



7. Quality Improvement Measurement of Outcomes for People With Disabilities

Closing the Quality Gap: Revisiting the State of the Science



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Practice

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Closing the Quality Gap: Revisiting the State of the Science

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Preface

The Agency for Healthcare Research and Quality (AHRQ), through its Evidence-based Practice Centers (EPCs), sponsors the development of evidence reports and technology assessments to assist public- and private-sector organizations in their efforts to improve the quality of health care in the United States. The reports and assessments provide organizations with comprehensive, science-based information on common, costly medical conditions, and new health care technologies and strategies. The EPCs systematically review the relevant scientific literature on topics assigned to them by AHRQ and conduct additional analyses when appropriate prior to developing their reports and assessments.

In 2004, AHRQ launched a collection of evidence reports, *Closing the Quality Gap: A Critical Analysis of Quality Improvement Strategies*, to bring data to bear on quality improvement opportunities. These reports summarized the evidence on quality improvement strategies related to chronic conditions, practice areas, and cross-cutting priorities.

This evidence report is part of a new series, *Closing the Quality Gap: Revisiting the State of the Science*. This series broadens the scope of settings, interventions, and clinical conditions, while continuing the focus on improving the quality of health care through critical assessment of relevant evidence. Targeting multiple audiences and uses, this series assembles evidence about strategies aimed at closing the “quality gap,” the difference between what is expected to work well for patients based on known evidence and what actually happens in day-to-day clinical practice across populations of patients. All readers of these reports may expect a deeper understanding of the nature and extent of selected high-priority quality gaps, as well as the systemic changes and scientific advances necessary to close them.

AHRQ expects that the EPC evidence reports will inform consumers, health plans, other purchasers, providers, and policymakers, as well as the health care system as a whole, by providing important information to help improve health care quality.

We welcome comments on this evidence report or the series as a whole. Comments may be sent by mail to the Task Order Officer named in this report to: Agency for Healthcare Research and Quality, 540 Gaither Road, Rockville, MD 20850, or by email to epc@ahrq.hhs.gov.

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Structured Abstract

Objective. To examine how health care outcomes for general medical care have been assessed for people with disabilities within the rubrics of care coordination and quality improvement.

Data Sources. MEDLINE[®], PsychINFO, ERIC, and CIRRIE through March 27, 2012; hand searches of references from relevant literature and journals. A search of high-quality gray literature sources was also conducted.

Review Methods. We included all forms of disability except severe and persistent mental illness for all age groups in outpatient and community settings. We focused on outcomes, patient experience, and care coordination process measures. We looked for generic outcome measures rather than disability-condition-specific measures. We also looked for examples of outcomes used in the context of disability as a complicating condition for a set of basic service needs relevant to the general population, and secondary conditions common to disability populations. Two independent reviewers screened all articles; disagreements were resolved through consensus. Included articles were abstracted to evidence tables and quality-checked by a second reviewer. Data synthesis was qualitative.

Results. A total of 15,513 articles were screened; 15 articles were included for general outcome measures and 44 studies for care coordination. A large number of outcome measures have been critically assessed and mapped to the International Classification of Functioning, Disability and Health. We found no eligible studies of basic medical needs or secondary conditions that examined mixed populations of disabled and nondisabled participants for disability as a complicating condition. Care coordination literature for people with disabilities is relatively new and focuses on initial implementation of interventions rather than assessing the quality of the implementation.

Conclusions. We found very few direct examples of work conducted from the perspective of disability as a complicating condition. The sparse literature indicates the early stages of research development. Capturing the disability perspective will require collaboration and coordination of measurement efforts across medical interventions, rehabilitation, and social support provision.

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Executive Summary

Introduction

This review is part of a new series of reports, *Closing the Quality Gap: Revisiting the State of the Science*, commissioned by the Agency for Healthcare Research and Quality (AHRQ). The series provides a critical analysis of existing literature on quality improvement strategies and issues for topics identified by the 2003 Institute of Medicine report *Priority Areas for National Action: Transforming Health Care Quality*.¹ As part of its charge to continuously assess progress toward quality and to update the list of priority areas, AHRQ identified people with disabilities as a priority population.

Health care for people with disabilities can present special challenges. For example, medical problems can be exacerbated or complicated by the presence of other medical, psychological, economic, and social problems. Likewise, the management of medical problems can be complicated by disability. Thus, optimal care requires coordination of services from various sectors to maximize the function and quality of life of a person with a disability. Since the care outcomes of function, quality of life, and community integration are interdependent, service coordination may need to span the spectrums of both care and support services (e.g., medical care and schools or social agencies). Coordination of care, with attention to the intersection of medical and social services, is congruent with recent policy attention on integrated care and medical homes.

This review examines how health care outcomes have been assessed for people with disabilities. Our report seeks to improve shared understanding among a broad audience of researchers, clinicians, and policymakers with varied exposure to disability outcomes or quality improvement research. We begin by discussing outcome measurement issues and exploring conceptual frameworks for thinking about measuring outcomes for research and quality improvement efforts. We examine the diverse perspectives that researchers grounded in different fields bring to bear on what and how to measure. As with all frameworks that deal with complex concepts, the categories, paradigms, or classes we present are at best “ideal types” rather than simple designations with clean boundaries. We follow this framework with the Key Questions and summary of the project scope. After outlining methods used, we present the results and discuss the implications.

What Is To Be Measured? Levels of Analysis

Examining outcomes requires a broad understanding of what is appropriate to be measured. The range of outcomes to consider depends in part on the goals for the research or evaluation. The research goals should drive the focus, content, and structure of the optimal measure.

We can address outcomes of care for people with disabilities from several levels. Table A illustrates the relationship between the level of focus and related salient questions or outcomes. We distinguish between interventions directed at a disability from specific interventions directed at a given medical problem for a person with a disability or comprehensive programs designed to integrate medical and social services for people with disabilities. A common approach for integrating services at this level is care coordination. Care coordination is a multidimensional construct that lacks general conceptual consensus; however, it usually relies on broad approaches

such as teamwork, information coordination, and care management.² Care coordination is closely linked to current initiatives to create health care homes.

Table A. Levels of analysis for research related to people with disabilities and related questions or outcomes

Level	Common Questions or Outcomes of Interest
Impact of public policy, geographic variation	Who gets services? How does prevalence vary?
Effect of organized programs	Who uses services? Where are people treated? Is there a change in amount of services used? Is there a change in use of other services? Cost of care?
Specific interventions directed at the disability	Changes in body function and structure, activities, and participation Quality of life
Specific interventions directed at a given medical problem, not necessarily related to the disability, for persons with a disability	Typical condition-specific outcomes for the problem Generic outcomes (e.g., function, quality of life) Costs Utilization of second-order services (e.g., hospitals, ERs)
Comprehensive programs designed to integrate medical and social services	Prevention of conditions secondary to the disability Typical condition-specific outcomes for the problem Generic outcomes (e.g., function, quality of life) Costs Utilization of second-order services (e.g., hospitals, ERs)

Note: Bold text indicates areas examined in this review.

Abbreviation: ER = emergency room

Within the context of medical interventions, disability may be viewed as a condition, or as a comorbidity or multimorbidity, that complicates care and changes case mix, but for which the same outcomes apply as for people without the disability. Under this premise, disability acts as a confounder that obscures the relationship between treatments and outcomes. In other words, disability exerts a direct effect on the outcome in addition to the effect of the disease.³ One way to address this issue is by treating the disability as a demographic descriptor, as suggested in Healthy People 2010.⁴ Alternatively, the disability may be considered a mediator that affects either treatment choice or effectiveness. For example, a disability may present special barriers to accessing care, from traveling to the source of care to getting onto an examination table. Likewise, the design of a physical activity regimen for an adult with uncontrolled diabetes will likely differ if the adult has a significant mobility limitation. In that instance, the disability must be analyzed as an interaction variable.

Determining relevant outcomes and the best way to approach disability depends on how disability is defined and viewed professionally. Further, how well a particular outcome measurement tool “fits” those with and without disabilities depends on a number of factors. Next, we explore both of these themes.

What Is Measured (And Why)

Disability Definitions, Models, and Professional Perspectives

No single definition of disability can apply consistently to the full human lifespan and range of abilities and activities. At a recent AHRQ meeting, nationally recognized experts concluded that a single consensus definition of disability is not feasible or desirable. Instead, they suggested that the definition should be governed by the research issue to which it will be applied.⁵

In the absence of consensus definitions, broad classifications can be a useful tool. Disabilities are classified variously according to different models of disabilities. The most commonly used models are the medical model, the social model, and the biopsychosocial model.

- The medical model views disabling conditions as a matter of pathophysiology and strives to treat or cure them.^{6,7}
- The social model separates the concepts of disability and health, views the disadvantages experienced by people with disabilities as generated by society, and frames the problem as being the societal response to the disabling condition rather than the person.
- The biopsychosocial model emphasizes the interactions among biological, psychological, social, and cultural factors, and the effects of these interactions on a person's experience of health or illness.^{8,9}

These three models inform and frame the perspectives of those who provide services for, or conduct research about, people with disabilities. Each model supports different treatment or service goals, which in turn drive the issue of which outcomes are salient.

The **medical perspective** is common among professionals who diagnose and treat people with disabilities via general medical care or care specific to the disabling condition. This model may posit illness as a complication imposed on a person with a disability, or disability as a complication of treating a specific illness. Depending on a provider's specialty, people with disabilities may be the focus of care or comprise only a minority of patients. Curing is an ideal for which to strive. Both the medical and biopsychosocial models may inform the work of these providers to varying degrees based on personal concerns and professional training. Often, interventional research and associated measures within the medical perspective are strongly influenced by the medical model.

The **rehabilitation perspective** is common among professionals from the medical and allied professional fields (e.g., psychiatrists and physical, occupational, or speech therapists). Patients include those with temporary disability due to trauma or illness and those with "stable" disabling conditions. This perspective strives to maximize function and optimize potential opportunities for an individual to participate in life as desired. Here, too, the medical and biopsychosocial models may inform providers' work. However, the biopsychosocial model, with its emphasis on person and environment factors, predominately informs commonly used disablement frameworks.⁶

The **social perspective** is common among professionals who (1) study people with disabilities and the effects of disabling conditions; (2) specialize in providing medical care to people with disabilities; or (3) focus on support services, including social work or special education. This perspective acknowledges the appropriateness of medical and rehabilitative efforts specific to a particular person but emphasizes supporting and empowering people who have disabilities to be full participants in their families, communities, and schools, whether or not their disability or related medical conditions can be cured or fixed. Within the social perspective, the biopsychosocial and social models are more influential, as evidenced by the emphasis on healthy adaptation and participation.

In practice, the "segment size" of each of these three perspectives varies with a person's life course and the etiology of the disability. Three useful categories of disability etiology/timing of onset are: congenital/developmental, acquired (disease or trauma), and aging. Each category holds different implications for treatment and coordination within the medical care system, as well as for determining the most salient outcomes.

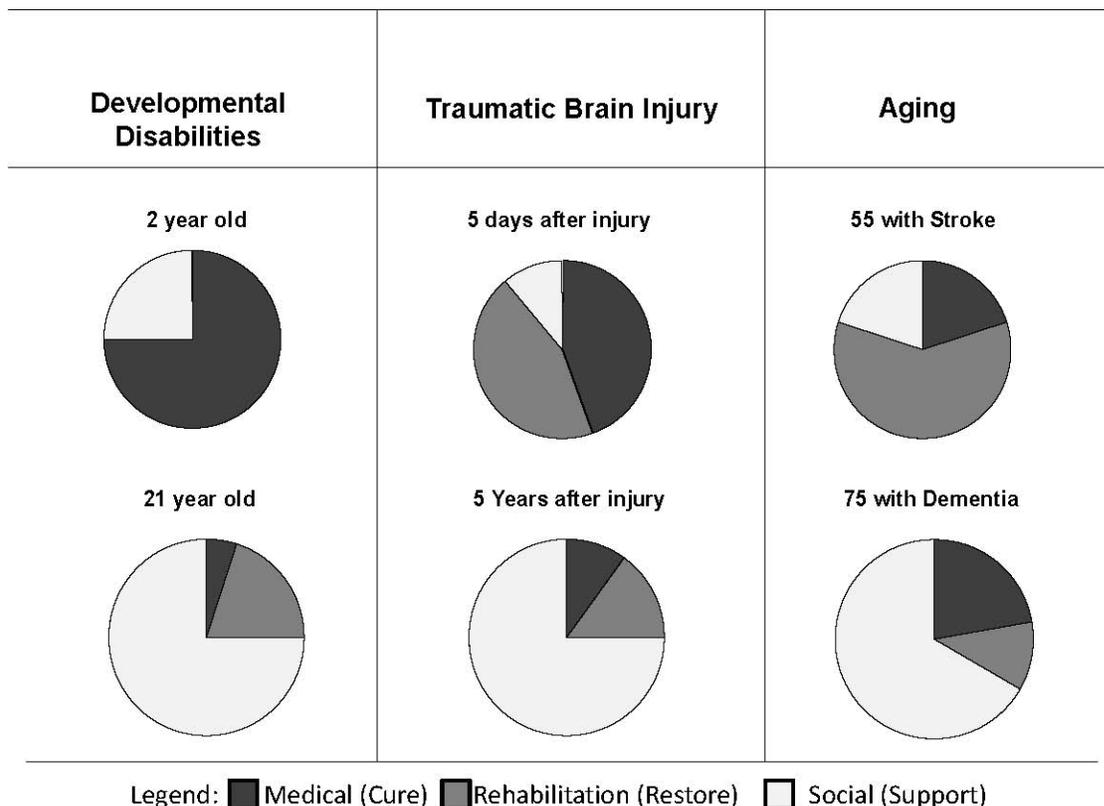
For people with developmental and acquired disabilities, care emphasizes support services. Medical care is relevant only to the extent that the individual suffers from problems commonly experienced by people of the same age or from specific disease complications of the underlying condition. At the same time, disabilities may present access barriers to medical care (e.g., getting onto an examination table). Medical practitioners may need special knowledge about how to treat a given disease in the context of the disability. Successful care is generally measured using outcomes related to societal integration.

In contrast, older persons' disabilities are more integrated into a disease framework. It is hard to extricate treating the underlying disease from treating the disability. Perhaps as a result of ageism, achieving societal integration is often viewed as less salient than improving the disease or disability level (or at least slowing decline). Efforts are actively directed at remediation of the problem or its symptoms. The distinction among these etiologies has become more complicated as more people with disabilities survive into old age, bringing with them new perspectives.

As an illustration of these different mindsets, consider the following scenario. A disability activist who has paraplegia and uses a wheelchair is visiting his father, who just recently began using a wheelchair because of a stroke. In response to the nursing home staff's efforts to establish a program of timed toileting and ambulation training for his father, the son responds, "Forget that. Put an external catheter on him and let's get on with life."

This illustration also reveals how people with disabilities—regardless of etiology—prioritize different components at different times in their lives. For example, parents of a child with a newly diagnosed disability often spend considerable time and energy seeking a cure or effective long-term treatment to eliminate or greatly reduce the impact of the diagnosis on the child's life course. In contrast, older children and adults who have lived with their developmental disabilities prioritize getting support needed to live a fully included life, even if the underlying impairment cannot be cured or function fully restored. For people with an acquired disability, an immediate effort to cure or fully restore function through a prolonged period of rehabilitation is followed by a lifetime of getting support needed to live fully included lives. Disabilities that result from degenerative conditions or from aging have a more insidious onset. As a result, those affected by these disabilities will often seek to cure or control the underlying condition (and use rehabilitative support) until it is clear that death is imminent, at which time palliative care is often sought. Figure A illustrates the relative emphasis of the medical, rehabilitation, and social perspectives among different types of disabilities, with traumatic brain injury as one example of acquired disability.

Figure A. Relative emphasis of medical care, rehabilitation, and adaptation for disabilities of different etiology



Note: These are stylized examples to illustrate relative differences.

The life-course perspective introduces another consideration in understanding outcomes. While many people *age into* disabilities through the advent of illness, some people with disabilities now survive into old age. Although many people who have serious developmental or acquired disabilities have attenuated lifespans, improvements in care have allowed more people with significant disability to reach much older ages, and thus *age with* a disability.¹⁰ While specific consequences vary by disabling condition, a common pattern is that this group may manifest age-related conditions earlier than those without disability.¹¹⁻¹⁶

Finally, the individual’s own perspective should not be overlooked. The health goals of people with disabilities do not differ greatly from those of the general population at comparable ages. People with disabilities emphasize their experience of health as distinct from their disabilities.¹⁷ This is in keeping with a view of disability as a complicating condition.

The paradigms and perspectives discussed above find traction in how the relevant outcome domains are examined and measured.

Relevant Outcome Domains

Consensus is lacking within the disability research community about the extent to which the outcomes of medical care should be assessed similarly for persons with and without underlying disability, especially developmental and acquired disability. Some view disability as a complicating condition to be included in an appropriate case-mix correction and argue that it

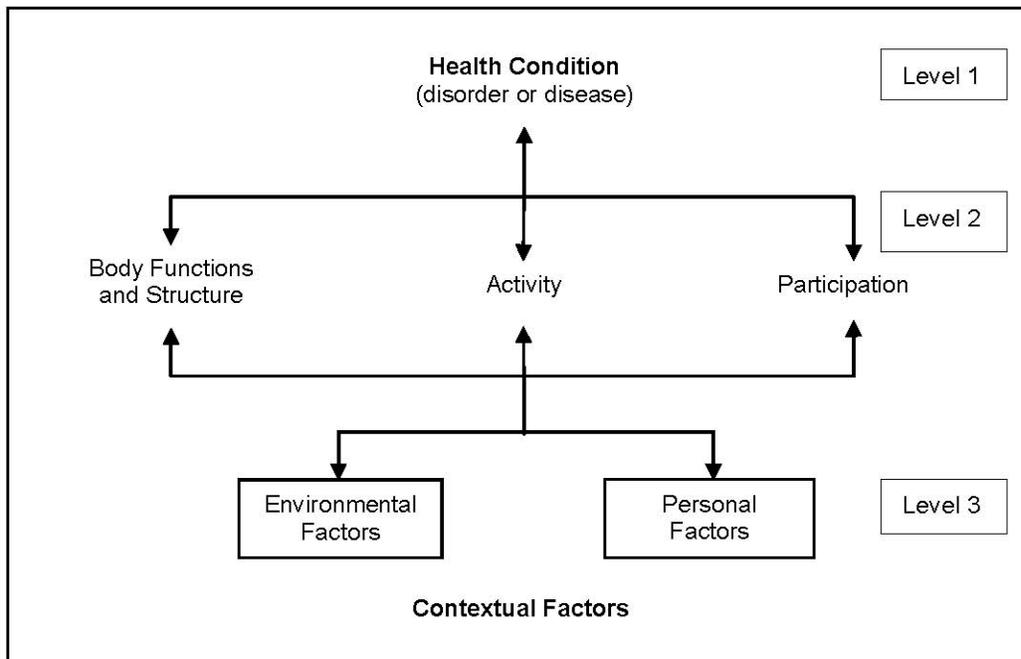
does not require different outcome measures from those applied to the general population. Others hold that, in addition to the outcomes measured for the general population, specific outcome domains and measures should be tailored to the populations of interest. They advocate for more individualized approaches that include additional outcomes related to managing disability and preventing secondary conditions. The latter camp argues that quality outcomes for disabling health conditions do not address considerations directly related to disability.⁵

Outcome domains shared with general populations may require modified methodological approaches for people with disabilities. Measurement instruments determine improvement or lack of improvement in outcomes of interest. The characteristics of measurement tools should be considered, along with how they are used to assess the outcomes of care for people with disabilities.¹⁸ Whether or not appropriate outcome domains differ between disabled and nondisabled populations, the methodological approach to assessing outcomes may require accounting for patient characteristics or case mix. Of interest are the independent variables relevant to accurately assessing outcomes.

ICF Outcome Domains

The International Classification of Functioning, Disability and Health (ICF) was created as a framework to classify and assess function and disability associated with health conditions.¹⁹ The initial motivation for the framework was to provide a way to classify the consequences of disease. The framework was later revised to emphasize a positive description of human functioning rather than the negative consequences of disease. The framework (Figure B) attempts to explicitly acknowledge the dynamic nature of disablement, which can fluctuate based on a number of contributing factors across an individual’s life course.

Figure B. Domains of the International Classification of Functioning, Disability and Health (ICF)



Source: World Health Organization. International Classification of Functioning, Disability and Health. 2001. www.who.int/classifications/icf/en/.

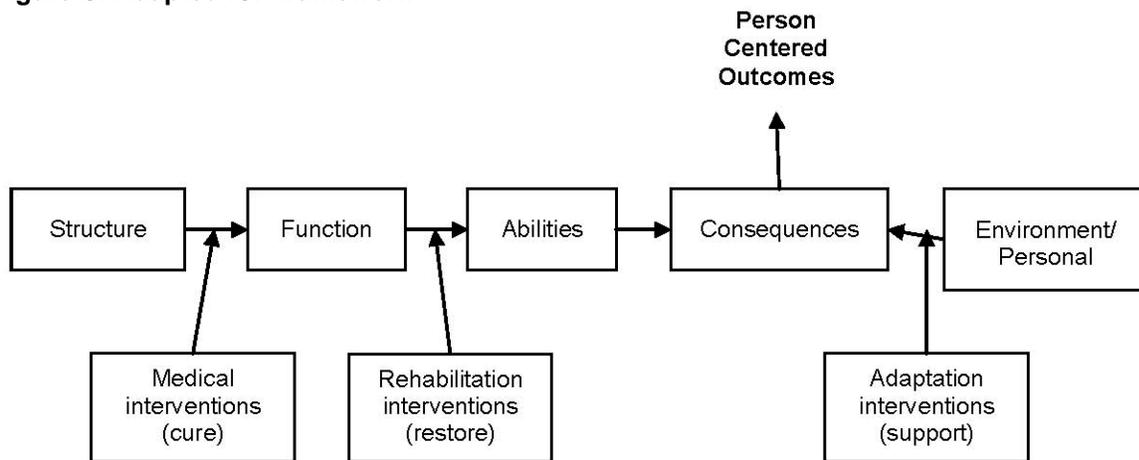
The framework identifies three levels of human functioning.

- The first level, health condition, designates functioning at the level of the body or body parts.
- The second level designates functioning at the level of the whole person.
- The third level designates functioning of the whole person in the context of his or her complete environment.

Within the whole-person level are three domains of human functioning: body functions and structure, activity, and participation. The body functions and structure domain involves the physiological functions of the body systems and the anatomical parts of the body. Impairments are problems with the body function or structure that result in a significant loss, defined as “deviations from generally accepted population standards.”¹⁹ Impairments may be temporary or permanent. A derived version, the ICF-CY, or ICF for Children and Youth, accounts for the developmental nature of children and youth.

Figure C provides a simplified linear illustration of the ICF to highlight how intervention points may differ for the “treatment” paradigms above. Intermediate measures that assess the immediate effect of an intervention would likely vary based on the intervention point. These interventions ultimately lead to person-centered outcomes, such as quality of life or living independently.

Figure C. Adapted ICF framework



Note: Adapted from: Colenbrander A. Assessment of functional vision and its rehabilitation. *Acta Ophthalmol.* 2010 Mar;88(2):163-73. PMID: 20039847.

The length and complexity of the ICF highlight the challenge of outcomes conceptualization, categorization, and assessment. The ICF, like the ICD (International Classification of Diseases) codes, involves numerous chapters within each of the body systems and the body function, abilities, participation, and contextual domains, with detailed coding. Some outcomes may be viewed either as intermediate points or endpoints, depending on the research perspective applied. Further, since the ICF is focused on coding function at the person level, it omits system-level outcomes that could be useful for evaluating quality of care or quality improvement initiatives. For example, the ICF would not gather cost and utilization numbers to examine use of second-order services noted in Table A, nor does the ICF encode satisfaction or process measures used to assess the effectiveness of a new program.

Unintended Consequences of Measurement

How we measure outcomes for research or quality improvement can have unintended consequences for people with disabilities. This may be true even for well-designed outcome measures with appropriate characteristics and psychometric properties for a given disabled population. For example, constructs such as the quality-adjusted life year (QALY) or the disability-adjusted life year (DALY) attempt to value health in a way that combines mortality and morbidity. These approaches place an immediate ceiling on the potential benefit achievable by people with a disability, because their baseline status downgrades the QALY score. Basing policy decisions on such measures has substantial implications for people with disabilities.

People with disabilities have also been disadvantaged in participating in research studies because of systematic bias in research fielding and measurement methods. Accommodation and universal design are two approaches promoted for improving access to research participation. Accommodation requires enabling the measurement tools and modes of administration to allow access to people with disabilities. The Medical Outcomes Study Short Form 36E (SF-36) is one example of a tool adapted to provide accommodation.²⁰ Universal design strives to develop methods and tools usable by all people, to the greatest extent possible, without adaptation or specialized design.²¹ The National Institutes of Health's PROMIS (Patient-Reported Outcome Measurement Information System) initiative is developing computer-assisted data collection tools based on the principles of universal design.²²

Key Questions

Our Key Questions (KQs) focus on the quality assessment component of quality improvement. Using the levels-of-analysis framework, we examined outcome measures for medical care and care coordination for people with disabilities, with an emphasis on outcome measures at the level of the individual rather than the population.

KQ1. How are outcomes assessed for people with disabilities living in the community in terms of basic medical service needs?

KQ1a. What general population outcomes have been validated on and/or adjusted to accommodate disabled populations?

KQ1b. What types of modifiers or case-mix adjusters have been used with the general population outcomes to recognize the special circumstances of people with disabilities?

KQ1c. What are key parameters for measuring processes related to basic service care access for people with disabilities?

KQ2. What measures have been used to assess effectiveness of care for people with disabilities living in the community in the context of coordination among health providers?

KQ3. What measures have been used to assess effectiveness of care for people with disabilities living in the community in the context of coordination between community organizations and health providers?

Project Scope

Our scope did not include severe and persistent mental illness as a primary diagnosis, since the disability profile and the cyclical nature of severe and persistent mental illness suggest that

some of the processes and outcomes needed for this population would be qualitatively different than those for people with other disabilities. Service settings included outpatient health, home, and community-based services, but not vocational rehabilitation. Medical conditions included basic medical care and secondary conditions common across populations of community-dwelling individuals with disabilities, including:

- Preventive dental care
- Preventive medical care
- Urinary tract infections
- Pressure ulcers
- Diabetes and diabetic complications
- Pneumonia
- Asthma
- Gastroenteritis
- Hypertension
- Obesity

We included measures for both process and patient-centered outcomes. In keeping with the perspective of disability as a complicating condition, we focused on generic outcome measures for the general population or for broad classes of disability. The alternative approach of searching for condition-specific measurement tools was either (1) too resource intensive if all disabilities were included or (2) overly restrictive of the review's applicability if only a few exemplary disability conditions were included. Developing and applying criteria to directly assess outcome measures or mapping the outcome measures directly to the ICF codes was beyond the scope of this review. Instead, we looked for organized collaborations between professional, research, or governmental organizations. We sought collaborations for which formal criteria were developed and used to generate shared knowledge and consensus on core sets of outcome measurements.

With this scope, our report provides sources for outcome material.

Methods

In conducting our searches we used as inclusion criteria:

- Physical, cognitive/intellectual, or developmental disabilities
- All ages
- Outcomes used to evaluate health services
- Outpatient and community settings

Our exclusion criteria included:

- Inpatient settings
- Institutional settings
- Severe mental illness
- Psychotropic medications used in medical/service environments
- Condition-specific outcomes
- Research for specific disability conditions

For KQ1a, we included reviews, compendiums, or suggested outcome sets only if they represented a significant collaborative effort. KQ1b was limited to randomized controlled trials (RCTs) and prospective studies that evaluated the efficacy of a treatment for basic medical service needs and secondary conditions common to people with disabilities, listed above.

Care coordination was operationalized as comprehensive coordination programs consisting of multiple care coordination activities and components. Specifically, we included programs with some kind of purposeful coordination between/among (1) medical providers, (2) medical providers and some community service providers, (3) medical providers and caregivers, and (4) social service groups that included some health component. Studies of single care coordination components were excluded.

We limited the literature to English-language publications after 1990 published in the United States, the United Kingdom, Canada, Australia/New Zealand, and the Netherlands, where service delivery settings are more likely to be applicable to the United States.

We searched MEDLINE[®], PsychINFO, ERIC, and CIRRIE through March 27, 2012. We hand-searched reference lists of relevant high-quality literature reviews. Two independent reviewers screened search results. Conflicts were resolved by consensus with a third independent investigator.

We searched the gray literature for monographs, white papers, and other high-quality sources of material on measurement tools using the New York Academy of Medicine Grey Literature Report and Web sites such as the Centers for Disease Control and Prevention Web site.

The included literature was maintained in an EndNote bibliography. Relevant data points were abstracted to standardized Excel spreadsheets. An outcome measurement tool was described in the summary of only one article, unless multiple articles evaluated multiple outcomes with overlap. Qualitative techniques were used to synthesize the literature. We used the ICF as an analytic framework where possible. However, classifying measures by matching items to the detailed ICF checklist was beyond the scope of this review.

Results

A total of 10,189 articles were identified for KQ1. Of these, 241 articles were pulled for full-text review and 15 were included in this review. For KQs 2 and 3, a total of 5,324 care coordination articles were identified, of which 45 were included. A complete reference list is available in the full report.

KQ1a. What general population outcomes have been validated on and/or adjusted to accommodate disabled populations?

Fifteen articles were included for KQ1a. Six articles critically reviewed available outcome measures for given populations and domains. Of these, five were part of a series of papers published in 2000 that used formal criteria to examine the state of outcomes research measurement in rehabilitation. Three studies evaluated the adaptation of general population measures for use in disability populations. Two studies were examples of disability-related outcome measures evaluated for expansion into another disability population (which suggests the possibility that the outcome measure may become more generic). Four articles reported the development of new measures. Table B gives a list of outcome measures either examined or developed by article and domain.²³⁻³⁷ Greater detail is available in the full report.

Table B. Outcome measure list

Study Domain	Outcome Measure List
Critical Evaluations of Available Outcome Measures for Given Populations and Outcome Domains	
Resnik and Plow, 2009 ²³ Participation (9 ICF activities and participation domain chapters: Learning and applying knowledge; General tasks and demands; Communication; Mobility; Self-care; Domestic life; Interpersonal interactions and relationships; Major life areas; Community, social, and civic life)	Community Living Skills Scale (CLSS) (all 9 ICF chapters) Mayo Portland Adaptability Index (MPAI) version 4 (all 9 ICF chapters) Participation Measure for Post-Acute Care (all 9 ICF chapters) Psychosocial Adjustment to Illness Scale (PAIS-SR) (all 9 ICF chapters) Assessment of Life Habits Scale (LIFE-H shortened V.3.1) (all 9 ICF chapters) Other outcome measures examined that did not map to all 9 chapters: Adelaide Activities Profile (AAP) Bybee Self Report Community Functioning Scale Craig Handicap Assessment Technique (CHART) Craig Handicap Assessment Technique Short Form (CHART-SF) Community Integration Questionnaire (CIQ) Community Integration Measure (CIM) Nottingham Extended Activities of Daily Living (EADL) Frenchay Activities Index (FAI) Frontal Systems Behavioral Scale (FrSBe) Functional Status Questionnaire (FSQ) Groningen Social Disabilities Schedule (GSDS-II) Groningen Questionnaire About Social Behaviors Impact on Participation and Autonomy Questionnaire (IPAQ) ICF Checklist Life Functioning Questionnaire (LFQ) London Handicap Scale (LHS) Multnomah Community Ability Scale: Self Report (MCAS-SR) Post-Traumatic Stress Disorder (PTSD) Checklist Military Participation Objective Participation Subjective (POPS) Participation Survey/Mobility (PARTS/M) Perceived Impact of Problem Profile (PIPP) Quality of Life Scale (QOLS) Rivermead Head Injury Follow-Up Questionnaire (RHFUQ) Reintegration to Normal Living Index (RNLI) Reintegration to Normal Living Index – Postal Version (RNLI-P) Social Functioning Questionnaire (SFQ) Social Functioning Scale (SFS) Sydney Psychosocial Reintegration Scale (SPRS) Subjective Index of Physical and Social Outcome (SIPSO) Work and Social Adjustment Scale (WSAS) World Health Organization Disability Assessment Schedule (WHODAS) 12 item self-report World Health Organization Disability Assessment Schedule (WHODAS) 36 item self-report
Vahle et al., 2000 ²⁴ Depression Symptoms	Brief Symptom Inventory (BSI) (tested in 4 disability groups) Center for Epidemiologic Studies Depression Scale (CES-D) (tested in 2 disability groups) Zung Self-Rating Depression Scale (SDS) Beck Depression Inventory (BDI) Depression Adjective Check List (DACL) Talbieh Brief Distress Inventory and Medical-based Emotional Distress Scale (TBDI) Sickness Impact Profile (SIP) Medical Outcomes Study Short-Form Health Survey (SF-36)
Andresen and Meyers, 2000 ²⁵ Generic HRQoL (mixed ICF domains)	SF-36 (examples included testing in 15 disability groups) SIP (examples included testing in 9 disability groups) Quality of Well-Being Scale (QWB) (examples included testing in 8 disability groups) Nottingham Health Profile World Health Organization Quality of Life Survey (WHOQOL-100) QWB (preference based – QALY) Health Utility Index (preference based – QALY) EuroQual EQ-5D (preference based – QALY)

Table B. Outcome measure list (continued)

Study Domain	Outcome Measure List
Lollar et al., 2000 ²⁶ Children's Outcomes (assessed by ICF level)	Rand Health Status Measure for Children (HSMC) – Person, Society levels Functional Status II-R (FS II-R) – Person level Functional Independence Measure for Children (WeeFIM) – Body, Person levels Pediatric Evaluation of Disability Inventory (PEDI) – Person, Society, Environmental levels School Function Assessment (SFA) – Person, Society, Environmental levels Child Health and Illness Profile – Adolescent Edition (CHIP-AE) – Person, Society levels Child Health Questionnaire (CHQ) – Person, Society levels Questionnaire for Identifying Children with Chronic Conditions (QUICCC) – Person, Society, Environmental levels POSNA Pediatric Musculoskeletal Functional Health Questionnaire (POSNA) – Body, Person levels ABILITIES Index (AI) – Body, Person levels Gross Motor Function Measure (GMFM) – Person level Youth Quality of Life Instrument – Research Version (YQOL-S) – Person, Society, Environmental levels Quality of Well-Being Scale (QWB) (measure may not be appropriate for children younger than 14) – Body, Person levels
Dijkers et al., 2000 ²⁷ Social Outcomes (participation)	CHART long form (broad ICF coverage) CHART short form (broad ICF coverage) CIQ (broad ICF coverage) ⁹⁴ Assessment of Life Habits (LIFE-H) (broad ICF coverage) LHS (broad ICF coverage) Other outcome measures examined deemed to lack broad ICF coverage: FAIWHOQOL SF-36 RNLI GSDS-II Social Adjustment Scale Self-Report (SAS-SR) Katz Patient Adjustment Scale R2 AAP EADL
Cohen and Marino, 2000 ²⁸ Functional Status	Katz ADLs Index Barthel Index Level of Rehabilitation Scale (LORS) Patient Evaluation and Conference System (PECS) Functional Independence Measure (FIM)
Single Studies Evaluating General Population Measures for Use in Disability Populations	
Kalpakjian et al., 2005 ²⁹ Body Function	Menopause Symptom List (MSL)
Burggraaff et al., 2010 ³⁰ Body Function	Radner Reading Charts (RRC)
Nanda et al., 2003 ³¹ Health Status – Multiple Domains	Abbreviated Sickness Impact Profile (SIP68)
Disability-Related Outcomes Evaluated for Expansion Into Another Disability Population	
Bossaert et al., 2009 ³² Environmental	Supports Intensity Scale

Table B. Outcome measure list (continued)

Study Domain	Outcome Measure List
Bagley et al., 2011 ³³	Activities Scale ASKp38
Activity and Performance	
New Measures	
Faull and Hills, 2007 ³⁴	QE Health Scale Holistic Health Measure
Multiple Domains	
Alderman et al., 2011 ³⁵	St. Andrew's-Swansea Neurobehavioral Outcome Scale
Multiple Domains	
Petry et al., 2009 ³⁶	QoL – Profound Multiple Disabilities
Multiple Domains	
King et al., 2007 ³⁷	Children's Assessment of Participation and Enjoyment (CAPE)

Abbreviations: ADL = activity of daily living; HRQoL = health-related quality of life; ICF = International Classification of Functioning, Disability and Health; QALY = quality-adjusted life year

Several efforts are underway to use the ICF framework to establish core sets of outcomes for patients with specific chronic conditions. A compendium of critically evaluated rehabilitation outcome measures for community settings was developed through a participatory process to address fragmented outcome measurement use. Further, a rehabilitation outcome database was developed through a collaboration between the Rehabilitation Institute of Chicago's Center for Rehabilitation Outcomes Research and Northwestern University Feinberg School of Medicine's Medical Social Sciences Informatics and funded by the National Institute on Disability and Rehabilitation Research (www.rehabmeasures.org).

KQ1b. What types of modifiers or case-mix adjusters have been used with the general population outcomes?

We found no eligible studies of basic medical needs and secondary conditions that examined a mixed population of disabled and nondisabled participants.

One tangentially related systematic review assessed the effect of exercise interventions as a preventive measure on subjective quality of life for both clinical/disabled and healthy populations. None of the 56 included studies used a mixed population of clinical/disabled and healthy populations; thus comparisons were indirect. The review collected severity information (mild, moderate, severe, chronic stable, frail, end stage) but did not use it in the analysis. Quality-of-life measures included SF-36 (Medical Outcomes Study Short-Form Health Survey), HRQoL (health-related quality of life) visual analog, SIP (Sickness Impact Profile), WHOQOL (World Health Organization Quality of Life Survey), POMS (Profile of Mood States), QWB (Quality of Well-Being Scale), and EuroQoL EQ-5D, among others.

Another tangentially related study addressed associations between the presence of chronic medical needs (chronic diagnoses) and perceived lack of accessibility features in the home according to ADL (activities of daily living) and IADL (instrumental activities of daily living) stage. Subjects were disabled and nondisabled older adults living in the community. The ICF-based stages define five strata for ADL and IADL (measuring the self-care and domestic ICF life

chapters). Stage 0 includes people without disabilities and stages I, II, III, and IV represent increasing disability.

KQ1c. What are key parameters for measuring processes related to basic service care access for people with disabilities?

We found no eligible studies of basic medical needs and secondary conditions to address this question. It is possible that the limits of the specific scope of literature, particularly being limited to an illustrative set of medical service needs rather than broader medical coverage, reduced our ability to locate such literature. (See KQs 2 and 3 for more results on care coordination process measures.)

KQs 2 and 3. What measures have been used to assess effectiveness of care for people with disabilities living in the community in the context of coordination among health providers or between community organizations and health providers?

Of the 45 included articles, representing 44 studies (Table C), 7 were RCTs, 9 were prospective observational designs, 3 were retrospective observational designs, 12 were before/after studies, 6 were systematic reviews/guideline studies, and 7 used survey methodology.

Table C. Number of studies by target group and age category

Target Group	Children (0-18)	Youth in Transition*	Adults (18-64)	Elderly (65+)	Mixed	Total
Children–developmental	2					2
Children–acquired	2					2
Children–mixed	16	1				17
Chronic elderly				5	4	9
Frail elderly				7		7
Immobile + transition from inpatient					1	1
Medicaid + disabled			3		2	5
Medicare + disabled + heavy users				1		1
Total	20	1	3	13	7	44

*Youth in Transition means youth who are being prepared to transition from youth to adult services.

Two studies of the effects of coordination focused on programs that coordinated primarily among providers. One of these programs was a coordinated followup of infants with prenatally diagnosed giant omphaloceles; the other was the PACE program (Program of All-Inclusive Care for the Elderly), which targeted frail, chronically ill older adults with the goal of keeping them in the community as long as possible.

This study also measured several health care use “outcomes,” but they were not used as outcomes per se. In addition to the primary outcome variable of functional status, several measures of service use were modeled, including short-term nursing home stays, hospitalizations, and day center attendance. The propensity of each studied site to provide those services was then used to model change in functional status for the key analysis of the study.

Nine studies focused on programs primarily concerned with coordination between providers and families, caregivers, social services, etc. Of these, seven served children or young adults (under age 21), one served stroke survivors, and one served frail older adults.

Several domains of measures were found in the studies of care coordination between providers and family/social services (Table D). Perhaps because care coordination programs are quite new, the literature focused primarily on the initial implementation of interventions rather than assessment of the quality of the implementation. We found no measures that assessed changes in process measures of quality over time.

Process measures were sometimes included as proxy outcomes. Participant adherence to treatment, frequency of contacts with physicians, school adherence to child's treatment plan, and the Measure of Processes of Care scale (MPOC) are examples of these process measures.

Table D. Number of measures (articles) for care coordination between provider and family/social services by age category

Measure Type	Children	Elderly	Mix	Total
Access	1 (1)			1 (1)
Caregiver	2 (1)			2 (1)
Cost and use		1 (1)		1 (1)
Goals	5 (3)			5 (3)
Health and function	9 (4)	4 (1)	2 (1)	15 (6)
Process	7 (5)		2 (1)	9 (6)
Satisfaction	4 (3)			4 (3)
Total	28	5	4	37

Of the 34 articles that addressed both types of care coordination, 27 were studies, 2 were expert guidelines, 4 were literature reviews, and 1 was a description of a program.

The most frequently addressed population was children, with 13 articles. The elderly were addressed in 11 articles. Seven articles looked at a mix of ages (although for some of these studies, the vast majority of participants were elderly). Three articles addressed adults (roughly ages 21 to 65).

A total of 109 measurements were abstracted from these 34 articles (Table E).

Table E. Number of measures (articles) for care coordination among providers or between provider and family/social services by age category

Measure Type	Children (0-18)	Youth in Transition*	Adults (18-64)	Elderly (65+)	Mix	Total
Access	9 (5)					9 (5)
Provider				1 (1)		1 (1)
Caregiver	8 (4)			8 (5)		16 (9)
Cost and use	7 (7)		5 (1)	5 (4)	11 (4)	28 (16)
Health and function	4 (4)		3 (1)	14 (6)	3 (2)	24 (13)
Process	5 (1)		1 (1)	2 (2)	1 (1)	9 (5)
Satisfaction	4 (1)		2 (1)	7 (7)		13 (9)
Self-efficacy				2 (2)		2 (2)
Qualitative feedback					1(1)	1 (1)
Guideline	6 (1)					6 (1)
Total	43		11	39	16	109

*Youth in Transition means youth who are being prepared to transition from youth to adult services.

The National Core Indicators (NCI) is an important collaborative effort among the National Association of State Directors of Developmental Disabilities Services, the Human Services Research Institute, and 28 currently participating States to report a standard set of performance measures. The goal of the collaboration is to develop a core set of measures States can use to manage the quality of developmental disability services, and to allow comparisons among States. A full listing of the measures included in the NCI is provided in the full report.

Discussion

This review found several examples of efforts to critically assess outcome measures for various disabled populations. Formal outcome measure assessment criteria can be leveraged and modified by researchers interested in extending the work to new populations. One example of this is the criteria used by Andresen and colleagues to assess the state of outcome measurement science in rehabilitation.¹⁸

Replicable processes exist for participatory collaborative methods for developing consensus around core outcome measurement sets that researchers can replicate or modify. For example, one process that engaged a broad range of stakeholders was Hillier and colleagues' effort to address fragmented use of outcome measures across rehabilitation in community settings.³⁸

We have identified a lengthy list of outcome measures that researchers may wish to apply to specific research endeavors. Current efforts offer potential for cross-fertilization. There is also potential for overlap in the important questions and appropriate outcomes for different disability groups. The level of detail necessary for a researcher to choose to successfully use the measures was beyond the scope of this report; however, the cited sources provide a starting point. Much could be gained from developing a core set of outcome measures, as discussed below.

Research Issues and Gaps

Our review clearly demonstrates that quality improvement efforts relevant to disability could greatly benefit from organized databases of critically assessed outcome measures. We identified examples of critical assessments and progress toward working with measurement tool databases. However, much work remains for establishing adequate banks of measures. This is easier said than done.

Synthesizing more knowledge in this area will require building consensus around which outcome measures should form the core of all studies. As with function in general, there are many ways to assess the same underlying problem. Each measure has its own performance characteristics, making it hard to aggregate the already sparse data on how treatments vary across people with different disabilities. Sometimes specific measures or variations are appropriate for ensuring that the right measurement spectrum is achieved for detecting a specific outcome. But the proliferation of measures impedes aggregation. In order to develop practical outcome measures that allow for comparisons across populations, a balance must be struck between granular measurements for specific groups and summary or generic measures for cross-group comparisons. Ultimately, specific group measures and summary or generic measures both serve important purposes.

Professional differences further exacerbate the variation in measurements. Different professions adopt their own standards for measuring the same underlying construct. Sometimes the differences are a matter of scale, driven by different goals. For example, a geriatrician might use a simple ADL that taps six domains, including dressing. The metric would range from "independent" to "doing the task with complete assistance." Intermediate steps (such as supervision, cueing, and partial assistance) might also be included. In contrast, an occupational therapist would likely break down the task into 26 steps (selecting the clothing, putting it on, fastening the closures, etc.). Primary concerns might be speed and level of performance (e.g., Are the clothes neat? Is the choice appropriate?).

Similarly, an adequate bank of measures for care coordination is needed. One framework for measures for coordinated care for people receiving Medicaid managed care suggests the

following categories: patient experience; family experience; family caregiving burden; provider experience; functional status, independence, and community participation; health status; and prevention of secondary conditions.³⁹ To these, we would add measures to evaluate fidelity to the care coordination process and measures that capture access to quality care.

We found very few direct examples of work conducted from the perspective of disability as a complicating condition. The scarcity of literature indicates the early stages of research in this area. The scarcity may also indicate a lack of awareness or unintentional systematic bias against examining disability as a complicating condition rather than the condition of interest itself, the legacy of an outdated separate-but-equal stance toward disabled populations.

How one determines the outcomes most appropriate for a particular research question will be affected by whether one views the disease as a complicating factor for the underlying disability. For example, will an infection exacerbate multiple sclerosis or make it more difficult to manage cerebral palsy? Conversely, does treating pneumonia differ depending on whether the patient has mobility limitations or not? Or does treating a urinary infection differ for a person with quadriplegia compared with someone without disability? Some responses to disability may be akin to ageism. We talk about people developing the problems of aging prematurely, as if they were the problems of aging when they in fact result from disease. Separating the etiology of a problem into normal aging or pathology is already difficult. How much more complicated is it, then, to classify the same problem in a person with an underlying disability?

The continuing presence of research “silos” remains a concern. Multidisciplinary research and coordination of efforts across researchers who focus on medical interventions to cure, on rehabilitation to restore function, and on supportive services for disabilities are crucial. Little has changed in the decade since Meyers and Andresen published the supplemental issue on disability outcomes research in the *Archives of Physical Medicine & Rehabilitation*,²⁰ as evidenced by the current lack of literature.

Ironically, researchers may actually contribute to a problem persistently faced by people with disabilities, which is that they suffer disparities in health care services while at the same time experiencing greater health care needs.^{40,41} Researchers contribute to this disparity through research designs and practices that either systematically exclude people with disabilities or incompletely capture the outcomes they value. Research silos contribute to this process, as do the context and environment within which researchers work.

The broad scope of the review was a useful endeavor because its findings underscored the need for coordination and collaboration among the three overarching approaches to studying outcomes—medical, rehabilitative, and supportive services. However, the broad sweep also made it difficult to adequately drill down into the literature. Having taken the broad view, future efforts will likely need to go about “eating the elephant” differently. Outcomes for quality medical care (whether treating the disabling condition or treating the disability as a complicating condition) is a vast topic. The trick will be to strike a proper balance between scopes constrained for successful search processes and scopes broad enough to allow for examining similarities and differences in outcome measures. Successful searches will need to be constrained along at least one dimension (e.g., by subpopulation, outcome domain, or outcome level). As the knowledge base around populations and outcomes further develops, mapping the areas of overlap among the three theoretical approaches will become more feasible, as will identifying the areas specific to each theoretical approach.

Limitations

The major limitation of this work is the lack of sensitivity and specificity of the search algorithms. This resulted from the project scope, as well as from the difficulty in creating keyword search terms that adequately capture care coordination and outcome assessment. The literature search was extensive, with carefully designed search algorithms, numerous citations reviewed, and a reasonable coverage of the literature within the scope of the review. However, due to the limitations of search algorithms for diffused literature that necessarily relies on natural language terms rather than MeSH terms, the articles cited should be viewed as a sample of a small and dispersed literature. As stated above, the planned breadth of the review contributed to the search strategy difficulties. Each of the KQs is likely partially answerable if more focused, narrow searches are undertaken in future reviews.

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Introduction

This review belongs to a new series of reports, Closing the Quality Gap: Revisiting the State of the Science (CQG Series). The original CQG Series¹ was commissioned by the Agency for Healthcare Research and Quality (AHRQ). The intent of the series is to assemble a critical analysis of existing literature on quality improvement strategies and issues for topics identified by the 2003 Institute of Medicine report Priority Areas for National Action: Transforming Health Care Quality.² AHRQ was also charged with continuous assessment of progress towards quality and updating the list of priority areas. Subsequently, AHRQ identified people with disabilities as a priority population.

People with disabilities can present special care challenges. Medical problems for a person with a disability can be exacerbated or complicated by the presence of other medical, psychological, economic, and social problems. Optimal care requires coordination among those involved in various sectors, the goal being to maximize the individual's function and quality of life. Since function, quality of life, and community integration are interdependent, coordination may need to span the care spectrum to address various elements of life (e.g., medical care and schools or social agencies). Coordination of care, with attention to the intersection of medical and social services, is congruent with recent policy attention on integrated care and medical homes.

This review examines how health care outcomes have been assessed for people with disabilities. Disabilities are often broadly categorized into general types: physical, sensory, or intellectual. They can also be differentiated by etiology/timing of onset: developmental disabilities, disabilities acquired through trauma, disabilities as manifestations of disease processes, and disabilities iatrogenically acquired from treatments for disease conditions. With aging, a person's existing disability profile may change (aging *with* disability), while otherwise healthy people may develop disability as a consequence of aging (aging *into* disability).

Regardless of disability type or etiology/onset, outcome measures are essential for evaluating quality care. Outcome measures may be even more useful in combination with *process measures* that address the extent and success of care coordination. For example, a process measure might evaluate the level of coordination between educational and medical services or between social and medical services. In general, little attention has been devoted to this intersection between outcome measures and process measures. Further, only modest efforts have been made to develop customized measures.^{3,4}

Outcomes may be expressed as elements that directly reflect a person's status, such as quality of life or social functioning. They may also be more intermediate measures, such as access to care—a common problem for many people with disability. This report emphasizes the former.

Here we discuss outcome measurement issues and explore conceptual frameworks for thinking about measuring outcomes for research and quality improvement efforts. As with all frameworks that deal with complex concepts, categories, paradigms, or classes we present are at best “ideal types” rather than simple designations with clean boundaries. We conclude with a summary of the project scope.

What Is To Be Measured? Levels of Analysis

Examining outcomes requires a broad understanding of what is appropriate to be measured. The range of choices depends in part on the goals for the research or evaluation. The goals should drive the focus, content, and structure of the optimal measure.

We can address outcomes of care for people with disabilities from several levels. Table 1 illustrates the relationship between the level of focus and related salient questions. We distinguish interventions directed at a disability from specific interventions directed at a given medical problem for a person with a disability, or comprehensive programs designed to integrate medical and social services for people with disabilities. Particularly for specific medical interventions not aimed directly at the disability, disability may often be thought of as a complicating condition that complicates the care (and changes the case mix), but for which the same outcomes apply as for people without the disability. However, some disabilities may impose a floor or ceiling on the outcome of interests. For example, problems with mobility that pre-date the disease may limit the potential for recovery or adaptation. A measure designed to tap deviations in performance for those expected to reach a near normal state may not be well suited for someone with an activity limitation.

Table 1. Levels of analysis for research related to people with disabilities, and related questions

Level	Common Questions or Outcomes of Interest
Impact of public policy, geographic variation	Who gets services? How does prevalence vary?
Effect of organized programs	Who uses services? Where are people treated? Is there a change in amount of services used? Is there a change in use of other services? Cost of care?
Specific interventions directed at the disability	Changes in body function and structure, activities, and participation QOL
Specific interventions directed at a given medical problem for persons with a disability	Typical condition-specific outcomes for the problem Generic outcomes (e.g., function, QOL) Costs Utilization of second order services (e.g., hospitals, ERs)
Comprehensive programs designed to integrate medical and social services	Prevention of conditions secondary to the disability Typical condition-specific outcomes for the problem Generic outcomes (e.g., function, QOL) Costs Utilization of second order services (e.g., hospitals, ERs)

Note: Bold text indicates areas examined in this review.

What Is Measured (And Why)

Disability Definitions

It is challenging to define disability in a manner consistently applicable to the full human lifespan and range of abilities and activities. For the purposes of the National Healthcare Disparities Report, AHRQ used a definition that strives for consistency with the wide range of Federal programs related to disability: “People with disabilities are those with physical, sensory, and/or mental health conditions that can be associated with a decrease in functioning in such day-to-day activities as bathing, walking, doing everyday chores, and/or engaging in work or social activities.”³ At a recent AHRQ meeting, nationally recognized experts widely agreed that

a single, consensus definition of disability is not feasible or desirable. Instead, they suggested that the definition should be governed by the research issue to which it will be applied.³

In the absence of consensus definitions, broad classifications can provide a useful alternative. Broad classifications offer a way to categorize outcomes for interventional or quality improvement initiatives for services for people with disabilities. Researchers have differed in their approaches to classification schemes. The medical approach focuses on pathology, such as classifications based on medical diagnosis, the body system affected, or functional loss or etiology of the disability. Psychological approaches tend to focus on the mental response to impairments. Social construction classifications distinguish between impairment and disability and tend to focus on discrimination against people with certain impairments, especially restricted access to services and opportunities.

Models of Disability

The different approaches to classifying disabilities reflect different models of disabilities. The **medical model** of disability^{5,6} emerges from Cartesian western medicine, which views treating or managing a disabling condition mostly as a matter of pathophysiology. That is, once the structural or biochemical deviations are understood, altering or controlling the disabling condition is then a compassionate and appropriate course of care. The biomedical model has been successfully used to guide the development of diagnosis and treatment. Due to this success, the model's unintended consequences were not seriously examined until the latter half of the 20th century. One consequence of great importance was that defining health as the absence of disease equates the presence of disability with poor health. Another unintended consequence stemmed from the medical model's narrow focus on solutions it could address, allowing for too little attention to nonmedical but important life outcomes including full participation in meaningful activity throughout the day and across environments (regardless of whether the underlying pathophysiology can be cured, controlled, or altered).

The **social model** of disability frames the problem as the societal response to the disabling condition, rather than the person. This approach separates the concepts of disability and health.^{5,7} The model holds that many of the disadvantages experienced by the person with the disabling condition are imposed by society, not inherent in the person's physical or mental state. Responding to disability may then be as much or more a matter of political action than of health care *per se*. Hence, the disability community's political agenda is based on a platform of civil rights, calling for equal access and opportunity.⁸

The social model acknowledges a person's limitations but focuses on providing supports to enable the person to participate fully in family life, school, community, and work, whether or not certain skills or capacities are ever fully regained (or, in the case of a developmental disability, developed). This difference in focus is critical in the context of federal policies and programs focus on the medical or even the rehabilitative models. Such policies and programs sometimes deny funding for medical care to maintain a level of functioning. For example, people with certain developmental disabilities, notably cerebral palsy, face coverage limitations for occupational, physical, or speech therapy, because they are unable to achieve the standards of progress required for continued funding. Denied the therapy needed to maintain function, the person's capacity to participate is thereby reduced. This problem particularly affects working age adults with disabilities who have aged out of school (and the medical and physical supports provided to children and youth in those settings under the IDEA legislation). There is some concern that physicians and other medical professionals who encounter children or adults with

developmental disabilities focus on the disability and fail to provide standard care.⁹ For example, doctor or hospital visits for people with disabilities may not include standard preventative care if the medical professional focuses on the “problem” of the disability rather than on the person with the disability. Research reviews have consistently reported significant gaps in otherwise standard practices such as preventative dental care; mammograms; and routine screening for diabetes, high blood pressure, and other conditions (e.g., Larson & Anderson¹⁰).

The **biopsychosocial model** emphasizes how interactions between biological, psychological, social, and cultural factors affect one’s experience of health or illness.^{11,12} Some view this third model as an attempt to integrate the medical and social models.⁵ This view may represent the perspective of some allied health professionals, such as physical or occupational therapists engaged in rehabilitation. However, not all professional providers of social service-based support agree that the biopsychosocial model fully incorporates important aspects of the social model. For example, the social model differentiates between rehabilitation, which is designed to improve function or recover skill, and habilitation, which provides instruction to support a person’s skill acquisition throughout the lifespan.

The social and biopsychosocial models have influenced a number of Federal initiatives, such as the Americans with Disabilities Act of 1990, the New Freedom Initiative, The Surgeon General’s Call to Action to Improve the Health and Wellness of Persons with Disabilities of 2005, and Healthy People 2010. If people with disabilities are viewed as being on a health spectrum, similar to what people without disabilities experience, then well-being and health promotion are legitimate goals.¹³ In pursuit of these goals, Healthy People 2010 made important assertions: (1) that disability be treated as a demographic descriptor rather than as a health outcome (more discussion below); (2) that Disability-Adjusted Life-Years (which assume that disability signifies reduced health status) be eliminated; and (3) that disability be seen not as a static phenomenon but as a condition that varies by developmental phase, point in time, environmental context, and type of disability.¹⁴

Other efforts are ongoing to develop integrative and comprehensive conceptual models that will (1) acknowledge and work with the complexity of disability-related research and (2) provide the full healthcare spectrum. One example is a biopsyo-ecological model,¹⁵ which incorporates theories of Health Environmental Integration (HEI).¹⁶ The model adopts functional systems theory, viewing a person and her health condition as an outcome of a dynamic network of integral components including people, health conditions, and environment. “Health and illness occur within ecologies where small perturbations at any level (from molecular/cellular to environmental) can have large effects on overall person-level functioning and experienced quality of life” (Stineman, 2010, page 1036).¹⁵

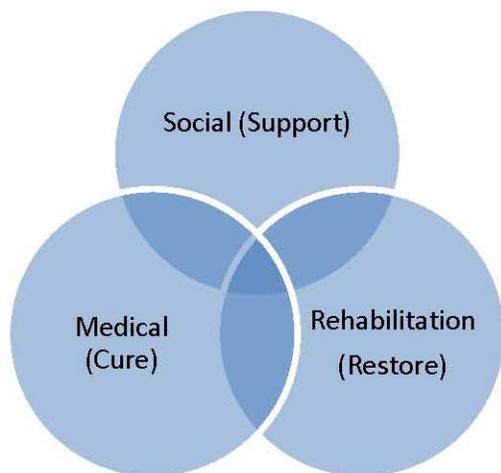
Disability Paradigms

These models can inform and frame the perspectives of the range of professionals providing services for or engaging in research related to people with disabilities. Useful insights can emerge from considering how this informing and framing occurs. Broadly speaking, Figure 1 illustrates how the three general paradigms on care and support for people with disabilities overlap.

The **social paradigm** is common among professionals who (1) study people with disabilities and the effects of disabling conditions; (2) specialize in providing medical care to people with disabilities; or (3) focus on supportive services, including fields such as social work or special education. This paradigm acknowledges the appropriateness of medical and rehabilitative efforts

specific to a particular person but emphasizes supporting and empowering people who have disabilities to be full participants in their families, communities, and schools, whether or not their disability or related medical conditions can be cured or fixed.

Figure 1. Major paradigms of professionals that work with people with disabilities



The **medical paradigm** is common among professionals who diagnose and treat people with disabilities and provide general medical care as well as specific treatment for the disabling condition. In this model, illness may be seen as a complication imposed on a person with a disability, or disability as a complication of treating a specific illness. Depending on the chosen specialty, a provider’s patient load may comprise only a minority of, or primarily, patients with disability. Curing is an ideal for which to strive. Both the medical and biopsychosocial models may inform the work of these providers. The relative weights for the models will be a function of personal concerns and professional training. Often the medical model strongly influences interventional research from within this paradigm.

The **rehabilitation paradigm** is common among professionals such as physiatrists and physical, occupational, or speech therapists. Patient populations include people with temporary disability due to trauma or illness, and people with “stable” disabling conditions. This paradigm strives to maximize function and optimize potential opportunities to participate in life as desired by the individual. Notably, the rehabilitation field is not cure focused, which is not the case for most other medical professions. Here as well, both the medical and biopsychosocial models may inform providers’ work. However, the biopsychosocial model, with its emphasis on person and environment factors, represents the dominant perspective that informs commonly used disablement frameworks.⁵

The different paradigms can play out in unintended communication problems as well. For example, the term “comorbidity” is variably used as a narrowly defined set of conditions that tend to travel together, such as diabetes and heart disease. Or it may be more broadly used as a synonym of multimorbidity, or any coexisting medical condition(s) that may complicate care for the medical condition of interest. However, co- and multimorbidity are medicalized terms and as such are often viewed as insufficient to describe the multidimensional and dynamic nature of a disability. To the extent that language shapes thinking, this impedes communication.

The figure presents the paradigms as overlapping because, as within any community, people use varying degrees of comprehensive or integrative perspectives. Some encourage or participate in bridging interdisciplinary work.

The Independent Living (IL) paradigm stands in contrast to the others. This paradigm proposes that people with disabilities are the best experts on their own needs and must take self-initiative in designing solutions for their needs. IL emphasizes the return of people to independent living and engagement in their larger community environments. People with disabilities are citizens first and consumers of health care second. IL is compatible with the biopsychological paradigm, both of which take into account the “full range of human experience in the world.”¹⁷

The Rehabilitation and Adaptation Perspectives

The course of addressing a disability can be divided into two basic segments: treatment/rehabilitation and adaptation. Each represents a distinct mind set about how a society responds to the challenges of disability. The relative size of these segments varies with the etiology of the disability. Three useful etiologies, or timings of onset, to consider are:

- Congenital or developmental
- Acquired (usually through trauma)
- Aging
- (Some would add a fourth category of iatrogenic)

The etiologies of disability affect the relative weight of the segments, in part based on life course issues. With developmental disabilities, for example, actions to address the underlying problem (e.g., surgery for spina bifida) are taken during a relatively brief period in early childhood (or infancy). Some people with developmental disabilities require medical treatment periodically as their bodies develop or their life circumstances change, or rehabilitation services at different life transitions (e.g., supported employment or job coaching). For some developmental disabilities no curative treatment is available. For most of the person’s life disability-related services are directed at helping the person with the disability develop skills and adapt his or her environment in order to foster the fullest participation possible.

People with acquired disabilities often face a prolonged period of treatment and rehabilitation. The goal, at least initially, is to restore the person to the same level of function as before the disability was acquired. However, for many, full restoration is not possible, and the emphasis shifts to coping with the remaining level of disability and preventing complications. Here again, emphasis is placed on adapting to a real living environment and actively participating in society. Thus, relevant outcomes include supported living, supported work, and full inclusion in the community.

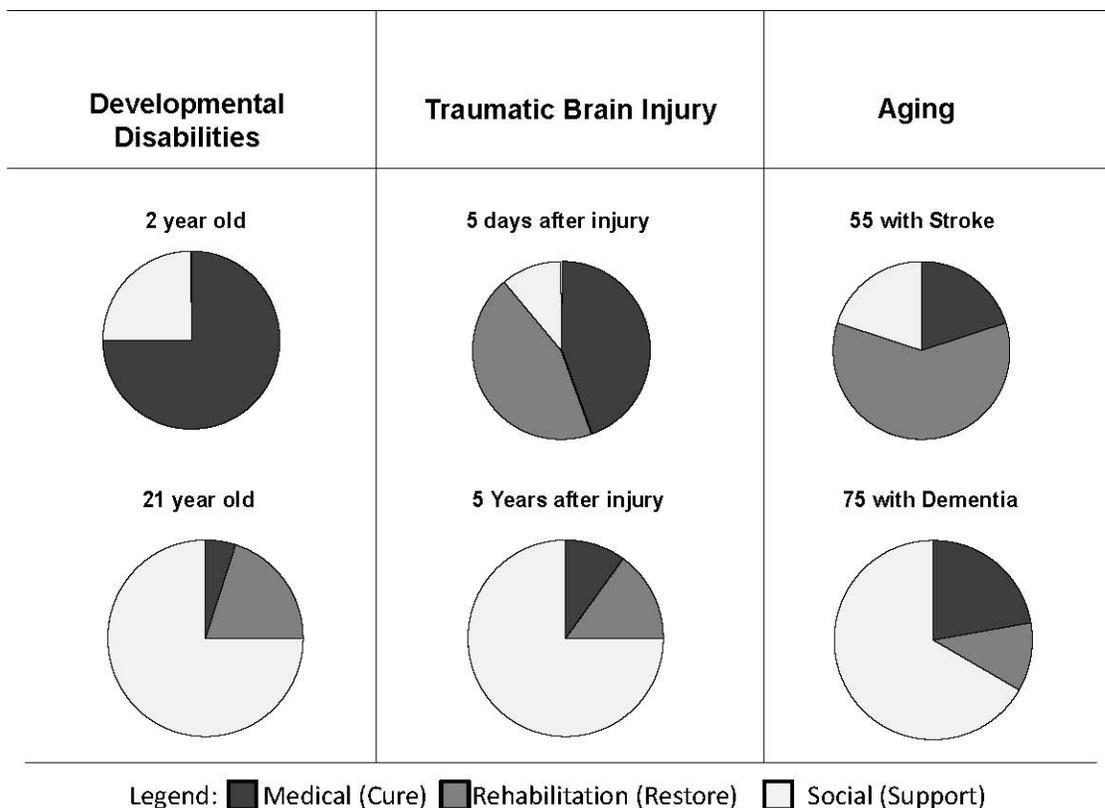
For people with aging acquired disability, onset is linked to chronic disease and is often more insidious (although an acute event, like a stroke, may occur). There is an underlying belief that treatment is central; simply coping is often viewed as inadequate. This concept of disability is strongly linked to disease. As a result, it embodies an expectation that effective care will change the course of the disability and hence reduce secondary utilization of other services. In gerontology, a mainstay theory is that of selection, optimization, and compensation, which addresses a major coping strategy.¹⁸

The distinction among these etiologies of disability is not pure. People with developmental disability may be at greater risk of acquiring further disability because of limitations imposed by

their primary condition. As larger numbers of such individuals survive into older adulthood, they are subject to age-related changes as well, and at younger chronological ages than the general population.¹⁹

People with disabilities, regardless of etiology, prioritize different components at different times. For example, parents of a child with a newly diagnosed disability often spend considerable time and energy seeking a cure or effective long-term treatment that will eliminate or greatly reduce the impact of the diagnosis on the child’s life course. In contrast, older children and adults with developmental disabilities prioritize getting support needed to live a fully included life, even if the underlying impairment cannot be cured or if function cannot be fully restored. For people with an acquired disability, an immediate effort to cure or full restoration of functioning is often followed by a prolonged period of rehabilitation and then a lifetime of getting support needed to live fully included lives. People with disabilities that result from degenerative conditions or the aging process often continue seeking curative or rehabilitative support until it is clear that death is imminent, at which time palliative care is often sought. Figure 2 illustrates the relative emphasis among these different types of disability.

Figure 2. Relative emphasis of medical care, rehabilitation, and adaptation for disabilities of different etiology



Note: Stylized examples to illustrate relative differences.

Here as well, thinking differs among professionals within different paradigms. Some social services professionals argue that this model illustrates one of the problems with services for older people. People receiving care for chronic treatments can continue to be active participants in their families, homes, and communities. Initiatives like the Center for Medicare and Medicaid

and Services' Money Follows the Person allow for more of the support people need to remain full participants.

These different conceptual etiologies have implications for the nature and extent of linkages with the medical care system. Care for people with developmental and acquired disabilities is directed at supportive services. Medical care is relevant only to the extent that the individual suffers from problems common to all people of the same age or from specific disease complications of the underlying condition. At the same time, disabilities may present access barriers to medical care (e.g., getting onto an exam table). Medical practitioners may need special knowledge about how to treat a given disease in the context of the disability. Successful care is generally measured using outcomes related to functioning and societal integration.

By contrast, older persons' disabilities are more integrated into a disease framework. Treating the underlying disease is hard to extricate from treating the disability. Perhaps as a result of ageism, achieving societal integration is often viewed as less salient than improving the disease or disability level (or at least slowing decline).

As an illustration of these different mindsets, consider the following scenario. A disability activist who has paraplegia and uses a wheelchair is visiting his father, who just recently became a wheelchair user because of a stroke. In response to the nursing home staffs' efforts to establish a program of timed toileting and ambulation training for his father, the son responds, "Forget that. Put an external catheter on him and let's get on with life." This also illustrates the occasional potential conflict between preferences (catheterize and "get on with life") and clinical judgment and best practices (avoiding catheterization).

These distinctions have important implications for measuring disability-related outcomes. Table 2 illustrates some relevant outcomes. Those for developmental and acquired disability are virtually the same; both emphasize societal integration. In contrast, those for aging emphasize more limited functional goals, and indirect effects on costs and utilization of additional services.

Table 2. Examples of outcomes by major disability etiology

Disability Type/Timing of Onset	Example	Outcomes
Developmental Disability	Autism Cerebral palsy	Living in and fully participating in inclusive communities with appropriate support Going to school/lifelong learning Doing paid work Meaningful social roles including as friend, spouse, or family member
Acquired Disability	Spinal fracture/quadruplegia	Living independently Going to school Doing paid work Meaningful social roles including as friend, spouse, or family member
Aging	Stroke Dementia	Slowing decline in ADLs/IADLs Reduced use of hospital/ER Prolonging life

Abbreviations: ADL = activities of daily living; ER = emergency room; IADL = instrumental activities of daily living

Returning to the concept of disability as a complicating condition that hinders general medical care, the health goals of people with disabilities (as noted in the Outcomes column of Table 2) are not so different from those of the general population at comparable ages. The Institute of Medicine (IoM) framework proposed in their report "Crossing the Quality Chasm" (2001)²⁰ outlines the basic goals for health care as follows:

- Safe (no harm)

- Effective (no needless failures)
- Efficient (no waste)
- Patient centered (no helplessness or unjustified routines)
- Timely (no needless delays)
- Equitable (no unjustified variation)

The IoM framework has been effectively used to distinguish healthcare for various subgroups, several of which are relevant to this discussion.²¹ Of the population segments outlined in the subgroups (given in Table 3) the groups most like the populations relevant to this review are subgroups 5 and 8. However, the population segments obscure the important distinction between disability and health. For example, a person living with a mobility disability may simultaneously inhabit more than one segment, perhaps having a “stable disability” but also a concern with maternal and infant health, or an acute illness unrelated to the disabling condition. A person with an intellectual disability may be healthy and have the same priority concerns and goals for health care as subgroup 1.

Table 3. Population segments and health priorities²¹

Subgroup	Priority Concerns	Goals for Health Care
1. Healthy	Longevity, by preventing accidents, illness, and progression of early stages of disease	Staying healthy
2. Maternal and infant health	Healthy babies, low maternal risk, control of fertility	Staying healthy
3. Acutely ill, with likely return to health	Return to healthy state with minimal suffering and disruption	Getting well
4. Chronic conditions with normal function	Longevity, limiting disease progression, accommodating environment	Living with illness or disability
5. Significant but relatively stable disability	Autonomy, rehabilitation, limiting progression, accommodating environment, caregiver support	Living with illness or disability
6. “Dying” with short decline	Comfort, dignity, life closure, caregiver support, planning ahead	Coping with illness at the end of life
7. Limited reserve and serious exacerbations	Avoiding exacerbations, maintaining function, and specific advance planning	Coping with illness at the end of life
8. Long course of decline from dementia and/or frailty	Support for caregivers, maintaining function, skin integrity, mobility, and specific advance planning	Coping with illness at the end of life

The “Aging Into” and “Aging With” Perspectives

Another recent major advance in understanding outcomes arises from applying a life course perspective. As noted, many people age into disabilities through the advent of illness. Many serious developmental or acquired disabilities have attenuated life spans. With improvements in care, many more people with significant disability now live to reach much older ages.¹⁹ Specific consequences vary by disabling condition, but in general this group may manifest age-related conditions at a younger age.^{22-26,27} Thus, distinguishing the issues attributable to the underlying disability from those associated with aging presents a special challenge. In this way, underlying disability accentuates a long-standing geriatric dilemma; that is, to identify the etiology of a problem as attributable to pathologic change or a normal aging change. This blurring may have more important implications for diagnosing health concerns in a timely fashion.

The Individual's Perspective

From the individual's perspective, the concept of health is dynamic, sensitive to the conditions present at the time it is measured.¹³ Participants with disabilities use different criteria and themes when rating their health compared to those without disabilities. For example, four major health themes emerged from 19 focus groups with people with disabilities: (1) the ability to function and the opportunity to do what you want, (2) independence and self-determination, (3) an interrelated physical and emotional state of well-being, and (4) being unencumbered by pain.²⁸ Compared to people without disabilities, these focus groups stressed the importance of resilience and emphasized their experience of health as distinct from their disabilities.

The paradigms and perspectives discussed above find traction in how the relevant outcome domains are examined and measured. In the next sections we discuss issues related to outcome domains and measurement. This is followed by a brief discussion of the World Health Organization's international classification system for outcomes to assess health and functioning.

Relevant Outcome Domains

Outcomes relevant to people with disabilities encompass more domains than are relevant for the general population. Along with the basic repertoire of condition-specific and generic outcomes measures, additional measures and methods may be required for assessing outcomes for people with disabilities (or for specific subgroups organized by type of disability).

Different camps within the disability research community disagree about the extent to which the outcomes of medical care should be assessed similarly for persons with and without underlying disability, especially developmental and acquired disability. Some view the outcome domains as similar to those applied to general populations. Essentially, they see disability as a complicating condition, to be included in an appropriate case mix correction, and argue that it does not necessitate the use of different outcome measures. In contrast, others hold that in addition to the outcomes measured for the general population, specific outcome domains and measures should be tailored to the populations of interest. This group advocates for more individualized approaches that include additional outcomes related to managing disability and preventing secondary conditions.

The latter camp also argues that quality outcomes for disabling health conditions do not address considerations directly related to disability.³ A committee of experts convened by AHRQ noted that “[c]ommon health conditions that can be profoundly disabling include some, such as diabetes and heart failure, [which] have quality measures that generally are widely accepted and used. Most of these quality indicators reflect processes of care (e.g., measurement of Hb [hemoglobin] A1c levels, ophthalmologic examinations, prescriptions for certain medications). These quality indicators do not address considerations relating to disability.”³ For example, treatment goals for a person with quadriplegia with an indwelling catheter may differ from those for a person recovering from hip replacement surgery. However, treatment goals for people with disabilities for conditions such as diabetes and heart disease may be very similar or identical to those for people without disabilities. So while health status may contain the same components for everyone, individuals may assign the components different weights based on their situations.²⁹

Outcome measures can be generic or specific to the particular issue. Generic measures are useful to policy questions or large conceptual problems that address multiple populations and/or interventions or services. Condition-specific outcomes may still be multidomain but are designed

for a particular population or situation. Condition-specific measures are usually more sensitive to change because they are more closely linked to the problem at hand. However, they limit the ability to compare across populations.

Recovery choice pathway measurement technique, where people are asked to select an optimal pattern of functional recovery that reflects their preferences, moves further toward the individual-level perspective.^{30,31} While recovery pathway methods are typically applied to rehabilitation, it may also influence medical care recovery for people with disabilities. Differences found in values assigned by different groups (such as patients or clinicians, or even subgroups within those) suggest implications for measurement goals setting, and how measures are scaled when addressing quality of life.

Health-related quality of life (HRQoL) focuses on how health status affects quality of life (as opposed to well being, which addresses the positive aspects of a person's life). Quality of life is often measured with health status measures, such as the MOS SF-36³² that describe, but do not value, health. Other measures attempt to value health as a way to combine mortality and morbidity, leading to constructs such as the Quality-adjusted Life Year (QALY), or the Disability-adjusted Life Year (DALY). The EuroQual's EQ-5D is a widely used HRQoL measure. Summary utility scores have also been mapped for SF-36 data, allowing the SF-36 to be used to generate QALYs.³³ These approaches place an immediate ceiling on the potential benefit people with disabilities can achieve because their baseline status downgrades the QALY score. Using such measures in making policy decisions thus has substantial implications for people with disabilities.

Health and functional status measures that give no credit for the adaptations made to achieve functional outcomes by people with disabilities will lower their scores on certain measures. For example, the SF-36E (for "enabled") was developed to accommodate people with physical disabilities³⁴ and thus substituted the word "go" for "walk" or "climb" in questions regarding personal mobility. The words "walk" or "climb" were at best confusing, and at worst, offensive to people who use wheelchairs. Questions were also reordered from shortest to longest distance so that people did not have to repeatedly acknowledge mobility difficulties.

Outcome Measures in Research for People With Disabilities

Outcome domains shared with general populations may require a modified methodological approach for people with disabilities. Quality research uses measurement instruments to determine improvements (or lack of) in outcomes of interest. The characteristics of measurement tools should be considered, along with how they are used to assess the outcomes of care for people with disabilities.³⁵ Characteristics to consider include:

- Psychometrics (bias, validity, reliability, responsiveness) of specific measurement instruments
- Availability of comparative norms and standard values
- Measurement timeframe and the potential for fluctuating levels
- Disability cut-points (if the measure is part of a general spectrum)
- Does the disability cut-point create a potential for floor or ceiling effect?
- Types of patient-centered measures
- Modes of administration and respondent burden
- Data sources

People with disabilities have been disadvantaged in participating in research studies. Standard research instruments are not accessible to people with disabilities.³⁴ For example, standard telephone sampling methods can miss those who cannot reach a phone by the 10th ring, or those whose primary mode of communication is not speech. Similarly, surveys that do not allow proxy response very often exclude people with intellectual or other cognitive disabilities. Most unfortunately, the concepts and wording of some health surveys are insensitive and even offensive to the firsthand experience of people with disabilities.³⁴

Accommodation and universal design are two approaches to providing access to research participation. Accommodation requires enabling the measurement tools and modes of administration to allow access to people with disabilities. The SF-36E is one example of a tool adapted to provide accommodation.³⁴ Universal design is being extended to the field of health services research.³⁴ Universal design strives to develop products that are usable by all people, to the greatest extent possible, without adaptation or specialized design.³⁶ The NIH's PROMIS (Patient-Reported Outcome Measurement Information System) initiative is developing data collection tools, including computer adapted testing, based on the principles of universal design, i.e., they are applicable to persons with and without disability.³⁷

Appropriate outcome measures may not differ between disabled and nondisabled populations, but the methodological approach to assessing outcomes may require accounting for patient characteristics or case mix. Of interest are the independent variables relevant to accurately reflect outcomes.

When not addressing disability as a direct cause of a medical condition, the relationship between disease and disability can be examined in terms of two different underlying paradigms. In one case, disability is a complicating condition acting as a confounder in elucidating the relationship between the treatment and the disease outcome. One technique to address this issue is treating the disability as a demographic descriptor, as suggested in Healthy People 2010. An example of this procedure can be found in a study analyzing access to care for people with various types of health care coverage in the National Health Interview Survey – Disability Supplement. In this analysis, outcomes such as short hospital stays and days of activity restriction in the previous 2 weeks varied with age, gender, race, overall health status, disability type, and health coverage status.³⁸ Alternatively, the disability may affect either the choice of treatment or the effectiveness of that treatment. For example, the design of a physical activity regime for an adult with uncontrolled diabetes will likely be different for people with or without a significant mobility limitation. In that instance, the disability must be analyzed as an interaction variable.

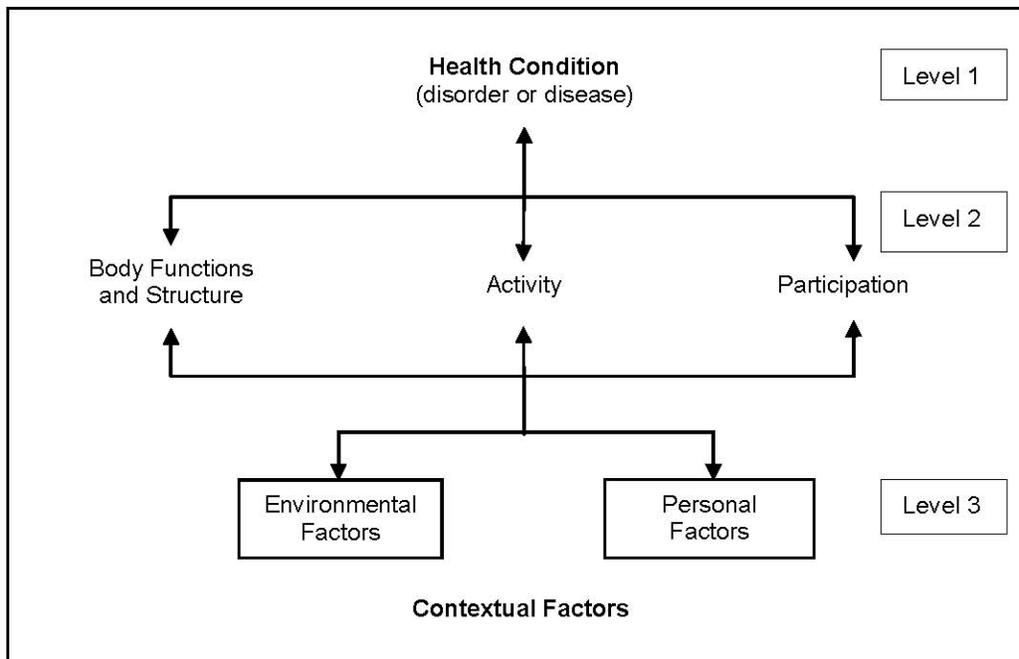
Outcomes such as independent completion of activities of daily living (ADLs) have been shown to fluctuate widely over time. A person's ADL level cannot be assumed to be stable.^{39,40} This variation imposes substantial problems in assessing treatment effects. At minimum, it implies a measurement error. It makes it more difficult to assess the extent of change. If the treatment actually changes the amount of variation in the ADL (e.g., stabilizes it), then its effect may be missed unless the research design is sensitive to the variation and magnitude of change.

ICF Outcome Domains

The International Classification of Functioning, Disability, and Health (ICF) was created as a framework to classify and assess function and disability associated with health conditions.⁴¹ The framework (Figure 3) rests on a positive description of human functioning rather than emphasizing the negative consequences of disease. This multidimensional model incorporates

several levels of functioning. The framework attempts to explicitly acknowledge the dynamic nature of disablement, which can fluctuate based on a number of contributing factors across an individual's life course.

Figure 3. The International Classification of Function, Disability, and Health (ICF)⁴¹



The framework identifies three levels of human functioning. The first level, health condition, designates functioning at the level of the body or body parts. The second level designates functioning at the level of the whole person. The third level designates functioning of the whole person in his or her complete environment. The whole-person level includes three domains of human functioning: body functions and structures, activities, and participation. The body functions and structures domain involves the physiological functions of the body systems and the anatomical parts of the body. Impairments are problems with the body function or structure that result in a significant loss, defined as “deviations from generally accepted population standards.” The impairments may be temporary or permanent.

Activity and participation domains attempt to distinguish between the execution of a task or action by an individual versus participation in life situations. Later evaluations of the framework combined activity and participation into one category because of the difficulty in differentiating between the two domains.⁴² Contextual factors include environmental (external) factors that shape the lived experience of disability and can arise from the physical world, human-built structures, and from social and cultural constructions and attitudes. Individual experience is also shaped by personal factors (age, sex, coping styles, education, and other person-level differences in attitudes and behavior patterns). Since fewer personal factors are open to interventions, less effort has been made to elaborate coding for them.

The ICF has been criticized for lacking the clarity and distinction between the basic model components necessary for empirical measurement and testing.⁵ Subsequent empirical research on the concepts has suggested that the activity and participation domains were not distinguishable and has pointed to five potential distinct subdomains: daily activity, applied cognitive (higher

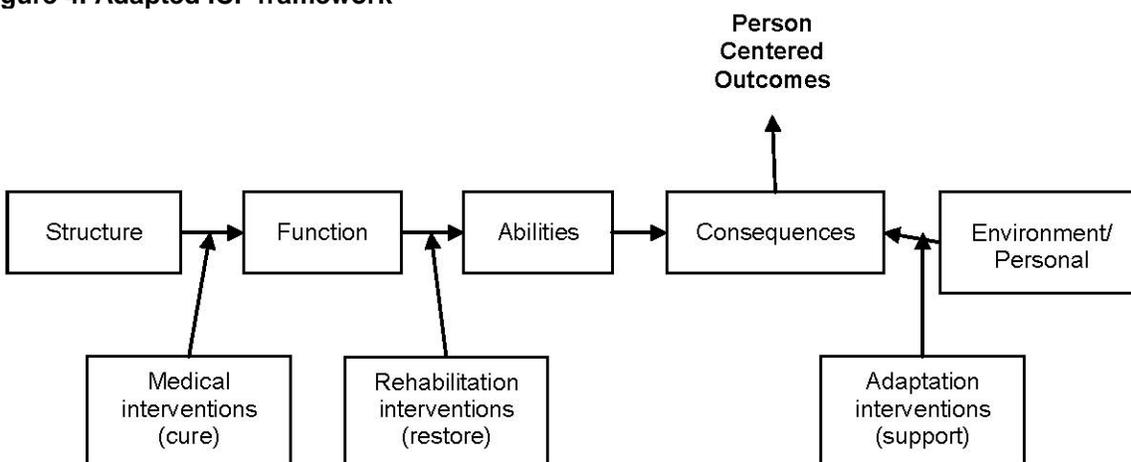
order intellectual actions such as paying attention to multiple things at once, or following voice mail instructions), role participation, mobility, and social participation.⁴² Likewise, ADLs and IADLs map to self-care and domestic life chapters of the ICF, but other activities within those chapters did not map to ALDs/IADLs.

The last few years have seen some progress toward the clarity and discrimination needed for empirical measurement, and testing has been done in the last few years. While that level of analytical detail is beyond the scope of this review, some notable efforts are being made to establish useful ICF-based measurement.⁴² For example, the technique of functional staging combines the functional relevance of coding schemes (such as the ICF) with the ability to reliably measure an individual’s change, or discriminate between groups. Functional staging uses scale scores and has been tested for basic mobility.⁴³

One commenter noted that the lack of a common conceptual scheme and language for disablement models has led to confusion within the scientific literature.⁴⁴ The internationally developed ICF scheme congruently maps with disablement frameworks developed and employed in the United States.⁵ The ICF can help develop and promote a common language for improving collaborative, interdisciplinary, and international efforts. Further, the IoM has recommended its use in their report “The Future of Disability in America” (2007).⁴⁵ Professionals involved in rehabilitation outcomes research suggest that the ICF framework will allow the sharing of outcomes across episodes of care that is necessary for evaluating quality coordinated care.⁴⁶ A systematic review of ICF-related literature between 2001 and 2009 found evidence for the diffusion of ICF research and a growing trend in the use of the ICF framework. The authors concluded that the size and growth trend of the literature offered evidence of a cultural shift in the way disability and functioning are conceptualized and researched.⁴⁷

Figure 4 provides a more linear illustration of the ICF to highlight how intervention points may differ for the “treatment” paradigms discussed above. Intermediate measures that assess the immediate effect of an intervention would likely vary based on the intervention point. Ultimately person-centered outcomes, such as quality of life, or living independently, remain somewhat universal to the intervention points. However, to be truly person-centered, the relevant outcome must relate to the goals as noted above.

Figure 4. Adapted ICF framework



Note: Adapted from Colenbrander 2010⁴⁸

The ICF framework has limitations for assessing relevant outcomes. Since the ICF is focused on coding function at the person level, it omits system level outcomes that may be useful in

evaluating quality of care or quality improvement initiatives. For example, cost and utilization numbers to examine use of second-order services noted in Table 1 above would not be gathered. Others suggest that tools developed by the World Health Organization that map to its ICF, the WHODAS II, could be useful identifying and aggregating information on utilization.³⁹ However, the ICF is not encoded to include satisfaction or process measures used to assess the effectiveness of a new program.

The discussion on the characteristics of measurement above is, of course, equally relevant with regard to the ICF. There are multiple disability etiologies, classifications, definitions, and disability profiles. Thus, we must attend to the relevance and psychometric fit (potential floor or ceiling effects, relevant cut-points, and possibility of fluctuations in measures) of a given outcome measure to a given patient group.

The ICF provides a common disablement construct that is comprehensive in scope and complexity. However, we cannot predict the impact of the ICF on the assessment of outcomes of health services for which disability is most helpfully viewed as a complicating condition. How should prevention or treatment be provided and assessed for a medical condition for a person who happens to be experiencing a disability at that moment in time?

Key Questions

Our Key Questions (KQs) focus on the quality assessment component of quality improvement for specific interventions directed at a given medical problem not directly related to the disability itself, or comprehensive programs designed to integrate medical and social services for people with disabilities:

KQ1. How are outcomes assessed for people with disabilities living in the community in terms of basic medical service needs?

KQ1a. What general population outcomes have been validated on and/or adjusted to accommodate disabled populations?

KQ1b. What types of modifiers or case-mix adjusters have been used with the general population outcomes to recognize the special circumstances of people with disabilities?

KQ1c. What are key parameters for measuring processes related to basic service care access for people with disabilities?

KQ2. What measures have been used to assess effectiveness of care for people with disabilities living in the community in the context of coordination among health providers?

KQ3. What measures have been used to assess effectiveness of care for people with disabilities living in the community in the context of coordination between community organizations and health providers?

The KQs were discussed with AHRQ, the CQG Series leader, participating EPC colleagues working on related projects, and members of the Technical Expert Panel (TEP). Discussions addressed the scope of this project in light of the structure and organization of the larger CQG Series and how this review could contribute to this area of research in disabilities.

Project Scope

The project scope included community-dwelling people of all ages who were diagnosed with and/or documented to have physical and cognitive disabilities. As a first cut, scope was confined

to efforts contained within the Department of Health and Human Services; thus vocational rehabilitation was not in scope. Severe and persistent mental illness (SMI) as a primary diagnosis was determined to be outside the project scope. The disability profile of people with SMI, and in particular the cyclical nature of SMI, suggest that some of the processes and outcomes needed for this population would be qualitatively different. Service settings within scope included outpatient health, home, and community-based services.

To keep the project scope within feasible bounds, we focused on specific interventions for a medical problem for persons with disability or comprehensive programs designed to integrate medical and social services (from Table 1 above). The other levels of analysis (research on impact of public policy or geographic variation, the effect of organized programs, or interventions for the disabling condition) were outside the scope.

Within the level of individual outcome analyses, the quality improvement rubric informed the areas of interest. We chose a finite set of medical services and associated outcomes to represent conditions experienced by people with disabilities most likely to be considered prime targets for future quality improvement initiatives. We also focused on coordination of care as a major component for potential quality improvement initiatives. These scope limitations are discussed in greater detail below.

Illustrative Medical Conditions

We further narrowed the review scope to a meaningful but manageable set of medical services and associated outcomes. Our aim in so doing was to provide an illustrative set of healthcare encounters not specifically related to treating the disabling condition or eliminating related impairments. This finite set was made meaningful by choosing several basic medical service needs. We defined basic medical service needs for this project as preventive dental and medical care.

We also addressed a set of secondary conditions common to people with disabilities. A secondary condition is “any condition to which a person is more susceptible by virtue of having a primary disabling condition.”⁴⁹ Preventing secondary conditions is identified as an important goal.⁴⁵ Research identifying secondary conditions is growing,⁵⁰⁻⁵⁴ including efforts to validate an instrument that identifies secondary conditions using ICD-9 codes.⁵⁵ For the purposes of this report, we chose secondary conditions that also mapped to ambulatory care-sensitive conditions. Secondary conditions that are also ambulatory care-sensitive conditions represent prime targets for future quality improvement initiatives. The list of basic medical service needs and secondary conditions for this review includes:

- Preventive dental care
- Preventive medical care (based on general recommendations of the U.S. Preventive Services Task Force)
- Urinary tract infections
- Pressure ulcers
- Diabetes and diabetic complications
- Pneumonia
- Asthma
- Gastroenteritis
- Hypertension
- Obesity

Care Coordination

No consensus definition exists for care coordination, even as it is pursued as an important domain of quality care.⁵⁶ A broad definition derived from a systematic review of care coordination within health care describes 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. Organizing care involves the marshalling of personnel and other resources needed to carry out all required patient care activities and is often managed by the exchange of information among participants responsible for different aspects of care.”⁵⁷ Coordination of care may extend beyond health care services to encompass other services for people with disabilities.

Care coordination is a multidimensional construct.⁵⁶ What is successful care coordination depends on the perspective, whether from the patient/family, provider/professional, or system-level. A number of frameworks to describe care coordination and facilitate related research have been developed.^{4,56} One framework cites coordination activities as including:⁵⁶

Establishing accountability or negotiating responsibility, including that of the patient and patient involvement

- Communication
- Facilitating transitions
- Assessing needs and goals
- Creating a proactive plan of care
- Monitoring, following up, and responding to changes
- Supporting self-management goals
- Linking to community resources
- Aligning resources with patient and populations needs

To these we add assuring that patient preferences are addressed and that the patient plays an active role in his/her care.

Broad approaches often used to carry out these mechanisms include: teamwork focused on coordination, health care homes, care management, medication management, and care coordination enabled by health care information technology. The mechanisms and broad approaches delineated above are expected to change as the general knowledge base expands.⁵⁶ A taxonomy of quality improvement strategies was developed for the original CQG Series.¹ These quality improvement strategies are:

- Provider reminder systems
- Facilitated relay of data to providers
- Audit and feedback
- Provider education
- Patient education
- Promotion of self-management
- Patient reminder systems
- Organizational change
- Financial, regulatory, or legislative incentives

To these approaches we also add process measures that capture evidence of enhanced patient/provider communication, and patient-centered care.

Other than incentive structures, the remaining eight strategies are potentially relevant to the coordination of care for people with disabilities, including potential links with other human services agencies.

Measures

Our search focused on outcomes, patient experience, and care coordination process measures because they were immediately salient to exploring the interface of medical care and disability. Given the review focus on the individual level of analysis discussed above, relevant outcome measures are at the individual rather than population level. Examples of patient-centered outcome measures include functioning, psychosocial adaptation to disability, community participation, and social relationships. Measures related to performance of care coordination were also of interest.

In keeping with the perspective of disability as a complicating condition, we focused on generic outcome measures for the general population or for broad classes of disability. An alternative approach, searching for condition-specific measurement tools, was either too burdensome if all disabilities were included, or the applicability of the review was too restricted if only a few example disability conditions were included. Likewise, detailed mapping of the outcomes to the specific coding within ICF chapters was outside the scope of this review.

Methods

Topic Refinement

Topics for the Closing the Quality Gap Series were solicited from the portfolio leads at the Agency for Healthcare Research and Quality (AHRQ). The nominations included a brief background and context; the importance and/or rationale for the topic; the focus or population of interest; relevant outcomes; and references to recent or ongoing work. Investigators from the Minnesota Evidence-based Practice Center then refined the questions for this project in consultation with a Technical Expert Panel (TEP). The TEP consisted of experts in disability and rehabilitation research, outcome and performance measurement, risk adjustment and modeling, community based care and personal care services, and healthcare quality and quality improvement. (See the Acknowledgments section for a full listing of TEP members.)

Inclusion/Exclusion Criteria

In conducting our searches, we used the following inclusion criteria:

- Physical, cognitive/intellectual, or developmental disabilities
- All ages
- Outcomes used to evaluate health services
- Outpatient and community settings

Our exclusion criteria included:

- Inpatient settings
- Institutional settings
- Severe mental illness
- Psychotropic medications used in medical/service environments
- Condition specific outcomes
- Research for specific disability conditions

Care coordination was operationalized as comprehensive coordination programs consisting of multiple care coordination activities and components. Specifically, we included programs where there was some kind of purposeful coordination between/among (1) medical providers (e.g., generalists/specialists, school nurse/primary care, etc.), (2) medical providers and some community service providers (generally schools), (3) medical providers and caregivers (usually family), and (4) social service groups including some health component (e.g., helping ensure children with disabilities retain health and SSI benefits when aging out of youth services; this is not a frequent finding). Studies of single care coordination components were excluded.

The literature was limited in several ways. We limited the literature to peer-reviewed, English-language publications after 1990. Quality improvement as a field and the science of quality measurement had formed by this time, and the interest is in current measures in use. We also limited the literature to the United States and to the United Kingdom, Canada, Australia/New Zealand, and the Netherlands, where service delivery settings are more likely to be applicable to the United States. Cross-fertilization of ideas between these health care settings has not been noted. Other international settings, however, were unlikely to be applicable to the U.S. setting.

KQ1a

To keep the scope of the project feasible, we conducted a search of methods-related literature documenting the development and testing of outcome measures. Thus, the inclusion/exclusion criteria were further limited to only include articles examining the characteristics of generic, rather than condition-specific, measurement tools. Reviews, compendiums, or suggested outcome sets were included only if they represented a significant collaborative effort. A publication was deemed to have shown significant collaborative effort if it used replicable methods and multidisciplinary investigators to search for and critically appraise outcome measures, and the results were intended to help establish professional consensus, often through partnership with professional organizations.

KQ1b

For KQ1b, the search was narrowed to a list of basic medical service needs:

- Preventive dental care
- Preventive medical care (based on general recommendations of the U.S. Preventive Services Task Force)
- Urinary tract infections
- Pressure ulcers
- Uncontrolled diabetes
- Diabetes complications
- Bacterial pneumonia
- Asthma
- Gastroenteritis
- Hypertension
- Obesity

Eligible study designs include RCTs and prospective studies that evaluate the efficacy of a treatment or program for any of the basic service needs or secondary conditions. We did not include studies of incidence, prevalence, or risk factors. To address the concept of a person with a disability as a patient with a potentially complicating condition but otherwise a segment of the general population, we looked for studies that enrolled both disabled and nondisabled populations for general population outcomes and how the study accounted for the possible mediating or moderating effects of the presence of disability.

Search Strategy

Published Literature

We searched MEDLINE, PsychINFO, ERIC, and CIRRIE through March 27, 2012. Search terms were grouped to capture the major constructs: populations of interest, literature related to methodological research, and relevant service settings. Searches were modified for each individual database by reference medical librarians. Search algorithms are available in Appendix A. We hand searched reference lists of relevant high-quality literature reviews. We also hand searched “Disability and Health” a journal dedicated to publishing health-related articles for disabled populations. The literature captured by the search algorithms were exported to EndNote

software (Thomson Reuters, New York, NY) and screened by two independent reviewers using screening codes based on the inclusion/exclusion criteria. Conflicts were resolved by consensus with a third independent investigator.

KQ1a

We used key words and MeSH terms for disability populations. The results were cross searched with terms for measurement tool development.

KQs 1b and 1c

For subquestions 1b and 1c, we used the same key words and MeSH terms to perform individual searches for each basic medical service need and secondary condition, while filtering for experimental research.

We also conducted several ad hoc searches, due to difficulty finding relevant literature.

We cross-searched all the basic medical service needs by the MeSH term “ADL” to isolate literature in MEDLINE expected to show differentiation based on one common measure of disability severity.

We searched MEDLINE by MeSH terms for developmental/intellectual disabilities to isolate a specific disability population and cross-searched with terms for obesity, diabetes and congestive heart failure. The obesity search was restricted to year 2000 to current for manageable screening. Six articles for obesity met the inclusion criteria and were abstracted.

KQs 2 and 3

We used the MeSH terms for KQ1 to identify the populations. We cross searched results with the care coordination terms related to the various quality improvement strategies often used in care coordination.¹

Grey Literature

We searched the grey literature for monographs, white papers, and other high-quality sources of material on measurement tools using the New York Academy of Medicine Grey Literature Report, and Web sites such as the CDC Web site. Grey literature was limited to measurement tools that are in active use by important end users, such as health systems or tools with established psychometric properties. (See Appendix A for grey literature source details.)

Data Management, Extraction, and Synthesis

The included literature was maintained in an EndNote bibliography. Relevant data points related to population covered, descriptions and development of the measurement tool, type of quality improvement research for which the tool was used, and data sources, was abstracted to standardized Excel spreadsheets (Microsoft Corporation, Redmond, WA). An outcome measurement tool was described within only one article, unless multiple articles evaluated multiple outcomes with overlap. Only the outcome being tested was abstracted. Measures used in psychometric testing for validity were not abstracted. We used qualitative techniques to synthesize the literature. We used the ICF as an analytic framework where possible. However, classifying measures by matching items to the ICF checklist was beyond the scope of this review. We did not impose a single disability classification scheme but rather noted the disability classifications used in the literature.

Applicability

As noted above, we addressed, where the literature was available, the differences in the findings for various subgroups such as age or type of disability.

Peer Review, Public Commentary, and Technical Expert Panel

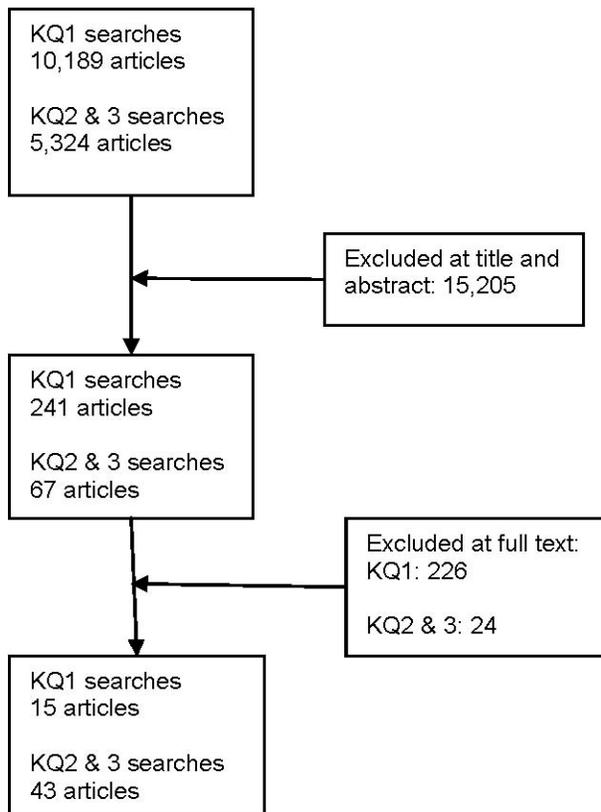
Experts in disability and rehabilitation research and policy, outcome and performance measurement, community based and personal care services, and healthcare quality and quality improvement fields and individuals representing stakeholder and user communities were invited to provide external peer review of this systematic report; AHRQ and an associate editor also provided comments. See the Acknowledgments section for a full listing of peer reviewers. The draft report was posted on the AHRQ Web site for 4 weeks to elicit public comment. Public comments were received from the American Academy of Physical Medicine and Rehabilitation, the American Physical Therapy Association, and the American Occupational Therapy Association. We addressed all reviewer comments, revising the text as appropriate, and documented everything in a disposition of comments report that will be made available 3 months after the Agency posts the final systematic review on the AHRQ Web site.

Results

Search Results

A total of 10,189 articles were identified with the search algorithms for Key Question 1 (KQ1) (Figure 5). Of these, 241 articles were pulled for full-text review and 15 were included in this review. For KQs 2 and 3, a total of 5,324 care coordination articles were identified, of which 43 were included.

Figure 5. Article flowchart



Abbreviation: KQ = Key Question

KQ1a. What general population outcomes have been validated on and/or adjusted to accommodate disabled populations?

The literature search identified a few major initiatives in development and assessments of outcomes and a number of individual studies. Without specific outcome measurement terms (such as the SF-36) or disease or disability conditions (such as spinal cord injury) to focus on, the search process was not sensitive or specific enough to qualify the search as exhaustive. At best, the search results can be considered a sample. However, they are indicative of early stages of outcome research development in fields that are undergoing considerable updating with the advent of the ICF.

In general, there are few direct examples of work from the perspective of disability as a complicating condition. The majority of the presented outcomes efforts generally stem from the

perspective of disability as the main condition of concern. We identified no articles that evaluated measures for the express purpose of care coordination or quality improvement. The outcome measures do not break down cleanly into disability etiologies, categories, or age groups.

Fifteen articles were included for KQ1a. Six articles critically reviewed available outcome measures for given populations and domains. Of these, five were part of a series of papers published in 2000 that used formal criteria to examine the state of outcomes research measurement in rehabilitation. Three studies evaluated the adaptation of general population measures for use in disability populations. Two studies were examples of disability-related outcome measures evaluated for expansion into another disability population (which suggests the possibility that the outcome measure may become more generic). Four articles reported the development of new measures. Table 4 gives a list of outcomes by article and ICF domain.

Table 4. Outcome measure list

Study Domain	Outcome Measure List
<i>Critical evaluations of available outcome measures for given populations and outcome domains</i>	
Resnik, 2009 ⁵⁸	Community Living Skills Scale (CLSS) (all 9 ICF chapters) ⁵⁹ Mayo Portland Adaptability Index (MPAI) version 4 (all 9 ICF chapters) ^{60,61}
Participation (9 ICF activities and participation domain chapters: Learning and applying knowledge; General tasks and demands; Communication; Mobility; Self-care; Domestic life; Interpersonal interactions and relationships; Major life areas; Community, social, and civic life)	Participation Measure for post acute care (all 9 ICF chapters) ⁶² Psychosocial Adjustment to Illness Scale (PAIS-SR) (all 9 ICF chapters) ⁶³ LIFE-H shortened V.3.1 (all 9 ICF chapters) ⁶⁴ Other outcome measures examined that did not map to all 9 chapters: Adelaide Activities Profile (AAP) ⁶⁵ Bybee Self Report Community Functioning Scale ⁶⁶ Craig Handicap Assessment Technique (CHART) ⁶⁷ Craig Handicap Assessment Technique Short Form (CHART-SF) ⁶⁷ Community Integration Questionnaire (CIQ) ⁶⁸ Community Integration Measure (CIM) ⁶⁹ Nottingham Extended Activities of Daily Living (EADL) ⁷⁰ Frenchay Activities Index (FAI) ⁷¹ Frontal Systems Behavioral Scale (FrSBe) ⁷² Functional Status Questionnaire (FSQ) ⁷³ Groningen Social Disabilities Schedule (GSDS-II) ⁷⁴ Groningen Questionnaire About Social Behaviors ⁷⁴ Impact on Participation and Autonomy Questionnaire (IPAQ) ⁷⁵ ICF Checklist ⁷⁶ The Life Functioning Questionnaire (LFQ) ⁷⁷ London Handicap Scale (LHS) ⁷⁸ Multnomah Community Ability Scale: Self Report (MCAS-SR) ⁷⁹ Post-Traumatic Stress Disorder (PTSD) Checklist Military ⁸⁰ Participation Objective Participation Subjective (POPS) ⁸¹ Participation Survey/Mobility (PARTS/M) ⁸² Perceived Impact of Problem Profile (PIPP) ⁸³ Quality of Life Scale (QOLS) ⁸⁴ Rivermead Head Injury Follow-up Questionnaire (RHFUQ) ⁸⁵ Reintegration to Normal Living Index (RNLI) ⁸⁶ Reintegration to Normal Living Index – Postal Version (RNLI-P) ⁸⁶ Social Functioning Questionnaire (SFQ) ⁸⁷ Social Functioning Scale (SFS) ⁸⁸ Sydney Psychosocial Reintegration Scale (SPRS) ⁸⁹ Subjective Index of Physical and Social Outcome (SIPSO) ⁹⁰ Work and Social Adjustment Scale (WSAS) ⁹¹ World Health Organization Disability Assessment Schedule (WHODAS) 12 item self-report ⁹² World Health Organization Disability Assessment Schedule (WHODAS) 36 item self-report ⁹²
Vahle, 2000 ⁹³	Brief Symptom Inventory (BSI) (tested in 4 disability groups) ⁹⁴ Center for Epidemiologic Studies Depression Scale (CES-D) (tested in 2 disability groups) ⁹⁵
Depression Symptoms	Zung Self-Rating Depression Scale (SDS) ⁹⁶ Beck Depression Inventory (BDI) ⁹⁷ Depression Adjective Check List (DACL) ⁹⁸ Talbieh Brief Distress Inventory and Medical-based Emotional Distress Scale (TBDI) ⁹⁹ Sickness Impact Profile (SIP) ¹⁰⁰ Medical Outcomes Study Short-Form Health Survey (SF-36) ¹⁰¹

Table 4. Outcome measure list (continued)

Study Domain	Outcome Measure List
Andresen, 2000 ¹⁰²	SF-36 (examples included testing in 15 disability groups) ¹⁰³ SIP (examples included testing in 9 disability groups) ¹⁰⁴
Generic HRQoL (mixed ICF domains)	Quality of Well-being Scale (QWB) (examples included testing in 8 disability groups) ¹⁰⁵ Nottingham Health Profile ¹⁰⁶ World Health Organization Quality of Life Survey (WHOQOL-100) ¹⁰⁷ QWB (preference based - QALY) ¹⁰⁵ Health Utility Index (preference based – QALY) ¹⁰⁸ EuroQual EQ-5D (preference based – QALY) ¹⁰⁹
Lollar, 2000 ¹¹⁰	Rand Health Status Measure for Children (HSMC) – Person, Society levels ¹¹¹ Functional Status II-R (FS II-R) – Person level ¹¹²
Children's Outcomes (assessed by ICF level)	Functional Independence Measure for Children (WeeFIM) – Body, Person levels ¹¹³ Pediatric Evaluation of Disability Inventory (PEDI) – Person, Society, Environmental levels ¹¹⁴ School Function Assessment (SFA) – Person, Society, Environmental levels ¹¹⁵ Child Health and Illness Profile – Adolescent Edition (CHIP-AE) – Person, Society levels ¹¹⁶ Child Health Questionnaire (CHQ) – Person, Society levels ¹¹⁷ Questionnaire for Identifying Children with Chronic Conditions (QUICCC) - Person, Society, Environmental levels ¹¹⁸ POSNA Pediatric Musculoskeletal Functional Health Questionnaire (POSNA) – Body, Person level ¹¹⁹ ABILITIES Index – Body, Person level ¹²⁰ Gross Motor Function Measure (GMFM) – Person level ¹²¹ Youth Quality of Life Instrument – Research Version (YQOL-S) - Person, Society, Environmental levels ¹²² Quality of Well-Being Scale (QWB) (measure may not be appropriate for children younger than 14) – Body, Person levels ¹²³
Dijkers, 2000 ¹²⁴	CHART long form (broad ICF coverage) ¹²⁵ CHART short form (broad ICF coverage) ¹²⁶
Social Outcomes (Participation)	CIQ (broad ICF coverage) ¹²⁷ Assessment of Life Habits (LIFE-H) (broad ICF coverage) ¹²⁸ LHS (broad ICF coverage) ¹²⁹ Other outcome measures examined deemed to lack broad ICF coverage: FAI ¹³⁰ WHOQOL ¹³¹ SF-36 ¹³² RNL ¹³³ GSDS-II ¹³⁴ Social Adjustment Scale Self-Report (SAS-SR) ¹³⁵ Katz Patient Adjustment Scale R2 ¹³⁵ AAP ¹³⁶ EADL ¹²⁹
Cohen, 2000 ¹³⁷	Katz ADLs Index ¹³⁸ Barthel Index ¹³⁹
Functional Status	Level of Rehabilitation Scale (LORS) ¹⁴⁰ Patient Evaluation and Conference System (PECS) ¹⁴¹ Functional Independence Measure (FIM) ¹⁴²
<i>Single studies evaluating general population measures for use in disability populations</i>	
Kalpakjian, 2005) ¹⁴³	Menopause Symptom List (MSL) ¹⁴⁴
Body function	
Burggraaff, 2010 ¹⁴⁵	Radner Reading Charts (RRC) ¹⁴⁶
Body function	
Nanda, 2003 ¹⁴⁷	Abbreviated Sickness Impact Profile (SIP68) ¹⁴⁸
Health status – multiple domains	

Table 4. Outcome measure list (continued)

Study Domain	Outcome Measure List
<i>Disability-related outcomes evaluated for expansion into another disability population</i>	
Bossaert, 2009 ¹⁴⁹	Supports Intensity Scale ¹⁵⁰
Environmental	
Bagley, 2010 ¹⁵¹	Activities Scale ASKp38 ¹⁵²
Activity and performance	
<i>New measures</i>	
Faull, 2007 ¹⁵³	QE Health Scale Holistic Health Measure
Multiple domains	
Alderman, 2011 ¹⁵⁴	St. Andrew's-Swansea Neurobehavioral Outcome Scale
Multiple domains	
Petry, 2009 ¹⁵⁵	QoL – Profound Multiple Disabilities
Multiple domains	
King, 2007 ¹⁵⁶	Children's Assessment of Participation and Enjoyment (CAPE)

Note: More detail on articles is provided in Tables 5, 8-10.

The discussion of the material included in KQ1a is given in several segments. First, we present literature that critically reviewed available outcomes for given populations and domains. Next, we present single studies evaluating general population measures for disability populations. We follow that with some examples of disability-related outcomes that were being evaluated for expansion into another disability population, which would suggest the possibility that the outcome measure may become more generic.

Articles That Critically Evaluated Multiple Outcome Measures

Six articles used formal criteria to assess multiple outcome measures for particular populations or broad outcome domains (See Table 5). Five articles are drawn from a series of papers published in 2000 from the Conference on the Science of Disability Outcome Research sponsored by the Center for Disease Control in 2000.^{93,102,110,124,137} The body of work documented a conceptual approach and provided criteria for evaluating the state of the science of rehabilitation outcomes research. The series evaluated outcome measures commonly used in rehabilitation research. Each paper focuses on a different category mapped to the ICF, which was known as the ICIDH at that time. The papers provide a considerable amount of detail on the psychometrics and appropriateness of the examined outcome measures. The majority of the measures were for adults or older adults across a spectrum of ICF domains. All the measures were generic, rather than condition-specific. One article addressed measurement issues for children with disabilities, noting that the environmental factors are crucial to children because of their dependence on family or other caregivers.¹¹⁰ The importance of a life-course perspective is also heightened because children's development process is pronounced and involves a larger array of domains, including behavioral, psychological, and social development.

The series of papers focused on disability as a primary condition, not a complicating condition. However, it was noted that while functional measures have often been used for program quality assessment, there is not adequate research to support the validity of the measures for such use.¹³⁷ Models for case-mix adjustment are also lacking.¹³⁷

A later paper examined a much larger set of outcomes measures for participation,⁵⁸ compared to the paper published in 2000, where the term social outcomes was used.¹²⁴ Both papers determined that five outcome measures comprehensively mapped to all nine chapters of the ICF. However, across the two sets of five there was only one overlapping measure, the Life-H.

While the article was not included in this review because it did not address a generic measure, Mortenson and colleagues¹⁵⁷ used the criteria established for the series on disability outcomes research³⁵ to assess wheelchair specific activity and participation outcome measures. The study provided a similar report card for six outcome measures.

A rehabilitation outcome database was developed through a collaboration between the Rehabilitation Institute of Chicago's Center for Rehabilitation Outcomes Research and Northwestern University Feinberg School of Medicine's Medical Social Sciences Informatics, and funded by the National Institute on Disability and Rehabilitation Research (www.rehabmeasures.org). The database was originally populated with measures for stroke and spinal cord injury patients. Traumatic brain injury outcome measures are currently being added. The database includes a range of generic general population measures to specific measures of body function and activity. ICF domains, but not specifics, are noted. Table 6 provides a selection of outcome measures from the database.

Table 5. Articles with critical assessments of outcome measures

Article	Domain	# of Measures Screened	# of Measures Evaluated	Criteria	Comments
Vahle, 2000 ⁹³	General Depression	7	2	Measurement characteristics; developmental testing of, and research using, measures	2 measures fully evaluated. Overlap of depression symptoms and physical impairments requires careful assessment of the tool.
Andresen, 2000 ¹⁰²	General Generic HRQoL	8	3	Measurement characteristics; developmental testing of, and research using, measures	3 measures fully evaluated. Despite relatively large research base, all require appropriate psychometric evaluation for specific populations. All 3 mingle impairment, function, and participation ICF domains.
Lollar, 2000 ¹¹⁰	Children 3 ICF levels, Environmental	13	13	Measurement characteristics; developmental testing of, and research using, measures	Children themselves are often not a part of the assessment process. Minimal measures for environmental issues.
Dijkers, 2000 ¹²⁴	Social Outcomes (adults)	16	5	Measurement characteristics; developmental testing of, and research using, measures	Outcomes include social adjustment, community integration, independent living, participation. Outcomes mapped to 9 ICF chapters.
Cohen, 2000 ¹³⁷	Generic Functional Status	5	5	Measurement characteristics; developmental testing of, and research using, measures	All measures need to be evaluated for appropriateness for the population. Barthel may have floor/ceiling effects, Katz using interview mode is not tested. Authors suggest FIM is least biased and highest in reliability, validity, and responsiveness, but ceiling effects for outpatients.
Resnik, 2009 ⁵⁸	Participation	40	34	Comprehensiveness – linked to all 9 ICF chapters	5 measures were comprehensive, but differed in specifics of coverage and approach.

Note: See Table 4 for more detail on specific measures screened and evaluated.

Table 6. Select measures from the rehabilitation outcome database^a

Outcome Measure (acronym, title)	Purpose	Area of Assessment	ICF Domain/ Domain	Assessment Type	Diagnosis/ Populations Tested	Age Range	Psychometrics SEM, MDC, MCID, Cutoff Score, Normative Data	Notes
CHART Craig Handicap Assessment and Reporting Technique	Based on ICDH to measure 6 domains. Assess how people function as active members of community	ADL; Behavior; Cognition; Coordination; Functional Mobility; Occupational Performance; Social Relationship; Social Support	Participation ADL	Patient reported	SPI, Stroke, TBI,	Adult, Elderly adult	Not established, Not established, Not established, NA, Yes	Ceiling effects for SCI; proxy rate more disabled. Most discrepancy for social integration
ABC Activities-Specific Balance Confidence Scale	measure confidence performing activities without falling	Balance, vestibular and non-vestibular; Functional Mobility	Activity Motor, ADL	Patient reported	MS, Stroke, Parkinsons, Vestibular disorders	18-65+	Yes (some), Yes (some), Not established, Yes, Yes	Possible ceiling effect above 80 score.
BI Barthel Index	Assess self-care ability; 10 ADL/mobility activities	ADL, Functional Mobility; Gait	Activity Motor, ADL	Performance	ABI, geriatrics, stroke	18-65+	Yes stroke, Yes stroke, Not established, Not established, Yes	
BDI-II Beck Depression Inventory	Quantifies depression severity	Depression	Body Function Emotion	Patient reported	Medical patients	13-64	Not established, Not established, Not established, Yes, Yes	Floor/ceiling not established. Self-report may be susceptible to context. Not tested for proxy. May yield high false positive rate in stroke patients.

Table 6. Select measures from the rehabilitation outcome database^a (continued)

Outcome Measure (acronym, title)	Purpose	Area of Assessment	ICF Domain/ Domain	Assessment Type	Diagnosis/ Populations Tested	Age Range	Psychometrics SEM, MDC, MCID, Cutoff Score, Normative Data	Notes
COPM Canadian Occupational Performance Measure	Assess perceived performance in self-care, productivity, and leisure	ADL, Functional Mobility; Life Participation; Occupational Performance	Participation ADL, Motor, General Health	patient reported outcomes	Designed for all populations	6-65+	Not established, Not established, Not established, Not established	Change of 2 points clinically significant. Interview process not standardized.
CES-D Center for Epidemiological Studies Depression Scale	Brief self-report on current depression symptoms	Depression	Activity Emotion	patient reported outcomes	General population, tested on multiple patient populations and ethnic context	13-65+	Not established, Not established, Not established, Yes, Yes	No indication of floor/ceiling. 6 and 4 item versions available.
CIQ-II Community Integration Questionnaire II	Assess social role limitations and community interaction	ADL, Life Participation	Participation	patient reported outcomes	23 conditions/ populations. Developmental, traumatic and disease-acquired, and aging	18-64	Not established, Not established, Not established, Not established, Yes	Some floor/ceiling effects may be present in sub-scales. Differences based on age, gender, education may be present.

^a<http://www.rehabmeasures.org/default.aspx>.

Specific disabling conditions are outside the scope of this review. However, an effort worth noting is underway to use the ICF framework to establish core sets for patients with specific chronic conditions. The process used may be informative to disability researchers as another example of a consensus process using formal criteria. Both comprehensive and brief sets for specific populations are being developed through a formal decisionmaking and consensus process that uses evidence and expert opinion.^{158,159} After the preparatory phase and the establishment of international consensus, the core sets will be tested and validated. Core sets are based on the ICF Checklist, a tool developed by WHO to generate patient profiles. Samples of patients of a particular population complete the checklist and frequency of responses is used to identify the most common problems for that population.¹⁶⁰ The core sets are intended to recommend data points for robust clinical records and to assist in outcome measure development. Core sets have been reported on for ankylosing spondylitis,¹⁶¹ breast cancer,¹⁶² depression,¹⁶³ osteoporosis,¹⁶⁴ chronic ischemic heart disease,¹⁶⁵ low back pain,¹⁵⁹ chronic widespread pain,¹⁶⁶ osteoarthritis,¹⁶⁷ stroke,¹⁶⁸ geriatric patients in early post-acute care rehabilitation,¹⁶⁹ obstructive pulmonary disease,¹⁷⁰ obesity,¹⁷¹ diabetes,¹⁷² and rheumatoid arthritis.¹⁷³ Similar efforts (though not necessarily specifically aimed at disabled populations) to establish common data elements to standardize data collection and comparability across studies have been underway in multiple federal agencies, such as the NIH, Veterans Administration, and Department of Defense's¹⁷⁴ collaboration on research in psychology and traumatic brain injury.

Another relevant example of consensus development is found in the work of Hillier and colleagues.¹⁷⁵ A compendium of rehabilitation outcome measures for community settings was developed through a participatory process to address fragmented outcome measurement use. With the ICF as the conceptual framework, a preliminary set of approximately 300 outcome measures were examined for acceptable criteria, including psychometric properties. Consultation between the project's steering committee and stakeholders, including clinicians, researchers, and managers/policymakers, eventually led to a revised set of 28 outcome measures covering all ICF domains. The compendium is reproduced in Table 7.

Table 7. Example of a compendium

ICF Domain	Outcome Measure
QoL	WHQoL-BREF ¹⁷⁶
Activity	Frenchay Activities Measure) ^{71,130}
Environmental factors	Home and Community Environment Instrument (HACE) ¹⁷⁷
Body structure function:	
Cognitive	Rivermead Behavioral Memory Test ¹⁷⁸
Psychological	Short Orientation-Memory-Concentration Test ¹⁷⁹
Neuromuscular	Geriatric Depression Scale ¹⁸⁰ Manual Muscle Testing ¹⁸¹ Tardieu Scale ¹⁸² Wolf Motor Function Test ¹⁸³ Grip Strength ¹⁸⁴
Activities	
Balance & falls	Step Test ¹⁸⁵ Activities specific Balance Confidence Scale ¹⁸⁶ Postural Assessment Scale for Stroke ¹⁸⁷
Mobility/gait	Timed Up and Go Test ¹⁸⁸ Motor Assessment Scale (mod) ¹⁸⁹ Six minute walk test ¹⁹⁰
Upper limb	Chedoke Arm & Hand Activity Inventory ¹⁹¹ Hand Active Sensation Test ¹⁹² Nine Hole Peg Test ¹⁹³
Communication & Swallowing	Frenchay Dysarthria Assessment ¹⁹⁴ Western Aphasia Battery ¹⁹⁵ Voice Handicap Index ¹⁹⁶ RBH Outcome Measure for Swallowing ¹⁹⁷
Personal factors	
Coping	Coping Strategy Indicator ¹⁹⁸
Behavior and affect	Neuropsychology Behavior and Affect Profile in Stroke Patient ¹⁹⁹
Activity and/or participation	
Goals	Canadian Occupational Performance Measure ²⁰⁰ Goal Attainment ²⁰¹
HRQoL	Assessment of QoL ²⁰²

Note: Hillier S, Comans T, Sutton M, et al. Development of a participatory process to address fragmented application of outcome measurement for rehabilitation in community settings. *Disability & Rehabilitation* 2010; 32(6):511-20.¹⁷⁵

General Population Outcomes Assessed for Disability by a Single Study

Three articles assessed single general population standardized tools for specific disabled populations. All were for acquired disabilities; polio-surviving women of menopausal age,¹⁴³ elderly patients with low vision,¹⁴⁵ and a mixed adult population with generally disease-acquired, or aging into disability¹⁴⁷ (Table 8).

Table 8. General population outcome measures assessed for disabled populations—single studies

Outcome (acronym, title)	Purpose	ICF Domain	Assessment Type	Populations Tested Age Range	Comments
MSL Menopause Symptom List (Kalpakjian, 2005) ¹⁴³ U.S.	Assess symptoms related to menopause	NA (body function)	Patient reported	Polio Acquired - disease 40-65	Factor analysis suggests underlying factor structure differs for women with disabilities. Possible ceiling effect for sleep disturbance. Post-polio sequelae may obscure classic menopause symptoms.
RRC Radner Reading Charts (Burggraaff, 2010) ¹⁴⁵ Netherlands	Measure reading performance	body function	Observer	Low-vision (Glaucoma, Maculopathy, Cataract, Diabetic retinopathy, Corneal disorders) Aging Mean 80.5	Fluctuating results leads to moderate reproducibility; best to create optimal reading conditions. High reliability.
SIP68 Abbreviated Sickness Impact Profile (Nanda, 2003) ¹⁴⁷ U.S.	Generic health status	Mixed	Patient reported	Multiple conditions Acquired – disease/Aging Mean 53.8	Authors conclude the instrument is promising but requires more research

The literature also provided some examples of outcomes measures created for disability populations. These were either extended to encompass more disability conditions (Table 9), or altogether new outcome measures for a disability population (Table 10).

Table 9. Disability-specific outcome measures assessed for extended disabled populations—single studies

Outcome (acronym, title)	Purpose	Factors	Assessment Type	Populations Tested Age Range	Comments
SIS Supports Intensity Scale (Bossaert, 2009) ¹⁴⁹ Netherlands	Assess support needs of people with disabilities	Personal and social skills; Community living activities, Activities of daily life, Work	Patient reported	ID/DD, extended to mixed 20-86 years	Factor analysis confirmed 5, rather than 6 factors and a shortened version, SIS-NID.
ASKp38 Activities Scale for Kids – performance (Bagley, 2010) ¹⁵¹ US	Assess frequency of performance of childhood activities	Activities of daily life, play	Patient reported	Extended to DD/trauma 6-20 years	Factor analysis confirmed 2, rather than 1 factor.

Table 10. Examples of new outcome measures—single studies

Outcome (acronym, title)	Purpose	Factors	Assessment Type	Populations Tested Age Range	Comments
QEHS QE Health Scale (Faul, 2007) ¹⁵³ New Zealand	Holistic health measure, includes spirituality	One principle component	Patient reported	Physical disabilities Mean 58.33	28 items Clinically valid, with satisfactory reliability and validity
SASNOS (Alderman, 2011) ¹⁵⁴ UK	Assess neurobehavioral disability	Interpersonal behavior; Cognition; Aggression; Inhibition; Communication	Observer	Acquired brain injury Mean 34	49 items Discriminant/diagnostic validity excellent, good reliability
QOL-PMD QOL Profound Multiple Disabilities (Petry, 2009) ¹⁵⁵ Netherlands	Assess quality of life for people with profound multiple disabilities	Physical well-being, Material well-being, Communication & influence, Social well-being, Development, Activities, Total score	“Informants”	Mixed 5-57 years	Medical condition most strongly correlated with scores. Setting and staffing level had significant effect on scores.
CAPE Children’s Assessment of Participation and Enjoyment (King, 2007) ¹⁵⁶	Measures participation in recreation and leisure activities	Recreation, Active physical, social, skill based, and self-improvement activity.	Interviewer	Children (6-18 years) with and without physical disabilities	Companion measure is Preferences for Activities of Children (PAC)

KQ1b. What types of modifiers or case-mix adjusters have been used with the general population outcomes to recognize the special circumstances of people with disabilities?

We found no eligible studies of basic medical needs and secondary conditions that examined a mixed population of disabled and nondisabled participants.

One systematic review was tangentially related. This review on the effect of exercise interventions as a preventive measure on subjective quality of life for both clinical and healthy conditions.²⁰³ None of the 56 included studies used a mixed population. Studies were examined by intervention purpose: prevention/health promotion, rehabilitation, and disease management. Patients engaged in exercise for rehabilitation from a health event included cancer, CVD, musculoskeletal, neurological, pulmonary, and renal diseases. Patients engaged for chronic disease management included the same disease set plus rheumatoid arthritis and fibromyalgia. While disease severity was collected (mild, moderate, severe, chronic stable, frail, end stage), the review did not use the variable in the analysis. Quality of life measures included FACT, SF-36, HRQoL visual analog, SIP, WHOQOL, POMS, QWB, EuroQoL EQ-5D, among others.

Another tangentially related study addressed associations between the presence of chronic medical needs (chronic diagnoses) and perceived lack of accessibility features in the home according to ADL and IADL stage in a mixed population of disabled and nondisabled elderly people living in the community.^{204,205} These ICF-based stages define five strata for ADL and IADL (measuring the self care and domestic life chapters). Stage 0 includes people without disabilities and stages I, II, III, and IV represent increasing disability.

KQ1c. What are key parameters for measuring processes related to basic service care access for people with disabilities?

We did not find any eligible studies of basic medical needs and secondary conditions to address this question. It is possible that the specific literature scope limits, particularly limited to an illustrative set of medical service needs, rather than broader medical coverage, reduced our ability to locate such literature. (See KQs 2 and 3 for more results on care coordination process measures.)

KQs 2 and 3. What measures have been used to assess effectiveness of care for people with disabilities living in the community in the context of coordination among health providers, or between community organizations and health providers?

Of the 45 included articles, representing 44 studies, 7 were RCTs, 9 were prospective observational designs, 3 were retrospective observational designs, 12 were before/after studies, 6 were systematic reviews/guideline studies, and 7 used survey methodology. (Table 11) A detailed list of care coordination articles is shown in Appendix B.

Table 11. Number of studies by target group and age category

Target Group	Children (0-18)	Youth in Transition*	Adults (18-65)	Elderly (65+)	Mixed	Grand Total
Children – developmental	2					2
Children - acquired	2					2
Children - mixed	16	1				17
Chronic elderly				5	4	9
Frail elderly				7		7
Immobile + transition from inpatient					1	1
Medicaid + Disabled			3		2	5
Medicare + Disabled + Heavy users				1		1
Grand Total	20	1	3	13	7	44

*Youth in Transition means youth who are being prepared to transition from youth to adult services.

Of the 44 included articles, 34 addressed interventions which included elements of both coordination among providers and coordination between providers and families or social services. This makes it difficult to address KQs 2 and 3 separately. The discussion below is organized into three sections: interventions mainly focused on coordination among providers, interventions mainly focused on coordination between providers and families or social services, and interventions that included elements of both.

Coordination Among Providers

Two studies of the effects of coordination focused on programs primarily coordinating among providers.^{206,207} One of these programs was a coordinated followup of infants with prenatally diagnosed giant omphaloceles;²⁰⁶ the other was the PACE program targeting frail, chronically ill older adults with the goal of keeping them in the community as long as possible.²⁰⁷

Danzer et al. used the Bayley Scales of Infant Development, which measures neurodevelopment in infants as their primary outcome measure.²⁰⁶ The very small sample size (n=31) and homogeneity of their sample meant that no outcomes were presented by independent variables (e.g., severity of omphalocele—all children studied had the worst category—giant omphalocele).

Temkin-Greener, et al. used change in functional status as their outcome measure; this was operationalized as a change in the number of ADL dependencies found during periodic assessments (at least every 6 months for 3 years).²⁰⁷ This outcome was not reported by any person-level variables, although characteristics such as disease state (a series of binary variables indicating the presence of diseases including arthritis, CHF, dementia, COPD, renal failure, etc.), lagged number of IADLs, bladder and bowel incontinence, and impairment in vision, hearing, communication, or cognition were included in the regressions to “risk adjust” the coefficient estimates.

This study also measured several health care use “outcomes” that were not used as outcomes per se. In addition to the primary outcome variable of functional status, several measures of service use were also modeled, including short-term nursing home stays, hospitalizations, day center attendance, etc. The propensity of each of the studied sites to provide those services was then used to model change in functional status for the key analysis of the study.

Coordination Between Providers and Family/Social

Nine studies focused on programs primarily concerned with coordination between providers and families, caregivers, social services, etc.²⁰⁸⁻²¹⁶ Of these, seven served children or young adults (under age 21), one served stroke survivors,²⁰⁹ and one served frail older adults.²¹¹

Of the child-focused studies, three focused on children or young adults with physical disabilities (one of these was a systematic review).²¹⁴⁻²¹⁶ and two looked at interventions for children with traumatic brain injury.^{210,213} One study addressed the broad category of children with special healthcare needs.²¹² One study was focused quite narrowly on children with dysfunctional elimination syndrome.²⁰⁸

Outcomes

The studies of children with TBI focused on functional outcomes related to the children's behavior (Table 12). Several scales were used: The Neurodevelopmental Inventory, Behavior Rating Inventory of Executive Functions (BRIEF), Behavior Assessment System for Children (BASC), Eyberg Child Behavior Inventory (ECBI). The systematic review of early interventions for children with physical disabilities also reported assessments of behavior, including parent's rating of the child's interactions with preschool peers and a structured questionnaire on peer acceptance.

Some children's studies reported goal development and attainment as outcomes of the intervention.²¹⁴⁻²¹⁶

Process Measures

Perhaps because care coordination programs are largely still quite new, the literature focused primarily on the initial implementation of interventions rather than the assessment of the quality of the implementation. That is, no measures were found that assessed changes in process measures of quality over time.

Process measures were sometimes included as proxy outcomes. Participant adherence to treatment,²⁰⁹ frequency of contacts with physicians,²¹² school adherence to child's treatment plan,²⁰⁸ and the Measure of Processes of Care scale (MPOC)²¹⁶ are examples of these process measures.

The two studies of adults/elderly people used standard clinical scales to assess health and health-related QOL: SF-36, Geriatric Depression Scale, APACHE III, SF-8, OASIS. This kind of scale was not generally used in the studies of interventions for children. The study of children with DES did, however, use a standard clinical measure for incontinence: number of wet days per month.²⁰⁸

Table 12. Number of measures (articles) by age category for care coordination between provider and family/social

Measure Type	Children	Elderly	Mix	Grand Total
Access	1 (1)			1 (1)
Caregiver	2 (1)			2 (1)
Cost and Use		1 (1)		1 (1)
Goals	5 (3)			5 (3)
Health and Function	9 (4)	4 (1)	2 (1)	15 (6)
Process	7 (5)		2 (1)	9 (6)
Satisfaction	4 (3)			4 (3)
Grand Total	28	5	4	37

Coordination Among Providers and Between Providers and Family/Social Services

Of the 34 articles that addressed both types of care coordination, 27 were studies, 2 were expert guidelines, 4 were literature reviews, and 1 was a description of a program.

Children represented the most frequently addressed population, with 13 articles. The elderly were addressed in 11 articles. Seven articles looked at a mix of ages (though for some of these studies the vast majority of participants were elderly). Adults (roughly ages 21 to 65) were addressed in three of the articles.

A total of 109 measurements were abstracted from these 34 articles (Table 13). A detailed list of measures used in the care coordination articles is in Appendix B. The two most frequently measured domains were cost/use (25 measures from 15 articles) and health/function (22 measures from 12 articles). Examples of frequently seen cost and use measures are number of emergency room visits, hospital length of stay, total costs of care, and frequency or number of interventions. Examples of frequently seen health and function measures include count of ADLs/IADLs, number of school absences, SF-36 or SF-8, incidence of secondary conditions, and survival without institutionalization.

Measurements of caregiver concerns were measured only in articles on children and the elderly. There were four articles each on children and the elderly that included these measures (a total of 15 measures). Examples include scales assessing caregiver burden and measures of caregiver satisfaction with care.

Only articles on children included measures of access to care (generally self-reported issues with access, but also including constructed items from the CSHCN survey creating a binary “access to medical home” measure). There were nine such measures from five studies.

Only articles on the elderly included measures of self-efficacy. Two studies measured this domain.

Thirteen articles included measures of satisfaction or experience of care. Two of these used the PACIC (Patient Assessment of Care for Chronic Conditions), and two used items from the CAHPS (consumer assessment of healthcare providers and systems) questionnaire.

Table 13. Number of measures (articles) by age category for care coordination among providers or between provider and family/social

Measure Type	Children	Youth in Transition*	Adults	Elderly	Mix	Grand Total
Access	9 (5)					9 (5)
Provider				1 (1)		1 (1)
Caregiver	8 (4)			8 (5)		16 (9)
Cost and use	7 (7)		5 (1)	5 (4)	11 (4)	28 (16)
Health and function	4 (4)		3 (1)	14 (6)	3 (2)	24 (13)
Process	5 (1)		1 (1)	2 (2)	1 (1)	9 (5)
Satisfaction	4 (1)		2 (1)	7 (7)		13 (9)
Self-efficacy				2 (2)		2 (2)
Qualitative feedback					1(1)	1 (1)
Guideline	6 (1)					6 (1)
Grand Total	43		11	39	16	109

*Youth in Transition means youth who are being prepared to transition from youth to adult services.

Care coordination is one component of quality. Within quality improvement, an important effort to develop and report a standard set of performance measures is the National Core Indicators (NCI).²¹⁷ The NCI is a collaborative effort between the National Association of State

Directors of Developmental Disabilities Services (NASDDDS), the Human Services Research Institute (HSRI), and participating states (currently 28 states). The goal of the collaboration was to develop a core set of measures that states use to manage quality of developmental disability services, and to allow between-state comparisons. The NCI includes outcomes related to health, wellness, and medications, among other consumer and family outcomes and system performance outcomes. While the scope of the NCI is larger than this review covers, the full set of outcomes is reproduced in Table 14. The domains and items provide insight into how quality indicators may be conceptualized and suggest potential areas of cross-fertilization between professions and disciplines.

Table 14. National core indicators (NCI) domains and items^a

Subdomains	Items
Community Inclusion	(in the past month, unless noted) Go shopping Go out on errands or appointments Go out for entertainment Go to religious services Go out for exercise Go on vacation (in past year)
Choice and Decisionmaking	(did you choose) The place where you live (if not family) The people you live with (if not family) The staff who help at home Your work or day activity The staff who help at work or day activity The case manager/service coordinator The daily schedule How to spend your free time What to buy with your spending money
Relationships	(proportion of people) Have friends and caring relationships with people other than support staff and family members Have a close friend, someone you can talk to about personal things Are able to see your (a) families and (b) friends whenever they want. Feel lonely Go on a date if you want to You get to help others
Satisfaction	(proportion of people) Satisfied with where you live Like to live somewhere else Satisfied with your job Have a community job but would like to work somewhere else Satisfied with your day program or other daily activity Go to a day program or activity but would like to go somewhere else or do something else during the day
Service Coordination	(proportion of people) Have met your service coordinator Your service coordinator asks you what you want Your service coordinator helps you get what you want Your service coordinator calls you back right away You helped make your service plan
Access	(proportion of people) Have adequate transportation when you want to go somewhere Use different types of transportation Get the services you need Your staff has adequate training

Table 14. National core indicators (NCI) domains and items^a (continued)

Subdomains	Items
Health, Welfare, and Rights	
Safety	(proportion of people who report) Never feel scared or afraid in their home, neighborhood, workplace, and day program/daily activity Have someone to go to for help when they feel afraid
Health	(proportion of people) Had a complete annual physical exam in past year Had a Pap test in the past 3 years (women 18+ years) Had a routine dental exam in the past year Have poor health Have a primary care doctor Had a vision screening in the past year Had a hearing test within the past 5 years Had a flu vaccination in the past year Ever had a vaccination for pneumonia Had a mammogram within the past 2 years (women 40+) Had a PSA test within the past year (Men 50+) Had a screening for colorectal cancer within the past year (50+)
Wellness	(proportion who maintain unhealthy habits) Smoking Weight Exercise
Medications	(proportion of people) Take medication for mood disorders, anxiety, behavior problems, or psychotic disorders
Respect/Rights	(proportion of people) Basic rights are not respected by others, including (a) having one's mail opened without permission, (b) having restrictions on being alone with others, (c) having restrictions on using the phone/internet, and having people enter their (d) home and (e) bedroom without permission Have participated in a self-advocacy group meeting, conference, or event Report satisfaction with the amount of privacy Most (a) day, (b) work, and (c) home support staff treat them with respect
Self-Determination	(proportion of people self-directing) Currently using a self-directed supports option Who employ their own support workers or use "agency of choice" Someone talked with them about individual budget/services Who have help in deciding how to use the budget/services Who report they can make changes to their budget/services if they need to Who report they get enough help in deciding how to use the budget/services Who receive enough information about their budget/services that is easy to understand Whose support workers come when they are supposed to Who get the help they need to work out problems with the support workers
Work	Average bi-weekly earnings of people who have jobs in the community Average number of hours worked bi-weekly Percent earning at or above the state minimum wages Percent who were continuously employed during previous year Percent who receive vacation and/or sick time benefits Average length of time they have been working at their current job Percent who work in each type of job Proportion of people who have a goal of integrated employment in their individualized service plan Proportion who have a job in the community Proportion who do not have a job in the community but would like to have one Proportion who go to a day program or have some other daily activity Proportion who do volunteer work

^awww.nationalcoreindicators.org

Discussion

This review examined outcome measures used in analyses that focused on specific interventions directed at a given medical problem, or comprehensive programs designed to integrate medical and social services for people with disabilities. Despite an abundance of outcome measures and some early efforts in care coordination and related outcome and performance assessment, research on a specific medical problem that incorporates disability as a complicating condition is lacking.

Our review found several examples of efforts to critically assess outcome measures for various disabled populations. Formal outcome measure assessment criteria³⁵ can be leveraged and modified by researchers interested in extending the work to new populations. The criteria used by Andresen and colleagues to evaluate some of the measurement tools reported in the results are one example of a useful approach.³⁵ Table 15 details their criteria. We would add impairments or the population(s) for which the outcome is relevant, and the level of measurement (person versus population level).

Table 15. Criteria to evaluate measurement tools for disability outcomes

Criterion	Application to Disability
Conceptual basis	Reflects ICF dynamic model of impairment and environment impacting participation
Norms	Includes standard comparative data from people with disabilities
Measurement model	Appropriate model: does not evidence severe ceiling/floor effects
Item/instrument bias	Data support lack of bias for people with disabilities
Burden	Brief, easy to administer, acceptable to people with disabilities
Reliability	Consistency of response, particularly when proxies are used
Validity	Adequate convergent/discriminant validity for people with disabilities
Responsiveness	Sensitive to meaningful change over time for people with disabilities
Accessible forms	Alternative administration ways show no mode effects for people with disabilities
Cultural adaptations	Adequate testing in subgroups: validated alternative language formats available

Abbreviation: ICF = International Classification of Functioning, Disability, and Health

Replicable processes do exist for participatory, collaborative methods for developing consensus around core outcome measurement sets. For example, one process that engaged a broad range of stakeholders was Hillier and colleagues' effort to address fragmented use of outcome measures across rehabilitation in community settings.¹⁷⁵

The review generated a lengthy list of outcome measures useful to research and quality improvement that researchers may wish to apply to specific endeavors, including care coordination. Current efforts offer the potential for cross-fertilization. Further, the important questions and appropriate outcomes have potential for overlap with different disability groups. For example, the NCI contains domains and items that could assess quality in long-term care for older adults, whether home-based or institutional. While the level of detail necessary for a researcher to successfully choose and use the measures was beyond the scope of this report, the cited sources provide a starting point. However, much could be gained from developing a core set of outcome measures, as discussed below.

Research Issues and Gaps

Our review demonstrates how much disability and quality improvement could benefit from organized databases of critically assessed outcome measures. While the review provides

examples of critical assessments and inroads into measurement tool databases, much work remains for establishing adequate banks of measures. This is easier said than done.

Disability status can affect the choice of a measure in terms of the spectrum of the targeted outcomes probed. With any outcome assessment, it is critical to use a measure sensitive to the range of possible effects. And just as with function in general, many methods can be used to assess the same underlying problem. Each measure has its own performance characteristics, making it hard to aggregate the already sparse data on how treatments vary across people with different disabilities. Further knowledge synthesis in this area will require greater consensus around which outcomes measures should form the core of all studies. In order to develop practical outcome measures that allow for comparisons across populations, a balance must be struck between granular measurements for specific groups and summary or generic measures for cross-group comparisons. Ultimately, specific group measures and summary or generic measures both serve important purposes.

Professional differences further exacerbate the variation in measurements. Different professions adopt standards for measuring the same underlying construct. In some cases, the differences are a matter of scale, driven by different goals. For example, a geriatrician might use a simple ADL that taps six domains, including dressing. The metric would range from “independent” to “doing the task with complete assistance.” Intermediate steps (such as supervision, cueing, and partial assistance) might also be included. By contrast, an occupational therapist would likely break down the task into 26 steps (e.g. selecting the clothing, putting it on, fastening the closures, etc.). Primary concerns might be speed and level of performance (e.g., are the clothes neat, is the choice appropriate).

The measurement tools we uncovered in this review are addressed at patient-centered and intermediate outcomes typically distinguished by systematic reviews. Access issues are a separate measurement concern. Access may be a matter of adequate transportation to medical care, or of navigating the medical care environment (e.g., getting on the table or into position for an x-ray), or of finding a medical practitioner who is comfortable and knowledgeable about treating the disease in someone with a disability. Organized databases should not undervalue access measures.

Patient reported outcomes, if used thoughtfully and judiciously, are promising for future research. In addition to improving the ability to aggregate data across studies, use of select patient reported outcomes within core outcomes sets may improve researchers’ ability to follow patients over time. When paired with improved measurement tool and fielding techniques, such as computer adapted testing methods, measurements may avoid some of the ceiling and floor effects problems mentioned earlier. However, patient reported outcomes have well-documented issues such as the subjectivity of the measures and the difficulty of establishing change values that represent meaningful differences for different patient populations.

A similar bank of measures would move the disability research field forward in assessing quality of care and care coordination as well. One framework for measures for coordinated care for people with Medicaid Managed Care suggests the following categories:⁴

- Patient experience
- Family experience
- Family caregiving burden
- Provider experience
- Functional status, independence, and community participation
- Health status

- Prevention of secondary conditions

To these, we would add measures to evaluate fidelity to the care coordination process and measures that capture access to quality care. The care coordination measure bank needs to be sensitive to care transition concerns and to the care complexity of people with disabilities. Measurement of transitions between medical services and social services is crucial. Likewise, transitions between medical service lines cannot comfortably rely on evidence based guidelines that are applicable to patients who lack such complexity.

We found very few direct examples of research conducted on specific interventions for medical needs not directly related to a disability from the perspective of disability as a complicating condition. At the very minimum, disability should (along with other chronic illnesses) be among the covariates examined for individual level outcomes. Disability should also be considered as a component of case mix when examining populations.

The lack of research may also indicate a lack of awareness or unintentional systematic bias against examining disability as a complicating condition, rather than the condition of interest itself. We view this as a legacy of an outdated separate but equal stance towards disabled populations. Alternatively, some disability researchers may disagree with such a formulation as being overly medicalized, and there are instances where such a view does provide a caution against other pervasive, unidentified biases.

A researcher's own views about whether disease is a complicating factor for the underlying disability (or vice versa) will influence how outcomes are determined for specific research questions. For example, will an infection exacerbate multiple sclerosis or make it more difficult to manage cerebral palsy? Conversely, does treating pneumonia differ according to whether someone has mobility limitations or not? Or does treating a urinary infection in a person with quadriplegia differ from treating the same condition in someone without a disability? Some responses to disability may be akin to ageism. We talk about people developing the problems of aging prematurely, as if they were actually the problems of aging itself, when in fact these problems result from disease. Separating the etiology of a problem into normal aging or pathology is already difficult. How much more complicated is it, then, to classify the same problem in a person with an underlying disability?

Researchers may be inadvertently contributing to a problem persistently faced by people with disabilities who simultaneously experience disparities in healthcare services and greater healthcare needs.^{218,219} Researchers contribute to this disparity by using research designs and practices that systematically exclude people with disabilities or incompletely capture the outcomes they value. The context and environment within which researchers work further adds to this problem. As Meyer and Andresen state, researchers design research in ways that exclude people with disabilities because researchers themselves also have constraints.³⁴

Ultimately, thoughtful consideration of the unintentional impact of research activities is the important message. Consulting with people with disabilities as partners in the research process is a good first step.

The continuing presence of research "silos" remains a concern. Multidisciplinary research and coordination or efforts across researchers who focus on the medical interventions who strive to cure, on rehabilitation to restore function, and on supportive services for disabilities is crucial. Little has changed in the decade since Andresen and colleagues published the supplemental issue on disability outcomes research, as evidenced by the ongoing lack of literature.

The most important goal might be to ensure collaborative efforts in disability outcome research and evaluation across the spectrum of research disciplines and approaches. Calls to action have been made by professionals who have dedicated their careers to disability-related research.²¹⁸ Based on the evidence reviewed, we suggest a few avenues for action. Federal agencies can continue their current efforts to support full inclusion of disabled populations in research by hosting consensus conferences. Such conferences would gather researchers and stakeholders from broad medical fields as well as from disability research communities to explore measurement and research design issues that encourage inclusion and examination of disability as covariate and case mix. Professional organizations can encourage and organize joint interdisciplinary conferences to probe divergent views and explore areas of overlap that might lead to fruitful research, striving to expand beyond organizations that are professionally or paradigmatically close neighbors. Funders could engage stakeholders to identify priority areas of quality improvement, particularly related to basic medical services and prevention of secondary conditions for people with disabilities. For a given priority area, stakeholders could identify, for example, all the linkages along a path of care coordination and request proposals that include multidisciplinary teams that represent the linkages. In response, policymakers would need to examine the explicit and implicit incentive structures for removing barriers that could prevent wide dissemination of the findings from such studies.

The broad scope of the review was a useful endeavor because its findings, in particular the lack of published material for disability as a complicating condition, underscored the need for coordination and collaboration among the three overarching approaches to studying outcomes—medical, rehabilitative, and supportive services. However, the broad sweep also made it difficult to adequately drill down into the literature. Future efforts will likely need to go about “eating the elephant” differently. Outcomes for quality medical care for people with disabilities (whether it targets disabling condition or treats the disability as complicating condition) is a vast topic. The trick will be to strike a proper balance: Scopes must be constrained enough for successful search processes and broad enough for examining similarities and differences in outcome measures. Successful searches will need to be constrained along at least one dimension, for example, subpopulation, outcome domain, or outcome level. Developing further knowledge around populations and outcomes will make it more feasible to map the areas of overlap among the three theoretical approaches, and to identify areas specific to one theoretical approach.

Limitations

The major limitation of this work is the lack of sensitivity and specificity of the search algorithms. This resulted from the project scope, as well as from the difficulty in creating key word search terms that adequately capture care coordination and outcome assessment. The literature search was extensive, with carefully designed search algorithms, numerous citations reviewed, and a reasonable coverage of the literature within the scope of the review. However, due to the limitations of search algorithms for diffused literature that necessarily rely on natural language terms rather than MeSH terms, the articles cited should be viewed as a sample of a small and dispersed literature. As stated above, the planned breadth of the review contributed to the search strategy difficulties. Each of the key questions is likely partially answerable if narrower, more focused searches are undertaken in future reviews.

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Acronyms and Abbreviations

AAP	Adelaide Activities Profile
ADL	Activities of daily living
AHRQ	Agency for Healthcare Research and Quality
BDI	Beck Depression Inventory
CAHPS	Consumer Assessment of Healthcare Providers and Systems
CDC	Centers for Disease Control
BASC	Behavior Assessment System for Children
BRIEF	Behavior Rating Inventory of Executive Functions
CES-D	Center for Epidemiologic Studies—Depression Scale
CHIP-AE	Child Health and Illness Profile—Adolescent Edition
CHQ	Child Health Questionnaire
CIQ	Community Integration Questionnaire
CQG Series	Closing the Quality Gap Series
CVD	Cardiovascular disease
DACL	Depression Adjective Check List
DALY	Disability-Adjusted Life Years
EADL	Extended Activities of Daily Living Scale
ECBI	Eyberg Child Behavior Inventory
EPC	Evidence-based Practice Center
EQ-5D	EuroQol 5 dimensions
ER	Emergency room
ES	Executive summary
FACT	Functional Assessment of Cancer Therapy
FAI	Frenchay Activities Questionnaire
FIM	Functional Independence Measure
FS II-R	Functional Status II-R
GMFM	Gross Motor Function Measure
GSDS-II	Groningen Social Disabilities Schedule
Hb	Hemoglobin
HEI	Health Environmental Integration
HMSC	Rand Health Status Measure for Children
HRQOL	Health-Related Quality of Life
HSRI	Human Services Research Institute
IADL	Instrumental Activities of Daily Living
ICD	International Classification of Diseases
ICF	International Classification of Functioning, Disability, and Health
ICIDH	International Classification of Impairments, Disabilities, and Handicaps
IL	Independent living
IoM	Institute of Medicine
Katz R2	Katz Patient Adjustment Scale R2
KQ	Key Question
LHS	London Handicap Scale
LIFE-H	Assessment of Life Habits
MeSH	Medical subject headings

MOS	Medical Outcomes Study
MPAI	Mayo-Portland Adaptability Inventory
MPOC	Measure of Process of Care
MSL	Menopause Symptom List
NASDDDS	National Association of State Directors of Developmental Disabilities Services
NIH	National Institutes of Health
NCI	National Core Indicators
Nottingham	Nottingham Extended Activities of Daily Living
PACIC	Patient Assessment of Care for Chronic Conditions
PAIS-SR	Psychological Adjustment to Illness Scale—Self Report
PEDI	Pediatric Evaluation of Disability Inventory
POMS	Profile of Mood States
POSNA	POSNA Pediatric Musculoskeletal Functional Health Questionnaire
PROMIS	Patient-Reported Outcome Measurement Information System
QALY	Quality-adjusted life year
QoL	Quality of life
QUICCC	Questionnaire for Identifying Children with Chronic Conditions
QWB	Quality of Well-Being Scale
RCT	Randomized controlled trial
RRC	Radner Reading Charts
SAS-SR	Social Adjustment Scale—Self Report
SDS	Zung Elf-rating Depression Scale
SF-36	Medical outcomes short-form health survey
SFA	School Function Assessment
SIP	Abbreviated Sickness Impact Profile
SMI	Severe and persistent mental illness
TBI	Traumatic brain injury
TEP	Technical Expert Panel
WHOQOL	World Health Organization Quality of Life Scale
YQOL-S	Youth Quality of Life Instrument

Appendix A. Search Sources and Algorithms

Key Question 1

Medline

- 1 exp Disabled Persons/
- 2 exp mental disorders diagnosed in childhood/ or developmental disabilities/
- 3 exp child development disorders/
- 4 limit 3 to yr="1990 - 1995"
- 5 exp Homebound Persons/
- 6 exp cognition disorders/
- 7 exp mental retardation/
- 8 intellectual disab\$.mp.
- 9 1 or 2 or 4 or 5 or 6 or 7 or 8
- 10 exp Disability Evaluation/
- 11 exp factor analysis, statistical/
- 12 exp Psychometrics/mt, st [Methods, Standards]
- 13 10 or 11 or 12
- 15 9 and 13
- 16 limit 14 to english language
- 17 limit 16 to yr="1990 -Current"

PsycInfo

1. exp disabilities/ or exp developmental disabilities/ or exp learning disabilities/ or exp multiple disabilities/ or exp reading disabilities/
- 2 exp Homebound/
- 3 elderly.mp.
- 4 disabled person.mp.
- 5 exp Cognitive Impairment/ or cognition disorder.mp.
- 6 1 or 2 or 3 or 4 or 5 177691
- 7 exp Disability Evaluation/ 34094
- 8 exp Factor Analysis/ 17649
- 9 exp Psychometrics/ 46844
- 10 7 or 8 or 9 93277
- 11 6 and 10 4042
- 12 limit 11 to (english language and yr="1990 -Current")

ICF Update Search

Medline

1. International classification of function\$.mp.
2. ICF.mp.
3. 1 or 2

4. limit 3 to (english language and yr="2008 -Current")

PsycInfo

1. international classification of function.mp.
2. icf.mp.
3. 1 or 2
4. limit 3 to yr="2008 -current"
5. limit 4 to english language

Key Question 1b

Medline

The basic search algorithm is presented first, using the diabetes secondary conditions as the condition of interest. For brevity, the basic search algorithm is followed by the specific search terms for the other basic medical service needs and secondary conditions.

- 1 exp Disabled Persons/
- 2 exp mental disorders diagnosed in childhood/ or developmental disabilities.mp.
- 3 exp child development disorders/
- 4 limit 3 to yr="1990 - 1995"
- 5 exp homebound persons/
- 6 exp cognition disorders/
- 7 exp mental retardation/
- 8 intellectual disab\$.mp.
- 9 1 or 2 or 4 or 5 or 6 or 7 or 8
- 10 exp frail elderly/
- 11 9 or 10
- 12 (randomized controlled trial or clinical trial).pt.
- 13 (randomized controlled trials or random allocation or clinical trial or double blind method or single blind method).sh.
- 14 exp clinical trial/
- 15 (clin\$ adj25 trial\$).ti,ab.
- 16 ((singl\$ or doubl\$ or trebl\$ or trip\$) adj25 (blind\$ or mask\$)).ti,ab.
- 17 (research design or placebos).sh.
- 18 (placebo\$ or random\$).ti,ab.
- 19 cohort studies/ or comparative study/ or follow-up studies/ or prospective studies/ or risk factors/ or cohort.mp. or compared.mp. or groups.mp. or multivariate.mp.
- 20 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19
- 21 11 and 20
- 22 exp diabetes mellitus/
- 23 (uncontrolled or noncontrolled).mp.
- 24 22 and 23
- 25 21 and 24
- 26 exp diabetes complications/
- 27 exp diabetes mellitus/co

28 26 or 27
29 21 and 28
30 25 or 29
31 limit 30 to (english language and yr="1990 -Current")

Pneumonia

22 exp Pneumonia, Bacterial/
23 exp pneumonia/
24 exp bacterial infections/

Asthma

22 exp asthma/

Gastroenteritis

22 exp gastroenteritis/

Hypertension

22 exp hypertension/

Obesity

22 exp obesity/

Pressure Ulcers

22 exp pressure ulcer/

Preventive Dental

22 exp Preventive Dentistry/
23 exp dental care/
24 exp bacterial infections/

Preventive Health

22 exp Preventive Health Services/
23 exp Preventive Medicine/

All of the above searches were repeated with frail elderly replaced by elderly and ADL terms:

21. exp elderly/
22. (ADL or Activities of Daily Living).mp.
23. function.mp.
24. 21 and 22 and 23

PsychInfo

1. exp disabilities/ or exp developmental disabilities/ or exp learning disabilities/ or exp multiple disabilities/ or exp reading disabilities/
2. exp Homebound/
3. elderly.mp.

4. 1 or 2 or 3
5. disabled person.mp.
6. exp Cognitive Impairment/ or cognition disorder.mp.
7. 4 or 5 or 6
8. exp Asthma/
9. 7 and 8
13. limit 9 to "2000 treatment outcome/randomized clinical trial"
14. exp "Activities of Daily Living"/
15. 8 and 14
16. preventive dental.mp.
17. exp Pneumonia/
18. 7 and 17
19. exp Diabetes Insipidus/ or exp Diabetes/ or exp Diabetes Mellitus/
20. 7 and 19
21. limit 20 to "2000 treatment outcome/randomized clinical trial"
22. gastroenteritis.mp.
23. 7 and 22
24. exp Hypertension/ or hypertension.mp.
25. 7 and 24
26. limit 25 to "2000 treatment outcome/randomized clinical trial"
27. exp Obesity/ or obesity.mp.
28. 7 and 27
29. limit 28 to "2000 treatment outcome/randomized clinical trial"
30. pressure ulcer.mp.
31. 7 and 30
32. preventive medical.mp.
33. 7 and 32
34. urinary tract infection.mp.
35. 7 and 34

Key Question 2 and 3

Medline

- 1 exp Disabled Persons/
- 2 exp mental disorders diagnosed in childhood/ or developmental disabilities.mp.
- 3 exp child development disorders/
- 4 limit 3 to yr="1990 - 1995"
- 5 exp homebound persons/
- 6 exp cognition disorders/
- 7 exp mental retardation/
- 8 intellectual disab\$.mp.
- 9 1 or 2 or 4 or 5 or 6 or 7 or 8
- 10 exp frail elderly/
- 11 9 or 10
- 12 exp Disease Management/
- 13 exp Patient Care Planning/

14 exp Patient-Centered Care/
 15 exp primary health care/
 16 exp progressive patient care/
 17 exp critical pathways/
 18 exp “delivery of health care, integrated”/
 19 exp health services accessibility/
 20 exp managed care programs/
 21 exp product line management/
 22 exp patient care team/
 23 exp behavior control/
 24 exp counseling/
 25 exp health promotion/
 26 exp patient compliance/
 27 exp after-hours care/
 28 ((coordination or coordinated or Multifactorial or multi-factorial or multicomponent or multi-
 component or multidisciplinary or multi-disciplinary or interdisciplinary or inter-disciplinary or
 integrated or community-based or organized) and (care or approach or intervention or strategy or
 strategies or management or managing or center\$ or clinic\$)).ti.
 29 exp “organization and administration”/
 30 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or
 28 or 29
 31 11 and 30
 32 limit 31 to (english language and humans)
 33 (randomized controlled trial or clinical trial).pt.
 34 (randomized controlled trials or random allocation or clinical trial or double blind method or
 single blind method).sh.
 35 exp clinical trial/
 36 (clin\$ adj25 trial\$).ti,ab.
 37 ((singl\$ or doubl\$ or trebl\$ or trip\$) adj25 (blind\$ or mask\$)).ti,ab.
 38 (research design or placebos).sh.
 39 (placebo\$ or random\$).ti,ab.
 40 cohort studies/ or comparative study/ or follow-up studies/ or prospective studies/ or risk
 factors/ or cohort.mp. or compared.mp. or groups.mp. or multivariate.mp.
 41 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40
 42 31 and 41
 43 limit 42 to english language
 44 limit 43 to yr=“2000 -Current”

PsycInfo

1 exp Disease Management/ (2338)
 2 exp Treatment Planning/ (3373)
 3 Patient-Centered Care.mp. (280)
 4 progressive patient care.mp. (1)
 5 critical pathways.mp. (24)
 6 health services accessibility.mp. (2)
 7 product line management.mp. (6)

8 patient care team.mp. (15)
9 medical home.mp. (160)
10 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 (6148)
11 coordination of care.mp. (202)
12 care coordination.mp. (267)
13 11 or 12 (442)
14 10 and 13 (53)
15 exp “Quality of Care”/ (6442)
16 exp “Quality of Services”/ (9682)
17 15 or 16 (9682)
18 13 and 17 (69)
19 10 and 17 (186)
20 14 or 18 or 19 (286)

ERIC

The ERIC database has limited search function. All searches were run and results imported into one bibliography from which duplicates were deleted. Articles were limited to 2000 forward.

“Coordination of care” OR “care coordination” OR “quality gap” OR “disease management” OR “medical home”

“access to health care” AND (“program effectiveness” OR “program evaluation” or “Integrated Services”)

“access to health care” or “integrated services” AND quality

“integrated services” AND (Health OR Medical)

Sources of Grey Literature

Appendix Table A1. Sources of grey literature

Federal and state agencies	Administration on Aging (AoA) Agency for Healthcare Research and Quality (AHRQ) Centers for Medicare and Medicaid Service (CMS) Congressional Research Service (CRS) Office of the Assistant Secretary for Planning and Evaluation (ASPE) U.S. Government Accountability Office (GAO) State Departments of Health or Health & Human Services Veterans Administration
Research organizations, foundations, and advocacy groups	AARP Abt Associates Alliance for Health Reform American Public Human Services Association Health Services Division Center for Excellence in Assisted Living Institute for Community Integration Kaiser Family Foundation LeadingAge Mathematica Policy Research Milbank Memorial Fund National Academy for State Health Policy National Association of Area Agencies on Aging National Association of Medicaid Directors National Center for Assisted Living National Conference of State Legislatures National Governors Association National Investment Center National PACE Association PAS Center for Personal Assistance Services, UCSF Robert Wood Johnson Foundation RTI International Scripps Gerontology Center The Clearinghouse for Home and Community Based Services The Commonwealth Fund The Hilltop Institute The John A. Hartford Foundation The Lewin Group The SCAN Foundation Urban Institute Visiting Nurse Service of New York

Appendix B. Care Coordination Evidence Tables

Appendix Table B1. Care coordination studies

Author Country	Study type	Target population	Age	Care coordination type	Implementation details
Both coordination types					
Boult, 2008 ¹ US	RCT both	Chronic multimorbid elderly	Elderly	“Guided Care”: family/caregiver education, evidence based guidelines, HER	7 RNs educated in guided care program
Claiborne, 2006 ² Claiborne, 2006 ³ US	RCT both	Chronic	Mix	Coordination “across array of health services,” education to patients and caregivers, social/psychosocial assistance. Family/caregiver education, patient education, social services/medical integration	Practice-based social workers
Cooley, 2009 ⁴ US	Prospective observational both	Mixed - CSHCN	Children	Varied	
Criscione, 1995 ⁵ US	Retrospective observational both	Mixed	Mix	NP coordinating care across all inpatient and outpatient needs; also working with family, group home, and agency staff to “assure an integrated approach to health care”	
Dicianno, 2010 ⁶ US	Descriptive both	Mixed	Mix	Patient advocacy, specialist/generalist, social/medical	Presents description of model of many types of providers coordinating to provide support to people with spina bifida and their families over the entire life course
Eklund, 2009 ⁷	Review	Frail elderly	Elderly	Varied	
Esposito, 2007 ⁸ US	Descriptive both	Medicaid+chronic+ immobile	Mix	Medical home	
Fitzgibbon, 2009 ⁹ US	Prospective observational both	Mixed - CSHCN	Children	Centralized services by health plan care coordinators	Case managers were registered nurses working for the health plan (1.5 FTE)

Appendix Table B1. Care coordination studies (continued)

Author Country	Study type	Target population	Age	Care coordination type	Implementation details
Fitzgibbon, 2009 ¹⁰ US	Prospective observational both	Mixed - CSHCN	Children	“Family support” (answering questions, advising on home management, advocacy for family/patients); “Condition management” (office visits, progress toward care plan goals); referral to specialty care, etc.	Clinics varied in number of interactions per patient and use of phone vs. office visits
Friedman, 2009 ¹¹ US	RCT both	Medicare+disabled+ heavy users	Elderly	Nurse case management: disease management, frequently across multiple chronic illnesses	
Hebert, 2010 ¹² Canada	Prospective observational both	Frail elderly	Elderly	Coordination-type integrated service delivery	Case managers (nurses, social workers, or other health professionals) working closely with PCP
Hughes, 2000 ¹³ US	RCT	VA Frail elderly	Elderly	Team-managed home-based primary care	Primary physician led. Emphasis on continuity of care and coordination across organizational boundaries.
Judge, 2011 ¹⁴ US	Before-after both	Frail elderly	Elderly	Family/caregiver, social/medical integration, IS to enable coordination among providers	
Marek, 2006 ¹⁵ US	Prospective observational both	Medicaid+eligible for inst	Mix	Nurse care coordination including home care services	
Mastal, 2005 ¹⁶ US	Expert recommendations based on visits to 7 pilot programs	Medicaid+disabled or chronic	Adults	Varied	Varied
McCusker, 2006 ¹⁷	Systematic review	Frail elderly	Elderly	Comprehensive geriatric assessments	
Melis, 2010 ¹⁸ Netherlands	RCT both	Frail elderly	Elderly	Integrated, interdisciplinary treatment plan and ongoing home visits for evaluation	Geriatric specialist nurse doing home visits; gps and geriatricians
Nishikawa, 2011 ¹⁹ US	Survey both	Mixed - CSHCN	Children	Preparation for transition from pediatric to adult healthcare	N/A
Oeseburg, 2009 ²⁰ International	Review both	Mixed - Chronic disease or frail elderly	Mix	Patient advocacy model (not “interrogative”/gatekeeper)	Varied

Appendix Table B1. Care coordination studies (continued)

Author Country	Study type	Target population	Age	Care coordination type	Implementation details
Ornstein, 2011 ²¹ US	Before-after both	Immobile+transition from inpt	Mix	Transition from inpatient to home	Led by Nurse Practitioner; initial 3 month pilot period during which program was introduced and "iteratively modified"--no data collected during pilot period
Palsbo, 2007 ²² US	Before-after both	Medicaid+ disabled	Adults	Holistic focus on care and service needs	
Palsbo, 2010 ²³ US	Retrospective observational both	Medicaid + disabled	Adults		
Raphael, 2009 ²⁴ US	Survey both	Mixed - CSHCN	Children	Medical home	Interprets results of the National Survey of Children with Special Health Care Needs
Schuster, 2007 ²⁵ US	Prospective observational both	Mixed - CSHCN	Children	Nurse or social worker coordinating care, mostly over the phone	
Singh, 2009 ²⁶ US	Survey both	Mixed - CSHCN	Children	Medical home	N/A
Stewart, 2009 ²⁷ Canada	Guideline development both	Physical and developmental disabled children	Children in transition	Transition from pediatric to adult services	Published/unpublished literature; focus groups and interviews with consumers, community members, service providers, and policy makers
Strickland, 2009 ²⁸ US	Survey both	Mixed - CSHCN	Children	Medical home	Interprets results of the National Survey of Children with Special Health Care Needs
Tourigny, 2004 ²⁹ Canada	Prospective observational both	Frail elderly	Elderly	Social/medical, between providers	
Turchi, 2009 ³⁰ US	Survey both	Mixed - CSHCN	Children	Specialist/generalist, family/caregivers empowerment and self-efficacy, social/medical integration, school/healthcare coordination	N/A
Van Achterberg, 1996 ³¹ Netherlands	Prospective observational both	Elderly+chronic disease	Elderly	Creating care plan and making sure it is carried out	Professional care coordinators (e.g., community nurse, family physician, social worker) and nonprofessional care coordinators (spouse, child, relative, etc.) who received instruction on care coordination
Wise, 2007 ³²	Review	Mixed - CSHCN	Children	Varied	Varied

Appendix Table B1. Care coordination studies (continued)

Author Country	Study type	Target population	Age	Care coordination type	Implementation details
Wolff, 2010 ³³ US	RCT both	Chronic - multimorbid elderly	Elderly	“Guided Care”: family/caregiver education, evidence based guidelines, HER	7 RNs educated in Guided care program
Wood, 2009 ³⁴ US	Prospective observational both	Mixed - CSHCN	Children	Practice-based care coordinators vs. agency-based care coordinators	Nurse care coordinators placed onsite in 3 practices along with training and quality improvement on principles of medical home
Wood, 2009 ³⁵ US	Survey both	Mixed - CSHCN	Children	Title V agency, medical home	Unclear--varied by practice
Coordination within					
Danzer, 2010 ³⁶ US	Prospective observational	Developmental	Children	Specialist/generalist	Pediatrics, surgical, neurodevelopmental specialists
Temkin-Greener, 2008 ³⁷ US	Claims review	Frail elderly	Elderly	Specialist/generalist, acute and chronic care	
Coordination across					
Boisclair-Fahey, 2009 ³⁸ US	Before-after	Developmental	Children	School/healthcare coordination	Nurse practitioner contacted school nurses
Dise-Lewis, 2009 ³⁹ US	Before-after	Acquired	Children	Social/educational	Parents and school personnel met with “consultants” 3 times to learn about and discuss the impact of brain injury on the child and how to best help the child learn
Douglas, 2007 ⁴⁰ US	Randomized trial	Acquired disability	Mixed	Patient/family/caregivers coordination and communication with physicians	Advanced practice nurse
Nolan, 2007 ⁴¹ US	Survey to assess family satisfaction with care coordination services	Mixed - CSHCN + physical disabled	Children	“Family centered care coordination”: communication with providers and b/w providers and schools; help getting access to medical equipment, acute care, specialists	Different coordinators for different needs: NP, SW, PT, OT all provide coordination
Wade, 2009 ⁴² US	Before-after	Acquired disability	Children	Education for caregivers: parenting skills, stress management, and coping	Web-based learning
Xenakis, 2010 ⁴³ US	Descriptive/program evaluation	Mixed - Girls with physical disabilities	Children	Patient empowerment and self-efficacy, social/medical integration	“Expert instructors” program coordinator

Appendix Table B1. Care coordination studies (continued)

Author Country	Study type	Target population	Age	Care coordination type	Implementation details
Ziviani, 2011 ⁴⁴ Australia	Descriptive	Mixed	Children	Family/caregiver empowerment, social/medical integration	Study focuses solely on organizational learning strategies: describes implementation of “program logic” sessions conducted with staff from each program; sessions resulted in detailed illustrations of the logical flow of inputs to outputs to outcomes to impacts for the programs being delivered
Ziviani, 2010 ⁴⁵	Review	Mixed	Children	Social/medical	10 included studies on early intervention programs for children with physical disabilities

Appendix Table B2. Outcomes used in care coordination studies

Author	Population	KQ	Category	Second category	Outcome/scale used	Longest duration of followup
Boisclair-Fahey, 2009 ³⁸	Children	Med-soc	Function		Number of “wet” days per month	6 months
Boisclair-Fahey, 2009 ³⁸	Children	Med-soc	Process		Parent-reported school bathroom survey: questions on access to bathroom, cleanliness, whether child is willing to use the bathroom	6 months
Boult, 2008 ¹	Elderly	Both	Satisfaction		Patient Assessment of Chronic Illness Care (PACIC): validated measure of pt perception of various qualities of chronic care	6 months
Boult, 2008 ¹	Elderly	Both	Provider	Process	Primary Care Assessment Tool (PCAT): physician assessment of quality of care and processes of care	1 year
Boult, 2008 ¹	Elderly	Both	Health	Function	SF-36 PCS and MCS	Only baseline reported
Claiborne, 2006 ^{2,3}	Mix	Both	Use		Inpatient and outpatient medical use; ER visits	3 months
Claiborne, 2006 ^{2,3}	Mix	Med-soc	Health	Function	SF-36 physical and mental	3 months
Claiborne, 2006 ^{2,3}	Mix	Med-soc	Health	Function	Geriatric Depression Scale (GDS)	3 months
Claiborne, 2006 ^{2,3}	Mix	Med-soc	Process		Adherence assessment: number of instances in which the patient did not follow through with medication regimen, appointments, dietary requirements, etc.	3 months
Claiborne, 2006 ^{2,3}	Mix	Med-soc	Process	Satisfaction	Service needs assessment: number of nonmedical services needed to improve patient outcomes; satisfaction with those services	3 months?
Cooley, 2009 ⁴	Children	Both	Use		Emergency department visits, hospitalization rate, ratio of primary care to specialty care (number of visits)	1 year
Criscione, 1995 ⁵	Mix	Both	Use	Cost	Hospital care: LOS, total charges	3 years of data used
Danzer, 2010 ³⁶	Children	Med-med	Health		Neurodevelopmental outcome: Bayley Scales of Infant Development	26 months
Dicianno, 2010 ⁶	Mix	Both	N/A		N/A	N/A
Dise-Lewis, 2009 ³⁹	Children	Med-soc	Process		Acquired Brain Injury Parenting/Teaching Proficiency Scale	Approx 6-7 months
Dise-Lewis, 2009 ³⁹	Children	Med-soc	Function	Behavior	The Neurodevelopmental Inventory: ratings of priority areas from 20 neurodevelopmental clusters (e.g., attention, emotion regulation, motor control, judgment)	Approx 6-7 months
Dise-Lewis, 2009 ³⁹	Children	Med-soc	Function	Behavior	Behavior Rating Inventory of Executive Functions (BRIEF): 86-item behaviorally anchored measure to assess executive functioning in everyday environments	Approx 6-7 months

Appendix Table B2. Outcomes used in care coordination studies (continued)

Author	Population	KQ	Category	Second category	Outcome/scale used	Longest duration of followup
Dise-Lewis, 2009 ³⁹	Children	Med-soc	Function	Behavior	Behavior Assessment System for Children (BASC): 126-131 item behaviorally anchored inventory designed to assist in differential diagnosis of behavioral and psychological disorders	Approx 6-7 months
Dise-Lewis, 2009 ³⁹	Children	Med-soc	Satisfaction	Goals	Evaluation of program: asked "to what degree the program specifically led to desired positive outcomes" e.g., improved morale, improved family/school working relationship, significantly improved learning on the student	3 months
Douglas, 2007 ⁴⁰	Elderly	Med-soc	Health	Function	APACHE III (Acute Physiology and Chronic Health Evaluation)	24 hours
Douglas, 2007 ⁴⁰	Elderly	Med-soc	Health	Function	SF-8	8 weeks
Douglas, 2007 ⁴⁰	Elderly	Med-soc	Health	Function	OASIS (Outcomes and Assessment Information Set)	8 weeks
Douglas, 2007 ⁴⁰	Elderly	Med-soc	Cost	Use	Resource use: standardized charges for rehospitalization, long-term acute care, rehab, SNF, home health resources, etc.	8 weeks
Douglas, 2007 ⁴⁰	Elderly	Med-soc	Health		Survival	8 weeks
Eklund, 2009 ⁷	Elderly	Varied	N/A	N/A	Varied (review)	
Esposito, 2007 ⁸	Mix	Both	Process	Use	Case manager and provider contacts (count)	
Esposito, 2007 ⁸	Mix	Both	Use		Hospital admissions and LOS, ER visits, nursing home admissions and LOS	
Esposito, 2007 ⁸	Mix	Both	Cost		Total costs of care and costs of personal care assistants, prescription drugs, nursing home use, inpatient visits, and durable medical equipment	
Fitzgibbon, 2009 ^{9,10}	Children	Both	Use	Process	Number of contacts; number of office visits; activities performed	8 months
Fitzgibbon, 2009 ^{9,10}	Children	Both	Use		Number of interventions per child	Not specified
Friedman, 2009 ¹¹	Elderly	Both	Satisfaction		Patient satisfaction (patient reported improved health, satisfaction with nurse tool, satisfaction with nurse relationship, satisfaction with PCP, general satisfaction with nurse intervention, improved relationship with family, satisfaction with primary care partnership meeting)	24 months
Friedman, 2009 ¹¹	Elderly	Both	Self-efficacy		General self-efficacy, health self-efficacy, 3 Multidimensional Health Locus of Control subscales	24 months
Friedman, 2009 ¹¹	Elderly	Both	Health	Function	Self-rated health status, SF-36 Physical Component summary and Mental Component Summary; 6 ADL dependence, 6 IADL dependence	24 months

Appendix Table B2. Outcomes used in care coordination studies (continued)

Author	Population	KQ	Category	Second category	Outcome/scale used	Longest duration of followup
Friedman, 2009 ¹¹	Elderly	Both	Caregiver	Satisfaction	Patient's improved health, satisfaction with nurse tool, satisfaction with nurse relationship, Satisfaction with PCP, general satisfaction with nurse intervention, improved relationship with family, satisfaction with primary care partnership meeting, satisfaction with nurse help to reduce caregiver stress	24 months
Hebert, 2010 ¹²	Elderly	Both	Function		Functional decline: institutionalization, death, loss of 5 points in SMAF score (Functional Autonomy Measurement System)	4 years
Hebert, 2010 ¹²	Elderly	Both	Function		Disability and unmet needs: SMAF (functional autonomy measurement system); includes functional ability in ADLs, mobility, communication, mental function, IADL	4 years
Hebert, 2010 ¹²	Elderly	Both	Function		Disability profile: IsoSMAF profiles--14 profiles generated including motor disability, mental disability, impaired mobility and ADL with cognitive and communicative deficits	4 years
Hebert, 2010 ¹²	Elderly	Both	Satisfaction		Satisfaction: Health Care Satisfaction Questionnaire--26 statements rated for perception and importance	4 years
Hebert, 2010 ¹²	Elderly	Both	Self-efficacy		Empowerment: Health Care Empowerment Questionnaire: similar to satisfaction questionnaire	4 years
Hebert, 2010 ¹²	Elderly	Both	Caregiver		Caregiver's Burden: Zarit Burden Interview	4 years
Hebert, 2010 ¹²	Elderly	Both	Caregiver		Caregiver's desire to institutionalize: Questionnaire adapted from Morycz Canadian Study on Health and Aging Working Group	4 years
Hebert, 2010 ¹²	Elderly	Both	Use	Process	Self-reported hospital utilization (ER and hospitalization)	4 years
Hughes, 2000 ¹³	Elderly	Both	Function		Barthel Index	12 months
Hughes, 2000 ¹³	Elderly	Both	HRQoL		Medical Outcomes Study MOS SF-36 – Patient and Caregiver	12 months
Hughes, 2000 ¹³	Elderly	Both	Satisfaction		Ware Satisfaction with Care scales	12 months
Hughes, 2000 ¹³	Elderly	Both	Caregiver		Caregivers Burden: Montgomery scale	12 months
Hughes, 2000 ¹³	Elderly	Both	Use	Process	Number of hospital readmissions days	12 months
Hughes, 2000 ¹³	Elderly	Both	Use	Process	Rates of readmission per patient	12 months
Hughes, 2000 ¹³	Elderly	Both	Use	Process	% of patients readmitted	12 months
Hughes, 2000 ¹³	Elderly	Both	Use	Process	Total units of service used across all other services	12 months
Hughes, 2000 ¹³	Elderly	Both	Cost		VA hospital, nursing home, outpatient, home-based primary care service use, durable medical equipment, pharmacy from VA and HCFA files	12 months
Judge, 2011 ¹⁴	Elderly	Both	Satisfaction		Survey to assess acceptability and feasibility of program; administered to 6 care coordinators	N/A
Marek, 2006 ¹⁵	Mix	Both	Health	Function	Short version of the MDS (Minimum Data Set): 1997 RUGS III Quarterly; used items on ADL, incontinence, cognitive performance, depression, and pressure ulcers	12 months
Marek, 2006 ¹⁵	Mix	Both	Health		OASIS: used items on medication management, dyspnea, and pain	12 months

Appendix Table B2. Outcomes used in care coordination studies (continued)

Author	Population	KQ	Category	Second category	Outcome/scale used	Longest duration of followup
Mastal, 2005 ¹⁶	Adults	Varied	Health		Incidence of bowel impaction	N/A
Mastal, 2005 ¹⁶	Adults	Varied	Health		Incidence of UTI in patients with catheters	N/A
Mastal, 2005 ¹⁶	Adults	Varied	Health		Incidence and duration at each stage of pressure ulcers; % detected for the first time at each stage; average length of time to heal; % of participants screened for PU risk; % of patients in high risk with annual Braden score	N/A
Mastal, 2005 ¹⁶	Adults	Varied	Process		Management complying with Paralyzed Veterans Association guidelines for autonomic dysreflexia	N/A
McCusker, 2006 ¹⁷	Elderly	Varied	Use		Emergency Department visits	Varied (review)
Melis, 2010 ¹⁸	Elderly	Both	Process		Adherence to recommendations	N/A
Nishikawa, 2011 ¹⁹	Children	Both	Process		% discussing adult health transition	N/A
Nishikawa, 2011 ¹⁹	Children	Both	Process		% discussing adult insurance transition	N/A
Nishikawa, 2011 ¹⁹	Children	Both	Process		% "encouraged in self-responsibility for health"	N/A
Nolan, 2007 ⁴¹	Children	Med-soc	Access		Access to services and referrals (several survey questions)	N/A
Nolan, 2007 ⁴¹	Children	Med-soc	Process		Frequency of communication: medical personnel to school, medical personnel to each other, information sharing	N/A
Nolan, 2007 ⁴¹	Children	Med-soc	Process	Caregiver	Responsiveness, choices and alternatives, involving caregivers in care decisions	N/A
Nolan, 2007 ⁴¹	Children	Med-soc	Process		Ranking issues related to access and care coordination	N/A
Oeseburg, 2009 ²⁰	Mix	Both	Use	Process	Hospital admission (6 studies)	10-36 months
Oeseburg, 2009 ²⁰	Mix	Both	Use	Process	Hospital LOS: 5 studies	10-36 months
Oeseburg, 2009 ²⁰	Mix	Both	Use	Process	Emergency department visits: 5 studies	10-24 months
Oeseburg, 2009 ²⁰	Mix	Both	Use	Process	Nursing home admission: 3 studies	12-24 months
Oeseburg, 2009 ²⁰	Mix	Both	Cost		Costs: 3 studies	12-36 months
Ornstein, 2011 ²¹	Mix	Both	Use		Admissions, 30-day readmissions	Study period (2 years)
Ornstein, 2011 ²¹	Mix	Both	Cost		LOS, case-mix index, revenue, direct care costs, indirect cost	Study period (2 years)
Ornstein, 2011 ²¹	Mix	Both	Function	Use	Discharge to home, nursing home, hospice; death	Study period (2 years)
Ornstein, 2011 ²¹	Mix	Both	Qualitative		Feedback from providers whose patients participated	Study period (2 years)
Palsbo, 2007 ²² Palsbo, 2010 ²³	Adults	Both	Cost		Median care coordination costs	10-40 months
Palsbo, 2007 ²² Palsbo, 2010 ²³	Adults	Both	Cost		Mean per member, per month costs	10-40 months

Appendix Table B2. Outcomes used in care coordination studies (continued)

Author	Population	KQ	Category	Second category	Outcome/scale used	Longest duration of followup
Palsbo, 2007 ²² Palsbo, 2010 ²³	Adults	Both	Use		ER and hospitalization rates (per member year)	10-40 months
Palsbo, 2007 ²² Palsbo, 2010 ²³	Adults	Both	Use		Adjusted LOS	10-40 months
Palsbo, 2007 ²² Palsbo, 2010 ²³	Adults	Both	Cost		Mean cost per hospitalization	10-40 months
Palsbo, 2007 ²² Palsbo, 2010 ²³	Adults	Both	Satisfaction		5 items addressing coordination of care (e.g., "someone helped manage health care services")	2 years
Palsbo, 2007 ²² Palsbo, 2010 ²³	Adults	Both	Satisfaction		Survey derived from CAHPS questions	2 years
Raphael, 1999 ⁴⁶ Raphael, 2009 ²⁴	Children	Both	Use		Emergency care use: having 1 or more emergency care encounters i the last 12 months	N/A
Schuster, 2007 ²⁵	Children	Both	Use		Frequency of therapeutic services (speech, occupational, physical)	
Schuster, 2007 ²⁵	Children	Both	Process		Whether therapeutic services were received at school	7 months
Singh, 2009 ²⁶	Children	Both	Access		Having a medical home	N/A
Singh, 2009 ²⁶	Children	Both	Satisfaction		Effective care coordination	N/A
Singh, 2009 ²⁶	Children	Both	Caregiver		Family centered care	N/A
Singh, 2009 ²⁶	Children	Both	Access		Problems with needed referrals	N/A
Stewart, 2009 ²⁷	Children	Both	Guideline		Collaborative initiatives are necessary supports for transition	
Stewart, 2009 ²⁷	Children	Both	Guideline		Building capacity of people and communities will enhance transition process	
Stewart, 2009 ²⁷	Children	Both	Guideline		Need for community navigators or facilitators to assist with transition	
Stewart, 2009 ²⁷	Children	Both	Guideline		Information, resources, and services should be accessible and available	
Stewart, 2009 ²⁷	Children	Both	Guideline		Education is a critical component of transition strategy	
Stewart, 2009 ²⁷	Children	Both	Guideline		Ongoing research and evaluation provides the evidence needed for success	
Strickland, 2009 ²⁸	Children	Both	Access		Access to medical home, usual source of care, etc.	N/A
Strickland, 2009 ²⁸	Children	Both	Access		Delayed/foregone care	N/A
Strickland, 2009 ²⁸	Children	Both	Access		Unmet health care need	N/A
Strickland, 2009 ²⁸	Children	Both	Function		11+ school days missed because of illness	N/A
Strickland, 2009 ²⁸	Children	Both	Access		Unmet need for family support services	N/A
Temkin-Greener, 2008 ³⁷	Elderly	Med-med	Function		Change in number of ADL's (functional status)	3 years

Appendix Table B2. Outcomes used in care coordination studies (continued)

Author	Population	KQ	Category	Second category	Outcome/scale used	Longest duration of followup
Temkin-Greener, 2008 ³⁷	Elderly	Med-med	Use		Service use	Note: this outcome was estimated as a propensity of each site to provide several services
Tourigny, 2004 ²⁹	Elderly	Both	Health	Function	Survival without institutionalization	3 years
Tourigny, 2004 ²⁹	Elderly	Both	Function		Desire to be institutionalized (four questions from Canadian Study of Health and Aging OR person has been institutionalized)	3 years
Tourigny, 2004 ²⁹	Elderly	Both	Health	Function	No deterioration at followup (deterioration defined as death, institutionalization, or loss of 5 or more points on SMAF)	3 years
Tourigny, 2004 ²⁹	Elderly	Both	Caregiver		French version of Zarit's Burden Interview	
Tourigny, 2004 ²⁹	Elderly	Both	Use		Administrative data from various sources for medical procedures, drug use, hospitalizations, day surgery, number and type of interventions, long-term care, rehab, day care , or geriatric ambulatory services	3 years
Turchi, 2009 ³⁰	Children	Both	Caregiver		Family-provider relations including presence of family-centered care	N/A
Turchi, 2009 ³⁰	Children	Both	Caregiver	Cost	OOP expenses, family financial burden	N/A
Turchi, 2009 ³⁰	Children	Both	Caregiver		Hours per week family spends coordinating care	N/A
Turchi, 2009 ³⁰	Children	Both	Caregiver		Impact on parental employment	N/A
Turchi, 2009 ³⁰	Children	Both	Function		School absences	N/A
Turchi, 2009 ³⁰	Children	Both	Use		Frequency of ED visits over previous 12 months	N/A
Van Achterberg, 1996 ³¹	Elderly	Both	Health	Function	Number of disorders	12 months
Van Achterberg, 1996 ³¹	Elderly	Both	Health		Perceived health	12 months
Van Achterberg, 1996 ³¹	Elderly	Both	Function		ADL and IADL impairments	12 months
Van Achterberg, 1996 ³¹	Elderly	Both	Process	Use	Types of caregivers, frequency of contacts	12 months
Van Achterberg, 1996 ³¹	Elderly	Both	Satisfaction		Satisfaction with caregivers	12 months
Van Achterberg, 1996 ³¹	Elderly	Both	Health	Function	Quality of life (unclear what the measure was)	12 months
Wade, 1985 ⁴⁷ Wade, 1989 ⁴⁸ Wade, 2009 ⁴²	Children	Med-soc	Process	Function	Parent-child interaction: Dyadic Parent-Child Interaction Coding System III (DPICS-III)	Not reported: end of treatment

Appendix Table B2. Outcomes used in care coordination studies (continued)

Author	Population	KQ	Category	Second category	Outcome/scale used	Longest duration of followup
Wade, 1985 ⁴⁷ Wade, 1989 ⁴⁸ Wade, 2009 ⁴²	Children	Med-soc	Function	Behavior	Child behavior: Eyberg Child Behavior Inventory (ECBI)	Not reported: end of treatment
Wade, 1985 ⁴⁷ Wade, 1989 ⁴⁸ Wade, 2009 ⁴²	Children	Med-soc	Satisfaction	Process	Process measures of satisfaction, etc.	Not reported: end of treatment
Wise, 2007 ³²	Children	Varied	Use	Cost	Health care use, health care expenditures	
Wise, 2007 ³²	Children	Varied	Process		Use of effective medication, equity of use of effective medication	
Wise, 2007 ³²	Children	Varied	Satisfaction		Satisfaction with care	
Wise, 2007 ³²	Children	Varied	Health		Asthma status survey	
Wise, 2007 ³²	Children	Varied	Access		Access to care	
Wolff, 2010 ³³	Elderly	Both	Caregiver		Caregiver depressive symptoms: CES-D (Center for Epidemiological Studies Depression scale)	18 months
Wolff, 2010 ³³	Elderly	Both	Caregiver		Caregiver strain: Modified Caregiver Strain Index (CSI)	18 months
Wolff, 2010 ³³	Elderly	Both	Satisfaction		Patient Assessment of Chronic Illness Care (PACIC): includes goal setting, coordination of care, decision support, problem solving, patient activation, aggregate of all of the above	18 months
Wolff, 2010 ³³	Elderly	Both	Caregiver		Caregiver productivity loss: Work Productivity and Activity Impairment (WPAI:CG)	18 months
Wood, 2009 ^{34,35}	Children	Both	Caregiver	Satisfaction	Parental rating of care coordination services and barriers to care: help with needed services, support from care coordinator, satisfaction with care coordination, barriers to getting health services	18 months
Wood, 2009 ^{34,35}	Children	Both	Satisfaction	Caregiver	Parental ratings of pediatric services: treatment by office staff, communication with pediatrician, partnering in decision-making	18 months
Wood, 2009 ^{34,35}	Children	Both	Access	Satisfaction	Connecting to outside resources: parent satisfaction with role played by pediatrician and his/her office staff in making and coordinating referrals	18 months
Wood, 2009 ^{34,35}	Children	Both	Caregiver		Caregiver burden: limitation of parent's ability to participate in regular activities, financial burden, days of work lost due to caregiver responsibilities	18 months
Wood, 2009 ^{34,35}	Children	Both	Health		Child health: severity of disease, overall health	18 months
Wood, 2009 ^{34,35}	Children	Both	Caregiver		Caregiver burden: to what degree caregiving limited parents' ability to participate in regular activities, financial burden from health care costs, days of work lost to caregiver responsibilities	N/A

Appendix Table B2. Outcomes used in care coordination studies (continued)

Author	Population	KQ	Category	Second category	Outcome/scale used	Longest duration of followup
Wood, 2009 ^{34,35}	Children	Both	Satisfaction	Caregiver	Parental perception of pediatric services: adapted from Consumer Assessment of Health Plans Study (CAHPS) and Medical Home Family Index (MHFI). Includes treatment by office staff, communication with pediatrician, partnering in decisionmaking, and connecting to outside resources	N/A
Wood, 2009 ^{34,35}	Children	Both	Access		Domains covered in focus groups: needs, services utilization and access, care management	N/A
Xenakis, 2010 ⁴³	Children	Med-soc	Goals	Health	Meeting health goals	3 years?
Xenakis, 2010 ⁴³	Children	Med-soc	Goals	Satisfaction	Effect of program on relationships, independence, goals	3 years?
Ziviani, 2010 ⁴⁵ Ziviani, 2011 ⁴⁴	Children	Med-soc	Goals		Lists of desired/planned outcomes and impacts of the programs (e.g., "Children are better able to mobilise functionally and comfortably within the community")	N/A
Ziviani, 2010 ⁴⁵ Ziviani, 2011 ⁴⁴	Children	Med-soc	Process	Caregiver	MPOC: Measure of Processes of Care 56- and 20-item versions-- five subscales enabling and partnership, providing general information, providing specific information about the child, coordinated and comprehensive care for the child and family, respectful and supportive care	
Ziviani, 2010 ⁴⁵ Ziviani, 2011 ⁴⁴	Children	Med-soc	Satisfaction	Caregiver	CSQ: Client Satisfaction Questionnaire	
Ziviani, 2010 ⁴⁵ Ziviani, 2011 ⁴⁴	Children	Med-soc	Satisfaction	Caregiver	SSICQ Satisfaction with School-based Intervention and Communication Questionnaire	
Ziviani, 2010 ⁴⁵ Ziviani, 2011 ⁴⁴	Children	Med-soc	Goals		Goal Attainment Scale	
Ziviani, 2010 ⁴⁵ Ziviani, 2011 ⁴⁴	Children	Med-soc	Function		AAPS: Arizona Articulation Proficiency scale--accuracy of speech production	
Ziviani, 2010 ⁴⁵ Ziviani, 2011 ⁴⁴	Children	Med-soc	Caregiver	Process	Parent survey based on CHOICES (Children's Health Care Options Improved through Collaborative Efforts and Services): provider and family communication and family involvement in decision-making	
Ziviani, 2010 ⁴⁵ Ziviani, 2011 ⁴⁴	Children	Med-soc	Caregiver	Process	Family Needs Assessment	
Ziviani, 2010 ⁴⁵ Ziviani, 2011 ⁴⁴	Children	Med-soc	Goals		Individual Educational plans progress toward goals	
Ziviani, 2010 ⁴⁵ Ziviani, 2011 ⁴⁴	Children	Med-soc	Function		British Ability scales	
Ziviani, 2010 ⁴⁵ Ziviani, 2011 ⁴⁴	Children	Med-soc	Function	Caregiver	Parent's rating of interactions with preschool peers; structured questionnaire on peer acceptance	

Appendix Table B2. Outcomes used in care coordination studies (continued)

Author	Population	KQ	Category	Second category	Outcome/scale used	Longest duration of followup
Ziviani, 2010 ⁴⁵ Ziviani, 2011 ⁴⁴	Children	Med- soc	Function		Griffith's Mental Development Scales	

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