

CLINICAL COMMENTARY

## Measuring participation of children with disabilities: Issues and challenges

WENDY COSTER & MARY ALUNKAL KHETANI

*Boston University, Sargent College of Health and Rehabilitation Sciences, Boston, MA, USA*

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### Abstract

*Purpose.* The aim of this paper is to examine conceptual issues that challenge development of valid and useful measures of children's participation.

*Method.* Ambiguities in the current definition of participation in the International Classification of Functioning, Disability and Health (ICF) are examined along with their implications for developing valid measures for children and youth.

*Results.* Developers of new measures must address three key issues that will affect the ultimate meaning of participation data obtained from these instruments: uncertain criteria to distinguish activity from participation; lack of consensus on whether measures should address objective or subjective aspects of participation or both; and appropriate choice of respondent when children are the focus. Variations in how the participation construct is operationalized challenge one's ability to develop a coherent body of knowledge about children's participation and the factors that influence it.

*Conclusion.* Given current variations in how participation is being defined, both developers and users of measures of participation need to be explicit about the definition of participation that a particular measure represents and the inferences that can be drawn from the scores.

**Keywords:** *Child disability, participation, measurement*

### Introduction

The introduction of the International Classification of Functioning, Disability and Health (ICF) [1] in 2001 provided a common framework and terminology to describe health and disability for practitioners, researchers and consumers of health-related services. This new system is a significant step forward from earlier classification systems in its use of positive terminology, identification of bidirectional influences between elements and recognition of the important role of the environment in the enablement/disablement process. However, both the authors of the ICF and subsequent reviews in the literature have acknowledged that there are areas that will need further work and revision in the future [2,3]. One recently completed refinement is the creation of a version for children and youth (ICF-CY) to address unique concerns related to the developing child such as age-related changes in functional skills, activities, participation and environment [4]. Other issues

receiving attention are examination of the match between current measurement tools and the ICF codes [5–7] and the need for new measures designed to be congruent with the dimensions and definitions of the ICF framework. Such measures would help facilitate implementation of ICF coding and are needed for research to test proposed relations among the elements of the framework and hypothesized pathways to health and disability across populations.

One critical element of the ICF acknowledged to be in need of better measures is the dimension of participation, particularly for children and youth [8–10]. Although participation has been identified as the overall outcome of greatest importance to children and their families, reviews have noted the paucity of appropriate measures of this dimension for this age group. Existing measures have limitations in content, feasibility or breadth that limit their application across diverse populations and research contexts [10,11]. As noted by McConachie et al. [9], in order for measurement to advance further conceptual work

is needed to clarify the meaning of the participation construct and the ways in which it can and should be operationalized. The purpose of this paper is to extend this discussion through an examination of several key issues regarding the definition of participation. Careful consideration of these issues by instrument developers and researchers will help guide instrument development and clinical research related to this construct. This study does not propose to offer definitive answers to these questions, but rather to encourage more dialogue about the issues. Although the specific interest is how these issues relate to measurement for children and youth, it is believed that most apply to measurement of adults as well.

### Participation as an element of the ICF

The ICF defines participation as ‘a person’s involvement in a life situation’ ([1], p. 213). This definition further stipulates that the construct represents the societal perspective of functioning. The presence of a restriction in participation is determined by comparing an individual’s participation profile to ‘that which is expected of an individual without disability in that culture or society’ ([1], p. 213). Elsewhere, further clarification indicates that the definition of participation includes the concept of involvement, which may further be defined as ‘taking part, being included or engaged in an area of life, being accepted or having access to needed resources’ ([1] p. 15). The authors add that ‘the concept of involvement should also be distinguished from the subjective experience of involvement (the sense of belonging)<sup>1</sup>. Although participation is identified as a distinct construct, the current version of the ICF does not specify unique content domains for this component of the classification system. The authors state that it was not possible to differentiate between the domains that represented individual (activity) and societal (participation) perspectives given international variations and varying professional approaches. Instead, a set of nine categories (chapters) is provided and users are given several options to differentiate activity and participation domains as suits their situation. These options vary in the degree of overlap in domains between the two dimensions. In addition, like the activity dimension, participation can be defined either as *capacity* (performance in a standard environment) or *performance* (what the person does in his or her current environment). Each of these qualifiers can, in turn, be applied either with or without assistive devices or personal assistance.

### Unresolved issues in measuring participation

The current version of the ICF has left the definitions of activity and participation open to a

variety of interpretations. This approach has the advantage of allowing maximum flexibility for application of the ICF for various purposes. However, the absence of clear definitions for these two constructs creates a dilemma for measurement. Measures that operationalize the various components of the ICF are a critical element of investigations designed to advance understanding of these phenomena in various populations and to test hypotheses about the relations between body function/body structure, activity, participation and environment. In the absence of clear definitions, different instruments may be developed that identify themselves as measures of activity or participation while actually embodying quite distinct definitions of these constructs.

Clear definition of the construct of interest is fundamental for validity, which in turn is the ultimate criterion for meaningful use of measures. A clear definition is necessary in order to create items that are consistent with the construct, that primarily reflect the construct of interest and not others, that reflect distinct aspects of the construct rather than aspects of each other and that can be ordered to represent different degrees of the underlying dimension. The definition of the construct also guides the selection of an appropriate scale with which to measure variations among individuals. These criteria of measurement must be met to ensure that one can draw valid inferences about what the scores (data) from the instrument mean.

There are three major issues that both developers and users of instruments must address regarding the definition of participation. This paper presents these as a set of questions to emphasize that the response of the individual instrument developer to each of these situations will determine the ultimate meaning of data derived from their measure.

- What is the distinction between activity and participation?
- Should measures of participation focus on objective indicators, subjective experience or both?
- Whose perspective should be measured?

The remainder of this paper examines each of these decisions and their potential impact on measurement of participation.

### The distinction between activity and participation

The definition of participation rests on the meaning of the term ‘life situation’, since it is engagement in these types of life contexts that the construct represents. In contrast, activity is defined as execution

of a specific task or action. However, the ICF does not offer any criteria with which to define life situations or to distinguish them from tasks except for a few statements indicating that life situations represent the interface of the person with the larger society. The complete absence of definitional criteria leaves this key element of the participation construct open to such a wide range of interpretation that the usefulness of the construct itself may be undermined. The specific life situations that are most relevant for children and youth will likely vary internationally. However, agreement on a common set of defining *criteria* would be a great advance in the field.

The domains defined by the nine activity and participation chapters of the current ICF appear to represent a combination of *means* that support or enable participation in a variety of culturally meaningful contexts (learning and applying knowledge, general tasks and demands, communication, mobility) and structured, culturally meaningful sets of daily life activities (self-care, domestic life, interpersonal interactions, major life areas, community, social and civic life). Therefore, participation measures whose items include content from the first four domains along with some from the last five have a potential problem in that one set of 'life situations' (e.g. mobility) may be embedded in or influencing the others (e.g. community, social and civic life). This potential dependence complicates interpretation of a profile of participation derived from scales constructed directly from the nine ICF chapters because the meaningfulness of relative differences in participation across domains will be unclear. The distinction between these chapters seems to be the implicit rationale behind the first alternative presented in the ICF manual for structuring the relationship between activity and participation. This option proposes that the first four domains be identified as activity domains and the last five as participation domains. However, as will be discussed in the next section, this alternative does not offer a complete solution to this definitional dilemma.

### **Alternative approaches to clarifying the domain of participation**

Given the challenges associated with using existing ICF chapters to define participation, several alternative guidelines have been considered. One potential solution to the dilemma of domain definition is to create measures of participation that are specific to one particular sphere of daily life. For example, the newly published *Children's Assessment of Participation and Enjoyment* (CAPE) [12] was designed to capture children's participation in formal and informal leisure and recreation. The authors of the CAPE

have adopted the terminology and general definition of participation from the ICF but not the specific contents of any single domain. The participation scale of the *School Function Assessment* [13] adopts a similar approach using the ICF terminology and general definition, but defining a set of situations that are specific to the elementary school environment. These kinds of measures may have great utility for clinical or research purposes that focus on the specific life areas that the measures capture. However, they do not resolve the dilemma of how to obtain a more comprehensive profile of a person's participation across life situations as might be desirable for a population survey.

Alternatively, McConachie et al. [9] recently proposed that life situations could be organized around several key themes that would yield a meaningful profile of participation. They identified four important themes to define types of life situations that are important for children's well-being: those essential for survival, those that support child development, discretionary and educational situations. However, the authors do not explore in detail the extent to which the structure of the ICF domains directly maps onto this set of themes and their review of existing instruments uses the existing ICF chapter structure as a guide. As another example, Dunst et al. [14] and Wilson et al. [15], drawing on data from a population survey, proposed a potential set of life situations that are relevant for very young children across home, school and community activity settings.

Some discussions of participation, for example Wade and Halligan [3], have linked the construct with that of social roles and suggested that life situations might be defined in this way. However, adopting the role construct does not resolve the definitional dilemma. Differences in theoretical orientation to the concept of social role have led to variable propositions about its key characteristics. While there is general agreement that social expectations provide important clues about how roles are generated and then learned through an individual's experience, the different schools of thought place varying degrees of emphasis on conformity to a broad, static and uniform set of expectations [16]. There is no agreed upon list of social roles and this is particularly true for children and youth. In addition, while there are some life areas that have clearly defined social expectations associated with them (e.g. student), it is not clear that all important life situations included within the ICF can be categorized under a specific role. There are important daily life situations and activities, such as play, self-care, home-related tasks and recreational pursuits that are not readily identified as components of a particular role. Thus, these domains might be excluded from

examination by a measure organized around role performance.

Many of the life situations often referred to as roles, such as student or family member, actually encompass a variety of situations across which participation (defined as involvement or engagement) could vary significantly. Thus, being a student may encompass participation in the classroom learning environment as well as participation in a variety of social, recreational and non-classroom based learning experiences. Thus, although a broad role might provide a starting point for measurement, there remains a need to define which specific situations or experiences should be sampled to obtain an overall assessment of participation.

Discussions of a child or youth's participation in the context of social roles often emphasize *role performance*. This, in turn, implies meeting normative expectations and behaviour that conforms to cultural, familial or setting-specific standards. However, this dimension does not have the same meaning as the ICF term *involvement*, which implies engagement, taking part and access rather than conformity to a particular social norm. Role theory has been criticized [17] because it emphasizes conformity to prescribed role definitions and does not sufficiently acknowledge the diversity of ways in which persons accomplish their goals and participate in society across the life span. As an example, women with physical disabilities adapt to and change their environments and expectations to redefine rather than conform to normative expectations of motherhood [18–20]. The authors have not identified any studies examining the extent to which this process of redefining social roles might be similar for children with disabilities.

Clear criteria to define life situations are critical to the task of developing measures of participation. Without some consensus on essential definitions, the field may see a proliferation of measures whose content overlaps imperfectly, if at all, and whose items address 'engagement' at very different levels of analysis. This source of confusion will hamper one's ability to synthesize findings across studies and it will limit the extent to which one can compare outcomes for groups assessed using different instruments.

### **Distinguishing tasks and life situations**

Lack of clarity about the definition of life situations is a major source of ambiguity about the boundaries between activity and participation. Although the definition of activity appears quite specific (i.e. execution of a task or action), it is not clear at what point a 'task' becomes a 'life situation'. One criterion that instrument developers could apply is to use the broader categories in each chapter to identify life

situations and the discrete sub-categories to represent the activity level. This is the second of four options offered in the ICF Manual ([1], p. 236). However, this option is problematic when applied uniformly to organize content across all nine chapters of the ICF. The domain of self-care provides a useful illustration of this dilemma.

In Chapter 5 of the ICF, the first level classification includes d510: Dressing, under which are five sub-categories that address specific aspects of dressing such as putting on clothes. Thus, in this chapter the distinction between life situation (dressing) and task (putting on clothes) appears to be clear and logical. If one attempts to apply this approach to other chapters, however, questions arise. For example, one of the first order categories in Chapter 2 is d210: Undertaking a single task. The sub-categories address simple vs complex tasks and tasks undertaken independently vs those undertaken in a group. If 'undertaking a single task' constitutes a life situation in the same way that dressing does, then it should be possible to write a definition of life situation that readily encompasses both of these examples. However, given that getting dressed might easily be described as undertaking a single task, this may not be possible. Alternatively, getting dressed might also be described as completing a series of single tasks, such as putting on a shirt. The ambiguity illustrated by this example can also be seen in McConachie et al.'s [9] review of existing participation instruments. In their comparison among instruments, the item 'brushing your teeth' (from the CAPE) is given as an example of content addressing Chapter 2 (General Tasks and Demands), whereas 'I put on my shirt by myself' (from the ASKp) is given as an example for Chapter 5 (Self-care).

Whiteneck [21] has proposed a series of characteristics that may help differentiate activity and participation. One characteristic is complexity: participation is a more complex process than activity performance. This suggests that participation would involve the orchestration of multiple activities; however, it leaves unanswered at what point the complexity reaches the distinction of defining a 'life situation'. Thus, one still would need criteria to determine whether brushing one's teeth should be classified as a life situation or as an activity. Whiteneck also proposes that participation is more likely to involve other people and to be more environmentally dependent. However, this distinction may not be helpful for children because they are typically engaged with others (caregivers) when performing daily activities and are often supported in their activity performance by environmental adaptations and supports (for example, seating supports or child-sized utensils). One additional

potential distinction is that in the current state of knowledge it is not always possible to eliminate problems in activity performance, but that theoretically it should be possible to eliminate most restrictions that prevent meaningful participation in family and community life. This distinction implies that participation may be achieved through multiple methods and that any measure of this outcome must be able to accommodate that diversity.

### **The complexity of life situations: Spatial and temporal considerations**

Of the options considered above, the characteristic of complexity offers the clearest direction for how to distinguish the dimensions of activity and participation, although further specification would be needed. Two potential aspects of complexity to consider are the temporal and spatial dimensions of daily life. Much of daily life is structured into sequences of activities that serve a common purpose, i.e. routines. Although the specific sequences may be highly individualized, the overall purpose tends to have societal or cultural importance. Thus, families have routines for mealtimes, special events or socializing. Research suggests that families identify these situations as important ones for the child's learning [14,22]. One way to describe participation is the extent to which the child actively engages or takes part in these common routines along with the other members of his or her family or community.

Many routines are also associated with specific settings such as the home, school and community, or even with specific areas within these settings. Thus, there is a spatial dimension to participation, which becomes quite clear when a person cannot participate because he or she cannot access the setting in which the event or experience takes place. Activities—the elements of participation—often can be performed in a variety of settings (e.g. clinic or home); however, participation as defined by the ICF implies a typical or accepted setting. Thus, a child can run and kick a ball in a great number of places, however he or she can participate in playing soccer only when there are willing playmates and an accessible space in which to do so.

### **A working definition of participation**

As an initial step toward a clearer definition, it is proposed that life situations are characterized by sets of organized sequences of activities directed toward a personally or socially meaningful goal. These goals are setting-specific and include sustenance and physical health, development of skills and capacities and enjoyment and emotional well-being. Some life situations may also form units that are part of larger

and more complex life situations, such as when dressing becomes part of play (dressing in costumes) or school routines (dressing to go outdoors as a component of participating in recess). Accordingly, activities are the units from which such sequences may be constructed. They include both simple functional actions (putting toothpaste on a toothbrush; buttoning a shirt; scooping food on to a spoon) and short sequences of functional actions with a common goal (e.g. brushing one's teeth; putting on a shirt; eating a sandwich). Participation reflects the extent of engagement in the full range of activities that accomplish a larger goal (caring for one's hygiene; clothing oneself; dining with family). Figure 1 illustrates these relationships.

### **Relevant dimensions of participation**

The ICF makes a distinction between the objective and subjective aspects of participation but, as noted earlier, specifically limits its definition of the construct to the first of these. The objective aspect is that which can be observed: whether a child can access a setting or whether he or she regularly takes part in or is included in the routine social activities in that setting. As noted earlier, the description of 'restriction in participation' makes clear that some comparison to a normative standard should be the basis of the measurement for this aspect. Both Forsythe and Jarvis [23] and Colver [24] have supported this viewpoint, arguing that this focus is necessary in order to be able to compare the objective circumstances of different groups. Objective indicators of participation can help identify areas of discrepancy or limitation, for example to guide policies concerning universal design, access to relevant community resources and eligibility for support services.

The ICF identifies the subjective aspects of participation as including a sense of belonging or satisfaction with the extent of one's involvement. Subjective aspects are related to the meaning and importance the individual may attach to particular life situations and the relative importance of participating in them. A number of authors in the field have argued strongly against exclusion of the subjective component from the ICF model. Their position is that the subjective aspect of participation is crucial for understanding the person's situation [3,25–27] and must also be a focus of measurement.

Reliance on observations as indicators of participation has been criticized as based on a false assumption that what is observed reflects the person's actual experience [26]. Thus, it is argued, a person may look uninvolved to an observer but may experience him- or herself as very involved in a situation. For example, children often participate in family social events by observing and listening while

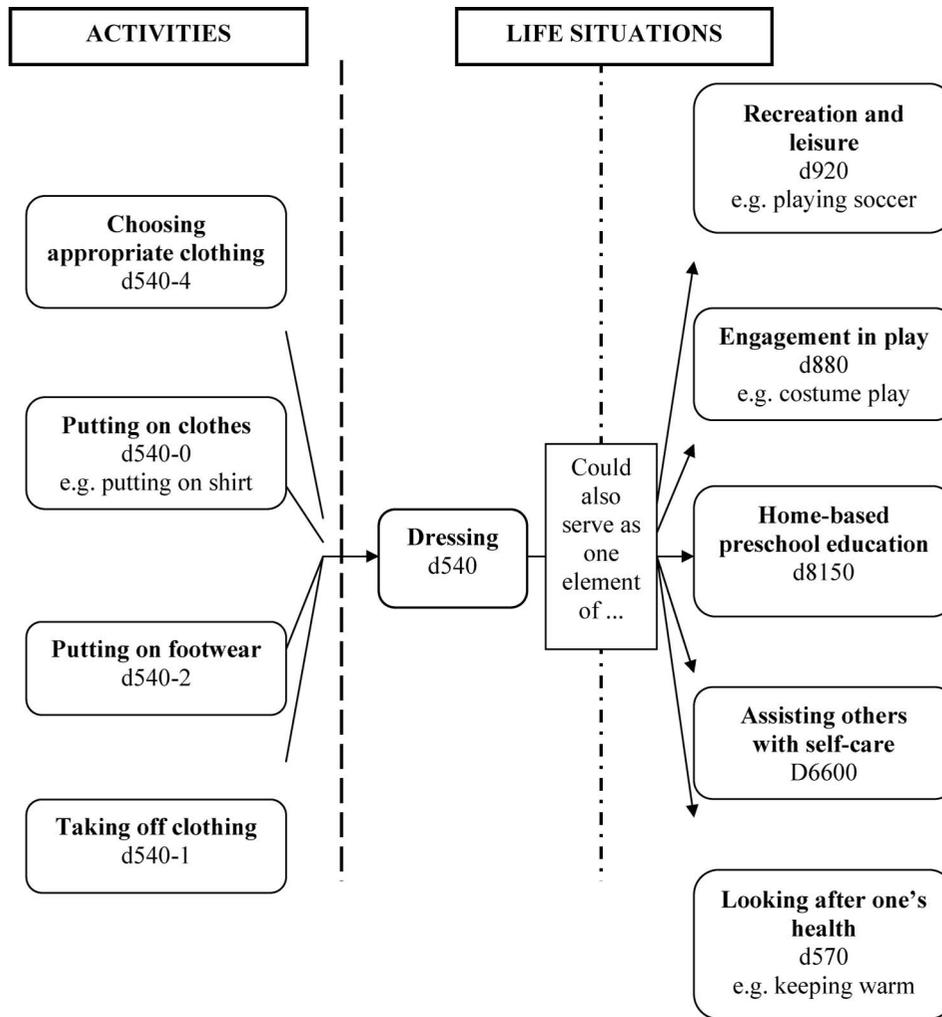


Figure 1. Discriminating activity and participation using the ICF: an example.

the older family members interact. It is unclear whether this behaviour meets the objective criteria for participation. If so, then it should be possible to write an operational definition of participation in this context, including which observed behaviours should be considered as indicators of participation and which would not be relevant.

A second concern raised by critics is that reliance on observed behaviour does not allow for differences in the meaning or importance of participation to a particular individual. Thus, although a measure of objective indicators of participation may highlight areas of more limited participation, it provides no indication of the extent to which these limitations are perceived to be important from the perspective of the person. For example, it would be difficult to evaluate whether or not an adolescent girl has participation restrictions if she holds a part-time job in lieu of involvement in other after-school activities without gathering information from the adolescent about how that choice was made. This limitation of objective measures may not be a major concern for

inquiries that are directed primarily to documenting the extent of objective participation across different groups of children and youth with disabilities, for example population studies to examine access issues. However, it presents a problem for research directed to understanding the pathways to participation because it does not acknowledge the extent to which individual choice and meaning may affect patterns of participation and their subsequent impact. For example, the impact of participation on perceived quality of life may have much to do with whether and how the person is participating in the life situations that *matter most* to him or her.

Some authors have argued that the subjective experience of participation is covered sufficiently by the construct of 'quality of life' since it addresses questions of personal satisfaction [23,24]. However, existing measures of quality of life do not focus consistently on this aspect of the person's experience and they often contain items that the ICF classifies as body function or activity performance [6,10]. In their review of activity and participation measures for

children and youth, Morris et al. [10] noted that quality of life has emerged as a 'catch all' expression and has been measured inconsistently due to differences in conceptualization. Thus, as currently operationalized, measures of quality of life may not provide an appropriate means to address the subjective experience of participation in research where separate indicators are desirable.

To the extent that measures of objective and subjective aspects of participation may contribute important, although different, information, it is proposed that for the time being both dimensions should be considered as potentially appropriate bases for instrument development. It is recognized that this decision would represent a departure from the current ICF definitions; however, at present there is no alternative term to apply to the subjective or 'experienced' aspects of participation. The recently-developed Community Participation Index [28] for adults has taken this approach based in part on the input from constituents with disabilities. The most important point is that instrument developers must make clear which dimension is being addressed in their measure (or sub-scale of the measure) and only draw inferences from the measure that are appropriate for the specific definition that it embodies. In particular, data captured using an objective measure should not be used to draw inferences about relative importance of participation patterns or their meaning to individuals or groups without corroborating support from other subjective indicators.

### Selecting measurement scales

Regardless of whether an objective or subjective perspective is adopted, a key component of the final operational definition of participation will be the dimension that is selected to measure variations across persons. There are many options, each of which presents challenges. If objective measures are intended to examine the extent to which normative expectations are met, the developer must determine how this will be expressed. This decision may depend to a large extent on how the relevant life situations were defined initially and which situations are included on a given measure. For example, if the definition focuses on routines that are a recognized part of daily life in a given culture, it may be possible to ask whether this child participates in those routines to the same degree as other children in the neighbourhood. This measurement approach worked well for the participation scale of the *School Function Assessment* [13] because elementary schools have well-established routines and teachers (the respondents) observe the participation of students in their classroom on a daily basis. Even so, there was still a need to carefully define meaningful

degrees of variation from 'full participation' to achieve a reliable and interpretable scale. It remains to be seen whether a similar approach will work in other situations.

Some measures of community participation have used frequency or quantity indicators for some items such as 'how many times a week do you visit friends?' The major criticism of this metric is that it equates quantity with quality [29]. In a number of situations there may be no clear normative standard of quantity or frequency or variations may be affected by contextual factors not related to disability such as geographical location [30]. For example, the number of visits to friends may be different depending on whether one lives in a rural or urban environment. On the other hand, some questions may lend themselves to this concrete response format, particularly those that are focused on access such as 'Does the child attend a general education (mainstream) classroom?' or 'Does the child participate in any organized after school activity groups along with his or her peers?' [31,32]. One challenge that will need to be addressed when using concrete indicators is that, although individual items may have clear meaning, it is not always certain that data from multiple items of this type can be aggregated into an interpretable summary score.

As soon as questions about participation move beyond the concrete question of access, the distinction between subjective and objective aspects begin to blur. Potential item formats such as 'How much is your child currently limited in his or her participation in self-care?' or 'Do you participate in classroom activities as much as you would like to?' introduce a more subjective element of definition. For example, it is not clear that 'somewhat limited' will have the same meaning to all parents or that the child's stated preference is the best standard for measuring classroom engagement. An even clearer subjective approach specifically addresses the extent to which the person is able to exercise choice and self-directedness in his or her participation [33].

One additional element of definition for the measurement scale is whether the response should reflect the standard environment of capacity or the usual environment of performance. Whiteneck [21] and others have argued that participation ought to be measured in the person's community and, in general, it can be difficult to identify a standard environment for most life situations. (Public schools may be one prominent exception.) However, the usual environment of performance for children both with and without disabilities often incorporates aids, caregiver assistance and environmental modifications. Should use of these supports affect the rating of participation? The LIFE-H provides a separate rating system to record aids and assistance, however these

elements also affect the final rating of accomplishment of life habits [34]. Thus, performance without difficulty but with the use of an aid or assistance receives a less-optimal score than performance without the use of supports. One could argue that this approach blends information about environment and participation in the same measure and makes it difficult to determine the impact of context on participation. This would clearly be a disadvantage for researchers who want to investigate this question; however, the blended scale may provide useful description information in other contexts.

### **Selection of respondents**

Decisions about whether to adopt a subjective or objective definition of participation also have implications about who should provide the relevant information for a measure. Whiteneck [21] proposed that the self or someone close enough to the person to serve as proxy is the most appropriate respondent to questions about participation. This argument is most valid if the subjective aspects of participation are the primary focus of a measure. On the other hand, if a measure adopts the objective perspective, then a number of observers such as a parent, practitioner or teacher may also be able to provide the relevant information.

### **Purpose guides the choice of respondent**

A case can be made that the appropriate respondent will vary according to the measure's explicit purpose. If the purpose of the measure is to obtain information about the child's own experience of engagement in meaningful life situations, for example to determine the extent to which a society has fulfilled its commitment to this goal, then the child needs to be the respondent. Similarly, if the measure was designed to support client-centred programme development, then the child's perspective is also critical. On the other hand, in some situations, the perspectives of others may be very relevant when gathered in conjunction with the client's self-report. This may especially be the case for parents and teachers who are charged with overseeing and supporting the child's achievement of culturally meaningful participation.

### **Developmental considerations**

The decision about how best to obtain information about the participation of children and youth is especially complex for a number of reasons. For the very youngest children participation is embedded within the family and it may not be possible to address the child's participation as a separate

phenomenon. As McConachie et al. [9] have suggested, participation during infancy and early childhood may be best assessed in relation to the family experience as a whole. Research evidence also suggests that children are not reliable self-reporters about their engagement in activity, especially on a comparative basis, until around age 8 or 9 [35]. For questions about the most concrete daily life situations and with the support of visual aids such as pictures, some younger children may be able to answer a more limited set of questions [36]. However, a broad perspective on participation (e.g. sufficient to create a profile) may be difficult to obtain until around the age of 8.

### **Family and child involvement in the design of new measures**

A number of authors have proposed that the perspectives of young people and their families should also be elicited to help define the important life situations to be included on a measure of participation. The authors agree that such an approach is consistent with the general view that participation should capture what is meaningful in people's daily lives. They would propose two caveats, however. First, when using the information obtained from these groups to develop measures, the items and scales must be constructed following a consistent set of guidelines, as discussed earlier. Otherwise, although the items may be grounded in child and family data, they may not yield an internally consistent scale that provides meaningful summary scores. As noted previously, meaningful summary scores will be crucial to support further research to understand pathways to more or less successful participation.

One also needs to include a broader representation of children with disabilities in work to develop new measures. To date almost all of the discussion of participation in the literature has focused on children with physical disabilities [9,10,37]. Focus groups with families have concentrated on this population with very limited investigation of the perceptions, needs and concerns related to participation of families of children experiencing limitations due to cognitive, emotional or behavioural conditions. Other literature indicates that these children also experience significant restrictions in daily life activities at home, at school and in the community [31,38,39]. In fact, one study reported that children with mental health problems had worse quality of life than a comparison group of children with mobility limitations [40]. In future work, it will be extremely important to recognize the true diversity of the population of children with disabilities so that the perspectives of all relevant segments are obtained during the development of new instruments.

### Ensuring psychometric soundness in measures of participation

This paper has focused on issues that are central to the issue of validity, that is to ensuring that one knows what the data yielded by a measure actually mean. As noted at several points, validity can only be discussed in relation to a particular purpose: what is appropriate for one purpose may not work for another purpose. Thus, a measure that works well for a population survey may not work at all for individual problem identification and programme development. Furthermore, the instrument development research necessary to determine the psychometric properties of the instrument will also vary with the intended purpose.

To date there has been limited application of newer instrument development methods such as item response theory (IRT) approaches to this area. Application of these methods would provide clearer evidence on whether the items on a given scale appear to be measuring a single common underlying dimension, whether they reflect distinct aspects of the construct rather than aspects of each other and whether the items can be ordered to represent different degrees of challenge or accomplishment of engagement or participation.

Emerging applications of IRT such as computer adaptive testing (CAT) also have the potential to help resolve the conflict between needing a wide range of items to capture the diversity of relevant life situations while keeping an instrument to a feasible length. To implement CAT, a large pool of participation items would need to be created from which only those items relevant or appropriate to a given situation or person could be drawn. Recent reports of applications of CAT in other areas of rehabilitation [41,42] have demonstrated that these methods can yield short but precise measures.

More attention also needs to be paid to whether a particular instrument is suitable for measuring change (i.e. its responsiveness). In some situations one needs to describe a profile of participation at one point in time, whereas in others one is interested in whether the profile changes after a period of growth and development or intervention. The latter situation imposes additional demands on an instrument that must be carefully considered during its development. In particular, the scale must be able to discriminate degrees of change that are likely to occur over the period of time of interest and to identify the areas where change did and did not happen. If one wants to be able to show that services for children with disabilities and their families have significantly enhanced participation, then one will need to be sure that the measures used for this purpose are specifically designed to be responsive to change.

### Future directions

As health services providers and researchers become increasingly familiar with the ICF—and particularly as the ICF-CY becomes widely available—one expects to see continued efforts to refine understanding of participation and the host of child, family and environmental factors that support and inhibit it over time. Thus, one also expects to see further development of new measures that are well-designed to support this scope of work, particularly for children and youth. Based on the current discussion, this paper offers several proposals to enhance measurement of this important construct.

- (1) Identify a set of explicit criteria that will be used to define 'life situations' in a given instrument. The definition should be relevant to and consistent with the stated purpose of the instrument. The definitional criteria should ensure that all items generated by following these criteria are at the same level of complexity and that no items are potentially nested within others.
- (2) Provide definitions of the scale points that will be used for measurement that go beyond the basic structure and descriptive terms used in ICF coding (severe, moderate, etc.). Providing more detailed definitions would enhance reliability as well as clarify the meaning of the scores reported for an individual.
- (3) Apply newer instrument development methodologies such as item response theory (IRT) approaches to enhance the validity of measures. Application of these methods would provide users with evidence that the items represent a coherent dimension which, in turn, would assist in interpreting the meaning of scores derived from the measure. However, effective application of these methods will require resolving some of the questions raised in this paper so that there is a sound definition of the construct of participation to guide future efforts.

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