, in both these programs, some key details of the care coordination intervention (for example, needs assessment process and care coordination intensity) were not described.

Adults with cognitive impairment. We found no studies of moderate or high internal validity demonstrating that care coordination improved independence for adults with cognitive impairment. We did, however, identify one study of at least moderate internal validity that demonstrated benefits on health status. A multi-site evaluation by Vickery et al. (2006) of the Alzheimer's Disease Coordinated Care for San Diego Seniors (ACCESS) Program (funded and organized by a collaboration of three private health care organizations and three community agencies) demonstrated that a specific guideline-based dementia care management intervention for 238 patients achieved a relative improvement in health-related quality of life, as reported by patients. This program featured use of case management software to develop and prioritize a problem list and care recommendations that case managers reviewed with caregivers. The employment arrangements for the care coordinators varied in this program, with some working for community-based organizations and some for care delivery organizations.

Adults with physical impairments. We found few studies overall and no studies with at least moderate internal validity addressing the effectiveness of care coordination interventions for adults with physical impairments.

Adults with multiple disabling conditions. Our systematic review found only one study of moderate or high internal validity offering evidence that care coordination improved independence for adults with multiple disabling conditions. That evaluation, by JEN Associates (2008), found a significant reduction in the rate of nursing home entry for 635 participants in Senior Care Options, an integrated Medicare and Medicaid managed

care program offered to elderly Massachusetts Medicaid beneficiaries. Several different senior care organizations (SCOs) provide a complete benefit package that includes the full range of Medicaid and Medicare services for enrollees. Each SCO undertakes some aspects of care coordination, but several key details vary across these organizations. Consistent aspects include the breadth of the services coordinated (medical services, behavioral health, prescription drugs, and long-term support services) and the integration of the care coordination function with the organizations delivering services.

We found several studies of at least moderate internal validity that showed improvements in quality of life under care coordination programs operating in various organizational and financing settings. Claiborne (2006) described a care coordination program for stroke survivors supported by mixed funding sources. The intervention group ($n = 28$) showed significantly improved quality of life, decreased depressive symptoms, and increased adherence to self-care practices. In this program, social workers coordinated a wide range of medical and social services in a link-and-referral model. The study describes the needs assessment approach and intensity of the care coordination intervention. Marek et al. (2010) reported improved ADLs as well as a decrease in pain and other symptoms for 55 nursing home-eligible elders in the Aging in Place program of integrated Medicare and Medicaid financing. The care coordination was provided by specially trained nurses who operated in a fully integrated model, managing a broad range of medical and long-term services and supports. Comprehensive needs assessment and periodic home visits were also elements of this care coordination intervention.

The additional two programs with at least moderate evidence of health status benefits were directed at frail elderly military veterans. Cohen et al. (2002) reported that nearly 350 veterans experienced significant improvement in mental health after participating in a program of outpatient geriatric evaluation and care coordination. After comprehensive geriatric assessment, the interdisciplinary geriatrics team coordinated a broad range of services in a fully integrated model. The report did not provide details on the type and intensity of the outpatient aspect of care coordination. Chumbler et al. (2004) reported on 111 military veterans who received “tele-health” care coordination through telephone conversations with registered nurses or nurse practitioners. These care coordinators collected data for managing complex health needs (needs assessment not described in detail) and also provided education on self-management principles. No details are provided on the range of services coordinated or the linkage with the other providers of clinical or support services. The treatment group had significant improvements in IADLs as well as motor and cognitive functioning.

Areas of convergence across studies. Despite substantial heterogeneity of population needs and financing models for coordinating services observed across the literature, several broad areas of convergence were identified among studies with at least moderate internal validity and a focus on independence or health status. First, an integrated service delivery environment was a common feature among studies with positive findings linking care coordination and increased independence. Indeed, of the nine programs highlighted above, six occurred in the context of the VA health care system, in another integrated delivery system, or within a program of integrated financing of services. Thus, integration of payment and service delivery may facilitate successful care coordination practices compared with other approaches to organizing and financing of care. Related to integration of service delivery was the role of the care coordinator with other care providers. Where it was documented, the care coordinators’ role was closely integrated with other providers in several of the studies showing positive findings on independence and health status. In this way, the role of care liaison provided by

care coordinators shows promise to facilitate communication between providers and can effectively link individuals with disabilities with providers resulting in improved care outcomes. Unfortunately, these features cannot be readily disentangled from another common element of these highlighted care coordination programs, which is an organizational mechanism that integrates either the financing or the delivery of care (often both).

Implications

Care coordination for adults with disabilities is the archetype of the “complex intervention” that challenges traditional systematic review methodology (Shepperd et al. 2009). The variety of programs for diverse populations of adults with disabilities inevitably resulted in the inclusion of studies that looked at many different interventions in a range of distinct payment and organizational environments. Furthermore, to be useful to different types of decision makers, we reviewed studies that measured a diverse set of outcomes; as a result, the comparative effectiveness of interventions in producing specific outcomes cannot be measured quantitatively, which is typically done in traditional systematic reviews of a clinical intervention like a drug or medical procedure. A second challenge stems from our decision to include studies in our review even when they did not systematically describe potentially important aspects of the intervention. Given the limitations of the existing body of literature, we provide recommendations for future implementation and evaluation activities to provide policymakers and other stakeholders with better evidence about the effectiveness of care coordination for individuals with disabling conditions.

Implications for policy and practice. Given the scattered findings and small sample sizes in the studies we reviewed, the evidence remains limited regarding the relative effectiveness of different elements of care coordination for adults with disabilities.

For decision makers considering the implementation of care coordination interventions within integrated care delivery settings (like the VA health system) or integrated Medicare and Medicaid financing programs (like the SCOs in Massachusetts), there is some limited evidence. Our systematic review identified several examples of effective programs, though most of the program evaluations described above have limited sample size and often occurred in relatively unusual settings. For many, the contribution of key dimensions of the care coordination program to the outcomes was not carefully examined. Thus, even if one wanted to replicate an effective program in the same financial and organizational circumstances for the same kinds of patients with disability, one can have only limited confidence that the program will perform comparably if the model is even slightly changed.

Moreover, most community-dwelling adults with disabilities are not presently cared for in integrated delivery systems, nor are they enrolled in health plans that receive capitated financing. For decision makers seeking to address the care coordination needs of most patients receiving care in the current non-integrated, FFS system, evidence of effectiveness of any particular care coordination program is even sparser. Clearly, the programs evaluated vary dramatically in many elements that may be critical to success. To have sufficient information to scale up or otherwise replicate care coordination interventions, policymakers will need much more robust evidence addressing several key questions: What target population can most benefit from care coordination? Which organizational and financing mechanisms increase the likelihood that care coordination will be effective? How do variations in specific features of care coordination (for example, coordinator training, coordinator linkage to the delivery system, needs assessment approach, intensity of patient contacts) affect program effectiveness? Given the long-term costs

of care coordination programs for adults with disabilities, and the uncertainties associated with their effectiveness, implementing truly effective programs will require rigorous evaluations to answer these important questions reliably.

Yet policymakers and organizational leaders often find themselves obliged to implement a care coordination intervention to address clients' pressing needs, even where robust evidence of program effectiveness is lacking. In such circumstances, we encourage policymakers to employ the concept used in the CER policy community: "coverage with evidence development." Faced with inadequate evidence, policymakers can condition funding of a new care coordination initiative on the ongoing collection of data required to evaluate the program's effectiveness. We recommend that any new care coordination initiative or pilot should do the following: serve a well-defined priority target population; and occur within financing and organizational approaches that are potentially applicable to the broader target population of concern to the agency or organization funding the pilot program (to facilitate scaling up and replication by policymakers, if evidence justifies). We encourage program developers to use the conceptual framework, particularly the key dimensions shown in Figure 2, as a checklist as they decide how to structure a care coordination program. During program implementation, we recommend that practitioners clearly describe these dimensions to evaluators in order to determine how variation in these dimensions may affect outcomes. The evidence development phase (that is, data collection/program evaluation) should be long enough that benefits relevant to the decision makers will emerge and be detected, and it should include prospective planning for a credible evaluation.

Implications for future CER on care coordination for persons with disabilities. Our systematic review highlights how researchers can refine and improve evaluations of care coordination programs to better meet the information needs of decision makers (state governments, private payers, provider organizations). Whether the study is a prospective controlled trial or an observational study taking place in the context of "coverage with evidence development," researchers should try to ensure that the care coordination program has a clearly defined target population, and makes explicit the incentives or disincentives to coordinated care inherent in the program's organizational and financing setting.

To enhance the external validity of care coordination studies, researchers should focus on the effect of specific care coordination components. The conceptual framework presented here can help build the evidence base that will allow us to discern the dimensions of care coordination that are linked to better outcomes. To further develop the evidence and facilitate meaningful comparisons of effectiveness, outcome measures must be consistent from one evaluation to the next. Among the outcomes that are typically examined, health status appeared to be the one that is measured consistently (using the SF-12, and the SF-36). The same is not true for quality of life, patient satisfaction, and caregiver outcomes.

To be of greatest help to decision makers, evaluations must provide actionable information within a realistic time horizon and investigate care coordination interventions that can be readily scaled up for broader application in the community with the right incentives and support. Given the cost of care coordination implementation, the evaluation design will need to ensure internal validity of findings as well as assess their likely generalizability across a range of providers and delivery settings.

Traditional systematic literature reviews alone are not enough of a basis for developing a clear understanding of "what works" for an intervention as complex as care coordination.

A qualitative analysis would provide even greater insight into promising programs. For instance, interviews with program developers, participants, and staff would deepen our understanding of the elements of care coordination that are tied to improved outcomes. Finally, systematic literature reviews traditionally focus on published results from randomized controlled trials as the best source of information on impacts. Yet, quasi-experimental designs that evaluate programs in real-world, real-time settings, may be more relevant to policymakers. We encourage researchers to include these studies in literature review, provided that the quality of the evaluation design is assessed.

Limitations of this review. Despite the general inclusiveness of our systematic review approach, we also imposed restrictions that excluded evaluations of some interventions of potential interest to policymakers and program directors. Because we focused solely on care coordination as the intervention of interest, we did not review the literature on comprehensive care models, such as PACE, which include not only care coordination but also a complex combination of other core elements such as adult day care and capitated payments. This kind of larger system re-design, though proven effective, is much more difficult to implement and diffuse. Our review may be less helpful to those seeking information on system re-design (for example, accountable care organizations). Because our review focused on programs that served (exclusively or predominantly) persons with disability, we excluded studies of programs for older adults with chronic illness but not necessarily documented frailty or disability, like the Geriatric Resources for Assessment and Care of Elders (GRACE) program or the Guided Care model. We further limited our literature search to care coordination programs evaluated in the last decade within the United States health care system. Older evaluations of long-standing approaches to care coordination for adults with disabilities (for example, assertive community treatment for individuals with SPMI) were likely to have been excluded on this basis. Finally, we excluded evaluations of consumer-directed programs like Cash and Counseling that empower patients with disability, and their caregivers, to coordinate their own support services.

LITERATURE REVIEW METHODOLOGY

In collaboration with Mathematica research librarians, we conducted a literature search for primary research studies on the effectiveness of various care coordination programs for adults with disabilities. We searched 11 databases that index the published literature relevant to medical care, health services, psychology, and social services research; this search was completed October 20, 2010. We also searched for the “grey literature” using a Google engine we created; this search looked at websites for federal agencies, state agencies, health and disability professional associations, policymaker organizations, managed care organizations, and stakeholder/advocacy groups. A second Google engine search looked for specific program names based on feedback from technical experts in the area of care coordination for adults with disabilities. Searches were limited to articles published between 2000 and 2010.

To expand our understanding of what activities work best for each population, we sought information on select components of care coordination from the checklist shown in Figure 2: for example, (1) targeting strategies or tools to identify populations in need of services, (2) use of needs assessments, and (3) use of an individual or team to provide service/outreach. Study interventions that consisted of only one simple task of case management (for example, reminder phone calls to patients about medical appointments) were excluded because the concept of care coordination suggests more active management than would be possible with a single, simple contact. We also excluded models whose main intervention was to provide services in institutions (for example, nursing homes and hospitals) or short-term services associated with transitioning out of institutionalized settings. Our focus was on ongoing care coordination services that have the potential to optimize independent living for community-dwelling adults with disabilities.

In examining the evidence base for the effect of care coordination on outcomes for adults with disabilities living in the community, we included a range of disability categories: physical impairment, severe and persistent mental illness (SPMI), cognitive impairment, intellectual impairment/developmental disability, and sensory impairment. The search strategy covered population terms, outcome terms, and terms related to care coordination.⁷

Each title was scanned by two reviewers to ensure that we excluded those that did not concern a care coordination intervention or people with disabilities, as well as those focused on people residing in institutions (for example, nursing homes) or outside the U.S. All needed data were extracted independently by two trained reviewers.

Approach to grading evidence. In establishing a set of criteria for rating the quality of a study, we considered many existing systems for grading quality. Those used by the Cochrane Collaboration and AHRQ’s Evidence-Based Practice Centers (EPC) are among the best known, but these systems focus heavily on randomized controlled trials (RCTs) of clinical topics. Similarly, the GRADE (Grades of Recommendation Assessment, Development and Evaluation) system helps developers of clinical practice guidelines evaluate bodies of evidence and then determine the strength of their clinical recommendations. However, based on our knowledge of the existing literature on care coordination for adults with disabilities, we expected to encounter a much wider range of study designs than RCTs, as well as reports on a rich variety of complex human and social service interventions that differ qualitatively from drugs, medical devices, and even purely clinical treatment or diagnostic strategies. In addition, whereas the Cochrane and AHRQ systems rely heavily on implicit judgments by content and methodological experts, we preferred a system that used more explicit criteria in assessing the evidence.

We therefore decided to use the general approach developed for Mathematica’s other large-scale rigorous evidence-review projects, including the What Works Clearinghouse, Home Visiting Evidence of Effectiveness, and Pregnancy Prevention Research Evidence Review.⁸ Those studies faced similar challenges, namely providing policy-relevant assessments of a broad range of programs whose evaluations employed a variety of study designs. All addressed this challenge by developing formal evidentiary grading systems that could be applied to a variety of study designs.

⁷Additional details on the search strategy and terms can be found in the full report, which can be requested by emailing chce@mathematica-mpr.com.

⁸The findings from the last two projects have been widely used by policymakers and recently received recognition from the Department of Health and Human Services.

LITERATURE REVIEW METHODOLOGY

We assessed study quality only for studies that met all of our inclusion criteria.⁹ Our assessment focused specifically on the internal validity of a study's impact estimates. Although there are other features that determine a study's overall quality and usefulness (such as generalizability and the feasibility of replication), we did not include those dimensions in our assessments because of the lack of widely accepted or well-developed explicit criteria for evaluating them. Our rating system used a stepwise approach based on the following criteria:

1. Randomized study design
2. Absence of confounding factors (such as differential data collection procedures between study groups or a study group with only one sample member)¹⁰
3. An analysis that did not reassign subjects from one study group to another following randomization (also commonly known as "intention to treat")¹¹
4. Low attrition
5. Adjustment for statistically different baseline characteristics (or no significant baseline differences)

Studies received one of the following three ratings for internal validity based on the extent to which they met these criteria: high, moderate, or low (similar to the AHRQ EPC assessments of good, fair, or poor). Studies that met all five criteria were judged "high" internal validity studies. We assigned "moderate" ratings to studies that met the majority of these criteria and included statistical methods to compensate for deviations from these standards.¹² Studies that met none of the criteria or lacked statistical controls to compensate for deviations were assessed "low" internal validity studies. Table 4 summarizes the characteristics of studies for each rating category.

⁹These included the following: focus on care-coordination activities, inclusion of adults, focus on people with disabilities who are living within the community, study that tests an intervention and includes outcomes, and study published in 2000 or later that was implemented in the U.S.

¹⁰We follow the usage of "confounding" in the Pregnancy Prevention Research Evidence Review, the What Works Clearinghouse, and the Home Visiting Evidence of Effectiveness methods; this usage is different from the conventional usage of the term in the epidemiological, clinical, and biostatistical literature.

¹¹"Intention to treat" means that all participants are analyzed based on their original randomized status.

¹²Detailed description of the rating system is available in the full report, which can be requested by emailing chce@mathematica-mpr.com.

Table 4. Characteristics of Studies for Each Internal Validity Rating

High Internal Validity	Moderate Internal Validity	Low Internal Validity
Randomized controlled trial designs with:	Randomized controlled trial designs that:	Studies that do not meet the standards for a high or moderate rating, for example:
<ul style="list-style-type: none"> • No confounding factors 	<ul style="list-style-type: none"> • Do not adjust for statistically significant baseline differences, but otherwise meet all criteria for high rating 	<ul style="list-style-type: none"> • Quasi-experimental designs with no external comparison group (pre-post designs)
<ul style="list-style-type: none"> • Analysis with no reassignment of sample members 	Quasi-experimental design or randomized controlled trial with high attrition or sample reassignment with:	<ul style="list-style-type: none"> • Quasi-experimental designs or randomized controlled trials that with high attrition that do not establish baseline equivalence
<ul style="list-style-type: none"> • Low sample attrition 	<ul style="list-style-type: none"> • No confounding factors 	<ul style="list-style-type: none"> • Studies with serious confounding factors
<ul style="list-style-type: none"> • Adjustments for statistically significant baseline differences 	<ul style="list-style-type: none"> • Demonstrated baseline equivalence of samples 	
	<ul style="list-style-type: none"> • Adjustments for baseline differences in the outcome measures 	

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