

# Improving Health Care for Children with Chronic Conditions: Toward a “Wholistic” Approach

Heidi M. Feldman\*

*Children’s Hospital of Pittsburgh, University of Pittsburgh School of Medicine, Pittsburgh PA, USA*

**Abstract:** Approximately 1 in 6 children have special health care needs and half of those have functional limitations or disabilities. Such children use health and related services on average two to eight times more often than children without these conditions. Health care systems and clinical practices are poorly designed to deliver high quality health care to children with chronic conditions. Reform efforts such as the Medical Home and the Improving Chronic Care Model have been shown to improve clinical outcomes but more progress is needed. This paper argues that establishing clinical goals and measuring health outcomes in the care of children with chronic conditions should focus on the nature and extent of functional limitations in a wide range of domains. The International Classification of Functioning, Disability, and Health (ICF) provides a conceptually-driven diagnostic and statistical manual that can be used at the clinical and public health levels to assess and monitor functional outcomes. The newly released ICF-Children and Youth Version has been designed specifically for children up to 18 years of age. The results of functional classification with the ICF can be integrated with medical and mental health diagnoses in a multi-axial assessment of the patient, providing a standardized and therapeutically relevant description of the individual with chronic conditions through a number of domains or axes. Each functional problem requires its own plan for intervention. Functional classification is compatible with other reform efforts, such as the Medical Home initiative. Routine use of functional assessment and classification in the care of children with chronic conditions will lead to a comprehensive or “wholistic” approach to the child and family.

**Keywords:** Developmental disabilities, children with special health care needs, functional classification, multi-axial assessment, chronic disease, disease management.

Health care in the United States is in need of fundamental reform [1]. Chronic conditions are now the leading cause of illness, disability, and death, accounting for the majority of health care encounters and expenditures [1]. The health care system must evolve from one designed to deliver predominantly acute, episodic care to one appropriately designed to delivery high quality care for individuals with chronic conditions [1].

This paper argues for health care reform in pediatrics. A focus on chronic care in pediatrics is justified based on the high proportion of children with chronic conditions, their characteristics, and their high utilization of health and related services. The paper will emphasize that care for children with chronic conditions must be directed toward improving their functional as well as clinical outcomes, a clinical approach that expands beyond the usual confines of the medical model. Functional approaches systematically evaluate multiple, well-defined domains and promote the implementation of management plans aimed at improving or at least maintaining function in those domains. It will recommend approaches for developing management plans to improve functional abilities that result in a comprehensive or wholistic model of care.

## WHO ARE THE CHILDREN WITH CHRONIC CONDITIONS?

Clinicians are likely to agree on which children have chronic conditions. Consider the case of a 4-year old girl who was born prematurely at 28 weeks gestation and developed respiratory distress syndrome of the newborn, prolonged oxygen dependency, and bilateral Grade IV intraventricular hemorrhages. By the end of the first year of life, she was diagnosed with bronchopulmonary dysplasia and gastroesophageal reflux, requiring daily inhalation therapy and small frequent meals. By the end of the second year, she developed spastic diplegia and required physical therapy and early developmental intervention services. Moreover, she lived in poverty and had multiple adult caregivers who smoked in her presence. At school age, she demonstrated cognitive and learning problems and was unable to toilet or dress independently. This child clearly faced multiple chronic health conditions plus unfavorable social conditions [2].

Definitions of chronic conditions vary considerably. The Maternal and Child Health Bureau defined the category of “Children with Special Health Care Needs” (CSHCN) as those who (1) have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and (2) require health and related services of a type or amount beyond that required by children generally [3]. Definitions of the term “disability” include criteria related to how the individual functions in every day life [4]. The Social

\*Address correspondence to this author at the Children’s Hospital of Pittsburgh, 3705 Fifth Avenue, Pittsburgh PA 15213, USA; Tel: 412-692-6300; Fax: 412-692-8729; E-mail: Heidi.Feldman@chp.edu

Security Administration classifies individuals under age 18 as disabled if they have a medically determinable physical or mental impairment that has lasted or can be expected to last for a continuous period of at least 12 months (or can be expected to result in death) and that results in marked and severe functional limitations [5]. A recent national survey defined children with disabilities as those limited in or unable to perform age-appropriate social roles because of a chronic physical or mental health problem [6]. For children younger than age 5 years, the criteria were operationalized as limited in or unable to engage in the kind or amount of play activities typical for the child's age or receiving early intervention services. For children ages 5 to 17 years, the criteria were operationalized as limited or unable to go to school, limited in other nonacademic activities, or receiving special education services [6]. Such definitions may fail to include children who achieve normal functioning through use of compensatory mechanisms. Stein and colleagues used an even more inclusive definition, requiring that the health condition either (1) result in a limitation in function, activities, or social roles in comparison to healthy peers, or (2) require medications, diets, medical technology, assistive devices, or personal assistance to compensate for the limitation of functioning [7,8].

#### **THE PROPORTION OF CHILDREN WITH CHRONIC CONDITIONS IS HIGH**

Regardless of definition, a substantial number of children in the United States live with a chronic condition, either with a special health care need or disability. Unfortunately, in the United States we lack administrative databases to determine accurately the proportion of such children. National household survey data concluded that 18% of US children less than age 18 years old, or 12.6 million children in 1994, could be classified as CSHCN [9]. Estimates of disability range from 6.5% [10] and 7.3% [6] to 12% [11-13]. The current figures may be underestimates of true prevalence. Interestingly, the prevalence of asthma, the most prevalent of the special health care needs has been estimated to be 7.5% [14] and the prevalence of Attention-Deficit/Hyperactivity Disorder, the most prevalent neurobehavioral chronic condition in childhood at 4 to 12% [15] each close to the prevalence of all disabilities. Multiple sources concur that the proportion of children with chronic conditions is increasing [4, 14, 16]. These changes have been attributed to the advances in science, technology, medicine, and public health. However, though once lethal conditions can now be successfully treated, morbidity from the conditions and their treatments contributes to the rates of chronic illness and disability [17].

Children with special health care needs use health and related services at a rate that is two to three times higher than the rates of the rest of the childhood population [6, 9]. Children with disabilities show even higher rates of hospitalization, physician and non-physician visits, and mental health and rehabilitation services in comparison to non-disabled peers. Expenditures for children with disabilities are approximately four to eight times higher than expenditures for children without disabilities [6]. Children with behavioral disorders have expenditures comparable to those of children with chronic physical conditions [18].

#### **INDIVIDUALS WITH CHRONIC CONDITIONS FREQUENTLY HAVE ADDITIONAL RISK FACTORS FOR UNFAVORABLE OUTCOMES.**

Many children with chronic conditions have more than a single condition [13, 19]. In Attention-Deficit/Hyperactivity Disorder alone, approximately half of the children have a co-existing neurobehavioral and learning disorder [15]. The high prevalence of multiple conditions increases the costs of care and emphasizes the importance of care coordination and communication among health care providers in the delivery of chronic care.

Rates of special health care needs and disability are highest among the poor [6, 10]. Poverty can be viewed as a consequence, cause, and moderator of disability. Disability is also associated with other risk factors for poor developmental, academic, and occupational outcomes, including poor access to care [20]. The prevalence of special health care needs is higher among African Americans and children living in single parent households than in white, two-parent households [9]. Thus, children with chronic conditions often face social and environmental challenges in their ability to attain favorable clinical and functional outcomes. Integrating health care and social services is essential for improving outcomes.

#### **HEALTH CARE FOR INDIVIDUALS WITH CHRONIC CONDITIONS IS INADEQUATE**

In 2001, the Institute of Medicine issued a thoughtful evaluation of the status of health care in the United States, entitled *Crossing the Quality Chasm: A new health system for the 21<sup>st</sup> century* [1]. The report concludes that the current health care system is failing individuals with chronic conditions. Moreover, improving the level of quality in health care cannot be achieved by simply tinkering with current systems of care. Health care systems must develop organizational capacity to support the redesign of care processes [1].

The health care system fails children and adolescents with chronic conditions. The Maternal and Child Health Bureau laid out six objectives for improving care for CSHCN that have now been included in the New Freedom Initiative of the Bush administration [21]. A recent evaluation of progress toward these objectives has been issued [22]. The evaluation demonstrates that the infrastructure for care for CSHCN is in place but that for the six goals at best only approximately 6 to 60% of children obtain the services required [23-27]. The weakest performance is in services to allow a smooth transition from pediatric to adult health care services [22].

#### **CHARACTERISTICS OF CHRONIC CARE ARE DIFFERENT FROM FEATURES OF ACUTE CARE**

Health care for children with chronic conditions should be structured differently from health care for acute episodic illnesses and injuries. Acute care is typically patient- or, in pediatrics, family-initiated, triggered by the onset of symptoms. The focus of the clinical encounter is diagnosis, which serves as a practical guide to treatment, course, and prognosis [28]. Typically, a single physician has the

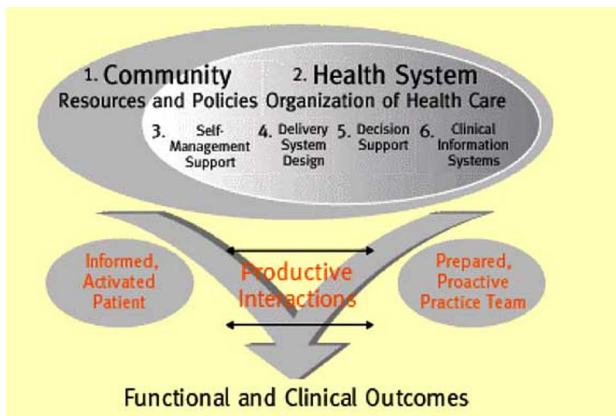


Figure from Wagner, EH. Chronic Disease Management: What Will It Take to Improve Care for Chronic Illness? *Effective Clinical Practice* 1998; 1: 2-4. Permission for reproduction obtained from American College of Physicians.

**Fig. (1).** Overview of the "Improving Chronic Care Model".

knowledge and skill required to adequately render acute care. By contrast, chronic care requires scheduled return visits for monitoring patient status and instituting secondary or tertiary prevention services. For example, the young child in our example should be evaluated regularly to determine if her hip becomes dislocated or her spine develops scoliosis. A continuous relationship between physician and family is optimal for longitudinal care [1]. Chronic care requires an explicit management focus and multiple issues must be addressed concurrently. Consequently, a team of professionals is generally required. Coordination among health care providers is a major challenge. The patient and family, ultimately responsible for delivering treatments, must participate in decision-making.

Reform efforts have incorporated many of these features of chronic care. The American Academy of Pediatrics (AAP) has formulated the concept of the "medical home" to meet the health care needs of CSHCN [27, 29, 30]. The medical home is an accessible, comprehensive, family-centered, and compassionate approach to care. In a medical home, a personal physician or nurse serves as the usual source for health supervision and acute problems. The medical home provides needed referrals and coordinates care [31]. The AAP has supplemented policy statements with funded demonstration projects and training programs [32]. The medical home is associated with better health status on the individual and population levels, lower overall costs of care and reductions in disparities in health between disadvantaged and advantaged populations [33-35].

The "Improving Chronic Care" model has spawned other efforts at reforming health care systems to provide high quality chronic care [36, 37]. Figure 1 shows the conceptual basis of the model. The goal of the model is improving functional and clinical outcomes. Achieving this goal requires that patients (and in pediatrics, families) becoming "informed" about their conditions and "activated" to participate in decision-making and care. Concurrently, physicians must forge appropriate health care teams [38] which are "prepared" and activated to participate in the patient's care. An important feature of the model is that

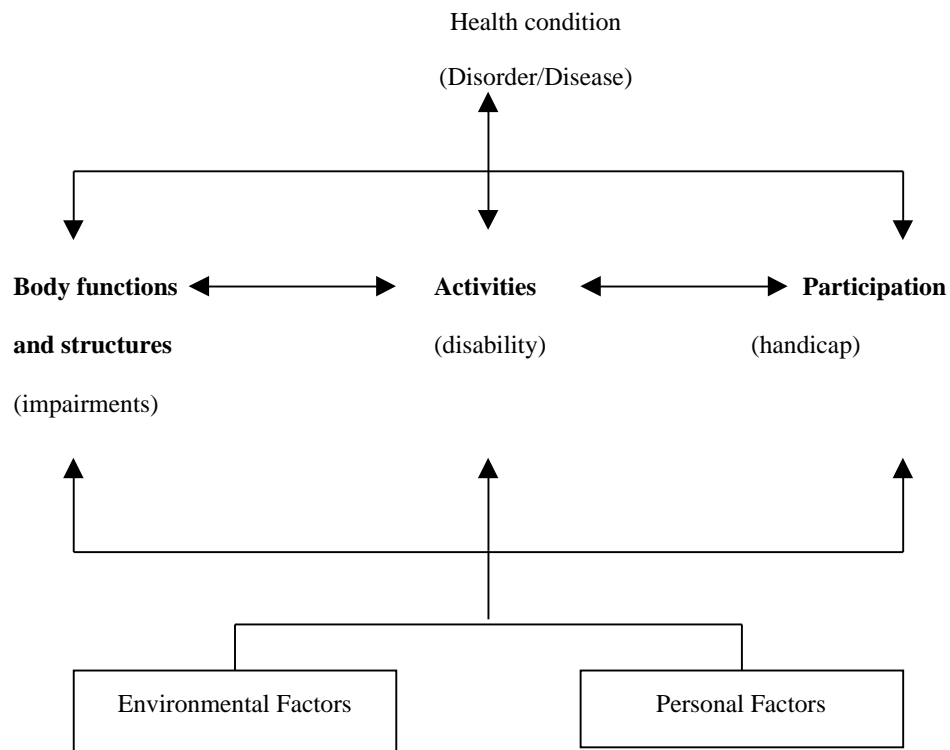
communication between the family and health care team must become bidirectional in order to become productive. The Improving Chronic Care Model goes further to specify that the changes in the clinical interactions must be linked to changes within health care system. Four specific features of the health care system can be improved: clinical information systems, decision support, delivery system redesign, and self-management. In addition, the Improving Chronic Care Model also identifies that community resources and policies are available for improving clinical and functional outcomes. This chronic care model has been applied in adults with highly prevalent clinical conditions such as diabetes, hypertension, and depression. Evidence suggests that impacting any one of the components of the health care system leads to improvements in clinical outcomes [39]. For example, improving self-management strategies for diabetes improves glucose levels. Involving community resources to assist with self-management strategies is also effective. The model may prove useful in reconceptualizing the nature of health supervision for children as well as for management of chronic conditions.

### CHRONIC CARE MUST BE DIRECTED AT IMPROVING FUNCTIONAL AS WELL AS CLINICAL OUTCOMES

Establishing clinical goals and measuring health outcomes in the care of children with chronic conditions should focus on the nature and extent of functional limitations in a wide range of domains. The primary focus must shift from cure to improving, and in some cases, simply maintaining functional status. The traditional "medical model" narrowly seeks to eliminate symptoms and cure conditions. Physicians expect that compliant patients who follow their orders will return to their pre-morbid, healthy state [40]. This expectation does not work in chronic conditions. Often cure or recovery from the chronic condition is out of the question. Functional status contributes substantially to the patient's quality of life, self-reliance, and social integration.

A focus on function rather than on prevention and cure has traditionally been associated with the "rehabilitation" model of care, as practiced by physical and occupational therapists, speech and language pathologists, and related disciplines. An alternative model of disability is the social model. The social model, articulated by individuals with disabilities, attributes disadvantages experienced by people with disabilities to environmental and social factors. For example, the child with cerebral palsy who requires a wheelchair for mobility will have functional limitations if her school is not accessible. Social factors can also limit the functioning of individuals with disabilities. For example, poor attitudes on the part of teachers and employers might result in poor self-esteem, depression, and reduced social interaction.

Chronic care requires an integration of the medical, rehabilitation, and social models. An assessment of functional status and environmental conditions as well as health status is appropriate in chronic care and serves as the basis for management planning and for the assessment of health outcomes [41]. Despite the importance of the



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**Fig. (2).** Conceptual mode of the International Classification of Functioning, Disability and Health [45].

functional and social perspectives, how to define, measure, and monitor functioning remains a challenge [42]. Physicians and medical students admit poor preparation for the competencies of chronic care [43, 44].

The *International Classification of Functioning, Disability and Health* (ICF) [45] is a comprehensive classification and coding system for how health-related conditions affect people's lives. The World Health Organization published the ICF in 2001 as a companion of other manuals, including the International Classification of Diseases, now in its 10<sup>th</sup> edition [46]. Like its predecessors, the *International Classification of Impairments, Disabilities and Handicaps* (ICIDH) [47-49] and the ICIDH-2 [50-52] the ICF was developed to provide a scientific basis for the understanding of health and health related conditions, to establish a common language for such issues, and to allow systematic coding for clinical care, epidemiology and public policy. The ICF is a potential tool for the clinician in expanding from strictly medical diagnoses and management for clinical improvement to individualized assessment and management for clinical and functional improvement. The wide range of issues that can be addressed within the framework warrants the label wholistic care. An ICF-Children and Youth Version (ICF-CY) was recently released [53], which should facilitate the use of this model in the care of children with chronic concerns.

The ICF rests on an underlying conceptual framework, represented in Figure 2. Functioning is an umbrella term, encompassing three levels of functioning: body functions

and structures, activities of everyday living, and social participation. Body functions and structures include mental and sensory functions as well as digestive and musculoskeletal functions. Activities include learning, communication, mobility and self-care. Participation includes interpersonal interactions and community and civic life. The model posits a dynamic interaction among the health conditions and these components of functioning, thereby capturing the complexity of chronic health care problems in which the health conditions are both the cause and effect of many different factors. To return to the example from earlier of a child with bronchopulmonary dysplasia and cerebral palsy, these health-related chronic conditions can impact voice quality and speech, which are included within the domains of body structures and functions. Cerebral palsy can also affect mobility and communication, both of which are in the domain of activities. Children with disabilities can also have challenges in finding opportunities for recreation and leisure, both of which are within the domain of participation. However, if the child with cerebral palsy participates in recreation activities in the community, such as swimming, she possibly could begin to show improvements in her mobility and increased breath support for her speech, in turn improving their communication. Ultimately, her social participation and physical activity would be associated with reductions in the severity of the underlying condition, cerebral palsy.

The ICF model also posits that environmental and personal factors interact at all levels of the system, directly

**Table 1. Domains and chapter of the International Classification of Functioning, disability and health.**

- Body functions
  - Mental Functions
  - Sensory Functions and Pain
  - Voice and Speech Functions
  - Functions of the cardiovascular, hematological, immunological and respiratory systems
  - Functions of the digestive, metabolic, and endocrine systems
  - Genitourinary and reproductive functions
  - Neuromusculoskeletal and movement-related functions
  - Functions of the skin and related structures
- Body structures
  - Structures of the nervous system
  - Eye and ear and related structures
  - Structures involved in voice and speech
  - Structures of the cardio respiratory, immunological and respiratory systems
  - Structures related to the digestive, metabolic, and endocrine systems
  - Structures related to the genitourinary and reproductive systems
  - Structures related to movement
  - Skin and related structures
- Activities and participation
  - Learning and applying knowledge
  - General tasks and demands
  - Communication
  - Mobility
  - Self-care
  - Domestic life
  - Interpersonal interactions and relationships
  - Major life areas
  - Community, social, and civic life
- Environmental factors
  - Products and technology
  - Natural environment and human-made changes to environment
  - Support and relationships
  - Attitudes
  - Services, systems and policies

on the health condition, or on body structures and functions, activities, or participation [45]. Thus, function represents the integration of health and environmental conditions and the ICF captures the medical and the social models. Environmental factors in the ICF include products and technology, natural and human-made changes to environments, support and relationships, attitudes, and services, systems and policies. Returning to the child with cerebral palsy, her communication functioning, if extremely poor, could be aided by assistive communication devices. Environmental factors can either promote or impede functioning and the effects may be specific to groups of individuals. As discussed in the ICF manual, curb cuts at intersections without textured paving facilitate mobility for people who use wheelchairs and present a barrier for people with visual impairments. Negative attitudes about disabilities can impede functioning of many different groups.

The ICF is an assessment and statistic manual. It provides specific alphanumeric codes for the integrity of body structures and functions, the ability of the individual to perform activities of daily life, the scope of the individual's social participation and the environmental factors. The initial letter prefix of the code indicates component. The "b" signifies Body Functions, "s" Body Structures, "d" Activities and Participation, and "e" Environmental factors. The numeric code starts with a chapter number and adds digits for increasing specificity. Table 1 lists the chapters within each domain. For epidemiological purposes, coding to one or two digits may prove adequate. For clinical care, coding to three or four digits is appropriate. For example, within the chapter on global mental functions, b126 indicates temperament and personality functions; b1260 indicates extraversion, 1261 agreeableness, and b1265 optimism. For any code, qualifiers denote the level of severity of the problem at issue. Qualifiers for the environmental codes include a positive or negative sign to indicate whether the factor is a barrier or facilitator. The set of codes and qualifiers for any given individual can be considered a comprehensive profile or a functional assessment of the person, complementary to his/her medical diagnoses. Using this system, we can distinguish between two children who both have bronchopulmonary dysplasia and cerebral palsy. The one whose mobility problems are limited to walking over distances and dressing independently would receive codes d4602 and 5400 respectively. The one whose profile includes major problems with speaking, walking, toileting, dressing, eating, and social interactions would receive codes d330, d450, d530, d540, d550 and d710. Using codes regarding participation, we can also distinguish adolescents and adults who are actively participating in community and social life, such as in employment or civic responsibilities, from those whose activities are restricted to home and family.

In adult medicine, the ICF has been used to assess general or clinical populations for the purposes of generating epidemiological data, planning public health programs, and clinical planning for individuals [41]. Use in pediatrics is just beginning. For example, studies of prevalence of CSHCN have not yet been grounded in the ICF. A recent analysis using the National Health Survey on Disability devised its own analytic scheme for the purpose, though the four domains surveyed—self-care, mobility, communication, and learning ability—would map easily to ICF codes in the domain of activities of daily living, as the authors recognized [12]. McDougall and colleagues re-analyzed national health surveys in Canada in reference to both the ICD and the ICF [54]. The team concluded that the domains of disability and environmental factors are under-represented in these surveys of school-aged children when the ICF was not used. Systematic data collection based on the ICF would allow greater comparisons across surveys and countries and would facilitate an understanding of the complex relations among health, disability, and environment in line with the underlying conceptual models.

The ICIDH and the ICF have been used successfully to create profiles of clinical childhood populations. Simeonsson and colleagues described the functional issues faced by children with communication disorders [55] and secondary

conditions that affect children with spina bifida [56]. Similarly, the ICF could be used to generate comprehensive profiles of individual patients. Boyd and Hays [57] demonstrated how the ICF could be useful in cataloging the positive effects of Botulinum toxin A on children with cerebral palsy. They reviewed several research and clinical tools that elucidate the changes in functioning at the level of body function (spasticity), activity (gross motor function and social skills), and participation (functional independence and family life). In general, the ICF opens up many possibilities for evaluating the impact of health conditions and their treatments on children in terms that relate directly to needs for resources and services [58].

### **THE ICF COULD CONTRIBUTE TO PROVISION OF CHRONIC CARE**

Functional classification using the ICF could play a central role in the clinical care of children with chronic conditions. As a supplement to medical diagnoses, functional classification would be useful for describing a person's current status, choosing target outcomes for management, designing interventions designed to improve or maintain functioning, and monitoring outcomes [40, 59]. For example, in a child with cerebral palsy, if the functional classification includes severe difficulty with mobility, then the treatment plan should include interventions aimed at improving or at least maintaining mobility, such as referral to physical therapy, prescription for braces or a wheel chair, or recommendations for accommodations at school or at the workplace to reduce the need to walk long distances. If by contrast, the child with cerebral palsy has mild problems in mobility, limited to outdoor distances but marked problems in communication, then the treatment plan might include a speech-language pathologist and related services. As implied by this example, the ICF could play a role in the assessment of children with spectrum diagnoses, such as cerebral palsy or autism where functional codes provide information about the severity and specific impacts of the underlying condition. For example, the ICF codes could be used to distinguish between children with cerebral palsy who do or do not have problems in learning and communication. Similarly, these codes would be helpful for designing interventions for children with autism who may or may not have difficulty in self-care, such as toileting, dressing, or eating.

The ICF provides operational definitions for the codes using colloquial everyday language. The definitions include essential attributes such as qualities or properties, inclusion and exclusion criteria, and anchor points for definitions. The straightforward translation of codes into simple language is designed to facilitate communication between families and professionals, among members of the interdisciplinary health care team, and among health clinicians, educators and human service providers who must collaborate in the care of children with chronic conditions.

The inclusion of functional classification using the ICF in the description or report on a child draws attention to the individuals with disabilities rather than to the disabilities themselves. The very act of coding functioning acknowledges that the level of functioning cannot be presumed on the basis of the medical diagnosis. For

example, assessing a child with Down syndrome and applying appropriate ICF codes could indicate whether the child has social or communication problems that could not be predicted on the basis of the diagnosis of Down syndrome. The ICF codes can also be used to code strengths as well as needs within the same coding format. This feature would encourage a broad and balanced view of children that would counter the usual "deficit" models of disabilities. Interventions can then be implemented that attempt to build on strengths as well as to habilitate or rehabilitate weaknesses.

ICF codes capture general categories or domains that should remain relevant across the life span. The same coding system can be used over time to document improvements in functional capacity or to capture changing patterns of strengths and needs. These features, taken together, make functional classification extremely useful for assessing outcomes of treatments or programs and following children over time. Functional classification can be particularly important for comprehensive planning when children face major transitions in service delivery, such as when they progress from early intervention to school programs or from pediatric into adult service systems. At such times, a systematic and comprehensive plan that considers multiple domains and the full range of services to meet the needs would be important to sustain or increase function.

Different assessment strategies are available for generating the appropriate ICF codes. One approach is to use existing functional assessment measures, such as the Vineland Adaptive Behavior Scales [60] the Pediatric Evaluation of Disability Inventory [61] or the WeeFIM [62, 63]. Coding ICF categories from an existing functional assessment measure leads to good but not excellent inter-rater reliability [64]. However, a brief screening interview based on the ICF leads to high rates of inter-rater reliability [65].

Adoption of the ICF to standardize underlying conceptualization and terminology about function would be an important step in improving chronic clinical care for children. It would move the health care system to a more wholistic view of the children than we currently have. However, without careful planning, functional and diagnostic information could remain fragmented across professionals and agencies. For example, a pulmonologist may diagnose and treat bronchopulmonary dysplasia but not have any information about the child's stamina during exercise. Primary care physicians, charged with the responsibility for coordinating care as part of the medical home, lack skills and tools for integrating these multiple perspectives into single care plan. Families might still be left with the burden of pulling it all together. Additional tools are required before we can achieve wholistic care for children with chronic conditions.

### **MULTI-AXIAL ASSESSMENT CAN INTEGRATE MEDICAL DIAGNOSES AND FUNCTIONAL CHARACTERISTICS**

An approach that could integrate traditional medical diagnoses with functional classification and evaluation of

social conditions is the multi-axial assessment system. In 1980, the American Psychiatric Association issued the Diagnostic and Statistical Manual for Mental and Emotional Disorders, Third edition (DSM-III) [66-68]. Among the major innovations of the DSM-III was the introduction of a multi-axial assessment system. The expansion from single-item diagnosis to multiple axes was intended to provide additional clinically relevant information for care of the patient with psychiatric disorders. Since psychiatric care involves chronic conditions almost exclusively, the lessons from psychiatry may prove useful beyond that discipline. For psychiatry, though the specific axes have changed over time, the overall commitment to multi-axial assessment has been maintained in subsequent revisions of the DSM.

Multi-axial assessment is a tool that could be used to systematically evaluate children with chronic conditions as the basis of understanding the totality of issues, designing management, coordinating care, and communicating across an interdisciplinary treatment team. A multi-axial assessment is "a contextual and standardized description of the clinical condition through a number of highly informative, therapeutically significant and systematically assessed axes or domains" [69]. This type of formation increases understanding of the biopsychosocial pathogenesis of conditions as well as assisting in treatment planning. Multi-axial assessment is often required in the U.S. for administrative purposes, eligibility determination or billing. Clinicians do not always use it for treatment planning [70]. However, when used, clinicians show acceptable rates of inter-rater reliability in most axes [71]. A version for individuals with intellectual disabilities has proven useful despite some uncertainties about coding procedures [72]. Multi-axial assessment could prove very useful in the collaborative process of care that involves patients, families, physicians, other health professionals and community agencies or services [73].

The Diagnostic and Statistical Manual for Mental and Emotional Disorders, fourth edition (DSM-IV), recommends a five-axis system [74]. Axis I includes the clinical syndromes, usually the psychiatric disorders that are the focus of attention or treatment. Axis II includes personality disorders and mental retardation and is a vestige of a broader listing of conditions that were thought to increase the severity of Axis I disorders in previous versions. Axis III includes any medical conditions that might be relevant to treatment. Axis IV lists environmental and psychosocial problems that may affect the diagnosis, treatment, and prognosis of the main conditions. Axis V is called the "Global Assessment of Functioning" or GAF and uses a 100-point scale to quantify the individual's level of psychological and social functioning at the time of assessment. The GAF relies on clinical judgments of multiple factors and does not leave much room for capturing the situation of a person with high levels of need in one area and high levels of skill in another. For example, it would be difficult to score the child with cerebral palsy who cannot care for herself but is intellectually and socially competent. To supplement the Global Assessment of Functioning (GAF), DSM-IV introduced two new measures of adaptive functioning for research: the Social and Occupational Functioning

Assessment Scale (SOFAS) and the Global Assessment of Relational Functioning Scale (GARF). Preliminary analyses suggest that the scales are reliable and valid [75, 76], however, it is unclear if they are useful in the treatment planning.

An alternative multi-axial assessment system was proposed by the IGDA Workgroup of the World Psychiatric Association [69]. This system combines mental and general medical conditions in a single axis. It adds an axis of disabilities and specifies that such disabilities could be encountered in personal care, occupational functioning, functioning with family, and broader social functioning, what we might label the domains of activities and participation from the ICF. (In addition, the IGDA approach includes an axis for the quality of life, which is a multi-dimensional and global assessment of the patient's self-perceived well-being in areas such as physical and emotional state; satisfaction with independent, occupational and interpersonal functioning, and with socioemotional and instrumental supports; and a sense of personal and spiritual fulfillment [69]. The IGDA Workgroup also recommends inclusion of "idiographic" or personal diagnostic formulation [77]. The idiographic formulation recognizes the distinct perspectives of the clinician, the patient and the family, on what is unique, important and meaningful about the patient. Any discrepancies must be discussed to permit their resolution and integration into a shared understanding of the case at hand).

A modification of these multi-axial assessment systems could provide a useful and comprehensive approach for clinical care of any chronic condition. The relevant axes are included in Table 2 and could be rearranged in order of priority at different times. The relevant axes are as follows: Medical conditions, Mental and Behavioral conditions, Psychosocial and Environmental Conditions, and Functional Classification. Each axis can be coded with a recognized diagnostic and statistical manual: Medical conditions can be coded using the ICD, Mental and behavioral conditions using the ICD or the DSM, and Psychosocial and Environmental Conditions can be coded using the ICD, DSM or ICF. Functional classification can be accomplished using the ICF. Table 2 shows a care plan that integrates these various axes.

The multi-axial care assessment can include not only codes for the present status, but also the clinical coordinator (professional, agency, or informal support) for that problem, the goals and strategies of treatment, time frame for re-evaluation, and outcomes to be assessed. This organization puts a vast amount of information into a single organizing framework. The multi-axial care plan should prove far more useful than a problem list, which typically has no internal organization and may include, in no particular order, chronic concerns, resolved acute problems, and social characteristics. Families can also get copies of this multi-axial care plan for their own organization and treatment monitoring. At a recent parent conference, we asked approximately 200 parents about how they organized the health information on their child. The majority of respondents had no systematic approach and/or was dissatisfied with their efforts. They were extremely excited by the multi-axial assessment as a

**Table 2. Multi-axial diagnostic system and care plan with illustrative examples of diagnoses and problems in the different axes.**

Axis	Conditions	Codes	Coordinating professionals	Goals	Strategies and treatments
<b>Medical conditions (ICD)</b> ↓	Cerebral palsy BPD	343.2 770.7	Primary care Pulmonologist	Spasticity Work of breathing	Physical therapy Controller medication
<b>Mental and behavioral conditions (DSM-IV)</b> ↓	ADHD  Expressive language	314.01  315.31	Primary care  Speech/language Pathologist	Attention and task completion Improve communication	Behavior management Individual therapy at school
<b>Psychosocial and environmental conditions (ICF codes)</b> ↑ ↑	Product for mobility Immediate family support	e110 e310+	Physical therapist Primary care	Mobility  Receive support as needed	Wheel chair  Evaluate at each primary care visit
<b>Functional conditions (ICF codes)</b>					
<b>-Learning</b>	Learning to read	d140	Classroom teacher	Read at grade level	Daily education
<b>-Tasks</b>	Carrying out a daily routine	d2301	Parents	Prepare for school independently	Pictured list
<b>-Communication</b>	Communicating – speaking	d330	Speech/language Pathologist	Produce longer sentences	Individual therapy at school
<b>-Mobility</b>	Walking and moving	d465	Physical therapist	Use wheel chair outdoors	Individual therapy at school
<b>-Self-care</b>	Dressing	d5400	Occupational therapist	Dress independently	Individual therapy at school
<b>-Interactions</b>	General interpersonal interactions	d7200	Parents	Make new friends in community	Parents to arrange play dates
<b>-Community life</b>	Recreation and leisure	d920	Physical therapist and parents	Learn to swim	Parents to take to local pool, therapist to assist as needed
<b>-Other</b>					

way to organize their own records and to prioritize their child's needs. We have also been using this approach to introduce pediatric residents to issues of chronic care. They report high levels of satisfaction with the approach. However, future research is required to determine whether this recommendation leads to systematic improvements in health care delivery for children with chronic conditions.

#### **WHAT ARE SOME OF THE NEXT STEPS IN THIS AGENDA?**

There is a pressing need for research to assess the reliability and validity of ICF coding for children with chronic conditions, both special health care needs and disabilities. Research sponsored by the WHO is currently underway. Moreover, it will be important to study whether systematic use of the ICF is useful for expanding the focus of chronic care, communicating across the members of the interdisciplinary health care team, and improving the functional outcomes of children. Effective and cost-effective methods of functional assessment will be required to move this approach into routine practice in order to facilitate the use of the ICF. Surprisingly there is little research on aspects

of the multi-axial assessment systems in psychiatry. The reliability, validity, and utility of this approach must also be evaluated in children with chronic conditions.

If functional classification and multi-axial assessment prove useful, then these approaches must be integrated in the medical home initiatives of the American Academy of Pediatrics. Families of children with chronic conditions report that they have a usual source of care. However, they also state that they receive few elements of the medical home, particularly family-centered care and coordination of services [26, 27]. Evaluation of functional status, establishing goals for functional improvement, creating care plans to meet those goals, and coordinating care across systems to implement the plans would move the primary care office toward the missing elements of chronic care. Formulation of a multi-axial assessment might provide the primary care physician with a systematic approach to addressing the broad range of needs in a family-centered manner.

Functional classification and multi-axial assessment can also be integrated into systems reform efforts inspired by the "Improving Chronic Care" model [36, 37]. Multi-axial

assessment can form the basis not only of interactions between the informed and activated patient with the prepared and activated health care team, but also can be used for health systems reform. For example, clinical information systems could be designed to include a multi-axial assessment from which care could be coordinated. In addition, decision support can be offered as a function not only each diagnostic category, but also each functional domain. The multi-axial assessment clarifies community resources and policies that can be brought into the clinical care plan. For example, if a child's condition includes functional problems in learning and applying knowledge, then public education system should be a partner on the care team, coordinating efforts at improving child's learning and applying knowledge. If children have problems with communication or mobility, then appropriate therapists and medical equipment can be ordered. If families are extremely stressed in their efforts to meet the demands of their child's chronic care, then respite or mental health services may be in order.

Finally, functional classification and multi-axial assessments may be useful for rationalizing reimbursement for chronic care. The use of these approaches captures the complex nature of care and the requirements for extra time and personnel to provide and coordinate efforts. Multi-axial assessment could be a way to design risk-adjusted reimbursement, whether on fee-for-service basis or through managed care contracts.

## SUMMARY

New approaches, strategies, and systems are required to meet the needs of children with chronic conditions. This review has sought to motivate reform efforts based on the substantial proportion of children with chronic concerns, the breadth of the issues they face, and the current disarray in systems of care. The review has focused on the issue of functional classification and multi-axial assessments as promising innovations in the chronic care of such children. These approaches dramatically broaden the scope of health care, integrating the rehabilitation and social models with the traditional medical model. They provide tools for systematic evaluation of children and creation of plans. They support careful monitoring of clinical and functional outcomes. They can serve to integrate management plans in a single comprehensive rubric that is made available to families as well as professionals as a map for long-term care.

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