Evidence-based Practice Center Systematic Review Protocol

Project Title: Closing the Quality Gap Series: Measuring Outcomes of Care for Persons With Disabilities

I. Background and Objectives for the Systematic Review

This review is part of a new series of reports on *Closing the Quality Gap: Revisiting the State of the Science* (hereafter, CQG series). The original CQG series was commissioned by the Agency for Healthcare Research and Quality (AHRQ) to assemble a critical analysis of the existing literature on quality improvement strategies and issues for the disease and practice priorities identified in the 2003 Institute of Medicine report *Priority Areas for National Action: Transforming Health Care Quality.* AHRQ was also charged with the tasks of continuous assessment of progress towards quality and updating the list of priority areas. These tasks included:

- Developing and improving data collection and measurement systems for assessing the effectiveness of quality improvement efforts.
- Supporting the development and dissemination of valid, accurate, and reliable standardized measures of quality.
- Measuring key attributes and outcomes and making this information available to the public.

The Improving Quality Measurement Work Group of the Quality Interagency Coordination Task Force categorizes quality measures into the domains of access, outcome, patient experience, population health, process, structure, and use of services. AHRQ has subsequently identified people with disabilities as a priority population.

This review will examine how the outcomes of health care for people with disabilities are assessed. Disabilities come in various types, often broadly categorized as physical, intellectual, or developmental. They can also be differentiated by etiology: developmental disabilities, disabilities acquired through trauma, disabilities which are manifestations of disease processes, and disabilities that are iatrogenically acquired from treatments for disease conditions. Persons with disabilities can experience a changing disability profile as they age (aging with disability), while otherwise healthy people may develop disability as a consequence of the aging processes (aging into disability). Regardless of disability type or etiology, outcome measures to evaluate quality care for people with disabilities are essential.

In addition to the basic repertoire of condition-specific and generic outcomes measures, additional measures, or the methods with which they are assessed, may be appropriate for this subset (or for specific subgroups organized by type of disability). For medical care, quality outcomes for health conditions that are disabling often do not address considerations directly relating to disability. 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.” For example, the goals for treating a quadriplegic patient with an indwelling catheter may be different from those in someone else. Appropriate outcome measures may not differ between disabled and nondisabled populations, but the methodological approach to assessing outcomes may require that patient characteristics or case mix be accounted for. The outcome measures may also be enhanced by using selected process measures that address the extent and success of coordination of care, for example, 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 and efforts to develop customized measures have been modest.4,5

People with disabilities can present special care problems. Their care is often complicated by inherent multimorbidity. Medical problems can be exacerbated or complicated by the presence of other problems, including medical, psychological, economic, and social. Thus, people with disabilities can present complex care needs that require coordination among those involved in their care to achieve relative health. If the goal of such care is to maximize the function and quality of life of a person with a disability, the coordination may need to extend across the care spectrum to address various elements of life (e.g., medical care and schools or social agencies). Achieving community integration requires care coordination across a number of disciplines or even social service agencies.

A consensus definition for care coordination does not exist, even as it is pursued as an important domain of quality care.6 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, and a number of frameworks to describe care coordination and facilitate related research have been developed (e.g., Sofaer et al.5 and McDonald et al.6). One framework6 cites coordination activities to achieve care coordination as including:

- Establishing accountability or negotiating responsibility
- 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
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 based expands. A taxonomy of quality improvement strategies was developed for the original CQG series. 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.

This review focuses on the process and outcomes measures alluded to above and their characteristics rather than the results of their use in specific quality improvement studies. The review will result in a mapping exercise that will clarify what general population outcomes have been assessed or adjusted for use with people with disabilities, how those outcomes are used, what care coordination measures have been used, and where there are important gaps in available outcomes and measures. It represents a step in helping to create a more systematic taxonomy for discussing these issues and is occurring in the context of other related efforts that will be noted in the review. This information will help researchers and decisionmakers address missing measures and design future quality improvement efforts.

II. The Key Questions

The Key Questions (KQs) have been 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 KQs focus on the quality assessment component of quality improvement. They are:

Question 1

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

Source: www.effectivehealthcare.ahrq.gov
Published Online: August 3, 2011
a. What general population outcomes have been validated on and/or adjusted to accommodate disabled populations?

b. 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?

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

**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?

**Question 3**

What measures have been used to assess effectiveness of care for people with disabilities living in the community in the context of community/health provider coordination?

We adapted the traditional systematic review PICOTS to fit the methodological nature of the KQs. The sections on population, outcome measures, and quality measurement research factors below provide specifics for the KQs.

- **Population(s):**

  We will focus on people of all ages with diagnosed and/or documented physical and cognitive disabilities who required basic medical services. Individuals with basically similar disabilities may face different challenges at different stages of their lives or may respond differently based on the etiology of the disability. Table 1 shows the populations as a matrix of age crossed by disability category. We will not include people at risk for developing a disability.

<table>
<thead>
<tr>
<th>Type</th>
<th>Children (0–17 yrs)</th>
<th>Transitional Age (18–26 yrs)</th>
<th>Adult (18–64 yrs)</th>
<th>Old (65+ yrs)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Developmental</td>
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<td>Intellectual</td>
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<td>Iatrogenic</td>
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Classification schemes are approached in different ways. One approach is to use a medical orientation, focusing 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. We will not impose a single classification scheme but rather note the disability classifications used in the literature.
People with severe and persistent mental illness (SMI) as a primary diagnosis are outside the scope of this review. The disability profile of people with SMI, including the cyclical nature of SMI, suggest that the processes and outcomes needed for this population would be qualitatively different. Also, the potential size and scope of a review such as this without reasonable scope boundaries would make the task unfeasible.

**Intervention:**

Technically, there is no intervention per se in this review, but we will use this category to define the nature of the services being addressed by our outcomes measures. We will use the concept of basic medical service needs to further narrow the review scope to a meaningful but manageable set of medical services and their associated outcomes. Basic medical service needs for this project are defined as preventive dental and medical care and care for common secondary conditions. For the purposes of this report, included secondary conditions are those conditions that also represent ambulatory care-sensitive conditions. This definition was chosen because these conditions represent conditions experienced by people with disabilities that are likely to be considered prime targets for future quality improvement initiatives. The list of basic medical service needs 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

**Outcome Measures:**

We will focus on outcomes, patient experience, and care coordination process measures, because these are immediately salient to exploring the interface of medical care and disability. We will note when outcomes are measured clinically, subjectively, or by proxy.

We will focus the review on outcome measures 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 are also of interest. A framework that lays out mechanisms for achieving care coordination, in conjunction with the quality improvement strategies noted in the background section, will guide our efforts.6
Research Timing:

We will assess the duration of followup generally applied with each measure.

Research Settings:

We will emphasize measures for people living in the community. Thus, settings will include outpatient health, home, and community-based services.

III. Measurement Properties and Issues

Measurement instruments are methods used in quality research to determine whether or not improvements in outcomes of interest occur. They are a component of a research analysis plan. We will examine the psychometric properties of measurement tools and ways that they are used in the literature to assess the outcomes of care for people with disabilities. We anticipate properties and issues of interest to include:

- Psychometrics of specific measurement instruments
- Measurement time frame and the potential for fluctuating levels
- Disability cut-points (if the measure is part of general spectrum)
  - Does the disability cut-point create a potential for ceiling effects?
- Types of patient-centered measures
- Data sources

IV. Methods

A. Criteria for Inclusion/Exclusion of Studies in the Review

We will conduct a search of methods-related literature documenting the development and testing of outcome measures based on the modified PICOTS above. We will exclude outcomes designated specifically for people with severe and persistent mental illness since this population is not included as a population of interest. We will focus on health-related services and will exclude other services such as job training.

Several limitations will be placed on the literature. We will limit 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 will also limit 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, are unlikely to be applicable to the U.S. setting.
B. Searching for the Evidence: Literature Search Strategies for Identification of Relevant Studies To Answer the Key Questions

Published Literature

We will search MEDLINE, EPOC (for organizational quality improvement efforts), PEDRO (physical therapy research database), the Cochrane Library (patient education, self-management, and behavior change interventions not covered by EPOC), PsychINFO, Social Services Abstracts, and Web of Science. Search terms will be grouped to capture the major constructs: populations of interest, literature related to methodological research, and relevant service settings. Searches will be modified for each individual database. We will also hand search reference lists of relevant high-quality literature reviews. Experts in the field will be asked to contribute publications from personal files as well. Search algorithm examples for the KQ searches discussed below are provided in Appendix A.

Key Question 1 searches. We will use key words and MeSH terms for disability populations and settings, and the results will be cross searched with terms for measurement development to answer subquestion 1a. For subquestions 1b and 1c, we will use the same key words and MeSH terms for disability populations and settings to perform individual searches for each basic medical service need, while filtering for experimental research.

Key Questions 2 and 3 searches. We will use the MeSH terms for KQ 1 to identify the populations. The results will be cross searched with the care coordination terms related to the various quality improvement strategies often used in care coordination that have been identified in previous CQG systematic reviews.¹

We anticipate books on measurement to be a rich source of measurement tools. Examples of such works include:

- Comprehensive Assessment in Health Care of the Elderly: An Information Source Book
- Understanding Psychosocial Adjustment to Chronic Illness and Disability: A Handbook for Evidence-based Practitioners in Rehabilitation

The literature examining populations that include people with disabilities is vast and suffers from indexing designed to identify disease conditions rather than functional abilities. Our strategy explicitly anticipates having to commence the search with a broad approach and the possible necessity of focusing later iterations of search and synthesis in areas that prove to have a sufficient literature base. Iterative search processes will be documented, including search dates, search terms, and article hits, for process transparency.

The literature captured by the iterative search algorithms will be exported to EndNote software (Thomson Reuters, New York, NY) and screened by two independent reviewers using standardized screening questionnaires based on the inclusion/exclusion criteria. Conflicts will be resolved by consensus with a third independent investigator.

Grey Literature

Source: www.effectivehealthcare.ahrq.gov
Published Online: August 3, 2011
We will search the grey literature for monographs, white papers, and other high-quality sources of material on measurement tools using the New York Academy of Medicine Grey Literature Report and Web sites such as the National Quality Measures Clearinghouse. Grey literature will be limited to measurement tools that are in active use by important end users, such as health systems or providers of State services, or tools with established psychometric properties. Examples of the kinds of resources for measurement tools that can be found through the grey literature include:

- Participant Experience Survey Elderly/Disabled Version: A Technical Assistance Tool for States (The MEDSTAT Group, Inc.)
- Compendium of Measures and Tools for Medicaid [Title XIX] Home and Community-Based Services (AHRQ): includes measures for people with disabilities
- Compendium of Recovery and Recovery-Related Instruments (Edmund S. Muskie School of Public Service, University of Southern Maine): includes outcome measures for services given to people with developmental disabilities
- National Core Indicators (National Association of State Directors of Developmental Disability Services and the Human Services Research Institute): includes outcomes important to State agencies in tracking the quality of care for people with developmental disabilities and in making comparisons across States

C. Data Abstraction and Data Management

The included literature set will be 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, data sources, and end users will be abstracted to standardized Excel spreadsheets (Microsoft Corporation, Redmond, WA) by two independent reviewers. Disagreements will be resolved through consensus with a third investigator.

D. Data Synthesis

We will use qualitative techniques to synthesize the literature. We will describe the properties of the measures such as psychometrics, disability cut-off points, and measurement time frames and the theoretical underpinnings and definitions of disability on which they are based. We will note groups and services that are lacking available measurement tools. We will also examine, where possible, differences in measurement tools for patient outcomes or care coordination by age group or category of disability. Tables 3 through 5 provide examples of anticipated report tables.

We will also explore table variations for the tables to examine differences by age categories.

<table>
<thead>
<tr>
<th>Type of outcome</th>
<th>Developmental disability</th>
<th>Intellectual disability</th>
<th>Physical disability</th>
<th>Acquired disability</th>
<th>Iatrogenic disability</th>
</tr>
</thead>
</table>

Table 3. General population outcomes adjusted for disabled populations (KQ 1a)

Source: [www.effectivehealthcare.ahrq.gov](http://www.effectivehealthcare.ahrq.gov)

Published Online: August 3, 2011
Table 4. Independent variables used for research on basic medical service needs (KQs 1b and 1c)

<table>
<thead>
<tr>
<th>Type of outcome (break into categories for condition)</th>
<th>Quality-adjusted life years</th>
<th>Access to informed care (e.g., physician knowledge of disability)</th>
<th>Access based on living situation (e.g., home care, physician home visit)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Developmental disability</td>
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<tr>
<td>Intellectual disability</td>
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<td>Physical Disability</td>
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<td>Acquired disability</td>
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<tr>
<td>Iatrogenic disability</td>
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</table>

(One table per condition searched. More extensive tables if important patterns are identified.)

Table 5. Care coordination measures (KQs 2 and 3)

<table>
<thead>
<tr>
<th>Providers (KQ 2)</th>
<th>Family/Caregivers (KQ 3)</th>
<th>Community (KQ 3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Specialist/generalist integration</td>
<td>Empowerment and self-efficacy for advocating for and promoting care coordination</td>
<td>Social/medical integration</td>
</tr>
<tr>
<td>School/health care coordination</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Developmental disability
Intellectual disability
Physical disability
Acquired disability
Iatrogenic disability

E. Assessment of Methodological Quality of Individual Measurement Tools and Grading the Evidence for Each Key Question

We will assess the psychometric properties of the measures and their applicability to various populations. Research to establish the validity and reliability of the outcome measures with regard to relevant psychosocial domains, time frames, and the ability to discriminate levels of disability will be of particular interest.

F. Assessing Applicability

As noted above, we will address, where the literature is available, the differences in the findings for various subgroups.

V. References


VI. Definition of Terms

The following are widely used definitions of disability.

1. Social Security Administration (SSA)

   Inability to engage in any substantial gainful activity by reason of any medically
determinable physical or mental impairment(s) which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months.⁹

2. Americans with Disabilities Act (ADA) of 1990, Sec. 12101

   The term “disability” means, with respect to an individual—(A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (B) a record of such an impairment; or (C) being regarded as having such an impairment.¹⁰

3. International Classification of Functioning, Disability, and Health (ICF)

   Umbrella term for impairments, activity limitations or participation restrictions concerning a person’s functioning and disability… as a dynamic interaction between health conditions (diseases, disorders, injuries, trauma, etc.) and contextual; factors, including the social, attitudinal, and physical environments and personal attributes.¹¹

VII. Summary of Protocol Amendments

   In the event of protocol amendments, the date of each amendment will be accompanied by a description of the change and the rationale.

VIII. Review of Key Questions

   For all EPC reviews, key questions were reviewed and refined as needed by the EPC with input from the Technical Expert Panel (TEP) to assure that the questions are specific and explicit about what information is being reviewed.

IX. Technical Experts

   Technical Experts comprise a multi-disciplinary group of clinical, content, and methodological experts who provide input in defining populations, interventions, comparisons, or outcomes as well as identifying particular studies or databases to search. They are selected to provide broad expertise and perspectives specific to the topic under development. Divergent and conflicted opinions are common and perceived as health scientific discourse that results in a thoughtful, relevant systematic review. Therefore study questions, design and/or methodological approaches do not necessarily represent the views of individual technical and content experts. Technical Experts provide information to the EPC to identify literature search strategies and recommend approaches to specific issues as requested by the EPC. Technical Experts do not do analysis of any kind nor contribute to the writing of the report and have not reviewed the report, except as given the opportunity to do so through the peer review or public review mechanism.
Technical Experts must disclose any financial conflicts of interest greater than $10,000 and any other relevant business or professional conflicts of interest. Because of their unique clinical or content expertise, individuals are invited to serve as Technical Experts and those who present with potential conflicts may be retained. The TOO and the EPC work to balance, manage, or mitigate any potential conflicts of interest identified.

X. Peer Reviewers

Peer reviewers are invited to provide written comments on the draft report based on their clinical, content, or methodological expertise. Peer review comments on the preliminary draft of the report are considered by the EPC in preparation of the final draft of the report. Peer reviewers do not participate in writing or editing of the final report or other products. The synthesis of the scientific literature presented in the final report does not necessarily represent the views of individual reviewers. The dispositions of the peer review comments are documented and will, for CERs and Technical briefs, be published three months after the publication of the Evidence report.

Potential Reviewers must disclose any financial conflicts of interest greater than $10,000 and any other relevant business or professional conflicts of interest. Invited Peer Reviewers may not have any financial conflict of interest greater than $10,000. Peer reviewers who disclose potential business or professional conflicts of interest may submit comments on draft reports through the public comment mechanism.
Appendix A

KQ 1a Measurement example search

1. exp Disabled Persons/ 39840
2. exp mental disorders diagnosed in childhood/ or developmental disabilities/ 124621
3. exp child development disorders/ 12098
4. exp Homebound Persons/ 403
5. exp Frail Elderly/ 5270
6. exp mental retardation/ 73952
7. cognitive impairment$.mp. 20112
8. intellectual disabilit$.mp. 3092
9. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 214730
10. exp Disability Evaluation/ 32515
11. exp Factor Analysis, Statistical/ 16942
12. exp Psychometrics/mt, st [Methods, Standards] 3568
13. 10 or 11 or 12 52177
14. 9 and 13 4943
15. limit 14 to (english language and yr="1990 -Current") 3663

KQ 1b Pressure ulcer example search

1. exp Disabled Persons/ 39840
2. exp mental disorders diagnosed in childhood/ or developmental disabilities/ 124621
3. exp child development disorders/ 12098
4. exp Homebound Persons/ 403
5. exp Frail Elderly/ 5270
6. exp mental retardation/ 73952
7. cognitive impairment$.mp. 20112
8. intellectual disabilit$.mp. 3092
9. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 214730
10. exp Pressure Ulcer/ 8794
11. 9 and 10 120

KQs 2 and 3 Coordinated care example search

1. exp Disabled Persons/ 39840
2. exp mental disorders diagnosed in childhood/ or developmental disabilities/ 124621
3. exp child development disorders/ 12098
4. exp Homebound Persons/ 403
5. exp Frail Elderly/ 5270
6. exp mental retardation/ 73952
7. cognitive impairment$.mp. 20112
8. intellectual disabilit$.mp. 3092
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55. exp Feasibility Studies/ 32768
56. exp Intervention Studies/ 4799
57. exp Program Evaluation/ 46207
58. exp Epidemiologic Research Design/ 694315
59. 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 4431564
60. 9 and 37 and 59 4282
61. limit 60 to (english language and yr="1990 -Current") 3658