

The Generic Lifestyle Assessment Questionnaire

LAQ-G

CHAPTER 1

INTRODUCTION

Childhood disability and the representation of participation

In the early 1980s, the Office of Population Censuses and Surveys OPCS undertook a number of disability surveys on behalf of the DHSS. One of the surveys reported that just over 3% of children under the age of 16 were affected by long-standing illness, disability or infirmity [1]. Since then, the introduction of preventive measures has led to a decrease in the prevalence of some disabilities [2]. Others have increased in prevalence [3, 4] and most health districts report a significant rise in the number of children with complex medical needs and technological dependency [5].

Most health districts now maintain registers of children with disability, usually for the purposes of describing epidemiology, improving service planning, monitoring the care of individual children and contributing to research. Information on these registers is potentially a valuable resource, but their appropriate use has been scrutinised on a number of occasions. The information held often fails to reflect significant variations in the morbidity experienced by children. Johnson argued in 1995 that to be “relevant and useful”, information needed to include some description of the severity and impact of a child’s disability [6] and Hall argued that describing a child’s experience in these terms would not only make information more useful, but would also make it more acceptable and easier to obtain [7]. Blair and Hutchison described how functional criteria may be more useful than diagnosis in sharing information with non-medical staff [8]. In a national survey of special needs registers, Hutchison and Harpin highlighted the need to measure and record severity of disability [9]. To do this meaningfully, it became necessary to consider broader measures of child health and wellbeing.

In adult health-related research, the first publication describing broader considerations about human feeling and function appeared in 1949 [10], and this approach was endorsed by the World Health Organisation in its definition of health as “a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity” [11]. Formal attempts to measure health in adults did not really emerge until the 1980s, and it was not until the early 1990s that the health of children and adolescents was defined in anything other than predominantly clinical terms.

There are currently two main approaches to describing health: subjective and objective. An objective measurement is one which can be confirmed by third

party observation. Subjective measures seek to capture people's preferences, their feelings and perceptions around their own health and therefore ideally should be self-reported.

One approach to objective health measurement was provided by the World Health Organisation in its recently revised International Classification (ICF; [12]). The involvement of an individual in a life situation was defined as *participation*. Participation was described along a number of health-related domains.

For the purposes of this research project, the concepts of the ICF have been retained: the severity of a child's disability and its impact on the life of child and family has been referred to as *participation restrictions*, and defined as "problems an individual may experience in involvement in life situations".

Brief review of recent literature

There is a paucity of published material about measuring participation, particularly in children, although recently a growing interest in describing and measuring the consequences of childhood disability and its resultant impact on participation seems to be developing.

The revised and reshaped **International Classification ICF**, mentioned above, demonstrated a number of key changes in global views about health and disability generally. Important changes in language and terminology reflected not only improved understanding but also a commitment to think positively about disability. In particular, the term *participation* introduced a concept which was tangible and potentially measurable.

Another important change in the ICF was the implicit acknowledgement of a social (rather than medical) model of disability, which appreciated the dynamic interaction between a person and their environment. The "linear" connections between impairment, disability and handicap used in the original International Classification (ICIDH; [13]) were replaced by an interlinked, multifactorial model, which included bodily functions and structures, activities, participation and contextual factors, both personal and environmental. Changes in any one factor within the model would necessarily produce changes in the others.

Finally, two new qualifiers were introduced in order to describe people's experience more meaningfully: those of performance and capacity. Traditionally, within a medical framework, clinicians have assessed what people do "at their best" (capacity) by assessing function in a standardised and often very artificial environment. However, within the real world, what a person actually does (performance) may be very different.

Although the ICF has given coverage to some characteristics of disability which are particularly relevant to children, such as learning, behaviour and some experiences concerning school and family, it was written primarily for adults and still largely disregards the influences of development, parenting

and the environmental context of family life, all of which may be more significant during childhood than at any later point in life [14, 15].

The **Assessment of Life Habits LIFE-H** tool was developed by Fougereyrollas and colleagues in Quebec, and although originally intended for adults, had been adapted and used in the assessment of children with cerebral palsy [16]. The authors have published a conceptual model of what they term the Handicap Creation Process, which like the ICF is multi-factorial and stresses the importance of contextual (environmental and personal) factors in the genesis of life habits, the impact of any disabilities, the participation of the individual and the interactive nature of all these factors [17]. Although developed for adults, interestingly this model acknowledged the importance of human development and the processes involved in the creation of social beings.

Both the ICF and the Quebec Classification have highly complex coding systems which make them unsuitable for day to day use in clinical practice, but both remain fundamental in continuing to stimulate debate and provide a conceptual framework within which all disability, including that of children, can be understood.

The **BACCH Classification of Disability** [18] was revised in the context of a major NHS R&D funded project entitled “Towards nationally useful definitions of disability”. The Project Report [19] outlined how the OPCS descriptors were validated against standard assessment tools, and how important environmental factors, thought to influence the lives of children, were assessed. The authors also described how disabilities tended to occur together in clusters. A stated aim of this project was to produce a unified tool which could be used to define disability for the purposes of establishing useful district databases of children with disabilities. The Report included a guide for doctors and other professionals on coding category and severity of disability. Like the original BACCH Classification, severity was still thought of in terms of mild, moderate and severe, but the new guide did provide a method of describing clusters of disabilities, and the authors argued that overall severity of disability was “more about how many disabilities a child has than how severe any individual disability is”.

In its present state, Hutchison’s guide remains a functional classification rather than a measure of participation, and there is unfortunately no information on how to include the important variables associated with the child’s environment in the classification.

A major research study is currently being conducted at The Centre for Childhood Disability Research in Hamilton. This is a longitudinal study named “Participate”, looking at participation in over 400 children with disability and their families [20] by using the **Children’s Assessment of Participation and Enjoyment (CAPE)** measure, which was developed specifically for their study. CAPE is interesting, in that it looks primarily at discretionary activities (i.e. activities which children choose to do) rather than obligatory ones such as activities of daily living or accessing education, and this approach will

undoubtedly provide interesting new ideas for measuring the participation of children with disabilities in the future.

Aims and objectives of this study

Taking into account all the issues mentioned above, the following research hypothesis was agreed:

The restrictions in childhood participation resulting from childhood disability exist along a severity spectrum which can be measured.

The aims of the research were twofold:

- to develop an instrument capable of measuring such restrictions in participation
- to field-test the instrument in order to assess its reliability and validity.

The specific objectives of the research were:

- To develop an instrument appropriate for use with special needs registers. This meant the instrument needed to be *discriminative*, i.e. able to discriminate between children with different levels of disability *at a given point in time*. It also needed to be *generic*, i.e. able to measure the impact resulting from any disability and *objective*, i.e. yielding results which could be confirmed by third party observation.
- To develop an instrument which addressed the broader concept of *participation* rather than disability itself. This meant the instrument had to be multi-dimensional and able to provide a profile of a child's experience based upon a meaningful representation of *health-related domains of participation*, in keeping with WHO taxonomy.
- To assess the instrument's reliability in terms of discriminatory power, i.e. its ability to show a predictable difference in the results achieved by disabled and non-disabled children.
- To assess the instrument's ability to generate results which were reproducible over a short period of time and between observers.
- To assess the instrument's validity by looking at the extent to which it related to other measures in a manner which was consistent with theoretically derived hypotheses.

A detailed account of this research in its entirety has been completed elsewhere [21]. The literature review formed part of a paper in *Neonatal Seminars* [22] and a paper outlining some of the key results was published in *Child: care, health and development* [23].

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