

CLINICAL COMMENTARY

Participation of disabled children: how should it be characterised and measured?

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Abstract

Purpose. The aim of the paper is to explore the issues involved in measuring children's participation.

Method. The concept of participation as encapsulated in the International Classification of Functioning, Disability and Health (ICF) is discussed as it applies to children. The essential components of any measure of children's participation are outlined, including participation essential for normal development and survival, leisure activities, and educational participation. Some existing instruments are briefly reviewed in terms of their coverage of the essential components and the adequacy of their approach to measurement.

Results. Key issues regarding the content of an adequate measure of participation include the need to consider the child's dependency on the family, and their changing abilities and autonomy as they grow older. Instruments may be most appropriate where they ask the child directly, implying use of visual as well as verbal presentation. Their focus should be on 'performance' such as whether and how often an activity is taken part in, and not incorporate degree of assistance within the measurement scaling.

Conclusions. Currently available measures of children's participation all have some limitations in terms of their applicability across impairment groupings, whether the child can directly respond, and in the ICF components covered. The feasibility of developing measurement instruments of children's participation at different ages is discussed.

Keywords: *Child disability, development, participation, activity*

Introduction

Disabled children have the same aspirations as all children, hoping for health, security, respect, opportunities to learn skills, meaningful occupation and the possibility of contributing to the lives of others. Therefore, it is incumbent upon society, including rehabilitation services, to work towards the real-life goals of young people, including having choices, developing relationships, and finding education and work; in other words: *Participation*. Disablement is in part manifest as restrictions in these major areas. Appropriate ways to measure participation as it applies to children are needed in order to understand the process of disablement and the developments needed in rehabilitation services. The aim of this paper is to explore the issues involved in measuring children's participation.

What is participation?

The International Classification of Functioning, Disability and Health (ICF) [1] is a classification of human functioning rather than of functional problems. The three levels in the ICF are body function and structure, performance of personal activities, and participation in communal life, as influenced by environmental factors and personal factors. It recognises that disability is a universal human experience and shifts the focus from cause to the impact it has on the lives of people in society. The ICF takes account of the social model of disability [2–4] which regards disability as a socially created problem and not as an attribute of an individual. For example, an adolescent boy using a self-propelling wheelchair in a well-adapted house might have full independence within the home but encounter serious

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difficulties in using public transport and local amenities (due to inadequately adapted paths, doorways and so on) and be excluded from school field trips because of insurance issues, thus affecting his independent participation in his community. The ICF has a universal focus and there are aspects of experience related to impairment, such as burden of medical care and increased anxiety about health status, which do not appear to be covered by it.

The ICF defines activity as 'execution of a task' and participation as 'involvement in life situations'. It does not limit the meaning of participation to the usual meaning in English of participating in something, often socially with others; life situations include basic activities such as eating, toileting, contemplation, and getting about, which are often undertaken alone and would not be regarded as social.

The main domains and sub-domains of Activities and Participation are shown in Figure 1. Some sub-domains have only an indirect relevance to children through their adult carers, for example acquiring a place to live (d610), or economic self sufficiency (d870). There are also important omissions relevant to childhood, and the recently published a version of the ICF for children and youth [5] has added sub-sub domains such as mouthing (d1200) and modified text descriptions of domains such as 'appropriate for age'.

It is important to be clear what participation is *not*. First, participation is not the environment around a person, even though it is influenced by this. The fact that there is a lift in the school, so the child can access the student common room, does not capture the experience of the time the child spends within the school (e.g., whether the child is actually doing the same things within the common room as the other students). Second, participation is not the person's quality of life. The WHO defines quality of life as the individual's subjective perception of their life [6]. Many measures of 'quality of life', however, capture a range of different concepts, some even assessing proxy quality of life which is a contradiction in terms. Also, previous reviews have pointed out that some instruments which measure objective phenomena are called quality of life instruments [7,8]. Third, participation is not a 'health utility' which rates health on a scale and applies a societal value. A measure such as the Health Utilities Index (HUI) [9] represents activity limitations and impairments of body functions and represents a health state within the individual; it does not take account of the interaction with the environment as required for participation.

It is also important to consider meaningful scaling of a measure of participation. The ICF classification supplements the activity and participation components with two qualifiers assessed on a five-point difficulty scale. The 'capacity' qualifier describes what an individual can do in a standardised environment.

The 'performance' qualifier describes what an individual does in their real lives, which is influenced by the environment and personal factors such as choice. Capacity relates to task execution, i.e., activity, and it is 'performance' in terms of frequency which is fundamental to the measurement of participation. Additional information (level of choice, enjoyment, assistance) is undoubtedly required in order to make meaningful interpretation of frequency differences. For example, if a child goes to the swimming pool, the number of times this happens is essential information; extra detail such as level of assistance required adds richness, but will not be a substitute for knowing how often the child participates in the first place.

There are a number of considerations specific to children that need to be appreciated before considering domains relevant to measuring participation.

The child within the family

Much of the lived experience of children is acquired in a family context such as leisure and shopping activities, visiting relatives and going on holiday. Thus the family is an important environmental factor interacting with the child; and conversely the child inevitably impacts on the participation of the other family members [10]. The difficulty in unravelling this interaction can be overcome by recognising that for some aspects and stages of childhood, participation is better assessed as it applies to the family. Another example of the blurring of parental and child participation is evident when we consider economic and social domains. Many families with a disabled child are impoverished by uncompensated extra costs and restricted employment opportunities [11]. This is exemplified by a comparison of community activity patterns between 2–5-year-old disabled and non-disabled children [12]. Though the study showed that the participation of children with and without disabilities was generally similar, most of the lower frequencies for disabled children's participation were in family oriented activities which depended on 'discretionary financial resources'. Therefore, where families of disabled children participate less, this may reflect indirect effects upon a family's financial resources rather than a direct impact of the child's impairment(s). In summary, it may not be practical to place a clear boundary around the child when describing their participation; survey instruments should encompass the notion that for some purposes the child participates as part of a family rather than as an individual.

The child's perspective

For most domains of participation, adjustments will be needed for children at different ages, both

Domains and sub domains	Additions for children and youth
d1. Learning and applying knowledge	
d110 Watching	d131 Learning through play
d115 Listening	d132 Acquiring information
d120 Other purposeful sensing	d133 Acquiring language
d140 Learning to read	d137 Acquiring concepts
d145 Learning to write	d161 Maintaining attention
d150 Learning to calculate (<i>arithmetic</i>)	
d175 Solving problems	
d2. General tasks and demands	
d210 Undertaking a single task	d235 Managing one's own behaviour
d220 Undertaking multiple tasks	
d3. communication	
d310 Communicating with – receiving – spoken messages	d331 Pre verbal communication
d315 Communicating with – receiving – non-verbal messages	d332 Singing
d330 Speaking	
d335 Producing non-verbal messages	
d350 Conversation	
d4. Mobility	d412 Spontaneous movement
d430 Lifting and carrying objects	
d440 Fine hand use (<i>picking up, grasping</i>)	
d450 Walking	
d465 Moving around using equipment (<i>wheelchair, skates, etc.</i>)	
d470 Using transportation (<i>car, bus, train, plane, etc.</i>)	
d475 Driving (<i>riding bicycle and motorbike, driving car, etc.</i>)	
d5. Self care	d565 Avoiding dangerous situations
d510 Washing oneself (<i>bathing, drying, washing hands, etc.</i>)	
d520 Caring for body parts (<i>brushing teeth, shaving, grooming, etc.</i>)	
d530 Toileting	
d540 Dressing	
d550 Eating	
d560 Drinking	
d570 Looking after one's health	
d6. Domestic life	
d610 Acquiring a place to live	
d620 Acquisition of goods and services (<i>shopping, etc.</i>)	
d630 Preparation of meals (<i>cooking etc.</i>)	
d640 Doing housework (<i>cleaning house, washing dishes laundry, ironing, etc.</i>)	
d660 Assisting others	
d7. Interpersonal interactions and relationships	
d710 Basic interpersonal interactions	
d720 Complex interpersonal interactions	
d730 Relating with strangers	
d740 Formal relationships	
d750 Informal social relationships	
d760 Family relationships	
d770 Intimate relationships	
d8. Major life areas	
d810 Informal education	d811 Engaging in play
d820 School education	
d830 Higher education	
d850 Remunerative employment	
d860 Basic economic transactions	
d870 Economic self-sufficiency	
d9. Community, social and civic life	
d910 Community Life	
d920 Recreation and leisure	
d930 Religion and spirituality	
d940 Human rights	
d950 Political life and citizenship	
Any other activity and participation	

Figure 1. Activity and participation in the ICF.

chronological and developmental. In particular the dependency of the child on their parents will change in quantity and quality as the child grows older, and special consideration needs to be given to the

adolescent years. Measuring instruments need to be well-founded within an 'ecological inventory' of what young people in that community do and value [13]. Furthermore, young disabled people may have

different perspectives from the mainstream population of young people, and from social planners, so capturing their experiences is fundamental to the development of any measure of participation.

In principle it is preferable to assess participation through child self-report or direct observation [10]. However, this raises the issue of developing age-appropriate questionnaires, in terms of both the items assessed and the method of response. For disabled children there can be added complexities due to impairments such as manual dexterity, communication difficulties, sight and hearing problems and learning difficulties affecting self-report. Where proxy measures are used it is important to choose appropriately. For example, teachers may be required to report school-based participation where children cannot, because parents may have little direct experience of their child's educational transactions.

General applicability

The ICF specifically endorses the principle that participation applies to all people regardless of age and culture. There is no justification, then, to measure aspects of participation intended solely for disabled children. However measurement applicable to children with a variety of impairments will necessarily include items more difficult for some than others, and the measurement of change may require greater detail in some domains. Although the dimensions themselves should not be different, different approaches may be needed to avoid 'floor and ceiling' effects. Furthermore, the field testing with adults of the ICF showed both differences and commonalities in the way disability issues are construed across the world, with recognition of a core set of human activities [14]. However, the study also concluded that measurement in different cultural settings would require sensitivity to differences in social attitudes and stigmatising values.

To sum up, the ICF provides a framework for defining a set of participatory domains which in general would be regarded as desirable, and in particular to which governmental resources might be directed. This does not mean that every child would necessarily want or be able to participate in all these but, from a population perspective, an instrument should be able to determine the extent to which children do so. When an instrument is intended for measurement with individuals, perhaps to assess the effect of clinical interventions, then it may be appropriate for a child to choose the domains most relevant to him or her at different ages and stages. It would certainly be appropriate to introduce scales of measurement that capture whether the child enjoys or feels in control of certain life situations. We propose that a hierarchy of more or less important children's activities and life

situations can be developed around several themes to create a profile of participation.

Which life situations should be covered by a measure of participation?

Participation essential for survival

These are the domains of daily living which 'must inevitably be accomplished as they are related to an individual's survival' [15]. The most essential are eating, excreting, basic hygiene and sleeping. At any age and with all impairments, these will always be achieved and the issue is to what extent they are achieved independently and in a manner which is satisfactory for the child. It could be argued that such activities should not be included in an instrument to measure participation because how these life survival situations are accomplished does not necessarily restrict appropriate engagement with a wider environment and with other people. However, we suggest it is illogical to exclude such important life situations from a participation instrument.

Participation in relation to child development

There are at least three aspects of activity and participation which are essential for normal development. The first is social interaction which assists the child's development [16]. The second is the opportunity for play and exploration; spontaneous exploration of the child's environment is highly desirable [17]. The third is mobility; however, there is a distinction to be drawn between being transported by others and self-directed mobility. Apart from being fundamental to wider participation, self-directed mobility is necessary for the child's neurological development in terms of visual perception and spatial orientation [18].

One example of an approach to measurement focussed on development is Dunst et al.'s [19,20] Family Life Survey and Community Life Survey. They made an extensive review of literature in order to select 50 family and 50 community-based activities having 'development instigating or enhancing features' for children less than 6 years old.

Discretionary participation

Discretionary situations are those not essential to life but represent what children can choose to do, rather than being required of them by families and society. Whether children are able to achieve participation successfully may be mediated by the availability of appropriate assistive technology, environmental modification or personal assistance, and therefore it is particularly for discretionary participation that it

may be relevant also to indicate degree of assistance and choice. Inventories of spontaneous choices of leisure activity made by their local peers can offer a route to quantify such discretionary participation.

Educational participation

In most cultures, education is a life situation which is neither strictly necessary for survival nor discretionary. A large proportion of waking time is spent in school and the key setting in which children gain much of their life experiences and skills. Compared to a mainstream school, a special school may be smaller, more distant from the child's home, cater for selected types of pupil and have different facilities; and these differences may determine many of the child's life experiences. Determining the aspects of educational participation that are more or less valuable to a child's progress requires detailed qualitative analysis [21].

How well do existing instruments satisfy the requirements we have proposed?

As participation is a relatively new concept, there are few instruments developed specifically to assess it. A number of instruments however capture some aspects of the concept and this paper will further explore five measures of participation appropriate to children, summarised in Table I in terms of their correspondence with ICF domains. The choice of instruments is not intended to be comprehensive. We have excluded instruments that predominantly assess activity-level indicators or subjective perception of 'quality of life' or which need to be administered by a trained assessor.

The LIFE-H was originally developed in consultation with a group of rehabilitation experts specifically to evaluate aspects of social participation and satisfaction of disabled adults, without taking the type of impairment into account. It was then modified for 5–13-year-olds by retaining the items pertinent to children's lives. The LIFE-H includes all nine domains mentioned in the ICF as it was strongly influenced by the Disability Creation Process [22], which itself influenced the ICF. Within the domains, non-discretionary and discretionary participation situations are represented. In the instrument, it is established whether participation occurs and then some assessment of its quality by rating the degree of difficulty and the type of assistance required for the accomplishment of each participation item. The LIFE-H also includes a second scale evaluating the individual's satisfaction in relation to his/her degree of accomplishment of each participation item. The LIFE-H does not have specific items related to child development issues

although one response option is 'not applicable' for which the reason can be the child's age. The LIFE-H has demonstrated inter-rater reliability between children and parents' reports [23], and convergent validity using other measures of disability in adult populations [24].

The Lifestyle Assessment Questionnaire (LAQ-CP) [25,26] was developed to measure 'handicap' in children with cerebral palsy and their families, which the authors later mapped onto participation domains. It was based on items from observational studies of children with physical impairments [27], and later refined by statistical item reduction to a number of domains and then by panel weightings to generate a single score [28]. The LAQ-G was subsequently developed by the same group. This is a generic measure of the impact of childhood disability, defined as a 'restriction in participation experienced by child or family as a result of a child's health condition or impairment' [26]. It covers a restricted set of ICF domains, in part because the questionnaire was developed for 5–7-year-olds. The LAQ-G scales have Cronbach α values of 0.66 or higher. Field testing has shown that the LAQ-G discriminates between children with and without impairments, is stable over time and has acceptable levels of inter-rater reliability [26].

The CASP [29] is a brief instrument using items developed from life domains identified from the literature, the ICF, and consumers and professionals as relevant to home, school and community life for children and young people with and without acquired brain injuries. Scores are standardised with higher scores indicating higher age-expected participation. It is designed for children aged 3 years upwards. The CASP has a high test-retest intra-class correlation (0.90, $n=33$) and high internal consistency (Cronbach $\alpha=0.98$). Preliminary results from Factor and Rasch analyses suggest the CASP functions as a unidimensional scale [30].

The ASK measures the frequency of participation in relation to physical functioning perceived as important to children themselves [31]. It is not generic as it is aimed at the disabled population. There are two versions covering the same activities but with different response options was developed for children aged 5–15 years. The ASKc measures what the child 'could do', whereas the ASKp measures what the child usually 'does do'. Test-retest reliability is excellent, the intra-class correlation coefficient is high and there is evidence of validity in comparison to clinicians global rating and in comparison to parent-reported ASK scores [32]. The ASK also has convergent validity, correlating highly with the Childhood Health Assessment Questionnaire (CHAQ) and a mobility indicator from HUI-3, and moderately with the Child Health

Table I. Appropriateness of instruments for measuring participation as defined by WHO ICF for children.

Domains of activity and participation in the ICF	LIFE-H (64 items)	LAQ-G (53 items)	CASP (20 items)	ASKp (38 items)	CAPE (50 items)
Learning and applying knowledge	Doing homework	–	Using educational materials in the classroom (e.g., books, computers)	I worked carefully with my hands (e.g., making models, sewing)	Doing homework
General tasks & demands	Shopping, running errands	–	Doing family chores, responsibilities and decisions at home	I put toothpaste on my toothbrush then brushed my teeth ...	Brushing your teeth
Communication	Using a telephone at home	How easily child communicates verbally or non-verbally with others	Communicating with other children and adults at home	I did my printing (or script writing) by myself ...	Talking on the telephone
Mobility	Riding a bicycle	What is the furthest distance your child has gone outside without your help over the last week?	Moving around the neighbourhood and community	I did my printing (or script writing) by myself ...	Bicycling, rollerblading, or skateboarding
Self-care	Dressing and undressing the upper half of body	Level of help needed for child to put on a vest/T-shirt	Doing self-care activities	I walked without any support ...	–
Domestic life	Taking part in meal preparation	–	Household activities (e.g., preparing some meals, doing laundry, washing dishes)	I put my shirt on by myself ...	–
Interpersonal interactions and relationships	Maintaining friendly or social ties with other young people.	How many times has your child seen his or her friends outside of school hours over the last week?	Social, play or leisure activities with friends in the neighbourhood and community	I made a snack by myself ...	Making food (e.g., making breakfast, lunch, or a snack)
Major life areas – education and work	Taking part in learning activities at school	–	Educational (academic) activities with other children in the classroom	–	Going to someone's house (e.g., for dinner, sleeping over, visiting a friend after school)
Community, social and civic life	Taking part in sports or recreational activities	How many out of school activities did your child do in the last week?	Structured events and activities with friends in the neighbourhood and community	I did my usual job or chores ...	Doing a chore
General applicability	Yes/no	No	–	I played team sports with others in my class ...	Doing team sports (e.g., hockey, soccer, baseball, basketball)
Respondent	Proxy	Proxy	Yes	–	Yes
Measurement	Capacity, performance	Impact of disability	Proxy	Child	Child
Origin	North America	UK	Ability to participate	Frequency	Frequency
			North America	UK	North America

LIFE-H, the Assessment of Life Habits for Children (Fougeyrollas *et al.* 1998); LAQ-G, the General Lifestyle Assessment Questionnaire (Mackie *et al.* 1998); CASP, the Child and Adolescent Scale of Participation (Bedell 2004); ASKp, the Activities Scale for Kids (Young *et al.* 2000); CAPE, the Children's Assessment of Participation and Enjoyment (King *et al.* 2004).

Questionnaire (CHQ) physical functioning scale. Although the ASK has a broad coverage of most ICF domains, some such as education and communication are represented by only one question each.

The CAPE [33] was developed to assess the participation of children with physical impairments aged 6–14 years, and covers only discretionary participations. It can be used with any child, with or without impairments, as it is a self-report measure of children's participation in recreation and leisure activities outside of mandated school activities [33]. Its items are presented as a drawing and text, providing information about three aspects of participation: diversity (number of activities done), intensity (frequency of participation measured as a function of the number of possible activities within a category), and enjoyment. The individual version also asks for information about with whom the child participates and where, all presented as visual scales. Preliminary assessments of the CAPE have demonstrated satisfactory internal consistency, test–retest reliability and validity [33]. As the items measure discretionary participation, education is represented by only one item, and self-care is not included.

Conclusion

The ICF has introduced the concept of *Participation*, with particular reference to adults. Recent work has focused on extending the concept to children, for whom issues of development, change and dependence are important to consider. This paper has outlined factors relevant to representation of childhood participation and has examined five available instruments.

All the instruments considered have some limitations. The LIFE-H has the most comprehensive coverage of ICF domains, and captures performance separately from capability, but is complex for even very literate adults to complete accurately. The ASK and CAPE offer advantages in their ease of completion by the child him or herself, particularly the CAPE with its visual presentation. However, the simplicity is at the expense of coverage: the ASK focuses on physical functioning to an extent which limits its applicability, and the CAPE covers only discretionary activities. The CASP does have good basic coverage of the ICF domains but is completed by a parent rather than the child. The LAQ-G, designed for children up to 6 years, has many items which measure restrictions on the family rather than the child. However, as discussed earlier, it is difficult to disentangle the participation of a young child from that of their family and it may be that *children's* participation can only be measured adequately after the early years. All five instruments have been developed in the UK or North America and are

likely therefore to carry cultural specificity, particularly the CAPE with its focus on discretionary activities.

One major issue for measurement is how to distinguish activity limitations from participation restrictions. For the CASP and parts of the LAQ-G (and one scale of the LIFE-H) the emphasis is on children's ability to take part, rather than on whether or how often they do. Measurement of participation will always require other instruments to be used alongside, in order to interpret the meaning of the child's participation profile. More participation may not be 'better' if the child does not have a say, or does not enjoy the activity much. The reasons for lower levels of participation need to be sought through separate measurement of degree of assistance available, family resources, and so on. Therefore measurement of participation should focus on 'performance' in terms of whether and how often an activity is accessed.

We think the ICF offers a good framework for participation on which instruments to measure it can and must be developed. The key concepts of participation are – what does the child want to do, how do most children behave, and what activities have high social, developmental or educational priority? The challenge is to identify a short list of life situations, ideally applicable to and valued by children in many countries, with age-appropriate normative standards, which are sensitive to the difficulties presented to children by the variety of impairments they may have and the environments in which they may live. Two age-bands are likely to be required in instrument development, given the growing autonomy experienced by adolescents, at least in many cultures. The challenge for measurement is to design user-friendly modes of presentation and response so that most children can report for themselves wherever possible. Such efforts must involve qualitative work with young people themselves, disabled and non disabled, as the basis for determining content and the best way to pose questions and scale the answers.

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