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Number XX

Closing the Quality Gap Series: Revisiting the State of the Science – QI Measurement of Outcomes for People with Disabilities

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Statement of Funding and Purpose

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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. To bring the broadest range of experts into the development of evidence reports and health technology assessments, AHRQ encourages the EPCs to form partnerships and enter into collaborations with other medical and research organizations. The EPCs work with these partner organizations to ensure that the evidence reports and technology assessments they produce will become building blocks for health care quality improvement projects throughout the Nation. The reports undergo peer review and public comment prior to their release as a final report.

AHRQ expects that the EPC evidence reports and technology assessments will inform individual health plans, providers, and purchasers 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. 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 e-mail to epc@ahrq.hhs.gov.

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Closing the Quality Gap Series: Revisiting the State of the Science – QI Measurement of Outcomes for People with Disabilities

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, and ERIC; hand searches of references from relevant literature and journals. A search of high-quality grey 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, and for examples of outcomes used in the context of disability as a comorbidity for a set of basic service needs 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, 14 articles were included for general outcome measures and 43 for care coordination. A large number of outcomes measures have been critically assessed, and mapped to the International Classification of Function, Disability, and Health. We found no eligible studies of basic medical needs or secondary conditions that examined mixed populations of disabled and non-disabled participants for disability as a comorbidity. Care coordination literature for people with disabilities is relatively new; it focuses on the 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 comorbidity. The literature gathered, or the lack thereof, indicates the early stages of research development. Disability and quality improvement research could benefit from organized databases of critically assessed outcome measures. Collaboration and coordination of measurement efforts across medical interventions, rehabilitation, and social support provision is needed.

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Executive Summary

Introduction

This review is part of a new series of reports on *Closing the Quality Gap: Revisiting the State of the Science* (CQG series)¹ 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*.² As part of its charge to continuously assess progress towards quality, and 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. Conversely, the management of medical problems may be complicated by the presence of a 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 function, quality of life, and community integration are interdependent, coordination may need to span the spectrums of both care and support services (e.g., medical care and schools or social agencies).

This review examines how health care outcomes have been assessed for people with disabilities. Outcome measures are essential for evaluating quality care, but they need to be appropriate for disability type or etiology.

We begin by discussing outcome measurement issues, and exploring conceptual frameworks for thinking about measuring outcomes for research and quality improvement efforts. This report seeks to improve shared understanding among a broad audience with varied exposure to disability outcomes or quality improvement research. We explore the diverse perspectives that researchers bring to bear on what and how to measure. We follow this with a 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 goals of the research should drive the focus, content, and structure of the optimal measure.

Outcomes of care for people with disabilities can be addressed from several levels. Table ES-1 illustrates the relationship between the level of focus and related salient questions. We focus on specific interventions directed at a given medical problem, or comprehensive programs designed to integrate medical and social services for people with disabilities (last two rows of Table ES-1). 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.³ Care coordination is closely linked to the current initiative to create health care homes.

Within the context of medical interventions, disability may often be thought of as a comorbidity that complicates the care (and changes the 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. One way to address this issue is by treating the disability as demographic descriptor, as suggested in Healthy People 2010. 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 getting to the source of care to getting on an examination table. Likewise, the design of a physical activity regimen 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.

Table ES-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 function 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	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)

Determining relevant outcomes and the best way to approach disability will depend 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.

Considerations for 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 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.⁴

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.^{5,6}
- The social model separates the concepts of disability and health, views the disadvantages experienced by people with disabilities as generated by society, frames the disabling condition, rather than the person, as the problem.

- The biopsychosocial model emphasizes the interactions between biological, psychological, social, and cultural factors, and the effects of these interactions on one’s experience of health or illness.^{7,8}

Several Federal initiatives of recent decades have reflected the social and biopsychosocial models of disability. 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 which outcomes are salient.

The **Medical perspective** includes 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 disability 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** includes professionals from the medical and allied professional fields, such as psychiatrists 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 perspective strives to return the person to “normal” functioning. For people with newly disabling conditions, this means restoring the level of function they enjoyed prior to the disability. 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.⁵

The **Social perspective** includes 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 these three perspectives varies with a person’s life course and etiology of the disability. Three useful categories of disability etiology include: 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.

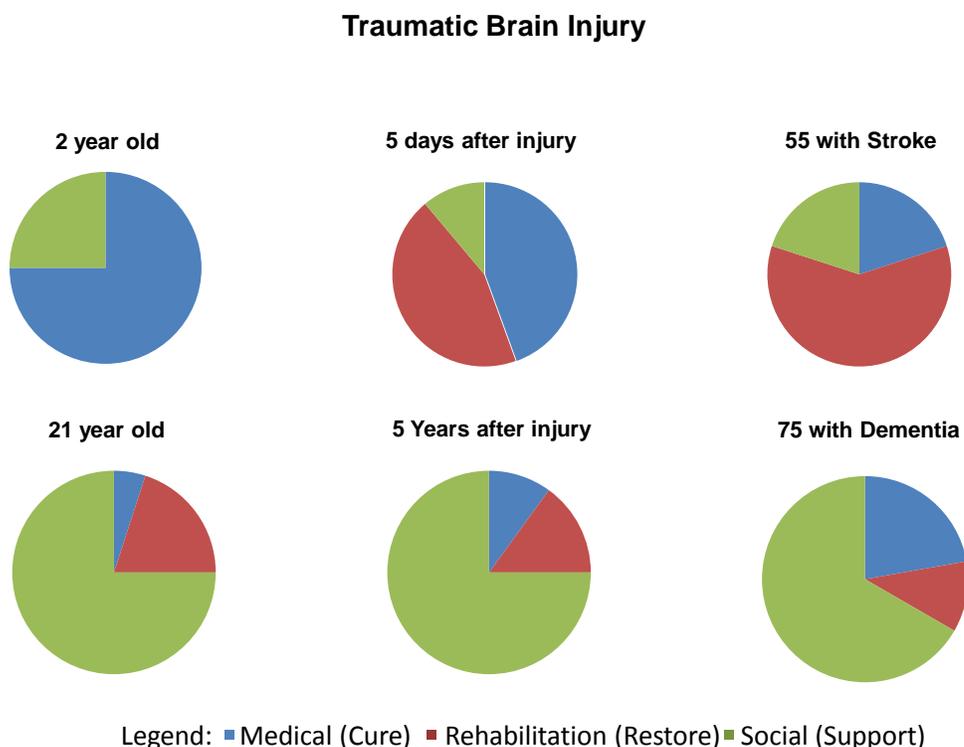
For people with developmental and acquired disabilities, care emphasizes support services. Medical care is relevant only to the extent that the individual suffers from general problems that people of that age group experience, or from specific disease complications of the underlying condition. At the 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 societal integration.

By 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 attitudes.

As an illustration of these different mindsets, consider the following scenario. A disability activist confined to a wheelchair because of a traumatic event is visiting his father, who is confined to a wheelchair 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 a catheter in 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 supports needed to live a fully included life, even if the underlying disability 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 supports needed to live fully included lives. Disabilities that result from degenerative conditions or the aging process generally 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 supports) until it is clear that death is imminent, at which time palliative care is often sought. Figure ES-1 illustrates the relative emphasis of the Medical, Rehabilitation, and Social perspectives among different types of disability, with Traumatic Brain Injury as one example of acquired disability.

Figure ES-1. Relative emphasis of medical care, rehabilitation, and adaptation for disabilities of different etiology



Note – Stylized examples to illustrate relative differences.

Yet another perspective, the life course perspective, represents a recent major advance in understanding outcomes. As noted, many people *age into* disabilities through the advent of illness. Although many people who have serious developmental or acquired disabilities have attenuated life spans, improvements in care have allowed more people with significant disability to reach much older ages, and thus *age with* a disability.⁹ While specific consequences vary by disabling condition, a common pattern is that this group may manifest age-related conditions earlier than those without disability.^{10-14,15}

Finally, the individual’s own perspective should not be overlooked. The health goals of people with disabilities are not so different from those of the general population at comparable ages. People with disabilities emphasize their experience of health as distinct from their disabilities.¹⁶ This is in keeping with a view of disability as a comorbidity.

Relevant Outcome Domains

The disability research community disagrees 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 comorbidity, to be included in an appropriate case mix correction, and argue that it does not require different

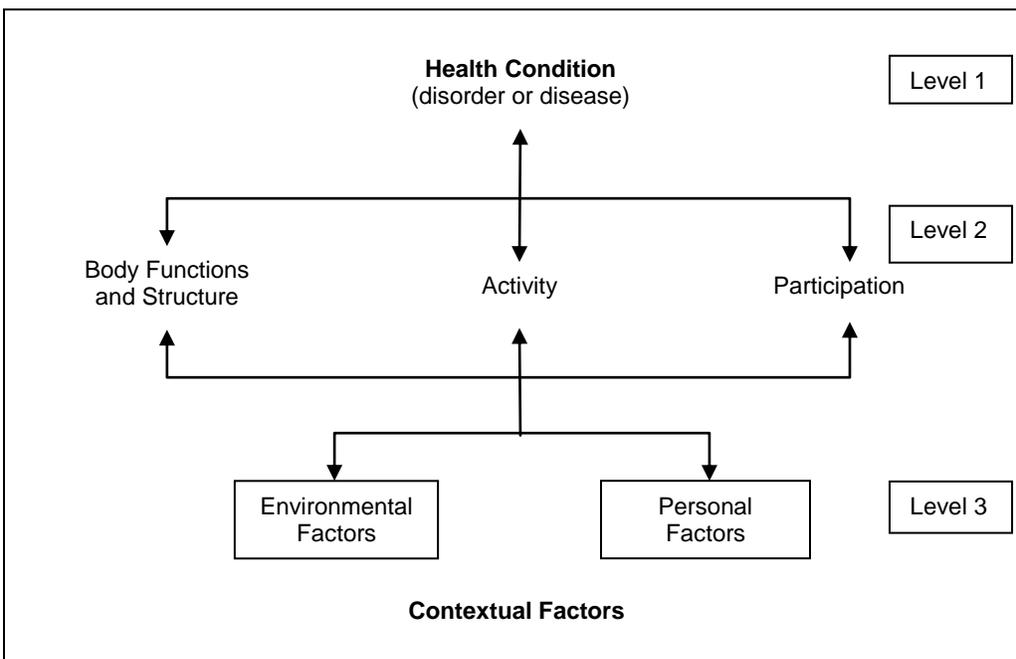
outcome measures. Others hold that in addition to the outcomes measured for the general population, specific outcome domains and measures should be tailored to the populations of interest. They advocate for more individualized approaches that include additional outcomes related to managing disability and preventing secondary conditions. The latter camp argues that quality outcomes for disabling health conditions do not address considerations directly related to disability.⁴

Outcome domains shared with general populations may require modified methodological approaches for people with disabilities. Measurement instruments 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.¹⁷ 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 as an Organizing Framework for Outcome Domains and Measures

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.¹⁸ 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 ES-2) 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 ES-2. Domains of the International Classification of Function, Disability, and Health (ICF)



From International Classification of Functioning, Disability, and Health: ICF. Geneva, Switzerland: World Health Organization; 2001¹⁸

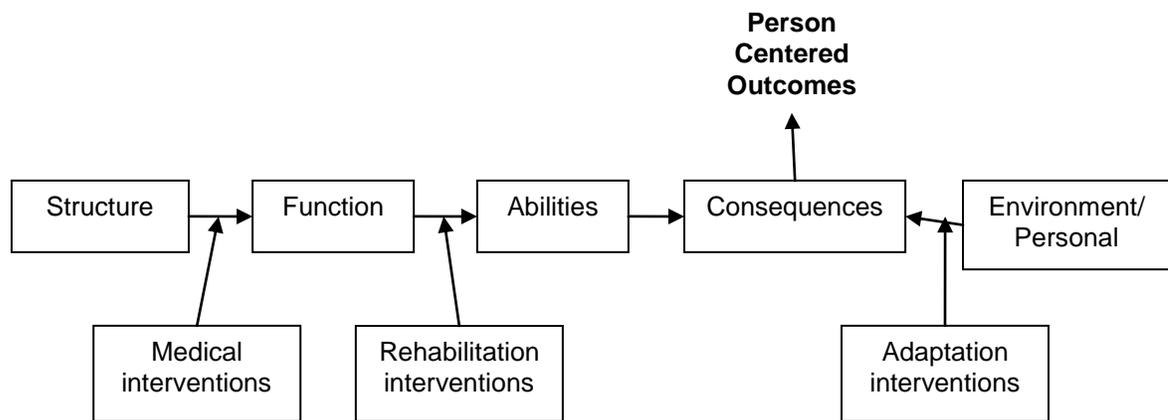
The framework identifies three levels of human functioning.

- 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 their complete environment.

Within the whole person level are 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. A derived version, the ICF-CY, or ICF for Children and Youth, was created to account for the developmental nature of children and youth.

Figure ES-3 provides a more linear illustration of the ICF to highlight how intervention points 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. These interventions ultimately lead to person-centered outcomes, such as quality of life, or living independently.

Figure ES-3. Adapted ICF framework



Adapted from Colenbrander 2010,¹⁹

The length and complexity of the ICF highlights the challenge of outcomes conceptualization, categorization, and assessment. The ICF, like the ICD codes, involves numerous chapters within each of the bodily systems, bodily function, abilities, participation, and contextual domains, with detailed coding to learn. Some outcomes may be viewed either as intermediate or end-points 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 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 ES-1. Nor does the ICF encode satisfaction or process measures used to assess the effectiveness of a new program

How we measure outcomes for research or quality improvement can have unintended consequences on 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 as a way to combine 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 SF-36E 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 NIH's PROMIS (Patient-Reported Outcome Measurement Information System) initiative is developing data collection tools based on the principles of universal design.²²

Key Questions

Key Question 1

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?

Key Question 2

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?

Key Question 3

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

We focused primarily on outcome measures for medical care and care coordination for people with disabilities, with an emphasis on outcomes measures at the level of the individual rather than the population. Service settings included outpatient health, home, and community-based services. Our scope did not include severe and persistent mental illness as a primary diagnosis, or work rehabilitation. Medical conditions included basic medical care and secondary conditions common across populations of community-dwelling disabled individuals, including:

- Preventive dental care
- Preventive medical care
- Urinary tract infections

- Pressure ulcers
- Uncontrolled diabetes
- Diabetes complications
- Bacterial pneumonia
- Asthma
- Gastroenteritis
- Hypertension
- Obesity

We included measures for both process and patient-centered outcomes. In keeping with the perspective of disability as comorbidity, 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) too restrictive of the applicability of the review 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 as a starting point.

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 Key Question 1a, we included reviews, compendiums, or suggested outcome sets only if they represented a significant collaborative effort. Key Question 1b was limited to 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 where there was 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.

We searched MEDLINE, PsychINFO, and ERIC. We hand search 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 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 websites such as the CDC website.

The included literature was maintained in an EndNote bibliography. Relevant data points were abstracted to standardized Excel spreadsheets. An outcome measurement tool was described within 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 Key Question 1. Of these, 241 articles were pulled for full text review and 14 were included in this review. For Key Questions 2 and 3, a total of 5,324 care coordination articles were identified, of which 43 were included.

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

Fourteen articles were included for Key Question 1a. 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 ES-2 gives a list of outcome measures by article and domain. Greater detail is available in the full report.

Table ES-2. Outcome measure list

Study Domain	Outcome Measure List
<i>Critical evaluations of available outcome measures for given populations and outcome domains</i>	
Resnik 2009 ²³	Community Living Skills Scale (CLSS) (all 9 ICF chapters) Mayo Portland Adaptability Index (MPAI) version 4 (all 9 ICF chapters)
Participation (9 ICF activities and participation domain chapters)	Participation Measure for post acute care (all 9 ICF chapters) Psychosocial Adjustment to Illness Scale (PAIS-SR) (all 9 ICF chapters) 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)

	<p>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 The 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</p>
Vahle 2000 ²⁴	
Depression	<p>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)</p>
Andresen 2000 ²⁵	
Generic HRQoL (mixed ICF domains)	<p>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)</p>
Lollar 2000 ²⁶	
Children's Outcomes (assessed by ICF level)	<p>Rand Health Status Measure for Children (HMSC) – 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 level ABILITIES Index – Body, Person level 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</p>
Dijkers 2000 ²⁷	
Social Outcomes	<p>CHART long form (broad ICF coverage) CHART short form (broad ICF coverage) CIQ (broad ICF coverage)</p>

(Participation)	Assessment of Life Habits (LIFE-H) (broad ICF coverage) LHS (broad ICF coverage) Other outcome measures examined deemed to lack broad ICF coverage: FAI WHOQOL SF-36 RNLI GSDS-II Social Adjustment Scale Self-Report (SAS-SR) Katz Patient Adjustment Scale R2 AAP EADL
Cohen 2000 ²⁸	Katz ADLs Index Barthel Index
Functional Status	Level of Rehabilitation Scale (LORS) Patient Evaluation and Conference System (PECS) Functional Independence Measure (FIM)
<i>Single studies evaluating general population measures for use in disability populations</i>	
Kalpakjian, 2005 ²⁹	Menopause Symptom List (MSL)
Body function	
(Burggraaff 2010) ³⁰	Radner Reading Charts (RRC)
Body function	
(Nanda 2003) ³¹	Abbreviated Sickness Impact Profile (SIP68)
Health status – multiple domains	
<i>Disability-related outcomes evaluated for expansion into another disability population</i>	
Bossaert 2009 ³²	Supports Intensity Scale
Environmental	
Bagley 2010 ³³	Activities Scale ASKp38
Activity and performance	
<i>New measures</i>	
Faull 2007 ³⁴	QE Health Scale Holistic Health Measure
Multiple domains	
Alderman 2011 ³⁵	St. Andrew's-Swansea Neurobehavioral Outcome Scale
Multiple domains	
Petry 2009 ³⁶	QoL – Profound Multiple Disabilities
Multiple domains	
King 2007 ³⁷	Children's Assessment of Participation and Enjoyment (CAPE)

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.³⁸ 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 non-disabled participants.

One systematic review was tangentially related. This review assessed the effect of exercise interventions as a preventive measure on subjective quality of life for both clinical and healthy populations.³⁹ While these studies were restricted to disabled populations, the examined clinical conditions included those that commonly lead to disability. None of the 56 included studies used a mixed population of clinical and healthy populations, thus comparisons were indirect. 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.

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.

Key Question 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 43 included articles, representing 42 studies, 6 were RCTs, 9 were prospective observational designs, 3 were retrospective observational designs, 12 were before/after studies, 5 were systematic reviews/guideline studies, and 7 used survey methodology. (Table ES-3)

Table ES-3. Number of articles 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				4	4	4
Frail Elderly				6		6
Immobile + transition from inpatient					1	1
Medicaid + Disabled			3		2	5
Medicare + Disabled + Heavy users				1		1
Grand Total	20	1	3	11	8	43

Two studies of the effects of coordination focused on programs that coordinated primarily among providers.^{40, 41} One of these programs was a coordinated follow-up of infants with prenatally diagnosed giant omphaloceles;⁴⁰ the other was the PACE program targeting frail, chronically ill elderly people with the goal of keeping them in the community as long as possible.⁴¹

This study also measured several healthcare 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 also modeled, including short-term nursing home stays, hospitalizations, day center attendance, etc. 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.⁴²⁻⁵⁰ (Table ES-4) Of these, seven served children or young adults (under age 21), one served stroke survivors,⁴³ and one served the frail elderly.⁴⁵

Perhaps because care coordination programs are quite new, the literature focused primarily on the initial implementation of interventions rather than the assessment of the quality of the implementation. That is, 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,⁴³ frequency of contacts with physicians,⁴⁶ school adherence to child's treatment plan,⁴² and the Measure of Processes of Care scale (MPOC)⁵⁰ are examples of these process measures.

Table ES-4. 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

Of the 32 articles that addressed both types of care coordination, 26 were studies, two were expert guidelines, three were literature reviews, and one was a description of a program (Table ES-5).

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

A total of 104 measurements were abstracted from these 32 articles.

Table ES-5. 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)			7 (4)		15 (8)
Cost and Use	7 (7)		5 (1)	2 (2)	11 (4)	25 (14)
Health and function	4 (4)		3 (1)	12 (5)	3 (2)	22 (12)
Process	5 (1)		1 (1)	2 (2)	1 (1)	9 (7)
Satisfaction	4 (1)		2 (1)	6 (6)		12 (11)
Self-efficacy				2 (2)		2 (2)
Qualitative					1(1)	1 (1)
Guideline	6 (1)					6 (1)
Grand Total	43		11	33	17	104

Discussion

This review found several examples of efforts to critically assess outcome measures for various disabled populations. Formal outcome measure assessment criteria may be leveraged and modified by researchers interested in extending the work to new populations. One example of such criteria is that used by Andresen and colleagues to assess the state of outcome measurement science in rehabilitation.¹⁷

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.³⁸

The review generated a lengthy list of outcome measures that researchers may wish to apply to specific research endeavors. Current efforts offer the potential for cross-fertilization, and there is potential for overlap in the important questions, and appropriate outcomes, for different disability groups. While the level of detail necessary for a researcher to successfully chose 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

We found very few direct examples of work conducted from the perspective of disability as comorbidity. The scarcity of literature indicates the early stages of research development in this area.

The most important goal might be to ensure coordination of efforts in disability outcome research and evaluation across various research disciplines and approaches. A major concern is the continuing “silos” of research, which include: 1) researchers who focus on the medical interventions who strive to cure; 2) researchers who focus on rehabilitation to restore function; and 3) researchers who focus on supportive services for disabilities. Not much has changed in the

decade since Andresen and colleagues published the supplemental issue on disability outcomes research,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 healthcare services while at the same time experiencing greater healthcare needs.^{51, 52} Researchers contribute to this disparity through research designs and practices that either systematically exclude people with disabilities, or incompletely capture outcomes important to people with disabilities. Research silos contribute to this process, as do the context and environment within which researchers work.

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, is treating pneumonia in someone with mobility limitations, or a urinary infection in a person with quadriplegia, different from treating the same condition in people without disabilities? 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?

Synthesizing more knowledge in this area will require building consensus around which outcome measures should form the core of all studies. As is the case 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 various disabilities. In some instances, specific measures or variations are appropriate to assure that the right measurement spectrum is achieved so an outcome can be detected. 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 standards for measuring the same underlying construct. In some cases, the differences are a matter of scale, and 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 and cuing 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).

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:⁵³

- 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 broad scope of the review was, however, 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 comorbidity) is a vast topic. The trick will be to strike a good 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, for example, by subpopulation, outcome domain, or outcome level. As the knowledge base around populations and outcomes further develops, it will become more feasible to map the areas of overlap among the three theoretical approaches, and identify 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 key word search terms that adequately capture care coordination and outcome assessment. The articles cited should be viewed as a sample of a small and dispersed literature.

Introduction

This review belongs to a new series of reports on *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. Thus, optimal care requires coordination among those involved in various sectors, the goal being to maximize the function and quality of life of a person with a disability. 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).

This review examines how health care outcomes have been assessed for people with disabilities. Disabilities are often broadly categorized as physical, intellectual, or developmental. They can also be differentiated by etiology: 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, outcome measures are essential for evaluating quality care. Outcome measures may be even more useful in combination with *process measures* which 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, efforts to develop customized measures have been only modest.^{4, 53}

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, which is 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. 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, which should then 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. This project is directed at the issues addressed in the last two rows. For that context, disability may often be

thought of as a comorbidity 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 a limiting disability.

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 function 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	Typical condition-specific outcomes for the problem Generic outcomes (e.g., function, QOL) Costs Utilization of second order services (e.g., hospitals, ERs)

What Is Salient For The Question At Hand? Multiple Perspectives

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.”⁴ 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.⁴

In the absence of consensus definitions, broad classifications can provide a useful alternative tool. 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 non-medical 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 disabling condition, rather than the person, as the problem. This approach separates the concepts of disability and health.^{5, 54} 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.⁵⁵

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. The person's capacity to participate is thereby reduced because of not receiving the therapy needed to maintain function. 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.⁵⁶ 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 & Anderson⁵⁷).

The **biopsychosocial model** emphasizes how interactions between biological, psychological, social, and cultural factors affect one's experience of health or illness.^{7, 8} 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.

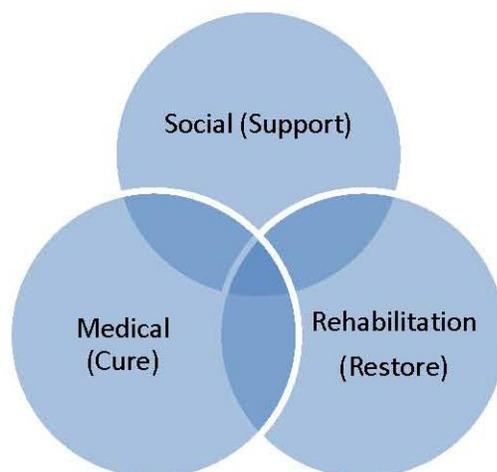
The social and biopsychosocial models have influenced a number of Federal initiatives, such as the Americans with Disabilities Act of 1990, the New Freedom Initiative, The Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities of 2005, and Healthy People 2010. 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.⁵⁸ 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.⁵⁹

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,⁶⁰ which incorporates theories of Health Environmental Integration (HEI). 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).⁶⁰

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 3 general paradigms on care and support for people with disabilities overlap. The **Social paradigm** is employed by 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** includes professionals who diagnose and treat people with disabilities, providing general medical care as well as care specific to treating 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** includes professionals from the medical and allied professional fields, 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 return the person to “normal” functioning. For people with newly disabling conditions, this means restoring the level of function they enjoyed before the disability occurred. 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 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 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 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 to adapt his or her environment in order to foster the fullest participation possible.

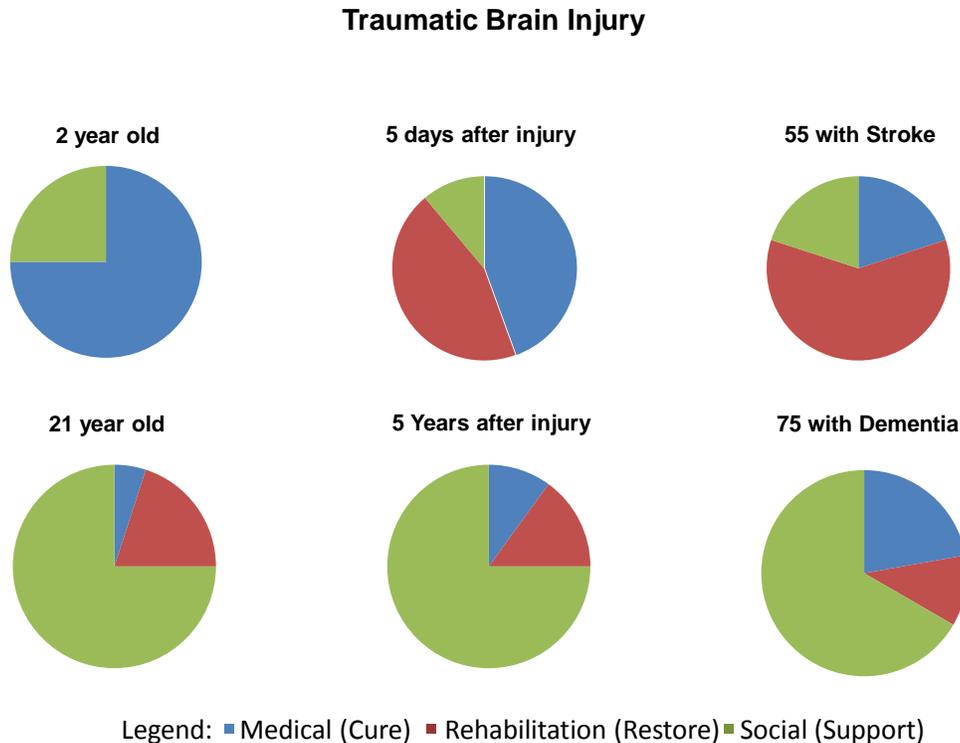
For people with acquired disabilities, the period of treatment and rehabilitation is often prolonged. The goal, at least initially, is to restore the person to the same level of function as before the disability was acquired. However, for many, full restoration is not possible, and the emphasis shifts 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 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. The theory of Selection, Optimization and Compensation, which addresses a major coping strategy,⁶¹ is a mainstay of gerontology.

The distinction among these etiologies of disability is not pure. Persons 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 persons survive into older adulthood, they are subject to age-related changes as well, and at younger chronological ages than the general population.⁹

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 supports needed to live a fully included life even if the underlying disability 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 supports needed to live fully included lives. People with disabilities that result from degenerative conditions or the aging process often continue seeking curative or rehabilitative supports until it is clear that death is imminent, at which time palliative care is often sought. The following diagram 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 Centers for Medicaid and Medicare Services’ Money Follows the Person allow for more of the supports 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 that all people of that age group suffer, 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 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 confined to a wheelchair because of a traumatic event is visiting his father, confined to a wheelchair 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 a catheter in him and let's get on with life."

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	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/quadriplegia	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

Turning back to the concept of disability as a comorbid condition that complicates 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. An extension of the IoM framework proposed in their report "Crossing the Quality Chasm" (2001)⁶² provides a comparison. The IoM 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.⁶³ Of the population segments outlined in the subgroups, given in Table 3, groups 5 and 8 are most like the populations with disability relevant to this review. 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 priorities

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 end of life

From Lynn J, Straube BM, Bell KM, et al. Using population segmentation to provide better health care for all: the “Bridges to Health” model. *Milbank Quarterly*, 2007;85(2):185-208

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.⁹ While specific consequences vary by disabling condition, a common pattern is that this group may manifest age-related conditions at a younger age.^{10-14, 15} Thus, distinguishing the issues attributable to the underlying disability from those associated with aging presents a special challenge. In this way, underlying disability accentuates the long-standing geriatric dilemma of identifying 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.⁵⁸ Participants with disabilities use different criteria and themes when rating their health compared to those without disabilities. For example, 4 major health themes emerged from 19 focus groups with people with disabilities: the ability to function and the opportunity to do what you want, independence and self-determination, an interrelated physical and emotional state of well-being, and being unencumbered by pain.¹⁶ Compared to people without disabilities, these focus groups stressed the importance of resilience, and emphasized their experience of health as distinct from their disabilities.

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 comorbidity, 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, and 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.⁴ 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.”⁴ For example, the goals for treating a person with quadriplegia with an indwelling catheter may differ from those in treating 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.⁶⁴

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 multi-domain, 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.

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-36,⁶⁵ 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.⁶⁶ These approaches place an immediate ceiling on the potential benefit any people with a disability 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 disabilities,²⁰ 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 re-ordered 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.¹⁷ 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.²⁰ 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 to the lived experience of people with disabilities and may even offend.²⁰

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.²⁰ Universal design is being extended to the field of health services research.²⁰ Universal design strives to develop products that are usable by all people, to the greatest extent possible, without adaptation or specialized design.²¹ The NIH’s PROMIS (Patient-Reported Outcome Measurement Information System) initiative is developing data collection tools based on the principles of universal design.²²

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.

The relationship between disease and disability can be examined in terms of two different underlying paradigms. In one case, disability is a comorbidity acting as a confounder in elucidating the relationship between the treatment and the disease outcome. Treating the disability as demographic descriptor, as suggested in Healthy People 2010, is one technique to address this issue. 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 –

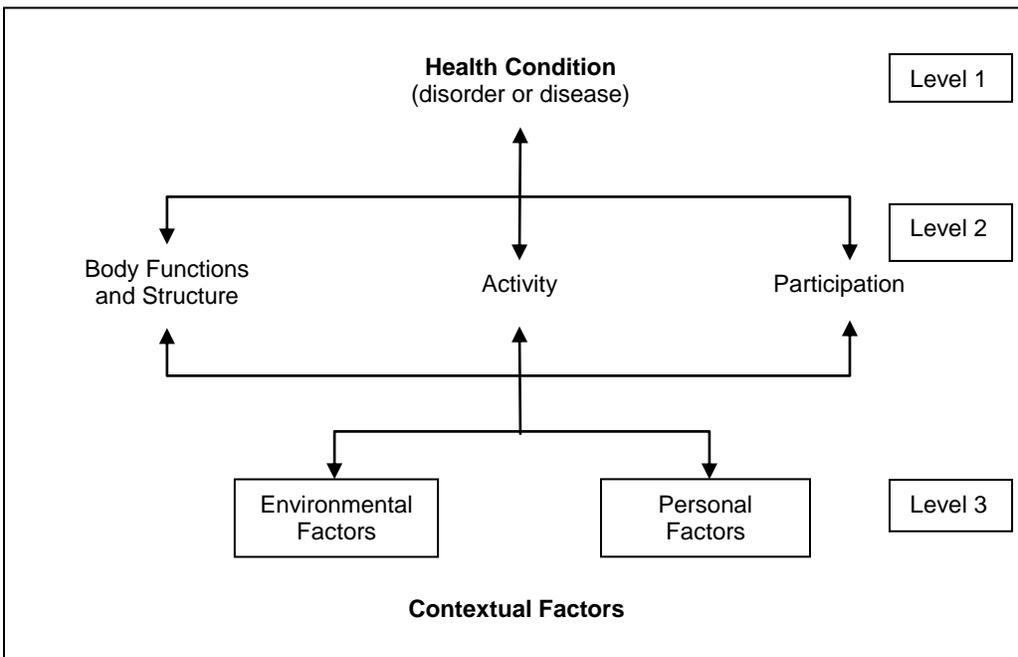
Disability Supplement where outcomes such as short hospital stays and days of activity restriction in the previous 2 weeks were found to vary with age, gender, race, overall health status, disability type, and health coverage status.⁶⁷ Alternatively, the disability may affect either the choice of treatment 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.^{68, 69} This variation imposes substantial problems in assessing the effects of treatment. At a minimum, it implies an error in measurement. It makes assessing the extent of change more difficult. 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 as an Organizing Framework

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.¹⁸ 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)



From International Classification of Functioning, Disability, and Health: ICF. Geneva, Switzerland: World Health Organization; 2001¹⁸

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 their complete environment. Within the whole person level are 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.⁷⁰ Contextual factors include environmental (or 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. Personal factors also contribute to an individual’s lived experience. Personal factors include 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 spent on elaborating 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 suggests that the activity and participation domains were not distinguishable, and has pointed to five potential distinct sub-domains: 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.⁷⁰

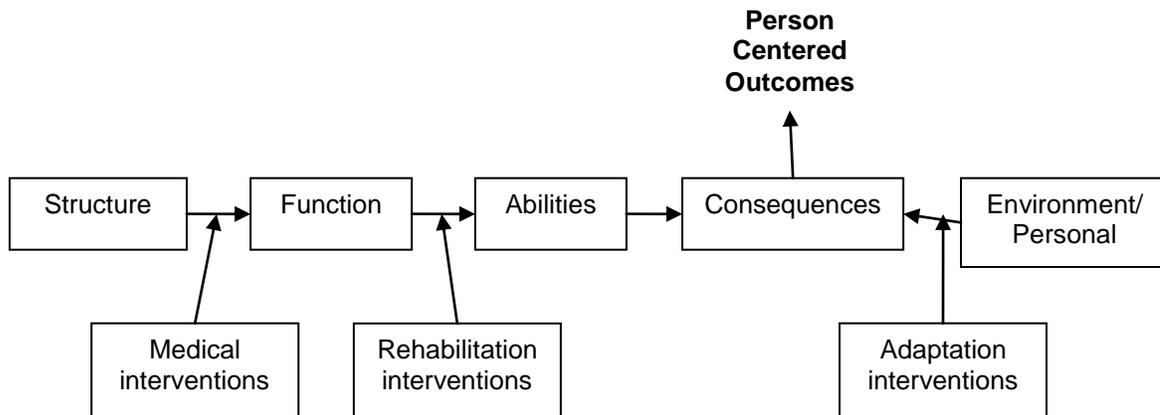
Some progress in creating the clarity and discrimination necessary for empirical measurement and testing has been made in the last few years. While that level of analytical detail is beyond the scope of this review, some notable efforts are being made to establish useful ICF-based measurement.⁷⁰ For 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, has been tested for basic mobility.⁷¹

One commenter noted that the lack of a common conceptual scheme and language for disablement models has led to confusion within the scientific literature.⁷² 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).⁷³ Professionals involved in rehabilitation outcomes research suggest that the ICF framework will allow the sharing outcomes across episodes of care that is necessary for evaluating quality coordinated care.⁷⁴ 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 conceptualizing and researching functioning and disability.⁷⁵

Figure 4 provides a more linear illustration of the ICF to highlight how intervention points 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



Adapted from Colenbrander 2010,¹⁹

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 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. Similarly, satisfaction or process measures used to assess the effectiveness of a new program are also not encoded in the ICF.

The discussion on the characteristics of measurement above is, of course, equally relevant with regard to the ICF. Since there are multiple disability etiologies, classifications, definitions, and disability profiles, it is important to 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 comorbidity. How should prevention or treatment be provided for a medical condition for a person who happens to be experiencing a disability at that moment in time?

Key Questions

The Key Questions were discussed with AHRQ, the lead Evidence-based Practice Center (EPC) of the CQG series, 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. Our key questions focus on the quality assessment component of quality improvement:

Key Question 1

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?

Key Question 2

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?

Key Question 3

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

The project scope included community-dwelling people of all ages with diagnosed 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 work rehabilitation was not in scope. Severe and persistent mental illness (SMI) as a primary diagnosis was determined to be outside the project scope, since 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 person 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.”⁷⁶ Preventing secondary conditions is identified as an important goal.⁷³ Research identifying secondary conditions is growing,⁷⁷⁻⁸¹ including efforts to validate an instrument that identifies secondary conditions using ICD-9 codes.⁸² For the purposes of this report, included secondary conditions are those that also represent ambulatory care-sensitive conditions. This definition was chosen because 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
- Uncontrolled diabetes
- Diabetes complications
- Bacterial 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.³ 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.”¹ Coordination of care may extend beyond health care services to encompass other services for people with disabilities.

Care coordination is a multidimensional construct.³ 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.^{3,53} One framework cites coordination activities to achieve care coordination as including³:

- 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 which we might add assuring that the 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.³ 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

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 comorbidity, 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 resource intensive if all disabilities were included, or the applicability of the review was too restricted if only a few example disability conditions were included.

Methods

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), 4) social service groups including some health component (e.g., helping ensure disabled kids 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. There has been noted cross-fertilization of ideas between these health care settings. Other international settings, however, were unlikely to be applicable to the U.S. setting.

Key Question 1A

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.

Key Question 1B

For Key Question 1b, 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. We looked for studies that enrolled both disabled and non-disabled populations.

Search Strategy

Published Literature

We searched MEDLINE, PsychINFO, and ERIC. 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.

Key Question 1A

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

Key Question 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.

- We handsearched for studies evaluating the program “Living Well With a Disability” Four journal articles were identified and abstracted.

Key Question 2 and 3

We used the MeSH terms for KQ 1 to identify the populations. The results were cross searched 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 websites such as the CDC website. 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.

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. 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 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.

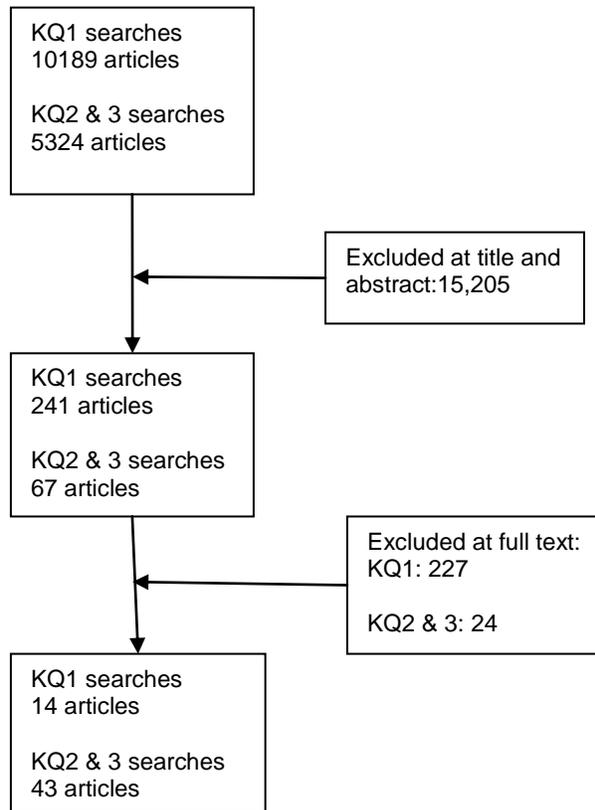
Applicability

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.

Results

Search Results

A total of 10,189 articles were identified with the search algorithms for Key Question 1. Of these, 241 articles were pulled for full text review and 14 were included in this review. For Key Questions 2 and 3, a total of 5,324 care coordination articles were identified, of which 43 were included.



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 comorbidity. The majority of the presented outcomes efforts generally stem from the perspective of disability as the main condition of concern. There were no articles identified 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.

Thirteen articles were included for Key Question 1a. Table 4 gives a list of outcomes by article and ICF domain. 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.

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 ²³ Participation (9 ICF activities and participation domain chapters)	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) 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 The 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 2000 ²⁴ Depression	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) Talbier Brief Distress Inventory and Medical-based Emotional Distress Scale (TBDI)

	Sickness Impact Profile (SIP) Medical Outcomes Study Short-Form Health Survey (SF-36)
Andresen 2000 ²⁵	SF-36 (examples included testing in 15 disability groups) SIP (examples included testing in 9 disability groups)
Generic HRQoL (mixed ICF domains)	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)
Lollar 2000 ²⁶	Rand Health Status Measure for Children (HMSC) – 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 level ABILITIES Index – Body, Person level 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 2000 ²⁷	CHART long form (broad ICF coverage) CHART short form (broad ICF coverage)
Social Outcomes (Participation)	CIQ (broad ICF coverage) Assessment of Life Habits (LIFE-H) (broad ICF coverage) LHS (broad ICF coverage) Other outcome measures examined deemed to lack broad ICF coverage: FAI WHOQOL SF-36 RNLI GSDS-II Social Adjustment Scale Self-Report (SAS-SR) Katz Patient Adjustment Scale R2 AAP EADL
Cohen 2000 ²⁸	Katz ADLs Index Barthel Index
Functional Status	Level of Rehabilitation Scale (LORS) Patient Evaluation and Conference System (PECS) Functional Independence Measure (FIM)
<i>Single studies evaluating general population measures for use in disability populations</i>	
Kalpakjian, 2005) ²⁹	Menopause Symptom List (MSL)
Body function	
(Burggraaff 2010) ³⁰	Radner Reading Charts (RRC)
Body function	
(Nanda 2003) ³¹	Abbreviated Sickness Impact Profile (SIP68)
Health status – multiple domains	
<i>Disability-related outcomes evaluated for expansion into another disability population</i>	

Bossaert 2009 ³²	Supports Intensity Scale
Environmental	
Bagley 2010 ³³	Activities Scale ASKp38
Activity and performance	
New measures	
Faull 2007 ³⁴	QE Health Scale Holistic Health Measure
Multiple domains	
Alderman 2011 ³⁵	St. Andrew's-Swansea Neurobehavioral Outcome Scale
Multiple domains	
Petry 2009 ³⁶	QoL – Profound Multiple Disabilities
Multiple domains	
King 2007 ³⁷	Children's Assessment of Participation and Enjoyment (CAPE)
Note – More detail on articles provided in following Tables 5,8-10.	

Critically Evaluated 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 2000.²⁴⁻²⁸ 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.²⁶ 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 was focused on disability as a primary condition, not a comorbidity. However, it was noted that while functional measures have often been used for program quality assessment, there isn't adequate research to support the validity of the measures for such use.²⁸ Models for case-mix adjustment are also lacking.²⁸

A later paper examined a much larger set of outcomes measures for participation,²³ compared to the paper published in 2000, where the term social outcomes was used.²⁷ Both papers determined that 5 outcome measures comprehensively mapped to all 9 chapters of the ICF. However, across the 2 sets of 5 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 colleagues⁸³ used the criteria established for the series on disability outcomes research¹⁷ to assess wheel-chair specific activity and participation outcome measures. The study provided a similar report card for 6 outcome measures.

Table 5. Articles with critical assessments of outcome measures

Article	Domain	# Measures Screened	# Measures Evaluated	Criteria	Comments
Vahle 2000 ²⁴	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 ²⁵	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 ²⁶	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 ²⁷	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 ²⁸	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 ²³	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.

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 6. Select measures from the rehabilitation outcome database (<http://www.rehabmeasures.org/default.aspx>)

Outcome Measure (acronym, title)	Purpose	Area of Assessment	ICF Domain/ Domain	Assessment Type	Diagnosis/ Populations Tested	Age Range	Psychometrics SEM, MDC, MCID, Cut-off 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 estab, Not estab, Not estab, 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 estab, 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 estab, Not estab, Yes	
BDI-II Beck Depression Inventory	Quantifies depression severity	Depression	Body Function Emotion	Patient reported	Medical patients	13-64	Not estab, Not estab, Not estab, 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.

Outcome Measure (acronym, title)	Purpose	Area of Assessment	ICF Domain/ Domain	Assessment Type	Diagnosis/ Populations Tested	Age Range	Psychometrics SEM, MDC, MCID, Cut-off 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 estab, Not estab, Not estab, Not estab	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 estab, Not estab, Not estab, 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 estab, Not estab, Not estab, Not estab, Yes	Some floor/ceiling effects may be present in sub-scales. Differences based on age, gender, education may be present.

While specific disabling conditions are outside the scope of this review, 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.^{84, 85} 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.⁸⁶ The core sets are intended to recommend data points for robust clinical records and assist in outcome measure development. Core sets have been reported on for ankylosing spondylitis,⁸⁷ breast cancer,⁸⁸ depression,⁸⁹ osteoporosis,⁹⁰ chronic ischemic heart disease,⁹¹ low back pain,⁸⁵ chronic widespread pain,⁹² osteoarthritis,⁹³ stroke,⁹⁴ geriatric patients in early post-acute care rehabilitation⁹⁵ obstructive pulmonary disease,⁹⁶ obesity,⁹⁷ diabetes,⁹⁸ and rheumatoid arthritis.⁹⁹

Another relevant example of consensus development is found in Hillier and colleagues work.³⁸ 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
Activity	Frenchay Activities Measure
	Home and Community Environment Instrument (HACE)
Body structure function:	
Cognitive	Rivermead Behavioral Memory Test
Psychological	Short Orientation-Memory-Concentration Test
Neuromuscular	Geriatric Depression Scale
	Manual Muscle Testing
	Tardieu Scale
	Wolf Motor Function Test
	Grip Strength
Activities	
Balance & falls	Step Test
	Activities specific Balance Confidence Scale
	Postural Assessment Scale for Stroke
Mobility/gait	Timed Up and Go Test
	Motor Assessment Scale (mod)
	Six minute walk test
Upper limb	Chedoke Arm & Hand Activity Inventory
	Hand Active Sensation Test
	Nine Hole Peg Test
Communication & Swallowing	Frenchay Dysarthria Assessment
	Western Aphasia Battery
	Voice Handicap Index
	RBH Outcome Measure for Swallowing
Personal factors	
Coping	Coping Strategy Indicator
Behavior and affect	Neuropsychology Behavior and Affect Profile in Stroke Patient
Activity and/or participation	
Goals	Canadian Occupational Performance Measure
	Goal Attainment
HRQoL	Assessment of QoL

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):511-20.³⁸

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,²⁹ elderly patients with low vision,³⁰ and a mixed adult population with generally disease-acquired, or aging into disability.³¹ (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) ²⁹ US	Assess symptoms related to menopause	NA (body function)	Patient reported	Polio Acquired - disease 40-65	Factor analysis suggests underlying factor structure differs for disabled women. Possible ceiling effect for sleep disturbance. Post-polio sequelae may obscure classic menopause symptoms.
RRC Radner Reading Charts (Burggraaff 2010) ³⁰ 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) ³¹ US	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 that 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) ³² Netherlands	Assess support needs of people with disabilities	Personal and social skills; Community living activities, ADL, 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) ³³ US	Assess frequency of performance of childhood activities	ADL, 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 (Faull 2007) ³⁴ 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) ³⁵ 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) ³⁶ 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) ³⁷	Measures participation in recreation and leisure activities	Recreation, Active physical, social, skill based, and self-improvement activity.	Interviewer	Children (6-18 yrs) 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 did not find any eligible studies of basic medical needs and secondary conditions that examined a mixed population of disabled and non-disabled 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.³⁹ 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.

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.

Key Question 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 43 included articles, representing 42 studies, 6 were RCTs, 9 were prospective observational designs, 3 were retrospective observational designs, 12 were before/after studies, 5 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 articles 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				4	4	4
Frail Elderly				6		6
Immobile + transition from inpatient					1	1
Medicaid + Disabled			3		2	5
Medicare + Disabled + Heavy users				1		1
Grand Total	20	1	3	11	8	43

Of the 43 included articles, 32 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 Key Questions 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 which included elements of both.

Coordination among providers

Two studies of the effects of coordination focused on programs primarily coordinating among providers.^{40,41} One of these programs was a coordinated follow-up of infants with prenatally diagnosed giant omphaloceles;⁴⁰ the other was the PACE program targeting frail, chronically ill elderly people with the goal of keeping them in the community as long as possible.⁴¹

Danzer et al. used the Bayley Scales of Infant Development, which measures neurodevelopment in infants, as their primary outcome measure.⁴⁰ 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).⁴¹ 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 healthcare 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 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.⁴²⁻⁵⁰ Of these, seven served children or young adults (under age 21), one served stroke survivors,⁴³ and one the frail elderly.⁴⁵

Of the child-focused studies, three focused on children or young adults with physical disabilities (one of these was a systematic review).⁴⁸⁻⁵⁰ and two looked at interventions for children with TBI.^{44, 47} One study addressed the broad category of children with special healthcare needs.⁴⁶ One study was focused quite narrowly on children with dysfunctional elimination syndrome.⁴²

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.⁴⁸⁻⁵⁰

Process measures

Perhaps because care coordination programs are largely still quite new, the literature was primarily focused 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,⁴³ frequency of contacts with physicians,⁴⁶ school adherence to child's treatment plan,⁴² and the Measure of Processes of Care scale (MPOC)⁵⁰ 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.⁴²

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

Both coordination among providers and between providers and family/social services

Of the 32 articles that addressed both types of care coordination, 26 were studies, 2 were expert guidelines, 3 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 9 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 21-65) were addressed in 3 of the articles.

A total of 104 measurements were abstracted from these 32 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 ER 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 in only articles on children and the elderly. There were 4 articles each on children and the elderly which 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 9 such measures from 5 studies.

Only articles on the elderly included measures of self-efficacy. There were two studies which measured this domain.

Eleven 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)			7 (4)		15 (8)
Cost and Use	7 (7)		5 (1)	2 (2)	11 (4)	25 (14)
Health and function	4 (4)		3 (1)	12 (5)	3 (2)	22 (12)
Process	5 (1)		1 (1)	2 (2)	1 (1)	9 (7)
Satisfaction	4 (1)		2 (1)	6 (6)		12 (11)
Self-efficacy				2 (2)		2 (2)
Qualitative					1(1)	1 (1)
Guideline	6 (1)					6 (1)
Grand Total	43		11	33	17	104

Care coordination is one component of quality. Within quality improvement, an important effort to develop and report a standard set of performance measures in the National Core Indicators (NCI).¹⁰⁰ The NCI is a collaborative effort between the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI). The goal of the collaboration was to develop a core set of measures states use to manage quality of developmental disability services, and to allow comparisons between states. 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 this review covers, the full set of outcomes is reproduced in Table 14.

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

Sub-domains	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
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

Discussion

This review revealed an abundance of outcome measures. Research that incorporates disability as comorbidity is lacking, despite some early efforts in care coordination and related outcome and performance assessment.

Our review found several examples of efforts to critically assess outcome measures for various disabled populations. Formal outcome measure assessment criteria (such as the criteria used by Andresen and colleagues to assess the state of outcome measurement science in rehabilitation)¹⁷ can be leveraged and modified by researchers interested in extending the work to new populations.

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.³⁸

The review generated a lengthy list of outcome measures that researchers may wish to apply to specific endeavors. Current efforts offer the potential for cross-fertilization, and there is potential for overlap in the important questions, and appropriate outcomes, for 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

We found very few direct examples of work conducted from the perspective of disability as comorbidity. This scarcity of literature indicates the early stages of research development. However, our sampling clearly demonstrates how much disability and quality improvement could benefit from organized databases of critically assessed outcome measures.

Typically, systematic reviews distinguish between patient-centered and intermediate outcomes. The tools we uncovered fall into both groups. Issues of access are a separate 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.

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, 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. 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 and cuing 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).

Much work remains for establishing an adequate bank of measures. The criteria used by Andresen and colleagues to evaluate measurement tools are useful for this.¹⁷ Table 15 shows how these criteria were applied to disability outcomes research.

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

Similar work is needed to move the disability research field forward in assessing quality of care and care coordination. One framework for measures for coordinated care for people with Medicaid Managed Care suggests the following categories:⁵³

- 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 most important goal might be to ensure coordination of efforts in disability outcome research and evaluation across the spectrum of research disciplines and approaches. A major concern is the continuing “silos” of research, which include: 1) researchers who focus on the medical interventions and who strive to cure; 2) researchers who focus on rehabilitation to restore function; and 3) researchers who focus on supportive services for disabilities. Not much 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.

Researchers may be inadvertently contributing to a problem persistently faced by people with disabilities, which is that they simultaneously experience disparities in healthcare services and greater healthcare needs.^{51, 52} Researchers contribute to this disparity through research designs and practices that systematically exclude people with disabilities, or incompletely capture outcomes important to people with disabilities. Research silos add further to this problem, as do the context and environment within which researchers work. As Meyer and Andresen state, researchers design research in ways that exclude people with disabilities because researchers themselves also have constraints.²⁰

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, is treating pneumonia in someone with mobility limitations, or a urinary infection in a person with quadriplegia, different than treating the same condition in people without disabilities? 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 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?

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 for people with disabilities (whether it targets disabling condition, or treats the disability as comorbidity) is a vast topic. The trick will be to strike a good balance between scopes constrained enough for successful search processes, and scopes 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 articles cited should be viewed as a sample of a small and dispersed literature.

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List of Acronyms and Abbreviations

AAP	Adelaide Activities Profile
ADL	Activities of daily living
AHRQ	Agency for Healthcare Research and Quality
BDI	Beck Depression Inventory
CDC	Center for Disease Control
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	Closing the Quality Gap series
CVD	Cardiovascular disease
DACL	Depression Adjective Check List
EADL	Extended Activities of Daily Living Scale
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
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
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
NIH	National Institutes of Health
NCI	National Cancer Institute
Nottingham	Nottingham Extended Activities of Daily Living
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
TEP	Technical Expert Panel
WHOQOL	World Health Organization Quality of Life Scale
YQOL-S	Youth Quality of Life Instrument