



Available at www.sciencedirect.com



journal homepage: www.elsevier.com/locate/cupe



What are we trying to do for disabled children?

Allan Colver*

Northumbria Healthcare NHS Trust and School of Clinical Medical Sciences (Child Health), University of Newcastle upon Tyne, Sir James Spence Institute, Royal Victoria Infirmary, Queen Victoria Road, Newcastle upon Tyne NE1 4LP, UK

KEYWORDS

Childhood;
Disability;
Quality of life;
Participation;
International classification of Impairment;
Disability and functioning

Summary

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

© 2006 Elsevier Ltd. All rights reserved.

Practice points

- The International Classification of Functioning, Disability and Health
- Participation and quality of life are the two key concepts for understanding what parents, professionals and policy-makers want to achieve for disabled children
- The social model of disability regards disability as resulting from the interaction between individuals and their respective environments rather than as something within the individual
- Children should be seen as 'human beings' rather than 'human becomings'

questions about the role of health professionals, the nature of disability, its meaning for society and the lives of disabled children.

The article has three main aims. The first is to introduce the concept of the social model of disability as an important way in which to think about disability. The second is to introduce the terms used by the International Classification of Functioning, Disability and Health (ICF).¹ The ICF is adopted worldwide, and although it may need modification in the decades ahead, it is a major advance over the 1980 classification. The final aim is to ask whether we should always aim to reduce the impairment of disabled children rather than ensuring that they can participate as much as possible, with their rights and entitlements as citizens properly realised.

Introduction

The question posed in the title of this article may seem to have a straightforward answer, but it in fact raises many

Two models

Two important recent developments in social science are the social model of disability and the new sociology of childhood. Their implications emphasise 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 between parents, young

*Tel.: +44 191 219 6672; fax: +44 191 219 6650.

E-mail address: allan.colver@ncl.ac.uk.

disabled people, professionals and planners, and they make clearer what we try to do when supporting disabled children and their families.

The 'social model of disability'² regards disability as resulting from the interaction between individuals and their respective environments rather than as something within the individual. It was developed in the UK and has been central to the development of disability studies. The model initially 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 the participation of disabled people by adequate environmental adjustment represented discrimination against a minority group and a denial of their human rights.

The model has now, however, been modified so that much but not all disability is regarded as attributable to the environment. Disabled people themselves say that impairments are relevant to them and that the elimination of impairment is desirable. However, small reductions in impairment may bring little improvement to their lives and may be accompanied by disadvantages, and much more is likely to be achieved by changing the environment.³

A normal newborn baby has many impairments compared with an independent adult—he or she is incontinent, cannot speak, cannot move about, etc. However, society and the environment make great adjustments. Mothers spend much time with their babies. Grandparents and neighbours help. Parents are allowed time off work. Special clothes and milks and foods are available on every high street. So a baby has impairments but is not disabled because society and the environment adjust to meet his needs. This usually does not happen for disabled people.

There has also been a major development in the sociology of childhood. Up to the 1990s, the prevailing social theory regarded childhood as a transitional state to adulthood and entry to the work place, and there were 'normal' stages of childhood and growing up. Now, however, childhood is recognised as a variable of social analysis, along with other categories such as class, gender, ethnicity and disability. Childhood is a social construction. A child's immaturity is a biological fact, but how this immaturity is understood and made meaningful is a cultural one. 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. The new approach is encapsulated by the notion⁴:

Children should be seen as 'human beings' and not 'human becomings.'

Throughout this article, the phrase 'disabled child' rather than 'child with disability' will be used. There are arguments to favour each approach,⁵ 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 being laudable for being person- and child-centred, nevertheless implies that the disability is something intrinsic to the child.

Participation and environment

In 2001, the World Health Organization published the *International Classification of Functioning, Disability and Health*¹—a title indicating that the classification encompasses a number of concepts or words in common usage. Its structure is shown in Table 1.

Participation is defined as involvement in life situations, typical examples for children being responsibilities, maintaining relationships, community life, education and recreation. Participation is about what people do in real life and is therefore strongly influenced by their environment and in accord with the social model of disability. Participation is different from handicap in at least three important respects: the concept applies to all people, not just disabled people; it has positive rather than negative connotations; and reduced participation results from the interaction between the individual and his or her environment, not simply from a problem within the individual.

The ICF considers the individual to 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 2. Personal factors include preferences, personal choice, past experience and social background. These personal factors are not, however, classified, and it is unclear to me why the ICF regards them as context rather than factors intrinsic to the person such as personality, temperament or 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. The classification is being refined for children, and there is a draft version for children and young people on the Internet.⁶ 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.

Quality of life

The term 'quality of life' was first used to describe health status at a more sophisticated level than just the diagnosis. There was an overlap in the literature with terms such as 'handicap', 'function' and 'activities of daily living',

Table 1 International classification of functioning, disability and health.¹

- Body structure and function
- Activity
- Participation
- Contextual factors
 - environmental
 - personal

Download English Version:

<https://daneshyari.com/en/article/4152223>

Download Persian Version:

<https://daneshyari.com/article/4152223>

[Daneshyari.com](https://daneshyari.com)