



Children with Disabilities

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How Can Quality Improvement Enhance the Lives of Children with Disabilities?

James M. Perrin

Summary

Much attention has aided measurement and improvement in the quality of health care during the past two decades, with new ways to define and measure quality, recognition that doing so can identify strategies to enhance care, and systematic efforts by both government and private insurers to apply these principles. In this article, James Perrin reviews these gains. Although children have benefited, these quality measurement efforts have focused mainly on adult health care. Now, two recent federal programs promise to expand quality measurement of child health care.

Enacted in 2009, the Children's Health Insurance Program Reauthorization Act provides systematic support for efforts to develop and implement a set of child health quality measures. This federal support represents the first major public investment in improving child health care quality. The Affordable Care Act, which became law in 2010, extends those activities by focusing attention on improving care for people with chronic conditions, including new ways to organize care using teams of doctors, nurses, and others focused on improving chronic care outcomes. For children especially, this team care should also focus on prevention of chronic conditions and their consequences.

Despite these significant efforts to expand quality measurement among children and youth, Perrin finds that most measures and improvement activities focus on children without chronic conditions, and few measures of chronic conditions go beyond examining what kinds of monitoring children with specific conditions receive. Only limited attention is paid to how well the children are functioning. A number of networks working with children with specific chronic health conditions (such as cancer, cystic fibrosis, and sickle cell disease) have developed effective measures of functioning for children with those conditions and active programs to improve such outcomes. These networks offer the best examples of how to improve care and outcomes for young people with disabilities. Broadening their impact to larger numbers of children with disabilities will require developing measures of functioning and quality of life and targeting interventions and efforts to improve those outcomes.

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The past fifteen to twenty years have seen substantial growth in the measurement of quality in children's health care and in systematic attempts to improve quality. Although support for and expansion of the quality of children's health care have lagged behind that for adult and elderly populations amid tremendous investments in Medicare since the 1960s, public and private support has fueled real growth in the number of organizations and investigators working on the quality of health care for children and adolescents. The National Association of Children's Hospitals and Related Institutions and the Child Health Corporation of America,¹ the National Initiative for Children's Healthcare Quality, the American Board of Pediatrics, the American Academy of Pediatrics, and the Child and Adolescent Health Measurement Initiative, as well as efforts at several major children's and other hospitals, have all added substance to efforts to examine and improve the quality of children's health care. This work has led to the development of new measures of quality, specific efforts to improve quality, and multiple studies of how well the health care system meets the needs of children. Some of this work has moved toward transforming clinical care and redesigning systems of care. The federal Agency for Healthcare Research and Quality (AHRQ), along with a few private foundations, has provided significant financial and organizational support to the development of quality efforts for children's health care.

This article reviews key progress in quality measurement and improvement and considers how well these efforts address the needs of children with disabilities. For the purposes of this article, several definitions of quality are used. The Institute of Medicine (IOM), the health arm of the National Academy of

Sciences, defines quality as "the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge."² Stephen Campbell and others consider two principal dimensions of quality—access and effectiveness—with effectiveness separated into clinical care and interpersonal care.³ One part of this article applies these notions—access, effectiveness, care processes, and outcomes—to children and youth with disabilities. Key leaders in quality, such as W. Edwards Deming and Joseph Juran,⁴ have advocated processes to improve quality that include planning change, carrying it out, studying its effects, and then taking action to achieve better outcomes, generally viewed from the perspective of the end user. These leaders call for continuous cycles of improvement. This article thus also examines improvement (as distinct from quality measurement), looking closely at what is known about improvement among children and youth with disabilities and the opportunities that exist for applying the Deming-Juran strategies of continuous quality improvement and system redesign to improve outcomes for children and youth with disabilities.

The phenomenal growth in the number of children with diagnoses of chronic health conditions during the past two decades (see Neal Halfon and others in this volume)⁵ indicates the importance of developing quality measures for these populations along with efforts both to prevent the conditions and improve the care of children who have them. Relative to other children, children and youth with disabilities have, as part of the broader work in children's health care quality, had greater attention paid to defining their service needs, developing better health status measures, and initiating improvement

efforts focused at least on some of the more prevalent chronic health conditions and disabilities.

Some of the best work to improve care for children with disabling conditions comes from efforts by condition-specific networks such as those that target cystic fibrosis, sickle cell disease, inflammatory bowel disease, and autism.⁶ All of these networks have some focus on quality assessment and improvement, although they generally have not led to the development of quality measures for use beyond their specific conditions. In general, these condition-specific efforts build from some consensus on best clinical practices and activities, with collaborative centers agreeing on common standards of care. In many cases, the limited evidence in support of many practices drives the use of consensus as the basis for guidelines and improvement, while research continues to provide better evidence about effective interventions.

Despite this substantial body of work, most activities that aim to address health care quality for children and youth have addressed issues other than chronic conditions. Most of the efforts related to chronic conditions have focused on narrowly defined biological outcomes (for example, indicators of diabetes control) rather than on broader measures of disability and functioning. Although improving clinical outcomes has clear value, especially when clinical improvement can be linked with longer-term functioning and improved ability, this article argues for a focus on measures that directly address disability and functioning.

The Importance of Prevention and Choosing the Right Outcomes

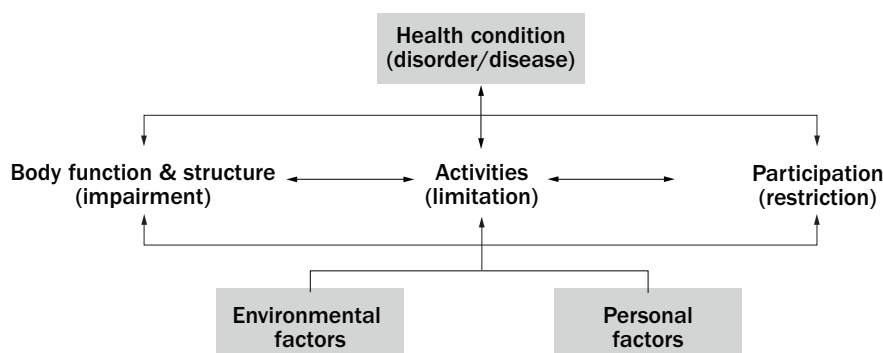
Any examination of chronic conditions affecting children and youth should distinguish

between the higher prevalence conditions (obesity, asthma, and mental health conditions) and less common chronic conditions that nonetheless cause substantial morbidity for affected young people (such as congenital heart disease, childhood arthritis, cancer, or sickle cell disease). Some of these conditions—perhaps especially the high prevalence ones—are appropriate targets for preventive efforts. Quality and improvement activities should address prevention of these conditions and especially the disabilities arising from having them.

Childhood chronic conditions provide opportunities for both primary and secondary prevention, that is, preventing the onset of a condition and preventing the consequences of a condition, including disability and dysfunction (see the article by Stephen Rauch and Bruce Lanphear in this volume).⁷ Nonetheless, as with medical research in general, relatively little work and attention have gone into measuring and improving prevention, primary or secondary. Given the dramatic growth in diagnoses of some conditions and the resulting increase in rates of recognized disabilities among children and young adults, public health and welfare systems will face extraordinary demands in the next decade unless greater resources are allocated to prevention.⁸

Work undertaken by the World Health Organization with the recently revised International Classification of Functioning (ICF) provides a framework to clarify the relationships among disease, disability, and functioning and particularly guides concepts of secondary prevention (figure 1).⁹ The ICF framework describes areas of concern that have led to new measures that support broader definitions and assessments of quality. Some promising work regarding

Figure 1. The International Classification of Functioning (ICF) Model



Source: World Health Organization.

secondary prevention of disability focuses on measuring quality of life among children and youth with various chronic conditions, recognizing that these measures provide important indicators of status beyond traditional biological or physiologic assessments.

The choice of measures and areas of concern must in part reflect the values of a society or the purposes of study, but researchers also should consider the items or areas that services might be expected to improve. Social and community factors have a major influence on functioning and participation in the activities of everyday life, and this influence may go well beyond the physical impact of a disability. Treating the disease directly may have limited impact on participation or functioning, while targeting functioning or quality of life could lead to a change in chosen interventions. In general, traditional medical treatments may have greater impact on biological measures (for example, blood pressure) but less effect on functioning or participation (such as getting to school or playing games). Improving disability among children and youth thus calls for comprehensive programs with sharply focused goals.

Issues in Quality Assessment

Several measurement issues are of particular salience to assessments of health care quality. These include the scope of the evaluation (whether the measurements are conducted at a single point in time or over a period of longer duration), the area being evaluated (type of disability, functioning, or quality of life), and whether the unit of observation and intervention is the child, the family, or society.

Short Term versus Long Term; Cross-Sectional versus Longitudinal

Much measurement of child health derives from cross-sectional (that is, point in time) data, a strategy that makes little sense in efforts to measure and improve chronic health conditions and their impact. Although cross-sectional studies allow assessment, for example, of access to or use of services, they do not allow measurement of whether the use of those services is associated with improvements in health and reductions in disability over time. That type of measurement clearly requires following individuals before and after the use of services. A critical issue for children's health, of course, is the

understanding that the full benefits of high-quality care often emerge many years in the future. Typical preventive services such as those aimed at curbing tobacco use or involving exercise and diet may translate into improved health years or decades later.¹⁰ For children with disabling conditions, improved outcomes also may result in the prevention of more serious disability in adulthood and improved social, educational, and vocational functioning.¹¹ Ideally, children should be followed for a long period in order to assess the effects of services on disability.

Nonetheless, some short-term targets merit attention, including the use and efficacy of medications, hospital and emergency department use, and the use and efficacy of specialized treatments such as speech, language, and occupational therapies. Quality measures must be developed in each of these areas. The use of psychotropic medications, especially stimulants and atypical antipsychotics, has grown markedly during the past two decades for a variety of conditions including attention deficit/hyperactivity disorder (ADHD), autism spectrum disorders, depression, and schizophrenia.¹² Although some of this use has support based on solid evidence, other practices (especially the use of multiple drugs concurrently) lack strong research support. The need to improve the evidence base for these treatments and to apply quality-improvement strategies based on solid evidence seems particularly critical in pediatric psychopharmacology.

Much pediatric hospitalization today involves children with very complex, often multi-system diseases.¹³ Are there opportunities to improve that care and diminish hospital use?¹⁴ Imaginative use of team care, meeting all the characteristics of the chronic care model,¹⁵ may decrease hospital use and costs

while improving outcomes, especially participation in normal childhood activities.¹⁶

Although there is much evidence on the general value of various specialized therapies such as speech and language therapy, occupational therapy, physical therapy, and respiratory care, little research has assessed the necessary scope and duration of these therapies or how they might be better tailored to individual circumstances. How much physical therapy should a child with cerebral palsy receive, how frequently, and for how long? What about behavioral interventions or speech therapy for young people with autism spectrum disorders, again areas where good evidence supports use in general but few data are available regarding scope and duration?¹⁷

Areas of Concern: Disability, Functioning, and Quality of Life

One can measure both condition-specific indicators of disease and its severity (for example, factor level in hemophilia, frequency and extent of bleeding into joints), as well as more generic indicators of disability such as mobility impairment and ability to participate in certain activities. The ICF has helped to define the main realms of disability and functioning, including indicators of performance and functioning that disability may affect. It focuses attention on the effects of conditions on mobility and body function and structure, activities and limitations, and social participation, and provides a framework to examine how conditions interact with the environment (including family factors) to affect functioning.¹⁸ The ICF spectrum of measurement ranges from biological indicators to functional measures to assessments of quality of life.¹⁹ It is important to recognize that rates or scores on many of these measures do not correlate highly. For example, two people may have the same fairly severe disease as indicated by

Table 1. Typical Domains of Quality of Life Measures

Physical functioning/role performance
Psychological/emotional state
Social interactions and functioning
Education functioning
Physical (somatic) symptoms*
Disease-specific symptoms*
Treatment effects*
Other, less common domains:
Views of the future
Role of the family

Source: Author.
*Typically limited to disease-specific quality of life measures.

biological measures but also may have very different observable characteristics of the illness, and the illness may have different effects on each person’s functioning and perceptions of quality of life.²⁰

Several other measures address functioning among children with disabilities. Some focus mainly on physical functioning and ability (the WeeFIM and PEDI²¹), while others such as the FS-IIR²² address broader concepts of functioning, for example, whether a chronic condition affects a child’s participation in school or play. These measures have the value of applicability across conditions, providing a way to compare degrees of functioning and ability regardless of the specific disorder. They have proven useful in general studies of childhood disability and in assessing improvement.

Quality of life reflects an individual’s perceptions of how (s)he is doing in several key life areas such as school activities, peer relationships, emotions, and play. Although subject to various interpretations (for example, adolescents with chronic conditions and their

parents often differ in their assessments of the adolescents’ quality of life), these measures provide a more substantial and relevant indicator of disability in most cases than biological measures. Quality of life measures assess characteristics across a broad spectrum, ranging from general factors (such as relationships, psychology, and participation) and general health-related considerations (for example, how much illness a person experiences or the extent to which illness interferes with important functions) to condition-specific measures such as abdominal pain in inflammatory bowel disease and joint pain or bleeding in hemophilia. Frequently used measures include the PedsQL model, the Child Health Questionnaire, and the Disabkids module, as well as condition-specific measures.²³ Table 1 indicates typical areas of focus in quality of life measures.

Unit of Observation and Intervention: Child, Family, or Society?

The prominence of family and community as determinants of child health raises the question of what unit of observation to use in measuring quality (and providing services). Parents in poor health face greater burdens in raising healthy children. Ill health among parents increases the risk of ill health among children, in part reflecting the continuing or aggregate burden of adversity and in part family or genetic predisposition. Providing better care for children can produce better results when the care needs of their parents are addressed at the same time. Investing in parent health and well-being will likely improve child health and disability and diminish the impact of disability on a child’s functioning and participation in common childhood activities.²⁴ Similarly, the measurement of quality in child health care will benefit from recognizing the value of measuring the quality of care for parents and

communities. In earlier work, my colleagues and I have described the system of services that children with chronic conditions make use of, recognizing that an understanding of how these services interact can lead to a better assessment of the variety of activities and improvements that can affect children's health, disability, and functioning.²⁵

The social impact of childhood disability involves both the present, through health care and other social costs, and the future, through growing demands on public support for basic needs as well as health care.²⁶ Thus, measurement should go beyond the child and family to populations and services, as well as service providers.

Current Efforts at Measurement

Several groups have worked to improve the measurement of children's health and functioning. The Child and Adolescent Health Measurement Initiative, based at Oregon Health and Science University, has specifically addressed issues of children with chronic health conditions, including some measurement of functioning, although the initiative's focus has been mainly on health care services and consumer views of those services.²⁷ In its work to improve care for children with various chronic health conditions such as asthma, autism, and sickle cell disease, the National Initiative for Children's Healthcare Quality has defined and implemented various measures of health care quality, appropriately more focused on short-term health care considerations than longer-term functioning or ability but providing a strategy for the application of such measures to child health. The National Quality Forum has addressed the current state of measurement in child health, noting gaps but also recognizing the availability of a number of measures that could have wider use.²⁸

The 2009 Children's Health Insurance Program Reauthorization Act (CHIPRA) included new provisions for the measurement of quality, including the first major investment to examine children's health care quality in publicly insured populations. Several activities have helped to determine the characteristics and foci of this investment. The AHRQ impaneled a group to develop an initial core set of child health measures. This set of twenty-four measures included a few that address the needs of children with chronic health conditions (such as emergency visits for children with asthma, follow-up for ADHD or mental health hospitalization, and diabetes monitoring), although none that directly address functioning or disability. The AHRQ recently funded seven centers around the country, the Pediatric Quality Measures Program (PQMP) Centers of Excellence, to develop focused measures for children's health care.²⁹ Based on the areas listed in the CHIPRA legislation, the agency recently announced priority measures for this program. Some of these measures, shown in table 2, reflect the original twenty-four, but all of these lists notably lack attention to functional measures.

A recent IOM report helps to frame the future of quality measurement in child and adolescent health.³⁰ The document emphasizes the need for broad measures beyond clinical care and health status to include assessments of the physical and social environment, much like the ICF. It also notes the necessity to collect longitudinal data to be able to assess the effects of any efforts to improve quality. Although focused on strategies for measurement, the report clearly lays out how better measurement supports innovation and experimentation in broad system redesign. Finally, the report acknowledges the value of a life-course approach to

Table 2. Priorities for the Pediatric Quality Measures Program (PQMP) Developed from CHIPRA

CHIPRA topic	Initial core set*	PQMP first set of priorities**
<i>Cross-cutting topics</i>		
Duration of enrollment and coverage	None met criteria	Two approaches: stand-alone measure (for quality of health care system) and case-mix adjustment (to use with other measures)
Availability of services	Child and adolescent access to primary care practitioners	Availability of services (focus on subspecialty care, mental health, high-risk obstetrics, dental)
Most integrated health care delivery setting	None met criteria	Care coordination within the context of a medical home
Outcomes	See below for condition-specific outcome measures and family experience of care as outcome measure	Outcome measures to be determined
Disparities identification of children with special health care needs	Stratifier and potential case-mix adjuster—not in use by measures in initial core set	Identification of children with special health care needs
Disparities identification by race and ethnicity	Stratifier and potential case-mix adjuster—not in use by measures in initial core set	Identification of approaches to identify disparities by race and ethnicity Framework for aggregation of measures by various levels of accountability and improvement (provider, plan, state, Medicaid, and CHIP programs)
<i>Preventive services</i>		
Prenatal care	Frequency of ongoing prenatal care	Content of prenatal care
	Timeliness of prenatal care	Content of prenatal care
	Percent of live births weighing less than 2,500 grams	Not included***
	Cesarean rate for nulliparous women with a singleton birth	Not included
Immunizations	Childhood immunization status	Not included
	Immunizations for adolescents	Not included
Other preventive services	Cross-cutting	Content of well-child and well-adolescent care
	Weight assessment	BMI assessment follow-up
	Developmental screening in the first 3 years of life	Not included
	Chlamydia screening	Not included
	Well-child visits in the first 15 months of life	Content of well-child care
	Well-child visits in the 3d, 4th, 5th, and 6th years of life	Content of well-child care
	Adolescent well care visit	Content of well-adolescent care
	Total eligibles who received preventive dental services as a percent of eligibles	Not included
		Adolescent depression screening and follow-up Vision screening and follow-up
<i>Acute care</i>		
	Appropriate testing for children with pharyngitis	Not included
	Otitis media with effusion—avoidance of inappropriate use of systemic antimicrobials in children—ages 2 through 12	Not included
	Total eligibles who received dental treatment services	Dental treatment

Source: Agency for Healthcare Research and Quality (AHRQ), *Crosswalk of the First Set of Priorities for the Pediatric Healthcare Quality Measures Program Centers of Excellence with the CHIPRA Initial Core Measure Set* (Rockville, Md.: June 2011) (www.ahrq.gov/chipra/crosswalk.htm).

*These represent some of the initial set of measures from the group impaneled by AHRQ.

**Areas of current focus by PQMP Centers of Excellence.

***Some of the items labeled “not included” are ones for which effective measures currently exist.

CHIPRA topic	Initial core set*	PQMP first set of priorities**
<i>Acute care (continued)</i>	Ambulatory care: emergency department visits	Not included
	Pediatric central-line-associated bloodstream infections—NICU and PICU	Not included
		Clinical subspecialty care—sickle cell disease
		Inpatient—neonatal care
<i>Chronic care</i>		Hospital readmissions
	Annual number of asthma patients 2 through 20 years old with one or more asthma-related emergency room visits	ED visits for asthma care
	Follow-up care for children prescribed ADHD medication	ADHD diagnosis and follow-up
	Annual hemoglobin A1C testing of children with diabetes	Not included
	Follow-up after hospitalization for mental disorders	Not included
<i>Family experiences of care</i>	CAHPS® 4.0 with Medicaid and Children with Chronic Conditions supplements applied to all children	Inpatient family experience of care

Note: Compiled June 2011 by the Agency for Healthcare Research and Quality.

ADHD = Attention-deficit/hyperactivity disorder

BMI = Body mass index

CAHPS® = Consumer Assessment of Healthcare Providers and Systems

ED = Emergency department

NICU = Neonatal intensive care unit

NCQA = National Committee for Quality Assurance

PICU = Pediatric intensive care unit

measurement to understand the complex interactions among development, health care, and environment over time. It is likely that a number of topics in these reports as well as from the PQMP will relate to disabling conditions among children. This systematic program of research should bring needed attention to the broad array of children's quality measures, including those for children with disabilities.

How Good Is the Quality of Care for Children with Disabilities?

Summary information about the quality of children's health care remains sparse, especially for children with disabilities. The systematic work of Rita Mangione-Smith and

colleagues provides some overview of children's health care quality, although their focus was limited to ambulatory care, with attention to only a few common chronic conditions such as acne, ADHD, allergic rhinitis, asthma, depression, and otitis media.³¹ Measures for these chronic conditions generally—and appropriately—addressed aspects of medical treatment and follow-up. They did not address any indicators of functioning or (dis)ability, for example, interference with school attendance or social participation from a health condition.³²

For children, as for adults, a large proportion of health care expenditures reflects in-hospital treatment. Most pediatric inpatients have

chronic illness and disability, with relatively few children hospitalized without having ongoing health-related problems. Although some have argued that marked decreases in childhood hospitalization rates have eradicated opportunities to lower health care costs by avoiding unnecessary hospitalization, some studies of hospitalization, especially among Medicaid-insured children, suggest that many cases still reflect preventable hospital use.³³ These cases often involve complex interactions among social and environmental factors and a child's illness. For asthma, one of the more common causes of childhood hospitalization, improved medical care can decrease hospitalization rates.³⁴ In many other cases, though, hospitalizations could be avoided by bolstering community support to help families care better for sick children at home. Major changes in these rates will require substantial investment in community and social services to make families less dependent on the health care sector for their children's needs. A key area of research relates to understanding the right mix of medical care improvement and systemic environmental efforts.

There are likely some opportunities to improve care for children with particularly complex chronic conditions, although the relative rarity of most individual conditions has hampered systematic approaches to assess quality; efforts to improve quality have been even more difficult to develop. Some recent work has identified the characteristics of children with recurrent hospitalizations, potentially providing an opportunity to augment care management, decrease hospital use, and improve functioning.³⁵ As discussed later, promising efforts in these areas often arise from the growth of condition-specific networks that pool patients and scientists across many sites to enhance quality measurement and seek care improvements.

Improving Quality and the Processes of Improvement

Beyond measurement, a number of efforts indicate promise in *improving* quality and outcomes for children with disabilities. Most of these efforts use measurement to support actions to drive learning and the redesign of health care systems. The National Initiative for Children's Healthcare Quality, building on models developed by the Institute for Healthcare Improvement, has carried out a number of collaborative efforts addressing several childhood chronic conditions, especially asthma, ADHD, autism, and sickle cell disease.³⁶ These collaboratives call for the definition of appropriate (generally short-term) objectives that indicate meaningful improvement in the health of targeted children. While often medical in nature, some of the outcomes addressed include measures of child and family functioning. Nonetheless, as with many efforts in quality improvement, the focus has been more on improving processes of care than in measuring outcomes. Similarly, measurement sets offered by the National Committee on Quality Assurance (NCQA) focus generally on care processes rather than outcomes.³⁷

Links between these process improvements and enhanced functioning among children remain fairly tenuous. Other promising efforts at care improvement have come from the Child Health Corporation of America, the American Board of Pediatrics, and the National Association of Children's Hospitals and Related Institutions, which have supported efforts to measure and improve the quality of inpatient care, for example, for children with bronchiolitis or sickle cell crises.³⁸ These efforts, however, aim more to address acute exacerbations of chronic conditions than to improve long-term functioning and ability. All of these activities point

to a need to broaden the focus to include functional measures and change over time. Indeed, Michael Porter's call for determining value in health care demands more complete sets of measures, used over time and assessed against the costs of multiple care services.³⁹ The ICF provides guidance regarding which areas to assess.

CHIPRA, in addition to supporting the AHRQ efforts in measurement development, also authorized the Centers for Medicare and Medicaid Services (CMS) to fund ten state initiatives to improve quality for CHIP-insured children. States have broad flexibility in their strategies, including improving both care and assessment. Among those with some focus on childhood chronic conditions or disabilities are Colorado and New Mexico, which are using school-based health centers to improve management of chronic conditions; Maryland, Georgia, and Wyoming, which are focusing on serious behavioral health needs; Massachusetts, which is using collaboratives to focus on ADHD, asthma, and obesity; North Carolina, which is focusing on special health care needs; and Pennsylvania, which is targeting early identification of children with developmental and behavioral issues and other complex medical conditions.⁴⁰ Still in development, these programs may draw attention to changing rates or impacts of disability. Collectively, they represent a major and serious effort toward quality improvement for children's health care.

Promising results have come from condition-specific clinical practice and research networks, such as pediatric oncology groups and the Cystic Fibrosis Foundation. Especially in their early work, the oncology collaboratives had an easy outcome to measure—mortality. Collaborative experiments to modify treatments in a systematic fashion led to significant

improvements in mortality for many childhood cancers.⁴¹ As mortality improved, the networks turned increasingly to improving clinical and functional outcomes for children surviving cancer, resulting in important changes that reduced central nervous system damage and other long-term consequences of treatment.⁴² Part of the work of the oncology groups (and similar work regarding long-term outcomes for children with acquired immune deficiency syndrome, or AIDS)⁴³ emphasized broad measures of functioning.

The cystic fibrosis (CF) network has taken approaches similar to those of the oncology groups. Here, a common agreement on health-status measures for young people with CF allowed network participants to identify differences among CF centers and seek explanations for those differences. These investigations led to changes in the management of infectious diseases and nutrition among young people with CF, and the combined work of forty years by the CF group has dramatically improved life expectancy for this population.⁴⁴ CF investigators and clinicians also have increased their efforts to measure quality of life and other aspects of functioning and to examine potential precursors of variations in these outcomes. Indeed, this work exemplifies some of the best strategies aimed at decreasing disability among young people.

The lessons that arise from this work have major implications for children with many other disabilities. These lessons include the use of a broad array of measures and the involvement of scientists skilled in their use. The important elements of these networks include collaboration across a wide number of sites, common assessments allowing data sharing and examination across sites of natural clinical experiments, involvement of

parents in helping to define research priorities, and the inclusion of more robust measures of outcomes as the networks grow and mature.

The impetus for much of this research into better care for children with specific disabilities has come from vigorous advocacy by parent groups seeking better answers for how to treat their children. Advocacy has led to direct support through fundraising for research as well as to public financing of substantial research through the National Institutes of Health and other federal agencies.

Building on earlier networks, new networks have begun for such diverse conditions as inflammatory bowel disease, sickle cell disease, congenital heart disease, and autism. Their learning from oncology and CF experiences should help speed the process of improving long-term outcomes and diminishing disability in these conditions. As networks develop, they increasingly carry out comparative effectiveness research and clinical trials to seek improved treatments.

The major causes for the increase in child and adolescent disability during the past few decades have been asthma, obesity, and mental health conditions such as ADHD, depression, and autism spectrum disorders (see Neal Halfon and others in this volume). These conditions may lend themselves particularly to prevention, especially in earlier childhood, although currently few options are available for prevention of conditions such as inflammatory bowel disease, leukemia, and cystic fibrosis. For high-prevalence conditions, quality and improvement efforts should address prevention, which in pediatrics has often been limited to screening and immunizations. A further challenge will be to determine whether the lessons from

It may be difficult to build a case for quality improvement in the care of children and youth with disabilities on the basis of medical cost savings alone, but improving care for children with disabilities can improve their parents' workforce participation and productivity.

condition-specific work on rarer diseases can be applied effectively to high-prevalence conditions.

Leadership, sometimes from federal agencies and sometimes from private insurers with an interest in quality, has supported increasing experimentation in clinical redesign, often with a focus on what is termed the medical home, a model of coordinated and comprehensive health care meeting the preventive and treatment needs of people with and without chronic health conditions. Academic groups and condition-specific associations increasingly recognize the redesign of complex social and health care systems as an experimental problem. That is, while it is important to conduct basic scientific research to understand the roots of disability, it may be possible to effect substantial improvements in the everyday lives of children with disabilities through experimentation and dissemination of successful strategies. Hence, the system redesign opportunity merits the attention of experts in improvement science.

The Affordable Care Act pays significant attention to chronic conditions and their impact on health care costs and utilization, and offers incentives to transform primary care practices into medical homes as well as other incentives and programs to improve community services for the management of chronic health conditions. Increasing evidence supports the need for a comprehensive model of coordinated and often team-based care for children with chronic conditions and disability, and in most ways the concept of the medical home fits this model (see the article by Peter Szilagyi in this volume).⁴⁵ The transformation of clinical practice to a medical home requires substantial commitment on the part of clinicians and staff, as well as financial incentives and support to bring about change and to sustain it.⁴⁶ Yet, without such arrangements, children with disabilities will likely continue to receive episodic, fragmented care that meets some of their needs but lacks a coordinated approach to enhancing long-term outcomes and limiting the negative effects of disability.

Arguments in support of the medical home often claim substantial cost savings from such care. Experience so far is sobering, however, with only a few experiments (for example, the North Carolina Medicaid experiments) suggesting major cost savings.⁴⁷ Many other experiments indicate that the costs of change are substantial and provide only incremental cost reductions that may not cover the costs of change. As noted earlier, much of the discretionary or avoidable hospitalization among children and youth likely reflects the interaction of social and environmental factors with clinical ones. As a result, programs to diminish such hospitalization will need to go well beyond improving the traditional medical home to include substantial family and social support services, a concept that

the Affordable Care Act to some degree recognizes.⁴⁸

Recent efforts have explored ways to assess the qualities of a medical home, including development of an NCQA accreditation method, as well as more intensive measures such as the Medical Home Index.⁴⁹ The NCQA medical home measure has gained respect, although observers note that a large majority of items in the assessment reflect information technology capacities in clinical care rather than more robust measures of what constitutes a medical home. Recent revisions have broadened the areas of interest to include more indicators of patient-centeredness, attention to patient self-care, and access to community services. Research into whether the medical home or a chronic care model works has generally focused on improvements in specific disease management for adults (especially metabolic measures in diabetes), despite increasing recognition that most patients do not fall into simple single-disease categories but rather bring a combination of issues such as vascular disease, kidney disease, and diabetes. A systematic review of the pediatric medical home literature provides evidence that medical homes improve effectiveness (mainly in asthma care), family-centeredness, and some aspects of health status.⁵⁰ To address issues of functioning and ability among people of all ages, measurement will likely need to involve combinations of conditions among people with chronic conditions. Children similarly need generic as well as condition-specific measures.

Financing Improvement: Gaining Value

As noted, it may be difficult to build a case for quality improvement in the care of children and youth with disabilities on the basis

of medical cost savings alone.⁵¹ A good deal of work, however, has shown the impact of children's disabilities on parents' health, well-being, and workforce participation.⁵² Fathers and mothers are more likely to be partly or fully unemployed if they have a child with a disability; parents of children with major mobility impairment or developmental disability are particularly affected.⁵³ Thus, improving care for children with disabilities can improve their parents' workforce participation and productivity (see Mark Stabile and Sara Allin's chapter in this volume).⁵⁴ Among employed parents, extra worry about their child's health and the nature of care or community services can significantly affect how well parents do on the job, their attention to their work, productivity, and morale. Measurement of the effects of interventions should include these parent outcomes among assessments of interventions to improve care for children and youth with disabilities.

New public funding for measuring and improving children's health care quality is promising. Meeting the needs of children and youth with disabilities will require targeting key clinical, developmental, functional, and quality of life outcomes and building efforts focused on their improvement.

The Future: Promising Next Steps

The important efforts now under way to develop and expand on a comprehensive library of measures of child health care quality should support a much broader and more consistent approach. Such an approach would be most beneficial if it were adopted across the panorama of funding agencies for such care and across the spectrum of childhood conditions. The recent IOM report lays out a comprehensive strategy for measurement, including broad definitions of areas to monitor, the need to follow children over time,

and the concept of a life-course approach to understanding what affects child and adolescent health and how childhood health affects future outcomes. It will be important to ensure that this effort includes systematic approaches to assessing care quality for young people with disabilities, including attention to disability and functioning, quality of life, and participation, all consistent with the IOM recommendations. Critical, of course, will be the translation of measurement work into actual improvement of care, that is, translating findings into specific interventions to improve outcomes. The IOM report provides a clear path for translating measurement into opportunities for improvement at multiple levels and support for the type of system redesign needed for children with disabilities. New activities supported by AHRQ and CMS are important steps in this process.

Efforts to strengthen both measurement and improvement of care for children with disabilities should distinguish between important groups of conditions. As noted, the major epidemics of common chronic conditions, accounting for much of the increasing disability rates among children, merit strong attention to prevention as a critical quality venture. Without prevention, rates of disability among people aged ten to forty may balloon over the next two decades. And for these populations—including children and youth with asthma, obesity, and mental health conditions—much work should address both primary prevention and the prevention of secondary morbidity and disability. What are the ways to provide care for ADHD and depression so that young adults with these conditions can find employment, personal satisfaction, and improved quality of life? Improvements for obesity and asthma should address similar questions and outcomes.

For less common conditions, much improvement will take place through the expansion and use of multisite collaboratives that enable attention to larger numbers of children and youth than any single site can amass and that allow systematic efforts at measurement and improvement. Some conditions fit between these common and rare groups, perhaps best exemplified by autism spectrum disorders. This category includes almost 750,000 people under age eighteen in the United States,⁵⁵ fewer than asthma or obesity but far more than cystic fibrosis, inflammatory bowel disease, or sickle cell anemia. Here, the notion of centers of excellence providing and improving care for children—the cystic fibrosis model—does not quite work (unless one envisions a few hundred centers, each providing care for thousands of affected children and youth). Defining the goals of improvement and especially the processes for improvement in autism spectrum disorders is particularly challenging, given the need to involve both primary care clinicians and likely many subspecialists, and recognizing that some of the main outcomes of behavior and academic performance lie in sectors other than health.⁵⁶

Following are some of the key elements of system redesign that may improve care quality for children with disabilities.

Development of comprehensive and integrated systems of care, linked in ways to ensure that children and youth with disabilities receive the types and scope of services that can diminish their long-term disability and improve their functioning and participation in common social, educational, and economic activities.

Transformation of child health practice along the lines of a comprehensive, team-based,

multidisciplinary medical home, with comprehensive care provided in both primary care and subspecialty units. Elements should include team care, coordination of care, information systems to support monitoring and improvement, and effective communication among levels of care and with parents and children.

Alignment of incentives with improvements in quality to extend best practices, for example, using pay for performance systematically to enhance quality.

Development of a strong focus and consensus on important short-term and long-term outcomes for children with disability.

Conclusion

Promising recent work has increased attention to long-term outcomes and ways to diminish disability among children and adolescents, building on the larger body of work that has addressed short-term health care processes and near-term improvements in health status among children in general. The most promising results for chronic conditions have come from condition-specific groups, where like-minded scientists, clinicians, and families have banded together with a common goal of improving critical outcomes for children with specific chronic conditions. These groups increasingly recognize the need to consider broad functional outcomes to judge the effects of treatment.

If action is not taken, growing numbers of children with chronic conditions and associated disabilities will lead to substantial public burdens on health care and social services in the next decade. There is a substantial possibility that children with disabilities will reap only limited gains from current efforts to assess and improve child health care quality.

A critical first step is the recognition of the importance of disability among young populations and the substantial risk that ignoring that disability will lead to major health and functional impairments among a large swath of young adults in the coming decade.

Improvement will require similar efforts broadened to the major causes of child and adolescent disability as well as efforts to prevent those conditions and their secondary effects. Substantial measurement already exists for quality in childhood illness and health care. For young people with chronic conditions, it is critical to build a stronger conceptualization of child health and well-being, based on formulations such as the ICF, which will allow systematic attention to key areas of child and adolescent short- and long-term functioning, along with better assessment of their physical and social

environment. Quality measurement needs to expand to include these areas of concern. Having agreement on these areas and on the best ways to measure them will help a good deal in efforts to improve long-term functioning and quality of life for people with disabilities.

Real improvement must follow from active use of measurement to identify promising targets for change. The increasing evidence that quality improvement based on clinical and system redesign can bolster care and outcomes, much of it currently from disease-specific applications, provides a framework for broader dissemination. The lessons learned—collaboration across sites, data sharing with transparency, implementation of quality improvement cycles, and involvement of parents—can apply to a wide variety of childhood disabilities.

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