

Discussion groups with parents of children with cerebral palsy in Europe designed to assist development of a relevant measure of environment

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Abstract

Background An instrument to measure environmental factors relevant to physically impaired children is being developed in a European context. Preliminary work in England had identified some potentially important themes. Further inquiry was needed to identify issues important in other European countries.

Objective To inform the content of a questionnaire relevant to the environment of children with cerebral palsy (CP) living in Europe.

Design A qualitative study using discussion groups.

Participants Parents of 28 children with CP from five countries; Denmark, France, Italy, Ireland and Sweden. One discussion group was held in each country with an average of seven parents per group.

Results The four themes identified in the preliminary work done in England were strongly confirmed across Europe – namely: Mobility, Transport, Support by and to parents, and Attitudes of individuals and institutions towards children. Two new themes identified in the discussion groups were Bureaucracy and Access to information about rights and entitlements.

Conclusions The environmental factors that cause concern to parents of children with CP are similar across Europe. A prototype environmental questionnaire has been developed based on these findings. The environmental questionnaire is in use in a study in nine European centres.

Keywords:

cerebral palsy, children, disability, discussion groups, environment, participation

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Introduction

The International Classification of Functioning, Disability and Health (ICF) (World Health Organisation 2001) defines participation as involvement in life situations and environmental factors as the social, attitudinal and physical environments in which people live. When these factors have a positive influence on an individual's participation they are called facilitators and when a negative influence, barriers.

If the components of the ICF are to influence social policy development and allocation of resources they must be represented by instruments, which enable them to be measured. Account must be taken of the special circumstances of disabled children and the differing environments in different countries.

In the SPARCLE study [<http://www.ncl.ac.uk/sparcle/> (last updated 26 April 2005)], the influence of environment on participation and quality of life of disabled children is being studied in nine European centres each with a population-based register of children with cerebral palsy (CP). Children with CP are representative of many disabled children as they have a range of physical, intellectual, hearing, vision and communication impairments; and there is a wide range of severity. As part of the study an instrument to measure environment is being developed in five stages:

- 1 A preliminary study showed that environment can be incorporated into statistical models and that such models confirm the social model of disability (Hammal *et al.* 2004).
- 2 Literature review of environmental factors (Mihaylov *et al.* 2004).
- 3 Semi-structured in-depth interviews in England to establish the factors perceived to be relevant to families of disabled children (Lawlor *et al.* 2006).
- 4 Discussion groups in five European countries reported in this paper.
- 5 Validation studies.

In this paper we report Stage 5, discussion groups of parents of children with CP in five European countries, that explored the same topics cov-

ered in Stage 3 – the qualitative in-depth interviews undertaken in England with families of children with CP. The purpose of the discussions was to inform the content of an environment questionnaire relevant to children with CP.

Methods

The importance of focus group methodology for disability research has been emphasized (Mullan 2000). Participants are selected because they have certain characteristics in common that relate to the topic of the focus group (Krueger 1994). It is the interaction in a focus group that generates the data and that distinguishes it from other types of groups (Morgan 1997). Focus groups are useful for reflecting the social realities of a cultural group, through direct access to the language and concepts that structure participants' experiences (Hughes & DuMont 1993). For our study a 'formal' focus group methodology was not deemed appropriate because the discussion guide had already been derived from the open-ended, in-depth interviews undertaken in the UK. Also the discussions did not allow completely free and open discussion about disability issues as their purpose was to inform the content of an instrument. Finally, the analysis of the transcripts presumed the conceptual background of the ICF.

However, a focus group has also been defined as 'simply a discussion in which a small group of people under guidance of a facilitator or moderator, talk about topics selected for discussion' (Clark *et al.* 1996). Focus groups generate the subjective views of a group of individuals and allow exploration and reporting of all issues relevant to the subject of the focus group. Therefore, the method used in this study had many similarities to focus group methodology but we have chosen the phrase 'discussion group' to avoid misrepresentation.

Participants

The discussion groups were conducted in the following five centres: Eastern Denmark; Grenoble, France; Viterbo, Italy; Cork, Ireland; and Goteborg, Sweden. They consisted of parents of 28 children with a mean age of 7 years (range 5–14 years) and

Country	CP Type	Walking ability			Associated impairments			IQ
		Bilateral spastic	Unilateral spastic	Dyskinetic	Without assistance	With assistance	Not walking	
Denmark	4	0	3	1	5	1	3	
France	1	3	1	1	2	2	0	
Italy	1	2	2	2	1	1	1	
Ireland	4	2	1	1	4	0	1	
Sweden	3	1	0	2	1	1	1	

CP, cerebral palsy.

Table 2. The parents attending

Country	Number of parents attending	Number of parents attending		
		Couples	Mothers	Fathers
Denmark	10	3	2	2
France	5	2	3	2
Italy	7	2	5	2
Ireland	8	1	7	1
Sweden	6	1	5	1

a range of severity and type of CP and associated impairments, presented in Table 1. Details of parents are shown in Table 2.

We wish to emphasize that the results reported in this study reflect the perspectives of a group of parents from one specific area in each country. These are by definition subjective accounts of the environmental situation in these areas. Although, they are likely to be broadly representative of the situation in the rest of the country, certain facilities are not equally available throughout the country. Therefore, although as a shortcut we will be referring to the country as a whole, results should be interpreted as the perspective of a group of parents residing in a certain part of the country.

Procedures

The following methods were agreed and followed by each centre. Parents of children with CP were invited to the discussion group to discuss the environmental factors affecting their child's participation. Each group met at a neutral venue and was led by a facilitator aided by a supporting person. After introductions the facilitator explained the purpose of the study and obtained consent from participants to record the discussion and report the results. The facilitator encouraged open-ended discussions to allow parents to express their opinions and experiences of their local environment in relation to their child's disability. The facilitator guided parents through the discussions using a topic guide based on the work of Lawlor and colleagues (2006), covering the following settings and topics: home, school, transport, health services, free-time and finances. The discussion groups, lasting between two and three hours, were held in autumn 2003.

Data analysis

All the interviews were audio-taped and transcribed. Each facilitator reviewed these, making a detailed report of the main opinions expressed and categorizing the main themes. As the transcripts were in different languages and each country's analysis was undertaken by a native facilitator, formal input to software such as NUDIS was deemed too complex and beyond the resources of the study.

Results

Parents said they enjoyed and felt empowered by the discussions, being listened to and contributing to the discussions in an area they knew well. Much energy and enthusiasm was generated. Facilitators reported that there was a strong desire by parents to discuss their own problems as well as the factors promoting their child's participation; it was an important role of the facilitator to ensure this was handled sensitively while at the same time reminding parents it was not the purpose of the meeting.

The aspects of the environment to which families in the different countries attached importance were strikingly similar between all countries. Lawlor and colleagues (2006) found that four main themes seemed to operate across all the subject areas covered in the interview schedule. These cross-cutting themes, Mobility, Transport, Support to and by parents and Attitudes, were robustly confirmed in the discussion group work. These themes operated across most areas of participation and in many settings. Below we give examples which confirm their relevance in each country. There were two additional important cross-cutting themes which emerged from the discussion groups – Bureaucracy and Information – and results on these are reported in more detail.

The mobility and transport themes relate to the physical environment, the supportive role of parents and bureaucracy to the social environment, and attitudes to the attitudinal environment. The information theme will be reported under the social environment but we recognize some elements relate more closely to the physical environment.

Physical environment

Mobility is both a pleasurable activity and a means of accessing places and participating in society. It is both an indoors as well as an outdoors activity. In Sweden a parent reported great satisfaction: 'The apartment was OK when our child was a baby but after some years a new house was bought to fit his needs. The house was totally adapted to our child, no stairs, no doorsteps. Everything became natural in the new house. No problems'.

French parents pointed out that enabling their child to move easily inside the home gives them more initiative when playing inside. One parent said 'the child is the motor of the change', meaning that by responding to the child requests for equipment and adaptations at home you give the child a better understanding of space and thereby autonomy and independence. The motorized tricycle is greatly appreciated. Since discovering the special tricycle, one dad and his son 'can do long strolls during the weekend and holidays. It has changed our lives'. Another parent said. 'It is a really sporty and practical transport'.

But *Transportation* in its usual sense was not the only issue. In Denmark, parents pointed to the accessibility of shops as a problem – very often the children cannot get into clothes shops as one mother described shopping with her son 'if we do get in, he can't move around inside the shop'. In the Ireland a parent said 'wheelchair access is very awkward in some cinemas. You may have to access from the back or alley way or through one cinema to get to another one. Also going to the beach is like moving an army; the wheelchair access is very limited'.

Transport liberates people enabling them to explore, travel, visit people and participate in work, school and social activities. In Denmark, nearly all families with a disabled child have a 'disability car'. There is no registration tax and they get financial aid for special fitting of the car. Therefore, they do not use the various taxi-arrangements with the exception of getting to and from school. But the Danish parents stress that transportation of the child is still a barrier to participation since the parents have to accompany the children on every trip, as there is a poor public transport alternative for disabled children.

In France, public transport is good; there are access ramps for the tramway and drop-down ramps on the buses. However in Italy, school buses are often not suitable for transport of the disabled. The lack of suitably equipped means of transport for the disabled is so great that parents do not even bother to enquire whether suitable transport is available. In Sweden, transport was a problem for nearly all the children. 'Wheelchairs are not allowed on trams.' 'Special taxis are a giant problem!' Arrangements for booking disability friendly transport 'never work!' In the Ireland, 'A wheelchair-adapted taxi does not mean a wheelchair-friendly taxi'. Also special buses may not be what they appear - 'There are low loading buses but people won't get out of your way. Maybe one bus per day is wheelchair-adapted?'

Social environment

Support to and by parents

Family, school and friends are important factors in the social environment for all in society. In France, the family is an essential emotional support for the handicapped child but also for the parents who have difficulties outside the home. 'Every family member is involved in the life of a child with cerebral palsy'. Likewise, in Italy the family is the most important resource available to the child in difficulty, but the family also usually feels inadequately supported by the state.

In the Ireland, resources for support are reported as inadequate 'we can't get a teenager to baby-sit our son, due to the requirements for a specialized sitter. This is very expensive, often too expensive to have time off'. In Sweden, support and practical help in the home are available which, although not always successful, can be good for the child 'it is very good with a helping person at home but it is difficult when there is a change in staff'. Excessive changes in personnel who help in the home can impinge on the family's right to privacy.

Parents in Italy considered the school to be the principal factor to improve social participation. The fact that there were no special schools was appreciated by parents even though there was a lack of specialized personnel in mainstream

schools. These difficulties increased significantly as the child moves up the system.

French and Danish parents stress that siblings make it easier to become socially integrated and accepted in school. Both Danish and Irish parents state that it was a big problem that the special schools were often located far from their homes, because friends then also lived far away. Another problem was addressed by a Danish parent saying 'to invite a friend with a disability demands that you are prepared to take care of two disabled children, we do not always have the energy for that'.

Bureaucracy

The difficulties associated with bureaucracy were a recurring theme discussed in each country and were felt to be a major factor affecting children. Bureaucracy is the largest barrier to obtaining financial entitlements in all countries.

In Italy, there are problems in obtaining grants and aids; the difference between the statutory entitlement and the daily reality vary and this is the key to the Italian situation. Due to lack of information parents are not aware of the great divergence between legislation and the reality.

In France, the whole process was reported to be time-consuming; parents have to argue to get administrators to understand the essentials that a child needs around the house to make everyday life easier. 'Financial forms take a long time to complete. It then takes 1½ years to get the Specialized Education Allowance.'

Similarly in the Ireland, numerous contacts have to be made to various departments to get, for example, adaptations and grants. 'It was recommended ages ago that we get a hoist for school, and it's only now months later that it's being put in. The department was so unhelpful. There were delays all the way.' 'In other words once a submission is made by occupational therapists, parents and services are powerless to do anymore. All they can do is wait for bureaucracy to kick in.'

Danish parents find that, although it is possible to get expenses reimbursed, often it is too time-consuming to bother. 'It is possible to get many expenses reimbursed, but it is much too time consuming to apply - consequently you do not apply

for help with everything.' Most of the aids for which the parents apply are granted. 'But nothing comes by itself; far too often it is a long struggle.' None of the parents thought they received any advance information as to what they might need for their children. Furthermore, they felt that social workers do not know enough about the specialist field of CP: 'the information about financial help is not adequate'.

In Sweden, the centre for aids and equipment was considered as a barrier for participation. 'You have to wait too long for everything; a wheelchair was delivered in small pieces after waiting months'!

Information

Parents feel isolated owing to lack of information, find things out through 'word of mouth' and often receive contradictory advice. This was summed up by Swedish parents who stated 'we need more especially need to know how to get the right information at the right time' 'Difficult to know what to do as a parent, we have to find out so many things by ourselves – we are tired of asking people in rehabilitation and the school for help, very tired!' Also in Sweden, special education has been reorganized and information about the changes was lacking.

In Italy, parents have great difficulty in finding information relevant to their needs and often receive contradictory advice. They are generally unaware of opportunities for holiday camps and holidays organized by the public institutions. Nearly all the parents said they had never been adequately informed about the rights of their children and their own rights as carers; or which public institutions to turn to for help. It is difficult to search out information personally, 'often receiving contradictory advice'.

Danish parents wondered why they must 'always try themselves to find the correct solutions.' Each child has many social workers as each has their own field of expertise. None of the parents thought they received any advance information as to what they might need. Furthermore, the social workers do not know enough about the special field they are dealing with. 'The information about available financial help is not adequate'.

French parents said that information is not accessible and information could be better disseminated to those who need it.

In the Ireland, no one individual outlines entitlements; it is usually known by word of mouth from a variety of people. 'You're often very isolated at the beginning due to the lack of information'.

Attitudinal environment

A Danish parent said 'it is irritating and unpleasant that people stare at us and our child in the street. It is OK for people to look and smile, but they should not stare. It was easier when she was a baby and simply looked cute'. However, in general, the parents agreed that in school the attitudes of teachers and classmates were positive and no one recalled episodes of bullying. Likewise, in Italy there were no serious complaints about negative behaviour from school mates or teaching personnel. On the contrary, the feelings of responsibility in integrated schools often helps overcome difficulties, although it is important to emphasize that there are no special schools in Italy so there is no alternative to integrated schools. Equally French parents said in general that they were happy about the attitudes of teachers and classmates: 'certainly, classmates view her differently but there is no anger, teasing or unpleasantness. French parents emphasized the importance of sibling support. However, parents said there was also some hypocrisy in the general attitude of the public towards their children when they go out – overhearing derogatory comments, for example. In the Ireland, one parent would like their child to be 'identified more as an individual and not as the disabled child and his whole life framed within this attitude.' And a Swedish parent said, 'You can never be invisible! Attitudes are negative; the children are tired of being stared at. It is better to be in a wheelchair than to use a walker'.

Finally, there were two specific issues that had not been captured by the preliminary work in England. The first was that parents in all countries thought there was a lack of knowledge of the medical aspects of impairments among staff in mainstream schools and that staff should receive more education about different medical conditions. The

second was that personal helpers for the child at home could be arranged in some countries.

Discussion

Cerebral palsy is the commonest cause of disability in children and it is estimated that there are 400 000 people living with CP in the European Union before its recent enlargement, with 10 000 new cases occurring each year. Our study outlines the difficulties faced by parents and families of children affected by CP in daily life. Many of these difficulties relate to the environment around the child and warrant in-depth analysis to inform public policy and legislation.

The similarities between parental experiences in each country are striking. Parents identified common barriers and facilitators in each country, and there was not a single issue that was unique to one discussion group. Sometimes however, the absence of an environmental factor was raised as a barrier to participation while in another group its presence was perceived as a facilitator, but this validates the issue as important and, of course, supports the hypothesis that some countries may have a more facilitatory environment than others. We have summarized some of these by illustrating the cross-cutting themes. At a more detailed level, mobility was an issue for Denmark and Ireland, transport for Denmark, Ireland and Italy. Excessive bureaucracy and poor availability of information regarding services and entitlements was an issue for all countries. Special schools in the Ireland and Denmark are far away from the child's home. With regards to holidays, an annual holiday for most is possible but in Ireland and Italy holidays are difficult with wheelchairs and appliances.

All countries complained of the excessive bureaucracy that they had to endure to get anything done for their child. The parents felt isolated because of the lack of information on rights, services, and the co-ordination of services. Parents said the information they receive is fragmented and needs to be better structured and co-ordinated.

Our study sought the factors parents thought relevant to their child's participation across different countries. We are exploring, in a separate study, the extent to which countries vary at the national

or macro level with respect to factors relevant to disabled children such as disability legislation, social security benefits, schooling policy and transport regulations – work described in an internal report available from the authors on request.

A difficulty for our study was that the discussion groups were conducted in five countries, speaking different languages and with different facilitators. However, each followed the same agreed protocol and the facilitators' first language was always that of the parents. A weakness in our study is that only parents participated. We do not have the children's views of what they find important in their environment to facilitate participation. Such views should be sought in future work, ensuring in particular that children with communication difficulties are represented and their views obtained via their chosen communication method. Communication aids are also an important facilitatory part of the environment and although they did not emerge from the discussion group work, the literature review in the earlier stage of instrument development had highlighted this.

We have not found other discussion group or focus group work investigating the environment relevant to disabled children. However, a study with disabled adults across 10 regions of the USA (Rimmer *et al.* 2004) used focus group methodology to identify barriers and facilitators to engaging in physically active lifestyles. This study was comprehensive but yielded a bewildering array of factors, with no obvious overriding or more significant factors. A strength of our study, perhaps because it had such a clear aim to facilitate instrument development, was that a small number of themes were identified – their significance determined by the parents of the children. The discussion group guide and subsequent discussions were not intended to allow completely free and open discussion about disability issues. The analysis of the transcripts presumed the conceptual background of the ICF and the emerging themes selected were those that would inform the content of an instrument. In the SPARCLE study (<http://www.ncl.ac.uk/sparcle/>) we are now collecting data from over 800 families across Europe about these environmental factors and relating them to the outcomes of participation and quality of life. The

intention is that the results will influence social policy across the European Union.

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