

Examining the Evidence

A series presenting findings from a systematic search of the literature on a specific topic and offering quantitative or qualitative analysis of these findings.

Rethinking quality in the context of persons with disability

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Abstract

Objective. To review the current health services literature related to quality of care for persons with disabilities and to highlight the need for a unique framework for conceptualizing quality and patient safety issues for this population.

Design. Drawing on quality measurement theory, we formulate a multi-dimensional model of quality of care for persons with disability. This model is then used to identify and summarize findings from existing health services research that relate to the quality of care for persons with disability.

Study selection. We searched MEDLINE and other databases for primary research and review articles containing the phrases 'quality of care', 'patient safety', 'access', 'patient experience', and 'coordination of care' in conjunction with the words 'disability' or 'impairment'.

Results. A review of health services research suggests several potential issues in the areas of clinical quality, access, client experience, and coordination. Physical barriers, transportation, communication difficulties, and client and provider attitudes present barriers to receiving appropriate client-centered care. Communication difficulties between provider and client may increase risk for accidental injury and decrease the quality of the client experience. Frequent contact with the health care system and the complexity of an individual's situation also increase the risk of accidental injury. Coordination, the 'lubricant' that facilitates links for all areas of quality for a person with disability, presents the most significant opportunity for improvement, because multiple medical and social providers are typically involved in the care of individuals with disabling conditions.

Conclusion. Health care providers need to embrace a multi-disciplinary approach to quality to meet the needs of persons with disabilities. Funders and purchasers need to provide flexibility in funding to enable a comprehensive primary care approach, while health service researchers need to adopt a broad view of quality to capture issues of importance for persons with disabilities.

Keywords: access to care, coordination of care, disability, patient experience, patient safety, quality of care.

The Global Burden of Disease Study dramatically demonstrated the impact of disability around the world [1]. The study used the metric of disability-adjusted life years, which combined premature mortality from disease with the disability resulting from disease, to identify the leading causes of disease burden. Among the top 10 causes of disability (measured in years lived with a disability) were unipolar major depression, congenital anomalies, and osteoarthritis.

Who are individuals with disabilities? This diverse group includes children with developmental disabilities, adults with chronic mental or physical problems, persons with severe acute injuries (work-related or not), and those with sensory disorders and associated communication difficulties. The individuals represent a range of impairments, from those who are fully self-sufficient at home and in the workplace, to those who are entirely dependent on others for custodial

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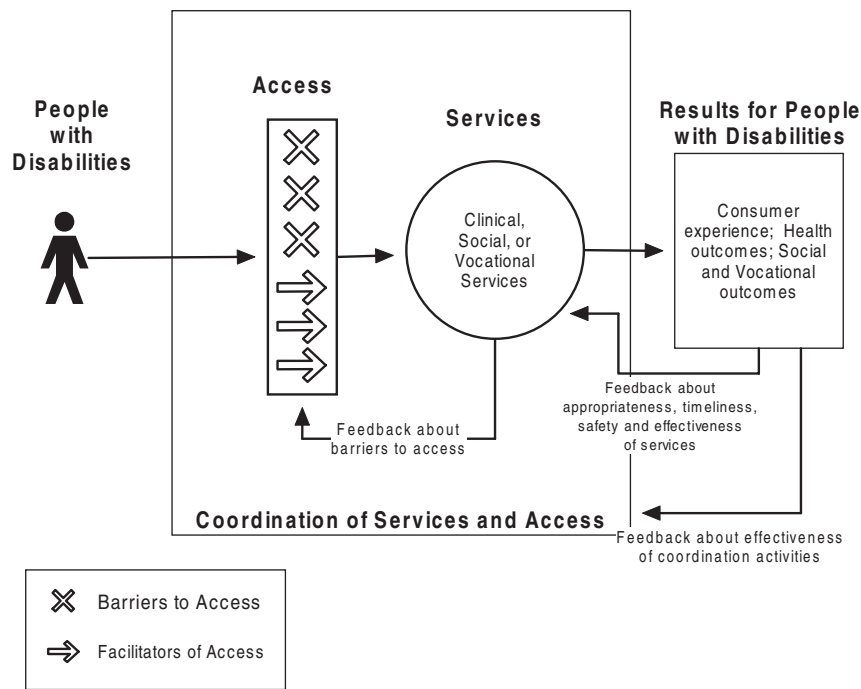


Figure 1 Domains of quality of care for people with disability.

care and decisions about their health care. The challenge to the health care system is to deliver services to people with disabilities that are appropriate, efficient, effective, and coordinated in such a way so that the unique needs of each member of this heterogeneous population are met.

This paper discusses the need for a comprehensive framework for conceptualizing issues of quality and patient safety for children and adults with disability. We begin by describing a model for organizing quality issues and then use the model to identify and summarize findings from existing health services research that relate to the quality of care for people with disabilities. We conclude by discussing the implications of our findings for providers of care, funders of care and health services researchers.

A model of quality for persons with disabilities

Quality is a complex, multi-perspective, and multi-dimensional concept. Since the definition of good quality depends on the perceptions and values of the definer [2], it would be easy to assert that good quality is always relative. It would also be naïve. Program developers, policy-makers, health care managers, and providers of care (physician and non-physician) continually express a need to define and measure quality so that better programs can be developed, better quality of care delivered, and programs and quality evaluated [3]. Below, we trace the historical development of the typical quality model and describe why it is inadequate to capture the essence of quality for persons with disabilities.

Since 1980, quality has been described primarily in terms of *clinical quality* [4,5]. Clinical quality, doing the right thing, in the

right manner (safe and timely implementation), and achieving the right outcomes is firmly grounded in the medical model of care. Patients have symptoms and illnesses that are treated with appropriate decision-making and technology. ‘Effectiveness’, ‘appropriateness’, ‘overuse’, ‘under-use’, and ‘misuse’ are frequently discussed in connection with clinical quality [6]. With the publication of ‘To Err is Human’ [7], patient safety has emerged as an important component of clinical quality. Failing to do the ‘right thing’ or failing in safe, timely, and accurate implementation, compromises patient safety. Patient safety is most likely to be maximized when the technical quality of care is high and the patient is informed and understands their care [7].

In 1990 the US Institute of Medicine (IOM) published its now widely used definition of quality: ‘Quality of care is the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge’ [8]. This definition explicitly included the concept of patient preferences by referring to ‘desired’ health outcomes. The IOM additionally stated that health care service benefit ‘...is expected to reflect considerations of patient satisfaction and well-being, broad health status and quality-of-life outcomes, and the processes of patient–provider interaction and decision-making.’ Phrases associated with the quality of the client’s experience include ‘communication’, ‘information’, ‘respect for patient preferences’, ‘shared decision-making’, and ‘satisfaction’, ‘continuity’, and ‘coordination’ [9]. By including client experience as an important domain of quality, the quality framework began to expand beyond the medical model’s concerns with prevention, diagnosis, and treatment/management to include psychosocial aspects of medical care.

Our model for assuring quality of care for persons with disabilities incorporates both the traditional, as described in the preceding paragraphs, and non-traditional aspects of quality (Figure 1). First, a person with complex needs (or their advocate) attempts to access medical, vocational, or social services. Access can be defined as the ease with which health care is obtained [10]. Access barriers (as represented by the x's) and access facilitators (the arrows) can affect the chance that a person with disabilities receives health care services. We include access to care as a major domain of quality, because without access to care, an individual has no opportunity to receive clinically appropriate or effective care.

Barriers to access have been well studied and include geographical barriers (location of services), financial barriers (cost of getting to care), organizational barriers (lack of appointments, long waits for care, transportation, or referral requirements), and cultural barriers (differing languages or health belief models). We believe that access to services, especially financial, physical, and organizational access, can present particularly potent challenges for persons with a disability.

Once access hurdles have been surmounted, a person receives services (represented by the circle in Figure 1). These services; medical, social, or vocational, should be appropriate to the individual, effective, and delivered in a safe and timely manner. Information about the receipt of services and about the frequency of receiving services provides feedback information about access barriers. Coordination can permit the smooth interaction of many providers of care and reduce fragmentation and barriers to care (shown as a box around access and services in Figure 1). The results of receiving appropriate, well-coordinated services may be captured by the individual's perception of the services or by assessing the health, social, and vocational impact on the person (depicted in Figure 1 as a rectangle outside the service delivery system).

This model suggests that high quality care and positive client outcomes result from the interaction of appropriate access to care, the delivery of appropriate clinical, social and vocational services, and the coordination of these services that is responsive to individual need. The model can be adapted to all types and degrees of disability. Although some quality issues are most pertinent to specific types of disability, e.g. high risk of communication barriers for deaf individuals, many quality issues cut across all disability types, such as the risk of complications from poly-pharmacy and the need to consistently measure the impact of care on quality of life.

Methods

We began by conducting a systematic search of the medical literature for research studies and reviews related to the domains of quality, especially as they relate to persons with disabilities. The strategy was intended to be broad and to identify cross-cutting quality issues rather than focusing on specific groups of people with disability, such as the frail elderly or individuals with physical disability. Thus we used

several specific terms and phrases related to key aspects of quality to maximize the yield of quality-related articles, in combination with a single general term, 'disability', to represent people with all types of disability.

An initial MEDLINE keyword search of titles and abstracts using the terms 'quality of care' and 'disability' for the years 1986–2002, yielded less than 100 English language original studies or review articles. Expanding the search to other databases (PsycINFO, Journals@Ovid, and the Cochrane Database of Systematic Reviews) increased the pool of articles to approximately 1000. We also searched on specific aspects of quality such as 'patient safety', 'access', 'patient experience', 'patient communication', 'satisfaction', 'quality of life', 'care coordination', 'social services', and 'vocational rehabilitation'.

The resulting pool of articles (approximately 2000) was further limited to research studies and review articles (about 600). We also searched for articles in European and Australian journals, or studies set in locations other than North America, irrespective of the type of article (about 400). The abstracts of the final set of articles were first reviewed for relevance and sample size (excluding case studies) and then the articles combed for quality issues for persons with disabilities within each domain of our quality model: access, quality of clinical, social and vocational services, client experience, and coordination of care.

Quality issues for persons with disabilities

Access to services

Disabled and non-disabled individuals experience barriers to access; however, certain access issues disproportionately affect persons with disabilities. We identified four major access barriers to persons with disabilities: physical and transportation barriers; limited access to assistive technology and equipment; limited access to medications, specialists; and limitations in access to personal care attendants. Complicating many of these access issues is the problem of financing; how to pay for needed care. Because a rich, extant literature describes financial barriers, we do not detail them here. However, we note that in the US, a fragmented financing system aggravates a fragmented delivery system and typically does not encourage, or pay for, care coordination [11]. Even in countries with a single-payer financing system, cultural beliefs may prevent or discourage care-seeking behavior [12].

Physical and transportation barriers. In the US, in spite of the provisions of the Americans with Disabilities Act (ADA), physical barriers to care still exist. The ADA was intended to increase the accessibility of many settings, yet physical barriers in primary care offices still exist [13]. Similar issues exist in other countries with disability laws such as Great Britain and Australia [14]. With respect to transportation access, persons with a variety of impairments face significant barriers [15]. Some individuals give up employment because of difficulties getting to their place of work [16]. In some countries, the lack of an adequate transportation

infrastructure presents serious barriers to both individuals with and without disabilities [17].

Access to assistive technology and equipment. Many people with disabilities struggle to obtain assistive technology and equipment [18]. The barriers may be financial or bureaucratic [19]. The consequences of this lack of access can be profound. For persons with mobility impairments, equipment such as wheelchairs create independence and self-esteem for the user, both of which improve the quality of life [20]. Financial and bureaucratic barriers mean that individuals must either do without, pay out-of-pocket, or face lengthy battles with insurers to obtain needed equipment. Mann *et al.* [21], in a randomized controlled study of provision of assistive technology to frail elderly in western New York, showed that although both control and experimental groups experienced functional decline during the study period, the rate of decline was less in the experimental group (group receiving assistive technology). In addition, hospitalization and other institutional costs were reduced.

Access to medications and specialists. Medications are the primary therapeutic modality of modern medicine. While access to appropriate medications is critical for all patients, people with disabilities may face additional barriers. For some disabled persons, an insurer may refuse to pay for drug treatment on the grounds that it is considered innovative or experimental. In sub-Saharan Africa, the problem for persons with HIV/AIDS is more fundamental; access to medication is frequently limited by the costliness of medication [22].

The adverse consequences of inadequate access to medication include increased disability and use of potentially more expensive services. Soumerai *et al.* [23] demonstrated that chronically ill New Hampshire residents who could not obtain needed medication were twice as likely to enter nursing homes or the hospital. In this study, residents who entered the nursing home stayed there permanently.

Individuals with no insurance or inadequate insurance are also at risk for not receiving needed medications. One adverse consequence of losing financial access to medications may be that individuals switch health plans to continue receiving drug benefits at the expense of continuity of care with their physician [24].

Current literature suggests that lack of access to specialists is most acute in children with special health care needs and adults with mobility-related disabilities [25]. Access issues are particularly severe in more remote geographical areas, where the nearest tertiary care center may be several hundred miles away. Policies of payers may contribute to the lack of access by requiring second opinions or pre-approval of treatment.

Access to personal care attendants. For persons with major physical disability, access to high quality personal care attendants (PCAs) is a major issue. Personal care services, particularly those directly managed by the individual with disability, provide a range of services and allow the individual to regain independence [26]. The services provided by PCAs also help to keep the person with disability healthy and reduce hospi-

talizations. The PCA–client relationship can, on the other hand, be problematic. For example, disabled individuals (primarily with cerebral palsy and spinal cord injury) interviewed by a team from the University of Wisconsin-Madison, report that finding and maintaining reliable, well-trained personal care workers was difficult, and that the client often had to settle for PCAs less well-trained or experienced than desired [18].

Some groups experience additional barriers to securing in-home assistance. Wallace *et al.* [27] report that the most disabled and isolated Latino elderly persons were less likely to have paid in-home assistance than non-Latino elderly. The availability and use of personal care or personal assistance services in other countries may be especially limited [28].

Quality of services

As described earlier, good quality service delivery means that choice of services should be appropriate to the individual, the results effective, and the services delivered in a safe and timely manner. This section summarizes literature related to the process and outcomes of delivering clinical, social, and vocational services.

Quality related to clinical services. We identified five major issues related to the quality of clinical care received by persons with disabling conditions: under-use of age-appropriate preventive health care, under-treatment of recognized co-morbid conditions, inadequate provider knowledge about appropriate and effective treatments, barriers to effective communication between providers and clients, and presence of risk factors for accidental injury.

(1) Under-use of appropriate preventive health services

Several studies document that persons with disabilities are less likely to receive indicated preventive care such as Paps mears, mammograms, or appropriate preventive dental care [29,30]. Lack of preventive health care can be a critical problem, as some subgroups of disabled persons may be at higher risk for persistence of risk factors such as smoking, obesity, and hypertension that can lead to increased susceptibility or illness.

Unmet preventive health care needs among individuals with disabilities may result from access and/or communication barriers. For example, Welner *et al.* [31] suggest that typical physician office equipment, such as the examining table, present a major barrier to the receipt of services for those with mobility impairments. Other barriers to receipt of preventive services include difficulty communicating [32], lack of awareness of the importance of prevention [30], multiple acute problems that crowd out preventive care, or poor patient compliance. Finally, lack of preventive health care may result from poor coordination among clinicians who care for the patient, so that each expects the other is addressing the preventive health needs.

(2) Under-treatment of identified health care problems

A second clinical issue that applies to all disabled populations is under-treatment of co-morbid conditions that are unrelated to the primary disability. For example, Redelmeier *et al.* [33]

report that elderly individuals with multiple chronic illnesses in Ontario, Canada, were often not treated for co-morbidities. In their study, persons with schizophrenia were less likely to receive treatment for arthritis. Depression is also commonly missed or under-treated among individuals with disability. Inadequately identified or treated depression increases the risk for further disability and acquisition of secondary impairments [34]. Several researchers report under-treatment of psychiatric conditions (other than depression) among those with cognitive impairments [35].

Persons with significant mental impairment (either chronic mental illness or dementia) seem to be most at risk for under-treatment of co-morbid conditions. Druss *et al.* [36], using the data from the Cooperative Cardiovascular Project, found that acute myocardial infarction patients with co-morbid mental illness such as schizophrenia and depression were less likely to undergo cardiac catheterization and subsequent CABG. Similarly, Moroney *et al.* [37] documented that stroke patients with significant dementia were less likely to receive aspirin or warfarin at discharge. Druss *et al.* [38] also show that under-use of key treatment modalities appears to increase mortality of persons with schizophrenia and depression in the year following an acute myocardial infarction.

(3) Provider knowledge of disabling conditions

The range of disabling conditions is considerable, making it unlikely that any single clinician will possess the requisite expertise to care for all individuals with disability that present to them for care. Several studies document the frustration experienced by patients and their families when they perceive their health care provider does not have expertise about their disability or about disabilities in general [39,40]. Individuals interviewed by Bowers *et al.* [18] noted that providers did not have information about most recent treatment advances, types of assistive technologies that could be helpful, or how other medical conditions and treatments could interact with the underlying impairment.

Training of clinicians may be part of the problem. A survey by Sneed *et al.* [41] shows that pediatricians often lack knowledge and confidence for prescribing treatments for children with special needs. Similarly, other researchers suggest that low numbers of dentists specializing in the dentistry of children with special health care needs or adults with disabilities leads to unmet dental needs [30,42]. Burstein *et al.* [43] showed that few providers receive any training about work-related disabilities in medical school, and the time devoted to all work-related health conditions averages less than 4 hours over 4 years. In the US, medical education tends to lead to a definition of 'care' that is highly restrictive, producing doctors who understand and focus on measurable clinical outcomes, or at most, 'pain reduction' as the ultimate measures of quality care. Some physicians have suggested that issues such as return to work, social rehabilitation, and community re-integration are non-medical, and thus not their concern [44].

(4) Barriers to effective provider–patient communication

Several studies document the presence of significant communication barriers between providers of care and

persons with disabilities. Persons at increased risk for communication barriers include individuals with altered mental states, or impairments of vision, hearing, or speech [45]. When faced with a patient with whom communication is difficult, the provider may have difficulty with: basic communication [46], understanding the patient's presenting complaint and therefore increase the use of testing [47]; obtaining a patient history [48]; promptly recognizing the appearance of a new health problem [49]; or probing for adverse effects of medication [50]. Providers may also infer problems that do not exist, e.g. intellectual impairments, simply because the patient has difficulty communicating [18].

For the patient, the clinical consequences of communication difficulties may include misunderstanding of the diagnosis or directions for self-care [51,52], poor patient adherence to treatment recommendations [53], and less than optimal clinical outcomes [54].

(5) Patient safety issues

Adults and children with disabilities may be at higher risk than the general population for accidental injury. While most persons with disabilities are quite healthy (e.g. the adult with a cognitive impairment who suffers only an occasional community-acquired illness), others have medical problems that require frequent trips to the doctor or hospital. Several studies document that more contact with the health care system is associated with greater risk for adverse events [55].

Likewise, the complexities of an individual's problems contribute to an increased risk for error [56]. Complex medical problems are often associated with multiple drug prescriptions, which increase the opportunities for adverse drug interactions [57].

Some disabilities are rare. The typical pediatrician will not have many children with spina bifida under his or her care. Conditions that are rare present medical management problems precisely because they are uncommon. Some authors suggest that clinical practice guidelines are useful in such situations, but may not address the full range of complexities that often occur [58]. Special treatment units focused on the specific disabling condition such as for spina bifida [59], stroke [60], or renal failure [61], may also help when the condition is uncommon.

Communication barriers such as those discussed above also increase the risk of accidental injury. For example, Brauner *et al.* [50] describe the case of an elderly woman with Alzheimer-type dementia who was unable to report her adverse symptoms associated with taking alendronate and expired following esophageal ulceration and rupture. Communication deficiencies may also result in reinjury or recurrence of a prior injury when appropriate information about prevention is not transmitted.

Quality of non-clinical services

As with clinical services, the delivery of non-health care services, such as vocational, housing, or social services, must be appropriate to the individual, the results effective, and the services delivered in an acceptable and timely manner. Unlike

the clinical field, however, the definition of appropriateness for other services tends not to be determined by randomized, controlled research studies. For example, the effectiveness of non-medical care services has been evaluated in the workers' compensation arena by a variety of return-to-work measures [62]. Much of the work from the last 10 years suggests that measures of 'appropriateness' of non-clinical services need to be client-centered [63–66], or jointly determined by consumers and their treatment advisors [67].

Consumer's experience with care

The quality of the consumer's experience with the delivery system has the potential to influence client outcomes, as discussed above. For example, patients with long-term relationships with a single provider have fewer hospitalizations and better outcomes, possibly as a by-product of better communication [68]. Additionally, persons with strong social support systems (such as a supportive family) experience a protective effect on morbidity and mortality [69]. We identified several issues related to the person with disability's experience with care: determining quality of life, conveying information, shared decision-making, and stigmatization.

Quality of life. Quality of life results from the interaction of the social, psychological, and physical domains of an individual's functioning [70]. Quality of life measures typically include assessment of physical functioning, social and emotional functioning, and work-role functioning.

A major disconnect seems to exist between what persons with disabilities value in terms of functional status and quality of life and what insurers, providers, and employers value. Research shows that individuals with disability value a broad concept of quality of life [71], providers and employers, on the other hand, focus on physical or work-role functioning. For example, Rothwell *et al.* surveyed individuals with multiple sclerosis and their neurologists and concluded that multiple sclerosis individuals, and possibly those with other chronic conditions, placed less emphasis on the physical impairments associated with their illness and more on mental health, vitality, and general health, while their neurologists emphasized physical functioning [72]. Bogardus *et al.* [73] report similar findings from a study of clinicians and family caregivers of frail elderly individuals. In mental health also, studies in schizophrenia have demonstrated significant differences between individuals and their families on the priorities for treatment outcomes. Individuals are more willing to tolerate disease manifestations, but are less willing to endure extrapyramidal and other medication side effects [74].

Current measures of quality of life for people with disabilities fall into two broad categories: those suitable for measuring quality of life across a range of disabilities and those tailored to a specific type of disability. Examples of measures that are not specific to a particular patient population include the SF-36 and its variants [75], and the EuroQual measure. Since generic measures of quality of life may not capture the components of functioning or life quality of most importance

to individuals [73], several disease-specific quality of life measures have been developed and tested [76–79]. In addition, few generic measures capture the dimensions of work most important to patients [80].

Information. Individuals with disabilities and families of children with disabilities place a high value on information. In a study of parents of disabled children, including children with spina bifida, deafness, spastic quadriplegia, and other chronic conditions, parents were most upset when the health care providers, whom the parents expected to be knowledgeable and informed about their child's condition, provided misinformation or inadequate information [39]. Parents want/need information about their child and prognosis [81].

Information about social services, coping with disability, and rehabilitation needs seems to be particularly lacking. Individuals with disability surveyed in a Scottish study report frequently turning to general practitioners for information, yet finding few answers [82]. Similarly, for disabilities affecting the ability to work, employers cite lack of appropriate information (regarding medical and adaptive needs) as a major impediment to re-integration into the workplace [83].

Shared decision-making. An important component of the trend towards patient-centered care is shared decision-making. When the patient is truly a partner in their health care, patient compliance with treatment recommendations and health outcomes improve [84]. Some patients may prefer the physician to take responsibility for problem solving, but want to be consulted about their preferences for treatment and outcomes [85]. At national levels, governments are beginning to make serious efforts to involve groups advocating for people with disabilities in service planning efforts [86].

Stigmatization. Persons with disability have historically faced stigma associated with their disability. Stigmatization can affect access to care, and the ability to communicate needs and have those needs understood, as well as the individual's quality of life [87,88]. An Australian survey documented that although different cultures accept disability to different degrees, the relative amount of stigma associated with specific disabilities remains stable across cultural contexts. The most highly stigmatized disabilities include psychiatric illness, AIDS, mental retardation, and cerebral palsy [89]. Several authors report that the more visible the disability (e.g. leprosy, epilepsy), the greater the degree of stigmatization [90]. In countries where women have low social standing, the stigma of having a disability, coupled with their social status, may mean that women delay seeking medical care until disability becomes severe [91]. A British study suggests that stigmatization of persons with mental illness results from a focus on the negative social consequences of the illness and from widespread perceptions that mentally ill individuals are somehow responsible for their condition [88].

Coordination of services

Coordination of care is the lubricant that keeps the diverse services working smoothly together without snags or hitches.

Without coordination, individuals may experience delays in receiving care or perhaps not receive services at all. The essential components of coordination, as described by researchers at Mathematica Policy Research, include: identifying each individual's needs that increase their risk of adverse health events; addressing those needs through integration of fragmented care, patient self-care education; and then monitoring individuals for potential problems [92]. The same study identifies two predominant models of coordination, case management, and disease management. The case management model serves persons at risk for fragmented care, irrespective of medical condition, while the disease management model organizes services around a single condition. Most of the extant literature on coordination evaluates one of these two models.

Case management. Case management programs typically serve a small group of clients and tailor the care plans to the specific needs of the client. The well-studied Assertive Community Treatment (ACT) model for severe mental illness is an example of a case management model [93,94]. The ACT model involves teams of case-workers who assist the client in obtaining services, managing medications, finding housing, and managing day-to-day activities of living. Randomized controlled trials of ACT have demonstrated reduction in hospital days, increased housing stability, and increased patient and family satisfaction.

Other examples of the case management model of coordination include the 'Boston Model' of the Boston Community Medical Group, relying on nurse practitioner coordinators to successfully provide coordinated and comprehensive health care to individuals with major physical disabilities [95]. Similar models in other countries coordinate care for children with disabilities [96].

Unsuccessful case management programs lack some or all of the essential components of coordination. For example, Chen *et al.* [92] report that programs missing adequate initial client assessment (e.g. information about co-morbid diagnoses, medication) or failing to build physician relationships during the implementation phase, or lacking a mechanism to respond to new information during the monitoring phase, all had no impact on costs or service use.

Disease management. The disease management model focuses on a single condition and relies heavily on evidence-based guidelines, protocols, and standardization [92]. Although disease management programs have been described for chronic conditions such as diabetes, heart failure, asthma, and depression [97,98], such programs place less emphasis on reducing the fragmentation between community services, social services, families, and caregivers. In addition, many disease management programs are run commercially, and depend on large numbers of cases to break even. Disease management appears less suited as a tool to achieve coordination of services for persons with disabilities.

Discussion

High quality of care for people with disabilities requires intimate links between the medical care system and the social and vocational services sectors. A care delivery system that focuses only on medical or clinical issues, or only on social and vocational issues, will fail to adequately address quality concerns for people with disabilities. We propose a model of quality that is based on high quality medical, social, and vocational services (appropriate, effective, safe, and timely care), and also acknowledges the importance of a first-rate experience with care (communication, respect for preferences), excellent access to care (physical, financial, cultural, geographical), and superior coordination of care. Application of the model requires the integration of traditional medical services, with services provided by agencies that address vital social needs such as housing, medical supply, transportation, and vocational and educational services. These non-medical services make a substantial contribution to a person reaching their full potential in terms of personal, vocational, and societal fulfillment [99].

Our review suggests several important issues that providers of care, funders of care, and health services researchers attempting to measure or evaluate care, should address. These categories of issues apply to most people with disabilities, irrespective of the disabling condition. Although people with disabilities represent a heterogeneous group, with much variation in environmental circumstances and needs, some quality of care issues are universal.

Firstly, in terms of access to care, we note that access barriers for people with disabilities appear more pervasive than for other population groups. Physical barriers to services still exist, perhaps because some providers of care decide not to invest in technology and equipment that facilitates access due to the cost of the equipment, or perhaps because funding systems do not offer adequate incentives for the acquisition of physically accessible equipment. Other important access issues include access to assistive technology, access to medications, and PCAs.

Secondly, major issues of clinical quality include inadequate preventive care, under-recognition or under-treatment of co-morbid conditions, and barriers to effective provider–client communication. Some of these barriers may be addressed at the provider level through the use of a structured approach to care management, use of preventive care flow sheets, or provider and consumer reminders to increase the use of preventive services. In addition, providers of care must be able to work within a delivery system that both allows adequate time for client visits and increases the availability of mid-level practitioners who can fill in the information and communication gaps. Funders of care need to re-think payment strategies so that case management, care coordination and time with the client are reimbursed.

Thirdly, a major issue relates to coordination of services. Care coordination has historically been an under-funded service. In addition, a potential barrier to coordination may be the initial identification of persons who could benefit from coordination. In an environment where patient confidentiality

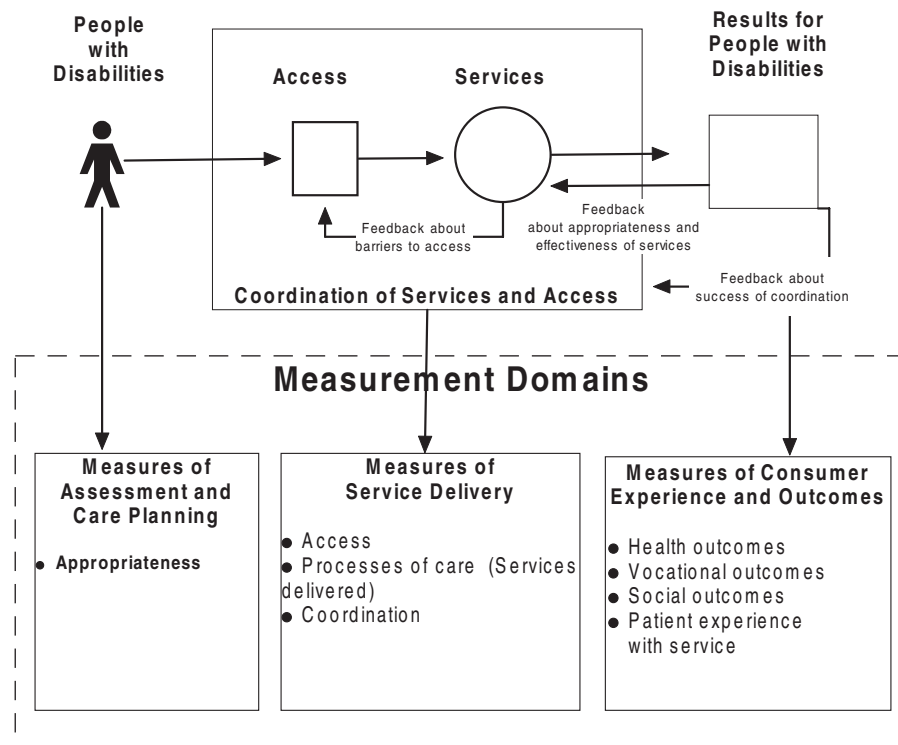


Figure 2 Measuring quality of care for people with disability.

is sacrosanct, developing and maintaining any kind of list or registry of persons requiring coordination may pose difficulties, although a disease management type model may offer a solution to the confidentiality problem. For health services researchers, the major issue is how to define and measure coordination. Looking for evidence of coordination within traditional sources of information, such as the medical record or administrative data, is like looking for a needle in a haystack, due to inconsistencies in documentation and coding practices.

Finally, a number of issues relate to consumer experience and outcomes. Providers and funders of care and health services researchers must base the success of programs on more than *health* outcomes alone. Vocational and social outcomes, as well as consumer perceptions of the care experience, are important products of the care delivery system. Of particular importance is the feedback loop from the consumer to the delivery system about what is appropriate and effective. Providers of *medical* services, in particular, must constantly be aware of the medical bias inherent in their training and within many of their organizational systems, and strive to embrace a client-centered approach to caring for persons with disability.

Based on our review of quality issues, we suggest three possible groups of quality measures related to our model (Figure 2). The first measurement domain might be assessment and care planning, as proposed by Mathematica Policy Research [92]. Effective delivery of services starts with a comprehensive appraisal of an individual's current status and unmet needs. The second measurement domain is service delivery and encompasses the areas of access to care, processes of care, and care coordination. The final

measurement domain includes measures of outcome and patient experience.

In summary, rethinking the design of service delivery for persons with disability leads to a system that integrates and coordinates medical, social and vocational services. The system should focus on issues of access, processes of care, coordination, and client outcomes. The performance of key aspects of the system can be measured and thus improved. A redesigned and integrated system has the potential to lead to substantial and real improvements in the quality of life for persons with disability.

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