Identification and description of environmental factors that influence participation of children with cerebral palsy

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Physical, social, and attitudinal environment may restrict participation in children with cerebral palsy (CP). Here we discuss existing/possible approaches in order to identify and describe this environment. We used a critical review of evidence from the World Health Organization Literature Review on Environmental Factors; a search of electronic databases; and talked to specialists in order to find unpublished papers and 'grey' literature. Both children with disabilities and their parents identified a range of barrier and facilitator factors. These included psychosocial pressures (family, school), financial difficulties, and inadequate public services. Observational studies suggest that building structure, loss of income, and provision of specific equipment have a direct impact on levels of child participation. Some available instruments attempt to capture environmental factors by client survey or objective measurement; most relate to adult contexts, but there are a few child-specific instruments for surveying attitudes of children to peers with disabilities and for observation of the school environment. Defining and measuring potential environmental determinants of participation for children with CP needs further development; and here we propose how this might be done.

The social model of disability, represented in the International Classification of Functioning, Disability and Health (World Health Organization 2001), proposes that the environment in which those with physical, learning, or sensory impairments live will significantly influence the extent of their participation. Participation is defined as involvement in life situations. Our previous article in this journal (Hammal et al. 2004) showed that, after factors such as type and severity of impairment have been controlled for, where a child with cerebral palsy (CP) lives does indeed seem to influence their participation.

What is it, therefore, about different environments that might explain such variations in participation of children with disabilities? Further, how might one attempt to understand the association in quantitative terms so that the environment might be optimized? In this article we summarize the conceptual and practical approaches that have been or could be developed for children.

Potential environmental factors that might influence participation are assigned to five chapters in the International Classification of Functioning, Disability and Health: (1) Products and technology; (2) Natural environment and human-made changes to environment; (3) Support and relationships; (4) Attitudes; and (5) Services, systems and policies (including health services and systems).

In this paper each environmental factor discussed will be allocated to the relevant International Classification of Functioning, Disability and Health chapter (1) to (5) as above. For those unfamiliar with the International Classification of Functioning, Disability and Health, Table I illustrates how the classification of Environmental Factors is defined further (see also World Health Organization website*).

Method

We began our enquiries by examining articles in the comprehensive World Health Organization Literature Review on Environmental Factors (World Health Organization 2000) that concerned children and were primary studies (i.e. reporting original data and not methodological or review papers). This was supplemented and brought up to date by searching electronic databases for primary studies in English up to 2002 by entering in the search criteria combinations of 'children', 'young adults', 'cerebral palsy', 'environment', 'measurement instrument', 'attitudes', 'services', and 'access'. We searched MEDLINE, EMBASE, PsychLit, Cinahl, Nursing Collection, and Web of Science. References in the papers identified were examined for further relevant studies, and experts in the field were contacted for advice on identifying additional published and unpublished papers. The internet was also searched for 'grey' literature, and unpublished studies were included if relevant.

We divided the articles for analysis into two sets. The first was of studies of the role of environmental factors as facilitators or barriers to participation. We had hoped to limit this to studies of children with CP but, because of the paucity of such work, we also included children with other impairments. The second set was of instruments designed to measure the aspects of the environment that affect the participation of people with disabilities. It had to cover an even wider range of impairments

*World Health Organization website: http://www3.who.int/icf/onlinebrowser/icf.cfm?parentlevel=1&child level=2&itemslevel=1&ourdimension=e&ourchapter=0&ourblock=0&our2nd=0&our3rd=0&our4th=0)

and age groups because there were few instruments specifically for assessing children or those with CP.

Results

BARRIERS TO AND FACILITATORS OF PARTICIPATION AS PERCEIVED BY THOSE WITH DISABILITY AND THEIR CAREGIVERS

Seeking the opinions of those directly affected was used to great effect in structured interviews with the parents of 100 children aged 5 to 15 years with disabilities, of whom 10% had CP (Hutchinson and Gordon 2001). Although the disability categories were based on functional skills rather than participation, they concerned what a child actually did rather than what they could do. After enquiry about each functional skill, such as mobility or communication, parents were asked, 'What problems in your everyday environment cause your child's difficulty in…?' With reference to the five International Classification of Functioning, Disability and Health environmental factors (see Table I), some examples of results are as follows: mobility was impeded by uneven surfaces or steps (1,2), inappropriate footwear (1), medication (1), dependence on supervision (3), and interference with balance induced by noise or stress (2). Personal care and continence were made more difficult by ambient temperature changes (2) and bullying (3), as well as by problems with physical access and reach (1). Communication was often compromised by stigma and lack of insight (4), noise and other distractions (2), and sometimes by policy (5) such as the non-use of sign language. A pervasive environmental factor across all domains was the disabling influence of time pressure (5).

The Joseph Rowntree Foundation has reported barriers that concern non-physical environmental factors, such as restricted information (5) (Joseph Rowntree Foundation 2000); lack of consultation (5) (Joseph Rowntree Foundation 2001); poor support for caregivers in employment (3) (Joseph Rowntree Foundation 1998a); poverty (1); and insufficient financial benefits (5) (Joseph Rowntree Foundation 1998b).

Questionnaire surveys of families with severely disabled children were undertaken by the Social Policy Research Unit in York to enquire into housing needs (Beresford and Oldman 2002) and special equipment needs (Beresford et al. 2002). Lack of domestic space (1) was a major factor for most families, both for housing special equipment and because it prevents children with disabilities from making their own decisions about where and when they wanted to move about the home. Requirement for private funding (1) of expensive play, safety, and learning facilities was commonly reported; and essential equipment, even when provided at home, was frequently unavailable in respite care or other community settings (5).

Parents report great difficulty when services are fragmented and poorly coordinated (5) and when professionals duplicate work while being unable to deal with gaps in services (Rees 1983).

A series of 12 home interviews and inspections explored how the home environment facilitated self-determination and independence (Cook et al. 1996). There were many relatively simple and inexpensive modifications that families had not undertaken, such as locating mirrors properly, lowering the bed, or widening all doors to allow wheelchair access. Reasons for this included parental lack of awareness of their child's need for autonomy (3) and reluctance to change conventional house architecture (4).

A total of 300 interviews in the UK with children aged 11 to 16 years with disabilities (Watson et al. 1999) identified several environmental barriers to social participation. Bullying (3) by peers, both with and without disabilities, together with attitudinal (4) and policy-based (5) segregation within schools, led to social isolation. The need for adult assistance (3) or the imposition of structure and unnecessary assistance by adults resulted in few opportunities for the young people to establish and explore peer relationships or for empowering them to find their own solutions to disabling situations. Another study presented by Connors and Stalker (2000) confirms how social exclusion can be caused by the way in which children with disability are treated by others when they want to interact with their physical environment. Children must be able to exercise choice and control to participate in the manner in which they want (Abery and Stancliffe 1996).

Interviews and focus groups with children with disabilities in Swedish (Hemmingson and Borell 2002) and Canadian (Pivik et al. 2002) mainstream schools revealed that barriers to

Table I: International Classification of Functioning, Disability and Health: definition of environmental factors

Environmental factors	*Definition*
(1) Products and technology	The natural or human-made products or systems of products, equipment, and technology in an individual's immediate environment that are gathered, created, produced, or manufactured; or any product, instrument, equipment, or technology adapted or specially designed for improving the functioning of a person with disability.
(2) Natural environment and human-made changes to environment	Animate and inanimate elements of the natural or physical environment, and components of that environment that have been modified by people, as well as characteristics of human populations within that environment.
(3) Support and relationships	People or animals that provide practical physical or emotional support, nurturing, protection, assistance, and relationships to other persons, in their home, place of work, school, or at play or in other aspects of their daily activities.
(4) Attitudes, values, and beliefs	The attitudes that are the observable consequences of customs, practices, ideologies, values, norms, factual beliefs, and religious beliefs.
(5) Services, systems, and policies	Services that are provision of benefits, structured programmes, and operations; systems that are administrative control and organizational mechanisms; and polices, rules, regulations, and standards.

Numbers refer to chapters 1–5 in the International Classification of Functioning, Disability and Health (World Health Organization 2001).

educational participation were found in the attitudes of pupils and staff (3) and patterns of organization of school activities (5) as well as in the physical environment (1). Lack of, or inaccessible, transport was raised by young people themselves as a major barrier to participation (Department of Health 2001).

FACTORS IN THE ENVIRONMENT CORRELATED WITH PARTICIPATION

A national survey of 1180 teachers of students with disabilities in the US (Simeonsson et al. 2001) demonstrated that the enhanced educational participation of students (based on six dimensions of social, recreational, communal, creative, civic, and academic activities) was associated with several aspects of school environments, in particular, size, location (5), and a supportive school atmosphere in the sense of a safe social environment with access to teaching in a supportive school (3,4).

An Italian study (Bottos et al. 2001) demonstrated significant improvements in independence and non-significant improvements in social participation after the provision of powered wheelchairs (1) to 29 three- to eight-year-old children with severe tetraplegic CP. It also showed positive changes in parental attitudes (4) to the use of such equipment – another important environmental determinant of child participation.

On average, families of children with disability have less earned income than those without such children; and 5% of income is spent on disability-related expenses (Office of Population, Censuses and Surveys 1989). Few studies have looked for an association between this and level of participation; however, one study (Finch et al. 2001) showed that lack of money was an important barrier to using local sport and leisure facilities.

The relationship between the physical environment and the social environment in the home is complex and can be restrictive or facilitative. Parents control the use of space and time in the home (Sibley 1995) and have variable expectations of their child with disability (Lewis 1986). Observational assessments in the US (Brotherson et al. 1996) showed that the home could be a restrictive environment for a child with disability.

INSTRUMENTS FOR MEASURING ENVIRONMENTAL FACTORS APPLIED TO THE PERSON WITH DISABILITY

There are three principal generic instruments, which are adult orientated and from North America: The Craig Hospital Inventory of Environmental Factors (Craig Hospital 2000); Measure of the Quality of Environment (Fougeyrollas et al. 1999); and Facilitators and Barriers Survey/Mobility (Gray et al. 2000). For each of these there is a matching instrument for measuring participation (respectively Craig Handicap Assessment and Reporting Technique [Whiteneck et al. 1992], Life-H [Fougeyrollas et al. 1998], and the Mobility Participation Survey [Gray et al. 2000]).

The Craig Hospital Inventory of Environmental Factors and Measure of the Quality of Environment instruments (Appendices I, II) start with a list of potential relevant environmental factors and ask directly whether it is 'a problem for you' or 'influences your daily life'. Both use a standard question format, differing in two respects: The Craig Hospital Inventory of Environmental Factors (25 questions) is more concerned with the frequency with which items 'are a problem', whereas, Measure of the Quality of Environment (109 questions) asks about the extent to which items are facilitators or obstacles. Measure of the Quality of Environment is more detailed in the range and specification of the items addressed.

By contrast, the Facilitators and Barriers Survey/Mobility is a longer instrument (120 questions) with eight different question styles. Most of the questions are similar to those in The Craig Hospital Inventory of Environmental Factors and the Measure of the Quality of Environment, and concern the extent and frequency with which individual items 'help' or 'limit' participation. However, because of the special emphasis on mobility, the remainder of the questions ask about settings (Appendix III). Participants are questioned generally about 22 different places (such as cinemas or shops) and 10 services (such as a doctor's surgery). They are then asked a specific question to establish what it is in these places that limits the level of access and the services available to them.

INSTRUMENTS THAT RECORD OBJECTIVE FEATURES OF THE ENVIRONMENT

Attitudinal environment

The British National Social Attitudes Survey (Exley et al. 2000) includes questions that explore adult attitudes to people with disabilities, disability legislation, public spending priorities, and prejudice in others. The extent to which people with disabilities are stereotyped has been recorded for books (Mellon 1989) and films (Longmore 1985); and this stereotyping can influence children's attitudes towards disability. Studies of children's attitudes have demonstrated widespread stigmatization among school-aged children of their peers with disabilities (Morrison and Ursprung 1987, Pirofski 2002). A survey instrument for children by Rosenbaum et al. (1986) assesses such attitudes and stigma. It is also possible to examine the extent to which attitudes might influence the formulation of national policy. Public policies (5), which could potentially influence disabled access to the built environment, were shown to have been developed and regulated with little reference to people with disabilities (Imrie and Kumar 1998). A more medical view of disability might also prevail (4) in which people with disabilities are viewed as having 'special needs', rather than having the right to universal and inclusive environmental design solutions (Zola 1989).

School environment

The Survey of School Environments (Simeonsson et al. 2001) is a teacher-completed instrument that has been used in a large-scale survey of schools in the US (referred to in the Method section). The key questions addressed by this instrument are: which of 27 educational activities are available to, and participated in, by a selected student with disabilities; which of 15 disability related services and facilities, such as therapy, assistance, or adaptations, are generally available within the school; and which barriers to participation are identified by school staff?

Home and transport environment

Researchers at Lund University in Sweden have attempted to describe housing and transport environments. The Enabler Concept (Steinfeld et al. 1979) determines the extent to which the environment required by an individual matches standards determined by legislation, regulation, and good practice guidance. Researchers at Lund University have used this concept to describe Housing and Travel Environments (Iwarsson 1999,

Iwarsson et al. 2000, Iwarsson and Slaug 2001). There are 188 potential housing barriers and 255 transport ones. A composite predicted barrier score is then attributed to each environment to assist in the prioritization of remedial measures or building design.

A North American instrument assesses those psychosocial aspects of the home environment that support self-determination (Brotherson et al. 1996, Cook et al. 1996). The instrument is based on dimensions of sociopsychological need identified as being critical to optimal child development (Miller 1986, Johnson 1987) and which the physical environment can support or impede. The dimensions of need are: nurturance (a sense of belonging and safety); territory (access to and control of spaces in the home); identity (positive cues to identity and self-worth); stimulation (stimulating senses, skills, and abilities); environmental manipulation (using and changing the different areas of the domestic environment); privacy (achieving and regulating); and sociability (with family and friends).

Policy and regulatory environment

A comprehensive review of UK policies and professional standards relevant to people with disabilities addressed transport (Salvage and Zarb 1995a), environment (Salvage and Zarb 1995b), citizens' charters (Arthur and Zarb 1995), employment, and planning democracy (Begum and Zarb 1995), and was conducted by the Policy Studies Institute, London, and the Disability Studies Group, University of Leeds. The review made several recommendations for auditable standards of local and central government performance and of professional practice across these domains.

Implementation of national guidance is undertaken in the UK by local authorities (Audit Commission 2000/2001); since the mid-1990s they have been required to report annually on a variety of environmental factors relevant to access for people with disability. Factors include: the proportion of public buildings, public toilets, and pedestrian crossings accessible to people with disabilities (1); the percentages of schoolchildren segregated in special schools (5); and the presence of written policies to reverse disability discrimination (5). They also have to report the amount of money spent on housing grants to enhance facilities for people with disabilities (Office of the Deputy Prime Minister 2002).

Discussion

We outline four key points emerging from this review. First, there is relatively little research specific to childhood that seeks relevant environmental factors or develops instruments to measure them. Second, although environmental description has been concerned mainly with assistive technology and access to and availability of remedial services (Schneider et al. 2001), there are now some studies that recognize other important factors, for example financial assets (1) and access to benefits (5), natural environment issues such as noise, and open space access (2), friendship and social integration (3), and attitudes of others and social exclusion (4). Third, because children's participation is the primary interest, the environment should be understood and described in relation to participation domains relevant to children and in particular to children with CP. And finally, the environment can be described at three principal levels: the individual's experience of their local environment; an objective assessment of the disability-friendliness or conduciveness to participation of a local environment; and the legislative, attitudinal, and regulatory framework for the environment at national level.

In order to improve information gathered on the individual's experience of their local environment, participation surveys should be extended to elicit information regarding relevant environmental factors. A key question (Schneider et al. 2001) for each element of participation would be: 'What features of the environment make it easier or more difficult for you (him/her) to …?' This approach could be further informed by detailed qualitative studies to ensure that critical pathways to participation are understood. These studies must include discussions with children themselves and must focus on those aspects of attitudes, support, and relationships that are important to them. Any methods or instruments developed must enable children with severe impairments also to be consulted. There is a small, but growing, literature on research that has included children with severe learning and physical impairments, and this will be a valuable resource (Beresford 1997, Morris 1998).

To improve the assessment of the disability-friendliness of a local environment, existing audit tools, such as the Enabler Concept (Steinfeld et al. 1979), should be reviewed for their applicability to children and child-relevant settings. These might be suitable for formal assessments of localities by panels of users with disabilities, or alternatively for self-completion questionnaire surveys of service providers and planners. Objective indicators might be more suitable for domains such as products and technologies, natural environments, services, systems, and policies; more qualitative surveys of the general public might be essential for other areas such as attitudes, support, and relationships. Local government and health service performance statistics should also be examined for current indicators of the relative disability-friendliness of different localities.

To take forward the characterization of the legislative, attitudinal, and regulatory framework of the environment at national level, there could be comparisons between legislative and regulatory guidance between countries. For instance, the international social expenditure database, which currently includes relative spending on disability cash benefits (Organization for Economic Cooperation and Development 2002), might be extended to encompass a comparison of legislative approaches to disability, such as the Disability Discrimination Act and the European Convention on Human Rights. The presence of other relevant regulatory frameworks, such as the British Standards Institution (British Standards Institution 2001), could be compared across countries in a similar manner.

Potential environmental factors from these three perspectives should be tested for their ability to discriminate participation levels between children with similar severities of disability in a wide variety of settings. The eventual 'criterion standard' for critical environmental factors will be the demonstration, in a controlled study, that change in those factors increases children's participation.

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Appendix I: Example question from The Craig Hospital Inventory of Environmental Factors (2000)

	Daily	Weekly	Monthly	Less than monthly	Never	Not applicable	Big problem	Little problem
In the past 12 months, how often has the availability of transportation been a problem for you?	0	0	0	0	0			
When this problem occurs has it been a big problem or a little problem?							0	0

Appendix II: Example question from Measure of the Quality of Environment (Fougeyrollas et al. 1999)

While taking into consideration your abilities and personal limits, indicate to what extent the following situations or factors generally influence your daily life.		Influence scale								
Public infrastructure services:		Obstacle ←			No influence			→ Facilitator	I do not know	Does not apply
	Public transportation services in your community (schedule, stops, frequency, trajectory, etc.).	Major	Medium	Minor		Minor	Medium	Major		
		–3	–2	–1	0	1	2	3		

Appendix III: Example of question from Facilitators and Barriers Survey/Mobility

8. Do you **go to restaurants**? ☐ *Yes* ☐ *No*

How does the accessibility of **restaurants** influence your participation in dining out?
☐ *Helps a lot* ☐ *Helps some* ☐ *Has no effect* ☐ *Limits some* ☐ *Limits a lot* ☐ *NA*

What about **restaurants limits you**? *(Check all that apply).*
☐ *Entrance* ☐ *Lack of personal finances* ☐ *Parking*
☐ *Lack of personal assistance* ☐ *Lack of child care* ☐ *People's attitudes*
☐ *Tables too close together* ☐ *Height of counters, tables, and booths* ☐ *Lack of transportation*
☐ *Lack of special equipment* → *What equipment would be helpful?* _____
☐ *Not limited* ☐ *NA* ☐ *Other* _____