

# Models of Disability, Quality of Life, and Individualized Supports: Implications for Professional Practice in Intellectual Disability

Wil H. E. Buntinx\* and Robert L. Schalock†

\*Department of Health Organization, Policy and Economics & Governor Kremers Center, Maastricht University, Maastricht, the Netherlands; and †Hastings College, Chewelah, WA, USA

**Abstract** In the past decade, new models have emerged with respect to the constructs of (intellectual) disability, quality of life, and supports. These models have implications both for understanding the underlying phenomena as for validating professional practices. The authors describe the context and key components of models of human functioning (American Association on Intellectual and Development Disabilities; International Classification of Functioning, Disability, and Health), supports, and quality of life, and demonstrate how these are related by synthesizing their similarities and differences. From this they discuss the implications for professional clinical and service good practice. It is argued that these models offer relevant frames of reference for guiding and integrating activities of medical, behavioral, and social disciplines in the field of intellectual disability services. It is also argued that knowledge of these models and their relationships facilitates communication among professionals and between professionals and policy makers.

**Keywords:** AAIDD model, assessment, ICF, intellectual disability, interdisciplinary good practices, quality of life, support

## INTRODUCTION

Fulfilling one's professional responsibilities in the field of intellectual disabilities (ID) involves understanding and applying best practices based on relevant conceptual models and frameworks regarding human functioning and disability, quality of life, and individualized supports. These models have important implications for the professional field. They explain the nature of disability, the meaning of personal well-being, and the important role that individualized supports play in the enhancement of human functioning and a life of quality. As common languages, they facilitate communication between different clinical disciplines and public policy makers (World Health Organization, 2001). However, it is not always clear how these models relate to one another, and in what ways and to what extent they are similar or complementary. In this regard, relevant questions are: what model should be used in clinical functions related to diagnosis, classification, and planning individualized supports? What are the implications for professional best practices? Should an individual supports plan be based on a human functioning/disability model or on a quality of life approach?

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Correspondence: Wil H. E. Buntinx, PhD, Associate Research Professor, Department of Health Organization, Policy and Economics & Governor Kremers Center, Maastricht University, P.O.B. 616, NL 6200 MD Maastricht, the Netherlands. Tel: +31 6 2079 8066; E-mail: w.buntinx@maastrichtuniversity.nl

This article has three purposes: (1) to describe the key components of three relevant models to professionals working in the field of ID—those models related to human functioning and disability, quality of life, and individualized supports; (2) to synthesize the similarities and differences among these models; and (3) to discuss their implications for professional practices in the field of ID. To that end, the article begins with a brief discussion of the historical context of each model, followed by a discussion of their most current iterations, including their similarities and differences. The article continues with a discussion of the relationship among the models and concludes with implications of these models for professional practice in the field of ID.

## HISTORICAL CONTEXT

Over the last 30 years, three scientific and societal developments have emerged that have a significant impact on professional practices in the field of ID. These three developments are an ecological conception of disability, the importance of focusing on a person's quality of life, and the role that individualized supports play in ameliorating the impact of one's disability, enhancing human functioning, and improving one's quality of life.

### *Concept of Disability*

The construct of disability has changed from focusing on pathology or a defect within the person to a socio-ecological

person–environment fit conception that focuses on understanding human functioning and disability based on the interactions between personal and environmental characteristics. The construct of ID has also changed (Mercer, 1992; Rioux, 1997; Wehmeyer et al., 2008; World Health Organization, 2001) consistent with this social-ecological focus. Conceiving ID in the context of person–environment interactions not only enhances our understanding of ID but also changes our approach to diagnosis, classification, assessment, and planning individualized supports. ID has come to be seen as not just a significant limitation in intelligence and adaptive skills; rather, it is viewed as a problem of the whole person in his or her life situation that impacts health, community participation, and the roles that the person plays in society. Information about intelligence and adaptive behavior offers only very limited understanding of the person's functioning and should be complemented by the assessment of the other dimensions of human functioning: health, participation, and context. Therefore, understanding and examining ID in an individual case requires a multiple perspective or multidimensional approach.

### Quality of Life Focus

Societal views on persons with disabilities have also changed significantly over the last 30 years. This change is demonstrated in the development of international conventions intended to guide the policy of states and public authorities. After the *Universal Declaration of Human Rights* (1948), the *Declaration on the Rights of Mentally Retarded Persons* (1971) specified what equality and fundamental rights mean for persons with disability, including ID. Rights, however, are not sufficient if they are not accompanied by opportunities to exercise those rights. *The Standard Rules on the Equalization of Opportunities for Persons with Disabilities* (1993) therefore were an important—though noncompulsory—additional international document defining the societal prerequisites of equality. In 2006, the Standard Rules were replaced by the *United Nation's Convention on the Rights of Persons with Disabilities* (United Nations, 2006). These rules stated the socio-political conditions for achieving equality, autonomy, nondiscrimination, participation, and inclusion in society. The convention stresses that persons with disabilities should be able to participate fully in all aspects of life, and specifies necessary attitudinal and legal conditions for achieving such participation. Convention articles address the following life functioning domains: rights (access and privacy); participation; autonomy, independence, and choice (i.e., self-determination); physical well-being; material well-being (work/employment); social inclusion, accessibility, and participation; emotional well-being (freedom from exploitation, violence, and abuse); and personal development (education and habilitation).

Whereas these conventions and articles focus on the socio-political or macrosystem level, the emerging construct of quality of life reflects the dynamics of personally desired (subjective) and objective conditions of life. This construct has become the link between the general values reflected in social rights and the personal life of the individual. It has also become a vehicle through which individual referenced equity, empowerment, and life satisfaction can be understood and enhanced (Brown, 1996; Schalock,

Gardner, & Bradley, 2007a; Shogren et al., 2009). Quality of life models capture the essential dimensions of an individual's life situation and operationalize them for use in enhancing and evaluating personal outcomes.

### Individualized Supports

Since the mid-1980s the supports paradigm has made at least three significant impacts on professional practices in the field of ID. First, the pattern of assessed needed supports has become the basis of individualized education and habilitation planning (Thompson et al., 2002). Second, the level or intensity of a person's support needs is being used as the basis for agency and systems planning and resource allocation formulas (Agosta et al., 2009; Fortune, Auerbach, Agosta, & Smith, 2008; Fortune et al., 2009). Third, the supports orientation has brought together the related practices of person-centered planning, personal growth and development opportunities, community inclusion, and empowerment (Luckasson et al., 2002). Over the last 30 years significant research and further conceptualization of the construct of supports has indicated that a useful and robust supports model provides the content basis for the provision of individualized supports as well as providing a person-centered approach to a systems of supports that focuses on improving human functioning and is developed, implemented, and evaluated in a systematic way.

## MODELS OF HUMAN FUNCTIONING AND DISABILITY

The construct of disability is best viewed within the larger context of human functioning. In that regard, disability can be defined as the expression of limitations in individual functioning within a social context that represent a substantial disadvantage to the individual. There are currently two frequently referenced models of human functioning or disability that reflect this ecological understanding of—and professional approach to—human functioning and disability: the *International Classification of Functioning, Disability, and Health* (ICF) model proposed by the World Health Organization (2001) and the conceptual framework of human functioning proposed by the American Association on Intellectual and Developmental Disabilities (AAIDD; Schalock et al., 2010).

### ICF Model

In 1980, the World Health Organization (WHO, 1980) presented the “International Classification of Impairment, Disability and Handicap—ICIDH” model of human functioning. This model introduced three planes of experience for human functioning: body structures and functions, activities within an individual context (skills and abilities), and activities in the social context (participation). The significance of this model was the conceptualization of disability as a multidimensional phenomenon. Three aspects of functioning—“impairment,” “disability,” and “handicap”—were clearly defined and linked with the

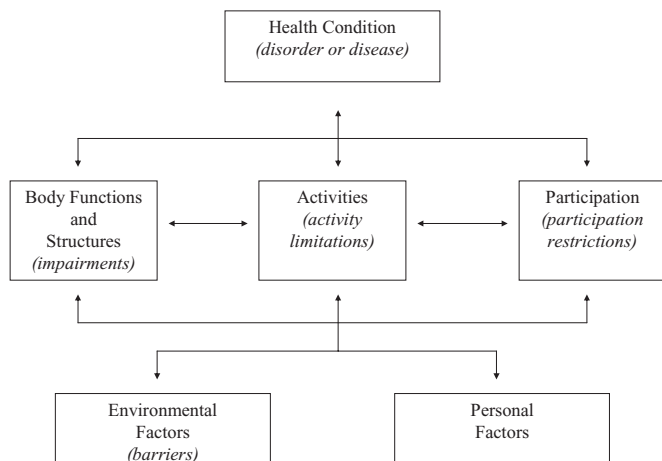


FIGURE 1

The ICF model of human functioning, disability and health: core components and their relations. ICF = International Classification of Functioning, Disability, and Health.

consequences of health conditions or etiology (Buntinx, 2006). However, the ICIDH was still rooted in a pathology paradigm and did not explicitly include the environment as a major determinant of human functioning. To overcome this limitation, the “Disability Creation Process” (Fougeyrollas, Cloutier, Bergeron, Côté, & St Michel, 1998; INDCP, 2009) model was proposed to integrate the environmental context of disablement. This model is still in use with practitioners and researchers for describing the disabling processes through risk factors, personal and environmental factors, and life habits (INDCP, 2009).

In 2001, the WHO published a completely revised classification—the ICF—followed in 2007 by the ICF Children and Youth version (ICF-CY; WHO, 2007). As shown in Figure 1, the ICF (and the ICF-CY) is also conceived within a person–environment interaction paradigm, a multiple perspective, and a bio-psycho-social approach.

The ICF is primarily a classification system. Although it provides codes for a wide variety of problems in different components of human functioning, it is not a diagnostic tool in itself. It allows one to identify and code problems that are observed and documented on the basis of available data (e.g., from diagnostic or assessment activities). The original purpose of the ICIDH and ICF was not for clinical use but for the comparison of data in statistical and epidemiological contexts. The ICF classification system however is based on a theoretical model that represents the different domains of human functioning and their relationships. It therefore is a “language” that allows professionals of different disciplines to communicate in clear terms and to compile information from different sources. In an individual multidisciplinary assessment process, the ICF model allows one to evaluate whether all dimensions of functioning were considered and it helps to organize available information into a meaningful “map” of limitations in functioning. Likewise, it allows one to develop and validate professional procedures of assessment

and to organize information from different disciplines. The development of ICF-based questionnaires adds to its clinical usefulness (Lollar & Simeonsson, 2005; WHO, 2003; WHO ICF-CY Work Group, 2003).

### The AAIDD Model

A multidimensional model of human functioning was first proposed by AAIDD (formerly AAMR, American Association on Mental Retardation) in its 1992 Manual (Luckasson et al., 1992) and elaborated upon in the 2002 Manual. The present model is shown in Figure 2 (Schalock et al., 2010). This conceptual framework of human functioning has two major components: five dimensions (intellectual abilities, adaptive behavior, health, participation, and context), and a depiction of the role that supports play in human functioning. This framework of human functioning recognizes that the manifestation of ID involves the dynamic, reciprocal engagement among intellectual ability, adaptive behavior, health, participation, context, and individualized supports.

The conceptual framework of human functioning depicted in Figure 2 is consistent with the ICF model summarized in Figure 1 (Buntinx, 2006). Furthermore, the ICF domains of “body functions” (impaired intellectual functioning) and of “activities” (limitations in adaptive behavior) refer to the diagnostic criteria specified in the AAIDD operational definition of ID (Schalock, Luckasson, & Shogren, 2007b, p. 118; Schalock et al., 2010, p. 1), which note that an intellectual disability is characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills and that these impairments originate before age 18.

Although comparable to the ICF model, the AAIDD model differs from the ICF model in three ways (Buntinx, 2006). First, the AAIDD model has been developed as a special system for ID. It contains current state of the art professional guidelines for diagnosis and classification and for the assessment of functioning along the five dimensions depicted in Figure 2. Second, whereas supports in the ICF are implied in the environmental factors, the AAIDD model defines supports as a distinct and major component of the model. The AAIDD places supports at the center as a key factor in the enhancement of individual functioning and an integral part of the assessment process. Third, the AAIDD model does not provide classification codes for administrative purposes, although as discussed later, it does outline the parameters to a multidimensional classification system.

### QUALITY OF LIFE MODELS

In our article, we adhere to the individual-referenced quality of life definition as outlined by Schalock, Keith, Verdugo, and Gomez (2010). This definition states that quality of life is a multidimensional phenomenon composed of core domains influenced by personal characteristics and environmental factors. They state that these core domains are the same for all people, although they may vary individually in relative value and importance. In this regard, the assessment of quality of life domains is based on culturally sensitive indicators.

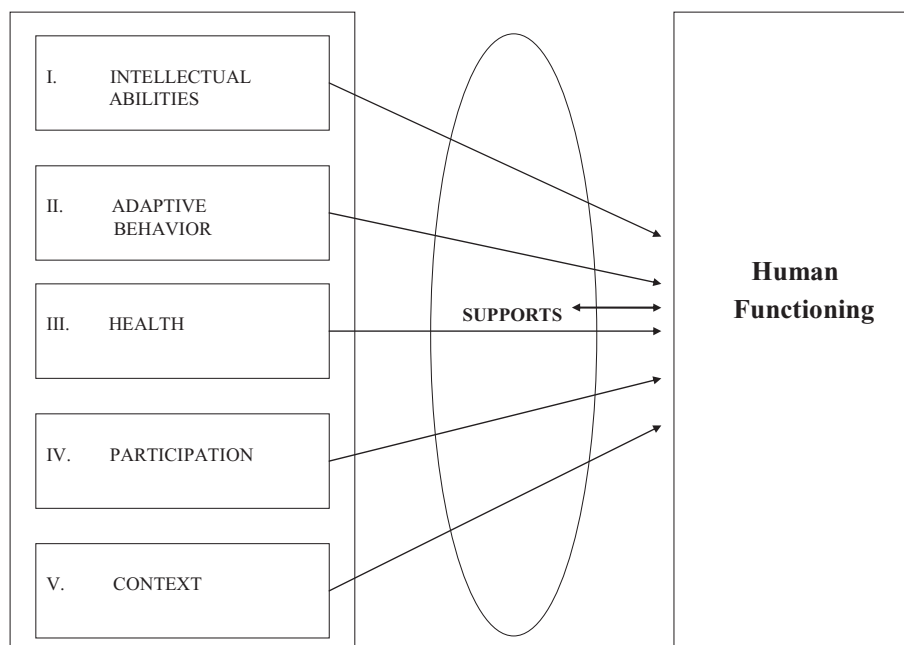


FIGURE 2

American Association on Intellectual and Development Disabilities conceptual framework for human functioning (Schalock et al., 2010).

Numerous quality of life models have been developed to both explain the quality of life construct and provide conceptual and measurement frameworks regarding its assessment. Examples can be found in the published work of Cummins (2005), Felce (1997), Renwick, Brown, and Nagler (1996), and the WHO (1993a, 1997). Across these models one finds reference to quality of life domains, quality of life indicators, and quality of life measurement strategies (see Table 1).

Quality of life models differ from the ICF and AAIDD disability models in at least five ways: their content, the focus of assessment, the evaluation metric, the role of the person with ID in the assessment process, and their intended purpose and use.

**Content** The content of the ICF and AAIDD models is either the core components of health and human functioning and contextual variables (i.e., personal and environmental factors) as contained in the ICF model (Figure 1) or the multidimensional components of human functioning, including the significant role played by individual supports as contained in the AAIDD model (Figure 2). In distinction, the content of QOL models are factors, domains, and culturally sensitive domain indicators as expressed in the daily life situation of the individual. The content of QOL models is more value oriented and less functionally oriented. An exemplary QOL model is presented in Table 1 (Schalock et al., 2007a; Wang, Schalock, Verdugo, & Jenaro, 2010).

**Focus of assessment** The focus of assessment in the ICF and AAIDD models is on limitations in human functioning across the

components of the respective model. In contrast, the focus of assessment in the area of QOL is the current status of the person's life conditions and circumstances vis-à-vis the exemplary factors, domains, and indicators summarized in Table 2.

**Evaluation metric** In the ICF and AAIDD models objective, professionally administered tools and methods are used to typically evaluate an individual's functional limitations, with comparisons made on the basis of standardized scores obtained from a comparison group. With QOL assessment, the metric can be subjective appraisal of life events, circumstances, or level of personal satisfaction, or objective appraisal from third parties regarding the status of the person on the life events or circumstances depicted in the culturally sensitive indicators used to summarize personal outcomes (see Table 2).

**Role of the person with ID in the assessment process** In the ICF/AAIDD models, assessment is professionally defined and conducted by trained evaluators. The individual is typically only a respondent, and frequently the evaluation of some of the model's components (e.g., participation and context) is done without any input from the individual. In distinction, in QOL measurement, the individual is the primary respondent, and increasingly and with suitable training, a person with ID is the interviewer of other persons with ID (Bonham et al., 2004).

**Intended purpose** Information obtained from the ICF model components is used primarily for classification and description

TABLE 1  
Quality of life domains, indicators, and life measurement strategies

Model factor	Explanation
Quality of life domains	These represent the range over which the quality of life concept extends and thus define the multidimensionality of a life of quality
Quality of life indicators	These are QOL-related perceptions, behaviors, and conditions that operationally define each QOL domain; their measurement results in QOL-related personal outcomes.
Quality of life measurement strategies	<p>These are interrogatories drawn from Brown, Schalock, and Brown (2009) and Verdugo, Schalock, Keith, and Stancliffe (2005):</p> <ul style="list-style-type: none"> <li>• <i>What to measure:</i> QOL domains and indicators and valued personal experiences and circumstances that: (1) follow as a result or consequence of some activity, intervention, or service; and (2) are measured on the basis of quality indicators.</li> <li>• <i>How to measure:</i> Subjective appraisal (e.g., satisfaction, importance) and/or objective assessment (e.g., objective indicators of personal experience and circumstances and/or traditional social indicators).</li> <li>• <i>Who should be involved:</i> individuals with ID and persons who know the individual well.</li> <li>• <i>Where to assess:</i> natural environment.</li> <li>• <i>When to assess:</i> depends on questions asked.</li> <li>• <i>Research methods:</i> multivariate designs and observational studies that focus on individual and environmental predictors of quality outcomes and methods that take into account the effects of individual choice.</li> </ul>

ID = intellectual disabilities; QOL = Quality of life.

TABLE 2  
Quality of life conceptual and measurement model

Factors	Domains	Exemplary indicators
Independence	Personal development Self-determination	Education status, personal skills, adaptive behavior Choices/decisions, autonomy, personal control, personal goals
Social participation	Interpersonal relations Social inclusion Rights	Social networks, friendships, social activities, interactions, relationships Community integration/participation, community roles, supports Human (respect, dignity, equality) legal (legal access, due process)
Well-being	Emotional well-being Physical well-being Material well-being	Safety and security, positive experiences, contentment, self-concept, lack of stress Health and nutrition status, recreation, leisure Financial status, employment status, housing status, possessions

purposes. However, some jurisdictions are using this information for planning and public policy formulation. In distinction, the conceptual and measurement framework of all validated QOL models allows one to use the data for evaluating personal outcomes and providing information for reporting and quality improvement (Keith & Bonham, 2005; Schalock, Verdugo, Bonham, Fantova, & van Loon, 2008b).

SUPPORTS MODEL

The next model impacting professional practices in the ID field is the supports model. Supports are currently defined by

Schalock et al. (2010, p. 175) as “resources and strategies that aim to promote the development, education, interests, and personal well-being of an individual and that enhance human functioning.” As conceptualized in the supports paradigm literature, a supports model has five components: a clear rationale, a conceptual basis, a clear focus or intent, a delineation of the content or life activities encompassed by the model, and a clearly articulated implementation process.

*Rationale* The rationale for a supports model in the provision of individualized supports is found in three phenomena: contextualism, social-ecology, and egalitarianism (Luckasson et al., 2002). Contextualism has three central themes that are relevant to

the rationale for a supports model: (1) an appreciation for the milieu, circumstances, environment, and perspective within which behavior occurs; (2) the realization of the dynamic nature of human functioning, with one's environment being transformed by its members, who are, in turn, transformed by the environment; and (3) the acknowledgement that the person is an active determiner of his or her own development.

There is clear evidence (e.g., Felce, 1997; Schalock, Bonham, & Verdugo, 2008a; Thompson et al., 2009) dating back to the 1980s that the successful adjustment of people with disabilities to their environment is related to both person-specific behavioral capabilities and setting-specific performance requirements. These results are consistent with a social-ecology model that explains a person's growth, development, and adjustment as depending on both the measurement and programming of person- and setting-specific factors and the facilitation of congruence between individuals and their environments. Facilitating this congruence involves determining the profile and intensity of needed supports for a particular person and providing the individualized supports that will enhance human functioning.

Egalitarianism is the belief in human equality, especially with respect to social, political, and economic rights. Since the 1960s we have seen the emergence of the egalitarian movement from both a legal and service-delivery perspective. Legally, we have seen that people with ID have a right to a free and appropriate public education, community-based services, and freedom from overly restrictive environments (Stowe, Turnbull, & Sublet, 2006). Programmatically, we have seen the egalitarian movement reflected in services and supports based on the concept of person-centered planning, self-advocacy, and personal empowerment, and personal, quality of life-related outcomes (Shogren et al., 2009).

**Conceptual basis** Three terms and their definition underlie the conceptual basis for a supports model: support needs, supports, and a system of support. *Support needs* is a psychological construct referring to the pattern and intensity of supports necessary for a person to participate in activities linked with normative human functioning (Thompson et al., 2009, p. 135). *Supports* are resources and strategies that aim to promote the development, education, interests, and personal well-being of an individual and that enhance human functioning (Schalock et al., 2010, p. 175). A *system of supports* can be conceptualized (and defined) as the planned and integrated use of individualized support strategies and resources that encompass the multiple aspects of human performance in multiple settings. A system of supports model provides a structure for the organization and enhancement of human performance elements that are interdependent and cumulative (Schalock et al., 2010). One such system of supports is that proposed by the AAIDD and reflects the integration of work in the area of human performance technology (Thompson et al., 2009). Support elements associated with "systems of supports" are organizational systems, incentives, cognitive supports, tools, physical environment, skills-knowledge, and inherent ability (Wile, 1996).

**Focus/intent** As defined above, supports are resources and strategies that aim to promote the development, education, interests, and personal well-being of a person and enhance human functioning. This approach to supports can be seen as a bridge

between the present state of functioning ("what is") and a desired state of functioning ("what could be"). As shown in Figure 2, the supports concept has a key position in enhancing the functioning of the individual. However, enhancing functioning should not be conceived as "fixing the functional limitations that were assessed" using the ICF or AAIDD dimensions of functioning. There are three reasons for this caution. First, many functional limitations cannot be "fixed" or compensated for since the complexity and severity of the disability or its etiology—in view of the present state of science and professionalism—does not provide answers that would "cure" or completely mitigate the disability. Second, compensating for weaknesses as assessed within a professional frame of reference does not necessarily correspond to the frame of reference of an individual's personal life. This involves personal preferences, strivings, experiences, and perceptions that are not expressed in technical and functional professional language. This individual perspective means that improving the life situation of a person requires individual planning and execution of relevant strategies that take into account personal preferences and objectives as well as available resources. Third, it can be argued that "fixing" limitations in personal competence and context on the basis of an objective professional assessment is not a sufficient way to help a person with ID experience a better life. It can also be argued that starting actions in order to improve the subjective satisfaction or objective weaknesses in QOL-related domains without taking into account a multidimensional disability assessment, would not be a wise approach and—in the case of missing important information on the disability—could lead to detrimental consequences for the person. It is obvious that both personally and professionally referenced approaches are relevant to clinical professional practice.

**Content** Any supports model—and the methods used to assess the support needs of persons with ID—needs to delineate clearly the behavioral parameters of the model and potential assessment areas. In reference to the AAIDD supports model, for example, the *Supports Intensity Scale* (SIS; Thompson et al., 2004) assesses the pattern and intensity of supports needed by the person to be more successful and participatory in the following seven life activity areas: home living, community living, life-long learning, employment, health and safety, social relations, and protection and advocacy. These life activity areas are closely related to the domains of the quality of life model. Additionally, the SIS also determines exceptional medical and behavioral support needs. In reference to exceptional medical support needs, the SIS assesses how much support is needed to maintain or enhance the exceptional medical needs (e.g., respiratory care, feeding assistance, and skin care), and how much support is needed to prevent or minimize the exceptional behavioral needs (e.g., externally-directed destructiveness, self-directed destructiveness, and sexually-related behaviors).

**Implementation process** Supports are resources and strategies that when integrated into a system of supports enhance human functioning. No individual will need all of the elements referenced earlier, and people's support needs differ both quantitatively (in number) and qualitatively (in nature). Planning teams are in the best position to identify the types of support system elements that people need. As summarized in Figure 3,

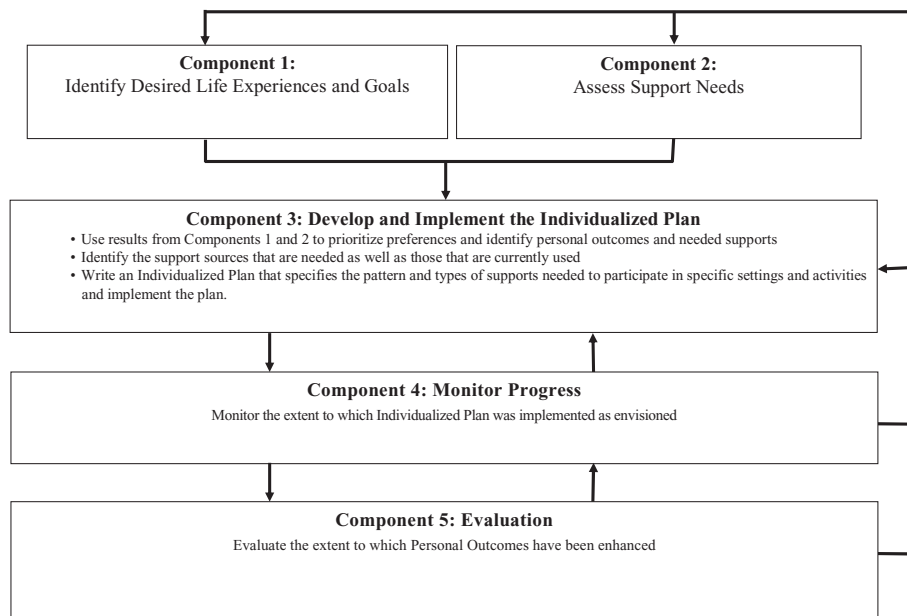


FIGURE 3

A process model for assessing, planning, monitoring, and evaluating individualized supports (Schalock et al., 2010, p. 118; Thompson et al., 2009, p. 140).

Thompson et al. (2009) and others (e.g., Van Loon, 2008; Van Loon, van Hove, Claes, & Schalock, in press) propose a five-step process model for identifying desired life experiences and goals of the person, assessing the nature of support a person will require to accomplish what he or she most wants and needs to do, developing an action plan to garner and deliver supports, initiating and monitoring the plan, and evaluating the status of the personal outcomes.

In summary, the five components of a supports model just discussed are external to—but not inconsistent with—the application of the ICF model of human functioning and disability (Figure 1). The five components are consistent with, basic to, and an integral part of the AAIDD conceptual framework of human functioning (Figure 2). In reference to the QOL model described earlier, an individualized system of supports provides a critical bridge between the individual's present state of functioning ("what is") and a desired state of functioning ("what can be") for a person with ID.

#### RELATIONSHIP AMONG THE MODELS

The three types of models described above (human functioning/disability, quality of life, and supports) reflect an emerging international consensus as to the conceptual and measurement framework that professionals should use in their interactions with persons with ID. As a foundation for the final section of this article in which we discuss a number of specific implications for professional practices stemming from these models, it is

important to summarize and compare their primary components (Table 3 below) and how collectively they provide a holistic assessment framework for the disabilities field (Figure 4).

#### Primary Components

At a descriptive level, the three types of models can be compared in terms of their conceptual basis, content, assessment focus, intended purpose, and role of persons with ID. This comparison is shown in Table 2.

#### Holistic Assessment Framework

The models are related in terms of the role they play in professional assessment and intervention. As shown in Figure 4, this role begins with the diagnosis and assessment of the disability (1), moving to the assessment of support needs from the perspective of the individual and the professional (2), in order to develop and implement support strategies (3), and ending with the assessment or measurement of quality of life-related outcomes (4). Incorporating feedback from the outcome evaluation into the appropriate step will start a new cycle directed at the improvement of a person's life quality. This cycle represents a logical sequence of actions that guide or support professional practices. Each model represents a valid framework for specific professional activities and the broader framework allows one to integrate and communicate information about specific activities. Additionally, within each model multiple methods and instruments can be used to obtain

TABLE 3  
Comparison between ICF/AAIDD, quality of life and supports models

Primary Component	Model		
	ICF/AAIDD	Quality of life	Supports
Conceptual basis	Human functioning dimensions; functional limitations	Personal well-being	Support needs Supports process
Content	Components of functioning, health conditions and context; dimensions of human functioning and supports	QOL factors QOL domains QOL indicators	Life activity domains Exceptional medical and behavioral support needs
Assessment focus	Strengths and weaknesses in the dimensions and components of human functioning—contextual barriers and facilitators	Objective status and subjective experiences of QOL domains and indicators	Pattern and intensity of support needs, both subjective (wants) and objective (needs as assessed by professionals)
Intended purpose	Description, classification; diagnosis of ID, assessment of functioning, classification and development of supports	Description of individual well-being; evaluation of outcomes; input for policy and practices; service quality management with respect to support content	Bridging support needs and enhancement of functioning and QOL
Role of the person	Secondary (“object” of assessment)	Primary (“subject” of and participant in evaluation)	Primary (“subject” of and partner in supports assessment and planning)

AAIDD = American Association on Intellectual and Development Disabilities; ICF = International Classification of Functioning, Disability, and Health; ID = intellectual disabilities; QOL = Quality of life.

data that become useful in building an image of the person’s functional limitations, support needs, and quality of life. As mentioned earlier, the concept of supports is the crucial link between the functional models of disability and quality of life.

IMPLICATIONS FOR PROFESSIONAL PRACTICE

There is an emerging consensus in the field of disability generally, and ID specifically, that the models described in this article should be incorporated into professional practices and standards. To that end, this section of the article discusses briefly how an understanding of these models and their primary components provides a conceptual framework for the alignment of clinical functions in intellectual disability and the alignment of organizational practices within a systems perspective. Although equally important, page limitations prevent a discussion of three additional implications (i.e., program development and evaluation [cf. Schalock et al., 2008a], research [cf. Schalock et al., 2010], and public policy [Shogren et al., 2009]).

*Alignment of Clinical Functions*

As shown in Table 3, the four components shown in Figure 4 can be elaborated into a framework for the alignment of the

clinical functions related to diagnosis and assessment of functioning (1), assessment of support needs (2), the planning and implementation of supports (3), and the assessment of personal outcomes (4). This alignment is built along four basic questions. First, what are the problems of the person in terms of diagnosis and present functioning? Second, what are the support needed by this person in order to enhance functioning and his or her quality of life? Third, what actions should be planned and implemented in order to respond to the person’s support needs? Fourth, did the person benefit from the support interventions and did his or her quality of life improve? Based on the three types of models discussed above, specific questions can be asked that will lead to best clinical practices in ID.

*Diagnosis* The questions raised are whether the diagnosis is established on the basis of the three applicable criteria (intelligence, adaptive behavior, and age of onset) and whether the assumptions in applying the diagnostic criteria were considered (Schalock et al., 2010, p. 1).

*Assessment of present functioning* The question raised is whether the assessment process involved a multidisciplinary and systematic analysis of strengths and weaknesses in all dimensions of an applicable model such as the ICF, ICF-YC or AAIDD. As discussed in reference to the AAIDD model, for example, the dimensions of human functioning comprise intellectual functioning;



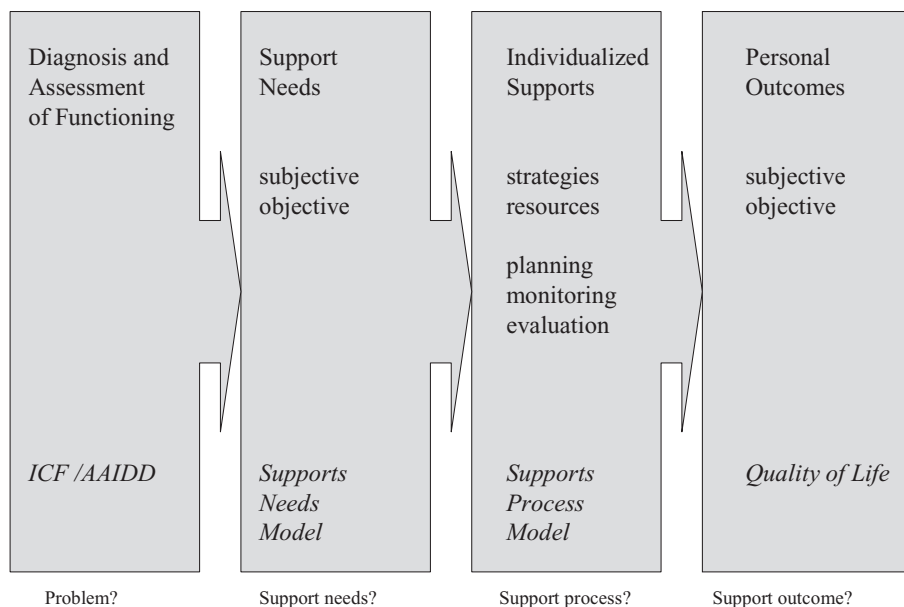


FIGURE 4

Relationship between the clinical functions of diagnosis and assessment of functioning, assessment of support needs, individualized supports process, assessment of personal outcomes and applicable modes. AAIDD = American Association on Intellectual and Development Disabilities; ICF = International Classification of Functioning, Disability, and Health.

conceptual, practical and social adaptive behavior; physical and mental health status and a multifactorial approach to etiology; participation in terms of roles and interactions in relevant life activity domains; and the person’s context in terms of characteristics of the environment (physically, social network, availability of health, educational, vocational and other services) and in terms of personal factors (life history, life style, character).

*Assessment of support needs* The question raised was whether the information about the desired life experiences and goals of the person was acquired by interviewing the person, or in the case of severe communication impairments, captured from relevant proxies. Further, was information from the professional’s perspective about the person’s support needs collected using an appropriate framework such as the supports need model (Schalock et al., 2010; Thompson et al., 2004)?

*Planning and implementing individualized supports* The question raised is whether desired outcomes, goals, and strategies are based on assessed support needs and are they realistically linked to available resources. Does the individualized support process follow a systematic control rule such as the Plan–Do–Check–Act quality improvement cycle (McLaughlin & Kaluzny, 2004; Grol, Baker, & Moss, 2004) or the components of the supports process model in Figure 3?

*Assessment of personal outcomes* The question raised is whether the assessment of outcomes is based on a valid quality of life

conceptual and measurement framework such as that shown in Table 2. Does this evaluation include a personal appraisal (subjective) and objective appraisal (according to objective life conditions and circumstances)?

Answering these questions will allow clinicians to evaluate existing professional assessment and intervention practices as well as developing new approaches. To what depth specific functions should be analyzed and which instruments should be used is subject to professional discretion. However, the frameworks provided by Table 4 and Figure 4 provide the means to validate, to guide, and to account for the process of professional assessment and intervention.

*Alignment of Organizational Practices Within a Systems Perspective*

Whereas professional assessment and interventions are directed toward facilitating the individual functioning of persons with ID, professional activities need to be facilitated by organizations and enabled through public policy. This means that a systems perspective is needed that encompasses the *microsystem* level of individual clinical assessment and support planning, the *mesosystem* level of organizations and agencies involved in assessment and professional support delivery, and the *macrosystem* level incorporating the societal perspective.

In order to achieve this, the following two considerations are important. First, it was already mentioned that the United

TABLE 4  
 Framework for assessment and supports process planning

Function	Specific purpose (in order to)	Examples of measures, tools and assessment methods and systems	Criteria examples
Diagnosis	Establishing presence of ID (also: eligibility for services, benefits, legal protections)	-Intelligence tests -Adaptive behavior scales -Age of onset	< 2SD IQ < 2SD AB -onset before age 18
Assessment of Functioning	Describing and understanding limitations in functioning Establishing base line information for future reference (also: inventory of health-related, behavioral, developmental, social, contextual problems that need to be addressed)	-AAIDD system -ICF classification -DSM-IV -ICD-10 -developmental tests -achievement tests -functional behavioral assessment -speech, language, motor, sensory assessment -ecological inventory -social network and support network inventories	-Strengths and weaknesses in five dimensions of AAIDD human functioning model -ICF classification qualifiers -Standardized population norms of scales and measures -Best practices criteria
Assessment of support needs	Describing and understanding support needs (for input in ISP <sup>a</sup> ; basis for resource allocation; comparison of individuals or groups)	Support needs model -Interviewing (subjective wants) -Supports Intensity Scale (standardized supports needs assessment)	SIS standardized norm tables
Planning and developing individual supports	Planning, performing and evaluating support activities	Person-centered Planning ISP, IEP, ITP <sup>a</sup> Plan-Do-Check-Act cycle (Deming) and related “quality improvement” methods	-eight domains of quality of life
Assessment of personal outcomes	Describing, evaluating and understanding an individual’s quality of life status Evaluation of supports effectiveness and ISP <sup>a</sup> outcome	Quality of life inventory; interviewing; ASK ME Personal Outcome Scale; self appraisal	-eight domain-related indicators of quality of life -standardized population norms

<sup>a</sup>ISP: Individualized Supports Plan; IEP: Individualized Educational Plan; ITP: Individualized Transition Plan.  
 AAIDD = American Association on Intellectual and Development Disabilities; ICF = International Classification of Functioning, Disability, and Health; ID = intellectual disabilities; IQ = Intelligence quotient; AB = Adaptive behavior; SD = standard deviation; DSM-IV = Diagnostic and Statistical Manual-IV; ICD-10 = International Classification of Diseases-10 (WHO, 1993b).

Nations (UN) Convention on the Rights of Persons with Disabilities reflects the same underlying values as the quality of life concept. This implies that *theoretically* there is consistency and congruence between public policy (following the UN Convention) at the macrosystems level and the endeavors of professionals at the individual intervention level. This means that goals and support actions that are focused on enhancing the quality of life of an individual with ID are supported by the same value system as the nation or state adopted by signing and ratifying this convention and not rooted in idiosyncratic or idealistic thinking of individual practitioners. Professional support to promote a person’s quality of life is therefore legitimated in a broader value system.

Second, between individual interventions at the microsystem level and the level of public policy or macrosystem, is the meso-system of organizations and agencies that facilitate the work of professionals by employing them and/or by providing the means and context for their work. At this level, it is necessary to integrate basic knowledge of these models, their relationships and implications in order to perform as an organization that—by its mission and vision—is dedicated to contribute to the quality of life of persons with ID. Although elaboration on this topic is beyond the scope of this article, it is conditional on the successful performance of the organization to understand these implications in their strategic, tactical, operational and quality management (Schalock et al., 2010, chapter 15).

## CONCLUSION

As reflected in the models discussed in this article, both academic and societal developments have influenced the concepts and models of ID over the last 30 years. The validity of professional practices is influenced by these developments and models. Relevant models offer important frames of reference for guiding and integrating activities of medical, behavioral and social disciplines involved in disability services. These models are “information organizers” and leave ample opportunity for discipline specific protocols and instruments. An important implication of the relationship among the models that were discussed is that diagnosis and assessment of ID is a necessary but not sufficient condition for providing professional assistance. Knowledge of the quality of life conceptual and measurement framework is also a prerequisite for enhancing supports and evaluating personal outcomes. Knowledge of the supports construct and its relationship to personal competences and quality of life-related outcomes is also necessary for a valid and effective process chain of professional assistance.

Combining different models in practice may pose some difficulties (Thompson et al., 2009). One finds, for example, different quality of life models, different conceptions of human functioning, and different support models. What is critical for professionals is to not be confused by such differences but rather to select an appropriate model for the function at hand (i.e., assessment of functional limitations, assessment of support needs, development and implementation of the Individualized Supports Plan and/or assessment of personal outcomes) and use best practices in completing the respective clinical functions.

Knowledge of the models as discussed in this article and their relationships will facilitate communication among disciplines and colleagues. Although it is true that no “golden standard procedure” results from considering the application of these models, their rationale, content, implementation, and evaluation should be used to validate current professional practices and should be included in professional education and training programs.

## REFERENCES

- Agosta, J., Fortune, J., Kimmich, M., Melda, K., Smith, D., Auerbach, K., et al. (2009). *Ten issues for states to consider in implementing individual or level-based budget allocations*. Portland, OR: Human Services Research Institute.
- Bonham, G. S., Basehart, S., Schalock, R. L., Marchand, C. B., Kirchner, N., & Rummenap, J. M. (2004). Consumer-based quality of life assessment: The Maryland Ask Me! Project. *Mental Retardation*, 42, 338–355.
- Brown, R. I. (1996). *Quality of life for people with disabilities. Models, research and practice*. Cheltenham, UK: Stanley Thornes.
- Brown, R. I., Schalock, R. L., & Brown, I. (2009). Quality of life: Its application to persons with intellectual disabilities and their families—Introduction and overview. *Journal of Policy and Practice in Intellectual Disabilities*, 6, 2–6.
- Buntinx, W. H. E. (2006). The relationship between the WHO-ICF and the AAMR-2002 system. In H. Switzky & S. Greenspan (Eds.), *What is mental retardation? Ideas for an evolving disability in the 21st century* (pp. 303–323). Washington, DC: AAMR.
- Cummins, R. A. (2005). Moving from the quality of life concept to a theory. *Journal of Intellectual Disability Research*, 49, 699–706.
- Felce, D. (1997). Defining and applying the concept of quality of life. *Journal of Intellectual Disability Research*, 41, 126–135.
- Fortune, J., Agosta, J., Auerbach, K., Kimmich, M., Melda, K., Smith, D., et al. (2009). *Developing reimbursement levels using the Supports Intensity Scale (SIS) in Louisiana*. Portland, OR: Human Services Research Institute.
- Fortune, J., Auerbach, K., Agosta, J., & Smith, D. (2008). *The Colorado supported living services waiver: Three potential waiver resource allocation models*. Portland, OR: Human Services Research Institute.
- Fougeyrollas, P., Cloutier, P., Bergeron, H., Côté, J., & St Michel, G. (1998). *The Quebec classification disability creation process*. Québec, QC: International Network on Disability Creation Process (INDCP)/CSICIDH.
- Grol, R., Baker, R., & Moss, F. (Eds.). (2004). *Quality improvement research*. London: BMJ Books.
- INDCP. (2009). *Disability creation process*. Retrieved on June 21, 2010, from International Network on Disability Creation Process website <http://www.ripph.qc.ca/>
- Keith, K. D., & Bonham, G. S. (2005). The use of quality of life data at the organization and systems level. *Journal of Intellectual Disability Research*, 49, 799–805.
- Lollar, D., & Simeonsson, R. (2005). Diagnosis to function: Classification for children and youths. *Journal of Developmental and Behavioral Pediatrics*, 26, 323–330.
- Luckasson, R., Borthwick-Duffy, S., Buntinx, W., Coulter, D., Craig, P., Reeve, A., et al. (2002). *Mental retardation: Definition, classification and systems of supports*. Washington, DC: American Association on Mental Retardation.
- Luckasson, R., Coulter, D., Polloway, E., Reiss, S., Schalock, R., Snell, M., et al. (1992). *Mental retardation: Definition, classification and systems of supports*. Washington, DC: American Association on Mental Retardation.
- McLaughlin, C. P., & Kaluzny, A. D. (2004). *Continuous quality improvement in health care*. Sudbury, MA: Jones and Bartlett.
- Mercer, J. R. (1992). The impact of changing paradigms of disability on mental retardation in the year 2000. In L. Rowitz (Ed.), *Mental retardation in the year 2000* (pp. 15–38). New York: Springer-Verlag.
- Renwick, R., Brown, I., & Nagler, M. (1996). *Quality of life in health promotion and rehabilitation: Conceptual approaches, issues, and applications*. Thousand Oaks, CA: Sage.
- Rioux, M. H. (1997). Disability: The place of judgment in a world of fact. *Journal of Intellectual Disability Research*, 41, 102–111.
- Schalock, R. L., Bonham, G. S., & Verdugo, M. A. (2008a). The conceptualization and measurement of quality of life: Implications for program planning and evaluation in the field of intellectual disabilities. *Evaluation and Program Planning*, 31, 181–190.
- Schalock, R. L., Borthwick-Duffy, S. A., Bradley, V. J., Buntinx, W. H. E., Coulter, D. L., Craig, E. M., et al. (2010). *Intellectual disability: Definition, classification, and systems of supports*. Washington, DC: American Association on Intellectual and Developmental Disabilities.
- Schalock, R. L., Gardner, J. F., & Bradley, V. J. (2007a). *Quality of life for people with intellectual and other developmental disabilities. Applications across individuals, organizations, communities, and systems*. Washington, DC: American Association on Intellectual and Developmental Disabilities.
- Schalock, R. L., Keith, K. D., Verdugo, M. A., & Gomez, L. E. (2010). Quality of life model development and use in the field of intellectual disability. In R. Kober (Ed.), *Quality of life: Theory and implementation*. pp. 17–32. New York: Sage.
- Schalock, R. L., Luckasson, R. A., & Shogren, K. A. (2007b). The renaming of mental retardation: Understanding the change to the term intellectual disability. *Intellectual and Developmental Disabilities*, 45, 116–124.
- Schalock, R. L., Verdugo, M. A., Bonham, G. S., Fantova, F., & van Loon, J. (2008b). Enhancing personal outcomes: Organizational strategies,

- guidelines, and examples. *Journal of Policy and Practice in Intellectual Disabilities*, 5, 276–285.
- Schalock, R. L., Verdugo, M. A., Jenaro, C., Wang, M., Wehmeyer, M., Jiancheng, X., et al. (2005). Cross-cultural study of quality of life indicators. *American Journal on Mental Retardation*, 110, 298–311.
- Shogren, K. A., Bradley, V. J., Gomez, S., Yeager, M. H., Schalock, R. L., Borthwick-Duffy, S., et al. (2009). Public policy and the enhancement of desired outcomes for persons with intellectual disability. *Intellectual and Developmental Disabilities*, 47, 307–319.
- Stowe, M. J., Turnbull, H. R., & Sublet, C. (2006). The Supreme Court, “our town,” and disability policy: Boardrooms and bedrooms, courtrooms and cloakrooms. *Mental Retardation*, 44, 83–99.
- Thompson, J. R., Hughes, C., Schalock, R. L., Silverman, W., Tasse, M. J., Bryant, B. R., et al. (2002). Integrating supports in assessment and planning. *Mental Retardation*, 40, 390–405.
- Thompson, J. R., Bryant, B. R., Campbell, E. M., Craig, E. M., Hughes, C. M., Rotholz, D. A., et al. (2004). *Supports intensity scale. Users manual*. Washington, DC: American Association on Mental Retardation.
- Thompson, J. R., Bradley, V., Buntinx, W. H. E., Schalock, R. L., Shogren, K. A., Snell, M., et al. (2009). Conceptualizing supports and the support needs of people with intellectual disabilities. *Intellectual and Developmental Disabilities*, 47, 135–146.
- United Nations. (2006). *Convention on the rights of persons with disability*. Retrieved on June 21, 2010, from United Nations website <http://www.un.org/disabilities>
- Van Loon, J. (2008). Aligning QOL domains and indicators to SIS data. In R. L. Schalock, J. R. Thompson & M. J. Tasse (Eds.), *Supports intensity scale companion guide: A resource for SIS users* (pp. 80–87). Washington, DC: American Association on Intellectual and Developmental Disabilities.
- Van Loon, J., van Hove, G., Claes, C., & Schalock, R. L. (in press). The supports intensity scale and its use. *Exceptionality*.
- Verdugo, M. A., Schalock, R. L., Keith, K. D., & Stancliffe, R. J. (2005). Quality of life and its measurement: Important principles and guidelines. *Journal of Intellectual Disability Research*, 49, 707–717.
- Wang, M., Schalock, R. L., Verdugo, M. A., & Jenaro, C. (2010). Analyzing the factor structure and hierarchical nature of the quality of life construct. *American Journal on Intellectual and Developmental Disabilities*, 115, 218–233.
- Wehmeyer, M. L., Buntinx, W. H. E., Lachapelle, Y., Luckasson, R. A., Schalock, R. L., Verdugo, M. A., et al. (2008). The intellectual disability construct and its relation to human functioning. *Intellectual and Developmental Disabilities*, 46, 311–318.
- WHO. (2003). *ICF Checklist. Version 2.1a*. Retrieved on June 21, 2010, from <http://www.who.int/classifications/icf/training/icfchecklist.pdf>
- WHO ICF-CY Work Group. (2003). *ICF CY Checklist, version 1.B, 3–6 years (for research purpose only)*. Retrieved on June 21, 2010, from [http://www.ccoms-fci-cif.fr/ccoms/pagint/PDF/ICF\\_CY\\_Checklist\\_3-6\\_years.pdf](http://www.ccoms-fci-cif.fr/ccoms/pagint/PDF/ICF_CY_Checklist_3-6_years.pdf)
- Wile, D. (1996). Why does do. *Performance and Instruction*, 35, 30–35.
- World Health Organization. (1980). *The international classification of impairment, disability and handicap*. Geneva: Author.
- World Health Organization. (1993a). *WHOQOL study protocol*. Geneva: Author.
- World Health Organization. (1993b). *International statistical classification of diseases and related health problems (10th ed.)*. Geneva: Author.
- World Health Organization. (1997). *Measuring quality of life*. Geneva: Author.
- World Health Organization. (2001). *International classification of functioning, disability and health*. Geneva: Author.
- World Health Organization. (2007). *International classification of functioning, disability and health: Children & youth version*. Geneva: Author.