The World Health Organization International Classification of Functioning, Disability, and Health: A Model to Guide Clinical Thinking, Practice and Research in the Field of Cerebral Palsy

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The way we think about health and disease determines to a considerable extent what we do and say in our clinical encounters with patients. The recent publication and promotion of the World Health Organization's International Classification of Function, Health, and Disability (known as the ICF) represents an exciting new way to consider health and disease. In the context of children and youth with cerebral palsy, this model offers many heretofore ignored "point of entry" for counselling and intervention with these conditions. This model also provides many possibilities to explore research questions with a fresh approach. This article outlines the ICF model and discusses these opportunities.

THE "CEREBRAL palsies" (CPs) have been described as "a group of non-progressive, but often changing, motor impairment syndromes secondary to lesions or anomalies of the brain arising in the early stages of development."[1] As a clinical "syndrome," CP is commonly seen and managed by pediatric neurologists and developmental specialists.[2] The approach to the assessment and management of children and youth with CP may depend to a considerable extent on the frameworks used to conceptualize diseases and disorders. The recent publication of the World Health Organization (WHO) International Classification of Function, Health, and Disability (known as the ICF)[3] provides an opportunity to integrate several perspectives about this important and prevalent group of childhood disabilities. In this article we provide an overview of the ICF model and discuss its utility for planning both interventions and research studies in CP.

BACKGROUND

In 1980 the WHO published the International Classification of Impairments, Disabilities and Handicaps (ICIDH).[4] The ICIDH was a classification of the "consequences of disease," developed by the WHO as part of a family of classifications to code a wide range of information about various aspects of health. The original ICIDH included a conceptual model in which "diseases" and "disorders" were linked to their possible impacts at several levels, specifically labeled as "impairments," "disabilities," and "handicaps." The model helped people recognize that a consideration of "disease" alone provided an incomplete perspective on health status. It also encouraged people to identify the impact of a disorder on an individual's function and capability to engage fully in his or her life.

Uptake of the ICIDH was relatively slow, and even today many front-line health professionals remain unfamiliar with the ideas contained in this work. The primary purpose of the ICIDH was to serve as a classification system, that is, to code the consequences of diseases; in this respect it represented a complement to the International Classification of Diseases (ICD). Many countries did not use the classification system, and many persons viewed the original ICIDH model (Fig 1) as problematic.

Among the concerns expressed by some who used the ICIDH, including people with chronic health conditions, was the negative portrayal of the consequences of disease in terms of "disability" and "handicap." People were also concerned about the linear (and unidirectional) connections among the elements of the ICIDH model. There is no doubt that this biomedical approach to disease has utility in many areas of health care (eg, in diagnosing the bacterial agent in many infectious diseases, leading to treatment with appropriate antibiotics). However, taken alone, the biomedical approach presents a rather narrow and limiting way of considering chronic health conditions such as

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DISEASE → IMPAIRMENT → DISABILITY → HANDICAP

Fig 1. The original ICIDH model (1980).[4]

CP for which specific "causes" are often unclear and "management" requires a broader scope than merely impairment-based treatments.

In the early 1990s an international effort was begun to revise and reshape the ICIDH. After 9 years of study and input, the WHO published a new classification system, the International Classification of Functioning, Disability and Health, or ICF.[3] The ICF focuses on the "components of health" rather than on the consequences of disease. The ICF approach encompasses all aspects of health and describes them in terms of health domains and health-related domains. It is intended to be a universal classification system, meaning that it covers all people, not just people with disabilities. The appendix at the end of this report provides definitions and examples for the key dimensions of the ICF.

A new model of human functioning and disability (Fig 2) was developed to reflect the *interactive* relationship between health conditions and contextual factors. The model graphically depicts some of major changes that have been made in the new ICF. The first key change is a shift in language from negative terms such as "impairment," "disability," and "handicap" to the neutral terms "body function and structure," "activity," and "participation," respectively. A second change is that the designation "disability" is now an umbrella term representing the dynamic interaction between person and environment. In contrast to the traditional view that disability resided just within the person, this change reflects the concept that "disability" is a social construction involving an interaction of the person and community or society. In addition, the change in terminology reflects a move toward the identification of "participation" as an important outcome of health.

A second important modification was made when the implied linear connection between "impairment," "disability," and "handicap" was changed with the inclusion of a series of bidirectional arrows that link these (and other) elements of health, functioning, and disability. Note that because all components of the model are now linked to one another, there is a formal recognition of the possibility that any aspect of function can and probably will affect others, in a nonlinear manner. Thus, for example, in the context of people with CP, an exercise and strengthening program addressing aspects of "body function and structure" (previously "impairment"), if done as part of a group event, involves "participation" and thus may enhance social well-being and probably also improve "activity" capabilities. This systemic way of thinking is richer and more relevant to life experiences than the linear connections presented by the original ICIDH model.

Two significant additions to the original ICIDH model, reflecting the social construction of disablement, have expanded the scope of the concepts contained in the ICF. These are classified as "contextual" factors that may impact a person's health state. The first of these contextual components is "environmental factors," which can be physical, social, cultural, or institutional in nature. These would include, among other factors, the availability, quality, expertise, and focus of intervention programs for children with CP. The second component is "personal factors," such as gender, age, education, and lifestyle. What is of interest to children with CP? What might they be prepared to work at because it is important to them and their families, and how might this make a difference to the "success" of a therapy program? These two contextual factors influence and modify the other components of disease or disorder, and they need to be identified and considered in the mix of forces that together contribute to the dimensions of "body function/structure," "activity," and "participation."

To summarize, the WHO has chosen a "biopsy-

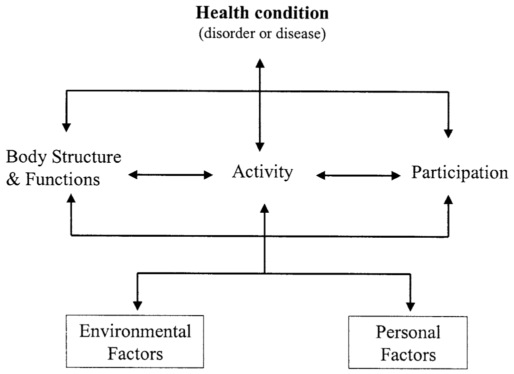

Fig 2. The ICF model.

chosocial" approach to health, functioning, and disability in the new ICF model, to provide "a coherent view of different perspectives of health from a biological, individual and social perspective" (WHO 2001, p 28). The WHO is encouraging application of the ICF internationally not only as a classification tool, but also as a framework for social policy, research, education, and clinical practice.

WHY IS THE ICF IMPORTANT IN CEREBRAL PALSY?

It is our impression that, unlike its ICIDH predecessor, the ICF model of human functioning and disability appears to have captured people's attention very soon after its publication. This may reflect the change in emphasis from disease to health, or perhaps the incorporation of "environment factors" and "personal factors" that round out what might previously have been seen as a worldview that was too narrow and 'medical'. Whatever the reasons, we believe that the ICF needs to be disseminated widely and understood by all people working in health care, research, and education, because it offers a global approach to thinking about health and health-related states. It provides a common language for describing health, functioning, and disability that is increasingly gaining worldwide acceptance.

Service providers may not wish to use the ICF as a classification system, but nonetheless will recognize that the model of functioning, disability, and health described in the ICF "provides the building blocks" (WHO 2001, p. 25) for clinical and research applications. Although it is acknowledged that no model is perfect, the ICF model does represent current worldviews of health and disability, and it is already being used in many countries for multiple purposes. In the rest of this article we outline some thoughts about the ways in which the ICF model can be used to guide clinical thinking and the delivery of services to children and youth with CP and their families.

THE ICF AND "CLINICAL THINKING" IN CEREBRAL PALSY

In the context of CP (as well as, of course, other childhood disabilities and chronic health problems), the new ICF model of functioning and disability provides many more "points of entry" for people seeking both to enhance the activity and participation of children whose functional well-being is at risk and to prevent secondary impairments.[5] The first and most obvious factor to identify is that the "environment" around a child involves the family. In an "ecological" way of thinking, the family is the context in which children develop. When the family "environment" is recognized as contributing to children's ultimate well-being, efforts to support families (eg, implementing and practicing family-centred service [FCS]) are important corollaries of this thinking. In addition to the philosophical principles of FCS[6] and the established connection between FCS and overall parent satisfaction and mental health,[7] it has been shown that the family can participate in identifying goals for their child's therapy. In so doing, the family can help the child achieve greater functional gains, with less effort, than are seen with traditional impairment-based therapy.[8]

Another concept that emerges from this expanded way of thinking about functional well-being involves considering the factors that mediate between people's "capacity" (what they can do at their best) and their "performance" (the execution of that activity in the real world).[3,9] A service provider assessing a child with CP usually wants to know what the child is capable of doing at his or her best (ie, capacity). For example, assessment of the mobility capacity of a child with CP is typically done in an environment most conducive to the child's best performance. Ideally this would be a barrier-free environment, with smooth surfaces and as few obstructions as possible, often in a clinic or gait laboratory setting. Of course, in natural environments such as home, school, and community, some surfaces are uneven, hallways are crowded, and stairs may need to be negotiated. Thus, for example, a child's school-based "performance" of independent mobility may be quite different from his or her clinic-based "capacity."

The ICF model identifies these issues and provides guidance on acknowledging and accommodating them into thinking, counselling, and practice. For example, when a person's "performance" of mobility is restricted by the environment, mobility aids become a viable intervention to narrow the gap between the person's capacity (as observed in the clinic) and desired performance in the real world. Whether reliance on mobility aids in these environments to facilitate independence for someone who can walk constitutes "failure" or "adaptation" depends to a large extent on one's philosophical emphasis on the relative importance of promoting "normal" activity or enhancing "participation" in whatever ways are appropriate to that individual. Note that in this example the "impairment" has not been addressed at all, but the net benefit to the child may be considerable improvement in function. It is also possible—even likely—that as mobility function is enhanced, there may be changes (improvements) in underlying impairments such as muscle strength, body alignment, weight shift, or stability.

How do "personal factors" enter into the discussion? Traditional thinking has often involved a belief that children with disabilities should be encouraged to try as much as possible to learn and to do things "normally." Interventions have often taken "normal" as the guidepost by which to structure what we prescribed and recommended. This approach does not factor in or take advantage of the developing child's preferences for activities to do or to avoid. The formal acknowledgment of the "personal factors" component of the ICF model recognizes the importance of personal choices, interests, likes, and dislikes of the person whose "activity" and "participation" are being addressed in a therapy program. In fact, it is likely that the impact of the "functional therapy" approach reported by Ketelaar et al[8] had much to do with the self-chosen goals pursued by the children and parents in the experimental group. People are simply more likely to work at things that are important to them than at things that others feel are important, even if the latter are potentially meaningful to the clinical observer.

Perhaps the most significant value of the ICF model is its importance in helping us expand our thinking beyond "fixing" primary impairments to a view that places equal value on promoting functional activity and facilitating the child's full participation in all aspects of life. The model "gives permission" to address people's self-determined goals very broadly. Such goals might include, for example, becoming "independently mobile" or being able to "communicate effectively," rather than focusing merely on "walking" or "talking." This emphasis argues that what people do is more important than the expectation that they do things "normally." In this sense the model asks us to accept variation and difference, to celebrate the achievement of self-defined goals accomplished in whatever ways are best with each person's particular and unique range of skills and limitations. This approach stands in contrast with interventions based on traditional thinking in which "normal" (whatever that means) is the standard on which to judge function.

HOW CAN I APPLY THESE IDEAS TO CHILDREN WITH CEREBRAL PALSY IN PRACTICE?

Health care providers are encouraged to use the ICF model to guide the selection of measurement tools both to inform goal setting and decision making processes and to determine meaningful outcomes. The outcomes that we measure need to be multidimensional, to encompass the impact of what we offer in treatment at different levels of body function and structure, activity, and participation. Equal emphasis should be placed on determining the influence of personal and environmental elements on a person's overall health and well-being. New outcome measures are being developed that provide the tools that we need to evaluate the effectiveness of our interventions at the participation level.[10-12] Taking this wider view will also allow us to explore the interconnections across measures of the different dimensions of people's health and functioning.

When counselling and educating families of children with CP, one of our tasks is to relate how our therapeutic activities are connected to the desired outcomes. An impairment-based approach to treatment addresses primarily the problems of body function and structure thought to underlie the functional limitations of the "disability." There is at least an implicit assumption that "treatment" will produce functional results, and also perhaps an unspoken belief that more therapy will produce better results. The ICF model provides an opportunity from the outset to talk with parents (and older children) about a different set of primary goals that address function ("activity") and social engagement ("participation"). In this way of thinking, impairment-based interventions may still play an important role in management, but the focus widens, so that *additional* perspectives gain currency and can be considered equally valid ways of encouraging children to become functional. For example, a child with CP that affects oromotor control may benefit from assessment and intervention focused on the motor impairments that make feeding or speech challenging. At the same time, service providers who address the "activity" of eating and the child's "participation" in family mealtimes, as well as alternative communication strategies, if necessary, are working to ensure that all components of the child's functioning and health are addressed at the levels of "body structure and function," "activity," and "participation."

We surely do not mean to diminish the role or importance of "impairment-based" interventions, but simply to acknowledge that interventions at any (perhaps all) of the elements of the ICF model may be important, appropriate, and interlinked. Bartlett and Palisano[13,14] have presented thoughtful ideas about ways to incorporate the ICIDH/ICF models into aspects of clinical decision making, in part to recognize opportunities for preventing secondary impairments often associated with CP and other developmental disabilities.

In the ICF model, the environment in which the person with a disability lives is important and must be considered when planning interventions. This orientation is consistent with models that consider "person" and "environment" as dynamic and interactive dimensions of an individual's situation, such as Bronfenbrenner's "ecological" model[15] and the person-environment-occupation model in occupational therapy.[16] The ICF model acknowledges that the settings in which people live their lives play a central role in the expression of their capacity to function. In the context of CP, this may mean allowing, even encouraging, the liberal use of "augmentative" interventions such as mobility aids, alternative communication devices, and related technical tools. This approach can have an important role in the lives of people whose functional abilities can be enhanced with such interventions. Furthermore, the social and cultural environment must be considered in assessment and intervention, because we know that the attitudes, values, and beliefs of others affect a child's participation in daily activities.[17]

Researchers and educators should consider ways to promote and apply the ICF model to their practice. Studies of children and youth with CP should include dimensions of activity and participation, as well as environmental factors, to capture the complex interactional nature of the life experiences of these children and their families. We also have a professional responsibility to study the application of this new model and to provide critical feedback to the WHO. Educators need to inform future health professionals about the ICF, which represents a global framework and common language to describe and classify health and health-related states.

The WHO is encouraging people around the world to view health, disability, and functioning in this manner and to adopt a biopsychosocial approach to service delivery.[18] We believe that the application of this way of thinking about the components of health in clinical practice offers fresh perspectives to service providers working with children with developmental disabilities and their families. We hope that the early enthusiasm with which the ICF model has been greeted will be followed by further conceptual and technical developments, as well as a range of new research efforts, all directed toward the full adoption of an international framework for the field of CP.

APPENDIX: DEFINITIONS OF KEY TERMS FOR THE WHO'S INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY, AND HEALTH

"Functioning" and "disability" are umbrella terms that are conceived as a dynamic interaction between health conditions (eg, diseases, disorders, injuries) and contextual factors (environmental, personal factors).

In the context of health, the ICF provides the following definitions:

Body functions: The physiological functions of body systems (including psychological functions)

Body structures: Anatomical parts of the body, such as organs, limbs, and their components

Impairments: Problems in body function or structure, such as a significant deviation or loss

Activity: Execution of a task or action by an individual

Participation: Involvement in a life situation

Activity limitations: Difficulties an individual may have in executing activities

Participation restrictions: Problems an individual may experience in involvement in life situations

Environmental factors: The physical, social, and attitudinal environment in which people live and conduct their lives

Personal factors: The particular background of an individual's life and living, composed of features of the individual that are not part of a health condition or health state. (Note: Personal factors are described but not "classified" in the ICF because of the large social and cultural variance associated with them.)

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