

Developing Quality of Care Measures for People with Disabilities: Summary of Expert Meeting



Contract Final Report

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Context and Goals

Today in the United States, at least 54 million people live with disabilities.¹ This number will increase substantially in coming decades, with aging “baby boomers” driving much of the growth. At the other end of the life span, rising numbers of children and youth are also living with disabilities, many assisted by technological breakthroughs and major advances in medical science. Worrisome trends linked primarily to obesity in children and young adults suggest that disability numbers also may increase when these young people reach middle-age. Thus, in coming years, a substantial fraction of the U.S. population will likely have one or more disabling conditions.

Disabilities are diverse, complicating efforts to describe the full range of specific health care needs of all those who have disabilities. The majority of individuals with disabilities need the same screening, preventive, and wellness services as do people who do not have disabilities – services to prevent or detect disease and maximize health and well-being. Depending on their physical, sensory, and cognitive status, however, people with disabilities might need these routine services to be delivered in ways that accommodate their particular impairments. In addition, that subset of individuals whose impairments result from specific diseases or clinical conditions also may require treatments or interventions for their particular underlying health conditions or functional impairments.

People also need care to prevent development of secondary conditions (i.e., other health problems causally related to their primary disabling condition). Yet others seek health services, not necessarily to treat or eliminate impairments, but instead to find ways to restore or remedy function (e.g., assistive technologies, such as wheelchairs for mobility). Data from public health insurance programs – Medicare and especially Medicaid – suggest that individuals with disabilities are among the heaviest and costliest users of health care services.

Despite these frequently intensive health care needs, little is known about the quality of care for people who have disabilities. Some information is available about the use of routine screening and preventive services among individuals with disabilities, with most studies documenting significant disparities in this care. *Healthy People 2010*,² the U.S. Surgeon General’s 2005 “Call to Action to Improve the Health and Wellness of Persons with Disabilities,”³ and the National Council on Disability’s 2009 report, *The Current State of Health Care for People with Disabilities*,⁴ address this topic. All highlight disparities in routine screening and preventive services for people who have disabilities.

In its annual *National Healthcare Disparities Report* (NHDR), the Agency for Healthcare Research and Quality (AHRQ) includes persons with disabilities and special health care needs among its priority populations (see <http://www.ahrq.gov/qual/measurix.htm>). Since 2007, the NHDR has focused on several different disparity indicators each year for persons with disabilities.^{5,6,7} In 2009, the NHDR looked at: access to care by examining delays and/or the inability to get dental care; health care utilization by quantifying dental visits; underinsurance for persons age 18-64 with private health insurance (family out-of-pocket medical expenses excluding premiums exceeding 10%

of total family income); and financial burden of health care costs for those ages 18-64 (family out-of-pocket medical expenses including premiums exceeding 10% of total family income).⁷ For all access to care measures, for example, within each race/ethnicity, income, and education group, individuals with basic activity limitations or with complex activity limitations experienced disadvantages compared with those who had neither basic nor complex activity limitations. In a number of instances, persons with complex activity limitations were more disadvantaged than those with basic activity limitations.

Although routine screening, preventive services, and the quality measures in the NHDR are important, these indicators provide relatively narrow insights into the quality of health care for persons with disabilities. However, there are several impediments to broader assessments of health care quality for people with disabilities. To address these and other issues related to measuring quality of care for people with disabilities, the Agency for Healthcare Research and Quality (AHRQ) convened a 1-day meeting of nationally recognized experts to begin the task of developing research priorities to guide future work in this field. This report summarizes the meeting, including a list of research priorities for measure development.

AHRQ Director Carolyn Clancy, MD, in her videotaped opening remarks for the meeting, noted the most fundamental problem: “The vast majority of [quality] measures and tools that we currently have at our disposal were developed without including this population. If we’re going to be truly successful in improving the quality, safety, efficiency, and effectiveness of health care for all Americans, that has to change.” Dr. Clancy noted that it was to be a working meeting, organized by AHRQ’s Division of Priority Populations Research within the Office of Extramural Research, Education, and Priority Populations, and that it was convened as part of an effort to formulate an action plan for developing quality of care measures from existing data that eventually could be used to track disparities in quality and access to care for persons with disabilities.

In his opening comments, Francis D. Chesley, Jr., MD, director of AHRQ’s Office of Extramural Research, Education, and Priority Populations, echoed Dr. Clancy’s goals. He urged meeting participants to be “driven towards a research agenda and actionable items for AHRQ.”

Expert Meeting: April 15, 2010

As noted by Dr. Clancy, the purpose of the meeting was to develop an action plan for creating quality of care measures for persons with disabilities, which could be derived from existing data. Although these quality metrics could eventually be used to identify disparities in care, identifying disparities was not the meeting’s purpose. The focus was explicitly methodological (i.e., measure development) with the goal of developing a research agenda for AHRQ concerning health care quality metrics for persons with disabilities. Given the structure and brevity of the meeting, however, its goal was not to reach an explicit consensus (e.g., ranked list of research priorities). Instead, the

purpose was to allow wide-ranging discussions to identify issues and for the interdisciplinary participants to present their perspectives and priorities.

The April 2010 meeting was the second meeting that AHRQ has convened to discuss a health services research agenda for persons with disabilities. AHRQ also sponsored a meeting on April 9-10, 2001, "Status of Health Services Research Associated with Disability." Results from that meeting were published in *The Milbank Quarterly* (Vol. 80, No. 2, 2002), with articles addressing the following topics: meeting health care needs of persons with disabilities,⁸ health care delivery system issues,⁹ health services research (HSR) for children with disabilities,¹⁰ evidence in disability outcomes and effectiveness research,¹¹ and using administrative data for HSR concerning disability.¹² The 2010 participants reviewed these papers before the meeting and sometimes framed their comments around elements of the 2001 discussions.

Dr. Clancy described the selection of meeting participants in her opening comments as follows:

We have selected participants with complementary expertise to consider the issue from multiple perspectives. Special competencies of this panel include health policy, physical medicine and rehabilitation, occupational science and therapy, geriatrics, gerontology, quality of care measurement, methodological and programmatic expertise, and expertise in many priority populations.

AHRQ aimed to invite relatively few participants so that the interdisciplinary group could engage each other fully in constructive dialogue and sharing of views. Inevitably, therefore, certain disciplines were not represented at the meeting. Participants were chosen based on their acknowledged expertise in relevant scientific and clinical areas and health services research; among Federal staff, individuals were selected from a range of agencies and organizations participating in disability-related activities within the Department of Health and Human Services (HHS), the Department of Education, and the Social Security Administration.

Appendix 1 lists participants at the 1-day meeting, which occurred at AHRQ's conference facility in Rockville, MD. Appendix 2 presents the meeting agenda. Lisa I. Iezzoni, MD, MSc, moderated the meeting, and given the explicit goal of developing a research agenda, Dr. Iezzoni frequently asked participants to frame their comments as research questions that could be addressed by AHRQ and/or its grantees. This report summarizes the meeting; the acronym **RQ** denotes the research questions (*written in italics*) articulated by meeting participants in making their points.

To further focus the discussion, Dr. Iezzoni made one additional stipulation. For AHRQ's National Healthcare Disparities Reports (NHDRs) and other Federal initiatives, considerable efforts have already been made, including by AHRQ staff, to develop population-based quality measures using national (e.g., National Health Interview Survey [NHIS], Medical Expenditure Panel Survey [MEPS]), and State (e.g., Behavioral Risk Factor Surveillance System [BRFSS]) survey data. Disability definitions for these

quality metrics are by necessity delimited by the questions contained in the surveys. Furthermore, none of these population-based surveys allow determination of quality performance at the level of individual health care providers (e.g., hospitals) or health plans.

To improve quality of care for persons with disabilities – which must be the ultimate goal – it will be important to generate quality information at the health care provider and plan levels. Only then will providers or plans have information about their shortfalls or data to track their improvements. Therefore, Dr. Iezzoni stipulated that the day’s discussion would focus primarily on designing quality measures that could be applied to individual health care providers or health plans, rather than population-based metrics derived from national or state surveys.

Defining Disability

Defining the motivating topic of the day – disability – was the first agenda item. At the outset, meeting participants recognized that their discussion was unlikely to produce a single, agreed-upon definition of disability that would suit all specific purposes. Dr. Clancy anticipated this problem in her videotaped opening comments, noting “... the heterogeneity of this population and the broad range of classifications and definitions of disability. There are more than 47 definitions that are currently in use in federally funded programs, [which] only adds to the challenges.” As an example, Table 1 presents two prominent disability definitions from Federal law; they are the definition used by the Social Security Administration (SSA) in determining eligibility for disability benefits (see <http://www.socialsecurity.gov/dibplan/dqualify4.htm>) and the definition from the 1990 Americans with Disabilities Act (ADA) (see <http://www.ada.gov/pubs/ada.htm>). Obviously, the SSA and ADA definitions serve very different purposes, and therefore it is reasonable for them to differ in emphasis and scope.

Table 1. Definitions of disability used by the Social Security Administration (SSA) and the Americans with Disabilities Act (ADA) of 1990

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."
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ADA Sec. 3(2): "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."

To summarize at the outset the results of a complex but insightful introductory discussion, the group agreed that a single, consensus definition of disability is not possible or necessarily desirable. The most appropriate, specific definition of disability will depend on the context in which it is used (e.g., establishing civil rights protections,

determining eligibility for income support programs, evaluating different dimensions of health care quality, and so on). Nonetheless, the group identified key principles in defining disability on which there was broad agreement. Participants also agreed that any initiative targeting disability must first start by defining disability for the specific purpose at hand.

AHRQ Disability Definition for Disparities Reports

In her introductory comments, Dr. Clancy stated, “Beginning with AHRQ’s *2007 National Healthcare Disparities Report*,⁵ the Agency has used a broad inclusive measure of disability. The measure is intended to be consistent with statutory definitions of disability, in keeping with the fact that factors important to people with disabilities go beyond health.” AHRQ bases its NHDRs on data drawn from the large national surveys (e.g., MEPS, NHIS), which were not the focus of the meeting. Nonetheless, to start the discussion and learn lessons from their experiences, Dr. Iezzoni asked AHRQ staff at the meeting to describe their process for defining disability for their annual disparities reports. Before starting this discussion, Ernest Moy, MD, MPH, recognized that AHRQ has not developed “specific quality measures that are unique for individuals with disabilities.” Instead, in examining disparities for persons with disabilities, the NHDRs consider the routine services that most people need, regardless of disability.

Dr. Moy noted that, given the range of Federal disability definitions, it took some years for AHRQ analysts to coalesce around a single, standardized measure of disability that would cut across Federal survey databases and could be used for multiple purposes. Frances Chevarley, PhD, briefly described efforts to derive this standardized disability measure. It began with AHRQ’s goal of including more information about persons with disabilities in the NHDR and in the *National Healthcare Quality Report* (NHQR). AHRQ convened a disabilities subgroup of the NHQR/NHDR Interagency Work Group with the assistance of the Interagency Subcommittee on Disability Statistics of the Interagency Committee on Disability Research, which comprised representatives from various Federal agencies. This group was charged with advising AHRQ on measures of disability for the NHDR/NHQR from existing data that (1) could track disparities in quality and access to care for individuals with disabilities and (2) would be comparable across national surveys. The disabilities subgroup adopted the *International Classification of Functioning, Disability, and Health* (ICF)¹³ as a model to guide the deliberations (Table 2).

Since the 2007 NHDR, AHRQ has used a broad, inclusive measure of disability that aims for consistency with statutory definitions of disability, such as the 1990 Americans with Disabilities Act (e.g., having a physical or mental impairment that substantially limits one or more major life activities) and other Federal program definitions of disability.^{5,6,7} For the purpose of the NHDR, 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. In displaying the data on disability,

Table 2. Definition of disability: International Classification of Functioning, Disability, and Health

"Umbrella term for impairments, activity limitations or participation restrictions," conceiving "a person's functioning and disability ... as a dynamic interaction between health conditions (diseases, disorders, injuries, traumas, etc.) and contextual factors," including the social, attitudinal, and physical environments and personal attributes.

paired measures are shown to preserve the qualitative aspects of the data. Limitations in basic activities represent problems with mobility and other basic functioning at the person level; limitations in complex activities represent limitations encountered when the person, in interaction with the environment, attempts to participate in community life. Limitations in basic activities represent problems with mobility, self-care (activities of daily living [ADLs]), domestic life (instrumental activities of daily living [IADLs]), and activities that depend on sensory functioning (limited to people who are blind or deaf). Limitations in complex activities include limitations experienced in work and in community, social, or civic life. These paired measures of basic and complex activity limitations are consistent with ICF's separate activities and participation domains. These two categories are not mutually exclusive: people may have limitations in basic and complex activities.^{5,6,7}

Barbara Altman, PhD, clarified that disability occurs "when the impairment or functioning limitation interacts with the environment and creates ... restrictions in participation." This perspective is consistent with ICF's definition of disability.¹³ According to Dr. Altman, the measures the subgroup could derive from Federal survey data indicate primarily that individuals were at risk of participation restrictions, depending on their environmental context. As Dr. Altman noted, in its 2007 report *The Future of Disability in America*, the Institute of Medicine suggested that disability data initiatives throughout the U.S. use ICF's basic multidimensional definition of disability.¹⁴

Building on this perspective, the subgroup sorted responses from a series of questions asked in MEPS, NHIS, and other surveys to produce its two measures of disability (limitations in basic and complex activities) for AHRQ's disparities report. Similar definitions and disability measures were also used in the chart book *Disability and Health in the United States, 2001-2005* produced by the National Center for Health Statistics.¹⁵

Following this presentation of AHRQ's disability definition for the NHDRs, the meeting participants opened the discussion to address a range of concerns about disability definitions, which fell into several different broad categories noted by the section headings used here.

Implications of Including the Environment

There was no disagreement among meeting participants about including the environment within a broad definition of disability, as does the ICF. Nonetheless,

extensive discussion considered the implications of its inclusion. The basic conundrum is that perceptions of disabilities could change as individuals' environments change. Margaret Stineman, MD, who uses a wheelchair, initiated this discussion as follows:

Stineman: The environment around all of us is constantly shifting. In my work setting, I am not disabled; I am participating. But when I try to get a taxi cab out in the streets of Philadelphia, my participation is really blocked. [This raises the need to consider] the individual in a standard environment, so that a person with a severe impairment who is completely compensated in a particular environment who becomes participation-restricted as they move out of that environment will not be lost in terms of [identifying disability].

Elena Andresen, PhD, concurred with this concern, observing, "As we look at the environment being the link between functional limitation and disability, there is a lot of variation in environment, even for an individual. Disability will depend on which environment they're in." Debra Saliba, MD, MPH, made a similar point, that "in an appropriate environment, [some people with disabilities] would not necessarily show up as disabled with the classic definition."

The group spent time discussing how to assess individual disability holding environmental factors constant (e.g., within a standard environment) and the implications of various approaches. Dr. Andresen mentioned a perspective advocated by some researchers, colloquially called "getting down to the `naked person.'"

Andresen: The concept is that if you took away all of the supports, then you could define someone in terms of [the] classic function of human beings. Then when you layer on the other aspects that we're talking about, you would get to environmental supports and health care system issues that might put the person at less or greater risk.

Dr. Andresen did not advocate this specific approach, but she highlighted the need to disentangle the various individual and environmental factors contributing to disability.

Gloria Krahn, PhD, addressed further the implications for measuring disability, suggesting the need to broaden the unit of observation into the person-setting.

Krahn: We're thinking about disability in an ICF framework or ... as more fluid and dynamic that varies across time and setting for people. That puts us into a different place – where the unit of measurement is person-setting. ... However, we might find that it's very difficult to [operationalize] that conceptual construct of person-setting combination.

Dr. Stineman agreed with Dr. Krahn's suggestion to combine the unit of observation, noting that "the person-setting unit is very critical because disability is dynamic, and it's dependent on the environment."

RQ: *How should variations in the environment be considered in identifying individuals as disabled? How would different approaches affect the specification of health care quality measures for persons with disabilities?*

Timeframe

Participants agreed generally with the timeframe suggested by Michael Marge, EdD, who stated that long-term time windows are important in defining disability: "It is important to perceive the health care needs of individuals with disabilities on a long-term basis, in fact throughout their lifetime, because health status is dynamic, and health needs will change over time. Also, the primary disabling condition increases the risk for additional health complications, such as secondary conditions, that exacerbate the individual's health problems and require more complex health care interventions." Whether the SSA's 1-year time window is the right time window for all purposes is unclear, but the basic point is that disability is chronic, not fleeting.

However, Kristi Kirschner, MD, raised concerns about conditions with fluctuating levels of functional deficits. She also highlighted the disabling effects of certain health conditions, such as cancer, not typically considered to cause disability, as follows:

Kirschner: If you look at what brings a lot of people to rehabilitation doctors, it may be a prolonged hospitalization in an intensive care unit. They might have had extensive cancer treatments. They may not be permanently or chronically disabled, but they are very disabled at that point in time. We need to get health care professionals to think about disability in the context of chronic illness or extensive conditions that require prolonged treatment. [Otherwise,] I think we're missing some folks.

RQ: *How should fluctuations over time be considered in identifying individuals as disabled? How would different approaches affect the specification of health care quality measures for persons with disabilities?*

Need for Clinical Specificity

Depending on the purpose of a quality measure, disability definitions focused specifically on underlying health conditions or functional impairments (as noted in ICF's umbrella definition) rather than on environmental factors may be most useful. Some quality measures will assess treatment (e.g., rehabilitation therapy) of functional impairments or medical interventions for disabling health conditions (e.g., treatment of multiple sclerosis or Parkinson's disease). In these situations, the environmental context may not be as critical as in quality measures evaluating, for example, individuals' participation in community activities.

Setting the Disability Cut Point

During the discussion of the environmental factors, Michael Weinrich, MD, raised a related issue as follows: "Disabled compared with whom? ... You put me in a group of

20-year-old Marines, and I am going to look pretty disabled. Is there an ideal standard, an age-matched ideal standard?"

Vincent Campbell, PhD, approached this concern from the perspective of population-based surveys. One challenge has been to ask meaningful questions about disability given the constraints in numbers of available question slots in certain Federal surveys:

Campbell: We did get two questions: ... "Are you limited in any way, in any activities because of physical, mental or emotional problems?" ... and "Do you now have any health problem that requires you to use special equipment, such as a cane, wheelchair, special bed, or a special telephone?"

We've received criticism for those questions because they suffer from both a lack of specificity and a lack of sensitivity. We have people answering "yes" to either of these, perhaps because they've aged out of the ability to downhill ski, which is an activity limitation for them. Or they have a broken leg, and they use a cane. But I don't know if we would consider those things to be a disability.

Bonnie Strickland, PhD, raised a related issue pertaining especially to children, particularly those with developmental or behavioral concerns.

Strickland: In the National Survey of Children with Special Health Care Needs, a lot of children with special health care needs don't have what their parents would say is a real limitation. When we go back and ask why, often it's because [their condition is] well-managed medically or there is sufficient support within the community. You don't want to miss those children or adults because they're well-managed with support in the community and they're doing just fine. Without those supports, they'd be a person with disability.

Related to Dr. Strickland's point, Dr. Marge asked a provocative question: If an individual is disabled according to our definition but their function is restored through technology or surgery, are they still disabled? In responding to this question, Dr. Stineman drew a distinction between surgery (e.g., hip replacement for someone with disabling arthritis) and restoration of functioning through assistive technology:

Stineman: Surgery is different because you change potentially the anatomic or physiological structure of the human being. If you have changed that structure to the point where there is no longer either a perceived or measurable activity limitation or participation restriction, that person is no longer by our definition disabled. ... [But if someone's function is] restored through a specific technology and that technology breaks down or they can't use it in a different environment, they go right back to being disabled. [In this example, the critical unit is the] person-setting, and technology is part of the setting.

These various issues track closely together: identifying meaningful cut points on a continuum to determine disability, and ensuring that questions and data collection about disability occur in ways that elicit these distinctions.

RQ: *Conceptually, what is the cut point on the continuum of functioning and activity participation between having and not having a disability? What is the best way to identify meaningful distinctions? How would different approaches affect the specification of health care quality measures for persons with disabilities?*

Patient-Centeredness

Closely related to the questions about the disability cut point, M. Elizabeth Sandel, MD, raised a critically important but operationally challenging concern: “People need to define [disability] for themselves, what category they see themselves in. That’s not something imposed. It’s really empowering the person in clinical settings to define themselves as having a disability and then what their needs are regarding that disability and health care environments.”

Dr. Sandel recognized the complexity of allowing individuals to define themselves as disabled or not, including concerns relating to individuals with cognitive limitations. In addition, different cultures have varying attitudes toward disability, raising the potential for inconsistencies between external perceptions and views of individuals. Despite these complexities, Paul Schyve, MD, agreed with the need for patient-centered definitions, linking this perspective to current efforts of The Joint Commission to eliminate barriers to equitable care across diverse subgroups of patients.

Dr. Stineman honed in on the complexities of operationalizing a patient-centered definition of disability relating to a “disconnect” between individuals’ self-perceptions and external views, as follows:

Stineman: In our study recently, we found that, among people at the highest level of ADL [activity of daily living] restriction, a certain portion of them ... don’t see themselves as having a disability. There is a disconnect between the sociological perceptions and whether a person chooses to label themselves ... with having a disability. ...

The objective measurement of an activity limitation, which is something that we do as clinicians, is separate from that subjective perception of the person-centered concept ...

The confusion has to do with the fact that the concept of disability itself has both objective and subjective components. ... We have to be very careful to distinguish between them.

Cecilia Rivera Casale, PhD, reminded the group that the ultimate goal of health care must be to improve quality of life – an inherently patient-centered and patient-defined concept.

RQ: *How could patient-centered perspectives on disability be captured (e.g., within routine data gathering systems)? How should these patient-centered definitions be used, recognizing potential effects of demographic and cultural differences? What are the implications of patient-centered disability identification for the specification of health care quality measures for persons with disabilities?*

Summary

The discussion about disability definitions ended with general agreement on several key points, including:

- **No single definition** of disability will work for all specific purposes.
- **Disabilities are diverse**, and considerations relating to one type of disability may not apply to another; similarly, considering disability across the lifespan is essential, but the consequences of disability at different points of the life course might vary.
- **Disability definitions** have implications for quality measurement approaches and goals.

Padmini Jagadish, MPP, made another critical point, not necessarily about the definition of disability, but about the implications of specific disabilities for certain quality measures. She used as her example cognitive or intellectual disabilities that affect individuals' abilities to understand certain concepts critical to disease self-management:

Jagadish: We often think of quality of care as something that happens while you're at the doctor's office. But for example, take somebody with dyslexia or an intellectual disability who needs to go home, read, and understand what is on their medication prescription. [When it says, "take the pill 3 times per day,"] does that mean take 3 pills at once or one pill three times a day? ... People with intellectual disabilities and problems with numeracy may have a really hard time understanding that.

Should a quality measure based on presumed adherence to that three-pill regimen consider the implications of intellectual disabilities in assessing providers' performance? Parallel scenarios could be constructed for a range of different disability types.

Implications of Disability Definition for Quality Measurement

The discussion of disability definitions transitioned into considering the implications of these definitions for constructing health care quality measures for persons with disabilities. Comments again fell into several broad categories, as follows.

Considering the Environment

As Dr. Andresen observed, embedding the environment within the definition of disability identifies, from the start, a critical quality measurement domain: accessibility of health

care environments to patients with disabilities. Access here is viewed broadly, encompassing not only physical access but also access involving the senses (vision, hearing), speech, and cognitive abilities (e.g., communication access). Access barriers along any of these lines would constitute a quality problem.

Dr. Sandel raised another environmental concern. As noted in the ICF, environmental factors encompass not only physical structures but also policies (e.g., health insurance benefit packages), societal attitudes, and other social practices.¹³ She focused specifically on unconscious bias among health care professionals concerning persons with disabilities. According to Dr. Sandel, that unconscious bias shapes the environment within which patients receive care, including the physical environment. For example, unconscious bias could affect the extent to which clinicians ensure that equipment is operational and lift teams in place when people with mobility disabilities arrive for care.

RQ: *How does unconscious bias concerning disability affect the care that health care professionals provide to persons with disabilities?*

Broadly considered, clinician training is also part of the environment within which patients seek care. Dr. Kirschner raised the issue of training of health care professionals about disability. She noted that many physicians and health care providers simply do not recognize disability. They also are uninformed about how disability affects patients' daily lives and the need for supports for patients to remain functionally independent. According to Dr. Kirschner, clinicians fail to recognize disability, especially among certain subgroups of patients:

Kirschner: I have seen a lot of pediatric cancer patients in my practice over the years, persons who had cancer treatment as children and are growing up and having a lot of secondary functional disabilities and complications, which need to be managed and treated in an ongoing fashion. Would that be considered classic disability in many health care providers' minds? I don't think so. ... How can we be very broad in terms of looking at where disability exists? How do we recognize it? And then what is the appropriate role of medical providers?

RQ: *How can clinicians be trained to recognize disability? What is the appropriate role of different health care professionals in addressing disability?*

Considering the environment might have other consequences for designing quality metrics. In her work on preventing pressure ulcers among individuals with spinal cord injuries, Florence Clark, PhD, adopts an ecological perspective: taking patients' "habitat into consideration [is critical in addressing] their ability to flourish." The problem comes with statutory and other limitations on paying for interventions that target the environment rather than patients' bodily functions. Typically, "medical necessity" requirements prohibit reimbursement for environmental modifications and certain assistive technologies. Thus, quality measures based on "best practices" for improving patients' safety within their environments might target interventions not covered by

insurers. If patients cannot pay for these interventions themselves, they may be unlikely to receive them.

Patient-Centered Definitions

Dr. Schyve stated that the patient-centered perspective is essential to drive quality measures: “We need to elicit, as health care providers, what are the particular perceptions and views of the individual, and how do we then address those in terms of the quality of care? So this linkage of patient-centered [thinking] and whatever the barrier, including barriers that may come from disability, is an important connection.”

Dr. Strickland concurred with the need to consider quality of life, the quintessential patient-centered outcome. She urged the group to remember that, depending on their underlying disabling condition, some persons with disabilities can have excellent physical health. That recognition is especially critical among children and youth early in their physical development. In these instances, health care quality metrics should assume a future-oriented, developmental perspective. Furthermore, this perspective should extend beyond physical health to examine the outcomes of social engagement and a broad concept of participation in community life. Dr. Sandel similarly urged a focus on wellness, even when the patient has significant medical conditions requiring clinical interventions. She gave the example of providing exercise and nutritional consultations to persons with spinal cord injury.

Rosalyn Correa-de-Araujo, MD, MSc, PhD, indicated that similar concepts underlie current community living initiatives from the U.S. Department of Health and Human Services: “When we talk about quality of life, we immediately link this to having or living a meaningful life in their communities. This is a definition that people with disabilities have to establish. What is meaningful for them, what works for them, what is happening in their lives that makes them comfortable?” Anita Yuskas, PhD, mentioned efforts by the Centers for Medicare & Medicaid Services (CMS) involving the home- and community-based service delivery system, which was developed to help people with long-term-care needs to live in the community.

RQ: *How does health care interface with quality of life for persons with disabilities? What are the community-based services and supports required to maximize social engagement, community participation, and quality of life for people with disabilities? What quality metrics could be based on these concepts and approaches?*

RQ: *What are the best models of wellness programs for persons with disabilities? How can wellness concepts be integrated into routine care of persons with disabilities?*

Margaret Turk, MD, raised another question related to patient-centeredness involving patients’ perceptions of their care, broadly considered satisfaction with care. She cited studies that find that people with chronic health conditions and disabilities approach the satisfaction question differently than do individuals without these conditions. Furthermore, satisfaction perceptions may vary by type of disability.

RQ: *How do persons with different disabilities perceive their health care and rate satisfaction with care? How do these perceptions vary across disabilities and by different types of chronic health conditions?*

Multidimensional Nature of Disability

As the ICF explicitly states,¹³ disability is an umbrella term encompassing multiple dimensions, ranging from impairments relating to specific diseases and disorders to participation limitations from various environmental barriers. Dr. Stineman summarizes this multidimensionality using the phrase “bio-psycho-ecological model.” Implicit within this bio-psycho-ecological approach is the need for services addressing the different components. Generally, this requires an interdisciplinary team of clinicians, and perhaps community-based supports, raising risks of fragmentation of care. Jay Himmelstein, MD, MPH, raised the issue of the role of personal care assistants (PCAs) as one critical component of the community-based services. As Dr. Kirschner noted, care often is provided in disciplinary silos, without adequate coordination. In particular, as Dr. Stineman observed, transitions across settings of care (e.g., from inpatient to outpatient settings) can be marked by temporary exacerbations of disability, requiring explicit oversight to ensure that community supports are in place to minimize this risk. Dr. Sandel wondered whether patient-centered medical home models might achieve the required coordination and improved outcomes.

Both Drs. Clark and Himmelstein highlighted the need for better research that clearly links health outcomes, including patient-reported quality of life, to the components of the bio-psycho-ecological model of disability. For this research, Dr. Clark emphasized environmental modifications, while Dr. Himmelstein concentrated on specific processes of care. Dr. Himmelstein also raised concerns about specific subpopulations of persons with disabilities, such as individuals with psychiatric disabilities.

RQ: *What are the major barriers to coordinating care across various disciplines caring for persons with disabilities? What are the major barriers to implementing a bio-psycho-ecological model of care? Are there condition-specific challenges to care coordination that must be addressed and, if so, how? How might patient-centered medical homes work to improve care and outcomes for persons with disabilities?*

RQ: *What are the links between different components of the bio-psycho-ecological model of care and patient outcomes, including quality of life? In particular, how do aspects of the environment link to medical conditions, such as pressure ulcers and other secondary conditions?*

Dr. Strickland reminded the group about the need to keep a life course perspective, recognizing that some dimensions of the multidimensional concept of disability may appear more or less important at different points over the life course. This could have implications for quality measurement in terms of emphasizing different factors at different points during the life span. In particular, children should not be treated simply as miniature adults; rather, developmental factors require explicit consideration.

RQ: *How should relative differences in the effects of disability dimensions be considered across the life span? What quality indicators reflect a life course approach?*

Summary

Dr. Schyve made comments that summarized well the general sense of the discussion around the implications of the disability definition for quality measurement:

Schyve: In reality, for any kind of complex system or situation, no one model is ever going to actually tell us everything we need to know about that. Different models help us look at it in different ways and understand different things. ... The fact is that there are probably different measures, different ways to measure, depending on which model we're using to look at the phenomenon that we're trying to understand.

Nonetheless, the multidimensional concept contains various core concepts, as delineated by the ICF definition,¹³ that in turn suggest directions for quality measurement.

RQ: *What might be a way of identifying disability in the context of routine care that could identify patients needing accommodations and advance care coordination, quality improvement activities, and new practice models (e.g., patient-centered medical homes)?*

Scientific Evidence Base for Quality Measure Development

The group discussed the scientific evidence base available to support development of quality measures for persons with disabilities. Without this evidence, as Dr. Turk noted, often quality measures (e.g., designated “best practices”) are based primarily on the opinions of practitioners. As an overall assessment, participants agreed that the body of research to inform quality metric development for persons with disabilities is limited.

Exceptions do exist. For example, certain disabling conditions, such as spinal cord injury and multiple sclerosis, have been fairly well studied. However, studies of disabling health conditions primarily focus on explicitly medical issues rather than psychoecological factors – they do not address the full range of disability dimensions. Few comparative effectiveness or patient-centered outcome studies have looked, for example, at the effects of community-based interventions, environmental modifications, or alternative models of care delivery (e.g., patient-centered medical homes, specific care coordination interventions). Even less information is available for children with disabilities, especially the life course of children living with disabilities and how interventions might work at various points in early life. A comprehensive research agenda is required to address these gaps.

Including Persons with Disabilities in Research Studies

Historically persons with disabilities have been automatically excluded from the randomized controlled trials (RCTs) that examine the comparative effectiveness of different disease-specific interventions (e.g., cancer treatments). This means that if a person with a disability develops that disease (e.g., cancer), the evidence base from RCTs may not apply to them. Not having RCT-level evidence can hamper efforts to develop scientifically rigorous quality measures for persons with disabilities.

In recent years, the National Institutes of Health (NIH) and AHRQ have required investigators submitting grant applications to explicitly address the inclusion of persons by sex and race and ethnicity. Both NIH and AHRQ grant applicants must justify the exclusion of people by sex, race, and ethnicity. NIH applicants must also address the inclusion of children and justify their exclusion. Beyond women and racial and ethnic minorities, AHRQ requires grant applicants to consider including the following “priority populations”: inner-city residents; rural residents; low income persons; children; elderly people; and those with special health care needs, including individuals with disabilities and those who need chronic care or end-of-life health care.

The meeting participants discussed adding persons with disabilities to the list of population subgroups whose exclusion from RCTs or other clinical studies must be explicitly justified by investigators submitting grant applications to NIH and AHRQ. This change in policy would raise important questions, such as what would be considered appropriate reasons to eliminate persons with disabilities from clinical trials. Any such reasons must not be openly discriminatory or reflect erroneous assumptions about persons with disabilities (e.g., ability of an individual to provide informed consent). Nonetheless, important human subjects protection issues might arise. Another important question involves how to handle data on a relatively small subset of study participants who do have disabilities (e.g., do investigators have sufficient statistical power to say something definitive about persons with disabilities). Addressing the implications of the diversity of disabilities presents yet another critical issue.

RQ: *What are the factors that need to be considered in requiring researchers to justify the elimination of persons with disabilities from clinical studies, including RCTs? How should the diversity of disabilities, small sample sizes, and legitimate efforts to protect human subjects be addressed to maximize inclusion of persons with disabilities in clinical studies?*

One specific type of observational research is ripe for the inclusion of people with disabilities: studies using Medicare claims files or other Medicare data sets. Often researchers exclude Medicare beneficiaries under age 65 (i.e., those qualifying for Medicare because of disability; end-stage renal disease is another special category of excluded cases) without explicit justification. Given that persons with disabilities constitute approximately 15 percent of the Medicare population, excluding them means that research results will not pertain to a substantial fraction of Medicare beneficiaries. Furthermore, given the size of the Medicare population, this 15 percent subset is likely to represent sufficient numbers of cases to perform meaningful subgroup analyses for

many research questions. Participants agreed that all research involving Medicare beneficiaries should include persons who qualify because of disability unless there are strong and compelling reasons to exclude them. In other words, all AHRQ- and NIH-funded research using Medicare-generated data should include persons with disabilities unless their exclusion is clearly justified.

RQ: *All studies using Medicare data should include beneficiaries under age 65 eligible because of disability. What would be considered legitimate reasons to allow investigators to exclude this subgroup of Medicare beneficiaries?*

Despite strong interest in including persons with disabilities in research studies, participants recognized some of the challenges as described above (e.g., sometimes small sample sizes, clinically legitimate concerns about protecting human subjects). The group therefore considered alternative approaches for gathering data about effectiveness of interventions for persons with disabilities. Dr. Weinrich suggested the possibility of adding disability information to data gathering for post-market drug and device surveillance by the Food and Drug Administration (FDA). In addition to routinely gathering basic demographic data on persons experiencing events related to drugs or devices, the FDA should add information about the person's functional status or disability. Over time, these routine data would snowball into sufficient sample sizes for meaningful statistical analyses.

RQ: *Would adding information on persons' functional status or disability to routine data gathering by the FDA for post-marketing surveillance of drugs and devices be an appropriate way to track the effectiveness of these interventions for persons with disabilities? If this seems like a productive approach, what data gathering approach would maximize the completeness and accuracy of the information about disability? How would these post-marketing surveillance data be used exactly to identify health risks and benefits for persons with disabilities?*

Relationship to General Quality Metrics

Common health conditions that can be profoundly disabling include some, such as diabetes and heart failure, have quality measures that generally are widely accepted and used. Most of these quality indicators reflect processes of care (e.g., measurement of Hb A1c levels, ophthalmologic examinations, prescriptions for certain medications). These quality indicators do not address considerations relating to disability.

Dr. Kirschner raised the concern about considering disability effects in efforts to develop quality measures that cut across broad populations. Her example involved osteoporosis, as follows:

Kirschner: Osteoporosis is a huge problem for persons with disabilities. ... Medically, we know a fair amount about the treatment of osteoporosis ... For most of my patients, though, osteoporosis relates to immobilization. ... Do we treat their osteoporosis the same way we do for post-menopausal women? Probably not.

RQ: *As quality metrics are designed that apply to large numbers of patients with common conditions, are there special considerations for persons with disabilities? How should any special concerns relating to disability be factored into the quality measure?*

Research on Care Delivery System Changes

Considerable discussion focused on the promise of patient-centered medical homes and approaches to improve care coordination but also the lack of clear research evidence about their merits for persons with disabilities. Costs of various care delivery models also require exploration, considering as well the implications for the health care workforce. Dr. Andresen raised the possibility of altering reimbursement structures to provide incentives for care relating to wellness and prevention. She also suggested research about ways to engage patients in self-management activities and having them become “a partner in the outcomes of their care.” Research concerning disease self-management has investigated conditions like diabetes, which are disabling. However, disability effects have not necessarily been the major focus of these studies.

With the growing interest in pay-for-performance reimbursement schemes, questions arise about whether these programs could affect persons with disabilities. Dr. Stineman worried about whether quality metrics designed for pay-for-performance would apply to persons with disabilities, and if not, would clinicians either: (1) avoid persons with disabilities or (2) provide inappropriate care to them? As Dr. Stineman asked, “If we move towards pay-for-performance, what are the special protections that people with disabilities need in place to make sure that there are not perverse incentives” relating to their care? If, for example, persons with disabilities should be eliminated from certain denominators in calculating rates for performance indicators, what is to stop clinicians from gaming these numbers (e.g., excluding persons inappropriately from denominators in rate calculations)?

A specific care delivery issue with insufficient evidence involves the transition into adulthood for youth with disabilities. Dr. Kirschner gave some examples:

Kirschner: I’ve been working a lot with adults with spina bifida. It’s a great example of where we really need to be ahead of the curve in thinking about prevention of complications. We’ve got a generation of people with spina bifida who started getting surgeries in the 1960s, 1970s. They had great pediatric centers of excellence that provided coordinated care with the urologists, orthopedists, primary care doctors, rehab doctors, and neurosurgeons. Once people turn 21, pediatric hospitals don’t want them anymore. There is nothing in the adult care system set up to meet their needs, and we’re seeing lots of problems – really dangerous problems.

Cystic fibrosis is a wonderful example. In cystic fibrosis, centers of excellence really make a huge difference. The life expectancy of people with cystic fibrosis has changed dramatically from about 18 to around 32 years old. The centers of excellence have shown that [health care professionals] who do this day in and

day out, who understand cystic fibrosis, can really have a dramatic impact on the quality of care.

Participants discussed the implications for creating centers of excellence of the small numbers of cases within given locales. Small numbers could be particularly problematic for rural areas. Telemedicine and other technologies to facilitate communication between remote and centralized centers of excellence might hold promise in these situations.

RQ: *What models of care delivery address the bio-psycho-ecological needs of persons with disabilities and improve their outcomes? How much do these models cost, and what are the implications for the health care professional workforce?*

RQ: *What are the implications of different reimbursement structures for persons with disabilities? Are there payment models that effectively improve self-management activities among persons with disabilities? How might pay-for-performance programs affect persons with disabilities?*

RQ: *How can high quality care be delivered in remote locations with few persons with disabilities and staffed by a health care professional workforce without specific expertise? What is the role of telemedicine and other information technologies?*

Methods Research

Participants mentioned several areas where additional methodological work is required. Developing strong outcome metrics related to care delivery is necessary. Examples include measures of health-related quality of life for persons with disabilities and outcome measures that could be tracked across the lifespan. Dr. Clark suggested looking at “gaps between what people want to do or need to do, like work, and whether or not they’re able to do it. That [approach] might start to get at quality of life in a different way.” Another area where more instrument design is needed is environmental assessments. According to Dr. Krahn, “We really have not moved very far in measures of environment. It might be ... to look within the [environmental] context at factors that either facilitate or impede you” and design more rigorous, usable instruments to capture these factors.

Dr. Marge raised concerns relating to potential biases in peoples’ self reports, especially of sensitive information (e.g., abuse by a caregiver). Obtaining self-reported information, including about satisfaction with care, from persons with intellectual disabilities also requires study. In particular, the role and potential biases of proxy respondents for persons with intellectual disabilities needs exploration.

Small sample sizes often present challenges to research on persons with specific disabilities. The small numbers problem may, in the end, be intractable, but additional methodological study should explore whether any new approaches might offer some benefits for studies involving small sample sizes. For example, the value of Bayesian analytic approaches should be examined in this context. Additional research on getting

the most out of observational data (e.g., propensity scores have been a significant advance) could be helpful. Dr. Stineman mentioned research attempting to reduce selection bias using administrative data.

With the increasing availability of electronic health information, research should also explore the use of health information technology (health IT) and electronic medical records (EMR) in routine health care settings to capture disability information and support research concerning the care of persons with disabilities. Dr. Sandel is based at Kaiser Permanente, which has extensive health IT resources. She described the value of these data:

Sandel: I work with the large databases within Kaiser Permanente. We have 2,900 patients with a history of polio in our Northern California system. I haven't done any research on them, but if you get a large enough database, you can do some pretty interesting work. ... We're [also using the data to look] at stroke mortality. ... We have about 29,000 patients in the database over a period of time. ... If you have a large enough database ... you'll be able to do some pretty significant work, although it's not controlled randomized trials.

Dr. Himmelstein noted that the current emphasis on setting standards for meaningful use of health IT and EMRs offers opportunities for considering how to include information about disability.

RQ: *What outcomes are critical to track in disability-related quality measurement research? What new outcome indicators must be developed, and how should data on these outcomes be collected? Can we create better measures to capture environmental factors that either facilitate or impede participation?*

RQ: *Are there new analytical approaches to using small samples of cases, observational data, or administrative data that could advance studies relating to quality of care for persons with disabilities?*

RQ: *How can the growing availability of health IT and EMRs be tapped to support disability-related quality measurement research? What should go into health IT systems and EMRs to gather credible and analyzable information relating to disability for quality measurement purposes?*

Summary

Dr. Iezzoni summarized the discussion as follows:

- With few exceptions, little scientific evidence is available to inform development of quality indicators for persons with disabilities.
- Hence, not surprisingly, relatively few quality measures exist specifically addressing disability-related issues.

- Those examples that do exist focus primarily on biomedical aspects of underlying disabling conditions rather than on functioning, wellness, quality of life, and the broad range of environmental concerns.

Examples where some quality measures do exist include those developed under the ACOVE (Assessing Care of Vulnerable Elders) initiative and for conditions like spinal cord injury, cystic fibrosis, and stroke. However, even among existing measures, few encompass the various domains required by a multidimensional definition of disability (e.g., ICF's definition, Table 2).

Data Issues for Measuring Quality for Persons with Disabilities

As noted previously, to focus the meeting because of time constraints, the discussion concentrated on quality measures applicable to individual health care providers (e.g., to help them improve or track their performance). The data discussion therefore also concentrated on information that could be aggregated for individual health care providers. Federal surveys provide data that support population-based quality measurement for persons with disabilities, but the group did not discuss this data source.

Administrative Data Sets

Administrative data include claims, encounter records, and other information generated during routine administration of health care services. Major sources of administrative data include Medicare, Medicaid, Veterans Affairs (VA), and private health insurance plans. As discussed earlier, participants agreed that all research involving Medicare administrative data should include persons who qualify because of disability, unless there are strong and compelling reasons to exclude them. Given current eligibility requirements (i.e., before implementation of eligibility changes mandated by the Patient Protection and Affordable Care Act¹⁶), Medicaid databases contain substantial numbers of individuals with disabilities.

Typically, administrative data include routine demographic information (e.g., age, sex, race and ethnicity, indicators of eligibility status) and basic information relating to a particular claim or health care encounter, including *International Classification of Diseases, Ninth Revision, Clinical Modification* (ICD-9-CM)¹⁷ diagnosis codes, codes for procedures, and service dates. Some administrative data may contain information pertinent to impairment-related services, such as Medicare data generated by inpatient rehabilitation facilities (IRF), skilled nursing facilities (SNF), and home health agencies (HHA). (Beyond administrative information, VA facilities also generate considerable electronic health information relevant to the discussion below.)

The group agreed that ICD-9-CM codes provide extremely limited information relating to disability. Thus, administrative databases relying for most of their clinical insight on ICD-9-CM codes have minimal utility for disability-related research. Although it is possible to

identify diseases and disorders that can be disabling, administrative data do not contain those additional multidimensional pieces of information about disability. Health care providers are scheduled to move to the updated ICD-10-CM for morbidity reporting and other administrative purposes on October 1, 2013.

RQ: *Will ICD-10-CM provide any additional insight into disability beyond the limited information in ICD-9-CM? How could ICD-10-CM be used to its maximum advantage in disability-related research?*

Despite bleak assessments of the value of standard administrative data, it is possible that data generated by IRFs, SNFs, and HHAs might hold greater promise for research addressing persons with disabilities. The obvious problem involves tying patient populations to care provided within specific settings (IRF, SNF, or HHA), and potential biases related to that selection process. Section 723 of the Medicare Prescription Drug, Improvement, and Modernization Act of 2003¹⁸ required HHS to make Medicare data about beneficiaries with chronic conditions readily available to researchers. The resultant database, the Chronic Condition Warehouse (CCW),¹⁹ selected its longitudinal cohort using the 5 percent national Medicare sample from 1999-2004, with all beneficiaries within that cohort tracked continually over time. From 2005 forward, CCW contains information for 100 percent of enrolled Medicare beneficiaries with the targeted conditions. CCW uses diagnosis and procedure data on Medicare claims to identify 21 chronic conditions (e.g., acute myocardial infarction, Alzheimer's disease, breast cancer, depression, diabetes, glaucoma, heart failure, hip fracture, osteoporosis, and stroke). Most importantly, all information gathered by IRFs, SNFs, and HHAs about these beneficiaries is merged onto the CCW data. Although this database offers a rich source of functional information, all of these data are derived during provision of specific services, raising the potential for bias relating to differences in service availability or use by individual patients.

RQ: *What quality measurement research can be done with Medicare IRF, SNF, and HHA specifically for persons with disabilities? How can the CCW be used to examine quality of care for persons with disabilities? Which quality dimensions relating to persons with disabilities do these Medicare data sources address?*

The potential of using prescription drug data to examine quality of care for people with disabilities was also raised. Dr. Weinrich raised the possibility of using Medicare Part D data, and Dr. Himmelstein described the value of pharmacy data within Medicaid data sets. In particular, Dr. Himmelstein noted the utility of prescription data for case finding (i.e., identifying individuals with specific conditions). The VA also has prescription medication data online.

RQ: *What quality measurement research can be done with prescription drug data specifically for persons with disabilities? Do different data sets containing medication information present different strengths and weaknesses for this purpose? Which quality dimensions relating to persons with disabilities might prescription medication data address?*

Electronic Medical Records and Health Information Technology

The potential value of EMRs and health IT had come up throughout the day, as noted above. During the afternoon session, the discussion became more specific. With some exceptions (e.g., the VA health system), information on disability is largely lacking within EMRs, just as it is in paper records. “The electronic medical record is only as good as the information that the clinicians and providers are putting in there,” observed Dr. Sandel, “and they don’t routinely assess functional status. It’s just not part of the routine assessment.” Other dimensions of disability are even less likely to be documented in EMRs.

Participants suggested approaches for enriching the disability data within EMRs. Dr. Sandel suggested identifying tools designed specifically for different conditions that capture relevant functional status and disability information. These tools could be embedded within EMRs, facilitating collection of these data about patients with the conditions for clinical uses, quality measurement, and research. More generic (i.e., diagnosis-independent) tools could also be useful, such as the method developed by Alan Jette and colleagues at Boston University, the Activity Measure for Post-Acute Care (AM-PAC).²⁰ Dr. Himmelstein speculated about creating an electronic disability record that would be longitudinal and track patient status over time. Dr. Campbell described developing health IT systems for specialized clinical settings focusing on rare conditions, such as the hemophilia clinic network. He is also working with other stakeholders interested in rare conditions (e.g., spina bifida, Duchene muscular dystrophy) to develop health IT tools to address specific goals.

Recalling the multidimensional aspects of disability, Dr. Clark recommended that any such systematic data gathering approach include a full range of information, including information about emotional health, pain, and fatigue. CMS is apparently working on new data gathering tools for hospital discharge evaluations and for post-acute care settings. EMR disability information templates could be structured to integrate seamlessly with CMS’s data tools.

RQ: *What data collection tools to gather multidimensional information about disability could be embedded within EMRs? How should these tools integrate with data gathering tools CMS is developing? How would the data generated by these tools be used for research and for quality measurement? What would be the feasibility and cost implications of routinely gathering disability data using such tools? Which clinicians would collect the data, how would they be trained, and how would data gathering costs be best compensated to provide incentives for complete and accurate reporting?*

Dr. Saliba raised concerns about some negative consequences of the practice of “copying and pasting” information within an EMR. Clinician participants raised situations where the extent or severity of functional impairments or other disability dimensions changes over time, thus necessitating the continuous reassessment and updating of records to reflect changes. “We see problem lists getting perpetuated from record to record,” recounted Dr. Saliba. “People support a goal of auto-populating a lot of the

fields in electronic health records based on prior diagnoses or prior history. But that earlier information may no longer be current.”

RQ: *How do “copy and paste” and “auto-populate” practices of clinicians using EMRs affect the accuracy of information in EMRs concerning patients’ level of disability? How can accuracy be tracked and errors resulting from these EMR practices be identified? How often should entirely new data be entered into EMRs to ensure that information about disability is up-to-date and accurate?*

Dr. Sandel also raised the general concern about conducting research or generating quality measures using EMRs: the fact that much of the crucial information is contained in narrative texts. The data are therefore difficult to extract and put into an analyzable format. Defining specific data fields for information about disability dimensions could assist the process of extracting relevant data. Dr. Himmelstein suggested that AHRQ is well-positioned to address this issue of specifying the format and content of disability-related information in EMRs to ensure that the data are easily identified for analysis.

RQ: *How should data concerning disability be entered into EMRs to ensure the data are easy to identify and can be extracted for analysis? How can disability data considerations be included in current AHRQ initiatives surrounding the design, content, and technological specifications of EMRs?*

John Hough, DrPH, suggested alternative approaches for resolving concerns about extracting information from medical records that have implications for research and quality measurement data. Extracts of his comments are as follows:

Hough: Between 2004 and 2006, the National Committee on Vital and Health Statistics (NCVHS), which advises the [HHS] Secretary, received recommendations on a variety of standards for setting up EMRs. NCVHS received those recommendations from various domain-specific working groups operating under the auspices of the Consolidated Health Informatics (CHI) Initiative, which had been an “eGov” initiative throughout all departments. The functions of the CHI Initiative, including continuing responsiveness to all its recommendations, now is primarily conducted by the HHS Office of the National Coordinator for Health Information Technology (ONC).

One of the CHI domain-specific groups had been assigned to work in the Functioning and Disability Domain. The CHI Functioning and Disability Working Group recommended to NCVHS that ICF be the language in which terms reflecting functional status or disability should be transmitted. Their recommendations, though quite valuable, primarily referred to ICF coding at the so-called “code stem level,” namely, one letter representing one of the four ICF domains followed by up to five digits before a decimal point. The ICF coding scheme involves a straightforward but nevertheless complicated system of post-decimal modifying digits, which reflect the judged or assessed level of severity associated with the impairment represented by the ICF code stem.

According to the World Health Organization (WHO), ICF codes have no inherent meaning without qualifiers, and by default, WHO interprets incomplete codes as signifying the absence of a problem. Thus, the qualifiers impart most of the meaningful interpretation in any ICF code. Therefore they are valuable and should be components of the standards associated with moving data represented by discrete ICF codes: all codes should be qualifier-modified.

As a secondary component of their recommendations, the CHI Working Group and NCVHS invoked the usefulness of “LOINC coding” for “question and answer sets.” LOINC stands for “Logical Observation Identifiers Names and Codes,” and LOINC codes are designed to accompany the codes or “answers” from other nomenclatures for easy and reusable transmittal of such discrete codes, for example, pathology laboratory values. This means that a reproducible LOINC code associated with a qualifier-modified ICF code could impart information representing any answer to any question, such as a scored value on a conventional functional assessment instrument like the Functional Independence Measure.

There are more than 100,000 qualifier modifications to those code stems, although the full complement of qualifier-modified ICF codes has not yet been calculated. This represents a shortcoming in existing ICF coding. But once catalogued, the full complement of qualifier-modified ICF codes would constitute an enormously useful tool for associating ICF-oriented concepts with ICF codes, that in turn would be associated with discrete, unique cases. In that approach, quite granular cases of functional impairment, activity limitation, or participation restriction could be identified in a standardized manner using the modified code stems. That is what the CHI Working Group on Functioning and Disability recommended, what the NCVHS advised, and now, since February, 2007, what the Secretary of Health and Human Services, has approved.

Therefore, one formative task still awaiting work by health services researchers would be to explicate the full universe of qualifier modified ICF codes. The goal would be not only to establish a catalog of codes, but also to associate them in a reproducible, reusable format with LOINC codes, which are designed to accomplish this parallel purpose. Any model of disability can be accommodated by these code stems; an investigator would not need to dispense with their preferred model of disability in order to utilize ICF coding and to associate a particular outcome within that model with a related, qualifier-modified ICF code.

The NCVHS recommendations called for us to develop this catalog of LOINC codes associated with qualifier-modified ICF codes. We call this process the “LOINC-ification” of ICF codes. A good start has been made by Regenstrief Institute scientists at Indiana University School of Medicine, who have already assigned LOINC code to a number of what are called “government forms.” For example, the CMS Minimum Data Set for skilled nursing facility services, Version

3.0, is now in the electronic LOINC environment, waiting to be matched to any set of questions, and various ICF codes representing functional status among nursing home residents could be one set of such questions for which LOINC codes would be the answers. Other government forms that have already been LOINC-ified include the Social Security Administration's Residual Functional Capacity form for both physical and mental functioning and OASIS [Outcome and Assessment Information Set], used in home health care. A small collection of very widely [available] assessment instruments, like the Geriatric Depression Scale, are already in this LOINC environment.

RQ: *How should ICF codes be used, to maximum advantage, within health IT systems to facilitate flexible but detailed definitions of disability? What algorithms could be designed to assist researchers with using ICF codes in an electronic data environment? How could these data resources be used for quality measurement?*

Data Provided by Patients

Information in medical records has historically been generated by clinicians. However, the advent of EMRs and secure patient portals for access to online information within health care settings has raised the possibility of patients contributing information directly to EMRs. For instance, the AM-PAC tool²⁰ mentioned above was designed for patients to self-administer. As Dr. Sandel suggested, "You could envision a world in which, for example, at Kaiser, a patient logs on to KP.org and [fills] out their health assessment form ... embedded in that could be the AM-PAC." Dr. Saliba described an evaluation of obtaining information directly from nursing home residents for Medicare's SNF Minimum Data Set items. The assessment found that:

Saliba: Direct patient self-reporting was feasible. It actually saved time over staff trying to eyeball the person and guess what was going on. And it was more accurate [comparing it] to independent 'gold standard' measures of what was going on with the individual.

We began with the hypothesis that there was an absolute cognitive cut point beyond which people could not self-report. ... We found that we were wrong: there is no absolute cognitive cut point below which people are not able to answer these questions and give more valid responses than staff observations or proxy observations.

RQ: *How could data about various disability dimensions be gathered routinely directly from patients? What validity, reliability, and feasibility issues are raised by disability data gathering directly from patients? How might demographic characteristics—including age, sex, race, ethnicity, socioeconomic status—and cultural factors affect data gathered through these self-reports? What are the costs of obtaining self-reported information?*

Dr. Saliba described one nursing home resident whom the staff had assumed, from the time of her admission 1 year previously, was cognitively impaired and incapable of

meaningful communication. During the study about gathering data directly from patients, research staff provided a hearing amplification device to the woman, who “then sat up, began responding to their questions, and pointed to answers on a card that they were using to guide their interview with her. She was reading and giving answers to the questions.” The woman was not cognitively limited; she had hearing loss.

Dr. Stineman raised concerns about “people in long-term care that have been misdiagnosed or mis-assumed not to have the ability to be autonomous and in control of their lives.” Dr. Kirschner raised specific concerns about persons with cerebral palsy who are dysarthric and assumed not to be cognitively capable. Assistive technologies can accommodate communication needs and allow these patients to self-report information. Harvey Schwartz, PhD, MBA, raised concerns about people with manual dexterity difficulties typing information into EMRs (e.g., as in the AMPAC example above).

RQ: *How might sensory and communication disabilities affect patients’ self-reports? How can communication needs be accommodated so that patients can provide their own responses to questions (e.g., concerning disability dimensions, perceptions of care)? For entering data directly online into EMRs, what types of accommodations are required to ensure full participation of all patients (e.g., including those who cannot use a keyboard)?*

Dr. Clark raised the point that certain types of information have inherent validity and accuracy when reported directly by patients. Examples include patients’ perceptions of communication or their experiences during clinical encounters. For quality measurement purposes, it is important to recognize that whatever items are gathered from patients will then likely become the targets of efforts to improve care. Therefore, it is critical to identify topics that reflect aspects of care that patients view as important.

Although there was general enthusiasm for the Consumer Assessment of Healthcare Providers and Systems (CAHPS®) set of survey instruments, there was some concern about the implications of the questionnaire that was developed specifically for individuals with impaired mobility. The intentions were good, given widespread physical barriers throughout the health care delivery system. But given the diversity of disabling conditions, proceeding disability-by-disability to design separate CAHPS instruments seems inefficient. It might be more appropriate to take a “universal design” approach toward measurement that would consider the full range of persons with and without disabilities in constructing question banks and use technologies (e.g., computer assistance) and methodological techniques (e.g., item response theory) to streamline administration.

It will be critically important to conduct extensive cognitive testing of different word choices and question formulations to capture critical concepts for different broad categories of disabilities. For example, in designing the CAHPS survey for persons with mobility impairments, the researchers found they could not use the word “barrier” in asking about the physical impediments that individuals encounter. They did not find an

alternative way of capturing that issue, which meant that a major area of concern was not included in the survey. Dr. Andresen suggested starting with ICF concepts and code categories to ensure that the broad range of disability dimensions is captured in a universally designed survey.

RQ: *What aspects of care are of particular importance to individuals with disabilities? How do these topics vary across different disabling conditions? What tools could be developed for patients to report on these important aspects of care? How could a “universal design” approach be implemented in designing and administering surveys about health care experiences?*

Research Priorities in Developing Quality Measures for Persons with Disabilities

The final 45 minutes were spent asking each participant to specify briefly what would be his or her top priority for AHRQ’s funding for research concerning quality of care for individuals with disabilities. As noted earlier, given the brevity of the meeting, the group did not have an opportunity to reach formal consensus about these priorities. Proposed priorities for research topics fell into the broad categories indicated by the headers below.

Overarching Considerations

- Consider the full range of disabling conditions and develop approaches that accommodate the diversity and multidimensional attributes of disability.
- Take a life span perspective whenever possible, considering individuals across the life course from early childhood to old age.
- Recognize the developmental context when considering children.
- Consider health, wellness, and prevention perspectives whenever possible.
- Develop a set of quality measures specifically for persons with disabilities, rather than only applying general population quality measures to these individuals.

Health Information Technology and Electronic Medical Records

- Develop methods to automate and capture electronically information about various dimensions of disability. Include methods where patients self-report information about disability dimensions in EMRs.
- Develop methods to include new media information about patients in EMRs (see below).

Describing and Classifying Patients and Their Disability Dimensions

- Use new media to capture information about patients and their multiple disability dimensions. Examples include photographic and video images of patients, including patients functioning within their standard environments. Develop methods to characterize patients and their environments using these visual images.

- Devise methods building on ICF to capture information about patients, their environments, and patient-environment interactions. Create a taxonomy of person, environment, and person-environment units of observation.
- Examine implications of changes in disability dimensions over time.
- Identify methods for capturing information on people with rare disorders and learn more about their life courses and treatment responses.
- Work with the international community on development of ICD-11, which will apparently roll the ICF into its ICD framework (end date of work projected late decade).

Patient-Centeredness and Perceptions of Care

- Devise methods to capture patients' preferences for care and outcomes across and considering different disabilities. A critical subtopic involves preferences for end-of-life care. Another critical topic includes patients' perceptions of their health care needs, more generally.
- Develop a universal design-focused approach for capturing patients' experiences of care, across and considering different disabilities. Methods would consider patients' cultural and sociodemographic characteristics. Ensure that formats for survey administration are also universally accessible.
- Allow for patient self-management of chronic health conditions.

Health Care Providers and Delivery System Issues

- Identify implicit bias and other stigmatizing attitudes among clinicians toward different types of disabilities, and the contribution of these biases to patients' health care experiences and disparities in care.
- Identify and characterize the full range of barriers to care, across different disabilities and varying impediments.
- Include education of health care professionals about persons with disabilities and their care, in the face of potential biased attitudes and disparities in care.
- Develop collaborative care models, with patients and clinicians partnering to set goals and design care plans.
- Develop methods to assess and improve coordination of care.
- Examine how patient-centered medical home concepts and approaches apply to persons with disabilities.
- Explore development of post-marketing surveillance of drugs and devices that can capture disability information and analyze data for a disabled subpopulation.

Methodological Topics

- Include persons with disabilities in all analyses involving Medicare beneficiaries, unless there are compelling, nondiscriminatory human subject or scientific reasons to exclude them. Include persons with disabilities in all clinical trials or effectiveness evaluations, unless there are compelling justifications for their exclusion.
- Develop methods for using observational data to conduct outcomes and comparative effectiveness research for persons with disabilities.

- Devise methods for analyzing small numbers of cases.
- Develop methods for using survey data to identify persons with disabilities, as well as methods to ensure all Federal surveys capture persons with disabilities, including those who might require accommodations to complete the surveys.
- Assess costs and feasibility of implementing all methods targeted for widespread use.
- Explore potential algorithms using ICD-10-CM to conduct research relating to persons with disabilities using administrative data after coding system changes mid-decade.

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Appendix 2. Developing Quality of Care Measures for People with Disabilities: Expert Meeting

Agenda

April 15, 2010

- 9:15 a.m. Welcoming remarks – Carolyn Clancy, Francis D. Chesley, Lisa Iezzoni
- 9:30 a.m. Participant introductions
- 9:45 a.m. What are we talking about when we say “people with disabilities”?
How are we defining people with disabilities?
- 10:15 a.m. What are the implications of that definition for quality measurement and
specifying metrics? Discussion on research gaps and needs
- 11:00 a.m. Break
- 11:15 a.m. Given that definition of people with disabilities, what sources of scientific
evidence are available to support measure development?
- 12:00 p.m. Working lunch/continue discussion of sources of scientific evidence
and research gaps and needs
- 1:00 p.m. Which data sources could be used to identify populations of people with
disabilities for quality measurement and to apply quality metrics?
Discussion on research gaps and needs
- 2:00 p.m. What is the current state of the art/What are the existing metrics?
Discussion on research gaps and needs
- 2:45 p.m. Break
- 3:00 p.m. Continue discussion on research gaps and needs
- 3:30 p.m. Wrap-up summary of the day and next steps
- 4:00 p.m. Adjourn

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