*Pediatric Rehabilitation*, July 2006; 9(3): 219–228

# A qualitative study of the physical, social and attitudinal environments influencing the participation of children with cerebral palsy in northeast England

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*(Received 1 January 2005; accepted 27 May 2005)*

**Abstract**
*Purpose*: The social model of disability considers participation to be determined by the social, attitudinal and physical environments experienced by an individual. This study aims to ascertain from families of children with cerebral palsy the features of such environments which facilitate or restrict participation.
*Method*: Thirteen in-depth interviews using a topic guide were conducted with the parents of children with cerebral palsy. Interviews were tape-recorded, transcribed and analysed with NVivo software.
*Results*: The main themes emerging from the interviews were the importance of mobility, transport, support by and to parents and attitudes of individuals and institutions towards children. Most parents did not raise the policies and legislation determining participation barriers, although these are also likely to be influential.
*Conclusions*: This study confirms the importance of the environment for the participation of children with cerebral palsy. Statutory agencies need to attend the attitudes and policies in their organization in order to plan the inclusive environments which parents report will facilitate their child's participation. This study also contributes to the development of a tool to quantify the environment to allow the development of models to determine the environments which maximize children's participation.

**Keywords:** *Children, cerebral palsy, environment, qualitative study*

*Propósito*: El modelo social de discapacidad considera que la participación esta determinada por los medios ambientes social, de actitud y físico, experimentados por un individuo. Este estudio tiene como objetivo determinar a partir de las familias de los niños con parálisis cerebral, las características de tales medios ambientes que facilitan o restringen la participación.
*Método*: Se condujeron trece entrevistas en forma profunda usando una guía de tópicos con los padres de los niños con parálisis cerebral. Las entrevistas fueron grabadas, transcritas y analizadas con software NVivo.
*Resultados*: Los temas principales que emergieron a partir de las entrevistas fueron la importancia de la movilidad, el transporte, el apoyo por los padres y para los padres, y las actitudes de los individuos e instituciones hacia los niños. La mayoría de los padres no promovieron las políticas y legislaciones que determinaban las barreras de participación, aunque estas pueden tener una influencia.
*Conclusiones*: Este estudio confirma la importancia del medio ambiente para la participación de los niños con parálisis cerebral. Las agencias que establecen estatutos necesitan prestar atención a las actitudes y políticas en su organización, con la finalidad de planear medios ambientes que incluyan a aquellos que los padres han reportado que facilitan la participación de sus niños. Este estudio también contribuye al desarrollo de una herramienta que cuantifica al medio ambiente, permitiendo esto el desarrollo de modelos que determinan los medios ambientes que maximizan la participación de los niños.

## Introduction

The social model of disability considers disability to result from the interaction between individuals and their environments rather than as something within the individual and that participation is determined by the social, attitudinal and physical environments around an individual. The model was developed in the UK [1,2] and a seminal book in 1990 [3] set out its essential features.

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ISSN 1363–8491 print/ISSN 1464–5270 online/06/030219–228 © 2006 Informa UK Ltd.
DOI: 10.1080/13638490500235649

The International Classification of Functioning, Disability and Health (ICF) [4], 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. By incorporating such a classification of environmental factors, the ICF takes strong account of the social model.

Much previous research has used a medical model of disability in which the important influences on participation are presumed to be impairments rather than environmental factors [5]. Some papers concerning childhood disability have described environmental influences in single settings such as schools [6–8] or home [9]. However, Palisano et al. [10] showed how important it is to consider different settings as levels of participation can vary widely between home, school and the wider environment. Hutchinson and Gordon [11] undertook structured interviews with 100 children, 10% of whom had cerebral palsy. Barriers to participation included uneven surfaces in the physical environment, increased dependence on adult supervision within the social environment and bullying in the attitudinal environment. They also mentioned the importance of institutional attitudes such as the absence of sign language facilities. Law et al. [12] identified social and institutional barriers as the most significant environmental barriers in their focus groups and interviews of families with disabled children.

Recent work in northeast England has shown that the degree of participation of children with cerebral palsy varies with district of residence [13]. The association with district remains when important case-mix variables such as impairments are taken into account. The implication is that such differences in participation are related to local environmental factors. This confirms the social model of disability [11]—that the environment must change or be changed to enable participation, not the person. This environment must be described and measured if the full significance of the social model is to be realized. The present study aims to identify these environmental factors, eliciting their nature and importance for children with cerebral palsy and their families; and in so doing contribute to the development of an environmental assessment tool for measuring the suitability of environments for participation.

## *Methods*

In-depth interviews were undertaken to explore the views and experiences of families of children with cerebral palsy. Families of children with cerebral palsy aged 4–17 years were identified from the North of England Collaborative Cerebral Palsy Survey [14]. The sampling strategy aimed to capture the range of parental experience rather than yield a statistically representative sample. Children were, therefore, purposively selected to represent diversity in terms of types and severity of cerebral palsy, living in urban, sub-urban or rural area. The families were invited to enter the study using a standard letter, information sheet and consent form. Of the families invited to take part, 28 responded and 26 of these expressed an interest in being interviewed. Of these, the first 13 families who replied were interviewed as time constraints did not allow further interviews.

Thirteen in-depth interviews were conducted. The interview structure was set out in a topic guide, developed from a literature review [15] and previous research undertaken in northeast England which had identified major domains of participation for children with cerebral palsy [16]; namely physical independence, mobility, participation in healthcare, educational participation, financial and economic participation and social and leisure participation. The guide introduced discussion of participation in home, school and community settings and allowed the interviewer to cover important areas of a child's participation, whilst at the same time providing sufficient flexibility for respondents to introduce their own ideas and concerns unbound by any pre-conceived categories of the researchers. The interviewer used open-ended questions such as 'What in your opinion are the good and positive things about the environment around you and your child that help you to take part in every day activities?' More specific questions related to the different participation domains and covered the physical, social and attitudinal environments within these domains. For instance, in the domain of physical independence, information was sought regarding the child's mobility at home and the child's independence in activities of daily living such as washing, dressing and going to the toilet. A typical question was 'Is your child/ young person able to get into all the rooms in the house you live in, if not why not?' Or for the educational participation domain, the families were encouraged to talk about travel to school, mobility within school and support for the child in the classroom and peer relationships.

The interviews were undertaken in the respondents' homes by a single interviewer (BW) and lasted between 45–150 minutes. All participants gave informed consent. The interviews were tape recorded and transcribed. The interviewer reviewed the transcripts, adding comments about whether the transcribed data corresponded to her impressions of the interview.

The transcribed data were analysed using a generative thematic approach, aided by qualitative analysis software package NVivo. The first three interviews were analysed independently by the interviewer (BW) and another researcher (SM) to identify emerging themes and provide inter-rater reliability for the themes identified. These were then adjusted or added to from analysis of the later scripts and discussed by four authors to identify a thematic framework for analysis. The agreed thematic framework was then applied to each transcript by the fifth researcher (KL) and environmental barriers and facilitators to participation were identified and coded within the themes. This analysis was then examined by the first four researchers and any disagreements were resolved, thus establishing further inter-rater reliability.

## Results and their relation to previous studies

Thirteen families were interviewed, but data are reported on only 12 due to electronic failure to transfer one tape recording to transcript. There were six boys and six girls, aged 5–17 years (by chance no parents of 4 year olds were interviewed). Interviews were undertaken with the child's mother in five cases, father in three cases and a grandmother in her role of main carer in one case. Three interviews were undertaken with both parents present. Children, although present during interviews, gave information in only two cases (child 5 and child 7). Nine lived in suburban, one in semi-rural and two in rural settings across the northeast of England. The children had a variety of mobility (six walking, six non-walking) impairments and associated impairments, as shown in Table I.

The data were explored to see whether environmental factors could be usefully grouped by ICF categories or in settings such as school or in relation to participation domains from the topic guide. However, what emerged from the thematic analysis of the interviews was that the environmental factors could most easily be grouped into four main themes, as shown in Table II: mobility, transport, support by and to parents and attitudes of individuals and institutions towards the children. These four themes operated across all participation domains. The mobility and transport themes relate to the physical environment, the supportive role of parents to the social environment and attitudes to the attitudinal environment as described in the ICF. The themes are further divided into barriers to and facilitators of participation. The terms 'barrier' and 'facilitator' are opposite sides of the same coin, but it is reported how parents generally reported: for example, parents reported lack of easy physical access as a barrier but did not single out ease of physical access as a facilitator. In reporting verbatim comments, those which best illustrate the relevance of the facilitator or barrier are quoted.

### *Mobility*

*Facilitators of participation.* The main facilitators of mobility were equipment and structural adaptations allowing access to places in the home and to the indoor and outdoor community environment. The equipment included wheelchairs, walking frames and hoists. Having an outdoor electric as opposed to manual or indoor electric wheelchair was seen as an invaluable piece of equipment facilitating parents and child's independence and participation in activities whilst at the same time reducing significantly the required level of support and supervision.

> Child 3 mother: '... his electric chair is a real help'.
>
> Child 4 mother: 'In due course, a powered wheelchair is going to be useful for his independence. But we're talking about a few years time. And if he wants to go out on his own'.

Some families had extensive adaptations to their homes in order to improve access and mobility for the children.

> Child 6 father: 'She has a downstairs bedroom, bathroom, shower and toilet. It's purpose built for her and we were involved in the plans. We have an intercom'.
>
> Child 2 mother: 'We have a through-floor lift. I think it's better than a stair lift—you just wheel her into the lift and it goes up, whereas if there's a stair lift then you've got to hoist her ...'.

*Barriers to participation.* The main barriers to mobility were also structural ones, operating both at home and in the community. These included steps, lack of lifts or ramps and poor path surfacing, making the use of wheelchairs difficult or impossible. Lack of space and the extra time required to use equipment was also mentioned.

> Child 2 mother: Talking about shops: 'Sometimes obviously the steps to get in and out can be a problem'.

Even in health service environments, barriers to access and mobility featured highly in respondents' concerns.

> Child 1 mother: 'The GP has a slope up into the surgery, the doors aren't good because the first door opens inward and the second door opens outward into the foyer so that's very difficult to deal with'.

Table I. Socio-demographic characteristics of the children and their families.

| Child | Sex | Age (years) | Cerebral palsy, mobility and health | House type | Location | Car ownership | Father's employment | Mother's employment |
|---|---|---|---|---|---|---|---|---|
| 1 | M | 5 | Cerebral palsy with stiffness. Moderate learning difficulties. Delayed speech. Limited walking with aids. | Semi detached, PP | Suburban | CO | F/T | N |
| 2 | F | 10 | Cerebral palsy with stiffness. Unable to walk. Severe manual difficulties. Severe learning difficulties, epilepsy, partial sight, feeding and communication difficulties. | Semi detached, LA | Rural | CO, adapted, DS | Not applicable | N |
| 3 | M | 11 | Cerebral palsy with stiffness. Walks with walker and uses wheelchair. Severe learning difficulties and severe hearing impairment. | Semi detached, LA | Suburban | No car | Not applicable | N, Grandmother is main carer |
| 4 | M | 11 | Athetoid cerebral palsy. Can walk without assistance for short distances, also uses wheelchair, epilepsy. | Detached, PP | Semi-rural | CO, not adapted | Retired, main carer | F/T |
| 5 | F | 17 | Cerebral palsy with stiffness. Can walk without aids, epilepsy. | Semi detached, LA | Suburban | CO, not adapted | N | N |
| 6 | F | 17 | Athetoid cerebral palsy. Unable to walk—uses wheelchair, severe manual difficulties; previous epilepsy. | End terrace. Adapted property | Suburban | CO, adapted | F/T | N |
| 7 | M | 14 | Cerebral palsy with stiffness. Unable to walk—uses wheelchair; moderate learning difficulties, epilepsy. | Semi-detached, PP | Suburban | CO, not adapted, DS | F/T | P/T |
| 8 | M | 17 | Cerebral palsy with stiffness. Unable to walk—uses wheelchair, severe manual difficulties, epilepsy. | Terraced, LA | Suburban | CO, not adapted, DS | N | N |
| 9 | F | 5 | Athetoid cerebral palsy. Walks with frame and also uses wheelchair, no learning difficulties. | 4 storey town house, PP | Suburban | CO | F/T | F/T |
| 10 | F | 14 | Cerebral palsy with stiffness. Unable to walk—uses wheelchair, limited speech. | Detached bungalow, PP | Rural | CO, adapted | F/T | P/T |
| 11 | F | 7 | Cerebral palsy with stiffness. Unable to walk—uses wheelchair; epilepsy, no speech—uses symbols and eye contact. | Semi detached, 3 bedrooms, PP | Suburban | CO, not adapted, DS | F/T | N |
| 12 | M | 9 | Cerebral palsy with stiffness. Walks unaided (wears splint), attends mainstream school. | Detached, 3 bedrooms, PP | Suburban | CO, not adapted | F/T | P/T |

PP: private property; LA: local authority housing; CO: car owner; F/T: full time; P/T: part time; N: not in paid employment; DS: part financed by disability scheme.

Table II. The emergent themes operating across all topic guide categories.

| Theme | Reported as barriers | Reported as facilitators |
|---|---|---|
| Mobility | • Structural access barriers to wheelchair use, e.g. stairs, kerbs, paths, doors, lack of lifts | • Specialized equipment, e.g. electric wheelchairs, walking frames |
| | • Inadequate space in design of public building restricts access | • Physical support and supervision from parents |
| | • Extra time required for activities | • Adapted home environments |
| Transport | • Access barriers in public transport | • Private transport large enough for equipment |
| | • Extra time and planning required for journey | • Good parking facilities |
| | • Lack of space for equipment | |
| Support by and to parents | • Lack of financial support to parents due to reduced earning capacity—giving up work to be carers | • Physical support from parents: lifting, etc |
| | | • Supervision from parents: mobilization and leisure activities |
| | • Lack of information | • Advocacy from parents: obtaining equipment and services |
| | | • Financial support from parents meeting equipment costs |
| | | • Respite care |
| Attitudes of individuals and institutions | • Staring or patronising attitudes of strangers | • Attitude of family in promoting child's independence: advocacy |
| | • Institutional attitudes | |

Choice of leisure activities was limited because of access difficulties.

> Child 9 father: 'We were going to go to Edinburgh but decided not to because there are stairs everywhere and you can't get around. What would normally have taken 5 minutes would take 20, it was impractical'.

Such access barriers have been reported by other studies. Berry et al. [17] found that the use of powered wheelchairs was restricted because of lack of space in homes, public toilets and within the aisles in shops. However, powered wheelchairs facilitate mobility and participation when the barriers to their use are removed, as was shown convincingly by Bottos et al. [18] in their study of introduction of powered wheelchairs rather than striving for independent walking.

Salvage and Zarb [19] reported access barriers as width restrictions in streets, kerbs, lack of ramps, allocated parking places and space. Pivik et al. [7] identified architectural barriers in school and the extra time required for children with mobility problems to get to class. Interestingly, mobility within the school was not a concern for the parents in the study, possibly because 11 of the 12 children attended special schools which were likely to have been suitably adapted for wheelchair use. The Social Policy Research Unit [20,21] also identified lack of equipment and equipment costs as barriers to mobility participation.

### *Transport*

*Facilitators of participation.* Time and again parents reported how vital good transport was for leisure activities, attending school and attending hospital appointments. Private transport and good parking facilities were the main facilitators to participation. Eleven families had private transport and this was a highly valued facilitator of family mobility.

> Child 11 father: 'Before we had the car we used taxis or we didn't go anywhere. We've had a car for about 4 years and we go everywhere in it, it's much easier'.
>
> Child 7 mother: 'He [child 7] does like the Metro so sometimes on a Sunday he and his dad go on the Metro to Tynemouth and come back in the car. No problems getting on and off'.

Public transport in some countries outside the UK was mentioned positively, with one family praising the Netherlands particularly.

> Child 10 father: 'We go to the Netherlands and they have been terrific. The public transport is quite geared up, this year we took a trip which involved getting on the train, a boat trip on the river and a steam train to bring you back to where you started. They had a ramp at the normal railway station, a wheelchair place reserved and when we got to the boat they took her on, there was a disabled toilet and a wheelchair lift'.

*Barriers to participation.* Barriers to participation included lack of space and time and problems with physical access to public transport. Using private transport presented some difficulties, namely the extra time needed for loading equipment and lack of parking facilities.

> Child 7 mother: '. . . because of the physical effort of getting [child 7] in and out the car for a short journey, I can't nip in the car and go off, I have

> to plan and think ahead what I'm going to do and if I'm going to take [child 7] what's the best way, which route to take'.
>
> Child 5 father: 'Parking at the shops is terrible; a lot of people use the disabled spaces. Builders' wagons use them. Traffic wardens just ignore it. If they put more pressure on them it might make a difference'.

Public transport was used infrequently because of barriers to access such as steps, narrow aisles and lack of lifts. When public transport was used, the metro train system was preferred to buses. Barriers specific to the metro were gaps between train and platform and stairs to the platforms at some stations.

Long distance transport was particularly useful for holidays, but difficulties included access barriers and lack of space for extra equipment and wheelchairs.

> Child 10 father: 'We haven't used a plane for a few years; we have too much equipment to make it practical. Apart from the wheelchair she's in, she has a sleep system she uses at night which comes in an enormous bag . . .'.
>
> Child 1 mother: 'It would be lovely to be able to fly off to Dublin for the weekend; doing that with [child 1] with all his problems; his big buggy, his walker and his sticks just as the basic is an absolute nightmare and you just think it's not worth going there'.

The literature on transport and childhood disability (as compared to adult disability) is surprisingly small. The findings are consistent with those of a Health Impact Assessment [22] in which transport was mentioned as one of the major barriers to participation of disabled children. Having one's own car was a crucial benefit for the families in the study because it gives more flexibility but also because parents can be confident that seat belts are adequate and the seating ensures optimal posture [23]. The experience of one family of excellent transport in the Netherlands shows what can be achieved. Tyler [24] describes how, for example, bus services could be re-designed and such knowledge about improved environments should be implemented. Whilst parents reported many barriers, it is clear that well-designed transport systems are great facilitators of participation for disabled people as they are for all people.

### *Support by and to the family*

*Facilitators of participation.* Much of a child's participation needed the commitment and support of adults. Parents mainly provided this, but sometimes grandparents helped. The main facilitators to participation, which will be covered in sequence below, were: physical support for activities of daily living and lifting; supervision of mobiliztion and leisure activities; and advocacy as parents sought equipment and services for their children. Respite care was also a facilitator of the child's independence.

Physical support for activities of daily living and lifting was required by many of the children for activities such as bathing, toileting, dressing and feeding, lifting. The major facilitator was the support required, particularly from parents.

> Child 8 mother: 'I lift him myself. We have two hoists, the bedroom one, an overhead one, breaks down all the time and is broken again and a bathroom one. In the mornings I can't hoist [child 8] because he's so stiff until he's had his medication, so I lift him, give him his breakfast, give him his medication and time to relax'.

Supervision of mobilization and leisure activities was required much more than for non-disabled children of their age.

> Child 4 mother: 'We're conscious of the fact that in the past he had minor epileptic fits. So we're conscious that someone's got to be there. For instance, when he goes swimming I obviously have to go in the pool with him, until they're quite happy about him staying there on his own'.

The increased amount of physical support required as children grow bigger and heavier can limit family activities.

> Child 7 mother: '. . . but as he's getting older he'll go on his knees and I have great difficulty getting him up so he's even more restricted to what he can do . . . As he's getting older it's getting harder because of his weight'.

These reports echo those from interviews with 100 families of disabled children conducted in Bath, UK [11]. Extra supervision needs and physical difficulties due to the increasing size were factors which affected many aspects of a child's mobility, manipulation, personal care and even communication. Beresford [25] also details the help parents have to give to their children with self-help tasks and mobility.

Advocacy was a further important support provided by parents which included 'fighting' for resources, adequacy of information, establishing good schooling and respite care.

> Child 5 father: 'Yes but we had to fight to get [motability allowance], we had the Disabled Children's Foundation involved. It took a long time to get it'.

Respite care provided a break for the parents, but it was the increased opportunities for their child's social participation which parents emphasized in the study.

> Child 4 mother: 'Unit X is a residential unit at the school and [child 4] actually goes there one night a week to give him a bit of development and independence'.
>
> Child 8 mother: 'He does a lot of things at school; most of his social life is at school. . . . Active Care takes him out when he's on holiday from school in term time'.

Robinson and Stalker [26] found the same and parents especially valued respite care with other families rather than at an institution.

*Barriers to participation.* The main barriers to participation were financial: meeting equipment costs and reduction in earnings and lack of information.

Although some parents were reluctant to admit it, the interviews revealed there were significant financial implications in having a disabled child which included the extra costs of equipment, adaptations to house and car, travel, clothes, laundry and consumables.

> Child 2 mother: 'In the past we've made the downstairs toilet for [child 2] and we got the stair lift. We paid for all that ourselves. When it came to asking for any kind of funding we weren't entitled'.
>
> Child 3 mother: 'We paid £3000 for the electric chair, we raised that. I wouldn't say he's cost me more, he doesn't ask for a thing'.

Dobson and Middleton [27] reported that the annual budget required for raising a disabled child is three times that of bringing up a non-disabled child.

For many of the families, earnings were reduced. One or both parents left work or took part time work in order to provide the extra support needed. In this study, of the 22 carers, nine worked full time, three worked part-time and 10 were not employed.

> Child 10 mother: '. . . if [child 10] were not disabled I would have gone back to work full time and that's probably the biggest difference it's made to the finances'.

In some cases extra support from grandparents meant that the parents could continue working.

> Child 9 father: 'We're very fortunate in that we have two sets of grandparents very close by. If we didn't have the grandparents I don't know what we'll do, one of us wouldn't be able to work'.

Benefits such as Disability Living Allowance were mentioned as facilitators, but lack of information about such benefits was reported as a barrier.

> Child 12 mother: 'It's very difficult when you haven't dealt with a situation like this before, you don't know what you're entitled to and what you're not entitled to unless someone, perhaps another parent, says to you did you know you can get so and so. I didn't even know you could apply for a benefit. It was the Health Visitor who told me about the DLA and made me fill the forms out, I wouldn't have bothered but she was adamant'.

Sloper and Turner [28] found that the highest areas of unmet need included provision of information about services and about the child's condition, childminding provision, services to improve the child's mobility and communication and help with transport and housing adaptations.

### *Attitudes of individuals and institutions*

*Facilitators of participation.* Attitudes of individual family members were not fully explored within the topic guide, but some emerged from observations by the interviewer and from the transcripts. Positive parental attitudes were inferred from the section on support by and to the family, in which physical support, supervision and advocacy by parents were essential for the child's participation.

> Child 6 father: '. . . if we we're going out for a drive we don't stop and think we can't go here because [child 6] can't get in, we just get there and see what we find'.

*Barriers to participation.* Reported barriers to participation were the attitudes of individuals and the ingrained attitudes of institutions.

Some difficult attitudes were people staring or being patronising.

> Child 12 mother: 'As he's getting older [child 12] is now getting to the stage where he'll say I wish people would stop staring at me, particularly when he's got shorts on and his splints visible. He gets embarrassed when people say 'what you have been doing to your leg?'
>
> Child 1 mother: 'We find more attitudes if he's using a walker or he's sitting in a big buggy, therefore he is stupid and we get a lot of 'hello poppet' and that type of thing rather than somebody just saying 'hello what's your name'.

The attitudes of strangers towards the child and family altered the choice of activity for some families.

> Child 11 mother: [in choosing a restaurant to eat] 'you choose your table very carefully because people stare, some more than others, so you tend to choose a table where she's still involved but she's not on show'.
>
> Child 8 mother: '[Child 8]'s been fed in a café before but he's quite a difficult feeder, he makes a lot of noises and drooling, dribbling which I don't feel embarrassed about but other people might. There's a little cafe we tend to go into and feed him, outside when it's a nice day'.

Some researchers have found that disabled children are at increased risk of bullying by their peers [7,29,30] and, although this was not prominent in the interviews, it was certainly raised as an issue by parents.

In general, respondents talked more about tangible barriers than they did about policies creating barriers to participation. However, some parents identified barriers inherent in systems such as the health service, local education authority and leisure industry.

> Child 10 father: 'One of the services that is a problem is wheelchair services. Everything takes forever. It's taken about 3 or 4 years to get the electric wheelchair organized. It's the waiting for assessment, waiting for money, waiting for approval, the paperwork to go through'.
>
> Child 1 mother: 'You write to the school saying that [child 1] is not getting occupational therapy and speech therapy, why not? And the school write back to say they haven't got the money from the education authority. So you contact the education authority, writing to the chief executive and say why isn't [child 1] being supplied with his education . . . then you go to the Secretary of State for Education, Estelle Morris; and after that you go to court. But who can afford to go to court? So Education sits there and does nothing'.

In general, families were not aware of disability legislation which might affect participation.

> Child 11 mother: 'I watch the news and if I hear something and it applies to us I'm interested in it and as [child 11] gets older these things will apply much more but I don't read up about it'.
>
> Child 12 mother: '[I would not search for information] unless it was something I needed to know about, but I think because we haven't come up against anything major we haven't felt the need to do that . . .'.

Hemmingson and Borell [31], in a study of the barriers to participation for children with physical impairments in mainstream schools, found it was poor organization that provided the most barriers to participation rather than physical barriers.

Access policies for buildings' design are frequently vague and poorly enforced [19,32]. Barnes [33] discusses the institutional discrimination against disabled people evidenced by the restrictions placed on mobility and access by poorly designed environments.

## Discussion

The ICF [4] describes the environment across three broad categories: the physical, social and attitudinal. As the thrust of the ICF is adult-oriented, there is a need to find meaning and relevance for the concepts in respect of the lives of children and their families. It cannot be assumed (indeed it is unlikely) that the environment which is relevant to disabled adults will address the peculiar problems of developing children and their families. This study tried to code the environmental factors according to the ICF structure, but the factors emerged disjointed, out of context. Thematic analysis revealed four themes which operated across nearly all participation settings: mobility, transport, support by and to parents and attitudes of individuals and services.

The themes identified are to some extent common sense, but the consistency with which they were reported by so many families means that attention can be profitably directed to alleviating barriers around the themes. For instance, for mobility there could be much easier access to powered wheelchairs; for transport there could be greater powers given to traffic wardens to prevent misuse of reserved parking bays; for financial support there could be regular surveys of the increased costs of caring for a severely disabled child; and for attitudes there could be work with media producers to ensure more realistic representation of disabled children in television, films and magazines. In order for parents to be more aware of law and policy relating to the environment they experience, they should receive more welfare rights advice and guidance on how to advocate.

The study methodology has a number of limitations. The study size was small but it used well-established qualitative techniques [34,35]. This study did not attempt to capture factors concerning family function, parental personality or coping styles which are also an important part of the child's environment. It is possible that families with high levels of participation may be more likely to respond to the invitation to be interviewed.

As the children in the study had cerebral palsy, with nine of the children using a wheelchair some of the time, it is not surprising that concerns about mobility and transportation were prominent. However, the children also had a variety of other impairments concerning learning, vision and language and this suggests the findings may be generalizable to children with other impairments.

The interviews showed that some families were restricted in the activities they undertake, so it might be important in future studies to ask what additional things they would like to do and why they do not do them. It would also be important in future to seek more systematically from the children themselves the facilitators and barriers about which parents might have been unaware.

### *Implications of this work*

In general, respondents talked more about tangible barriers than they did about policies creating barriers to participation. This may indicate a lack of knowledge of disability policies. Parents also tended to accept the environment as a given rather than something that could be changed. Parental reports of bureaucratic delay and obfuscation with the apparent intent to contain expenditure on equipment such as wheelchairs and on defined special educational needs betray unacceptable corporate attitudes. It seems that a vital component of corporate responsibility and responsiveness should be to undertake regular surveys of how public services and their intended integration are actually experienced by parents. There should also be a suite of local authority performance indicators directly relevant to childhood disability.

Parents reported the difficulty they have in understanding the complex web of potential financial, education and mobility benefits. This is not a new message, but it is a major criticism of statutory agencies that the situation does not improve. Either the regulations should be greatly simplified or there should be a more proactive attitude from public services to help families take advantage of what they are entitled to.

Planning improved or new services must enable the disabled child to experience the same 'ease' of living which the non-disabled experience. This requires two fundamental changes. First, service managers must facilitate integration between services so the child, as he moves through different environments to participate in say taking a holiday, is unaware of the necessary environmental adjustments being financed and planned by many agencies. A good example is that reported by the family on a day trip during their holidays in the Netherlands. The second fundamental change is that physical changes to the environment should use 'universal design'—that is a structured approach to environmental design and audit which maximizes the participation of all citizens. At its most elaborate, we should aim to incorporate a proper societal value for achieved participation of all children into the cost benefit equations which influence these crucial design decisions. One of the few examples of such practice directed to disabled children as compared to adults is the 'Good practice guide to developing accessible play space' [36]. This publication is well researched, consulted disabled children and makes practical recommendations based on experiences in a number of Local Authorities.

Finally, this work has provided information to help in the design of an environmental assessment tool to be used in quantitative work to describe the environments of children with cerebral palsy. Development of such a tool must initially take account of data available from other studies with children and from environmental instruments designed for adults [15]. This work has indicated additionally the need for specific questions to ascertain characteristics of the social and attitudinal environments as well as the more concrete and easily imagined physical environment. The prototype instrument is available from the authors on request. Such an instrument is essential if the social model of disability is to influence change on the basis of firm evidence. Quantification of the environment enables models to be developed to determine the optimal environment for maximum participation and these can then inform policy directed to alteration of the environment.

## Acknowledgements

We thank all the children and parents who agreed to be interviewed.

The study was funded by the Tyne and Wear Health Action Zone Child Health Group, as part of its Child Health Information Project. Ethics approval was obtained from the Joint Ethics Committee of Newcastle and North Tyneside Health Authority.

## References

1. Union of the physically impaired against segregation. Fundamental principles of disability. London: Union of the physically impaired against segregation; 1976.
2. Abberley P. The concept of oppression and the development of a social theory of disability. Disability, Handicap and Society 1987;2:5–19.
3. Oliver M. The politics of disablement. Basingstoke: Macmillan; 1990.
4. World Health Organisation. International classification of functioning disability and health. Geneva: WHO; 2001.
5. Beckung E, Hagberg G. Neuro-impairments, activity limitations, and participation restrictions in children with cerebral palsy. Developmental Medicine and Child Neurology 2002:44:309–316.

6. Simeonsson RJ, Carlson D, Huntington GS, Sturtz Mcmillen J, Lytle L, Brent J. Students with disabilities: A national surveyof participation in school activities. Disability and Rehabilitation 2001;23:49–63.
7. Pivik J, Mccomas J, Laflamme M. Barriers and facilitators to inclusive education. Exceptional Children 2002;69:97–107.
8. Shevlin M, Kenny M, Mcneela E. Curriculum access for pupils with disabilities: An Irish experience. Disability and Society 2002;17:159–169.
9. Stark S. Creating disability in the home: The role of environmental barriers in the United States. Disability and Society 2001;16:37–49.
10. Palisano RJ, Tieman BT, Walter SD, Bartlett DJ, Rosenbaum P, Russell D, Hanna SE. Effect of environmental setting on mobility methods of children with cerebral palsy. Developmental Medicine and Child Neurology 2003; 45:113–120.
11. Hutchinson T, Gordon D. Toward nationally useful definitions of disability: Final project report. London: NHS Research and Development, Maternal and Child Health, Department of Health; 2001.
12. Law M, Haight M, Milroy B, Willms D, Stewart D, Rosenbaum P. Environmental factors affecting the occupations of children with physical disabilities. Journal of Occupational Science 1999;6:102–110.
13. Hammal D, Jarvis S, Colver A. Participation of children with cerebral palsy is influenced by where they live? Developmental Medicine and Child Neurology 2004;46:292–298.
14. Colver AF. Annual report: North of England Collaborative Cerebral Palsy Survey. Newcastle-upon-Tyne: Regional Maternity Survey Office, University of Newcastle upon Tyne; 2000.
15. Mihaylov S, Jarvis S, Colver AF, Beresford B. Identification and description of the environmental factors that influence participation of children with cerebral palsy. Developmental Medicine and Child Neurology 2004;46:299–304.
16. Mackie P, Jessen E, Jarvis S. The Lifestyle Assessment Questionnaire: An instrument to measure the impact of disability on the lives of children with cerebral palsy and their families. Child: Care, Health and Development 1998; 24:473–486.
17. Berry ET, Mclaurin SE, Sparling JW. Parent/caregiver perspectives on the use of powered wheelchairs. Pediatric Physical Therapy 1996;8:146–150.
18. Bottos M, Bolcati C, Sciuto L, Ruggeri C, Feliciangeli A. Powered wheelchairs and independence in young children with tetraplegia. Developmental Medicine and Child Neurology 2001;43:769–777.
19. Salvage A, Zarb G. Measuring disablement in society: Working Paper 2. Gaining access: Disabled people and the physical environment. Policy Studies Institute. Measuring Disablement in Society; 1995.
20. Beresford B, Oldman C. Housing matters: national evidence relating to disabled children and their housing. York: Social Policy Research Unit, University of York; 2002.
21. Beresford B, Williams J, Lawton D. Community equipment: Use and needs of disabled children and their families. York: Social Policy Research Unit, University of York; 2002.
22. Farrel B, Elliott I, Ison E. Partnership with parents and disabled children. Health impact assessment of the All-Inclusive Wraparound Project for children with a disability. Environmental Impact Assessment Review 2004;24:245–254.
23. Falkmer T, Gregersen NP. Perceived risk among parents concerning the travel situation for children with disabilities. Accident Analysis and Prevention 2002;34:553–562.
24. Tyler N. Accessibility and the bus system: From concepts to practice. London: Thomas Telford; 2002
25. Beresford B. The needs of disabled children and their families. December Findings Report. York: Social Care Research 76. Joseph Rowntree Foundation; 1995.
26. Robinson C, Stalker K. Respite care—summaries and suggestions: Final report to the Department of Health. Bristol: Norah Fry Research Centre, University of Bristol; 1991.
27. Dobson B, Middleton S. The cost of childhood disability. July Findings. York: Joseph Rowntree Foundation; 1998.
28. Sloper P, Turner S. Service needs of families of children with severe physical disability. Child: Care, Health and Development 1992:18:259–282.
29. Stone E. Consulting with disabled children and young people. July Findings. York: Joseph Rowntree Foundation; 2001.
30. Watson N, Shakespeare T, Cunningham-Burley S, Corker M, Davis J, Priestly M, Barnes C. Life as a disabled child: A qualitative study of young people's experiences and perspectives. Edinburgh: Department of Nursing Studies, University of Edinburgh; 1999.
31. Hemmingson H, Borell L. Environmental barriers in mainstream schools. Child: Care, Health and Development 2002;28:57–63.
32. Imrie R, Kumar M. Focusing on disability and access in the built environment. Disability and Society 1998;13:357–374.
33. Barnes C. Disability and discrimination in Britain. London: Hurst and Co Ltd; 1991.
34. Mays N, Pope C. Qualitative research in healthcare: assessing quality in qualitative research. British Medical Journal 2000;320:50–52.
35. Murphy E, Dingwall R, Greatbatch D, Parker S, Watson P. Qualitative research methods in health technology assessment: A review of the literature. Health Technology Assessment 1998;2:1–274.
36. Office of the Deputy Prime Minister. Good practice guide to developing accessible play space. London: Office of the Deputy Prime Minister; 2003.