A shared framework and language for childhood disability

Review

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The social model of disability and the new sociology of childhood emphasize respectively the relevance of the environment to participation and the importance of quality of life. Such ideas can be readily understood by and shared among parents, young disabled people, professionals, and planners. They also make clearer what professionals are trying to do when supporting disabled children and their families. This article discusses these concepts and shows how they must be expressed in quantitative terms if they are to influence research, planning, and clinical practice.

Two important and relatively recent developments in the social sciences are the social model of disability and the new sociology of childhood. Their implications emphasize respectively the relevance of the environment to participation, and the importance of quality of life (QoL). Such ideas can be readily understood by and shared among parents, young disabled people, professionals, and planners, and they make clearer what we are trying to do when supporting disabled children and their families.

Two models

The 'social model of disability'[1] regards disability as resulting from interaction between individuals and their respective environments rather than as something within the individuals themselves. It was developed in the UK and has been central to the development of disability studies.[1–3] Originally the social model took the uncompromising position that all disability is caused by societal and structural barriers – whether they be environmental, such as inaccessible buildings, institutional, such as segregated schooling, or attitudinal. Any failure of society to ensure sufficient environmental adjustment represented discrimination against a minority group and a denial of their human rights. However, the model has been modified to indicate that not all the disadvantage resulting from their impairment can be overcome by changing the environment, not least because physically disabled people themselves say their impairments are relevant to their lives and to their interaction with their environment.[4]

In the other recent development in sociology, childhood is now regarded as a variable of social analysis, along with other categories such as class, sex, ethnicity, and disability. Childhood is a social construction: 'A child's immaturity is a biological fact: but how this immaturity is understood and how it is made meaningful is a cultural one'.[5] Children are not seen as passive objects owned by their parents but rather as social actors in their own right, contributing in various ways to their families and their communities. In the 1990s, this new sociology of childhood also set itself against past theories of child development, which it criticized as setting up false 'criterion standards' of adulthood and developmental norms.

The new approach is encapsulated by the notion that 'Children should be seen as "human beings" and not "human becomings" '.[6]

Throughout this article, the phrase 'disabled child' will be used rather than 'child with disability'. There are arguments to favour each approach[7] but the social scientist, although agreeing with the phrase 'child with impairment', will always use 'disabled child' because the child is disabled by society or the environment. The phrase 'child with disability', although laudable for being person and child centred, nevertheless implies that the disability is something intrinsic to the child.

Participation and environment

In 1980 the World Health Organization (WHO) published the *International Classification of Impairments, Disabilities and Handicaps*[8] with the structure shown in Table I. It was succeeded in 2001 by the WHO *International Classification of Functioning, Disability and Health* (ICF),[9] a title that indicates that the classification encompasses several concepts or words that are in common usage. The structure of the ICF is shown in Table II. Participation is defined as involvement in life situations, and typical examples for children are responsibilities, maintaining relationships, community life, education, and recreation. Participation is about what a person does in real life and is, therefore, strongly influenced by their environment, and is in accord with the social model of disability. Participation is different from handicap in at least three important respects: (1) the concept applies to all people, not just disabled people; (2) it has positive rather than negative connotations; and (3) reduced participation results from the interaction between the individual and their environment, not simply from a problem within the individual.

The ICF considers that individuals live in a 'context' consisting of environmental and personal factors. Environmental factors are 'the physical, social, and attitudinal environment in which people live and conduct their lives' (examples are shown in Table III). Personal factors include preferences, personal choice, past experience, and social background. However, these personal factors are not classified and it is unclear why they should be regarded as context rather than factors intrinsic to the person, such as their personality, temperament or, indeed, impairments.

The ICF was designed for use with adults, and some domains of the ICF have only an indirect relevance to children through their adult carers; for example 'acquiring a place to live' or 'economic self-sufficiency'. There are also important omissions relevant to childhood, such as engaging in play, preverbal communication, and avoiding dangerous situations. There is a need to refine the classification for children[10] and there is a draft version of it on the WHO website for children and young people.[11] So far, there has been no attempt to modify for children the classification of environmental factors.

The ICF, although not perfect, is a powerful international framework for giving definition to the social model of disability and health.

Quality of life

QoL was at first used to describe a patient's condition at a level other than diagnosis. There was overlap in the literature with terms such as handicap, function, and activities of daily living, depending on authors' philosophy and background. However, the literature is now clearer and, although a number of definitions of QoL exist, the subjective, self-reported element is now common to all. A broad definition is used by the WHO: 'the individual's perception of their position in life in the context of their culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns'.[12] Most instruments identify several crucial dimensions,[13] as shown in Table IV.

Much progress has been made in the assessment of QoL in children but it lags behind the work in adults. Some of the special issues to take into account in childhood are the following: the reliability of children's self-reports, the status of reports from proxy respondents,[14,15] the different values that children place on particular health states in comparison with

Table I: Structure of International Classification of Impairments, Disabilities and Handicaps (WHO 1980)

Impairment	Level of organ
Disability	Level of whole body
Handicap	Level of society

Table II: Structure of International Classification of Functioning, Disability and Health (WHO 2001)

Body structure and function
Activity
Participation
Contextual factors:
  Environmental
  Personal

Table III: Examples of environmental factors from IFC

Attitudinal	*Social*	*Physical*
Institutional attitudes	Emotional support	Adaptations
Encouragement	Physical support	Accessible toilets
Inclusiveness	Communication	Transport
Attitudes of	Time to do things	Aids
Family, peers	Service coordination	Finances
Teachers, therapists		Services
Strangers, services		

ICF, International Classification of Functioning, Disability and Health (World Health Organization 2001).

Table IV: Quality of life variables

Emotional well-being
Interpersonal relations
Material well-being
Physical well-being
Pain and discomfort
Self-esteem
Self-determination
Social inclusion
Individual rights

adults,[16,17] and a child's perception of the passage of time.

Participation and QoL can be considered to be the two essential outcomes for the description of health status and the assessment of interventions to support disabled people, with the former being an objective measure, the latter subjective. The former derives from the social model of disability and the ICF, the latter from the new sociology of childhood and the status we should give to the lives of children and young people 'here and now' rather than valuing childhood simply as a transitional phase to adulthood. These concepts now need to be applied to research, policy and service development, and clinical practice.

Research

DEVELOPING INSTRUMENTS

Before the ICF, the term 'handicap' was used to represent the disadvantage experienced by people with impairments, and from the 1980s, there were attempts to operationalize the concept of handicap for adults. With two exceptions,[18,19] no development took place for children and young people. There remains a need to evolve instruments of participation with young people involved in their development, and which are completed by the young person rather than a proxy. The Children's Assessment of Participation and Enjoyment (CAPE) is one such instrument being developed at the moment.[20]

Many of the instruments first developed for assessing the QoL of children were modified adult instruments. This is changing, and although it is generally recognized that the dimensions of QoL should be universal, the questions asked should be determined by age and culture and the content should be derived from what children say they value in their lives.

QoL is a subjective measure and requires especially strong evidence of psychometric properties because subjective concepts are captured by mapping answers to specific questions to an underlying latent concept that cannot be directly observed or verified. A major recent advance is Item Response Theory, which enables the researcher to be confident that the latent variable is captured on a unidimensional interval scale by questions that behave in the same way in different settings and with different children. For example, if a question on being liked by peers contributes to the latent concept 'self-esteem', it should be extremely unusual for a child (regardless of sex, culture, impairment, etc.) with high overall self-esteem to answer 'I am not liked by peers'. Recently an instrument, KIDSCREEN,[21] with these properties has been developed and is valid in 12 European countries.

Assessment of the environment relevant to disabled children is at a much earlier stage of development. Although some instruments have been developed in North America and Scandinavia for adults,[22] there is none to assess the environment with regard to disabled children. One child study[23] used district of residence as a crude measure of environment.

EVIDENCE FOR THE SOCIAL MODEL

Qualitative and quantitative studies indicate that the social model of disability applies in some situations, but how pervasive is it, and how much of participation is accounted for by environment?

Concerning sport, for example, a cross-sectional survey by Sport England[24] of participation in sport by disabled children revealed that they did significantly less sport in school than non-disabled peers; however, the reduced participation was much more marked for out-of-school sport, indicating that factors in the environment probably operate outside school that are additional to underlying impairment severity or child motivation.

In Chicago,[25] a series of in-depth interviews were undertaken to discover the barriers to sports participation; the interviews with disabled adults, city planners, and architects across 10 regions of the USA revealed a raft of design, information, training, and policy barriers.

A small qualitative study[26] of the social participation of four males aged 7 to 12 years with fragile X syndrome was conducted in Australia at four different schools, using ethnographic methods. One of the children had much less social participation than the others, but this was not due to an intrinsic problem in the child; rather, difficulties lay in the following factors: he was being taught in a segregated class so other children perceived him as different; his family lived a long way from the school and he was transported by taxi to and from it; and his school had no programme specifically to promote his social interaction.

In the study by Hammal et al.,[23] participation of children with cerebral palsy (CP) was found to vary depending on the district in which a child lived. A multivariate regression model was developed into which impairments, social factors, and district were entered. Their main conclusions were as follows: participation varied with district of residence, confirming the social model; the effect of district on participation was of the same magnitude as the effect of IQ; and variation in the social restriction domain was determined almost entirely by district of residence. Introduction of variables such as CP type, walking ability, feeding, or seizures had no additional effect.

HOW MUCH PARTICIPATION IS ACCOUNTED FOR BY ENVIRONMENT?

A Colorado group studied the sequelae of spinal cord injury in adults.[27] It showed that only 5% of the variance in participation was accounted for by environment, whereas 10% of QoL was accounted for by environment. Although the study was impressive because it embraced the social model, used the ICF, and developed its own instruments to measure environment, participation, and QoL, there were weaknesses. In spite of data on 2500 people, there were 3000 who were lost to follow-up and a further 1000 who did not want to take part. In addition, only barriers were studied. But, of course, every barrier is a potential facilitator and many studies omit to ask about this, thereby reducing the measured influence of environment.

In Boston, Bedell and Dumas[28] studied children with acquired brain injury; 10% of the variation in participation was accounted for by the environment, mainly its institutional, social, and attitudinal rather than physical elements. This was a pilot study, which assessed only 60 children with acquired brain injury using instruments that are still being developed.

The McMaster University group[29] studied family and family-centred services and is interested in the social model of disability. This group is developing a measure of childhood participation and has conducted qualitative work into what parents feel are important environmental facilitators and barriers.[30] The group suggests that the influence of environmental factors seems to be mediated by certain family characteristics such as parents' perceptions of health, family cohesion, and family recreation orientation.[31]

Policy and service development

Three studies are offered as examples of where these concepts are being used for service and policy development. The first study was of services for young adults with physical disabilities. In a retrospective cohort study,[32] two English districts, each providing services through a Young Adult Team, were compared with two other English districts providing ad hoc services. The participation scores were significantly different between the groups. After controlling for pain, stress, and low energy, which were all associated with lower participation, the people cared for by the Young Adult Team were three times more likely to have good participation than those cared for by the ad hoc services. The financial costs of the two approaches were the same.

The Family Fund, which makes financial payments on behalf of the UK government to families of children who are ‘very severely handicapped’, is undertaking work to establish more objective methods for its decision making. Currently, a home visit is made by a social worker to establish how disabled the child is and the level of need of the family. Over the past six months, families have also been asked to complete participation and environmental instruments. Responses to these do not influence the Family Fund’s decision but the data are being collated to model several independent variables including participation and environment, against the dependent outcome – ‘decision to award money’.

A large study around policy development is taking place across Europe, funded by the European Commission.[33,34] The study’s principal hypothesis states that: ‘Children with similar severity of cerebral palsy will experience variable participation and QoL in different countries due to variation in environmental factors.’ In any one country it is difficult to unravel the contribution made to participation by environmental factors operating at a national level – factors such as anti-discrimination legislation, transport policy, or regulations on access to buildings. By studying different countries it should be possible to unravel the influence and contribution of these several factors and so identify those that promote optimal participation.

Clinical practice

The concepts discussed so far are not new to parents. Parents may not call them participation and QoL, but they are the outcomes that all parents want for their children. The following quotation is from the mother of a child with multiple severe impairments: ‘The most important thing to remember is that when a child is born, that child is a child first to his or her family. It is his well-being, not his disability, which affects all our everyday lives. It is hard to adapt to a life where our child may face low expectations and stigma because he is disabled.’[34]

All parents want their children to be happy; but they also want them to join in society, to develop their skills, to become aware of all that life can offer and discover what suits them. There will be times, for instance, when children would prefer not to go to school but parents will still insist that they go. It is no different for disabled children.

How should these models and concepts influence clinical practice? Perhaps we should try to indicate during consultations that we, like the child, are interested in how they feel and what they do – not because of a polite interest but because this should influence whether a treatment or therapy or programme would be relevant. We can encourage children to think about these things so that as they get older they become used to reflecting on how a proposed medical adjustment might affect them – and so be empowered. We should think carefully how a proposal might affect participation and QoL rather than how well it adheres to a protocol.

Could the multidisciplinary team use the concepts of participation and QoL to provide a common language for children, parents, and professionals and a shared overview of objectives? This possibility was explored in an intervention study in the Netherlands across six rehabilitation centres.[35] They examined professional satisfaction and the degree to which management plans were more goal-oriented, showing marked improvement in the intervention group. However, they did not measure the outcomes of participation and QoL. A Quebec group[36] studies children in a rehabilitation centre for traumatic brain injury. Participation is assessed at regular intervals and the young person is asked which aspect of participation they want to work on; then the multidisciplinary team decides which of the members can help. As in the Netherlands, there was a 2-year lead-in time while concepts were introduced to all the relevant professionals. This work is being evaluated, with results available next year, but preliminary impressions suggest the following outcomes of such an approach: it introduces objectives that are self-evidently desirable and expressed in a common language; it helps professionals to communicate with each other and parents; and it enhances the motivation of child and family and reduces dependence in professionals.

Conclusion

Two recent theories in the social sciences – the social model of disability and the new sociology of childhood – emphasize respectively the relevance of the environment to participation and the importance of children’s QoL. These ideas should influence our thinking and provide a vocabulary that can be shared between parents, young disabled people, professionals, and planners.

Shakespeare[4] is developing a new understanding of disability that links these two themes. His research with young people[37] tells us that young people with impairments recognize the barriers, stigma, and prejudice that they face and are cross about them. But they also wish not to be classified as ‘the impaired’ or ‘the disabled’. They are young people and want others to see them as young people. What young disabled people want are their rights, their full entitlement to resources, and policies that ensure that the environment facilitates their participation. They want to be engaged at a personal level by all of us in ways that recognize their individual aspirations, their autonomy, and their emotional life.

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