Understanding the Impact of Physical, Social and Attitudinal Environments on the Participation of Children with Cerebral Palsy in North East England

“The individual is rarely going to be altered very much whereas the environment slowly but surely can.” Thomas Shakespeare.

Project Report
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Introduction to document

This document is a comprehensive report of a qualitative study using interviews with parents to ascertain the environmental factors influencing the participation of 12 children with cerebral palsy in the North East of England.

The document contains background information about the study, describes the study design and methodology, the demographics of the families involved and gives a summary of the main themes of the interviews. The bulk of the document gives excerpts from the transcripts of interviews with the children’s parents to illustrate barriers and facilitators to participation. These are divided into categories as described in the data analysis section. A contents page is provided.

This detailed document is designed for reference and for other independent researchers to work from. The report will also be available in summarised form for the families involved in the study and in the form of a research paper for interested professionals.

Background to study

The ICF, International Classification of Functioning, Disability and Health defines participation as involvement in a life situation. In the ICF model, participation is related to body structures, the functions and impairments of these and also to contextual factors which include personal factors and environmental factors. Environmental factors describe the social, attitudinal and physical environment in which people live. These factors can have a positive influence on an individual’s participation, when they are referred to as facilitators, or a negative impact, when they are referred to as barriers.

Recent work in the North East of England has shown that the degree of participation of children with cerebral palsy varies with geographical location. It is possible that these differences in participation are related to local environmental factors. This study aims to address these environmental factors, eliciting their nature and importance for children with cerebral palsy and their families. The study is designed as a pilot to provide information for a large, multi-centre study which will look at the effect of environmental factors on the participation of children with cerebral palsy in North East England and across Europe. The information from this pilot work will contribute to the development of an environmental assessment tool to provide a measure of the suitability of an environment for the participation of children with disabilities.

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1 Is the participation of children with cerebral palsy influenced by where they live?, Donna Hammmal, Steven Jarvis, Allan Colver on behalf of the North of England Collaborative Cerebral Palsy Survey, (in press)
Roles of Professionals involved in study

**Lead Researcher:** Professor Stephen Jarvis, MD FFPHM
Community Child Health
Newcastle upon Tyne
(Study design, research protocol, application for ethical approval)

**Research team:**

Dr Philip Lowe, MScTech, PhD- Senior Research Associate
(Study design, research protocol and application for ethical approval)
Brenda Welsh, MBAOT- Consultant Research Associate
(Interviews, data analysis)
Dr Svetozar Ivanov Mihaylov, MD MSc- Research Associate
(Literature review, data analysis, written report, research protocol)

Dr Katherine Lawlor (written report)

**Persons with responsibility to patients included in study:**

Dr Allan Colver, Consultant Paediatrician North Tyneside
Dr Mary Gibson, Consultant Paediatrician Newcastle
Dr Christine Jessen, Consultant Paediatrician Northumberland

**Funding and Ethical approval**

The study is funded by Tyne and Wear Health Action Zone Child Health Group as part of the Child Health Information Project.

Ethical approval was obtained from the Joint ethics Committee of Newcastle and North Tyneside Health Authority

**Study design**

The study uses two techniques common in qualitative research: interviewing for data collection and a framework approach for data analysis.

Semi structured interviews were chosen as the optimal method for collecting the views and experiences of the families involved. A loose structure was required to allow the interviewer to cover as many areas of the child’s life as possible, but at the same time being flexible enough to allow the respondent to express their views and particular concerns.

The framework approach to data analysis involves: familiarisation with the data, identification of a thematic framework, indexing of the data using this framework, charting or rearranging of the data into the appropriate part of the framework and then interpreting the resulting scheme. The advantage of this approach is that some ideas and themes are identified prior to data collection, but these are added to during the data analysis. In this case the themes of environmental barriers and facilitators identified before the study were
informed by previous local research and a review of the literature. These themes were reflected in the interview topic guide.

**Study methods**

**Study Methods-Sampling**

Families of children with cerebral palsy were recruited using the North of England Collaborative Cerebral Palsy Register (NECCPR). The local NECCPR conveners for Newcastle, Northumberland and North Tyneside were approached to suggest suitable participants. These areas were chosen in order to provide a mix of urban (Newcastle and North Tyneside) and rural (Northumberland) situations.

The age of children recruited was 4-5 year olds and 12-17 year olds. 6-11 year olds were excluded as this group will form part of the future European Study.

The families suggested by the local NECCPR convenors were then invited to enter the study using a standard letter and information sheet and consent form. (appendix 1). Of the families invited to take part, 28 responded and 26 consented to interview. Of these 26 families, the first 13 families replying to the invitation were interviewed. Difficulties with tape recording and transcript meant that one interview was excluded, leaving 12 for analysis. Time constraints did not allow any further interviews.

**Study Methods- Qualitative Interviews**

The interviews were carried out by Brenda Welsh in the respondents’ own homes. In each case, demographic details were collected prior to the interview proper. These included; age, sex, type of disability, household composition, type and location of housing, employment status of parents and car ownership or access to a car. A topic guide of key questions and themes was used to provide the interview with a loose structure. The respondents were encouraged to talk in depth about areas they considered important, with questions tailored to their responses.

The topics listed in the topic guide (appendix 2) were chosen as a result of an extensive literature review, a review of the ICF (International Classification of functioning, Disability and Health) classification and previous research undertaken in the North East which identified major domains of participation for children with cerebral palsy. The latter research created a Lifestyle Assessment Questionnaire for Cerebral Palsy with dimensions of physical independence, mobility, clinical burden, schooling, economic burden and social integration.

The resulting topic guide was divided into categories including: home, education, mobility, transport, health related services, social environment and financial services. The prompts for each of these categories were designed to include the categories for environmental factors in the ICF, namely products and technology, natural environment

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2 The Lifestyle Assessment Questionnaire, Philip Mackie, Christine Jessen, Stephen Jarvis, on behalf of The North of England Collaborative Cerebral Palsy Survey, published by RMSO, Newcastle upon Tyne.
and human made changes to the environment, support and relationships, attitudes, services systems and policies.

The interviews were tape recorded and then transcribed. The interviewer added her own comments about whether the transcribed data corresponded to the impression and ideas that she took away from each interview, in order to provide respondent validation. Some alterations were made to the transcripts to match the original taped data.

**Study Methods-Data Analysis**

The transcribed data was reviewed by Brenda Welsh and Svetozar Mihaylov. A thematic framework was identified giving key concepts and themes. The data was indexed into categories according to these concepts. The index categories were partly assigned prior to data collection but these were added to during and after data collection, applying techniques of grounded theory. The categories were agreed between both researchers, indicating inter-rater reliability. The transcribed data was imported into a computer programme for qualitative analysis- QST NVivo, 1.1. This allowed some major themes to be identified. The data was also examined manually, increasing the validity of the study. The charting process whereby data was rearranged into the index categories was performed using the NVIVO programme and manual techniques. A comprehensive report was written by Brenda Walsh and Svetozar Mihaylov using the aforementioned categories to provide a structure. The report includes interpretation of the key issues. Each section was also re-coded according to the International Classification of Functioning Disability and Health (ICF) framework. This coding is represented in table form showing barriers and facilitators to participation for each section of the report. (Katherine Lawlor)

**Categories defined prior to data analysis:**
- Home
- Education
- Transport
- Health related services
- Social environment
- Financial Services
- Mobility

**Categories added during data analysis:**
- Attitudinal barriers
- Barriers to leisure and recreation

Also:
- Services
- Parental attitude
- Parental abilities
- Parental surveillance
- Factors affecting parental choice
- Time

Further categories added by reading of transcripts, these are not included in the Nvivo programme but are identified in the report.
Profile of the children with cerebral palsy and their families

12 families took part in the semi-structured interviews. The 12 disabled children with CP comprised 6 boys and 6 girls, aged from 5 to 17. They lived in suburban (9), semi-rural (1) or rural (2) settings across the North East of England. The children had a variety of mobility and health impairments (see table 1).
Table 1. Socio-demographic characteristics of the children with CP

<table>
<thead>
<tr>
<th>ID</th>
<th>Sex</th>
<th>Age, Years</th>
<th>Form of CP, mobility and health</th>
<th>House/type</th>
<th>Location</th>
<th>Car ownership</th>
<th>Employment status of parents</th>
</tr>
</thead>
</table>
| R1 | M   | 5          | Diplegia. Moderate learning difficulties. Delayed walking with aids. | Semi detached, PP | Suburban | CO, PP | F/T  
|    |     |            |                                 |            |          |               | N               |
| R2 | F   | 10         | Quadriplegia. Unable to walk with severe manual difficulties. Severe learning difficulties, stroke, epilepsy, partially sighted, feeding and communication difficulties. | Semi detached, LA | Rural | CO, adapted, motability | Not applicable | N     |
| R3 | M   | 11         | Diplegia, walks with walker and uses wheelchair. Severe learning difficulties and severe hearing impairment | Semi detached, LA | Suburban | No car | N/A | Grandmother is main carer- N |
| R4 | M   | 11         | Athetoid cerebral palsy, can walk without assistance for short distances, also uses wheelchair, epilepsy | Detached (5 bedrooms) PP | Semi-rural | CO, not adapted, PP | Retired, main carer | F/T |
| R5 | F   | 17         | Hemiplegia, can walk without aids; epilepsy | Semi detached, LA | Suburban | CO, not adapted, PP | N  
|    |     |            |                                 |            |          |               | N               |
| R6 | F   | 17         | Athetoid cerebral palsy, unable to walk- uses wheelchair, severe manual difficulties; previous epilepsy | End terraced. Adapted property | Suburban | CO, adapted, PP | F/T | N |
| R7 | M   | 14         | Quadriplegia, unable to walk- uses wheelchair; moderate learning difficulties, epilepsy | Semi detached, PP | Suburban | CO, 2 cars not adapted, 1 motability | F/T | P/T |
| R8 | M   | 17         | Quadriplegia, unable to walk- uses wheelchair, severe manual difficulties, epilepsy | Terraced house. LA | Suburban | CO, not adapted, motability | N  
|    |     |            |                                 |            |          |               | N               |
| R9 | F   | 5          | Athetoid cerebral palsy, walks with frame and also uses wheelchair, no learning difficulties | 4 Storey town house, PP | Suburban | CO, PP | F/T | F/T |
| R10 | M   | 14         | Quadriplegia, unable to walk-uses wheelchair; limited speech | Detached bungalow. PP | Rural | CO, adapted PP | F/T | P/T |
| R11 | F   | 7          | Quadriplegia, unable to walk-uses wheelchair; epilepsy, no speech-uses symbols and eye contact | Semi detached, 3 bedrooms. PP | Suburban | CO, Motability, not adapted | F/T | N |
| R12 | M   | 9          | Hemiplegia, walks unaided (wears splint) attends mainstream school | Detached 3 bedrooms. PP | Suburban | CO, 2 cars, PP | F/T | P/T |

Findings from 12 semi-structured interviews with families of children with CP, a summary of main themes

The interviews revealed a complex web of environmental barriers that influence the participation of children and young persons with cerebral palsy and their families in everyday life activities. The majority of the facilitators were simply the other side of the ‘barriers’ coin. I have not therefore reversed all of the reported barriers, but have included ‘facilitating factors’: those features of the environment that were reported to positively influence participation of the children with CP and their families.

Although the interviewer followed a semi-structured topic guide (appendix 2) as question prompts for the main topics of interest, the questions were open ended and respondents were given every opportunity to speak freely.

The topic guide was designed to reflect the social model of disability and to identify a wide range of features of the physical, social and attitudinal environment that families of children with CP consider as barriers or facilitators to their child’s participation in major life activities. These participation categories are: physical independence, mobility, health and social services, education, social integration and impact of child’s disability on the family budget.

The main themes to emerge are summarised below:

**Mobility:**

- Wheelchair inaccessible natural environment
- Wheelchair inaccessible public areas and open spaces in community environment
- The need of extensive and constant physical support and supervision
- The importance of space
- The importance of time
- Disabled toilets: lack of disabled toilets and /or unmet needs for special equipment in disabled toilets

**Transportation:**

1. **Private transport**

- Size of the vehicle (**space** is of major importance)
- Unmet needs for appropriate adaptations
- Unmet needs for special equipment
- Difficulties with parking

2. **Public transport**

- Inaccessible vehicles
- Inaccessible stops
- Urban-rural differences in relation to accessibility of the public transport
3. Long distance transport

- Unmet needs for assistive equipment
- Unmet needs for relevant adaptations
- The importance of space (to accommodate the relevant assistive equipment)
- Disabling transport policies: (luggage limitations, front seats in the plane are the most spacious and convenient but also most expensive)

Support and relationships

Parental support: supervision, physical support, advocacy and financial support:

Supervision and physical support particularly important for mobility and activities of daily living
Parents advocating for the child’s needs: e.g. with health and education services for resources

Support from grandparents: child care, financial
Support from other sources e.g. friends, other parents and also health, education and social services for information needs

Attitude to disability:

1. Other people's attitudes

- Staring
- Patronizing, talking down to the child
- Verbal abuse/ calling names
- Prejudices (preventing non-disabled children playing with a disabled child)
- Overly sympathetic attitude
- Visibility of disability: Public acceptance /tolerance varies from “We haven’t noticed that” (people pretending that they do not see the child) to looking disapprovingly (e.g. when the disabled child makes noises and spills food when eating)
- Bullying
- Mistreatment of disabled parking bays

2. Attitude of the services:

- Lip service to accessibility
- Exclusion policies and practices
- Attitude of the staff

Educational services:

- Mainstream schools vs Special school
- School transport
- School ethos
- Accessibility
- Unmet need for post school clubs and activities

**Barriers to using health services**

- Difficulties with parking
- Long waiting lists
- Unmet needs for special equipment
- Exclusion policies (e.g. council policy to locate dental surgeries on the second floor)
- Attitude of the staff
- Service expectation that one of the parents will be available to provide support for the child

**Financial burden on the family**

- One or both of the parents have to leave work to meet the high level of support needs required by the child
- Extra cost to cover the house/car/adaptations and assistive equipment needs
- Long waiting lists and difficult to obtain benefits and assistive equipment
- Travel expenses
- Clothing and footwear expenses (including washing powder)
- Recreational and leisure expenses (going on holiday is more expensive, co-payment for post school activities or summer clubs).
- Information about what is available for disabled children is often poorly targeted, timed and placed.
- Others (e.g. pads etc)
- Desired service and participating in activities they have joined

These themes are reported in detail in the following report, with illustrative quotations within the shaded areas. The identifiers from table 1, for example IDI for respondent 1, have been used to anonymise the views expressed by the parents of the children with CP.

**Key to data**

ID1: family 1
ID1F: father in family 1
ID1M: mother in family 1
ID1C: child in family 1

I: interviewer, text always given in black

Red text indicates a barrier to participation
Green text indicates a facilitator to participation

*Italic* type indicates transcript i.e. interviewer or respondents transcribed speech

**Bold** type indicates a theme or category

Note that a section of transcribed text containing several different themes may be included in more than one category.
Mobility

Barriers and facilitators related to mobility emerged as the major issue from the interviews that cut across all respondents accounts. (See table 2)

<table>
<thead>
<tr>
<th>ICF category:</th>
<th>Facilitators:</th>
<th>Barriers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Products and technology</td>
<td>Mobility</td>
<td>Mobility</td>
</tr>
<tr>
<td>1. Mobility devices (wheelchair, buggy, walking frame etc.)</td>
<td>1. Wheelchair inaccessible natural environment and public areas: steps, kerbs lack of/inappropriate ramps entrances, narrow doors, lack of/broken lifts, parked cars on the pavement, inaccessible/inadequate toilets + lack of special equipment</td>
<td></td>
</tr>
<tr>
<td>2. Adaptations of the environment to facilitate wheelchair access such as ramps, slopes at the end of streets, automatic doors/widened doors, lifts, flat access</td>
<td>2. Lack of own car, inappropriate size, not adapted car, unmet needs for special equipment</td>
<td></td>
</tr>
<tr>
<td>3. Having own spacious and adapted transport</td>
<td>3. Inaccessible public transport and stops</td>
<td></td>
</tr>
<tr>
<td>4. The amount of physical support and supervision required</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Natural environment and human-made changes to the environment</td>
<td>1. Wheelchair unfriendly natural environment: hilly places, little paths with rocks and twisty bits, gravel paths, muddy places, and inadequate road surface.</td>
<td></td>
</tr>
<tr>
<td>2. Uneven/cracked pavements</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support and relationships: Attitudes, values and beliefs</td>
<td>3. Space does matter</td>
<td></td>
</tr>
<tr>
<td>Transport: Accessible and adapted disability friendly public transport: low level buses</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trolleys, which fit on the front of a wheelchair</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Space does matter: wide aisles in the supermarkets</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Services, Systems and policies</td>
<td>Transport: low level buses are only on the main roads, attitude of some bus drivers, design of the transport vehicle does not provide enough space for disabled people (e.g. for special equipment)</td>
<td></td>
</tr>
<tr>
<td>Shops: Children’s section in shops is upstairs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Displays are close together, displays in the middle of the aisle</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Restaurants: Space</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tables are too close together</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chairs may be fixed to the table</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Safety road policies sometime become barrier for wheelchair use</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not in a category</td>
<td>The importance of time</td>
<td></td>
</tr>
</tbody>
</table>
## Facilitators and barriers to mobility in ICF format

<table>
<thead>
<tr>
<th>ICF category</th>
<th>Facilitator</th>
<th>Barrier</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Products and technology</strong></td>
<td><em>e115: products and technology for personal use in daily living; trolley to fit wheelchair when shopping</em>&lt;br&gt;<em>e120: products and technology for personal indoor use and outdoor mobility and transportation; wheelchairs, K frames, hoists, adapted car, adapted trike</em>&lt;br&gt;<em>e150: Design, construction and building products and technology of buildings for public use; ramps, adequate space, lifts, toilets operated by radar key</em>&lt;br&gt;<em>e160: products and technology of land development; ramps, good paths</em></td>
<td><em>e120: products and technology for personal indoor use and outdoor mobility and transportation; heavy electric wheelchair difficult to lift up steps</em>&lt;br&gt;<em>e150: Design, construction and building products and technology of buildings for public use; steps, escalators lack of lifts, unsuitable disabled toilets, lack of space eg displays in supermarket aisles</em>&lt;br&gt;<em>e160: products and technology of land development; kerbs, narrow paths, paths with unsuitable surface for wheelchair, poor parking</em></td>
</tr>
<tr>
<td><strong>Natural environment and human made changes to environment</strong></td>
<td><em>e210: physical geography; hilly environments, gravel paths</em></td>
<td><em>e215: population; busy places more difficult to negotiate with a wheelchair</em>&lt;br&gt;<em>e225: climate; precipitation can lead to paths becoming muddy and difficult for wheelchairs</em>&lt;br&gt;<em>e245: time-related changes; extra time required to get around in wheelchair and pack equipment</em>&lt;br&gt;<em>e250: sound; some</em></td>
</tr>
<tr>
<td>Support and relationships</td>
<td>$e310$: immediate family; constant supervision with wheelchair use, physical effort of using manual wheelchair. Grandparents provide childcare $e320$: friends; give advice about places that might be suitable to visit using a wheelchair $e325$: acquaintances, peers, colleagues, neighbours and community members; support from church grouping providing a rota of people to help with care of the child when mum broke leg $e335$: people in subordinate positions; helpful shop personnel, $e345$: strangers; help to move tables out of way of wheelchair in restaurant</td>
<td>$e310$: immediate family</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Attitudes</td>
<td>$e410$: individual attitudes of immediate family members; $e445$: individual attitudes of strangers; people being helpful and moving tables out of the way</td>
<td>$e410$: individual attitudes of immediate family members; parent feels less able to see her own friends because of care responsibilities, feeling of “being in the way” $e420$: individual attitudes of friends; advice from friends about leisure activities can be inappropriate because of their lack of understanding of the child’s need $e445$: individual attitudes of strangers; people parking inappropriately and so obstructing flattened kerb for disabled access, people bumping into wheelchair- not</td>
</tr>
<tr>
<td>Services, Systems and Policies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>--------------------------------</td>
<td>----------------------------------------------------------</td>
<td>----------------------------------------------------------</td>
</tr>
<tr>
<td></td>
<td>e515: architecture and construction services, systems and policies; Metro centre is spacious with good access for wheelchairs. Policies which have good planning for wheelchair access: wide aisles, lifts, ramps, slopes,</td>
<td>e515: architecture and construction services, systems and policies; narrow aisles, displays in aisles, lack of lift</td>
</tr>
<tr>
<td></td>
<td>e520: open space planning services, systems and policies; planning of urban environment e.g. high kerbs, inadequate paths</td>
<td></td>
</tr>
<tr>
<td></td>
<td>e545: Civil protection, services, systems and policies; traffic wardens not enforcing parking regulations in use of disabled parking bays by non-disabled people</td>
<td></td>
</tr>
</tbody>
</table>

It is necessary to point out that the responses to questions related to the impact of environment on mobility and the level of extra physical support required to assist the child, depended on two major non-environmental factors mainly:

1) Factors related to the family
2) Personal factors related to the child

**Factors related to the family**

The interviews revealed that the impact of environment on child’s mobility depends on certain factors related to the family:

- Parents perceptions of barriers to access in the community
- Family participation patterns
- Family demographic and socio-economic characteristics (e.g. age of parents, type of the family accommodation e.g. four floors town house vs bungalow, car ownership etc.)
• Attitude of the parents: some parents were more over-protective while others were trying to help their child to achieve independence.

**ID6F** School have said they wish more parents were like us because we do get A out and about where some kids get home from school and they don’t go out the door again until the next day for school. They are in their room and that’s it. A lot of parents have that attitude; we know some who won’t have a ramp at the front door. Why stay in during the summer holidays we should all get together for the day in the park with a picnic but it never came off.

**ID6F** If it’s something specific we’ll decide where we need to go for it but as a rule if we’re going out for a drive we don’t stop and think we can’t go here because A can’t get in, we just get there and see what we find, so we more or less find out stuff by trial. We wouldn’t actually phone up and ask about access.

*I:* Are the roads round here okay?  
**ID8M** They’re fine. If we go food shopping we make sure L is out on Active Care or we go when he’s at school. We try not to go with L.

### Personal factors of the child

**• Age/weight issues**

Families of older children with CP reported significantly more access **barriers** than families of younger ones. Ageing and gaining weight was found to influence mobility in two major ways:

- Levels of physical support required to overcome access barriers and care for the child (eg toileting) increase as child ages. Parents/grandparents are no longer able to provide appropriate physical support when accessibility problems arise since the child becomes heavy and difficult to manage

- Children with moderate to severe physical impairments become wheelchair dependent and their mobility deteriorates due to the high prevalence of accessibility barriers to wheelchair mobility in both outdoor and indoor community environment as well as in the natural environment.

Respondents revealed that in terms of physical support required it is relatively easy to care (eg toileting, lifting) for younger children with CP because they are lighter and easier to manage. As the child ages and gains weight, participation in activities is affected negatively due to the inability of the parents to provide the required assistance when accessibility problems arise.

**ID7M** He has loads of toys 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. I bring things down for him to play with here or he goes to play on his Playstation, but I tend not to let him until I know it’s nearer the time his dad will be in so that he can lift J up. He’s got
board games and things like that but now it’s getting to the point where we’re restricted because even getting him down can be quite dangerous but getting him up is even harder. As he’s getting older it’s getting harder because of his weight. (Moving around the house)

ID9F: At the moment it won’t be much of a problem because I can still lift her up but if she’s getting bigger it would be quite unwieldy because she can’t stand on her own so it would be a case of holding her up whilst trying to fold the wheelchair, then getting on and paying the fare. (Talking about getting into the bus)

ID10F: sometimes it seems the bigger she gets the less it is possible to do together. When she was small we’ll just pick her up and take her. Skiing was never a possibility but we’ll get her on a sledge holding her on your knee but you can’t do that with a 14 year old. Things where you have to get her out of her wheelchair and lift her into something else get harder and harder until you just don’t do them. Every now and then you realise there’s more things you don’t do that you used to do. Everything’s more restricted now. We used to be able to leave G with her grandparents but it’s getting much harder for them now they are older so that’s not particularly feasible.

I: So where do you think you found a problem?
ID2F: We actually stayed in a caravan for a couple of days. It was one with a ramp, but we found it was the bathroom, and that was very difficult, because it was a shower cubicle. Well, trying to bath her or shower in there was very awkward, but as, well of course when you’re in a caravan anyway you’ve got limited room and you can’t, you couldn’t get the wheelchair along there so you had to carry her.

I: She wouldn’t have been able to use the hoist either?
ID2F: No, well there was no room for one. I mean, with her being smaller it wasn’t so bad, but if it was a teenager or whatever, I think you would have a bit more of a problem. (Talking about going on holiday)

• Mental impairment: learning difficulties, epilepsy etc.

• Locomotion: severity of the mobility impairments
As expected, children with mild mobility impairments experienced less accessibility barriers, required low level of physical support and supervision by parents and carers, and enjoyed diverse and higher levels of participation in everyday life activities compared to children with moderate to severe form of mobility impairments. The latter group depended on wheelchair use, required higher level of environmental adjustments and physical support to participate in everyday life activities.

ID4M: Wherever we go we don’t really take much account of what the building’s like because he can do some walking for short distances, so we’re not governed by accessibility as much as other children.

I: So if there were steps to something, that wouldn’t necessarily be a major problem for you – you can get up the steps OK?
IDM4: Yes, just take Ashington main street. It’s probably about 100-200 yards from _ _ we won’t use a wheelchair for that we walk along there going to the shops

I: So it doesn’t make any difference really does it, as to whether there’s a step or something?
IDM4: Obviously someone’s got to be there for him because he’s still got that balance problem, in Ashington at one end it’s got a high step and he needs support to get up the
(Note: Certain level of physical support and supervision is required even for children with less severe form of CP. However, it is to a lesser extent compared to children/young people with more severe form of CP.)

ID12M: We don't have a problem with going anywhere. He goes swimming, we go shopping just normal family things and because W isn’t so badly affected we haven’t come across the problems of access and things like that. We don’t not do anything because of W. We go to the cinema, out for meals; he likes to go shopping at the Metro Centre then for coffee. We do a lot of walking with having the dog; we have a lot of family trips out to the beach or woodlands walks. He enjoys walking or taking his bike. He gets a little bit frustrated if we go to a park and there are big climbing frames with ropes and nets, he struggles with that type of thing, he usually gets to the top and then can’t get down or he falls halfway up. So we say be careful or don’t go up. There are no buildings we don’t go to because we have problems getting in.

Facilitators to mobility

Wheelchair equipment There was a universal agreement among parents of children with moderate to severe forms of CP that having a wheelchair is the major facilitator for their child’s independence, mobility and participation in major life activities.

Some parents emphasized that having an electric outdoor wheelchair is preferable to having an indoor electric or simply manual wheelchair. It facilitates and has beneficial effect on their child’s independence, reduces the level of extra physical support required for pushing the wheelchair in uneven/hilly terrain and improves opportunities for the family and the child to join in on community activities.

I: Is there any piece of equipment you would really like, that you haven’t got or anything you’ve got that you don’t need?
ID3M: I think he’s got everything; his electric chair is a real help.

I: Is there any piece of equipment you would like to have but do not have?
ID4M: 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.

ID7M: I’ve found in the holidays if I’ve taken J I’m limited to how much shopping I can get because I have to carry a basket, the trolleys don’t fit on to his wheelchair. This year because he’s got his power chair I’ve managed to get a trolley and put a few bags on the back of his chair and get a little bit more. He’s very good and enjoys that independence. He can go and look at the books and magazines while I go off to get something and I know he’s fine.

ID9F: Electric wheelchair with kerb climber: We have a little manual chair and a relatively new big electric one. (Had it a month or so). She previously had an indoor electric but now she has an outdoor electric. It’s a dual control so outside I drive because it wouldn’t be safe for her to steer herself. (parents taking control over the assistive equipment !???) It has a kerb climber, once we get used to it, it should be better than the manual. I find it
quite traumatic driving straight at the kerb and believing it will go and G gets a bit of a fright. If we're just going for a few things we walk and then the electric chair is a real boon because it pushes itself back up the hill, anywhere in Morpeth is up a hill. (Natural environment: Morpeth is hilly)

However, some respondents highlighted situations where a manual wheelchair was preferable to use in terms of access and physical support required due to the following reasons:

- An electric powered wheelchair is heavier than a manual wheelchair and can be difficult to handle when physical support from the parents is necessary to overcome accessibility barriers in the open space and built-up community environment.
- It is also larger in size and requires more space to manoeuvre and store away (eg to accommodate the wheelchair in the bus, train, or in the car)

**ID10:** We go to the bookshop and it takes a bit of getting into, two steps up and a narrow door. I drag her up the stairs backwards in her manual wheelchair. So I have to plan where I'm going as to which chair I put her in. We have to be careful which wheelchair we use if we're going elsewhere in Morpeth because a number of the shops have steps up and we could drag her in the manual chair but in the electric chair we haven't a hope.

While wheelchair use was seen as a major facilitator for improving a child’s mobility and independence, barriers to wheelchair access in the natural environment (eg hilly and rocky terrain, twisted paths etc.) and built-up community environment (eg lack of or inappropriate ramped entrances, kerbs, lack of/broken lifts, stairs, narrow doors and inappropriate or lack of disabled toilets etc) were reported to have negative impact on child’s mobility and participation resulting in:

- Restriction of the choice and the opportunities for the family and the child to participate in daily life activities.
- Increased level of extra physical support required to avoid or to overcome (lifting, pushing etc.) the environmental barriers to wheelchair access.
- Extra time required for planning accessible routes and avoiding barriers

**Barriers to Mobility**

Since the majority of the children in the sample had moderate to severe CP and were wheelchair dependent, barriers to wheelchair access in the open space and community environment emerged as the major theme from the interviews.

**Access barriers**

- **Barriers to wheelchair access in open space (natural) environment**:

  **ID8M:** We go to the Metro Centre quite often, once a week in the holidays because it’s easy access for wheelchairs. South Shields because that’s easy access to the beach, the walk way around the beach. We haven’t really looked into where we could go, not we can’t go there we can’t get the wheelchair round there. We generally just go to the same places. If we go out for the day we go to Berwick, Haggerston Castle because we know we can get him around.
ID1M: If you go out for the day you have to think where you’re going to go, Cragside is totally hopeless for disabled people but Wallington Hall is great, lots of flat hard paths for them to use.

I: So you find a great difference between certain environments that you use?

ID1M: Very much so, you’re very limited if you want to have a day out where you can go. Somebody might say Souter lighthouse is great and it’s fabulous but of course you can’t go up Souter lighthouse, or this walk’s really good but does it have a good path, a path through the wood is no good. All sorts of places that lead on to other places, public buildings you can’t go to.

I: So if someone said let’s go to such and such a place what would your initial reaction be?

ID1M: To ask them if they’re aware of it’s suitability for disabled people and possibly to go and look at it beforehand. I have my parents well trained, who now whenever they go anywhere will come back and say it’s suitable for P because there’s a really flat path and there’s no roads he can stray on to, and this is suitable for P because there’s a lift there and there’s decking and a slope and a ramp. But just to go somewhere completely out of the blue you run the risk of getting there and finding you can’t use it.

ID2F: grass and gravel surfaces.

Sometimes we have a problem with that, some things are slightly uphill, or if it’s on grass, grass is very hard to push a wheelchair on – things like grass or gravel, you just can’t.

I: Do you find a lot of places have got either gravel or grass?

ID2F: Now and then we find it. Farms and that we do, but farms you’ve got to expect the grass. Most of the places, she goes horse riding, it’s run for the disabled so they’ve got the facilities there. She goes to Brownies at the Church, and I would say it’s pretty good there really. Obviously, again, when they play outside on the ground it’s a bit more difficult, but we just kind of laugh with it if you know what I mean. She loves going over bumps and if you go over cobbles she loves it. Don’t you, bumpy-bump and you like it. And again, most of the kids, they know her. They’re quite helpful with her now. They’ve got used to her.

I: So I suppose you tend to go to the places that are familiar that you know that are going to be OK. It’s more difficult having to suss out the other ones.

ID2F: Obviously there is, it doesn’t matter where you go there’s always going to be somewhere where you can’t get in. be it a shop or whatever.

I: Is what you do affected by where you live, the amount of help you need, the length of time it takes to do something?

ID10F: We’ve tried very hard not to let it stop us doing things. We always loved to go hill walking and really we can’t, but we do try. If we go to Cragside there’s good access around the lake but most of the other paths are not wheelchair accessible so we can’t do them together anymore. Very often it turns out we go somewhere to walk and my husband and one daughter will go one way and G and I will take the other way round which is not ideal.

I: Is that because it’s not possible to adapt the other way?

ID10F: It would be very hard, at Cragside you’re talking about little paths with rocks and twisty bits. Wallington could probably do better than it does. Bolam could do better than it does. Sometimes you go places and they have paths that ought to be accessible and they’ve put gravel on them and that’s horrible to push on. Sometimes when they make
paths they haven’t had advice as to what would be an easy surface to push on. We don’t go places that are particularly muddy. The weather makes a difference; we take that into consideration when we go somewhere.

**Need for additional support and transport**

*ID10F* She’s a member of the Guides and where they meet is fine. When they go out places it’s more difficult and quite often we get a note saying we can’t manage this with G so she does miss quite a bit especially during summer when they do cookouts in the woods. They do try, they go bowling and she can manage that but I need to go as well because they can’t manage transport for her with the wheelchair.

**Barriers in the open space community environment**

*ID4M:* **Getting to places.** What is going to affect G, as he gets older more than it does now, is accessibility.

I: The actual getting to the place?

*ID4M:* everywhere. They don’t have ramps. They do, but they’re too high, they go round the back and if I’m on my own I won’t do it.

*ID4M:* A lot of this is historic. But what we’ve noticed especially and I touched upon this in the beginning. With the electric wheelchair we’ve become more aware of, certainly outside the estate, there’s high kerbs and what it means is that if he’s in that wheelchair, he wouldn’t be able to get out at that stage on his own. There would be a way round, which would be an extra _ of a mile through another estate. But what he was also talking about was even where the kerbs apparently are low; they’re still too high for small wheels at the front of that wheelchair. What G was touching upon, and we’ve talked about it haven’t we G, what you really need is one with the big wheels at the back. It wouldn’t make any difference to the kerbs outside our estate, the nearer we get to the main street in Ashington, the more wheelchair friendly it becomes. It’s actually getting there in the first place. Some parts, you have a kerb but it’s relatively low. That’s the basic design fault of the wheelchair.

I: But you can get kerb climbers (wheelchairs).

*ID4M:* The one we’ve got is on loan, it’s more of an indoor type powered chair. We’ve got that on loan, but the plus point of it all is that it’s made us more aware of the shortfalls and difficulties.

*IDM4C:* Can I say something? When you go to the road where I live there is a ramp. There are problems on the ramp, when you go down it.

*ID4M:* There is a slight bump. He could possibly just get up with the small wheels, but what they’ve done is, before we even moved there, put a fence against that lower part and the reason for that is, speaking to neighbours, because it’s an entrance road for cars coming into the estate.

I: It’s a safety thing?

*ID4M:* Yes, but even then we wouldn’t be able to get up to the path on the other side without crossing the road – about 50 yards up the road.

I: So it’s a hazard if you’re in a chair?

*ID4M:* In one respect it’s a safety thing, that’s good. But it’s caused a problem in another direction.

*IDM4C:* If I owned my own power wheelchair and I went on my own going down the ramp, you have to go down and drive on the road. There’s no ramp in there now. I probably can do it in North Tyneside.
I: You’re saying you would probably have to live in North Tyneside is that right?
ID4M: What he’s thinking of is not quite like that. He’s conscious of the certain difficulties getting around. We’re always aware that what we’ve got to do is to try and make G as independent as possible. Around Forest Hall, where P H School is, everything is wheelchair friendly, but as I point out to him that doesn’t mean that it’s like that at other parts of North Tyneside. What I say is you’re going to get these problems in different parts wherever you are, and obviously what he’s aware of, and this is his point, this is the factor he would have to take into account.
ID4M: When the application comes in for the powered wheelchair. I’m dying for the school to do that. They’ll take this into account. To be perfectly honest I’m sure that they’ve always been aware of that.

Uneven/cracked pavements, cars parked on the pavements:
ID1M: and there are places in town: shops, restaurants, cafes and museums you just don’t go to because it’s impossible. P has what’s called a K walker which he holds at the sides and it goes round the back of him and is on four wheels, which he uses to walk but there are some pavements which are very poor for him because they’re uneven with cracked paving. Recently the council in this area put in a lot of slopes at the end of streets so that you can get buggies and wheelchairs down off the pavement nice and easily.
I: Are they flat slopes?
ID1M: Completely flat, there are very good slopes at the end of our street but the residents often just park straight across them so they’re no good at all. If I’ve got P in a buggy who now weighs 34lbs or so and I’ve got his walker on the buggy so we can use it at the other end where We’re going and a change bag should there be an accident, because whilst he’s been toilet trained he still wets himself from time to time, and a bag with toys on I find it incredibly difficult to get P up a kerb because the buggy is so heavy, and you want to use these slopes and you can’t.
I: Do you find cars parked a lot on pavements?
ID1M: Yes not just on our street it’s a lot of streets. In the locality wherever you go the road is not particularly wide so people do park up on pavements.
I: So that restricts your access?
ID1M: Very much so, and you have to be very aware when P’s walking down that he’s well away from cars so he doesn’t make a gouge down the side of it.
I: It’s actually illegal to park on the pavement.
ID1M: You can see that if they don’t the street would just be blocked off so you can see why people do.

I: When you’re going somewhere is there anything you would have to think about beforehand?
ID9F: Wheelchair access, if it’s somewhere with a lot of stairs and there was an alternative we would take that. If it was somewhere we really wanted to go and it was going to be really awkward we would take B out of the wheelchair and carry her upstairs. We are aware that the time will come when we won’t be able to do that. We went to Lanzarote a couple of times because the first time we noticed it was all set up with ramps and lots of access. 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.

Barriers to wheelchair access in built-up community environment
Telewest arena – wheelchair inaccessible

ID2M: Yes. So you wait and sort of get out. Where else do we visit J? We went to the Telewest Arena when you went to see S Club Seven didn’t you? And we had a bit of confusion there. When I booked it I made sure that it was for wheelchair access and when we got there, there was no way a wheelchair could have got in. But where she actually ended up was looking down on the balcony, so it was probably better, because again, it was on the flat and she would have had people in front of her anyway.

I: What facilities do they have? Are they better?

ID2M: They have a small lift in the Arena to go up and down. In fact we didn’t really have a problem there. I mean it’s very busy there anyway, so it’s difficult to get around because when it’s a big concert like that, it was very busy, but I mean that’s not their fault.

The Theatre Royal

I: Do you choose places because of access?

ID10F: If we found access was a problem we wouldn’t go. Most local places aren’t too bad; the City Hall will let you in around the side. The Theatre Royal is quite difficult. We tend to go to the City Hall for classical concerts with G but we can’t get away with theatre performances because she doesn’t like people dressed up, she’s improving slowly but we could never take her to a pantomime. (I am not sure about this)

Shops

I: So there are some key reasons why you would use a building or a service?

ID2M: Yes. If it’s just we go shopping or something, I know a lot of shops, one in particular in Blyth, where the children’s section is upstairs, and they haven’t got a lift, so I mean sometimes I get quite annoyed. I say well, you’ve lost a sale because I’m not buying it without seeing it, you know. And obviously you can’t leave them while you go upstairs to have a look. So I mean there’s things that I’ve got – I mean if I was going shopping and I couldn’t get anything I would just go back (need for supervision)

ID10M Shops

I: What about shops?

ID1M: Supermarkets are fine because the aisles are nice and wide, a lot of other shops including shops in town you have to think, “Do they have a lift?” Adams sells children’s clothes; boys’ clothes are on the first floor with no lift only stairs. I can’t get P up there it’s impossible, he’s a 5 year old who can’t go up that number of stairs apart from crawling which he’s not going to do in a public place. I can’t get the buggy up there and I can’t carry him. There’s a lot of shops like that in town, there’s also a lot of shops where displays are so close together that actually getting through with a large buggy which is what we have, and presumably a wheelchair which is one thing that we will go onto before too long, is very difficult.

ID10F bookshop

ID10F: We go to the bookshop and it takes a bit of getting into, two steps up and a narrow door. I drag her up the stairs backwards in her manual wheelchair. So I have to plan where I’m going as to which chair I put her in.

ID10M: In Morpeth the supermarkets are generally fine, the access is fine and they have automatic doors and trolleys which fit on the front of a wheelchair so if I’m on my own I can do that. If I’m on my own I wouldn’t go to Liddells because their trolleys don’t fit on the front and I can’t push and tug at the same time. If we all go shopping as a family I’ll
generally use a big trolley and use G’s lap trap to give her a basket and she and her sister go off to find things and bring them back for me which she finds great fun. We have to be careful which wheelchair we use if we’re going elsewhere in Morpeth because a number of the shops have steps up and we could drag her in the manual chair but in the electric chair we haven’t a hope. We have a little manual chair and a relatively new big electric one. (Had it a month or so). She previously had an indoor electric but now she has an outdoor electric. It’s a dual control so outside I drive because it wouldn’t be safe for her to steer herself. It has a kerb climber, once we get used to it, it should be better than the manual. I find it quite traumatic driving straight at the kerb and believing it will go and G gets a bit of a fright. If we’re just going for a few things we walk and then the electric chair is a real boon because it pushes itself back up the hill, anywhere in Morpeth is up a hill.

**ID10F Church**

I: What does G do in her spare time?

ID10M: She goes to Guides, we’re church members so she comes to church with us. Access at church could be better, we’re working on that but they do have a small lift. The church has been very helpful over the years, I broke my ankle and they set up a rota of people to come in and help. She is a member of the 13plus group but she doesn’t go very often partly because she doesn’t want to but also they tend to go off and do things that might not be accessible and they don’t want mum tagging along especially my other daughter. That can be a problem if G needs me there to support her and the other one wants to just go off and be a teenager. We have friends we go and see. We have good friends who are in the same position so their house is adapted and is easy to get into as well.

**Impact of access barriers on choice**

Accessibility barriers were reported to affect family choices to participate in activities and visit places. It was suggested that environmental adjustments put in place to facilitate and improve wheelchair accessibility are often inadequate and inappropriate from the point of view of the wheelchair users.

**ID1M**

I: Do you find it difficult to rely on other people giving you information?

ID1M: Yes because people’s perception of what is suitable for disabled people including those people that run the house or museum are totally different to an actuality. People say that’s a flat path but it’s full of knobbly stones so the buggy goes bumping about all over the place so the poor child’s going to feel seasick. Or this is suitable for disabled people it’s just a little slope, but the little slope is so high to get up to, to get onto the next level it’s really very hard to push P up and coming back down you’re quite out of control.

I: It’s difficult unless you’ve actually experienced it then you can’t say what is right and what is wrong.

ID1M: Absolutely before we had P and before I was ill, because I used a wheelchair for a time, our conception of what was suitable and what is actually suitable for disabled people is totally different. You might think there’s a ramp there or whatever and it’s no good at all. So if we go out for days with P even if we’re here or away on holiday it’s not unusual to get somewhere and find it’s totally unsuitable. Therefore you go back to places that are suitable again and again.

I: So you tend to repeat where you’re going?
I: Is there a reason why you choose a particular building or service?
ID1M: Yes because it’s accessible and no because it’s not.

I: Do you go to some services or buildings without your child?
ID1M: Certainly if for example my parents have P for a day M and I can go somewhere and do something that we wouldn’t do with P because it’s easier. You haven’t got to think about lifts, ramps, and slopes because I can manage stairs and escalators to a degree which P can’t. You can go to places that P wouldn’t find boring or tedious which you can do with any child, but P although he’s five has developmental delay overall and so cognitively he’s much delayed, so we feel we’re dealing with a child who’s three for example so yes you do things without P which you wouldn’t do with him but equally I think there’s an awful lot of overlap there still with the fact that he’s a young child because all parents will do things by themselves without their children.

The importance of space (although you can get in easily it’s then hard to get round)

Space emerged as a specific and important barrier to wheelchair mobility. Shop policies of putting displays in the middle of the aisle and narrow aisles, crowds and lack of appropriate space for manoeuvres and getting around, and in some circumstances lack of space for storage of the wheelchair equipment were all reported to have direct or indirect impact on mobility and participation in activities.

Displays in the middle of the aisle, inappropriate disabled toilets:
I: Are there any particular reasons why you use a building or service?
ID10M: Obviously whether we can get in or not is important also whether we’re going to be welcome there. Locally, we can get into Safeway but they have a terrible habit of putting displays in the middle of the aisle, we have knocked one over once. Etam put things quite close together, so although you can get in easily it’s then hard to get round. When we have to go into the city to do shopping we’re likely to choose the MetroCentre because you can get everywhere, it’s easier to get around. You know it’s always going to be possible to get to where you want to be.

Narrow aisles, steps, trolleys that fit on wheelchairs:
ID2M: Shops – depends on the shops. Sometimes obviously the steps to get in and out can be a problem, but I find that a lot of the time once you’re inside, there’s either aisles, or they’ve got stands and things. You’re limited in where you can go with her and sometimes if you park to one side somewhere, it doesn’t matter where you’re parking, you’re going to block somebody, or you know she’s going to be in the way somewhere, so sometimes that can be difficult, depending on the shop again.
I: I suppose getting your shopping as well is difficult isn’t it? So do you just take a basket or something, or is there a proper wheelchair?
ID2M: It depends which shop you’re going into. If it’s like a supermarket, a lot of them do the trolleys to clip onto the wheelchair so it looks like she pushes the trolley and you push the wheelchair. In smaller shops it tends to be I would say that you hold them, or try to balance the basket on her handles, the handles of the wheelchair. I would say a lot of the time when I go shopping, you know when you go out physically for certain kinds of shop,
sometimes if I know that there’s going to be a bit too much or whatever, my mam will come and watch J while I do it or whatever.

I: You feel that it’s too much of a hassle?

ID2M: It’s not so bad round here because I mean with it being quite a smallish place and in general, if they don’t know you they don’t want you. In the summer in south beach she has an adapted trike, which has got a basket on the back so I can get my food in there.

Shops: narrow aisles and compact with things in the middle, lack of easily accessible lift

ID7C: I like to go to the shops, Game, HMV and Virgin for music and videos.

ID7M: Game is a very narrow shop so it’s difficult to stop and look, the aisles are very narrow and compact with things in the middle. You feel in the way with the wheelchair. HMV in Newcastle have all the videos upstairs and no lift, you have to ask to use the staff lift so consequently we don’t go there as often. Virgin is okay. He likes Fenwicks for toys and games; we can get up in the lift.

Supermarkets are spacious

I: Would you say, there is a reason why you use a particular building or a service, and how important do you place it in your, and J’s life? Say, I choose that building because, or I go there because?

ID2M: I use supermarkets for instance if they’ve got a certain kind of trolley that clips on – some of them are better than others and some of them aren’t very good for keeping on the wheelchair, so sometimes I try and avoid those particular shops and try and go to another supermarket which has got a better trolley for her when I’ve got J. Mind you it’s not too bad in the supermarket. It’s normally quite wide anyway.

Shops, stairs, restaurants, lack of lifts, tables are too close together, peoples attitude

I: So do you go to some services or buildings without J when you would like to take her but can’t? I know you’ve mentioned one or two places, but is there anything else?

ID2M: Again, it would be certain shops where you’ve got an upstairs where they haven’t got a lift available. Possibly certain restaurants, because the tables are that close together. But saying that I must admit generally, I would say people are quite helpful, generally. They would move their chair out the way, or they would make room for her.

Things are narrow

I: Some of those places that you go into are, the seats are fastened onto the floor aren’t they – and you can’t move them – so has that been a problem for you?

ID2M: If they’re too narrow and you can’t move it and it’s trying to find another way along, if you can get in another way you know. A lot of things I would say with J, is getting things close enough sometimes, say when she’s been to a farm and she can’t see the things to, they’re obviously fenced off or what have you – and it’s getting to things close enough so she can actually see these things, where other kids can go up to them and stroke whatever it is.

Tables are to close, crowded places

ID7M: Eating-places can be a bit awkward, Burger King is not disabled friendly at all, for wheelchairs and it’s too compact. Everything is too close together: the disabled toilet is at the back with a table right in front of it. What we’ve ended up doing if We’re hungry is
buying a sandwich from Greggs and sitting on the seats in Northumberland street, it’s easier and we have so much more room.

Crowds
I: When do you use these services and how often? Is there a certain time of day, how long and why?
ID1M: I wouldn’t say we use any of the services on such a regular basis or at a particular time. Obviously if we go somewhere with P it’s easier to go at quieter times because the buggy’s big and just getting through a lot of people can be hard work.

Crowds
ID6F Nine times out of ten she’ll go in her manual chair in the market because there are that many people there. It’s quite congested and people don’t see her in the chair so she ends up hitting a lot of people if she’s behind them and they stop to look at something. She doesn’t like being driven around, us taking over the controls on the electric chair. Sometimes she asks us to but it’s too heavy to push form the back with the wheels down so we tend to use the controls and walk alongside but it takes up that extra bit of space.

Toilet provision

Lack of/inadequate disabled toilet emerged as another important barrier to mobility restricting the choice of visiting places.

- Lack of enough disabled toilets (restricted only to the city centre and big shops)
- Toileting a child with CP outside home requires lots of support and assistance from family members. The bigger the child the more difficult it is to manage. Hence requires more extra physical support from the parents.
- Lack of essential special equipment need for toileting a child with mobility impairments. ID10 Lack of hoist, special seating, a big changing table (products and technology) (perhaps it depends on the severity of mobility limitations).

Disabled toilets: lack of appropriate special equipment
ID10F: We’ve never been able to use outside toilets at all. To get G to the toilet I need a hoist, special seating, a big table to undress her to start with so disabled toilets are completely useless to me. So it’s getting to be a problem, when she was smaller I changed her in the back of the van but she’s getting awfully big to try and do that. It’s not nice, it’s hard work and it’s not pleasant for her. She wears pads all the time. So far we haven’t said no we can’t do that, if we can change her we do and if we can’t we just change her when we get home. G doesn’t become particularly distressed if she’s wet. She would much rather wait and get changed when she got home than have me struggle somewhere else, she gets really distressed if I do it in the back of the van.

ID7M: not all facilities are provided with disabled toilets, it becomes problem when on short holiday and there is no previous information on where the disabled toilets are in the area
ID7M: I don’t think there are always enough disabled toilets in accessible places, like in the centre of towns. We have a radar key’ which is a godsend because if you see a sign for a disabled toilet and you get there and if haven’t got a radar key’ you can’t use it, but there needs to be more. In Newcastle we know where the toilets are, but we went to Filey for a
week and Bridlington and trying to find a toilet there was a nightmare. You go into a shop and ask if they have a disabled toilet and it’s only the big stores that do.

ID7M: He likes to go for walks in parks but it’s the facilities, toilets and things like that. In Jesmond Dene we’re now at the point because he’s so big and heavy there’s only so far we can go because it’s uphill or it’s not a proper path.

Other barriers suggested to impede mobility were:

- **Time:** eg restricted time for a journey (eg need to go back home for medication), time for avoiding access barriers and planning accessible routes.
- **Need for constant support and supervision**

ID2F: Need for constant support and supervision: the importance of time
I: You’ve probably got quite a bit of support coming in now as well – with all the home care and stuff and
ID2M: A lot of the time you find you’re quite restricted, quite restricting, and the fact that you’re very limited in what you can do because everything’s child engineered and where if you’re out at the shops you can’t be half an hour late. If you wanted to go and do something else you’ve got to be back for the certain time. I mean, I find that quite restricting. Obviously it means that on a nighttime you can’t just go off with her like other kids, other people put their kids in a car and go off and see one of their friends. You can’t do that, you know.
I: So you’re stuck here to the routines of things?
ID2M: Which, I mean, can get to you sometimes. It would get to anybody. But that’s just the way that it is, you know. But I’ve never, never really gone to a support group. I had a counsellor for a couple of years, but that wasn’t directly to do with J, it was through other things as well. I was there for about two years, but that was a lot of things all interwoven. But other than that, with having, as you say, with having so much, so many professionals involved with us, and home carers and _ We have social workers and what have you, in terms of. You don’t want any more anything else, so, as normal as you can

- **Low tolerance of children with CP towards noise,** (dressed up people perhaps related to noise)

low tolerance:
I: So there is a time limit that you’ve got?
ID1M: Absolutely. Whereas you’ll take a mainstream, average’ child as it were, out for the whole day and they’ll be quite happy because you’ve got the next thing and do and this, that and the other, P’s tolerance at doing something is much less.

Time:
ID 10F: You always have to bear in mind it will take much longer to get ready to go out than you think it will. We have to change G before we go, that would take 10 minutes when she was small but now with hoists and the size of her and her sitting brace it takes half an hour so you have to bear that in mind. If We’re going out in the morning we have to think if We’re going to get up early, three times a week she has enemas first thing in the morning so we have to work out if it’s one of those days. If we were on holiday and doing trips that take all day we’ll probably try to do them on days when we didn’t have to do that.
Need for constant one to one support even for children with mild mobility impairments:

ID5F: Staircases, if you into any buildings you’ve got to make sure there’s a hand rail on her left side because of her problem with her right side. On the tram at Beamish I had to get her to come down the spiral stairs backwards so I could keep hold of her. ID5F: So you have to think of things like that in advance, because she won’t use lifts or escalators. She’s been on an escalator before but she’s very wary. ID5C: I don’t like lifts that are closed in.
I: Would you use them if you had to?
ID5C: If there was somebody in it but not on my own.

Need for safe storage place:
ID4M: We went out yesterday to the Leisure Centre, I took him swimming and he went on the same day he went to Ashington, just say up the street. I’m very much aware that this was a good day and he had his power wheelchair. We were conscious of the fact that it was on loan and the Leisure Centre were quite happy to keep the wheelchair at the back of their office. We went out for lunch yesterday to Woodhorn Grange.
**Transportation**
Transportation emerged as the second most important themes related to mobility and participation of children with CP and their families.

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**Environmental barriers and facilitators to transportation in ICF format**

<table>
<thead>
<tr>
<th>ICF category</th>
<th>Facilitator</th>
<th>Barrier</th>
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<tr>
<td>Products and technology</td>
<td><em>e115: products and technology for personal use in daily living;</em> supported chair car seat, adjustable hospital type bed on ferry <em>e120: products and technology for personal indoor use and outdoor mobility and transportation;</em> wheelchair, car, adapted van with tailgate lift, metro and low level buses. Cars most valued means of transport, then metro (good access). Large size car important for carrying equipment Ferries with cabins for disabled. Wheelchair space on train. Disabled toilet on train. Motorised cars in airports <em>e150: Design, construction and building products and technology of buildings for public use;</em> Large double doors and lift at discovery museum, lifts at metro stations, ramps at train stations <em>e160: products and technology of land development;</em> adapted, flattened kerbs, bus stop nearby</td>
<td><em>e115: products and technology for personal use in daily living;</em> personal equipment requires extra planning to transport, and extra space, <em>e120: products and technology for personal indoor use and outdoor mobility and transportation;</em> narrow aisle in metro, lack of space on plane and coach for stretching out. Lack of room on plane for special equipment. Small disabled toilet on train. Inadequate design of disabled cabin on ferry. <em>e150: Design, construction and building products and technology of buildings for public use;</em> metro platform not at same level as train, steps between metro or railway platforms <em>e160: products and technology of land development;</em> inadequate numbers of disabled parking spaces, disabled bays not wide enough for</td>
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| Natural environment and human made changes to environment | wheelchair access, kerbs prevent wheelchair access  
|                                              |                                                                                                                                             |                                                  |
| Coaches cheaper than planes for longer distances. Concessions for child and carer |                                                                                                                                             |                                                  |
| Taxi travel is expensive                      |                                                                                                                                             |                                                  |
| Planning ahead required for booking suitable accommodation and places on public transport |                                                                                                                                             |                                                  |
| Support and relationships                     | physical support required for lifting child in and out of cars, for carrying child up steps or lifting wheelchairs up steps. Planning ahead required for booking suitable accommodation and places on public transport  
<p>|                                              | elegant classification                                                                                                                     |                                                  |
| Attitudes                                    | requirement to advocate for services on behalf of child, allowance of lots of time to get about.                                                                                                          |                                                  |
| Attitudes                                    |                                                                                                                                             |                                                  |
| Attitudes                                    |                                                                                                                                             |                                                  |</p>
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<th>Services, Systems and Policies</th>
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<td>e515: architecture and construction services, systems and policies; multi storey car park has adequate disabled access</td>
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<td>e540: transportation services, systems and policies; Planning of services e.g. provision of low level buses and time tables for these. Metro service usually has good access except for some stations. DFDS Seaways ferry had good facilities-disabled cabin with special height adjustable bed</td>
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<td>e520: open space planning services, systems and policies; planning of urban environment e.g. kerbs, inadequate disabled parking facilities- number of places and size</td>
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<td></td>
<td>e540: transportation services, systems and policies; buses with poor access for wheelchairs, stations with unsuitable access for wheelchairs</td>
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<td></td>
<td>e580: health services systems and policies; parking provision for hospital outpatient appointments is poor</td>
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<td>Motability scheme: this was cited by a few parents. It is a charity (e555: associations and organisational services systems and policies), providing schemes to supply cars and powered wheelchairs to disabled people who use their DLA mobility allowance , (e570 social security services, systems and policies) to purchase or lease the</td>
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Private Transport:

**Having a private vehicle (car/van/adapted vehicle) (E1)**

Car ownership was the second major facilitator for the child/family mobility after wheelchair use, positively affecting participation in activities. Only one out of 12 families did not have an own private vehicle and was reliant exclusively on public transport to get to places. Private transport was the most valued, convenient and preferable mode of transport for getting to places perhaps suggesting existing difficulties and access barriers for using public transport systems. The following quotes illustrate the importance of having a car for family mobility.

**ID4M:** I use the car. Each time if it wasn’t for the car, say if he was walking or in the wheelchair, there would be a problem in each case because of the problems of getting out of the street.

**I:** I think we’ve talked about going to places or not going to places because of problems with access. But I suppose that the difficulty for you living in Ashington is that you’ve got to rely on the car for a lot of the transport.

**ID4M:** We’re a bit fortunate because there could be children in that position that don’t have a car, so we’ve not got a problem, We’re more fortunate.

**I:** Do you use any forms of transport other than the car?

**ID5F:** No.

**I:** Do you have motability? Is it full or partial?

**ID5F:** Yes but we had to fight to get that, we had the Disabled Children’s Foundation involved. It took a long time to get it. She has full mobility for the car but only lower rate care. The car has definitely been a godsend for getting her round.

**ID11F:** 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.

**I:** You got the car through Motability, is it adapted?

**ID11M:** No she has the big special car seat. I just lift her in and out.

**I:** How often in the past week have you gone out?

**ID11M:** Most days in the car. Every weekend we’re out at least one day. V likes going out.

**I:** Do you use public transport?

**ID12M:** No, nine times out of ten I take the car anyway unless we’re going into town and it’s a treat for him to go on the bus. The bus stop is quite close and we have no problems getting on and off. He likes the Metro, that’s a treat because with having a car it’s something we don’t do very often.

- **Size does matter; the size of the vehicle: spacious /adapted car/van:**

The respondents expressed preferences for having a spacious, wheelchair accessible and adapted vehicle for several main reasons:
1. It provides easy access and enough space to accommodate all assistive equipment needed in everyday life for a child with mobility impairments (e.g., wheelchair, walking frame, extra luggage needed to meet the child’s specific needs etc.).
2. It facilitates and reduces the level of physical support required for getting the child in and out of the vehicle.
3. It facilitates and has positive effect on family participation in social and recreational activities by providing enough space for all other family members (e.g., friends, extended family).

I: Did you get the car on Motability?
ID9F: No we’ve had the car 3 years so it was just about when B was diagnosed. The next one we get we’ll look at the Motability scheme. In an ideal world we’d like a camper van because B is keen on the idea of camping but we’re not sure how practical it would be so a camper van with a lift on the back for a wheelchair would be ideal.
ID9F: Large estate car (school transport): It’s an estate car with a big boot to fit in a K frame and wheelchairs.

ID10F: Not since we’ve had the van. We’ve had it almost 3 years and it has made an enormous difference. I didn’t like taking her places on my own because I was worried I wouldn’t be able to get her out the car at the other end, lifting her from her car seat. It’s very hard to do with 2 people in fact so it was just a nightmare.

I: Talking about L’s wheelchair (putting it in the car)
ID8M: Very difficult, because you’ve got to put L in the chair and there are two straps at the back and you’ve got to lift the whole seat off so that has to lie flat in the back of the boot and then there’s another wooden block, that comes off and into the car and then the chair folds and into the car. I’ll love something where we could just fold it down and put it straight in the car, but obviously because of the way L has to sit and for the support this is the new one so this is bigger again. It seems every time the wheelchairs getting bigger it’s getting harder. At one time this base used to go into the car and he’ll sit in it and we could just lift him, that was 6 or 7 years ago and he’s getting bigger and his wheelchairs getting bigger. There’s not a lot of room after the wheelchair goes in, we should have a car adaptation where it just goes into the car but we’re 10 weeks before we need a new car so we haven’t got time to go into motor finance and ask them for a specially adapted car. Maybe next time.

Extra time (and space) for packing and take on board the required special equipment:

ID8M: We have the car but if we want to be out at a certain time we’ve got to start about an hour before to get the wheelchair sorted. Sometimes we feel D (son) would like to take a friend out with us and we can but it’s not very often because L’s in the back with me and D’s in the front so it’s a case of putting D’s friend at the side and we’re a bit squashed. I have to sit next to L in case he starts to topple over; he sits on the booster seat. We have a Ford Escort Estate, which the wheelchair will go in but if we go on holiday we won’t be able to get the suitcases in. We’ve had this car for 3 years and we haven’t been on holiday so it won’t become a problem until we start to try and go on holiday.

Need for spacious car:
I: Do transport problems influence the number of times or the times that you go out with P?
ID1M: Not hugely because we have a car at our disposal. We live next to a Metro station so that’s very convenient. P as a disabled child and I travel on the Metro as a concession which makes things cheaper for us and he has a school bus pass, during term time he travels free and with a small sum of money in holidays. We don’t often use the bus; there are buses available on our routes locally that are low level for taking buggies etc.
I: But they’re not on all the time though are they? Would you use them more if they were?
ID1M: possibly, possibly not. I personally find travelling on public transport tiring and the Metro is more convenient.
I: Would you use the car given a choice?
ID1M: With the difficulties of taking P about, by the time you’ve loaded the buggy up with all the various clobber that you need the car is more convenient. From the point of view of a car we have a Fiat Brava, which is a reasonable size, but we are thinking that next year or the year after as P’s walker, sticks etc get larger we are going to have to buy an estate probably. That’s a transport issue I suppose but at this stage there aren’t huge transport issues.

Barriers for using the car

- Inappropriate size, not adapted private vehicle (including special equipment such as mobile hoist)
- The importance of time
- Difficulties with parking

The importance of time:
Respondents told us that every car journey needed to be planned well in advance in relation to wheelchair accessibility and time needed for getting the child and all the assistive equipment in the vehicle as well as finding the most accessible place to get out.

I: Do transport problems influence the number of times you go out with B?
ID9F: Not at all. We have to plan though. We have the wheelchair, the reins, her earphones on, a padded hat in case she falls over and the K frame. You get into a routine with a mental checklist but we quite often forget something.

Physical effort to get the child in and out of the car, need to plan in advance:
I: Does transport influence the number of times you go out?
ID7M: In a way, because of the physical effort of getting J 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 J what’s the best way, which route to take.

Need to detour to find wheelchair accessible crossing:
ID4M: Nothing specific. You have to bear in mind, for instance coming along to the hospital we had to detour because we parked beside the Hancock Museum, we had to do a detour to get to a proper crossing instead of going straight across as we normally do, to get up the kerbs. But nothing really specific. This is where G has greater mobility as opposed to some other children with cerebral palsy,
Difficulties with parking

Disabled parking bays: systems and policies/special equipment

One of the major barriers to car mobility raised spontaneously by most of the respondents was difficulty with parking.

Disabled parking spaces are not sufficient, inappropriate disabled parking policies:

I: What public buildings for example libraries, swimming baths, school and what services, hospitals and doctors do you and P use?

ID1M: We certainly use hospitals; P goes to the Freeman hospital for hearing tests, which has very few disabled parking spaces. It has horrendous parking anyway, not enough parking spaces so it’s very difficult to park at the Freeman hospital. They do have a lift up to the first floor, which is great. He goes to the RVI sometimes and the General sometimes, both of which are okay using his buggy, but the parking again is horrendous. There are just not enough spaces overall and nowhere near enough disabled car parking spaces. The rules at the RVI actually say that unless the disabled person is driving the car you still have to pay even though you have a disabled parking disc, which is a nonsense because a 5 year old cannot drive a car.

Parking: need to allow additional time for finding a parking space:

ID1M: the actual parking when you get there is so difficult. So you end up setting off an hour and a half before your appointment time to make sure you can park. And if you can’t you’ve got time to walk there from wherever you can park. Because I haven’t got the tolerance, being ill, to be on public transport for a long time, to do a Metro journey and then a bus journey I find far too tiring, I’m reliant on people giving us lifts to and from the hospital.

Hospital parking: difficulty finding a parking space

I: How often has K attended the doctors, dentist and hospital in the last year?
ID5F: The RVI for the EEG 4 times, it’s about 18 miles away. Sometimes it’s difficult to find a parking space needed to get a parking space:

I: Does V go very often to the hospital?
ID11F: Just for regular checkups every 6 months. She’s very healthy since she had her tonsils and adenoids out.
I: Did you find any problems getting there?
ID11F: No. I tend to use the multi storey car park at the RVI because you can rarely get parked right outside, but there’s no problem I just wheel her along. I always give myself lots of time; I’m that kind of person.

Although there were policies in place designed to facilitate families of children with disability with parking three major problems were identified:
• Mistreatment of disabled parking bays especially during the weekends and peak hours.
• Failure to enforce accessible parking permit policies by the responsible authorities
• Inadequate disabled parking bays
• Parking fees

Inadequate disabled parking bays:

ID 1M: Postscript: When using disabled parking bays there are some that say they are for disabled people but they are not wide enough. Not enough space has been left for people to get out if they are using wheelchairs or special buggies. They have a sign but not enough space. About 50/50 of disabled parking bays are like this, and are usually in supermarkets/restaurants.

Shop parking: mistreatment of disabled parking bays and failure to enforce parking policies in place designed to assist disabled people:

ID5F: Parking at the shops is terrible; a lot of people use the Disabled spaces. Ashington is chronic. Builders’ wagons use them. Traffic wardens just ignore it. If they put more pressure on them it might make a difference. I’ve got stickers for K’s car but I wouldn’t dream of using them when K wasn’t there. I’ll rather go and find a normal parking space than abuse the system. The security man at ASDA explained that the disabled bays there are concessionary, given as a gift for the disabled, they’re not official so they can’t do anything if they are misused. Because they’re not local authority car parks.)

Shop parking:

ID4M: There are special bays. Like everywhere they tend to get mistreated.
I: Do you find that people park in them when they shouldn’t be parking?
ID4M: That’s one of the bees in my bonnet. We notice it at Asda and at the leisure centre on a Saturday morning. But other times we’ve got plenty of disabled places. But when it is misused it is on a Saturday and it’s for things like football training. They think they’re OK parking. They don’t think about anybody with disabilities. Even if we can’t get in, there’s G extra mobility as against other children with these conditions. It’s not such a great problem as far as we are concerned.

Museums: inadequate/wheelchair unfriendly road surface

ID7M: He likes museums; he’s been to the Discovery museum. That’s okay for getting around. It has large double doors at the entrance and a lift. Parking is a bit awkward. There’s not a lot of parking spaces, it’s cobbled and you end up parking on double yellow lines. There are only a few disabled parking bays that get taken by able-bodied people. We’ve been to the Baltic. It was very good.

Inadequate space to get the wheelchair out of the vehicle, space:

I: Would you say there was enough space at the side of the bays?
ID7M: The two I’ve quoted, yes. There are bays elsewhere when it’s not always the case. In fact when I first took early retirement – it might be resolved by now because I’m talking about four years ago – I did summer work at one or two _. Disabled bays there, there were about two or three, they were totally inadequate and I pointed it out to them with my experience of G. You couldn’t really open or shut the door properly. Now, OK the willingness was there, but it was done without the proper awareness. That might have been resolved. But I could see straight away, not while I was there, but they wouldn’t be doing anything during the summer anyway, because that’s when tourists come in. I know that there were plans to tarmac the car park, so it might have been resolved. That’s just one example that comes to mind. There are other examples. The Metro Centre, the disabled bays there, if you’re lucky, there’s plenty room there.

Policies that required disabled people to pay for a parking place:

Hospital parking:

ID9F: We used to have frequent visits to various hospitals to the point where it’s become a social thing for B, if you tell her she’s going to the hospital she’s quite pleased, she knows she’s going to lots of fuss. We have a disabled sticker and there’s usually disabled spaces we can park in. Before we had the badge we parked in the multi storey at the RVI and that was quite a faff. Similarly at Rake Lane we found it a bit off that you had to pay for parking if you’re going into a hospital. Most places you don’t pay at all.

Public Transport

Respondents revealed that public transport services present many obstacles to families of children with CP in terms of inaccessible vehicles, stops and stations, poor availability of accessible transport vehicles outside the main roads in urban areas.

Metro service

The Metro was seen by most of the families as the most accessible, convenient and desirable form of public transport. Respondents emphasised the major positive impact of the service for improving their access to places and participation in social and recreational activities.

ID10F: The Metro is closer and easy access so we tend to use that. I suppose it means we only go places where there’s a Metro station fairly close by.

I: Do you use any form of public transport when you go out?

ID7M: He does like the Metro so sometimes on a Sunday J and his dad go on the Metro to Tynemouth and come back in the car. No problems getting on and off.

I: If you think of somewhere new do you go and check it first or get somebody else to or do you hear about it?

ID3M: I fancy taking him to Wet and Wild and my eldest son say’s we’ll enjoy it but it’s the transport.

I: You’ve mentioned you’ll like a low level bus, have you used the Metro at all?
ID3M: Yes. We got it at Gosforth; we got a lift there. It was just for the experience, we try to let him experience what other kids get.

I: Was the Metro okay for you?

ID3M: No bother. He’ll rather sit in a seat than the wheelchair. Sometimes in the taxi we fold the wheelchair up and let him sit in the seat.

However, some respondents highlighted some obstacles in relation to accessibility of the service and stressed that there are still metro stations that are not wheelchair friendly. Lack of, and broken, lifts; gaps between the platform and the train and stairs that connect different platforms were all mentioned as obstacles to accessibility resulting in need for extra parental physical support or extensive manoeuvres to overcome these obstacles.

E2: Stairs (difficulties changing platforms)

I: Is there a time limit on how long you would be out?

ID1M: Yes including travel time to and from somewhere whether that’s by car or Metro. The Metro station is only a hundred yards away so we do use the Metro; it’s very convenient for us.

I: Is it accessible for you as well?

ID1M: It’s accessible in that we can join the Metro to go to Newcastle via Haymarket or the Central station then over the river from this side. If we want to go over to the other side of the platform to go to Monument and St James we have to go over the bridge and that’s all steps. So if we want to go over the bridge to the other side we have to come out into the street again along the road over the road bridge and down the next street to come back in so that is not accessible. It’s a real performance and there are still quite a few Metro stations like that, which is very inconvenient. So we do use the Metro and the car for travel but to go to and from somewhere and have our time out it’s about 4 hours before P’s asking to come home.

Platforms are connected with stairs:

ID9F: Asda is fine for access as is Tynemouth station with the exception that you can’t get over from one side to the other easily. Tynemouth Metro station has stairs. It wasn’t much of a problem when she was in her buggy, we could pick it up and carry her, now she’s in a wheelchair it’s more tricky we’ve mastered the art of bumping her up the stairs which I can do while she’s little. The only way around it involves going out of the station, up and around the road and back down the other side which is quite a hike. Wallsend library is very well adapted. Most of Wallsend is easy to get around with a wheelchair because they’ve adapted all the kerbs. She’s very pleased with the Metro because she’s noticed that there’s a little area with the wheelchair symbol, that’s her special bit. The station is about 3 minutes walk from us. No problem getting on and off, the stations have lifts.

Gaps between the platform and the train:

ID4M: Actually with some of the platforms to the Metro, they’re not quite right for wheelchairs. Some of them are perfectly OK, they vary.

I: So some don’t actually go quite as close to the side as they should do.

ID4M: That’s right. Sometimes the level’s not quite right. I think there’s one or two where it does cause a problem gap for a wheelchair.
Space (narrow aisle)

ID2F: So the only thing I think when we went to the Newcastle was the Metro, which my mum takes, because my mum lives in Monkseaton, so she goes on the Metro all the time, but what happens was, when we got to the station, the doors on the platform where we had to get off wouldn't open and you couldn't get the wheelchair up the aisle to get to the next doors, so one of my friends just said, we've got to lift her before the doors shut. Otherwise we would have had to go to a station where the other doors would open so we could get off and then go back again and which obviously wasn't, because we had to be there for a certain time and there were other children because a few of us had gone altogether with their kids. We had to literally, but if there had been anyone sitting in the seats, I mean we couldn't have done it because it would have hit their heads with the wheelchair.

I: So you had to lift it really high?
ID2M: So we had to lift it really high, yeah.
I: So the corridor, the little passageway, needs to be wider?
ID2M: It was just a little bit too narrow. But when I said to my mam she said, I've never had that problem. Typical! I think it was because of those doors not working in particular. Pity you can't get off the other side.
I: But that's something that you can't predict isn't it? Something would happen and people obviously haven't taken that into consideration. They think that when you go in you've got to go out the same way.

When metro is crowded space for buggy may be an issue:

I: Can you identify the good and bad points of the public transport that you use?
ID1M: As I said previously with the Metro its just problems at some stations with access but apart from that the Metro is great.
I: With the Metro you know when they're coming along too whereas with the bus you wouldn't have that facility would you?
ID1M: I think they do say on the timetable which ones are easy access. But we don't use the bus very often.
I: Do you have any problems going out with P in the wheelchair with using transport?
ID1M: Not really because it goes in the car and his big buggy goes in the car. We would tend not to go on the Metro at the rush hour time because the buggy is big, generally we have managed to get his buggy in the space for a buggy/wheelchair so that's been fine.

Bus services

Bus services in general were seen as less convenient and accessible form of public transport compared to the Metro. However, they were the most widespread and readily available mode of public transport.
Respondents emphasised the introduction of low-level wheelchair accessible buses as a positive step towards improving the accessibility of the service with positive impact on mobility.

ID10M: We gave up on buses a long time ago, although recently they've raised all the kerbs and they might be getting more accessible buses in Morpeth.
I: Do you use any form of transport other than the car?

ID11M: Buses on occasion before I had the car, the low liner buses. We’ve been on the Metro twice and had odd trips on trains, we’ve just rung up ahead and got the seats for a wheelchair and there’s been somebody there to help her on if we’ve needed it.

I: So you’ve had no problem with that, the facilities have been there each time you’ve requested it?

ID11M: It hasn’t been a lot but it’s been there. The very first time we went on a train C had booked the seats and we were miles back in the carriage, it would have been nicer if he’ll said we want this seat. It was a case of we don’t want to bother people but we’ve learnt if you want to be happy and comfortable and the facility is there and the child is entitled to it you have it. You don’t get anything you don’t ask for basically.

However, it was suggested that low-level wheelchair accessible buses tend to be on the major routes and less represented in rural, compared to the urban areas.

Low level buses underrepresented in rural areas:

I: Do you use the bus at all?

ID9F: We don’t use it very often and not since she got the wheelchair. At the moment it won’t be much of a problem because I can still lift her up but if she’s getting bigger it would be quite unwieldy because she can’t stand on her own so it would be a case of holding her up whilst trying to fold the wheelchair, then getting on and paying the fare. Some of the buses are low-level access but they tend to be on the major routes. The bus is probably the most complicated way of getting about. The Metro is closer and easy access so we tend to use that. I suppose it means we only go places where there’s a Metro station fairly close by.

ID8M: We have a low liner bus as well that takes us straight to the town and L loves it. But I can only go to certain places in the town, L starts to shout a lot, he doesn’t like going round the shops. He loves the bus and the Metro.

I: What are the good and bad points regarding transport?

ID8M: It’s better now than what it was. When K had his accident he wasn’t allowed to drive for 12 months and the low liners weren’t available then so we didn’t go anywhere. We got Active Care in and they took him out. That was quite difficult especially in the 6 weeks holidays. It was a long haul.

I: You can’t go on public transport?

ID3M: No. Newcastle is grand because they’ve got the ones that are lower and you can get the wheelchair on no bother. I was asking the bus driver if there’s any chance of us getting them at Bedlington? He said sometime.

I: So you haven’t actually got them yet?

ID3M: No, but we could do with something like that for him

I: You would use that, if you had something like that to get out and about?

ID3M: Oh yes. When there are a few of us going out for the day, we order a minibus and we just put together.

Low level buses underrepresented in rural areas:

I: Obviously you’ve got your own transport, so you won’t use public transport very much do you.
ID2M: No. Well, up here where we live we had a year where we didn’t have any transport for her. We had to really rely on other people because there was no buses that came up here that you could get a wheelchair on and which obviously is no good for J. We don’t have a Metro up here, so I mean basically, wherever we go it tends to be in the van.

I: Did you use taxis at all?

ID2M: I try to avoid them for, obviously, money wise. But when she goes down to my mam’s or whatever, she will take her on the Metro, and as I say I’ve never had a problem with the Metro, it’s only when I wanted to go to the arena. But obviously the Metro’s got ramps anyway so it’s good for J. But buses, we’ve never really dealt with buses. Wherever I go I tend to use the van. It’s much easier and if you go anywhere where any children come with us, I mean it’s a novelty to them to be in the van and to go in the lift with her and what have you.

Long distance transport:

One of the areas of concern in relation to transportation was difficulties and barriers for using long distance transport such as trains, planes and ferries/boats. Excessive luggage, inaccessible and non-adapted transport vehicles (eg lack of space and important assistive equipment, lack of disabled toilets) were often mentioned spontaneously as one of the major difficulties that families encountered when going on holidays or short breaks.

- **Inaccessible** and most often **non-adapted** transport vehicles (narrow seats, lack of disabled toilets)
- Unmet needs for special equipment on board of the vehicle (eg hoist, adjustable bed etc)
- Space barriers (extra room is required for accommodating assistive equipment. )
- Restrictive transport polices (excess luggage policies, front seat policies)
- Money (see financial burden)
- The importance of time: extra time required

**Barriers and difficulties for using long distance transport:**

- **The amount of extra luggage** including the assistive equipment which had to be taken on board and excluding practices of some transportation services (eg the baggage limits imposed by air companies, the most spacious front seats being the most expensive ones) discourage families from using some forms of transport such as air planes and restrict their holiday opportunities.

**Excessive luggage and assistive equipment is a barrier to use air transport:**

*Note: Are there any policies allowing higher baggage limits for disabled families travelling on a plane?*

ID10F: 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 sleep system which she uses at night which comes in an enormous bag its an symmetric sleep system it has a Velcro sheet to go on top of her own mattress, then a little mattress of it’s own which goes on top of that
and you put her in the middle and there are Velcro L-shaped cushions underneath to hold her in a good position to try and protect her spine and her hips, she tends to be very windswept and we were trying to control that. Then we have the toilet chair and that’s before you start on clothes, we need lots of clothes for her so it would be a nightmare on an aeroplane, we would have so much excess baggage and how to pack the toilet chair to go on a plane I can’t imagine. We were trying to work out whether to fly, my husband’s parents live in Switzerland and that’s a long way to get to in one go. When they were smaller we used to camp on the way but I can’t manage her in a tent any more, she’s too big to lift up and down. The only thing to do would be to send my husband and other daughter across with the van and all the equipment and G and I to fly out a few days later. We haven’t done that yet, we went to Holland instead because it was easier.

Excessive luggage:

I: What would be your ultimate pleasure?
ID1M: To go away and stay in a hotel. That’s difficult with P, you can’t be in a hotel with P because you’ve got to have that feeling to be able to come and go. It would be lovely to be able to fly off to Dublin for the weekend, doing that with P 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. So when we go away we do this country, which is lovely because there are lots of places to go in this country, in a holiday cottage that we have to book almost a year ahead to ensure we get a bungalow with no stairs. P is fine with our flight of stairs, he knows he’s not allowed to go up it but when you go somewhere else it’s new and you’ve got to set the boundaries which takes him a while to take all those on board. And equally when we go away here we have to think how long is the journey going to be. We’ll love to go to the southwest of England but can’t; it’s far too long a journey for P because he can’t comprehend it. You can’t say P from the time it takes you to go to school till when you come home that’s how long we’re going to be driving for means nothing. So really about four hours in the car is maximum with regular stops so that he can walk about, exercise his legs and so on.

Space emerged again as one of the major barrier issues related to transportation.

Design of the vehicle:
Lack of space between seats: Respondents revealed that children with mobility impairments need more space compared to children without disability for various reasons. Therefore lack of sufficient space between the seats in the transport vehicle combined with the higher cost and the restrictive policy to provide the most spacious front seats for business class passengers was another obstacle towards using planes.

ID12M: extra legroom required for the child (design of the transport vehicle: plane seats are too close together and policies that the most spacious seats are the most expensive ones +perhaps attitude of the service: “they don’t like children sitting there”
ID12M: If We’re flying anywhere we prebook the seats and ask for extra legroom for him, but if they give you the bulkhead seats at the front with nothing in front they don’t like children sitting there. There are certain seats we have been given and when we got on the aircraft the staff were really quite surprised that we’ll given these seats because we had children. That’s the only problem we’ve had when going abroad.
Money is a factor that determine mode of transport:

ID2M: Yes, So and I get that. I mean coaches are – the only thing I think, I know we went to Disneyland Paris a few years ago and we went on the bus because it’s that much cheaper than flying. I think for three of us – my mam came obviously to help me. I think it was over _1000 for three of us to go there for three days. Well on a coach you only pay a fraction of that really, but again it’s bad for her sitting for that length of time as well, because she has problems with her right leg and her hip. She had an operation on her hip and she’s actually going back in for another operation next year, so obviously sitting for any length of time I think would be hard for her, not being able to stretch out. It’s that sort of thing I think, you know. If you go further afield, if you want to go on a trip somewhere, that’s what the problems are because that’s when you’ve got to either pay a lot more to have a different kind of transport or drive myself. I mean I would like to take her to London but I’m not going to drive down to London. If I went on a plane I would be two minutes, so I mean it’s finding how to get down, the best way to get down with her or whatever.

Trains: space, narrow disabled toilets, accessible hotels:

ID7M: We went to London for a long weekend, which was good, but on the train he had to sit in his wheelchair for the whole of the journey, if you wanted what is called a disabled space. We had asked for that beforehand but we thought it would be nicer for J to actually sit in a seat than to travel in his wheelchair, which is not that comfortable. So it meant D lifting him out of his wheelchair, then when it comes to the toilet everything is so narrow that it was awkward. We used black cabs for getting around in London. We didn’t want to chance the underground when we didn’t know the system. The hotel was all right. We didn’t check it out beforehand but it was quite big and had lifts.

• Unmet needs for special equipment: Lack of special equipment on board the transport vehicle:

It was suggested that providing wheelchair accessible vehicles is often only a baseline requirement. Availability of relevant special equipment was seen as a major prerequisite for providing the opportunity for an enjoyable journey and to reduce the level of physical support required.

Special equipment and adaptations:

ID10F: We go to the Netherlands and they have been terrific, we go to a place where they have adapted bungalows. 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, a wheelchair lift on the stairs and when we got to the steam train one of the carriages was converted.

Boats: lack of special equipment to transfer/lift the child:
I: Do you find any difference in cost when you go out?

ID11F: It’s cheaper; V gets a lot of concessions. At the pool I don’t pay as V’s carer. We were going to go on a boat trip at Seahouses and I couldn’t understand why V wouldn’t be paying because she would be sitting like everybody else, taking up an area, and I was a bit put out when the lady said to spare V’s dignity there wouldn’t be any charge. And I thought why not, I don’t begrudge spending anything. I can understand concessions where she wouldn’t benefit but not when she’ll be doing the same as anyone else. We didn’t go in the end because the access didn’t seem very good; there was a ramp down to the boat but then nothing. There was no hoist; they would have to help us. There was nothing to tie the wheelchair down.

DFDS ferry; lack of special equipment:

ID10F: We have also used the ferry from Newcastle to Amsterdam to go on holiday, that’s great. They have adapted cabins and they park you beside a lift if you tell them you need to be. They’re very helpful and the disabled cabins are generally very good. They vary from ship to ship, some are a nightmare, I’ve been in one which had a wide door but was then ramped from the door to the other end of the cabin and it was terrible. That was the Hull-Zeebrugge crossings.

I: Do you ever get the feeling that it’s a token gesture that people have made?

That was a bit of a token gesture, it’s like you have a wide door what’s your problem? The DFDS crossing is much better. They’ve thought things out much better, one of the cabins we were in had an adjustable, hospital type bed, which was amazing.

Time

- **The importance of time**
- **Extra Time** was required in terms of packing and getting on board of a transport vehicle.

ID4M: When we go to the airport – we’re going to Majorca in the October half-term holiday. The arrangements are already made at the airports and they’ve confirmed that. When we go to the check-in we let them know the problems, we tell them he can walk short distances and we leave the decision to them as to how they want to do it. Because, yes, he can walk if he has to walk up some steps, but they won’t let him take his time. They want people in quickly and when we say can he take his time they always say we’ll put you on separately.

ID4M: We always take his own wheelchair with us and he goes in the wheelchair onto the plane so basically they wheel him, they insist on that and that’s understandable, they’re protecting themselves.

ID4M: Yes. We’re always first on the plane and last off and basically we just wait for them to bring the wheelchair round, especially in Spain, in Majorca, even when you’re last off, you’re often first with the cases because, in Spain they’re excellent. They insist on giving him these motorised cars. We went to Marrakech, the whole family went there when they were younger, there were two cars and one was racing the other.

Train Services
Inaccessible train stations:

**ID10F:** Trains are a problem, we would like to use trains more if we get off the other side of the station, if we didn’t have to be so careful about making sure that we’ve got the right train to come back, get one that stops at Morpeth. Other wheelchair users do the same thing, they make sure they get on a train that’s going to turn at Morpeth so they can go into the siding and come back, there’s nothing else you can do. It’s so restricting. It would be much better to use the train going into Newcastle, I don’t really want to try and park the car in Newcastle, but it’s a nightmare coming home again. We have used the Metro and that’s fine, it’s level. Sometimes they go on outings from school on the Metro.
### SOCIAL ENVIRONMENT

#### Barriers to Leisure and recreation

**Table of barriers and facilitators to participation in leisure and recreation in ICF format**

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<td><em>e110: products or substances for personal consumption</em>; provision of blended food in restaurant</td>
<td><em>e115: products and technology for personal use in daily living</em>; only single bed available in family disabled room</td>
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<td></td>
<td><em>e150: Design, construction and building products and technology of buildings for public use</em>; ramps in caravans, adequate space for wheelchair in caravan, disabled toilets and shower block in caravan site, disabled changing room in Elswick baths, good wheelchair access in UCI cinema</td>
<td><em>e150: Design, construction and building products and technology of buildings for public use</em>; stairs in cinema, lack of adaptations in old or listed buildings, slow chairlift in Hancock museum, lack of space for wheelchair in caravan, lack of lift in travel lodge hotel, lifts long way from place where needed, limited number of disabled rooms in Travel lodge hotel</td>
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<td><em>e155: design, construction and building products and technology of buildings for private use</em>; Facilitators for private caravans as mentioned above</td>
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<td><em>e160: products and technology of land development</em>; ramps in Flamingo Land, good access to beach, jetties provide firm ground for wheelchairs</td>
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<td>Natural environment and human made changes to</td>
<td><em>e210: physical geography</em>; hard sand on</td>
<td><em>e210: physical geography</em>;</td>
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<td>Environment</td>
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<td><em>e215: population;</em> child dislikes crowds</td>
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<td><em>e225: climate;</em> child dislikes extremes of temperature and rain on face</td>
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<td><em>e240: light;</em> strobe light induces epilepsy, therefore family avoid this</td>
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<td><em>e250: sound;</em> some children dislike noise e.g. police car or ambulance</td>
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**Support and relationships**

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<td><em>E320: friends;</em> give advice about places that might be suitable to visit using a wheelchair</td>
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**Attitudes**

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<td><em>E410: individual attitudes of immediate family members;</em> parent irritated by people staring, parents not keen for child to go on fairground rides by self because of potential injury</td>
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<td>Services, Systems and Policies</td>
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The vast majority of respondents stressed the importance of going on holidays and involvement in leisure activities for both the child and the family as whole.
Access to leisure activities including going on holidays emerged as one of the main cause of concern affecting the choice of leisure opportunities.

Wheelchair access is a counterpoint:

I: Do you check places out before you go?
ID2M: A lot of the time. If we’re going specifically to a place obviously I would phone up to make sure that it was accessible, like we did for the concert. I phoned up to make sure that there was wheelchair access. The same when I went to Flamingoland. I phoned them up and made sure that there was wheelchair access around and it was a caravan with a ramp and what have you.

ID7M: He likes museums; he’s been to the Discovery museum. That’s okay for getting around. It has large double doors at the entrance and a lift.

I: So is what J does in his spare time affected by where you live, the amount of help you need?
ID7M: Definitely. Being sure when you go somewhere that it’s wheelchair friendly. We try to check that first, or if we got somewhere we’ll turn around and come back if it wasn’t.

The most commonly cited barriers to leisure and recreation were as follow:

- Barriers to using a long distance transport (see Transportation)
- Access barriers (eg in natural environment and leisure facilities environment).
- Exclusion policies
- Need for constant support

- Access deprivation to leisure activities

Access deprivation to leisure facilities emerged as one of the main areas of concern to many respondents. Access barriers in both natural and built up community environments were reported to prevent families of children with CP participating in recreational activities. In some cases improved access was associated with high cost which contributed to the financial burden of disability on the family budget (eg small cinemas are cheaper but inaccessible compared to the big cinemas).

Small cinemas are cheaper but inaccessible: stairs, USF is accessible:

ID2F: I mean like in summer for the cinema for instance I go to the big one rather than the little one in Blyth, because it’s all stairs and of course it’s cheaper to get in slightly in smaller ones, it’s been there for years, but obviously I've got to go to the one that’s got the access for J, so I suppose in that respect I prefer to choose the UCI.

Lack of lifts in the listed buildings, stairs, special eating requirements:
I: What kind of places do you visit, how often do you use them, why do you choose them?

ID11M: Parks, swimming pool, country parks. V loves the park but she’s limited to what she can use, she can’t use anything on her own. As regard old buildings there are not always the facilities for her to see it properly because there aren’t lifts and things but we manage to lift her chair up and into all these places so she sees everything. We went to Bamburgh castle and the highlight for her was being lifted up the stairs in her chair, it’s not really practical we need better access really but I realise listed buildings like that can’t have lifts and things. The Hancock Museum has got a stair lift but we’ll have got up quicker carrying her in the chair because it was so slow. The swimming pool is not a problem, we go to Elswick pool which is geared for the disabled and we get the big disabled changing room so we can all go in there. We don’t book it, its usually available. They have hoists to get her into the pool when she gets bigger.

I: Would you say there’s anything else that would stop you using certain buildings?

ID11M: Just the stairs. In parks it would be nice if there were something geared more for disabled children. There was someone doing a survey in the park and I mentioned it would be nice to have a swing for a disabled child, they can be used by any child as well, just so she can sit on her own and not on my knee, a bit of independence. Paths aren’t much of a problem and with Exhibition and Leazes Park we can drive because V has her blue badge. Shops can sometimes be a problem, the older shops. Lifts tend to be miles from where you want to be. Going out to eat can be a bit of a problem, she’ll eat whatever we have as long as it’s slightly blended and I think more places should have the facility where you could ring beforehand and explain you have a child with feeding difficulties and arrange that then she could eat what we have because she loves that, being out.

Inaccessible natural environment: beaches:

ID9F: If there is we haven’t come across it yet.

One thing about access which I can’t see a way of getting round – the beach. It’s virtually impossible to get a wheelchair over sand. We can carry her now but in the future I’m not sure how we’ll do it. She can walk if someone holds her steady but it’s slow progress.)

Inaccessible natural environment: beaches, country parks:

ID11M: It would be lovely to go for walks in country parks but you end up having to go over stiles, we can put her in a backpack but she’s getting too big now. So more access so you can get to the little areas where you may have to climb to get to because they’re the interesting bits. Bolam lake isn’t too bad because they have little jetties that go out into the water, beaches are hard. The only one I’ve found easy is at Beadnell, its totally flat and easy to get onto. Other places you can get fairly near to the beach but can’t get over to where you want to sit. But how do you sort that one out? You’ll have to be segregated off. When you’re dragging the wheelchair up the beach you feel like you’re the complete focus of attention, everybody’s staring at you and that irritates.

I: But would you choose, say for example if you went on holiday,

ID4M: Yes, that’s true. We always have a word with the agent. We don’t go on last minute deals because we want to get one that’s good for G, to make sure they’re OK. But we
always check the resort to make sure it’s flat. It’s all right for muggings, he’s in the wheelchair, but we’ve got to push him! For instance, let’s take Gran Canaria – a few years ago. Playa del Ingles. That’s fairly flat, that’s not bad. But there are a lot of hotels which are basically on the side of a cliff. We checked for level before we went.

I: So you would ask the travel agent about it?

ID4M: Yes, they’ve got a black book at the back where they go into more detail. But we’ve got a computer and we also go on the Internet at home and make enquiries and check on that. For instance, next year it’s my 25th and we’re going to go away ourselves next year and his elder brother’s going to keep an eye on him. The one place we’re looking at is Madeira, which is a place we wouldn’t go with G because it’s very hilly. So the opportunity of going somewhere there which we’d like to go to wouldn’t be feasible for G, I don’t know if that answers your question.

Wallsend park: The park is no problem, the paths are okay and all the gates are easy to open.

I: Have you been away on holiday?

ID8M: It’s over 7 years ago. My husband had a crash 5 years ago and was pretty bad so we haven’t been away at all. When we did go away it was no problem, but now he’s getting bigger he’s in the wheelchair and then he’s got another support system on top of that. We are planning on going away next year but we don’t know where and look for wheelchair access, it’ll be in this country, I don’t think L could cope with the heat abroad. He doesn’t like extremes, hot or cold. His face is so sensitive he can’t stand the rain at all.

• Restricted from play in theme parks due to lack of adapted rides:

Theme parks: lack of disabled tailored/inaccessible fairground rides:

D10F: She loves the dodgems but would like to drive, she loves fairground rides but we’ve given up with them because it’s hard to get her on most of them. She’s fine with the noise and lights at fairgrounds. She’s very sociable.

ID11F: She loves fairground rides but she can’t sit on her own. We’ve been on a roller coaster; if I can hold her she’ll go on it. We all paid, she took a seat up so that was fine. She can’t go on the swings or the carousel. She loves the atmosphere so it would be nice if she could get a bit more from that while she’s little.

Amusement, theme parks:

ID2F: Where else do we go J? She went to Flamingo Land last year. That was good. They were quite helpful there with getting her on and off rides and things. Again, getting around was fine, it was all ramps and it’s all on the flat anyway, but they were helpful in getting her on and off rides.

• Lack of appropriate information:

Need for clear indication whether the rides are disabled friendly:

I: What do you do when you go to Blackpool?
ID5C: I like the Pleasure Beach, I’m in the arcades every night.
I: What kind of rides do you go on?
ID4M: She can’t go on a lot because of her epilepsy. We noticed that the Ghost train had a notice warning of the strobe lighting, but when we went to the Circus it didn’t and we had to leave.
ID5F: The doctor said with K the light doesn’t really affect her epilepsy but K won’t take any chances, she doesn’t want to have another fit. Even when strobe lights are on TV she’ll turn away.
I: Do you find it affects K?
ID5F: We don’t stay long enough to find out, we leave.
ID5C: I’ve been to a disco before and that was alright.

Restrictive policies:

Wheelchair accessible but front seats are not comfortable:

I: About public buildings, so what public buildings do you and J use?
ID2M: Well, she likes to go to the cinema, so she goes there. There’s not normally a problem there – it’s all quite flat though on the particular one we go to, which is UCI Northumberland, to go there, or even the one at the MetroCentre as well, that’s fine as well, that’s all on flat. They tend to have spaces where wheelchairs, although they are a lot of the time at the front, which is harder sometimes to see the screen, but there are spaces available there.
I: Do they make them all in one particular place?
ID2M: They usually do them near the front, you know where all the seats are, but I think it’s better now. It always used to be on the flat and now they rise up, so at least she hasn’t got people blocking her now, which I think you usually find in a lot of things where the seat is on the flat.
I: Do you find at both cinemas that the seats are in the same place?
ID2M: It depends which studio you go in – sorry, which screen you go in, because they’re all sort of set out a bit differently. But they’re all more or less near the front.
I: Are they beside an exit or something?

Space:

Going on holidays: environmental adjustments: ramps

Non-adapted holiday accommodation (caravans do not have doubled doors, lack of ramps)
ID6F: We book a disabled caravan, and again for hotels we booked up for ground floor and then we found out that they did disabled. It made it a little bit easier for us. The caravan site we stayed at this year had disabled toilets and showers but no disabled caravans. They were the same layout but didn’t have a ramp up. We asked for a key for the disabled shower block. We’ve bought our own caravan that’s big enough for A to sit in her chair if she needs to and there’s a double bed for her. The toilet isn’t as bad as in a static caravan, it’s more compact and holds her in better.
I: Did you look for anything special when you were looking for the caravan?
ID6F: Just size, we made sure it was big enough to get her chair in backwards and sit her at the back end and we are around her. No caravans have double doors to get in so access will be a problem. We’ll use it to go down when she’s at college; we’ll go down on the Friday night and get settled then see A on Saturday.

**Staying in caravan, Space: limited room, shower inappropriate, no room for hoist, extra physical support is required:**

I: So where do you think you found a problem?
ID2M: We actually stayed in a caravan for a couple of days. It was one with a ramp, but we found it was the bathroom, and that was very difficult, because it was a shower cubicle. Well, trying to bath her or shower in there was very awkward, but as, well of course when you’re in a caravan anyway you’ve got limited room and you can’t, you couldn’t get the wheelchair along there so you had to carry her.
I: She wouldn’t have been able to use the hoist either?
ID2M: No, well there was no room for one. I mean, with her being smaller it wasn’t so bad, but if it was a teenager or whatever, I think you would have a bit more of a problem.

**Lip service to disability, lack of lift, no double room for disabled people:**

ID9F: We’ve stayed in Travel Lodges and were pretty disgusted with them. The first one had no lift and although they did have one disabled room on the ground floor it was booked, but we thought we’ll manage and still ended up on the first floor. It wasn’t a problem but it would be in the future or if it was B on her own. We were aware that they weren’t particularly bothered; it was as if there was lip service to the idea of accessibility but that was it. In the next one we asked for a disabled family room and found it had one single bed and a pull out sofa for the three of us. It seemed to imply that disabled people would only be in a single bed, wouldn’t have a partner. We weren’t happy with that at all. It was as though they’ll seen there are regulations that have to be adhered to and they’ll done as much as they needed to but they hadn’t put any thought into it on a larger scale.

**Other: noise, crowds**

**Facilitator: special lever, Barriers: noise and strobe lights**

ID7M: He likes shopping and we go bowling occasionally, he likes that and they have the special lever which he can use to send the balls down. We haven’t been to the pictures because we think it would be too noisy with the surround sound. He finds noise difficult and any sudden noise would make him jump.
I: What about strobe lights?
ID7M: We try to avoid them because of his epilepsy.

**Crowds, perhaps noise:**

I: Do you go to leisure centres or libraries?
Support and relationships

Sometimes a child’s access to leisure activities depends on having one to one support.

Growing older and becoming heavier was associated with an increase demand for care and physical support and was both a barrier to mobility and a barrier to involvement in leisure and recreational activities where physical support was required.

**Growing older requires additional extra physical support and restricts child’s mobility: ICF: Support: Lifting:**

*ID7M:* When he was younger he went to Tanfield railway and places like that but now his tastes have changed, he likes music and videos. When we used to go to farms he liked the tractors but now he’s too heavy to lift on.

**One to one support is required:**

*ID4M:* Yes just for support in case anything happened. We’re conscious of the fact that in the past he, very rarely, had some 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 first time he went in, I stayed there until they made their own independent assessment and after that first day they said there’s no need to stay.

It’s more the type of things he’ll want to do and we’ll be cautious of what he’s capable of doing. To give you an example we went to Lightwater Valley. He wants to go on the Dodgem cars himself. We’re not going to let him do that basically because it can be a bit rough. You can easily bang your head, so we’re always conscious of that, especially with the balance side of it. Same with the go-karts – he wanted to go in the go-karts himself.

*ID4M:* Take his swimming, for a start. I mentioned the Fun Club, the very fact that there’s a club. Swimming, obviously he’s going in with mainstream children. He can’t do what they can do; he needs a lot of help. For instance he can swim on his back, he has more difficulty on his front. The important confidence that develops, G would be to be able to do the breaststroke eventually and stop panicking.

**Support but lack of independence in play due to constant surveillance:**
**ID6F:** We find our own way, when we used to go fishing with the kids at Rothbury we used to find a shallow part in the river, put her manual chair in, put her in, give her a fishing line and we’ll be standing next to her the whole time. She enjoyed herself she could put her feet in the water. It wouldn’t stop us doing something. We had her on the beach, she gets heavy and she was hot so we took her manual chair and pushed it into the water and she sat next to me.

**Info about access:**

**ID2F:** But if it was some sort of entertainment thing or something specifically for J, I would check, whether we were going to a restaurant or something like that, I would check it all out or I would go myself first to have a look, or sometimes people say to me, I went to such and such – it would be excellent for J. People come back and say to you – the holiday that we had, actually it was one of J’s home carers had been with her husband and she’ll come back and said it would be great for J you know, because it’s all on the flat. As long as you get the downstairs apartment and everything else is on the flat. So a lot of it is people just coming back and saying things.

**Support and Supervision**

**Table of barriers and facilitators to participation in ICF format**

<table>
<thead>
<tr>
<th>Environmental factor category</th>
<th>Facilitators</th>
<th>Barriers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chapter 3: support and relationships</td>
<td>e310: immediate family; parents provide constant supervision, accompany child to parties, siblings help child’s development, grandparents help with care, parents advocate for children by writing letters to authorities</td>
<td>e310: immediate family; parents tired, less able to provide support</td>
</tr>
<tr>
<td></td>
<td>e315: extended family; aunts and uncles help with child care</td>
<td>e355: health professionals; multiple professionals involved in care</td>
</tr>
<tr>
<td></td>
<td>e320: friends; help with childcare</td>
<td>e355: health professionals; multiple professionals involved in care</td>
</tr>
<tr>
<td></td>
<td>e340: personal care providers and personal assistants; nanny, Active Care worker, home carers</td>
<td>e355: health professionals; multiple professionals involved in care</td>
</tr>
<tr>
<td></td>
<td>e355: health professionals; community health visitor</td>
<td>e355: health professionals; multiple professionals involved in care</td>
</tr>
<tr>
<td></td>
<td>e360: other professionals; counsellor for parent</td>
<td>e355: health professionals; multiple professionals involved in care</td>
</tr>
<tr>
<td>Chapter 4: attitudes</td>
<td>e410: individual attitudes of immediate family members;</td>
<td>e410: individual attitudes of immediate family members;</td>
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<td></td>
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<td>child limits activities of parents, e.g. seeing friends,</td>
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<td>e410: individual attitudes of immediate family members;</td>
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<tr>
<td></td>
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<td>child limits activities of parents, e.g. seeing friends,</td>
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parents need more support and information about entitlements, parents feel guilty about seeking respite care, parents feel lack of time to do everything, parents do not wish to attend a support group.

<table>
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<tr>
<th>Chapter 5: services, systems and policies</th>
<th>e555: associations and organisational services, systems and policies; weekly support group meetings</th>
<th>e570: social security services, systems and policies; lack of information about entitlements</th>
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<tr>
<td></td>
<td>e580: health services, systems and policies; physiotherapy and hydrotherapy</td>
<td>e575: general support services, systems and policies; lack of help with behavioural problems</td>
</tr>
<tr>
<td></td>
<td>e585: education and training services, systems and policies; excellent preschool portage system</td>
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**Need for constant support and supervision**

Need for constant support and supervision cuts across all themes and is a vital barrier or facilitator for child's participation in activities. It has a major impact on mobility, involvement in leisure and recreational activities, toileting and feeding. Growing older and becoming heavier together with the high prevalence of access barriers is the major barrier for providing such help.

- wheelchairs especially electric wheelchairs can be too heavy to push and sometimes there are not enough people to help. This is particularly the case if there are access barriers (eg one of the parents waits until the other comes home from work in order to take the child upstairs to his bedroom.)
- transportation needs- somebody needed to drive the child to school and to post-school activities, clubs or leisure facilities.
- Help with feeding, dressing, lifting, toileting etc

**Need for constant support and supervision: the importance of time:**

*I:* You’ve probably got quite a bit of support coming in now as well – with all the home care and stuff and

*I*DM: A lot of the time you find you’re quite restricted, quite restricting, and the fact that you’re very limited in what you can do because everything’s child engineered and where if you’re out at the shops you can’t be half an hour late. If you wanted to go and do something else you’ve got to be back for the certain time. I mean, I find that quite restricting. Obviously it means that on a night-time you can’t just go off with her like other kids, other people put their kids in a car and go off and see one of their friends. You can’t do that, you know.

*I:* So you’re stuck here to the routines of things?

*I*DM: Which, I mean, can get to you sometimes. It would get to anybody. But that’s just the way that it is, you know. But I’ve never, never really gone to a support group.
had a counsellor for a couple of years, but that wasn't directly to do with J, it was through other things as well. I was there for about two years, but that was a lot of things all interwoven. But other than that, with having, as you say, with having so much, so many professionals involved with us, and home carers and ___ We have social workers and what have you, in terms of. You don’t want any more anything else, so, as normal as you can

Need for constant supervision:

I: What in your opinion are the good things in the environment around you and your child and what are the bad things? Physical, socially and attitudes?
ID1M: We’ve already covered the attitudes thing and we’ve talked a lot about the accessibility of the sort of places we would go to. We are very aware that if P is invited to a party for example you have to think about how long it’s going to be, where it’s going to be and the fact that one of us would have to be with him and that would have to be M really.
I: So one of you would always be with him wherever you went?
ID1M: Yes and as a consequence and because of people’s lack of understanding of really how much caring for P involves, ie you’ve got to have your eye on him all the time whether he’s getting on and off a chair, wanting to go upstairs, whether he needs to be toileted, whether he needs to be helped with his fork or spoon, you can’t just leave P somewhere when people aren’t aware of this because if you did they get a big shock at how much work and caring they have to do for P and perhaps then they wouldn’t be able to give attention to other children. It’s okay with families that we know.
I: They may not know what his needs are?
ID1M: Absolutely and consequently if P is invited to a party more often than not he doesn’t go. At this age where he’s not actually bothered it’s not an issue but it could become so in the future or if his friend invites him here or there or wherever we have to think quite carefully how that was going to work.

Families cope alone:

Need to know that the support is there for them if needed:

I: Do you feel that you need support in any areas?
ID8M: I’m quite comfortable at the moment but I would like to feel the support is there if I need them.
I: How important is going out to L, how would you rate it on a score of 0-10?
ID8M: It’s one of his most important activities, he loves to socialise to see new faces, new people.
I: When L goes out does he have one to one support from Active Care?
ID8M: Yes.

Support and relationships: brothers and sisters:

Support from family members and brothers and sisters
ID4F: We’re members of Scope, we haven’t joined a support group because we don’t feel the need. One of the advantages G’s got, though the house is chaotic, is having 2 brothers and a sister; that has helped his development. They don’t show him any favours.
So there’s that support at home, we know there are support networks out there should we need them but we haven’t actually used any.

I: Do you have any other families that you see or talk to?

ID4F: Just with the school, events like concerts. There are facilities through Social Services and Scope so if we felt there was a need we could go there.

Support and relationships: grandparents are getting older

Grandparents help:

ID1M: M works full time as an optometrist, I having had a cancerous brain tumour and radiotherapy in 1998/1999 am not in good enough health to work and can’t care for P myself. I look after him for about 3 hours or so and then I’m too tired to carry on. So whilst M and I are the full time carers for P we need assistance. During an average week I look after P on Monday and Tuesday after school, my mum comes and helps me on Wednesday after school, I look after him by myself on Thursday after school and my mum. comes and helps me on Friday. M works alternate Saturday mornings and P would go to stay at his Grandparents or a friend during that time and be dropped back an hour or so before M finishes work and then M and I look after him together. But my day may well be doing some housework, doing a few odd jobs, writing numerous letters about P, his education and health etc and then having a rest in the afternoon.

I: So you rely a lot on extended family and friends. So it’s important that where you live is close to everyone?

ID1M: We’re fortunate that M’s parents live quite close and my parents live in Newcastle, 15-20 minutes in the car. My brother and sister-in-law live in North Shields and M’s sister and brother-in-law live in Whitley Bay, and we have friends a few streets away who help us. Very much the same people help so there’s continuity for P. When I was first ill P was only 20 months old and so he couldn’t be parcelled out to different people. We wanted, whilst he was at home when I was really quite ill, to be very sure he was going to the same places and have a sense of security.

I: Do you have any other support or help in the house?

ID11M: My mum and dad help me out a lot. They just live in the next street. They used to come every night but we stopped that, it was too much for them, so maybe a couple of times a week they’ll get one of the girls from school. We don’t go out in the evening a lot but if we do they’ll baby-sit. Neither of the girls has ever stayed at their granny’s.

Support for the families reduces as the child gets older:

ID8F: He visits family who live around here. We don’t get so much support now from family, especially the grandparents now they are getting older. L likes to go out and visit, he’s quite happy popping off for an hour to grandma’s and then back home. K or I would take him there.

Friends of children with disabilities:

Support mainly from friends and extended family:
**Lack of support:**

**Lack of support: information regarding entitlements; counselling support:**

> ID10F: From a parent's point of view I think parents need more support. I think it's very hard when you're told there's something wrong with your child and there's no support there. You're told and that's it you've got to get on with it. The Health Visitor was as good as anybody but there's no one to talk to, no groups. Eventually we got to go to the Sanderson every Friday, which was fine because there were other parents there with children but I don't think there's enough support for parents. I'm not just talking about Cerebral Palsy it could be anything, there needs to be some back up somewhere, where you can go and talk to somebody and find out really what it all means because they use so many medical terms and it goes right over your head and you don't hear a lot of what they're saying to you because once you've been given that initial diagnosis you just want to get out and not hear what else they've got to say. I think you could do with talking to somebody and find out what they said means for your child and that person can then tell you what you're entitled to, and the next step. Or even somebody that comes to you, whatever. But there is definitely a lack of support. As a parent you have to come to terms with what's wrong with your child and still do the best and it's very hard. It affects dads as well.

**Demand for more information about their child condition:**

information needs; need to know more how to deal with the child’s condition, child psychologist referral

> I: Would you like to have someone to support you through that?

> ID12M: I like to think that there was someone there if we needed them. We often have little worries about W behaviour wise more than anything in that he gets very agitated and obsessive about things, is that normal? We don't know. We need to learn how to deal with that because we know there are times when we don't deal with it properly.

> I: Where do you see that point of contact coming from?

> ID12M: I've spoken to the doctor about it and she said if necessary we would have an appointment to see a child psychologist as a family unit. I wouldn't know who else to contact.

**Demand for respite care; preoccupied with disability; difficulties following the legislation and asking for care**
I: Do you know anything about policies and legislation?
ID10M: We try to keep abreast of what is going on. We’re delighted to see someone is taking Ryanair to court. I did a great long letter and sent it to the Government when they were looking for a consultation on Special Needs Education. Sometimes you are just so tired that you haven’t got time to do all these things. We did have problems getting Respite care, that was very difficult. We got our MP involved with that in the end. When you get to the stage of needing Respite care you are in no fit state to fight back. I think it’s something that should be built in for parents from a very early stage so it’s taken as a matter of course and they never have to get to the stage of admitting that they can’t cope. It’s horrendous admitting you can’t look after your own child, you feel so guilty.

I: Do you think parents would want to think about it when the child’s young?
ID10M: I think if it was presented to them as something that would happen as a matter of course when their child got to age such and such, that it was taken for granted that this would be provided that would help get round a lot of the guilt.

preschool specialist services:

preschool services support:
ID4F: Initially, when G was first diagnosed, before he started school, the portage scheme in Northumberland, there’s no doubt about it, was excellent. I that some say it’s not really required, but it certainly made a big difference.

I: Would you like to explain that?
ID4F: It’s run through Hepscott Park by Northumberland County Council. They have this scheme whereby they come out and see children with difficulties. It could be someone like G with cerebral palsy, it could be someone with Downs Syndrome, and they give them exercises. It’s more of an educational thing to help develop certain skills. Obviously they don’t cross the border because we also had the physiotherapy service coming out at that time as well.

I: How old was G when this happened?
ID4F: Probably when he was between 2 and 3 when it started, because he started going to PH when he was 3 _ I think, so it certainly started before them. But he had that backup beforehand so it helped, the very fact that they came out to our home. What they also did, there was a hydrotherapy pool at the High School in Ashington, and Linda used to take G there as well along with some other children and that was run by the physiotherapists. The physiotherapists, apart from coming out, also had sessions in Morpeth that he used to go to where they had a few, say about four or five children together, all doing exercises. All these preschool things were of great benefit. I don’t think any of them were legal requirements as such, but it was a service which was being offered and it made a big difference.

Attitudinal barriers:

The respondents revealed that they often face not only physical but also attitudinal barriers to participation in activities as a result of their child’s disability. These attitudinal barriers could be summarised in two main categories namely:
- Barriers in the form of other people's attitudes towards their child
- Attitudes and exclusion practices of services and institutions

**Table of attitudes in ICF format, showing barriers or facilitators to participation**

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<tr>
<th>ICF category ; attitudes, chapter 4</th>
<th>Facilitator</th>
<th>Barrier</th>
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<td><strong>e410: Individual attitudes of immediate family members</strong></td>
<td>Mother tells strangers not to stare</td>
<td>Parent feels that other people might be embarrassed by the child drooling when promotion of child’s disability for own benefit</td>
</tr>
<tr>
<td><strong>e420 individual attitudes of friends</strong></td>
<td>Child accepted by friends and family friends</td>
<td>Bullying by local children</td>
</tr>
<tr>
<td><strong>e425: individual attitudes of acquaintances, peers, colleagues, neighbours and community members</strong></td>
<td>Locally, people more accepting of child and his disability as people recognise or know the child</td>
<td></td>
</tr>
<tr>
<td><strong>e435: individual attitudes of people in subordinate positions</strong></td>
<td>Shopkeepers can be helpful in ensuring access to shop</td>
<td>Staff can be unhelpful- eg. Hotel staff not providing a man using a wheelchair with ground floor accommodation, restaurant staff refusing to blend food, airport staff rushing family</td>
</tr>
<tr>
<td><strong>e445: individual attitudes of strangers</strong></td>
<td>Helpful</td>
<td>Staring in restaurants restricts choice of restaurant and leisure activity Pretending not to notice Patronising, talking down to child Being rude e.g. about wheelchair taking up space</td>
</tr>
<tr>
<td><strong>e450: individual attitudes of health professionals</strong></td>
<td>Doctors who know family well helpful</td>
<td>Poor communication by doctors to child- pitch at</td>
</tr>
</tbody>
</table>
| Staff extending role- e.g. helping parents to fill in forms | wrong level or just talk to parents  
Professionals lumping child into one category, so that whenever anything is wrong it must be to do with cerebral palsy and could not be something unrelated  
Doctors lacking patience  
Doctors wanting to see child by self but parent concerned that child does not understand |
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<tbody>
<tr>
<td>Policies of systems and services designed to enhance participation could be considered as “attitudes” of these services, but in the ICF classification are coded under chapter 5</td>
<td></td>
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</tbody>
</table>

**Chapter 5, services, systems and policies also important**

<table>
<thead>
<tr>
<th>Other people's attitudes:</th>
</tr>
</thead>
</table>
| **Staring**  
**Patronizing, talking down to the child**  
**Verbal abuse/ calling names**  
**Prejudices (preventing non-disabled children from playing with a disabled child)**  
**Overly sympathetic**  
**Visibility of disability: Public acceptance/tolerance varies from “We haven’t noticed that” people pretending that they do not see the child to looking disapprovingly (eg when the disabled child makes noises and spilt food when eating)**  
**Bullying**  
**Mistreatment of disabled parking bays** |

**Staring, prejudices, verbal abuse, inappropriate comments, patronizing and being overly sympathetic:**

A number of families recalled distressing experiences of the ways in which adults or children, both known to the family and strangers, had treated their children. These included staring, giving verbal abuse, making inappropriate comments, being patronizing, overly sympathetic or prejudiced. This disabling social treatment influenced participation of the child in variety of ways ranging from causing irritation when avoiding crowded places to preventing disabled children from participating in sporting activities or engaging in play activities with non disabled children.
Staring: (may restrict his participation in sport activities):

ID12M: When he was first diagnosed as soon as we mentioned it to anybody you could see the shock on their faces. As he’s getting older W’s 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 wears a splint all the time and he’s becoming more and more conscious of people looking at his leg. He gets embarrassed when people say what you have been doing to your leg. His friends don’t comment on it but it’s people who don’t know. I personally tell them not to stare; it’s adults more than children and not particularly older adults.

Prejudice towards disability and staring:

I: How do you find people’s attitudes and manners towards J?

ID2M: I would say generally we are quite lucky. A lot of people know J or know of J – J is J. A lot of our friends, a lot of my friends’ children have known J since she was little, and J is J and that’s where it is. There’s no question to them. That’s just J, and its – when you get the young ones, ‘well why can’t she do this, why can’t she do that’, and I think sometimes when the mam says ‘you don’t ask that’ I think, well no, because they don’t understand. I think, kids, it’s an innocent curiosity, you know, they’re not being – I know a lot of the things can sometimes come from the adults. I remember when she was at this playgroup when she was very little and I think it was a boy on a seesaw and J wanted to play on the seesaw as well, together, and the mother came and took the child away, and I thought well, I wasn’t there, it was my mam really who took her at the time. I said to my mam, I would have been furious, because the child was quite happy playing with her.

I: How long ago was that?

ID2M: She was very little then, very little. She would have been maybe about two or something. But I would say generally, most people are fine with her. They talk to her. I think children, when they get to know her, she’s got quite a lot of children around her, just friends’ children or kids in the street, or else she goes to Brownies and she’s got other girls around her here that come and play and when they know her, then you find they’ll come in and they’ll talk to her and what have you. Some of them, if they’re not sure, because it takes sometimes a lot of time for her to respond, well she doesn’t play, you know. But it’s an innocent thing, it’s not being nasty or anything. It’s just, I think until they understand about it. I would say round here everyone is really good with her, and everyone talks to her.

I: And when you go out to the shops or the town. How’s that?

ID2M: Most people, locally, yes. Everyone’s fine because they know her, or if they don’t know her, they know of her. When I go out I’ve never really had a problem with anybody. When I went to Germany (my mam’s German and we’ve got family in Germany) and they treat her totally different. They’re opposite – they’re quite prejudiced over there. And there’s a lot of staring and things going on there. Children stare, but children are staring because you can see the questions going round in their minds – you know, you like can see them thinking ‘well why’s she wearing that and why’s she got that and why can’t she walk and why can’t she do it and why does she hang her head’ but a lot of, like, when she started Brownies, one of the Brownies group ‘she’s hanging her head and she won’t get it up’ and I said ‘well just go over to her and say, J get your head up’, so she went away, she came back, and she said ‘I told her and she put her head up, but then she put it down again’. But now they know it’s a thing she does and of course, unless they ask, they don’t know.
Staring:

_ID11F:….. Beaches are hard. The only one I’ve found easy is at Beadnell, its totally flat and easy to get onto. Other places you can get fairly near to the beach but can’t get over to where you want to sit. But how do you sort that one out? You’d have to be segregated off. When you’re dragging the wheelchair up the beach you feel like you’re the complete focus of attention, everybody’s staring at you and that irritates.

Staring and patronizing:

_I: So what about people’s attitudes?
_ID1M: Attitudes again are variable. P, for want of an other way to describe it although I don’t mean this in a derogatory term at all, does actually look normal he doesn’t look, apart from his body, as though he has anything wrong with him. He wears appliances on his legs and has his sticks or his walker or is sitting in his big buggy. You are very aware that a lot of people find him quite an engaging chap because he’s got a wicked sense of humour, he laughs a lot, he talks to everybody and chatters away not always understandably and a lot of people obviously think he’s lovely and chat away to him and also P walks down the street and says hello to everybody and is obviously very bemused when people don’t speak to him. However you are very aware that often children stare at him but I think what annoys us more is when adults stare at him and you think well if adults don’t know any better but just stare at a child or nudge each other then no wonder children stare because they get their attitudes from their parents or their peers.

_I: Do you find it happens quite often?
_ID1M: Not a huge amount. We find more attitudes of he’s got his legs in an appliance, 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”. You do get people doing that it’s not everybody and it can be very irritating because when people think they’re being nice it’s very difficult to knock them down and say just talk to him normally.

_I: Do you find it happens in any particular place more than another?
_ID1M: No. I was going to say I think quite a lot of the older generation tend to do that, treat him as a baby because he uses a buggy. That doesn’t apply to all, with all these things you can’t say everybody does that. But places I’m not sure that it does particularly.

Staring at restaurants force the family to choose a table out of people’s sight:

_I: If you’re thinking about going somewhere would you suss it out first?
_ID11M: We’ve only started doing that, up till now we’ve had a lot of picnics outside or had fish and chips. But 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. We do go to places first to look at the seating, to see if there is a place we can be together as a family, with privacy for V without being hidden away in a corner. We found a nice place with nooks and crannies but it didn’t have a children’s menu and it didn’t blend food so it was back to square one.

_I: What about the attitudes of other people when you’re out?
_ID8M: Locally they’re okay because they know him. We get the kids that stare but that doesn’t bother us at all.
I: Does D's friends come in?
ID8M: A lot of his friends know L. A couple last week didn’t and they looked at L but that was it.

Verbal abuse/ Calling names:

I: How do you find people’s attitudes when you go out?
ID3M: I think it’s when you head to Newcastle. Eldon Square – we’ve had some horrible responses to the wheelchair. I had him in the wheelchair and the daughter had the little Down’s Syndrome one in the pushchair and this lad and lass just young ones, said if we would just blooming move ‘bloody pushchairs all over the place and wheelchairs’ and he went on and on and on and kept beside us and I stopped and said ‘I’m sorry to tell you but I hope when you get married and you’ve got a little bairn you’ve got to take it out in a wheelchair or a pushchair and see how you feel when people are uncivil to you’ and then we went in the shop and we had the same couple – I don’t know whether he was trying to be funny or what, but the little one got a hold of the woman’s skirt with his little hand and she went on and on, she called him everything – and mind the lingo – I could have slapped her face at the finish.

I: And how old were they would you say?
ID3M: About 25-26. They should have had more sense, you can see he’s Down’s Syndrome. These ones (school children in room) aren’t bad because they are used to them.

I: You find it different here, like a villagy atmosphere to the town?
ID3M: Yes. I thought it was horrible. I said ‘I’ll never come back here’

I: So what were the staff of the shops like – were they OK?
ID3M: You get some canny folk in the shops mind – ‘can you get out’ and ‘can you get in’ and things like that. I’ve seen us go to the shops in the past and things have been in the shop door and they’ve moved them out and everything.

I: So do you find that older people are more understanding or tolerant, or the younger?
ID3M: It’s more or less just the same. If you have any hassle it’s more off young ones.

Patronising/ overly sympathetic vs. “we haven’t noticed that”, “somebody’s else problem” + visibility of disability (wheelchair + food spillage seems to trigger public acceptance)

I: What about the shops in Eldon Square?
ID9F: It’s easier now she’s in a wheelchair than when she was in the buggy. It’s easier to manoeuvre, but also an attitudinal thing on behalf of the people. If you’re in a crowded shop with a 5 year old in a wheelchair they move out of the way if you’re with a 5 year old in a buggy they don’t. That’s the most marked difference since she got her wheelchair. In café’s when she eats there tends to be quite a bit of spillage and now she’s in a wheelchair you don’t see people looking so disapprovingly as they did when she was in a buggy because the wheelchair. At the same time in some places you get this polarization between ‘somebody else’s problem we haven’t noticed that’ or quite sickly sweet patronising stuff. We don’t get dirty glances from the staff, there’s a bit more understanding.

Patronising attitude:
I: Going out socially is important to B?
ID9F: She comes with us and visits our friends and plays with their children.
I: Do you feel when you go out that people understand B’s needs?
ID9F: No. There are two ends of the spectrum people can be either so incredibly over the top patronising that B takes the mickey out of them or … …in terms of B’s reaction ie on holiday a young girl was speaking directly to B and asking questions and understanding what was going on and B’s reaction was absolutely unprecedented, she blew her kisses and waved to her, trying to signify her appreciation. Generally speaking in Wallsend it’s sort of somebody else’s problem field people don’t notice, the only other people who notice are those in wheelchairs. The staff in shops we go into a lot know B fairly well and now she’s in a wheelchair it’s clicked in their minds that that’s why she doesn’t talk back and there’s been a bit of a change in attitude, some have gone more gushy but some do make a point of talking to B.

Talking down to the child:

I: Do you feel that people understand that K has problems when you go out together?
ID5F: No, they see her as normal but when they do know they talk down to her. Some people can treat her as a child and she doesn’t like that. K does feel like she’s growing up now but she’s still drawn to babyish things, Winnie the Pooh socks, and that’s when you find people looking and you feel embarrassed. When she goes to fairgrounds it’s important for her to win something on games like ‘Hook the Duck’. It doesn’t matter how much she spends on it as long as she wins something and a lot of people can’t understand that.

Less obvious examples:

perhaps implies that younger people are not willing to help:

I: How do you find peoples attitudes?
ID7M: Older people are fine, a lot of people are quite helpful and willing to move out the way. I’ve been offered help before when I’ve been out in Newcastle.

I: Do you think people understand G’s needs when you go out somewhere, the general public or people working in various places, understand?
ID4M: I would say so. The attitude is okay, people are much more tolerant now, you always get the odd one but we don’t have a great problem. And G is prepared to communicate as well. He tends to be more social. We don’t let it be a problem.

Public acceptance/tolerance of disability

It was revealed that that visibility of disability (making noises, food spillage, drooling, dribbling) often causes embarrassment and uneasiness. This combined with low public acceptance and disabling social treatment such as staring, looking disapprovingly, pretending that the child does not exist may become an obstacle to participation in recreational activities such as going to restaurants or cafes. Furthermore, the reported coping strategies that families adopt to avoid attention may often lead to social isolation and have negative impact on the child social interaction.
Public acceptance, low tolerance towards disability: avoiding people, feeding the child outside.

I: Do you ever eat out?

ID8M: Very rarely. We take a packed lunch and find a place that’s nice and quiet, like a picnic area, and feed L and then go into café and me, K and D will have something to eat. L’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. We have to paste his food. In Berwick there’s a little café we tend to go into and feed him, outside when it’s a nice day. We feel comfortable there and there aren’t a lot of people around. Feeding and taking him out is one of the hardest parts, but we’ll find a park area and as long as it’s warm and dry he’s quite happy or we’ll walk along and have fish and chips. If he doesn’t have a packed lunch then we have to come home.

Bullying

Several respondents reported that their children have been bullied. Bullying occurred mainly in school or in the child’s neighbourhood. It was reported that bullying often leads to play deprivation (children being banned from playing with their peers) which may further contribute to social isolation of the disabled child. In one case bullying had such a profound effect on family life that the family considered moving out of the area.

ID12M: When it’s light he just wants to play out. He comes home gets his homework done has his tea and then he’s out on his bike. We’re having problems with children on the estate at the minute, I suppose it’s a form of bullying and it’s being directed very much at him and he backs off now. If he’s out playing and there are certain children out he’ll come in and we’ve told him he has to stick up for himself but he doesn’t like the confrontation. He’s not allowed out of the estate, he can ride his bike around the block. That’s not because of W, I wouldn’t generally let them out.

A LOT HERE ABOUT THE FORM THE BULLYING TAKES WHICH I DIDN’T INCLUDE (the transcriber)

It seems he’s the butt of everybody’s jokes, if they’re going to have a go at anybody it’ll be him. I find it very difficult to the extent that I’ve said to D I really would like to move …

ID3M: Horse riding, swimming. He plays in the yard, he’s not allowed out. The last time we let him in the yard the kids stood on his fingers and all sorts. He doesn’t mix with them.
Negative attitude and exclusion practices of services and institutions

The majority of the respondents reported that there were considerable improvements in policy legislation and social treatment of disability compared to the past. However, they also identified a wide range of exclusion practices and management of impairment by services and institutions such as schools, restaurants, health services which created difficulties and had negative impact on participation in activities. This could be summarised as follows:

- **Lip service to accessibility**
  - inadequate parking bays: narrow parking bays
- **Exclusion policies and practices**
  - children's section in shops is often located on the first floor
  - trolleys that do not fit in front of the wheelchair
  - council policies that state that dental surgeries should be located on the first floor
  - excess baggage policies of the air companies
  - wheelchair users are banned from using some services (eg thermal bath in Switzerland)
  - disabled family room had only a single bed which seems to imply that disabled people wouldn't have a partner.
  - a restaurant refuses to blend food for a disabled child.
  - disabled seats in the cinemas are located at the front which creates difficulties in seeing the screen and enjoying the film
  - spacious front seats in the plane are the most expensive ones. Staff are reluctant to allow these seats to be used by disabled children with more space requirements
  - staff at the airport do not allow the child to do the things at his own pace due to pressure of time/ again it is like a lip service to disability, not well organised.
  - Some positive experiences: can be quite accommodating, eg. keeping the buggy on the plane
  - disabled place in the train assumes that you will travel in a wheelchair
  - "everything takes forever", lots of paperwork, under funded wheelchair service, long waiting times for vital equipment such as an electric wheelchair.

- **Attitude of the health service and health staff** will be covered under the sections Education and Health Care.

**Travel Lodges: Lip service to accessibility:**

*ID9F*: We’ve stayed in Travel Lodges and were pretty disgusted with them. The first one had no lift and although they did have one disabled room on the ground floor it was booked, but we thought we’d manage and still ended up on the first floor. It wasn’t a problem but it would be in the future or if it was B on her own. We were aware that they weren’t particularly bothered, it was as if there was lip service to the idea of accessibility but that was it. In the next one we asked for a disabled family room and found it had one single bed and a pull out sofa for the three of us. It seemed to imply that disabled people would only be in a single bed, wouldn’t have a partner. We weren’t happy with that at all.
It was as though they’d seen there are regulations that have to be adhered to and they’d done as much as they needed to but they hadn’t put any thought into it on a larger scale.

Hotel: a disabled person was given first floor apartment in a hotel without a lift:
ID2F: although at the apartments that we stayed at, I mean we didn’t have a problem there at all. We got the ground floor apartment, but there was another disabled man who’d been given one upstairs, and they wouldn’t change his apartment to the ground floor and he had to actually pull himself up the stairs sitting on his bum pulling his wheelchair up behind him, which I think was disgusting. And I think it was all English. It was run by an English company, so it was all English in the complex. I think if they’d said to somebody who was on the ground floor, like explained the situation, I’m sure someone would have probably swapped with him you know. So, us personally, we didn’t have a problem.
I: Was there a lift in the building?
ID2M: No. No lift. That’s why I kept saying over and over it’s got to be on the ground floor, because there’s no way we could get up. It’s a very heavy wheelchair as well. But other than that it was brilliant – she thoroughly enjoyed it. There was a lot of kids there. It was like a family, well it was for her, it was her holiday, so that’s what we wanted around her you know.

Leisure: Systems, Services and Policies: exclusion practices; wheelchairs are banned from a thermal bath:
ID10F: We had problems in Switzerland on holiday, they wouldn’t let her into a thermal bath because they said she was a risk to the public safety, she was very upset. It was her first holiday with the wheelchair and it was a place we’d been to before with the buggy and it had never been a problem but with the wheelchair they wouldn’t let us in. It would have been so good for her, it was something we could do. I’d never encountered anything like that before, we wrote a lot of letters and we got the Swiss equivalent of Scope involved but they don’t have any legislation, here I don’t think that it would be legal for them to turn her away. Apparently they had had an accident involving a disabled person and they decided at that point we just won’t let them in. Everyone in a wheelchair was excluded.

Restaurant: refusal to blend food:
ID11F: We found a nice place with nooks and crannies but it didn’t have a children’s menu and it didn’t blend food so it was back to square one.
I: Do you find people are obliging or not?
ID11M: The chap at this place was very nice and said it had been put to them before, a lot of places now have facilities to blend baby food, but I find it hard to believe a big place serving food doesn’t have a blender. He said you can bring your own food but that’s not the point. So that would be nicer, I know the majority of people aren’t disabled but there are a lot of disabled children and adults.

Wheelchair accessible but wheelchair friendly front seats are not convenient to see the screen:
I: About public buildings, so what public buildings do you and J use?
ID2M: Well, she likes to go to the cinema, so she goes there. There’s not normally a problem there – it’s all quite flat though on the particular one we go to, which is UCI Northumberland, to go there, or even the one at the MetroCentre as well, that’s fine as
well, that’s all on flat. They tend to have spaces where wheelchairs, although they are a lot of the time at the front, which is harder sometimes to see the screen, but there are spaces available there.

I: Do they make them all in one particular place?

ID2M: They usually do them near the front, you know where all the seats are, but I think it’s better now. It always used to be on the flat and now they rise up, so at least she hasn’t got people blocking her now, which I think you usually find in a lot of things where the seat is on the flat.

I: Do you find at both cinemas that the seats are in the same place?

ID2M: It depends which studio you go in – sorry, which screen you go in, because they’re all sort of set out a bit differently. But they’re all more or less near the front.

Lack of patience: do not allow children to do things in their own pace: airports

ID4M: When we go to the airport – we’re going to Majorca in the October half-term holiday. The arrangements are already made at the airports and they’ve confirmed that. When we go to the check-in we let them know the problems, we tell them he can walk short distances and we leave the decision to them as to how they want to do it. Because, yes, he can walk if he has to walk up some steps, but they won’t let him take his time. They want people in quickly and when we say can he take his time they always say we’ll put you on separately.

ID4M: We always take his own wheelchair with us and he goes in the wheelchair onto the plane so basically they wheel him, they insist on that and that’s understandable, they’re protecting themselves.

ID4M: Yes. We’re always first on the plane and last off and basically we just wait for them to bring the wheelchair round, especially in Spain, in Majorca, even when you’re last off, you’re often first with the cases because, in Spain they’re excellent. They insist on giving him these motorised cars. We went to Marrakech, the whole family went there when they were younger, there were two cars and one was racing the other.

Staff at the airport do not seem very organised:

ID2F: Last year we took her on holiday to Majorca and obviously then we had to check from start to finish. It was a major operation from start to finish to make sure from getting on the plane at this end that you had the facilities at Newcastle airport. On the plane, when you got off at the airport, and then again on the coach. We actually found the people in the Spanish airport were much better than here.

I: Really, how did you find it?

ID2M: They were a lot more helpful there. I mean, they weren’t unhelpful here, but there, I don’t know, they just seemed more organised, more helpful, more willing to help carry her on when necessary, you know. And just generally. But few years ago we went to France and the people over there were – it was terrible. The bus driver nearly went off with the wheelchair, slung it on the coach and everything. People were banging on the coach for him to stop. because some luggage was still on. So it wasn’t just us having the problem, it was everybody and, just their attitude there was very flippant and they weren’t very helpful at all there, but as I say, in Spain they were brilliant.

ID2F: Even when we were actually in Spain itself, we went on like a Safari, even the tourists there were helping with J, getting her on to it. You know it was, they were, most people around us were really helpful. And I think they seemed more organised as everything was sort of ready in Spain as well, where here they were waiting for the things, and there was a lot of waiting going on you know.
Even though you had told them in advance that you were going to be there, they weren't necessarily prepared for it?

ID2M: Well they knew she was there and what have you, but it seems that they didn’t organise what they needed to get her on the plane until actually she got into that department. Once you got through the customs or whatever it was, once you got into that department then they would sort it, whereas in Spain they just did everything you know. It was really good.

Wheelchair service: “everything takes forever”:

ID10F: 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 organised. There’s never enough money for funding it. It’s the waiting for assessment, waiting for money to be available, waiting for approval, the paperwork to go through – there always seems to be something which means it won’t happen for another 6 months. It’s one of the few things where you do feel you’re banging your head against a brick wall. You almost feel that once you’ve got one you need to start working on the replacement. The manual chair is on its last legs and she’s growing out of it. She has a moulded cushion on it, she’ll need a new one but they did an extra one when they did the one for the electric chair so it’s waiting for her. So that was good thinking, the OT suggested that.

Some positive experiences:

I: What about getting on the plane, how did you find the airport?

ID9F: The last time we had the buggy and it wasn’t much of a problem. They were quite understanding at Newcastle and we could keep the buggy until we boarded the plane. They stowed it in the front of the cabin and we got it back as soon as we got off. They were quite accommodating. There was no difference between the staff here and those abroad.

Parental attitude to disability

It was also suggested that parental attitude to disability may also be disabling and have negative impact on child’s development and participation in activities.

Attitude of the parents of disabled children: competition as to who is the worst off

ID2F: So I would say a lot of problems I think, a lot of parents I’ve found of disabled children seem to think it’s some kind of competition on who’s the worst, which I think is a bit sad. I’ve found that a couple of times with children with disabilities. Not all of them, just a couple of times, I’ve found that. Where it’s, I don’t know, they just, they’re a bit off-hand with you.

I: Off-hand with you as a person you mean?

ID2M: I don’t know, it’s just seems a lot of the time. I don’t know, to them it seems like ‘well, my child’s the worst, my child’s disabled, and a lot of them use the disability I think, to get what they want, which I don’t agree with. And I think sometimes that child’s going to
grow up with a complex when the mother keep’s saying ‘I’ve got a disabled child’ blah, blah, blah.

Well to me there’s always a child worse than yours, it doesn’t matter what’s wrong. She’s been in hospital, had operations and there’s been children there off the cancer ward – well to me that’s worse again than J, you know. There’s always something, somewhere in the world there’s always a child worse than that. She’s had, since she started school there’s been six children died through different reasons, connected directly or indirectly with their disability which I mean, to me, we’re lucky to have them, you know. So I think that annoys me sometimes, especially when a lot of parents use the disability of a child to get what they want and when whatever it is has got absolutely nothing to do with whether the child’s disabled.

Factors influencing positively public attitude to disability:

- knowing the child for a long time
- talking directly to the child

ID2F: But I would say generally, most people are fine with her. They talk to her. I think children, when they get to know her, she’s got quite a lot of children around her, just friends’ children or kids in the street, or else she goes to Brownies and she’s got other girls around her here that come and play and when they know her, then you find they’ll come in and they’ll talk to her and what have you. Some of them, if they’re not sure, because it takes sometimes a lot of time for her to respond, well she doesn’t play, you know, But it’s an innocent thing, it’s not being nasty or anything. It’s just, I think until they understand about it. I would say round here everyone is really good with her, and everyone talks to her.
# Health Related Services

## Dealing with Health Care Service and Health and Professionals

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<td><strong>1. Access:</strong> Mobility (1. Stairs, 2. Lifts in the hospitals are sometimes broken) 2. <strong>Unmet need for essential special equipment</strong> in some departments eg mobile hoist. (10F) 3.</td>
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Dealing with the health care service and health professionals: a table of environmental factors influencing participation, in ICF format

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equipment policies: lack of hoist in X ray dept, budget constraints reducing choice of equipment e.g. splints. Hospital services: inefficient orthotics service, lack orthotics clinics, lack of dental and optician appointments, long waiting lists for orthopaedic operations - two years for hip operation.

*585: Education and training services, systems and policies;* Mum anxious about reducing school support, will miss this.

*585: Education and training services, systems and policies;* school mini bus made hospital trip for several children to get X rays at same time, children see orthotist, dentist and doctor at school (school therapy services mentioned in education section).
1. Barriers related to Mobility- already discussed under the sections of mobility and transportation. Illustrative examples related to using the health care service.

- Access to hospitals may be a problem due to difficulties with parking and in some circumstances parking fees.

### Parking: problems with parking, multi-storey parking is not disabled friendly design:

**I:** You’ve obviously been to the hospital quite a lot of times. Everything’s been OK for access for has it?

**ID2M:** The only thing I think we have a problem with is getting parking. Especially the Freeman. The RVI’s quite bad actually as well, with it being multi-storey. But the Freeman, we spend quite a lot of time up at the Freeman, and getting parked in there’s just absolutely atrocious. I would say that’s the main problem that we have with the hospitals.

**I:** I’ve heard that before actually about the Freeman.

**ID9F:** We have a disabled sticker and there’s usually disabled spaces we can park in. Before we had the badge we parked in the multi-storey at the RVI and that was quite a faff. Similarly at Rake Lane we found it a bit off that you had to pay for parking if you’re going into a hospital. Most places you don’t pay at all.

### Expensive parking fees, Disabling parking policy:

**I:** Do you have any problems getting to the hospital?

**ID10M:** Parking can be exciting, particularly at the RVI parking is dire, but we don’t go there very often. Occasionally G needed X-rays but very often there’s a crowd of them need X-rays so they tend to go in the school minibus and have a lovely time. We have gone more often to the Freeman for check ups and it’s not too bad for parking, they have a funny rule which always annoys me - you have free parking with your disabled badge but only in a disabled space, if you park in an ordinary space you have to pay. When we were there when G was in hospital for a week or so I had a go about it and the second time we were in they didn’t charge us for the parking

**I:** Is there any part of the health service you think could be improved upon that would make it easier for P?

**ID1M:** Parking. There is very little disabled parking. It definitely needs to be improved. At the Freeman the attitude to disabled parking in that only a disabled driver on disc doesn’t have to pay is nonsense.

### Accessibility of the hospitals/ GP surgeries:

- **Facilitators:** flat access, slope, ramps, lifts, wide and automatic doors etc.
- **Barriers:** stairs, broken lifts, narrow doors, design of the doors: doors that open inward
Big swing doors:

I: When you go to the doctors etc the community nurse takes you, is it easy to get into these places?
ID3M: You have the lifts for the clinic, when he goes for his ears there’s a lift. The doctors has got two big swing doors.
I: Do you get the support from the staff?
ID3M: Yes.
I: You’re satisfied with the services you get?
ID3M: Yes

Disabled friendly, accessible GP surgery:

ID7M: Thankfully the doctor’s has just changed and had a new practice built and it’s very disabled friendly, automatic doors, they’ve thought it through. He goes to the Dental hospital and that’s fine. The hospitals are not too bad.

Design of the doors:

I: Are the places you visit adapted for wheelchair access?
ID1M: Certainly the clinic in North Shields is. The RVI is well adapted; it’s completely flat with a lift up to the first floor. The Freeman is completely flat. 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. Although its stairs to the surgeries upstairs they do also see people downstairs which is what we do with P. The dentist has steps up into it, which is awkward but there’s always someone there to help so it’s not a problem.
ID2F: But other than that, I think inside it’s made for wheelchairs and things like that within the hospital itself.
I: Is the doctor’s surgery OK for you?
ID2M: It’s not bad. It’s a little bit difficult to get in, but they’re very helpful there. I mean, she always says can I open the back entrance for you, but I mean it’s a bit of a clart for them you know. But, it’s not too bad. It’s quite a highish step. Once you get in, it’s fine – it’s just the actual getting there.
ID8M: He’s not often at the doctors. When he does need the doctor he’s normally poorly so the doctor comes out to us. It’s only up the street so we put him in the buggy and take him up for his reviews, depending on the weather. He could go in his wheelchair if it’s warm. If it’s cold we’ll take him in the car. Hospital’s no problem, the RVI, we can get him in there in his chair, Freeman as well. The parking is fine.
I: How often has B been to the Doctors, Dentist and hospital in the past year and what is the access like?
ID9F: The doctor is opposite our house and the Village Green surgery in Wallsend is on one level. The staff are fine, they understand B. As for the dentist as far as I know there aren’t any problems, it’s on the ground floor. B sees the dentist at school.
I: How about the doctors and dentist?

ID11M: No problem but I tend to carry her into the doctors from the car park. I could get her chair in, the doors don’t open automatically but they are wide enough. She goes to the dental hospital through the automatic doors into the lift and you’re there. No problems with the staff.

The Attitude of health professionals /Ethos of the Health Service

Parents were very positive when talking about the wide range of health professionals with whom they had contact such as GPs, consultants, nurses, physiotherapists, occupational therapists etc. They often described health staff as very helpful and suggested that building a long term relationship between the professionals and the child could have positive influence on the health care they receive:

Helpful doctors:

ID2M: The doctor’s isn’t too bad. I mean the doctors that we go to and the GP in particular, I’ve been to them for years, so they know me. I went there for prescriptions and things. They know J and they’re quite helpful there.

I: Is it far to the doctors?
ID7M: Five minutes in the car.
I: Do you receive support from the staff when you attend J’s appointments?
ID7M: Yes.

I: When you go into these places are the staff okay, do you receive the support you need from them?
ID1M: Absolutely.
I: Are you satisfied on the whole with the services you receive from the hospital?
ID1M: We’ve been very happy with the care P has received.

I: How often does the nurse come in?
ID3M: If I want her I just ring and she comes straight away. She takes us for appointments at the hospital, or things like his school review. She’s really good. If I’ve got any forms to fill in she helps. I get on with the Occupational Therapist as well.

- Health professionals who build up a relationship with the disabled child over time are described as helpful.

Helpful doctors, long term relationship:

ID2M: The doctor’s isn’t too bad. I mean the doctors that we go to and the GP in particular, I’ve been to them for years, so they know me. I went there for prescriptions and things. They know J and they’re quite helpful there,
However, they also highlighted some disabling practices of the health care staff towards the children with CP which will be summarised as follows:

- **Health professionals do not try to talk directly to the child during a consultation**

  *I: Do you feel that the staff at the hospital and doctors surgeries are okay?*

  *ID10M: Sometimes they tend to talk to me rather than G which is understandable because she would probably look at them suspiciously but I do feel that people ought to try especially hospital staff.*

- **Some health professionals speak to the child in language that is difficult to understand**

  *I: So you think it's something to do with her epilepsy medication?*

  *ID5M: When she was on the Tegretol she was more grown up.*

  *ID5F: She didn't have voices in her head till she was 16. Now it's everyday. We've told her specialist, a neurologist, but she's very outspoken and talks to K as a grown up and K doesn't understand her.*

  *ID5M: The tablets make her very tired. She sleeps a lot and is always in a bad mood with tiredness.*

  *ID5F: I don't think she's as tired now because she's starting to get used to the tablets. But every 2 minutes if your doing nothing she's lying on the bed sleeping. Boredom has a lot to do with it. When we're at Blackpool she's a chance to be different again, because there's that much to do.*

- **Tendency to view the child not as an individual but as an impairment (labelling and categorisation).**

  *Labelling and categorising the child:*

  *ID11F: My mum always said V has to know she's loved and she has to see happy faces around her and that's what we've done. I think professionals tend to lump your child into one category, if there's a problem it's to do with her Cerebral Palsy. I was always told when she was in special care she's a baby first and her Cerebral Palsy's second but whenever there's been a problem like with her nose and her throat immediately it was reflux, but I knew it wasn't. It couldn't be treated as a common childhood ailment first and if that doesn't work then go onto the Cerebral Palsy and that infuriates me. Not all children with Cerebral Palsy are the same like any child's not the same.*

  *ID11F: I used to hate the physio coming because they were so negative and they weren't telling me what I wanted to hear, that V would be able to do things but as time goes on you realise those things aren't important, the fact that you have a healthy happy child is important. We would love it if she could sit and stand and walk and talk but she can't but there are lots of things she can do.*

- **Doctors do not have patience**

  *"Doctors have no patience", lack of ability to get the child to communicate with doctors in the absence of the parents:*

  *I: Are the staff at the places you go to okay, their attitudes?*
ID5M: The staff at my doctors have no patience. They don't know if they're coming or going. When we try to make appointments for K now they want to see her on her own. They see her as a big strong girl who can look after herself but she can't. When the doctor asks her questions if we aren't there she doesn't tell them what's wrong, she just wants to get out.

Services, systems and policies

Respondents also identified some exclusion and disabling policies that are barriers to successful participation of children with CP in receiving health care. The three main themes to emerge were:

- Council policies to forbid dental surgeries being located on the ground floor which resulted in problems for accessibility
- Unmet needs for special equipment (e.g., mobile hoist)
- Long waiting times, bureaucracy, and delays in receiving specialized dental care

Dentist surgeries are located upstairs: wheelchair inaccessible:

Services, systems and policies: local council wouldn’t give planning permission for Dental surgeries to be build on the ground floor:

I: How about the doctors, dentist?
ID10M: The dentist comes out to see her, all the dentists in Morpeth are up stairs. We did complain to our dentist because he moved premises but the local council wouldn’t give planning permission, they said they weren’t a retail outlet and they couldn’t have downstairs premises. There is one surgery they would be able to book if she needed treatment. The doctors are fine, there’s access to the ground floor and the doctor will come and use one of the downstairs surgeries to see her. On the whole they’re very helpful and very supportive.

I: How about access, attitudes of staff?
ID4M: No problem. The Opticians, they know him and his difficulties. Access isn’t a problem. The Dentist, we’ve got the steps, so if you were in a wheelchair on your own you’d have difficulty. With him it’s not important.

Dental surgeries are often on the first floor:

ID2F: but we’ve just actually changed dentist and we went there for the first time yesterday. Well, we haven’t changed dentist, he’s moved I should say. To Jesmond from Whitley Bay, and the dental practice he’s in now is actually better wheelchair access because it’s all downstairs, it’s all on flat, whereas he used to actually come downstairs to see J and use one of the other dentists’ surgeries or the dental, hygienist’s room. But I mean he used to come down and see J. It wasn’t, there was never a problem, or whatever, you know.
I: And you followed him?
ID2M: Yes. I have a lot of work done on my teeth, and I’ve been with him for a long time so he knows. I want really to stay with him although it’s a bit further away. But it is actually better than the one’s here in that it’s all on the flat. And she could come in the room with me. Whereas if it was me, you see, I had to go upstairs, so I always had to get
somebody to watch J because obviously I couldn’t take her with me when I was going upstairs.

- **Unmet needs for special equipment:**
  - Waiting list + lack of special equipment and service attitude:

  I: Do you feel that the staff at the hospital and doctors surgeries are okay?  
  ID10M: Sometimes they tend to talk to me rather than G which is understandable because she would probably look at them suspiciously but I do feel that people ought to try especially hospital staff. **But on the whole they’re very good.** One thing I do think is in the X-ray department they should have mobile hoists.

  I: So if they want to X-ray G you have to lift her?  
  ID10M: I do the lifting, people have offered to help me but quite often they just let me get on with it. But I think they should have hoists as a matter of course, it shouldn’t even occur to them that I would lift a 14 year old by myself. A nurse wouldn’t do it but they expect me to.

  I: Is there any part of the health service you think could be improved upon to make it easier for you and G to use?  
  ID10M: **Waiting lists.** Her hip operation we waited 2 years for, we’ve been waiting a year for her foot operation.

- **Waiting list**

  I: Do you think you receive the support from the staff at the hospital or doctors when you go for your appointments?  
  ID8M: Yes, no problems at all.

  I: Do you receive any other services from the hospital apart from seeing the doctor?  
  ID8M: At the Freeman we got to orthopaedics for his hip and legs and his growth. He’s had a few operations on his hip, feet and to correct his posture. **There was a 2 year waiting list for his hip operation.**

  I: So the main areas for concern are the OT’s, the waiting lists and the speech therapy.

  ID8M: We don’t have a speech therapist now. He had a lot of trouble with feeding difficulties and drinking but I can cope with that a lot more now he’s getting older.

  I: In your opinion are there any parts of the health service or other services that could be improved?  
  ID8M: **Physio.** Information on these two years which are L’s transitional years for moving from school, who I can chat to. I’m anxious about it because his day will be cut by quite a bit hour wise and school are such a big support so I’m going to miss that quite a bit. It’s going to be a big change for L and me. It gives me a break and now I’m getting older I think I need more support than when I was younger. (need for support)

  I: How often has G attended doctors and hospital appointments?  
  ID10M: Her general health is excellent, she rarely sees her GP. We see Dr - once a year at school as a matter of course, occasionally outside that. She sees Surgeon- at the Freeman for orthopaedic problems, she had a big hip operation 2 years ago and is currently waiting for an operation on her foot.

**Bureaucracy waiting for a new sling:**
I: Is there any part of the health service or any service you feel could be improved?

ID12M: I find it extremely frustrating when he needs a new splint. Bureaucracy. It’s all budget related unfortunately, “we could maybe get another few weeks out of that” his splint’s been rubbing and we went last week and they’re going to leave it until we’ve been to see Dr - at the end of the month. We know fine well he needs a new one. So we’ll wait till September then it’ll go from Dr - back to them, we then have to wait for an appointment to get a cast done, from that we have to wait for the splint to be made, then it has to be fitted and then the shoes. It’s a cycle that goes on and on. We usually see the same people.

I: Can you see any way in which that could be made easier?

ID12M: I don’t think they have enough clinics, they’ve cut the clinics down at the Sanderson to one a fortnight. We have attended one at school at Kingston Park they do one after school there but the chap who does the casts maybe only attends there once a fortnight because he’s somewhere else the next week.

I: So you think there’s too few staff to do the work that needs to be done?

ID12M: Whether that’s the case or not but it could be perhaps sharpened up a little bit. It’s a big thing when he gets a new pair of shoes, like most children he wants to put them on but he has to wait. If he says he wants transfers on his splint I have to pay for those, instead of plain white or black he’s had a football one and an army one. That doesn’t come in the budget but I pay the difference and get invoiced separately, it’s quite annoying because you’re talking about $8 for the transfers and you think he only has one splint a year, but budgets you see. It’s frustrating as a parent.

Delayed provision of dental care:

I: In your opinion is there any part of the health service that could be improved on?

ID7M: We have noticed that he doesn’t get his teeth checked as regularly as you or I and he’s only ever had fillings once because they have to put him under a general anaesthetic, so I think they prolong doing any kind of dental treatment because of how it’s performed. That’s at the dental hospital. He goes once a year. When he was small he had a squint and had that checked and they did as much as they could as far as eye tests but with spatial awareness he’s never had his eyes checked for a long time since he was sent away from the RVI, a good few years ago, and he’s probably more able now to recognise signs than he was then so I think maybe he should be checked for that once a year. So that’s something that maybe should be changed.
## Education

### Table of barriers and facilitators to education, in ICF format

<table>
<thead>
<tr>
<th>ICF category</th>
<th>Facilitator</th>
<th>Barrier</th>
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| Products and technology                           | *e115: products and technology for personal use in daily living; standing frame*  
*e120: products and technology for personal indoor use and outdoor mobility and transportation; school transport: black cab taxis, ramps on taxis, large car with boot for wheelchair, bus for wheelchair access, powered tailgate for wheelchair access  
*e125: products and technology for communication; symbol book  
*e130: products and technology for education; word processor, writing aid  
*e140: products and technology for culture, recreation and sport; equipment for horse riding, swimming  
*e150: Design, construction and building products and technology of buildings for public use; school on one level or has a lift- good wheelchair access, automatic doors* | *e120: products and technology for personal indoor use and outdoor mobility and transportation; lack of seatbelts or heating in one school transport taxi* |
| Natural environment and human made changes to environment | Nil                                                                                                                                                                                                                                                                                                                                                                                                    |                                                                                                                                                                                                                          |
| Support and relationships | e310: immediate family; parents fight for resources, inform teachers of child’s needs  
| e320: friends; other children are supportive  
| e325: acquaintances, peers, colleagues, neighbours and community members; other parents at school are supportive  
| e335: people in subordinate positions; helpful taxi driver- nice to the children  
| e340: personal care providers and personal assistants; taxi escort helpful  
| e355: health professionals; physio, SALT, OT, school nurse  
| e360: other professionals; key worker, classroom assistants, nursery nurse, support worker |  
| e355: health professionals; lack of therapists |  

| Attitudes | e410: individual attitudes of immediate family members; parents want child to be treated the same as other children  
| e435: individual attitudes of people in subordinate positions; taxi driver nice, brilliant with children |  
| e455: individual attitudes |  
| e410: individual attitudes of immediate family members; parent not wanting child to be statemented, parent feels that there is less social contact with classmates outside school  
| e420: individual attitudes of friends; bullying by other children  
| e435: individual attitudes of people in subordinate positions; taxi driver unhelpful  
| e440: individual attitudes of personal care providers and personal assistants; care worker embarrassed child about incontinence |
| Services, Systems and Policies | e515: architecture and construction services, systems and policies; planning and design of the special school buildings allowed easy wheelchair access. e540: transportation services, systems and policies; provision of escort by school transport services useful, running of transport service not always smooth in past. e575: general social support services, systems and policies: Active Care provide care and respite in holidays. e580: health services, systems and policies; provision of therapy services, occupational therapy, physiotherapy and speech and language therapy and school nurses. e585: education and training services, systems and policies; special schools provide a number of valued facilities: residential units, therapies such as physio, hydrotherapy, OT and SALT, school nurse, horse.
| of other professionals; school teachers approachable, attitudes of teachers positive, teachers encouraging child’s independence. head teacher not willing to provide specialist support in mainstream school, head teacher not accepting that bullying was occurring, one teacher horrible to a child. | e540: transportation services, systems and policies; long distance from school, multiple pick ups makes journey long; changing the escort annually means that children have to get used to someone new. e580: health services, systems and policies; shortages in therapy staff and long waiting lists. e585: education and training services, systems and policies; lack of staff for therapy services, lack of resources, resources required in Statement of Educational Need not met. |
riding, swimming and school transport. Parents value the small class sizes and the specialist teaching provision including key workers, nursery nurses, classroom assistants. The special schools provide emphasis on life skills, independence, communication skills and mobility.

one child not Statemented, lack of facilities for backing a child in mainstream school

**Type of school attended:**

All but one of the parents were positive about the educational service. The vast majority of the children in the sample attended special schools with only one (with mild form of CP) out of all attending a mainstream school.

**Parental attitude to mainstream education of a child with a mild form of CP:**

*ID12M: We haven’t had any problems educationally wise, it’s not like he’s been refused, there’s no reason why he should be. We haven’t contacted St Cuthberts yet, we intend to go and have a look around the school and talk to them and also perhaps Emanuel College at Gateshead. Rightly or wrongly we don’t want W treated any different to anybody else because in our eyes he isn’t, we don’t want any preferential treatment at school, we don’t want him excluded from sports - if he’s finding it difficult well tough he’s just got to get on with it, we want him accepted like everybody else. I don’t want him singled out for anything.*

**Mainstream school**

Only one child from the sample attended a mainstream school and another one attended both a special school (because of the specialist services available) and a mainstream school (for its literacy) simultaneously. The most valued quality of mainstream education
cited by parents was its focus on education (developing literacy and numeracy) as opposed to special school education which focuses on developing life skills and improving personal independence.

Some obstacles to mainstream education raised by respondents, consistent with those pointed out by the parents of children attending special schools, suggested that inclusive polices for children with high levels of support needs should be reviewed.

- mainstream schools do not have the back up facilities to support disabled children with moderate to severe mobility limitations
- Perhaps Urban-Rural differences: Mainstream schools in Northumberland do not have the support services needed to support a child with CP.

The education and the social services side – the policies can vary between different areas.

**ID4M:** On the whole, Northumberland is regarded as being pretty good, they had an afternoon club and a few of us said after the club it would be a good idea for the children to stay over at the residential unit. When we applied they offered us once a fortnight and they actually gave us once a week, so that was excellent, more than what we asked for. Part of the problem is the cost side of a community running their own facilities, in Northumberland we don’t have the specialist type of school backing for such as G, because he has the understanding of a child in mainstream, they don’t have the facilities for backing him in mainstream. So you’ve got to be prepared to push them.

Lack of specialist services in mainstream schools:

**I:** W goes to a mainstream school, is it close to you?
**ID12M:** Literally just around the corner (St John. Catholic school). We walk to school with my younger son and I pick them both up. He’s just joined the choir at school and it’s going to be choir practice on Tuesday night and he wants to walk home on his own. He hasn’t got any busy roads to cross but I’m not sure I want him to do that yet.
**I:** Can W get round school okay?
**ID12M:** No problems, it’s flat.
**I:** How do they respond to him?
**ID12M:** MrsH They’re very good, when he first started I went in to every new teacher he got and explained about his splint and showed them how to do it but he’s now in year 5 and he doesn’t want me to do that, he says he can manage it himself. I will go in if there is a problem. Because we don’t make a big thing about it they forget he has problems. He does sports day and tries on the apparatus. His writing is fine because he’s right handed. He may have problems with keyboards on the computers, they were asked to practice at home with the keyboard and he said he can’t get his fingers to move separately so he may struggle. I’m not aware of any services in the school that could support him with that. If it’s a major thing I’d speak to his physio and she would go in. He wanted to learn an instrument so I went to see the music teacher to see which would be the best instrument for him and she said the keyboard and he’s just passed his first exam, which we were delighted about. She explained to the examiner that he has limited use of his left hand.
**I:** He doesn’t get any help or support in the classroom?
**ID12M:** No he’s not statemented. We didn’t feel there was a need, we felt we’d be laughed out the education authority because he does have limits physically but not to the extent
where he needs extra help. I don’t think that will change as he gets older, he’ll just get on with it.

Barriers to inclusive education:

Special school

Parents of children with moderate to severe form of CP (eg high level of mobility limitations and communication and cognitive impairments) expressed preferences for special schools rather than mainstream schools. Respondents felt that special schools are better equipped to meet the high level of support needs, special services and assistive equipment required by these children to participate in the educational process. The most valued qualities of the special school cited by parents were:

- wheelchair accessibility
- capability of providing a high level of support due to the availability of (often one to one) support for the child (key workers, helpers) and small classes.
- availability of wide range specialists services (therapies) (physiotherapy, speech and language therapy, occupational therapy
- school better equipped with relevant special equipment (wheelchairs, walkers, hoists, special equipment designed to facilitate educational process: symbol book, different communication devices etc)
- parental beliefs that bullying is less prevalent in special schools then in mainstream schools
- Parents of children with communication and cognitive impairments felt that special school is better tailored to meet their children’s communication needs including communication with children with similar impairments.
- better attitude of peers and staff
- encouraging independence and development of relevant life skills required to cope with the impairment
- Provision of information on relevant services, policies and disability allowances through staff or other parents of disabled children.

Special school: wheelchair accessible, extra support, specialists services:

I: So, does J manage to get around school OK?
ID2M: Yes. Well obviously she’s in the wheelchair, so they push her.
I: I expect she’s OK in the special school?
ID2M: Right. It’s a special school anyway so it’s all right for wheelchairs and different types of equipment like walkers and what have you.
I: Does J have support in the classroom, apart from the teacher, any other support?
ID2M: It depends what she’s doing. She does book works and they do one-to-one. Obviously physio and things, she’s got to have somebody there. When they do speech therapy she gets one-to-one.
I: So you’re quite happy about the services that go with the school?
ID2M: Yes, normally they’re pretty good. We can approach them at the school. The only thing I’ve got a problem with is the carry on we’ve got with the walker at the moment. But other than that, I’d say that they’re pretty approachable.

**Education is not prime objective of special school, on-site support, special school is more suitable for children with communication problems:**

ID4M: When it came to choosing school, ironically, they were only having trouble between mainstream or PH. We checked the mainstream, had a word with the headmistress, first she was very keen and when we explained all the difficulties she backed down. She realised she had to think twice about it because there was a lot of support which she would need to give him. We found out very early that somewhere like PH could be the best for him. It’s understandable where education’s been for children of his age, that PH would be somewhat better because they had the on-site support for the patient – all the therapies. Obviously that takes a bit away from the education. There was always a possibility that he may get transferred to mainstream in due course, but we still agree that he’s better off at PH, because he’s got his own independence, because one of the big problems with mainstream he could have had communication problems you’ve got to get tuned in to G, and he might find himself worse off because of that lack of communication and support and he might become frustrated and be worse off.

**Class room support, specialists services, small classes, parental belief that bullying is less prevalent in special school:**

I: Does G have support in the classroom?

ID10F: Yes, there are 7 children in her class, there’s a teacher and 3 support workers plus physios, OT’s.

I: Are you happy with the school? Is there anything you’d like G to that she isn’t?

ID10F: Very happy. She’s not on the national curriculum, she’s on an individual programme and they’re concentrating much more on life skills and independence and driving her wheelchair. She’s a good communicator but her speech is limited, we get short sentences from her, she can make her wishes very clear. She uses the symbol book as well so she can point and that’s improved a lot over the last year because she’s in such a small class and the rest of them are symbol users as well.

I: Has she experienced any problems like bullying at school?

ID10F: Never. With her always being in a special unit the other children aren’t capable of doing such things, if she was in a mainstream school then it might be a problem. The children have always been very supportive of each other, they really look after each other. When G was off poorly 2 of her classmates were in tears because she wasn’t there and the teacher phoned up so they could speak to her to see if she was alright.

**Staff treat her as a normal person, availability of relevant specialists services:**

ID9F: B has been at WL school for 2 years, she was in the early years assessment unit part time and in a mainstream nursery. There was definitely a difference, because at the time she left she was 2 and she couldn’t do anything, all the other children were starting to get up and about and B couldn’t crawl or sit up unassisted at that point so she spent most of the day in a standing box, which sounds almost Dickensian but she loved it and it was very effective because it meant she could interact and play with the others. And a lot of the time she was being spoilt rotten by the staff and being carried around because she
was this cute little doll and she’s very good at manipulating peoples perceptions of her. If she wants to be carried around she can usually get it to happen, she can get people to do what she wants without communicating through speech. Then she got to WL where they’d seen it all before and she was just one of the kids, nothing special. She was a bit taken aback at first but now she’s settled in and it works great, they’ve done wonders in terms of her mobility.

I: How do you feel about special schools?
ID9F: We were initially deciding between WL and PH and we decided we preferred WL overall. We felt PH was more regimented, WL is more flexible and they’re more prepared to treat B as an individual because they have children with mixed ability. They were more prepared to try things that haven’t been tried if they thought it was possibly of benefit and if it wasn’t they would drop it and explore different avenues. They have a nurse, swimming pool, physiotherapist, speech therapists, OT’s and it was the overall attitude of the staff.

I: Were the services okay?
ID9F: Yes, especially the physio. Having the swimming pool makes a hell of a difference, once she started swimming we could see the difference in terms of her strength and she was so incredibly confident.

I: Does B receive any specific help in the classroom?
ID9F: It has an average of about two to one. This year they’re sending her across to L primary school next door, a mainstream primary school which is used to having kids integrated slowly, B is going there for her literacy and numeracy and then back to WL for everything else. When she goes there she’ll have one to one support.

I: Is there anything B would like to do at school but she can’t?
ID9F: She’s very keen on using a pen and she hasn’t got a very good grip but it is improving. They try to get her to use a thing called the bird to rest the pen and move it around and B was adamant that she wasn’t using that because the other kids weren’t. That caused a bit of truculence with her teacher because they couldn’t work out where she was at for her assessment. They got round it by sorting out a word processor and getting her to do her literacy stuff on there instead. So in terms of what she wants to do they’ll usually find a way of letting her muck in whether or not she can do it to the standard she wants is up to her to decide.

I: She obviously gets round school okay?

On site support and assistance (key worker):

I: Do you have any help or support in the classroom apart from the teacher?
ID4C: With my writing. Someone will write for me but I can do it and write it.
I: So what you’re saying is that if you’re having problems with writing somebody writes for you, if you’re not using your laptop or something like that?
ID4C: Yes
ID4M: All the children have a key worker. It might be one key worker for two children. There’s usually a maximum of three children to each key worker. Sometimes he works with his key worker.
I: If your key worker’s out of the room or something, helping somebody else, and you need somebody, then you would ask another person.
ID4M: Key workers can sometimes be, for instance, the likes of physios. You get people in class to help out. Some of them are basically the assistants. There’s always someone there.

Onsite support (classroom assistant):
I: Do you have any help or support in the classroom, help to get to the toilet?
ID7C: Yes classroom assistants.
ID7M: They encourage independence; get him to do as much as he physically can. He probably does more at school for himself than he does in the house. The teacher of his new class said they’re teaching them that they’ve got to ask if they need help, if they don’t put their hand up they won’t get it.

Relevant support services provided at home:

I: Most of the services you receive through school, physio and OT, are you happy with those?
ID7M: We’re able to get in touch with them and if they’re not available they ring us back. They do come to the house.
I: There’s nothing you wished that they did or have problems with?
ID7M: All the way through school they’ve been very good.

I: She can get round school okay?
ID11M: No problem at all.
I: Does she have any help or support in the classroom?
ID11M: There are about 6 or 7 children and 3 teachers so it’s 2 to 1. She has a speech therapist and the physio’s there. She has all the services available, more would be nicer. She gets speech therapy twice a week and physio and she has hydro and horse riding at school.
I: The school provides all your services, do they give you support?
ID11M: I’ve never really asked for anything, if I have a problem I tell them. I’m there every day so I know them all. I go in hydro with V.

Unmet needs for therapy services

Unmet needs for therapy services emerged as one of the main reasons for concern and many respondents reported long-running difficulties securing appropriate specialist services.
The main reasons behind this were: lack of appropriate funding and shortage of staff. This led to children been deprived- in quality and quantity- of vital specialist services, irrespective of their eligibility status underlined in their statement of educational needs. The following examples provide a good illustrative account:

I: Does P receive any support or help in the classroom?
ID1M: Not specifically, he doesn’t have somebody individually with him all the time. He is one of 5 children and they have a class teacher, a nursery nurse and a class assistant so there is a lot of support there. Whether that will stay the same next year I don’t know. It’s an excellent ratio, he does need a lot of help but not one to one help all the time.
I: So they would see that he gets to the toilet, gets his lunch okay and all the things that he needs help with?
This question is maybe for the older children about anything they would like to do at school but they can’t and why?
ID1M: I’m not sure whether it’s that way round or whether round what we would like them to do but they can’t. In order to get P’s statement as special education needs which has been for the spring and summer terms this year we had to go to tribunal because his statement was very poor, very vague in terms of what it was going to supply for P and we
wanted a much more specific statement for him because the school could have got away with doing as little as it possibly could for P and we would have had no come back at all. We went to tribunal and now at nearly the end of summer term we are still fighting to get some of the things that he should be getting via his statement, which is legally binding, to happen. That is mainly because they have no money in terms of what North Tyneside will give them and because there are staff shortages particularly in speech and language therapy and in occupational therapy. Physiotherapy is on the knife edge, they have enough staff at the moment so he does get physiotherapy every day and is therapied by the actual physiotherapist twice a week but if one of those members of staff goes that would be very difficult to supply.

I: Were they the things on the statement that you were actually querying/questioning?
ID1M: We were querying the fact that Occupational Therapy is not offered in a special school for the physically disabled and we are still querying that now. We are still in correspondence with the school, the education authority, the health authority and our MP regarding that. It’s very frustrating to know that it says on P’s statement that he should receive occupational therapy on a daily basis, which should be pervasive in his daily school life and that he should be therapied by the OT once a week but he sees the OT once a half term because OT’s do not work in the school.

I: That is what it says on the statement but in reality it doesn’t happen?
ID1M: It’s very difficult but you can criticise the school because you can say why have you not insisted that your children require OT because surely they require physio, SALT, classroom teaching, as children with physical disabilities they require OT. Its natural that a child should be assessed and even if it’s decided this child actually needs very little OT the assessment should have taken place and its not even offered. So we did from that get an OT assessment but the OT’s don’t work in school, which is an issue the school and the education authority should have taken up with the health authority and equally there are no OT staff because there’s a national shortage. In North Tyneside there is one paediatric OT with 60 children on her waiting list and the other two paediatric OT’s are on maternity leave and there are no replacements. There is a lot that could be done for P but money and staffing are the issues that are stopping him being therapied appropriately, which is very frustrating. Yes the school, the health authority, the education authority and government policy is at fault but its kind of . all that together. We tried to get P’s school changed so that he would get the appropriate OT and we didn’t succeed because the school and the education authority said they could provide all this so either at tribunal they were very ill informed as to what they could actually supply or they sat and told lies and we don’t know the answer to that.

I: I was surprised when you said WL because I thought that P would have gone to PH. That’s what the school is there for, for children with Cerebral Palsy.

ID1M: That’s where we wanted him to go but I think in their eyes P is not severe enough. However PH offered him a place and were adamant they could do a lot for him but I don’t think we’ll go down that route because my blood pressure might start to rise!

I: So obviously education is a big issue?
ID1M: It is you have to fight for everything and I don’t believe you should have to. The difficulty arises because an education authority is only obliged to provide adequate education for a child and what is the definition of adequate.

I: What a child needs should be in their statement.
ID1M: It is but equally although parts 3 of the statement is legally binding having come back on that is very difficult because you write to the school saying P’s not getting the OT and SALT he should be, why not and the school writes back and says I haven’t got the
staff and we haven’t got the money from the education authority. So you contact the education authority, writing to the Chief Executive of education and say why isn’t P being supplied with his education as you are required to do so, then you write again because she doesn’t reply then you write a third time because she again doesn’t reply and at that stage your next line is to go to the Secretary of State for Education, Estelle Morris, who looks after all the statements of SEN in the country which is an absolute nonsense because she can’t possibly look after all them but that is where you go and after that you go to court. Who can afford to go to court? So the LEA sit there and do nothing. You’ve got to fight for everything, we write letters the whole time and you’ve got to write them constructively and not be derogatory because you’ve got to work with these people. We are getting what is good for P but it could be better with what they said they could do.

I: So you don’t feel he’s in the right environment for him educationally?

ID1M: It’s very difficult to know whether P would have done better at PH as to how he’s doing at WL. We looked at the OFFSTEDs of both schools and whilst WL is a beacon school and PH is not the LEA made a huge issue of this. We asked my sister-in-law who’s a school governor to look at the 2 OFFSTEDs and say what she thought of them and she said she’d be happy for any of her 3 children to go to either of those schools they’re both excellent. Which is what we felt but I think the therapy side at WL can be lacking, the physio P has had is excellent. His speech therapy we really feel has been rather hit and miss, we’ve not had any homework for P since February and we don’t even know what his targets are. We can’t get them now his Speech Therapist is off sick and there’s no replacement because there aren’t any staff to replace her. It’s this whole saga, it’s very difficult to totally knock the school when the staff aren’t there but I do knock the school in that they should be demanding money to have an OT. P can’t be the only child in that school who requires Occupational Therapy. They say “physio and Occupational Therapy overlap and classroom teaching and Occupational Therapy overlap so really we cover it all” and you think yes but you could do so much more for these children. So it’s difficult to say he would have done better at PH if you want to say we’re totally unhappy with WL we’re not but there aspects of WL school that we are unhappy with. We are unhappy with the LEA because they have failed to provide, to fulfil, his statement of SEN. You don’t know how many parents realise what options they have available to them and how many parents are actually willing to fight. But you’ve got to fight for everything for your child and that whole atmosphere aspect is wrong, you shouldn’t have to fight for your child.

I: Does P experience any social problems at school like bullying?

ID1M: No it’s a lovely school in that aspect the staff are all very nice. The school itself is lovely, the pupils are all lovely if you go into the school they all say hello to you as you go past.

Difficulties in getting specialist services:

ID8M: The OT’s are hard to get, but he’s on the list now. If he goes off the list and back on again he’s at the bottom. There’s an 18 month waiting list. We’ve just been allocated a social worker a few weeks ago after 3 years. I had to write to Social Services to ask for one with it being his transition year next year. He has two more years left at school. I’m not very happy with Physiotherapy because they’re very short staffed so he might see one for half an hour once a week at school. The physio only does 2 days a week in a school of 150 children so she’s hard pushed so that’s gone down radically. We don’t have physio at home. The wheelchair clinic has gone down radically. The doctors are fine. The community nurse asked me what we wanted of her, it’s just about L’s nappies, his incontinence, making sure I’m doing everything right. Everything changes next year when
he's 18, we have to apply for nappies somewhere else and so hopefully she'll keep me on top of things like that, more information and make sure he's getting everything he's entitled to.

Distance to travel

- Special school catchment areas and distance from school appeared to be barriers to maintaining and developing local friendships:
  One of the disadvantages of attending a special school was that they were often located at some distance from children's local communities. Hence, distance from school appeared to be a barrier for developing friendships with local children as well as an obstacle to engaging in play and socialising with classmates after school (see below).

Table of proximity of the school from the child residence

<table>
<thead>
<tr>
<th>ID</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID1M</td>
<td>taxi and escort, WL school in West Monkseaton, which is about 2-2.5 miles</td>
</tr>
<tr>
<td>ID2F</td>
<td>taxi (like a minibus), 15/20 minutes in the car.</td>
</tr>
<tr>
<td>ID3M</td>
<td>About 25 miles, taxi</td>
</tr>
<tr>
<td>ID4M</td>
<td>About 17 miles</td>
</tr>
<tr>
<td>ID5F</td>
<td>problems mother drives her</td>
</tr>
<tr>
<td>ID6F</td>
<td>taxi, problems in the past, didn’t have seatbelts or ramp for them</td>
</tr>
<tr>
<td>ID7M</td>
<td>10 minutes in the car, bus</td>
</tr>
<tr>
<td>ID8M</td>
<td>Sir Charles Parsons., Across the other end of the city, bus, rush travel., It’s quite a big bus, 4 wheelchairs and about 6 walk-ons with an escort, changing escorts.</td>
</tr>
<tr>
<td>ID9F</td>
<td>6 or 7 miles. She’s picked up by taxi and dropped off, estate car with a big boot to fit in a K frame and wheelchairs.</td>
</tr>
<tr>
<td>ID11F</td>
<td>Pendower school, a mile away, Either her dad or I takes her in her wheelchair.</td>
</tr>
</tbody>
</table>

The large catchment areas of the special schools makes it difficult for the children to get together and socialise after school. School is the main place for socialising with peers and friends:

I: Have you been quite active in parents groups?
ID6F: We tried to set our own group up. CAN’T HEAR. I sent letters out, I tried, but they didn’t want to know. I didn’t have one reply apart from her friend who said it’s a bit far. The problem is her friends from school are spread far and wide, this club was going to be after school at 7pm and they’d be on the road for an hour before they got here so I can see their point of view. They could have said it’s a nice idea but. School is the only main outlet she had with her friends apart from her friends coming here but then it’s twice as much work for us. We wanted opinions from people, what would be best. CAN’T HEAR

Pupils attending one school come from a wide geographical area:
I: Does she see anybody outside school?
ID10F: Not from her class. It’s very difficult because they come from all over; her boyfriend lives in Co Durham which is a problem during summer holidays. One night a week she stays at school at the Leyburn unit, we’re trying to get that up to two and she went to the summer school so she saw a number of people there. She loves it, she’d rather be at Leyburn than here.

Making friends and lack of social network of peers:

ID9F: We’ve seen her sit and play with friends children and she’ll interact with them. We can see the difference with our friend’s 7 year old and 18 month old daughters. B is not as far advanced as the 18 month old and there was a bit of tension over sharing toys. The 7 year old used to be great with B, she viewed her as a cross between a doll and a cat, but the fact that she doesn’t speak is becoming a problem because it’s difficult to communicate with her. We don’t see them often, 3 or 4 times a month. Only one school friend lives fairly close so she sees him every other weekend.
School Transport Service:

The interviewer reported that the school transport system is an issue in Newcastle but this did not come out in the interview transcripts. However, there were problems in the past.

The majority of the children relied on some form of organised school transport service (eg taxi, minibus, or bus) to get to and from the school. All but one of the parents were satisfied with the current provision of school transport.

Dissatisfaction with the School Transport time schedule led to transporting the child to school with a private transport:

I: Was it far to travel to school? And how did she get there?
ID5F: Guidepost is about 3 miles away. I used to drive her. At one time a bus came to the gate, picked her up and dropped her off again. Then they started faffing about with the transport and it got to the stage she was having to go out at 8.30am on to the main road to get the bus at 8.55am and she wasn't getting back here until after 4pm and the school came out at 3.15am. I wasn't happy with that so I ended up taking her back and forward till she left.

However, some parents recalled negative experiences with the school transport in the past including:

- unfriendly attitude of the drivers and the escorts
- wheelchair inaccessible school transport
- lack of relevant assistive equipment
- unsafe and uncomfortable school transport.

Lack of ramps and seatbelts, lack of heating, unhelpful and unfriendly attitude

I: How close do you live to PH school?
ID6F: It’s about 10 miles. She shares a taxi with a 4 year old from Blyth. It’s a black cab, it’s really good, from Newcastle. We have had problems in the past, 10 or 12 years ago, one didn’t have seatbelts or ramp for them. We said if you get them we’ll fit them for you but nothing. That was a standard car, she got transferred to sit in the back seat before it was the law to have seatbelts. Then another taxi firm, they’d stop the taxi outside and it wouldn’t start again, these were exceptional for Ashington. At the time A started having fits we asked if they could get a radio in the taxi and they were really nasty, saying “what’s a radio going to do if she has a fit?” Some times we refused to let her go and some of us got together and phoned County but they couldn’t care less, the kids were getting to school and back and the price was right, they went for the cheapest option all the time. They had no heating, they had to sit with their coats on and plastic bags on the windows where the windows had been smashed at the weekend. I was on the phone to County every week, screaming down the phone. It takes the kids a long time to build confidence and then come the next financial year that taxi company might have been 10 dearer than what they were the year before and County just said use a new taxi company and these kids are very vulnerable, it might have sunk in because you see them taking very little now, Northumberland.

I: Do you think they’ve got more professional?
ID6F: Yes the new law about the escort came in. The taxis we had they didn’t pay escorts
it was the driver’s mother or aunt who did it for a laugh. When we got on about seatbelts they were talking about us in front of A, saying who do they think they are asking for seatbelts, A would come home crying. CAN’T HEAR The one we use now is registered through Newcastle, they’ve got all the badges. different authorities have different guide lines.

Asked about the current provision of school transport most parents agreed that there have been some improvements in the service compare to the past. The most valued qualities of the service as reported by parents were:

- wheelchair accessibility (ramps) and lifting devices
- friendly attitude of the drivers and the escort
- introduction of compulsory escort system
- having a big boot capable to accommodate the assistive equipment of the child (eg big boot to fit in a K frame and wheelchairs)

Changing escorts, helpful and with good attitude driver vs. it’s been more of a job to them than anything you know, school transport provided by the education authority, large estate car:

I: Does she get school transport?  
ID2M: Yes. The taxi’s provided by the education authority. She gets a taxi – it’s like a minibus  
I: So she shares with others?  
ID2M: Yes. It’s been the same group of children that have been going to Parkside for a number of years now.  
I: Do you find any problems with it at all?  
ID2M: No. Not at all. The taxi driver they’ve got at the minute, he’s brilliant with the children. We’ve had some other ones where they’ve been maybe not as good – it’s been more of a job to them than anything you know, and then you get the odd ones that are just brilliant. They’re like one of the kids, they’re just as daft, you know. The one we’ve got at the minute, he’s good with the kids. He’s always teasing them and they have games together and, when they’re in the car, and taking the mick out of each other and things, so he’s really good, the one we’ve got at the minute.  
I: And the access into it’s OK?  
ID2M: Well he actually lifts her in – he takes her in the wheelchair and he lifts her in, which he doesn’t find a problem. I mean, I’ve said as long as he doesn’t find a problem, then fair enough, but he has ramps in the back to get her wheelchair in. I think he is actually looking at getting one where she just wheels in. And she has respite, one weekend a month, and that taxi, I think she just gets wheeled in and clamped in, but that taxi driver I don’t have an awful lot to do with, because a lot of time that she goes to respite she goes straight from school to respite then from respite to school on the Monday morning. I’ve spoken to him on the ‘phone and what have you – there’s been the odd time when she’s off school, you see, the bus from her respite comes and picks her up and takes her, so even then I don’t have a lot of contact with them, but I’ve been assured, I mean I’ve spoke to them, I’ve spoke to their bosses and obviously her teachers have had contact with them, so I speak to them. So she seems quite happy.

Large care with a big boot to accommodate the assistive equipment:

I: How close do you live to school?
ID9F: 6 or 7 miles. She’s picked up by taxi and dropped off, we’ve never had any problems. She shares with 2 other children, the driver and an escort. It’s an estate car with a big boot to fit in a K frame and wheelchairs.

I: So, you don’t live very close to your school do you. About 17 miles? How do you get to school?
ID4C: Taxi
I: Do you share it with somebody?
ID4C: Yes, D. She lives at Bedlington Station.
I: And do you have any problems getting to school – does the taxi come on time and bring you back on time, or did you have any problems with that?
ID4C: Well it was a bit of a problem
ID4M: If you go over all the years you’re going to experience some problems very occasionally, but the current firm, which starts in September. Actually we do know it’s with Phoenix, we’ve had the letter of confirmation.
I: So are you quite happy with that
ID4M: Let’s be honest if you go over all the years he’s been going, since 3 and he’s now 11, if you didn’t have that it would be an absolute miracle. But generally you’ve got to say that it’s very good and certainly the driver and the escort are very good with the children.

However, some parents expressed some dissatisfaction:
- policy of frequently changing the escort annually
- sometimes there were delays
- lack of enough space in the vehicle to accommodate a wheelchair
- attitude of drivers it’s been more of a job to them than anything

Changing escorts:

ID8M:...He’s transported on Rush Travel and he’s the first pickup of the day at 8am which he doesn’t mind because he’s up at 6am anyway. He likes the bus, but he’s tired at the end of the day and he sometimes works himself coming home, not very often. He’s the last drop off at about 4.10pm.
I: Have there been any problems with the transport?
ID8M: Not really, sometimes they’re late. A couple of years ago when it was a different company L had just had his hip done and they missed picking up for 3 days running, and they knew they had to. That’s the only problem we’ve had. It’s quite a big bus, 4 wheelchairs and about 6 walk-ons with an escort. There’s only a problem when they change the escort until they get used to the kids. There will be a new escort at Christmas, they normally change every year.

Changing escorts:

I: He goes to a special school; does he have any problems getting around the school?
ID3M: He can get the wheelchair around by himself.
I: You go into every day with them to school? Is that out of choice?
ID3M: They’ve had a few escorts, but you also have kids from 2 kids from Blyth, I from Morpeth and 1 from Ellington, J and D. Talk about kids from hell, they would call you
anything if they couldn’t get their own way. The taxi went off and nobody would have it they were all frightened of him. I offered to help out for a month and they quietened down. I: So are you happy with being the escort now, do they bring you back? ID3M: We leave at about 7.50am we get back here at 10am and they pick us up again at 2.30pm and we’re back for about 4.50pm. He’s happy; he used to get confused with different escorts. He likes the taxi driver, she’s nice to him and that makes a big difference.

Can’t accommodate wheelchair in transport:

I: How do you get to school? ID7C: By bus, school transport. I: How do you find that? ID7C: Quite easy. ID7M: They can’t accommodate J in a power chair on the bus so this holiday we had to go and pick his chair up and bring it here and will have to take it back to school. I: Is it a minibus? ID7M: It’s the next size up with a powered tailgate.
Access within school:
The majority of the parents were positive about the physical access within the school (flat access, lifts, automatic doors) with only one parent reported accessibility problems (stairs and special school not adapted for wheelchair users)

Lifts+ classroom assistants:

I: Is getting around school all right? He can get into all the rooms?
ID8M: No problems, there’s a lift to take him upstairs for computers. They have classroom assistants.

ID7M: Automatic doors, flat terrain:
I: Can you get round school okay with your chair, is there anywhere you can’t go because of access?
ID7C: At the old building at the old school there were some places I couldn’t get in.
ID7M: The new building is all one level and they’ve got automatic doors, that’s for the older children.

I: Can P get around the school okay?
ID1M: He can it’s completely flat in school. There are some slopes such as down into the medical and physio wing where the pool is but it’s absolutely fine. No problems getting into classrooms or toilets.

Problems with accessibility:

Accessibility of the school, not adapted for wheelchairs:

I: Did K get round the school okay?
ID5F: She was very careful on the stairs; she’d let the other children go down before she did. It wasn’t adapted for wheelchairs. They had her doing everything and half of it she couldn’t do. A case of no pain no gain.

School ethos and attitude of the staff
Most parents were appreciative of the attitude of the educational staff to their children. However, two main attitudinal factors were identified in causing distress among children and having a negative impact on their participation in school activities:

- Improper treatment of disability from staff in some special schools Although most of the parents did not have first hand insights they were happy with the school service and the attitude of the school staff to disability. However, in few cases parents recalled distressing experiences with the improper treatment of their children from some of the school staff (eg being abusive and nasty to children, do not respecting their privacy and dignity.

I: Did she have any help or support in the classroom?
ID5F: When she first started she had her own helper. Then as she moved through the classes she worked independently. They had helpers in the classroom and whenever K
told her anything she’d tell her to shut up, don’t be so silly. She really embarrassed K one
dinnertime over her slight incontinence.
(K has slight incontinence due to her epilepsy tablets. She didn’t used to have that until
they changed her tablets, it’s one of the side effects. We told her Consultant and she said
it was definitely not from the tablets, but she was alright before. She wears pads.)
ID5M: I used to get nappy bags to dispose of them in the box but this day it was full and K
told her helper and she took K into the staffroom and showed her what to do. K already
knew what to do and was nearly crying, there were male teachers there. I was really
angry about it but I felt as thought I was always on the phone complaining.

Special school: under funding and the retirement of head master had deteriorating
effect on the school service:

ID5F: I think that school has lost the plot, they think they’re a mainstream school and
forgot they’re a special school. When K first started the Headmaster was a nice, quiet
spoken man but he controlled the children and if you told him anything he’d listen to you
but he retired, he couldn’t get the funding and he was disillusioned, and the school hasn’t
been the same since. It’s wild. Gone from bad to worse. It got to the stage where K was
coming home you’d be thinking what’s she going to be like today, there was always
something about the school.

Improper treatment:

ID5F: When she was leaving school she wouldn’t go to collect her leaving certificate, we
had to make an excuse and keep her off school that day and get it from the teacher
because she was beside herself, in tears.
MrsB I was annoyed with the way the school went on about it, they made a joke of it and
they kept on all through the week, instead of trying to help her. We thought they might
have more compassion with it being a special school.

Attitude of the staff/school ethos had negative impact on her:

ID2F: Normally if there’s something she’s not happy with, that’s when she starts fitting, so I
always know when there’s something wrong with her, if there’s a certain atmosphere round
her, so if there’s a very tense or that kind of atmosphere, a bad atmosphere, that’s when
she starts having fits, and that’s how it comes out with her. She had one school, one that
she went to before Parkside, she was getting sent home nearly every day. She was
having seven fits a day and I kept saying to them at school ‘is there something at school
that she’s not liking, is she getting told off?’ ‘No, no, no, there’s nothing the matter’, but it’s
one of those things when, you know when you get a feeling but there’s nothing you put
your finger on, but you just don’t like it? And we had different problems with – the nurses
used to say we haven't been able to give her all the medication, so I’d phone them up, well
why not? She’s got to have this for a reason, she needs to have it. I mean, they’re a
nurse, they’re supposed to be able to administer these drugs. I mean, we used to go, we’d
phone up her dad’s brother when she was ill. Well his family would have absolutely
nothing to do with her, so they wouldn’t know what to do with her. They would tell my mam
that I didn’t live where I lived and, you know, things like this, and they had her on
diazepam for about a week, every day for about a week. Well, she was like a rag doll, to
try and knock it out of her. We changed medication and everything, and since she’s left
there and started at the new school – she’s been at the new school for about four years I think, she’s had two fits. She was having about seven a day there. So it’s got to have been school. Whenever there’s been some kind of upset at home, and it’s just that she’s been upset at home for whatever reason, and that’s how it comes out of her.

I: So what do you think was the problem at the other school?

ID2M: I don’t know what it was. It was just, it seemed that when we went in the teachers used to be all over J. Now, to me, you treat them all the same, so obviously whatever else was going on, then they’d be all over that child, you know. I don’t know, there was just an impression that we got, you know, it just didn’t feel right, and my mam had actually went in and caught one of them being a bit nasty to J – one of the teachers, calling her horrible child and what have you. My mam just went off it and so there was obviously things going on in the classroom that we weren’t aware of, but whatever it is, well she’s a lot happier now, and so obviously there’s no problems

“Treated as a number not individually”:

I: Thinking about the laws and policies there are around to help families and children, do you get involved, do you go to any support groups?

ID8M: No just talking sessions at school, which the school arrange. Coffee mornings and phone numbers of other parents.

I: You don’t know about any laws and legislation that come out?

ID8M: No. School would know. We had a meeting for when L comes to 19 and someone came to advise us but he couldn’t even advise us properly. You just feel like you’re treated as a number not individually.

• Bullying in special schools

The second reason for concern that emerged from the some of the respondents accounts was bullying (in special school from disabled peers). Some of the parents felt that school was too defensive in facing the problem with bullying. However, it was difficult for the parents to identify the problem without having first hand insights.

Bullying in school, school being too defensive instead of facing the problem:

I: When you think about K’s independence is their any person or service that’s been particularly helpful.

ID5M: Scope. The person we used to see has left and I miss him because we have had a lot of bother and he could have sorted it out.

I: What kind of things?

ID5M: A lot of bullying at school.

B Was it a special school?

ID5F: School at Guidepost, a special needs.

ID5M: We had months of that, another girl, she was too possessive, kissing and cuddling her and wouldn’t leave K alone. She was kicking K and we went to the school about it and the Head denied it and said it was just two girls having a ‘tete a tete’.

I: Was she upset by it?

ID5F: She used to come home crying. We had a woman from County Hall with us once and he still wouldn’t say there were any problems. Now she's finished that school so hopefully things change from now.
I: But that has an affect on you, going to school and how happy you are.
ID5F: It does. She didn’t want to go to school in the morning, she was crying.
ID5M: When we used to go to the school for various reasons the teacher was on the defensive as soon as we went in, we felt that they were thinking here they are again.
I: So you didn’t get on very well with the school
ID5M: No the last year was a nightmare.
ID5F: I wanted the last year to be really special for her, to have a nice quiet year but it didn’t work out that way.

Attitude of peers:

I: Does V experience any problems at school, bullying?
ID11M: Her last class was a little bit hard there was one person in particular who did disrupt the class and some of the children would be quite tense, that affected her until she got used to him. I never have the feeling she’s not happy, she loves school.

Bullying:

I: Does she experience any bullying?
ID9F: There were a few occasions when we were getting reports coming back that she was biting other children. It started off she was biting children who were more able than herself and we suspected that was where children were perhaps being physical with her and she didn’t like it. Then that died down and she started biting children who were less able than herself and we were quite disturbed, but it seemed to be a phase that died down. Without being able to talk to B about it, it was very difficult to work out what was going on. The staff tried their best but they were doing it when the teachers weren’t looking so it will probably remain a mystery. It lasted about a month.

Demand for post school activities (respite care, post school clubs)
Parents often praised schools and post-school services for organising recreational and social activities that made a difference to their children’s social lives and independence.

ID8M: Yes his school takes him out a lot. He goes to school at 8am and comes back at 4.10pm and because he’s been out with the teachers he’s not interested in going anywhere else after that because he’s sore from being in the wheelchair, so we tend not to go out in the evening at all. He’s quite happy to stay in. He loves his school day.

ID4M: Acorn is a residential unit at the school and G actually goes there one night a week to give him a bit of development and independence. It’s been agreed through social services. There is a 16+ section at the school and this is what he’s talking about.

I: Do you think everything L does is appropriate for him?
ID8M: It’s brilliant at school. He does swimming, cooking, goes to college. When they go into 6th Form they tend to go out a great deal, getting them into the community. He loves school. The school nurse is fine. We’ve got no problems at school apart from the physio side, which is important. I do a lot at home. I know generally what to do. But you don’t
Another theme that emerged from the interviews was the demand for post school clubs and activities. Parents felt that their children do not have enough opportunities to play and socialise with their peers. Most of the parents tried to improve their children’s social life through signing them up for different forms of post-school activities including respite care and different after school clubs tailored for disabled children. However, joining such activities often depended on having one to one support or at least someone who can help the child with transportation. Respondents cited a wide range of obstacles such as need for co-payment, long waiting lists, lack of and limited number of available places as well as distance from their homes and lack of wheelchair accessible transport as factors preventing their children from engaging in such activities.

School support services (OT), Post school service: respite care (he has no social life):

I: Would you say there’s any service that you’ve found particularly helpful?

ID7M: At school the OT’s he’s had there have been very helpful and put us in the right direction. At the moment we are in contact with Social Services because we really feel that he needs to have one night a week at Leybourn as respite for us but more for J’s independence, because he has no social life.

...they’ve offered for the future but it really goes down to cost but at his age, 14, to send him somewhere where it would be completely strange wouldn’t be fun. It would be punishment.

Lack of available places:

I: You go to most places with your mum and dad. Do you go to any clubs?
ID7C: Summer school.

ID7M: That was organised through school. They raised a lot of funds but we had to contribute towards it as well, about 50. It was only on one week, Monday to Friday 9am – 4pm as they relied on staff. I’ve tried several times for these clubs and there’s nothing. A lady who runs one of these clubs, the Friday Club, says that children who go tend to stay for years and years.

I: Does J go to Respite? Are you discussing it at the moment?

ID3M: R says he’d be better going because he’s only used to him, if I go out anywhere my daughter has him or his mam and dad. They’re the only ones that have him so he’s only used to us. I’ve been talking to somebody who’s little boy goes and she says it’s the best thing she’s ever done. So I’m thinking about it after the holidays. The kids from school go so he might settle.

I: Does J need any help or support in the classroom?

ID3M: He has hearing pairs, a speech therapist, a physio, 3 teachers and 2 assistants.

I: Is there anything at school that you would like to happen that doesn’t?

ID3M: I wasn’t happy with the speech therapist, I thought he wasn’t getting enough but when I went to the review I brought it up and they upped it.

I: Does J have any problems with bullying?

ID3M: No. When they’re in the yard they have a lot of folk looking after them, we had to sign a consent form for them to take the children into the yard.

ID8M: We put in for Active Care for a Saturday but he’s been on the waiting list for quite a while. D does football and L would get cold watching. That’s D’s space, his environment with his friends and I would like to go and watch him. The only services I get off Social Services are the 3 days in the term. He doesn’t go to Respite, so I asked for Saturdays but the buses are full. They were going to take him by bus but he wouldn’t tolerate the cold or rain so the best scenario was a wheelchair transport bus but they’ve got no room at the minute so we’ll have to wait. So transport is the problem.
Financial burden

Economic barriers

Additional financial costs to family not covered by benefits (eg adaptation of home, specialist equipment etc), parental employment.

Table of facilitators and barriers

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<th>Facilitators</th>
<th>Barriers</th>
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<tr>
<td>Grandparents support</td>
<td>One or both of the parents had to leave work to care for the child</td>
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<td>Support from the employer (flexible working hours etc)</td>
<td>Health service and school expectations that one of the parents should be available to care for the child</td>
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<tr>
<td><strong>Benefits</strong></td>
<td>Policies to withdraw care allowances if both of the parents work</td>
</tr>
<tr>
<td>1. Disability benefits (DLA, MA, etc)</td>
<td>1. Lack of awareness/information of what financial help and subsidised services they are entitled to. Poorly targeted information on what financial help is available</td>
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<tr>
<td>2. Money raised through different charities, trade union voluntary organisations (eg interest free loans for adaptation of the house/car, purchasing a car)</td>
<td>2. Lack of sufficient funding and often restrictive eligibility criteria</td>
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<tr>
<td>3. Assistive equipment provided through LA or different voluntary organisations or through fund raising</td>
<td>3. Administrative burden: long and difficult to complete application forms</td>
</tr>
<tr>
<td>Purchasing an own vehicle</td>
<td>4. Most of the disability allowances covered only the basic requirements extras such as diesel or spacious car had to be covered by the families themselves</td>
</tr>
<tr>
<td>Motability, Voluntary organisations and forms of community financial support (eg church, trade union etc)</td>
<td>1. Long waiting times and difficulties to get on time essential for the child independence special equipment.</td>
</tr>
<tr>
<td>Other</td>
<td>2. Often they need to cover the extra cost for adaptation of the equipment to suit the needs of the child</td>
</tr>
<tr>
<td>1. Financial support from</td>
<td>1. Restricted in choosing the right model (the more disability friendly models eg spacious diesel van are more costly)</td>
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<tr>
<td>Clothes and special footwear</td>
<td>2. The travel expenses (patrol, parking fees)</td>
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<tr>
<td></td>
<td>3. Often need to pay for car adaptations from their own pocket</td>
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extended family (grandparents ID9F)
2. various disability discounts (free museums, free entrances to certain venues transport etc)

Washing powder
Buying pads due to their child incontinence,

services, systems and polices

Things like going away on holiday are more expensive, on the ferry we need a disabled cabin, which doesn't hold 4 people so we need 2 cabins and that puts the price up. Front seats in the airplane are more expensive. Small cinemas are cheaper but in accessible while new cinemas are accessible but more expensive

Finances: table of environmental factors influencing participation, in ICF format

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<tr>
<th>ICF Chapter</th>
<th>Barriers</th>
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| Chapter 1: Products and technology | e115: Products and technology for personal use in daily living; clothing more expensive, lots of washing is expensive, incontinence pads cost money  
e120: Products and technology for personal indoor and outdoor mobility and transportation; petrol costs, disabled cabin on boat costs more, poor access on boat prevented family going on trip  
e150: Design, construction and building products and technology of buildings for public use; small cinemas cheaper but less accessible | e115: Products and technology for personal use in daily living; free incontinence pads  
e120: Products and technology for personal indoor and outdoor mobility and transportation; wheelchair, car a “godsend”, van, disabled cabin on boat  
e125: Products and technology for communication; communication aid  
e165: Assets; costs: of clubs, brownies, riding lessons, clothing and washing, special | e165: Assets; parents pay for equipment eg special bike, both parents able to work creating good |
<table>
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<tr>
<th>Chapter 2: Natural environment and human made changes to environment</th>
<th>Nil</th>
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| Chapter 3: Support and relationships | **e310: Immediate family:**
difficult for parents to find childcare in school holidays when parents at work,

**e340: Personal care providers and personal assistants:** no support or care in house, childcare difficult in school holidays

**e310: Immediate family:**
parents provide attention and support, parents accompany child to numerous hospital visits, parents pay for special equipment eg bike, van, wheelchair, car and housing adaptations, parents “fight” for resources, parents fill in forms and contact social services regarding benefits, parents fundraise for equipment, parents provide physical support eg. lifting; grandparents give childcare support and financial support, support from grandparents mean that parents can continue working.

**e320: Friends:** friends provide information about resources, benefits

**e325: Acquaintances, peers, colleagues, neighbours and community members:** information provided by other parents at school re: benefits

**e340: Personal care providers and personal assistants:** Active Care

**e355: Health**
| Chapter 4: Attitudes | e410: Individual attitudes of immediate family members; mum thinks that benefit forms are geared to trick people  
|                      | e455: Individual attitudes of other professionals; and  
|                      | e460: Other professionals; health and education professionals expect one parent not to work to provide child care  
|                       |  
| Chapter 5: Services, systems and policies | e510; Services, systems and policies for the production of consumer goods; costs of equipment, clothing, incontinence pads  
|                      | e555: Associations and organisational services, systems and policies; parents did not know of support groups, Motability scheme does not pay for car adaptations and limits family’s choice of car, parents had to fight for Motability scheme  
|                       |  
|                       | e540: Transportation services, systems and policies; Tyne tunnel transport free  
|                       | e550: Legal services, systems and policies; solicitor helping in social services benefits claim  
|                       | e555: Associations and organisational services, systems and policies; Disability North provided bike, Whizzkids provided wheelchair SCOPE provided information, charities paid for equipment: fire brigade, police, sunshine fund provided funds for equipment, concessions for child and carer with
<table>
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<th>Description</th>
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<tbody>
<tr>
<td>e565</td>
<td>Economic services, systems and policies; lack of financial advice, lack of information regarding concessions for leisure activities, holidays more expensive - need disabled cabin on ship</td>
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<tr>
<td>e570</td>
<td>Social security services, systems and policies; parents lack knowledge of benefit entitlements, difficulties in applying for benefits - forms long and repetitive, policies of restricting home care allowances if parents working, not entitled to grants for home adaptations unless parental salary under set amount, NB all benefits now dealt with by department of workforce planning, but closest match of description of code remains with e570 rather than e590</td>
</tr>
<tr>
<td>e580</td>
<td>Health services, systems and policies; not funding all equipment - eg wheelchair bought by charity funding for £3000, incontinence pads, long process of application / long waiting list for wheelchair and wheelchair equipment (pommel)</td>
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English Heritage and National Trust, Disabled Children’s foundation helped parents to fight for Motability scheme

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<tr>
<th>Code</th>
<th>Description</th>
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<td>e570</td>
<td>Social security services, systems and policies; Policies of benefit provision: DLA (care and mobility), Invalid care allowance, family allowance, fostering allowance, help from income support officer and social worker</td>
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<tr>
<td>e575</td>
<td>General support services, systems and policies; Active Care</td>
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<tr>
<td>e580</td>
<td>Health services; policies to provide funding for equipment eg. electric wheelchair, communication aid, incontinence pads - reduces costs incurred by parents</td>
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<tr>
<th>Code</th>
<th>Description</th>
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<tbody>
<tr>
<td>e585</td>
<td>Education and training services, systems and policies; play scheme in holidays organised by school, school is a source of information for parents, and of equipment resources</td>
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</table>
Attitudes

When respondents were prompted to discuss the impact of their child’s disability on their finances some seemed reluctant to admit that any extra cost exists:

I:  
Do you think that having a disabled child is more of a financial burden on you?

ID2M: Not really, because I think it kind of equals out because I haven’t got her saying I want this, I want that, can I have a pound for that. At the same time, I mean, I spend, when you include her clubs and her Brownies and her riding lessons that she goes to, and it works out quite a lot of money a week. But then again she doesn’t get pocket money like most kids do, and she doesn’t get like, in the holidays, I’m going here can I have some money. So it kind of it just equals itself out in the long run.

Pride influences accepting concessions for disability:

I:  
Do you find any difference in cost when you go out?

ID11M: It’s cheaper, V gets a lot of concessions. At the pool I don’t pay as V’s carer. We were going to go on a boat trip at Seahouses and I couldn’t understand why V wouldn’t be paying because she would be sitting like everybody else, taking up an area, and I was a bit put out when the lady said to spare V’s dignity there wouldn’t be any charge. And I thought why not, I don’t begrudge spending anything. I can understand concessions where she wouldn’t benefit but not when she’ll be doing the same as anyone else. We didn’t go in the end because the access didn’t seem very good, there was a ramp down to the boat but then nothing.

I:  
So you don’t think having a child with a disability has placed more of a financial burden on you?

ID12M: No it hasn’t for us.

I:  
Have you had any extra financial costs? Has having J cost you more than it would normally?

ID3M: 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. He doesn’t eat sweets but I buy them I think through guilt when I’m buying for the other grandchildren. I get pads free
I: Would you say you’ve had any extra financial costs?
ID9F: Clothes and washing. Eating is such a messy business that she goes through 3 or 4 sets of clothes a day. But from financial point of view it’s not that bad because we get help from her Grandparents. B is not incontinent but she doesn’t pay as much attention as she could do, I think it’s a tactic she uses. At the moment having a disabled child hasn’t put more of a financial strain on us, we would probably have moved house anyway for a garden though it wouldn’t be as urgent so that is an issue.

Employment: Giving up work

Giving up work to care for the child, the extra costs needed for home adaptations and the purchase or adaptation of assistive equipment were the three major factors leading to financial deprivation of families with children with CP.

Parents or in one case the grandparent were the main source of support for the child. In the vast majority of cases one or both of the parents had to leave work or at the very least change to part time work in order to secure the high level of support needs required by a child with CP. The most common factors reported to have negative effect on employment opportunities of parents of children with CP were:

- growing up of the child was associated with an increased level of support needs and demand for care.
- current policies to withdraw care allowances if both of the parents work (eg withdrawing care allowances when both parents work was cited to reduce employment opportunities for one of the parents because they still needed to pay somebody to look after and support their child)
- high demand for health care of children with CP and
- expectations of the health and other services that one or both of the parents should be available to provide care for the child.

I: Do you think it’s placed more of a financial burden upon you?
ID10M: I think it does, if G 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. After I stopped work it became obvious that she needing more attention, there were more hospital visits at that time.

I: Would you say that you’ve been stopped from working as a result of L’s disability?
ID8M: Yes. When he was younger we were forever at hospitals, it was impossible to go back to work with looking after L. I haven’t even thought about it. Plus L doesn’t sleep at night so I haven’t slept properly for 17 years.

I: So you said that you actually left work to care for J?
ID2M: Yeah. Well, I fought actually to go back to work, but they won’t let me. I’ve got SCOPE involved, I’ve got Welfare Rights and everything involved, because they were telling me if I went back to work it means we’ll lose all the home care and when she came
out when she had her stroke and that, when she was, eventually she couldn’t do anything – she didn’t know who anybody was – everything got wiped out, and, seeing her now, she’s like 200% better than what she was. I mean, she had no responses, you know there was nothing there, and feeding her was difficult. She couldn’t eat and so it was a great problem and I used to say well, you know when I’m at work she’s still got to eat and have baths and what have you, and as I say I fought to go back but I couldn’t I’ll lose all the home care so in the end I had to leave.

I: So they wouldn’t do that without you being at home?
ID2M: And as I say, I mean, it didn’t matter whether I was at work or not, she still had to have the things done, but, that’s the way it works.
I: You were working full time?
ID2M: I was until she was born and then I went part time, but a lot of the time I did extra hours and then obviously when she had the stroke, that’s when I left.

ID2M: Well since I left work when she had her stroke, I think I’ve been on the benefits anyway.
I: Did you leave work to look after K?
ID5: I have health problems of my own but it’s just as well as K needs transport to get around.

Services expect that one of the parents will drop out of work:

I: Do you have any support or care in the house?
ID9F: No. In the holidays she went to a play scheme everyday organised by the school. She was picked up and dropped off. We’re very fortunate in that we have 2 sets of grandparents very close by and when B comes home from school at 3.30pm she’s dropped off at J’s parents who give her her tea and we collect her when we get back from work. There does seem to be a widespread attitude in the Health services and education services that if you have a disabled child both parents don’t work and its an assumption that one will be available and it’s often not the case. If we didn’t have the Grandparents I don’t know what we’ll do, one of us wouldn’t be able to work. I’m not aware if there is any after school support out there. In the work I do I’ve got a lot of flexibility in the hours I work, I can pick and choose, I could alter it so I could work part time and come home and look after B until J got home and go back to work in the evening, which would be a pain.

I: Your husband works full time and you part time, would you say that you would have been working full time if you weren’t prevented from doing so?
ID7M: Probably. I work as a health care assistant at the Freeman and they’re very flexible with their hours.

I: Would you consider working if it wasn’t that you needed to be here for V?
ID11M: I don’t know because I need to be here for both of them when they come out of school and go to school. We don’t want for anything and we do lots of things and I’ll rather be here for the girls. Then you have the headache of school holidays.

In the case where both of the parents were able to continue with their employment, grandparents were the main source of support. Parents reported that grand parents also provide financial help to families:
I: So you’re both in full time employment that is a choice you’ve made but it would be very difficult if you didn’t have the backing.

ID9F: I think we could get by if one of us didn’t work but without the support of the grandparents there in terms of child care that would be very difficult and it would impact financially.

Other factors that were reported to facilitate employment opportunities of parents were flexible working arrangements and positive attitude to disability of the employer:

ID10F: My previous employers were very understanding when I had to take time off, at one point I spent a month in the General with her because she’s not a child you can leave so I used up all my holidays on that. My husband did take over for a couple of nights but he’s a teacher so he couldn’t just stay off work. I’ll been working for them for a very long time and I don’t know if a new employer would be quite so keen on me saying I won’t be in for a month, and it’s not something you can plan for, we don’t know when it may happen.

Benefits

- Getting benefits; getting older the more difficult to get help

The majority of the families were receiving a wide range of disability allowances such as Mobility, Invalid Care Allowance, DLA, designed to assist families to meet the extra cost resulting from their child’s disability. However, obtaining such allowances was not an easy process due to high demand, lack of sufficient finances and strict or in some cases restrictive eligibility criteria. Some parents reported to be involved in legal battles and had to pay solicitors fees in order to obtain or retain such benefits.

I: Does J receive any benefits?

ID7M: He gets a Mobility and a Disability allowance, mobility at the high rate. I don’t get care allowance because I work part time, 16.5 hours.

I: Do you have any problems in getting the benefits?

ID7M: No. Initially with the disability living allowance they didn’t offer us the higher rate so we had to appeal, we did that ourselves.

Payments to a solicitor to get their entitlement back, going to hospitals prevents getting a job:

I: L gets allowances?

ID8M: He gets DLA, Higher rate Mobility and Care.

I: You get Invalid Care Allowance and all the benefits you should be getting. Have you had advice for that?

ID8F: When he turned 16 he had to sign for himself for the DLA. They tried to take his Invalid Care Allowance back. I had an accident, the case is just about finished so you have to pay your sick pay benefits back but they’ve added in family allowance and L’s ICA, they’re asking for that back. It’s cost us £500 to get it back. I had to claim back the family allowance and ICA. It’s not resolved yet, we have a solicitor helping us and he’s been helpful.
I: Thinking of all the services and environments what do you think are the best things, what you can say has really made a difference to your lives?

ID8F: We’ve only had Active Care since I had the accident and that is a real good help.
I: Is there anything that’s really bad that’s stopped you from doing things?
ID8M: When you think of the whole lot he’s getting the less anybody’s bothered. As he’s getting older it’s getting more difficult to get help. You just seem to be fighting to get anything. It took nearly 12 months to get a fitting for the new wheelchair. They took his pommel away for 3 months to drill one hole in. I adjust his wheelchair if possible because nobody knows him better than us.

In addition, administrative difficulties such as long, difficult, non-child orientated assessment forms put additional burden on the families already preoccupied with their child’s disability.

- administrative burden: filling long and repetitive forms:

Burden of filling forms is an issue, financial support from grand parents, clothing and washing:

I: Does B receive all the benefits she’s entitled to?
ID9F: She gets DLA which came through very easily, we had no problems at all. If I’m being cynical it’s because her mum has Dr in front of her name and she’s good at filling in forms. We have the higher rate mobility and high care. We don’t get invalid care allowance.

Long and difficult forms, not specifically geared to the children:

I: You’ve said G gets benefits. Have you had any problems getting those?
ID4M: They’ve always come through straight away but the length of the forms is totally ridiculous and unnecessary. They could be simplified a lot more. I complete the forms because I get the carers allowance. They don’t take into account my pension. If it was my old age pension they would, but not my company pension. Personally I don’t think it should affect the care allowance if you’re working or not because you’ve still got to care for him or arrange for someone to care for him. I get the impression that the forms are geared to try and trick you so they can pick an element to refuse.
I: They are very difficult and it’s the same form for children and adults.
ID4M: It doesn’t specifically say for children.

Burden of filling in repetitive forms:

I: Obviously J gets benefits?
ID2M: Yes.
I: Does she get all the benefits she needs? Have you had any problems getting benefits?
ID2M: Well since I left work when she had her stroke, I think I’ve been on the benefits anyway.
I: You’ve been on them obviously as well, yourself? Care allowance and that?
ID2M: Yeah, I get the invalid care allowance now with not working, and she has disability living allowance and mobility parts – she has the car.
I: And as for the adaptations. Social Services did that?
ID2M: Yes
I: Did you have to contribute towards those?
ID2M: No. That was pretty good. I mean the disability allowance they’ve given her it for life, which I think it would have been reviewed, would have had to be reviewed every so many years, but I think with her being that little bit older now, they said, well they’ll given her it for life, but every now and then they’ll probably just check her details, which is fair enough. I mean, I find that there’s an awful lot of forms to fill in for them, and a lot of the forms repeat themselves, but again, they’ve got to sort of sieve out the right from the wrong, so I suppose you’ve got to bear it haven’t you.

Parents also reported difficulties in obtaining relevant information on what financial help is available, suggesting that information related to disability allowances is insufficient, and poorly targeted. (One parent even argued that this is on purpose as a cost-containment policy of the government). Most of the time, information about the available benefits was obtained through friends, other parents of children with CP, educational or social workers.

Lack of awareness of benefit, services and equipment entitlements:

I: You only get physio? No social worker or anything?
ID12M: That’s right. We’ve never been offered it and I presume we haven’t needed it. 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.
I: When your child goes to a mainstream school you’re maybe not mixing with other parents who would be using the same services, so how do you get to know?
ID12M: You don’t unless there’s a particular problem crops up where I would contact the physio, she’s my main point of contact, I have nobody else. If there’s a problem with his splint or his leg I will contact her and she’ll come out and it’ll go from there. If there were anything else I’m particularly worried about I would contact the doctor.
I: So how did you find out you were entitled to a benefit?
ID12M: It was either a friend that told me or my Health Visitor.
I: So you wouldn’t know if W was eligible for another one if circumstances change?
ID12M: I really don’t know because they don’t send anything out. It was only because I was reading something that I realised I could get my car tax paid.
I: You’re not part of a support group or have any contact with any other families? So the information you get isn’t even from school?
ID12M: No. The information that I got was really at the start. I’ve had nothing. 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. Unless I was notified by the benefits agency I wouldn’t know if there were any changes. I suppose if necessary I could ring the Child Development Centre and I presume there’ll be someone there who could tell me.

Lack of information on the disability allowances and discounts:
I: Would you say the cost of doing something has stopped you from going anywhere?
ID6F: No, you normally get a little bit cheaper if anything but you’ve got to know, they don’t tell you. It’s through talking to other people. We only found out a few years ago that we get the Tyne Tunnel free. In some theme parks carers get in for nothing so friends who’ve been there tell us. Sometimes they make A pay and the carer will get in free. But again they don’t directly tell you that, they’ll let you pay full prices and then mention it. There’s no information you can get to tell you. We got through the Dartford tunnel free because I just asked.

I: What benefits does W get?
ID12M: DLA, Mobility higher rate and lower rate Personal Care. He was on the middle rate Personal Care but they’ve dropped that and given him the Mobility. We don’t get Invalid Care Allowance.

I: He can manage to walk, he has no difficulty in sustaining that?
ID12M: Yes but you have to be careful when he gets tired. He has to have his splint on because he does fall.

I: As you said before if circumstances change you won’t be made aware of that?
ID12M: I don’t know if it’s an automatic thing that the benefits people send you something. I only know about Invalid Care Allowance because a friend told me.

Information provision from school:

I: Is there any service that’s been particularly helpful?
ID9F: The people at Disability North were quite useful. There wasn’t much they could do at the time we went because she was too small for a wheelchair but they found her a bike with an attachment on the front to steer her and straps on the pedals. We paid for that. The most useful out of everybody has been WL school, they’ve put us in touch with various organisations and it’s a very smoothly run operation, virtually anything we’ve needed has materialised. The wheelchair, her communication aid, her dynabox appeared and we didn’t have to pay for that which is good because it’s about £4000. It’s not essential at the moment but in the future in terms of going out and interacting with the environment that’s going to be the next big one, using it to communicate all the time. You don’t see people in public with communication aids, the technology is not fantastic and they’re okay to use indoors but it’s not practical to use them in sunlight because of the way the screen is. That’s something for the future, the next generation that can be used in the park, on the beach, small enough to carry.

Information is available most often on an informal basis with no professional advice, no approach by a support group:

I: How important do you think it is to get information from others?
ID11M: For me very important. Early on I just needed to be talking to somebody about the whole thing, what do you do and where do you get things from. It was friends of friends and Scope put me in touch with one person, I didn’t find them very good apart from that. The solicitor put me in touch with someone and one of our friends has a little boy with Cerebral Palsy and through the school. I’ve never had anyone (information) on a professional basis it’s been more friends and family.
ID9F School provides information about what is available for disabled children:

I: Are you aware of laws and policies regarding the disability discrimination act etc?
ID9F: Haven’t got a clue. We don’t know of any support groups. We would ask at school, most of the things we’ve asked they’ve come across before and if they haven’t they’ve given us pointers and we’ve found the information ourselves. They regularly send out information.

Facilitators: income support officers, social workers provide information and assist with filling in forms

I: Does G get all the benefits?
ID10M: She does, she gets the higher rate of DLA and the night time part as well, and mobility allowance. I get invalid care allowance. We had no problems getting the benefits.

Income support is a facilitator, income support officer:

I: Do you get invalid care allowance for K as well as the other benefits?
ID5F: Yes
I: Did anyone help you with getting them?
ID5F: We filled forms in and one led on to another. We had someone from Income Support here a few weeks ago checking what benefits we’re getting and he said we’ll still get Income Support until K’s 19, but if she didn’t take to the college she could either go on to Job Seekers or Income Support if she’s not capable of having a job.

Social worker checking benefit eligibility and telling mother:

I: Does J get all the benefits he’s entitled to?
ID3M: When I took him on the social worker did all that for me because I didn’t know anything about it. I get Mobility, Invalid Care Allowance, DLA. If [the social worker] thinks I’m entitled to something she tells me. They stopped my Income Support because I get Fostering Allowance. She says when he’s 16 he gets other things.
I: Do you still have a social worker now?
ID3M: No. I didn’t like them.
I: Did you have to pay towards the adaptations and equipment?
ID3M: No.

Many parents felt that government benefits were designed to cover only basic needs for home adaptation and specialist equipment. The adaptations and specialist equipment purchased through government benefits were often seen as inadequate. In addition, long waiting lists prevented families from acquiring such benefits and equipment on time leading to a negative effect on child independence and participation in activities.

Assistive equipment is often inappropriate:
I: Is there any piece of equipment you couldn’t have done without?  
ID6F: Her wheelchair. CAN’T HEAR We bought her first one about seven years ago. They wouldn’t get her one so we bought one out the paper and padded it out and made it fit so see how she’ll manage and she got used to it. CAN’T HEAR The one she has now is supplied by Northumberland health authority, she travels to school in it. She’s got another one but she’s outgrown it. She got one from Whizkids, the charity, before that one but she doesn’t like it so she’s going to give it to school to use as a spare or one of the younger kids can have it.

I: Is there any piece of equipment you haven’t got that you’ll really like?  
ID6F: A new Pathfinder. A new chair too, she’s waiting to be assessed for her chairs, it’s a long drawn out process. I want it replaced before she goes to college, college have said if she comes down with that one they would reassess her because she can tap into their money, it would be part of North Nottingham health authority. The trouble is Northumberland don’t use that type of chair and it’s widely accepted that chair’s not good enough for her it’s not strong enough, it’s the wrong shape but that’s all they’ve got so it’s that or nothing or you spend £8000 of your own money and all the repair bills on top. So it would be nice for her to get a new one and go down and have 12 months of learning how to use it when we’re not going to be there. School have said the same about the Pathfinder, she had it on trial and F.. College have said they’re buying her one when she goes to them but I said it would be better if she had it now because she’ll have to learn how to use it, so the speech therapist at school is busy looking into it. She doesn’t need it with us very much.

Hence various strategies were adopted by families to secure the desired up to date equipment ranging from paying the extra cost themselves to different forms of fundraising through various charity and voluntary organisations.

I: Any special equipment you have, did you get it from loan equipment?  
ID9F: The wheelchair is from joint loans in North Tyneside, the Wheelchair services and the table. I’m not sure who paid for the Dynabox. The only thing we’ve bought is the bike.

Extra cost is covered by charities and other organisations:

I: Does V get all the benefits?  
ID11M: Yes, DLA and Motability. I get Invalid Care Allowance. She’s got the highest rate. For the first few years she was on the middle rate of DLA and her Physio said she should be on the higher rate so I contacted them and it was backdated. I’ve had no problems.

I: Would you know where to go to if you wanted help with looking into finances if circumstances change?  
ID11M: No.

I: Would you say you’ve had any extra financial costs?  
ID11M: We haven’t borne the brunt of the costs because we’ve used Charities. The Fire Brigade and Children Today Charitable Trust bought her bike between them. The Sunshine Fund bought her swing. The Police bought her corner seat. Her wheelchair was partly funded on the voucher system because it was 2000. My sister did quite a bit of fundraising for that and the Police helped out again. I made the phone calls to the Charitable Trusts. We’ve bought mainstream toys but when it comes to the bigger items
it’s either don’t have a holiday and don’t buy things you need in the home so we can buy a bike or a swing. We can’t say to R you can’t have this because V needs her bike, and she does need her bike because it’s good for her physically. It’s got maximum support, the callipers, the hip strap, the swing away trunk support.

Extra cost of the assistive equipment /adaptations

I: Has the local authority helped with the special equipment and adaptations to the house?
ID10M: or ID5M: The equipment has been provided. We did ask for a grant but we’ll have had to spend about 36000 before they would give us any help for adaptations. We were given a small amount by a local charity towards converting the bathroom. We didn’t ask for that it was through the church.

Cost of the special equipment, long waiting times:

I: Do you think the statement’s very important?
ID4M: It’s essential to identify their needs and focus people’s attention because it actually puts in writing what’s needed. The trouble is the dynamite for G was identified at least 3 years ago and we’ve only just got it. Part of it is obviously the costs. But that was sorted out at the end.

I: Have you had any extra financial costs? Has having J cost you more than it would normally?
ID3M: We paid £3000 for the electric chair, we raised that.

Problems with using the equipment AQ in outdoor environment:

ID?: Communication aid, her dynabox: The wheelchair, her communication aid, her dynabox appeared and we didn’t have to pay for that which is good because it’s about £4000. It’s not essential at the moment but in the future in terms of going out and interacting with the environment that’s going to be the next big one, using it to communicate all the time. You don’t see people in public with communication aids, the technology is not fantastic and they’re okay to use indoors but its not practical to use them in sunlight because of the way the screen is. That’s something for the future, the next generation that can be used in the park, on the beach, small enough to carry.

I: You’ve had some adaptations carried out to the house?
ID 7M:The downstairs toilet, his bedroom we had doubled in size to give him more floor space. We paid for all that. We weren’t entitled to any grant.
I: Do you find that puts a financial burden on you?
ID7M: Yes, definitely, it penalises us because we both work and my husband has a decent wage. (house adaptation.)

• Cost of purchasing own vehicle
While Motability Scheme was seen as beneficial (4 vehicles were purchased through Motability scheme) in reducing the financial burden for families of children with CP by assisting them with purchasing their own transport vehicle, some respondents raised issues around limitations of this service which can be summarised as follows:

- It limits family input in the decision making process in relation to characteristics of the vehicle such as size and model (diesel models are less costly in terms of running costs but more expensive to purchase compared to petrol models. Petrol models are cheaper to buy initially, but in the long term cost more to run in terms of fuel).
- It does not cover the extra cost arising from the need to adapt the vehicle to meet the specific needs the children with CP. This cost was said to be covered by the families themselves. (only 3 out of eleven car owners had an adapted vehicle).
- Difficult to meet eligibility criteria and long waiting lists for the scheme: “have to fight to get the service”

**ID10M:** We got a grant for the van from my husbands union and they gave us an interest free loan towards that as well.

I: So you had to pay for the adaptations to the van on top of the cost of it?

**ID10M:** Yes. It wasn’t through Motability because they have complete control over the kind of vehicle you get and it’s the smallest and cheapest one you could get away with, there’s not a great deal of consideration given to things like the amount of equipment you need to go away on holiday, and we also wanted one where if our parents come to stay we could all go out together than in two vehicles. They won’t allow you extra seats, we wanted diesel as its cheaper to run and they won’t supply diesel because they are more expensive in the first place. So what we did was applied to my husbands union which has a benevolent fund and asked if they’ll help and they gave us grant of £5000 and an interest free loan of £6000. It was a year before they’ll take any money from us. So we have the vehicle we want, it’s got 2 fold down seats at the back so we have plenty of room for when we go away and when we have extra family members we can get them in the van with us.

I: One of the down side is you couldn’t get it through the Motability scheme because of the things you’ve mentioned.

**ID10M:** Yes but they’re a charitable trust and they can’t provide luxury bits only essentials.

I: Do you have motability? Is it full or partial?

**ID5F:** Yes but we had to fight to get that, we had the Disabled Children’s Foundation involved. It took a long time to get it. She has full mobility for the car but only lower rate care. The car has definitely been a godsend for getting her round.

**ID10F:** The van is a big vehicle so we have to pay more to take that. It’s difficult to put a price on things.....

In addition adaptations are expensive and if the vehicle is on lease the adaptations need to be removed before handing it back:

I: What are the good and bad points of transport? You mentioned the car hasn’t got easy access so that you have to lift J in and out.

**ID7M:** I can manage to lift him but I think I could hurt him because I’m lifting him in an awkward way to try and keep him and myself safe and then twirling him to get his long legs in. Once he’s in it’s fine.

I: Might you change your car or look at adapting it to help?
ID7M: We had a Scenic before on 3 year lease but it’s so expensive to adapt and you have to pay for the adaptation and if it’s on lease you have to take the adaptations off before you hand it back.

Other barriers contributing to the financial burden

- washing and clothes and special footwear

I: Have you had any extra financial costs as a result of G?
D10M: She creates a lot of washing…..

I: Would you say you’ve had any extra financial costs?
ID9F: Clothes and washing. Eating is such a messy business that she goes through 3 or 4 sets of clothes a day. But from financial point of view it’s not that bad because we get help from her Grandparents.

ID3M: He gets through trousers with crawling about in the yard, two or three pairs a day but if I see a cheap pair I just buy them. The only thing I spend a lot on is for school, I buy him expensive tracksuits because you can tie them and they don’t come down, they’re not allowed to wear a uniform. He has special boots for school, callipers and that. I don’t put them on him in the holidays, I tell the school though, he doesn’t like them and he can do more with them off than with them on. They’re off as soon as he gets in from school.

I: Have you had any financial costs in the past year because of G’s disability, any extras you’ve had to pay for?
ID4F: I can’t think of anything specific. The dynamite is covered by the county as is his wheelchair. We don’t need special clothing for him; we replace shoes as you do with any normal child the only difficulty is getting ones with Velcro fastens.

I: Is there anything else that J needs as a result of his disability, extra clothing?
ID7M: He does have some trouble toileting so he’s changed more regularly but we manage.

- going away on holiday is more expensive:
  - planes: money determines the mode of transport, front seats are most expensive
  - need to book two cabins instead of one
  - specialist services, clubs etc.

I: Have you had any extra financial costs as a result of G?
ID10M: She creates a lot of washing. Things like going away on holiday are more expensive, on the ferry we need a disabled cabin, which doesn’t hold 4 people so we need 2 cabins and that puts the price up. The van is a big vehicle so we have to pay more to take that. It’s difficult to put a price on things.

I: Do you think that having a disabled child is more of a financial burden on you?
ID2M: Not really, because I think it kind of equals out because I haven’t got her saying I want this, I want that, can I have a pound for that. At the same time, I mean, I spend,
when you include her clubs and her Brownies and her riding lessons that she goes to, and it works out quite a lot of money a week.

- disposable pads
- Travel expenses (petrol, parking fees (see parking))

Pads and petrol:

I: Have you had any financial costs in the past year as a result of K’s disability?
ID5F: Buying the pads. She gets incontinence pads for night time but they are too big. We buy 2 packs of TenaLady pads a week, about 4 each pack.
I: Do you think having a disabled child places more of a financial burden upon you?
ID5F: It costs a fortune in petrol. We’ll be taking K for a run today just to get her out the house and it mounts up. She likes to be out in the car and we think it helps take her mind off the voices, which come on more when she’s bored.

Accessibility policies:

ID2M: Small cinema are cheaper but inaccessible: stairs, USF is accessible
I mean like in summer for the cinema for instance I go to the big one rather than the little one in Blyth, because it’s all stairs and of course it’s cheaper to get in slightly in smaller ones, it’s been there for years, but obviously I’ve got to go to the one that’s got the access for J, so I suppose in that respect I prefer to choose the UCI.

Facilitators: various discounts parking fees, tunnel fees etc

Accessibility barriers + various discounts and free entrance for the carer when visiting national trust buildings:

I: Looking at the cost, accessibility, buildings, toilets, specialist equipment, local facilities, convenient transport all the things that we’ve really talked about and things that we haven’t like staff, people’s manner, attitudes, and support services around you. Thinking about all these things would you say that you’ve changed anything, any service or going to any building that you use over a period of time? For example if you went somewhere and you didn’t use it again was there any particular reasons why you didn’t, taking into account was it too expensive, not accessible, what was people’s manner like, was it hard to get to?
ID1M: The accessibility is obviously a biggy. Cost can be a variable issue, you find quite often that P would get in at a child rate aged five and that either M or myself get in free as a carer, which is obviously an attraction because you don’t want to spend a lot of money on somewhere for P to want to go home. Or spend a lot of money on somewhere you’ve not been before and you couldn’t check out and discover that it is totally unsuitable and you’ve wasted your money to get in. We’ve joined the National Trust because for myself and P to join annually we’ve already covered the costs and M gets in free as a carer so if we go somewhere National Trust and find it’s not suitable we can have a quick look around, M go off by himself for a little while and I can go off by myself for a little while and
come straight out again and we feel that we've not lost anything for the places that we can
go to which are good.
I: When you get your information from the National Trust does it tell you what
buildings are accessible?
ID1M: It does, some information from the buildings is better than others. With places such
as Wallington Hall for example, you'll have a map of the grounds and it has non-stepped
routes, or for routes with steps it will tell you how many steps it has. Now 3 steps M and I
can just pick the buggy up or bump him down, but 14 steps is impossible, so you know
which route you can take so that sort of stuff is great. The National Trust is pretty good at
that but not overall they're still variable. So cost could be a prohibiting factor if we really
weren't sure but a lot of places do let you in free as a carer.

Disability discounts:
I: What about costs?
ID7M: English Heritage are quite good because they tend to let the disabled person and
the carer in free but a lot of other places do charge.

Policies:
I: Do you keep informed about laws and policies like the Disability Discrimination Act?
ID11M: I watch the news and if I hear something and it applies to us I'm interested in it and
as V gets older these things will apply much more but I don't read up about it.
I: Are you a member of a support group?
ID11M: No, not because I don’t want to its just something I've never been approached by.
At odd times the Child Development Centre has rung me and put me in touch with
someone who’s baby is in special care and I'll talk to them if I think I can help. As regard
to support for me I feel like I get plenty from the school and my family and the doctors and
physios.

Need for respite care. Difficult for parents to say that they need help to look after
their children:
I: Do you know anything about policies and legislation?
ID10M: We try to keep abreast of what is going on. We’re delighted to see someone is
taking Ryanair to court. I did a great long letter and sent it to the Government when they
were looking for a consultation on Special Needs Education. Sometimes you are just so
tired that you haven’t got time to do all these things. the end We did have problems
getting Respite care, that was very difficult. We got our MP involved with that in. When
you get to the stage of needing Respite care you are in no fit state to fight back. I think it’s
something that should be built in for parents from a very early stage so it’s taken as a
matter of course and they never have to get to the stage of admitting that they can’t cope.
It’s horrendous admitting you can’t look after your own child, you feel so guilty.

I: Do you think parents would want to think about it when the child’s young?
ID10M: I think if it was presented to them as something that would happen as a matter of
course when their child got to age such and such, that it was taken for granted that this
would be provided that would help get round a lot of the guilt.
I: Are you aware of any legislation around disability? You wouldn't search it out?
ID12M: No. Not 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. We haven't had any problems educationally wise, it's not like he's been refused, there's no reason why he should be. We haven't contacted St Cuthberts yet, we intend to go and have a look around the school and talk to them and also perhaps Emanuel College at Gateshead. Rightly or wrongly we don't want W treated any different to anybody else because in our eyes he isn't, we don't want any preferential treatment at school, we don't want him excluded from sports - if he's finding it difficult well tough he's just got to get on with it, we want him accepted like everybody else. I don't want him singled out for anything.
The Home Environment: barriers to physical independence and mobility

Barriers
- Design of the house (e.g. town house with lots of stairs, lack of ramps etc)
- Unmet needs for special equipment
- Lack of appropriate adaptations
- When parents are not able to provide relevant physical support

• Facilitators
  - One level house with a toilet on the first floor
  - Adaptations in the house (through-floor lift vs stair lift, bathroom adaptations, baths toilets, rails etc)
  - Appropriate assistive equipment including mobility equipment (K frame and indoor wheelchair), assistive equipment for physical independence (special cutlery, remote controls, special shoes with velcro fasteners) (Special communication equipment)

Barriers in the home and barriers to physical independence in ICF format

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<tr>
<th>ICF Chapter</th>
<th>Barriers</th>
<th>Facilitators</th>
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<td>Chapter 1: Products and technology</td>
<td>e115: Products and technology for personal use in daily living; equipment takes up space, lack of equipment for lifting, or hoists not working / too time-consuming to use / too large for space, lack of bath aids / suitable bath seat</td>
<td>e115: Products and technology for personal use in daily living; special equipment for washing, dressing and toileting: pads, pull up pants, commode, adapted toilet surround, bath with handles, spa bath, height adjustable bath chair, Velcro shoes, leg splint; special furniture: adjustable chair, corner seat, standing frame; equipment for eating: cutlery with large handle, spinning plate, anti-slip mat, special Top Hat dish; other equipment: lowered light switch, Extend remote control; equipment for lifting: mobile hoist, track hoist</td>
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<tr>
<td>Chapter 2: Natural environment and human made changes to environment</td>
<td>e245: Time-related changes; hoist takes a long time to use</td>
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<td>Chapter 3: Support and relationships</td>
<td>e310: Immediate family; parents have difficulty in lifting the child- getting heavier</td>
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<tr>
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<td>e310: Immediate family; parents help with “everything”: physical support: lifting, carrying, transferring, pushing wheelchair, bathing; supervision for activities such as bathing; support in activities of daily living: feeding, dressing, washing, toileting; financial support for equipment and adaptations</td>
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**Chapter 4: Attitudes**

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<th>Description</th>
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<td>e355: Health professionals</td>
<td>parents waiting for OT to assess for hoist (lack of resources),</td>
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<tr>
<td>e410: Individual attitudes of immediate family members</td>
<td>parent underestimates child’s abilities- didn’t realise how mobile she was until seen at school, ?parents over protective- child has to be careful going up and down stairs, dislike of some of the special equipment for aesthetic reasons eg lifts, ramps, bath seats, hoists</td>
</tr>
<tr>
<td>e455: Individual attitudes of other professionals</td>
<td>parents and OT disagree about equipment needs</td>
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**Chapter 5: Services, Systems and Policies**

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<th>Codes</th>
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<tr>
<td>e510: Services, systems and policies for the production of consumer goods</td>
<td>suitable shoes with Velcro difficult to find</td>
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<tr>
<td>e570: Social security services, systems and policies</td>
<td>parent disliked unsightly social services ramp, parents not entitled to financial support for house adaptations</td>
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<tr>
<td>e575: General support services, systems and policies</td>
<td>policy of home care workers not being</td>
</tr>
<tr>
<td>e555: Associations and organisational services, systems and policies</td>
<td>Disability North provided adjustable chair. St Cuthbert’s Care support weekly</td>
</tr>
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</table>
Design of the house:

Accessibility of the house: Mobility
Flat access: ground floor accommodation facilitates a child’s mobility:

I: Can A get into all the rooms in the house?
ID6F: Downstairs. 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.

I: Can you get into all the rooms in your house?
ID5C: Yes

I: Can W get into all the rooms in the house?
ID12M: Yes. He has to be careful going up and down the stairs only because he’s so busy thinking about other things he might slip but he manages the stairs very well.
I: You don’t have any equipment?
ID12M: Nothing.

Town house design is a barrier to mobility within the house + assistance:

Stairs in townhouse vs one level bungalow:
I: Can B get into all the rooms in the house you live in?
ID9F: We have four flights of stairs, we’re looking to move to a bungalow. We didn’t realise she could walk as much using the K frame until we saw her at school. It may be difficult finding a 3 bed roomed bungalow so we’re thinking of looking at houses where we could fit a downstairs toilet and if there’s a dining room it could potentially become B’s bedroom so she has access on one floor. She has to be carried to bed; she can walk up the stairs with someone holding her. She needs someone to help her with the toilet, we have one on the ground floor so she can get in but needs assistance to get onto the toilet. Same with the bath.
Adaptations to the house are not feasible for every type of house:

ID9M:...the kitchen and living room here are on separate floors. The only thing that would make a difference where we are now is a stair lift. But that’s not practical because of the way the stairs are organised, we’d need 7 really. (the family lives in 4 floors town house.

FACILITATORS FOR IMPROVING MOBILITY WITHIN THE HOUSE:
Adaptations to the house

Home adjustments: special equipment: through floor lift:

<table>
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<th>Through floor lift and hoist vs. stair lift:</th>
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<tr>
<td>I: Have you got a stair lift?</td>
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<tr>
<td>ID2M: We’ve got a through floor lift.</td>
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<tr>
<td>I: And that works OK?</td>
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<tr>
<td>ID2M: So far. We had a couple of things where we had to get them out, but generally, yes, that’s been fine.</td>
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<td>I: How long have you had that?</td>
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<td>ID2M: We’ve been here five years, so I think probably about four years, roughly.</td>
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<td>I: That would make a difference to you?</td>
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<tr>
<td>ID2M: Yes. I mean, you couldn’t carry her upstairs now, she’s too heavy – she’s too tall.</td>
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I: Have you got a hoist? Do they use a hoist?
ID2M: I’ve got a mobile hoist downstairs you can take anywhere and in her bedroom she’s got a track hoist there.
I: You’ve really got quite a lot of equipment haven’t you?
ID2M: Yeah. Well they’ve had to fit it with me, and the home care you see. They’ve had to put it in for the home care.
I: So, would you say there was any piece of equipment that you have here that is helpful to you. I mean there’s nothing you would say that you wouldn’t have it if it was going to be useful to you.
ID2M: (brief comment in agreement)
I: Which would you say was the best one.
ID2M: It’s got to be the through floor lift. We had once, when it did actually break down one night and we had to take her upstairs and we were sweating by the time we got to the top. It was hard work.
I: It makes you realise how useful it is doesn’t it?
ID2M: Well she’s quite tall as well. She thought it was funny but we were shattered by the time we got there. So I would say, yes, it's got to be the through floor lift out of all of them I would say.
I: Is there anything else?
ID2M: Although you’re not supposed to for safety reasons for yourself, for your back, what have you, it can be done in other ways, where getting her upstairs is a lot more difficult. I think it’s better than a stair lift as well. It’s a lot better because it’s the time it takes as well. With having the home carers here only for a certain length of time, so you’re limited in what you can do in that time. So obviously with that 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 out of that, put
her into that, somehow I mean, she’s got to have a wheelchair or something upstairs – you can’t take it upstairs – that would be more equipment to get. Of course, I can bring the lift down and she’s got that bit extra space.

Accessibility

ramped entrances: mobility, inaccessible door leading to the garden

ID2F
I: And I notice you’ve got ramped access at the front as well
ID2M: I’ve just had that done, but I got that done myself – I paid for that myself. Well, if they’d put a ramp in – Social Services or whoever it is who’s responsible – it’s one of those big metal things. Well, to me there’s no need for them. You don’t want a great big thing just for that and I used to catapult her out, sort of ready, steady, bump and fling her out, so now it’s much better. In the back garden we had a fence with a gate and the path used to be that wide, the path was there, so when she used to go in I used to tape them and then the gatepost was getting quite dangerous, so we’ve actually now got a new front path put in. It’s much smoother and it just straight. The only thing I’ve got a problem with is getting her out of the back door, because when you go out of the kitchen you’ve got the back door, but you’ve got outhouses and toilets and what have you there. If, and you’ve got a sort of step – there’s no room for a ramp there, so again, there’s a bit of a knack to it, doing it, so most people take her so far and say ‘right, here you are, you do it’. It seems it’s getting a bit worse every year, so I’m going to have to try and speak to somebody I think in the next couple of years to, but I think that’s the only thing now that we have any kind of problem with in the house.

Design of the rooms

Extra space is required:

Fixed equipment is a barrier, extra space is required for a room:

I: First of all, can J get into all the rooms in the house? If not, why not?
ID2M: Yeah, I think she can more or less. Obviously some rooms you’ve got to shift one bit of equipment to get another bit in and what have you, but if the equipment wasn’t there, yes, she could. There’s nothing there that’s fixed that she can’t ever get into a room you know. It’s a question of moving one thing to get another thing in, but yes, she can fit into every room.

NB: Home adjustments to meet the needs of the child may be beneficial for the child but have negative impact on the family

I: Is L able to get into all the rooms in the house?
ID8M: We’ve had an extension built on, the old sitting room and dining room is now L’s bedroom and bathroom downstairs. It has made a difference but our living area is now much smaller, so we’ve gained in that L doesn’t go up the stairs but we’ve lost our dining room so we eat and entertain in here as well and we’ve got a big family so we can’t have everyone at the same time. It’s good for L but bad for the family.
Bathroom equipment:

I: What about baths then?
ID2M: Well, she’s got bath equipment at the moment, but we’re actually looking at that. We’ve been looking at it last year actually for new bath equipment and we don’t quite agree at what’s needed. So that’s sort of getting debated at the moment.
I: Is that the difference between maybe a hoist or a shower, or what?
ID2M: The bath – what they say is there’s got to be height just above the bath end no matter what. Well, they’re wanting this equipment and that equipment to put in. We’re saying we have tried – there was one particular bath that we’ve used, the Parker bath, which, once she’s got a strap on here, the lap strap on, we found it the easiest to bath her in. It’s really, really easy to bath her in, but they’re saying, no, it’s dangerous, and I said, well I wouldn’t put her in danger. Once she’s got the strap on there’s no way she’ll fall out. She’s never left in the room, there’s never less than two people anyway in the bathroom. She’s always got two people in the bathroom whenever she’s getting bathed. But they’re wanting bits of equipment going in and we’re saying well it’s hard to get underneath it, or if she’s too reclined you can’t get forward to do her back because of extensions and things like this, and the OT’s saying something else, and I keep saying, well I’ve been bathing her all her life and you’ve never bathed her. I find that quite frustrating and the home carer who helps me with bathing her as well. She’s sat and said to her, look, we thought that one was a good one and she’s been bathing her for a number of years, so I mean, the OT’s never ever bathed her yet. So I find that quite frustrating, when they never do. We’ve had it before, it was just something else, I’ve forgot what it was now, with another OT and she’s saying ‘you can’t do this and you can’t do that’. She says, ‘can you show us how …’
I: So you’ve actually had quite a lot of problems with professionals?
ID2M: I would say with things in the home, like, it tends to be with equipment, that’s what we have problems with, with equipment and deciding what’s best.

Delays in providing assistive equipment:

ID2M: At the minute we’ve had a problem – I’ve been waiting for over two years for a walker for her, and now they’ve got the walker at school they’re saying they’re not allowed to put her in it now.
I: Why not?
ID2M: Because they haven’t got the staff to do it. I said, well if you’d done it two years ago when she was supposed to have got it done, she was smaller then, and she would hopefully be a bit more independent now and she’d be able to use it a bit more for herself because I mean the bike, when she first got the bike, she got assessed for both bike and, the trike I should say, and the walker at the same time. They said, well if you get one, we’ll get the other. She’s had the trike for two years. When she first got that we said, just get to the end of the street here and back and it took her about three quarters of an hour to an hour, and at the same time she goes into the village, she goes round into the shops. I mean, I measured one day, she did a mile and a half and we went into the park and that’s where she’d been. I mean that’s the improvement she does on a bike in less than a year. Well to me, until you try it, I always think that unless you try it you don’t know. If you try it and it doesn’t work, fair enough. You know you’ve tried it and it hasn’t worked. But if you
never try it, then you don’t know and J’s, even if she can’t do something, she always wants to try and do it and I think that’s half the battle. She’s struggled and she can be quite independent. Don’t you? Nothing wrong with your ears is there? I would say that’s the main problem we’ve had with, more with equipment than anything.

Getting shoes is difficult:

I: How about eating?
ID12M: He has trouble with a knife and fork and we still cut his food up, he can do it with a struggle but transfers his fork to his right hand. He doesn’t use any special cutlery. 
Shoes He has wide feet so he has to have shoes with laces. Getting shoes is a problem, I hate it, he has a very wide foot anyway so to get an H fitting shoe that fits his splint as well. Every time he gets a new splint I have to get him new shoes, but that’s only once a year so his shoes and trainers last him a year. I usually go to Bainbridges or Clarks. His shoes then have to go away to get built up so we usually find we get measured for a new splint, then have to wait a fortnight for that, then I have to go out and buy shoes, the shoes then go to the physio to go and get built up and we usually have to wait a fortnight for that so it takes about 4-6 weeks depending on how busy they are at the factory, sometimes it’s within a week. He has a new splint once a year because he’s growing so the splint gets too short in the leg and for his foot length as well and it becomes uncomfortable for him. If for some reason his splint had to go in we put the insole in his old shoes so they fit, and the same with his trainers at night when he takes his splint off to play out. There’s no point in buying two pairs of shoes because one pair wouldn’t get worn. The splint makes a difference to his walking he gets a very good heel strike with his splint on, when he’s tired with his splint off he tends to go back up on to his toes.

Support required from families and social services:

ID9M: Support and relationships: e310 immediate family: She has to be carried to bed; she can walk up the stairs with someone holding her.

Adjustments are needed to improve access as the child gets older:
I: Can V get into every room in the house.

ID11M: Yes, she couldn’t get into the toilet in her chair because it’s little but she doesn’t use the toilet. We don’t have a stair lift, she gets carried everywhere or pushed in her chair. As she gets bigger we’ll have to think about a stair lift or one of those awful things that go up to the ceiling, which I wouldn’t want. She’d love a stair lift.

A high level of lifting and extra support is provided by the family:
I: Can J get into all the rooms in the house?
ID7M: No.
ID7C: The only room I can get into is my bedroom.
ID7M: He can get into his room, our room and the bathroom. We’ve got the room we had built on with two steps, that’s where the computer is. He can get into it if we lift him into it.
We have a stair lift but it only goes straight so when we get to these two steps it’s a physical thing. He needs help to get off the stair lift and into his wheelchair. We now have a commode, which we got on loan from the equipment service which he sits on and wheels from there to his bedroom. We have a bathroom chair for when we get him to the top of the stairs to move him from there to the bathroom or his bedroom. The garage he can’t get into but there’s probably no reason. The kitchen’s laid out awkwardly because we have a unit which divides and it’s getting him around into that but he does get in, there’s not one room he couldn’t get into with effort.

ID7M: Yes. Every day of the holidays it’s what are we going to do today. He has loads of toys 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. I bring things down for him to play with here or he goes to play on his Playstation, but I tend not to let him until I know it’s nearer the time his dad will be in so that he can lift J up. He’s got board games and things like that but now it’s getting to the point where we’re restricted because even getting him down can be quite dangerous but getting him up is even harder. As he’s getting older it’s getting harder because of his weight.

I: Do you need to feed J?
ID2M: Yeah. I have a home carer comes. They come for feeding, medication and bath time, or putting her to bed.
I: How often do they come?
ID2M: Well, we have them at breakfast time every morning – about an hour and a half, and then obviously when she’s not at school they come at lunch time, for lunch and to help change her and at teatime they come for feeding – well she gets a bit longer at teatime because that’s when she has like, a proper meal, and she has her meal put in her mouth and then she either goes upstairs to get her changed to get her ready for bed, or she goes in the bath and she has a bath three times a week. And she gets half an hour for that as well.
I: That’s good. That’s good support for you isn’t it? Is that every day?
ID2M: That’s every day. Obviously when she’s at school she doesn’t have her lunch.

ID9M: She has to be carried to bed; she can walk up the stairs with someone holding her. She needs someone to help her with the toilet, we have one on the ground floor so she can get in but needs assistance to get onto the toilet. Same with the bath.

I: Does she need help with everyday activities, toileting, dressing?
ID9F: She can take her socks off and put a hat on her head. We don’t know whether that will change in the future. She can’t do what an average 5 year old can do. She can feed herself finger foods, slightly messily. Next years aim is to try and get her to use cutlery.

I: He needs help with everyday activities?
ID8M: Everything, dressing, cleaning, bathing.
ID8M: We’ve just got a community nurse after 16 years so we’ve just had one visit so far. We do everything ourselves.

Help:

I: Anything else you need help with? Getting dressed?
ID5M: Fastening her bra, she can’t do laces, washing her hair, getting in and out of the bath, coats – she can fasten buttons and zips but it takes her a bit of time.

Broken equipment:

I: What pieces of equipment would you say have been helpful to you?
ID8M: I haven’t used any. I lift him myself. We have 2 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 L 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. Then I could hoist him but by that time I’m getting him ready for school and into the wheelchair so I just lift him. He’s not that heavy, it’s just a routine I’ve got into but the hoists are there in case. I don’t use the bathroom one because it takes a considerable time longer. We’re waiting for the OT to have another look at this, because we would like a manual one so we can move him around and it would be far easier.
I: Is there any piece of equipment you’d like to have but don’t?
ID8M: Just the manual hoist.

Support:

ID12M: He’s very good at getting himself dressed because when he was little I pushed him with his buttons and laces so he could do them when he went to school like everyone else. Some days he likes help with his splint but he struggles to get his foot into his shoe so he asks for help with that.

Special equipment facilitating independence:

I: Do you have anybody that helps you at all in the house? Do you have any support from any of the services?
ID3M: He has a community nurse. He has an Occupational Therapist.
I: You’ve had some adaptations done to the house? The toilet’s all right for him?
ID3M: The ramp at the front first, the stair lift, the shower, the sliding doors and they lowered the light switch upstairs. He’s got a proper surround for the toilet, he doesn’t use it but we’re trying to get him there. He won’t use the toilet. We’re working on that, he has to have medicine to make him go to the toilet. He wears pull up pants/pads. He’s doubly incontinent. We try to get him in the mornings at school, we ask them to put him on the toilet when he gets there, they’ve adapted the toilet for him with a frame around. Some mornings he was getting up bone dry and by the time he got to school he was soaking, other mornings he was wet here and dry at school. He hasn’t got a rhythm yet. because we’ve got a proper shower in and we’ve got a hoist. We don’t use it much because he doesn’t like it. He’s got a nice chair to get into the shower, it’s better that way
and it’s not so hard for me and when he’s finished he tries to chair and dries down a bit and comes into here and I finish him on the carpet.

Ex Tend device:

ID9M: We’re looking into something called Ex Tend, a method of turning devices on and off. It’s some sort of standard set up that’s an attachment you can put onto a plug socket for an electrical device so that it can be activated from a remote control handset and can go from things like kettles, lights, stereos, televisions, doors and curtains. We’re definitely thinking of that for the future for B.

I: Is there any piece of equipment that you have that you couldn’t do without?  
ID9F: Her chair, which is designed specifically for kids with movement disorders, it’s got a strap and wide arms and a very wide base. One thing we really couldn’t do without is the mat we put over her table because it tends to be quite a messy experience. We can’t feed her on a carpet, it wouldn’t last very long so we put the table on the wooden floor. It’s just a picnic mat. The chair came from Disability services in North Tyneside; it’s adjustable so as she grows we can keep it so her feet touch the ground and puts her in the right position.

Special equipment for eating:

ID6M: She has a mechanical aid, spring loaded with a plate sits on a cup and the plate spins and A moves her arm down with the spoon on and it goes into the plate and lifts up and brings it up to her mouth and she takes it off her mouth. She’s used it for years at school. We chop her food up but with mashed potato or something she’s fine, it’s nice because she can choose what she wants she can spin it round and decide whereas if we’re feeding her you’ve got to guess. She drinks from normal cups, with a straw sometimes.

I: What about your eating – do you have special cutlery?  
ID4C: Yes  
I: Do you use that a lot?  
ID4F: It depends what he’s having. He has special cutlery with bigger handles that help him with the grip. He has these special dyem mats to stop them slipping, and he has special bowls more for scooping. If it’s something like, say sausage and chips, we would end up having to cut it for him so he can stab it and then he doesn’t need the special bowl for normal food. He can drink out of a cup but we tend to make sure that he drinks out of a straw at home basically because he might knock it over.  
ID4F: If we go out we just take his cutlery. If we need it we use it.

Non-slip mat for eating:

I: Would you say there has been anything that’s been of special help to you?  
ID5C: The non-slip mat that I had at school to put my dinner tray on.

I: You don’t have one at home?  
ID5C: No.
Bathing:
I: What bath equipment have you got?

ID8M: None. We just put him in the bath. We have a spa that we bought and it’s a case of holding him. He loves his bath, he won’t have a shower because he doesn’t like the feel of it.
I: With the double incontinence you don’t use the toilet at all?

I: You manage to get to the loo alright?
ID4C: Yes
ID4F: He does all that himself. If he has a bath, for safety reasons one of us is there. He’s a bit old for that but we’re still conscious of his balance – whether it’s right or wrong I don’t know
ID4F: I prefer a bath because with a shower you’re standing up and if he was to lose his balance and fall down. We’ve the bath with two handles inside so he can get in and out by himself

Dressing: Velcro fasteners
Products and technologies that makes children with CP independent:
ID4M

PHYSICAL ENVIRONMENT (HOME)
I: Can you get into all the rooms in your house?
ID4C: Yes
I: Do you need help to get dressed and to get washed?
ID4C: Not really
ID4F: There’s one pair of trousers with zips on that he has difficulty with. What would be better than the trousers we’ve got. Instead of a button at the top, if we could find ones with a Velcro fastener. Whether you could have Velcro instead of zips. Just like the shoes. Such is the size of his feet now that it’s very difficult to get something which has a Velcro fastener. So we try and look at things which make him independent. Shoes are now more difficult because he’s older, the size of his feet. Trainers we usually find that every time he has to change them, we end up round Newcastle because it all depends what are popular or the amount they’ve got in.

I: Does V need help with everyday activities?
ID11M: Everything.
I: Do you use any special equipment?
ID11M: No, we have no hoists, I haven’t wanted any. She’s quite light. She has a special chair to sit in for eating. She has a good supportive wheelchair with trunk support, it’s like her chair at school. She has her upright chair, a more relaxing chair, a standing frame, a corner seat, a bike and a swing.

However special equipment may be uncomfortable:
I: Is there anything you would like that would make life easier for you?
ID11M: A bath aid would be handy, I don’t have a bath seat as I haven’t seen one that I personally like, is practical and V would be happy in. They either don’t let the child get
right into the water, and I don't see how you could possibly wash a child's hair. They are cumbersome, hard and it can't be relaxing or comfortable. Even mesh can't be comfortable and you'd be getting cold because you're out of the water, you're tense because it's hurting and there are straps everywhere. I just hold her in the bath and that's fine until I find something that I really think will be of benefit, her bath is important for relaxing.

ID11M: She wears pads but she's aware of when she's doing something. She can't sit on the toilet but school were looking into getting a special little toilet.

Lifting is predominantly by families, lack of hoist can be a problem for support workers:

ID7F: We have got a service with St Cuthbert's Care. We have a lady who calls once a month but with her family commitments it's not always possible to get her when it's possible for us. When it comes to his toilet needs she's not allowed to lift him and we haven't got the equipment for her to do anything plus I sometimes think he'd be better off with a male carer. She comes on an evening or Saturday afternoon and she stays for a couple of hours. That was offered to us but at the time we were looking we wanted something which would involve J with more people his age or with a younger male person not just replacing me in a way.

Lack of the equipment in all areas that it is required
Home: support

I: What about eating meals?
ID7M: We tend to cut the food up for him, soup we put in a cup.
I: Have you any specially adapted cutlery?
ID7C: At school the cutlery is just like a normal one but with thick handles.
I: Do you have a dish which slopes so you can push things?
ID7C: Yes a Top hat.
I: So you don't have that at home?
ID7M: No he just manages with ordinary things.
I: Do you have anything special to help in the bath?
ID7M: We have a chair which raises up and down. The more physical thing is that you sit him on sideways and actually getting his legs in and twist it and he tends to slide down so you have to lift him up, but the actual up and down is brilliant.
I: He has to have help to be bathed?
ID7L: He has a good go at washing himself, we do his back and his hair.
I: Is there any piece of equipment that you'd like to have but don't?
ID7L: A hoist would be very handy, but whether it would fit into the house. In the past we've made the downstairs toilet for J 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.
**Products and technologies:**

**Other**

<table>
<thead>
<tr>
<th>ID4</th>
<th>We don’t need special clothing for him; we replace shoes as you do with any normal child the only difficulty is getting ones with Velcro fastens.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>Facilitators: Reins, padded hat, K frame:</strong> The reins, her earphones on, a padded hat in case she falls over and the K frame. (BH)</td>
</tr>
<tr>
<td></td>
<td><strong>Unattractive special equipment:</strong></td>
</tr>
<tr>
<td>I:</td>
<td>Is there anything you’ve found really helpful?</td>
</tr>
<tr>
<td>ID6F:</td>
<td>Care are really good (can’t hear very well) … they come in the morning, we’ve used them at night. They’re more like friends to her now. I prefer that because we had another pair of workers who’d come in, do their job.</td>
</tr>
<tr>
<td>I:</td>
<td>Are they Local authority home care? Do they use a hoist, is she okay with that?</td>
</tr>
<tr>
<td>ID6F:</td>
<td>Yes. She’s got no choice unfortunately. School’s the same, Leyburn have got to use them as well and it’s now an accepted part of her life. She’s not too keen on her hospital bed she really hates that, again it was legal requirements for her - every week carers come in and her bed had to be adjustable for their backs. We had to take the bars off and make it look as much of a bed as possible, it has a normal headboard now. She didn’t want a hospital bed in her bedroom.</td>
</tr>
</tbody>
</table>
Interviewer feedback

Respondent validation is provided with interviewer feedback. These comments also bring out some factors that the interviewer gleaned from the interviews, which are not necessarily contained within the transcripts.

FACTORS EMERGING FROM INTERVIEWS, WHICH MAY HAVE AN IMPACT ON THE FINDINGS OF THE PROJECT.

1. The role that services play within the family was a key factor. If services were appropriate and timely, the effect on the family was noticeable: e.g.

   less stress
   less physical support required
   • more effective time management i.e. less time required to carry out tasks

   If services were not available or effective:
   • more stress
   • more physical support required
   • less effective time management

2. Services working in isolation
3. Lack of co-ordination between services
4. Lip service by some services – policy not carried through to practice e.g. services indicate they are wheelchair accessible, but do not carry this through to all facilities

5. The Structure of the Family
6.
   • Two parent families shared in caring for their child. Some fathers being the main carer
   • Single parent families relied more on extended family/friends/carers

7. Policies in Relation to e.g. Education, varied from area to area (this could be funding issues and/or collaboration with other agencies e.g. Therapists working within the school). These policies often determined the type and quality of Education provided.

8. Age of the child related to the places the families visited

   • Younger children are lighter to lift, often use less equipment, therefore less barriers to overcome
   • Older children may use more equipment and carers find lifting and moving their child more difficult
• Ageing parents and older parents find managing their child/young person more difficult

9. Parental Attitude

• Some parents see situations as barriers which cannot be overcome
• Some parents see the same situations as barriers to overcome e.g. access to shops/theatres/travel

10. Weather?
Appendix 1: Subject letter

[Date]

[Subject's name]
[Address]

Dear [Subjects Name]

We are writing to ask for your help in an exciting new study. The work involves asking children and their families about the environment around them, and how it influences their everyday life. The study is funded by Tyne and Wear Health Action Zone.

The purpose of the research is to produce a way of measuring what it is in the environment that prevents some children with movement difficulties from taking part in life on an equal basis with others.

We would like to hear about your experiences (both good or bad) and to invite you to take part in this study. A form asking about your willingness to be interviewed is enclosed with this letter.

If you agree to take part in the study we will contact you to arrange an interview and meet you wherever you would feel most comfortable. This could be either your home or somewhere else convenient for you. We expect that an interview will take about one hour, but it may be slightly longer.

We have enclosed an information sheet that tells you more about the study and attempts to answer questions you may have. Please read it carefully. If you are happy to be interviewed, you should keep this information sheet and sign the consent form that is enclosed with this letter. Please then return the signed consent form within two weeks to us in the reply paid envelope enclosed.

There is, of course, no obligation for you to help in this way, but we really would appreciate your assistance.

If you have any further questions and would like to discuss this study further with someone, please feel free to contact us at the address or telephone number given on the information sheet.
If we do not hear from you, we will trouble you no further.

We look forward to receiving your reply. Your help is very much appreciated.

Prof. Stephen Jarvis
Donald Court Professor
of Community Child Health
Encs

Convenor/Clinician
Appendix 1: Information sheet

What in the Environment Affects the Opportunities that a Child with Movement Difficulties has to join in Everyday Life Activities?

We would like to invite you to take part in our research study. We are trying to find out what the barriers are which may prevent children with movement difficulties and their families from taking part in the life of the community.

This information leaflet answers many of the questions you may have. If there is anything you are not clear about please ask the research team. Our details can be found at the end of this leaflet.

Who is doing the study?
We are a team of researchers based in the Royal Victoria Infirmary at the Department of Child Health. The study is funded by Tyne and Wear Health Action Zone.

Why is this study being done?
We hope that you can help us to identify the most important problems in the environment that children with movement difficulties and their families face in their daily lives. Problems common to you and other families will be highlighted and identified as pilot measures for larger studies and to inform policy development.

How and why have I been picked in this stage of the study?
You have been chosen to take part because you have a child with movement difficulties and your experiences are valuable. Your child has been identified by the consultant who looks after him/her.

Do I have to take part?
It is entirely up to you whether or not you and your child take part. If you do decide to take part you are still free to withdraw at any time without giving a reason. Your health services will not be affected.

What do I have to do if I take part?
You will have an informal one to one meeting where we will ask you different questions. The interview could be in your home or a place of your choice. The main interviewer of the project is a woman, but if you would prefer a man we can arrange this.

**Will what I tell you be kept private?**

Everything you tell us will be kept private. When we type up the interview, we will not include any names. The interview record, and any tape recordings made with your permission, will be destroyed at the end of the study.

**Can I find out more about the study?**

If you would like more information about the study please contact Dr. Philip Lowe (Principal Researcher), University of Newcastle, The Sir James Spence Institute of Child Health, RVI, Newcastle Upon Tyne, NE1 4LP, Tel: 0191 202 3012 / 0191 477 6000.

Thank you for taking the time to read this information. We look forward to hearing from you.

Yours Sincerely,

Principal Researchers: Professor Stephen Jarvis and Dr Philip J Lowe
Assistant Researchers: Brenda Welsh and Svetozar Mihaylov

**What do I do next?**

**If you are happy** to be interviewed:

1. You should keep this information leaflet.
2. Return the signed consent form to us in the prepaid envelope.
3. We will then contact you by phone or post.

**If you do not want** to be interviewed:

1. Please tick here.
2. Return this leaflet in the prepaid envelope.
Appendix 2
Topic guide

**Topic Guide (revised)**

- What **Public Buildings** (e.g. libraries, swimming baths, schools) **Services** (e.g. GP’s, hospitals, shops, post office, leisure activities) do you and your child/young person use?
- When do you use these services and how often do you use them (e.g. time of day and for how long)?
- Is there a reason why you choose to use a particular building or service, and how important do you rate it in you and your child/young person’s daily life?
- Are there any key reasons why you choose a particular building or service?
- Do you go to some services/buildings without your child when you would rather they came with you?

**Checklist**

Cost
Accessibility of buildings/ramps/disabled toilet
Specialist equipment
Local Facilities
Convenient Transport
Staff/peoples manner/attitude
Support services

- Have you changed the buildings or services you use over a period of time? If you have, what are the reasons for doing so, and what difference has it made.

- What in your opinion are the **good** and **positive** things in the environment around you and your child that help you to take part in every day life activities (physical, social, attitudinal)? (See checklist above).

- What in your opinion are the **bad** and **negative** things in the environment around you that stop you and your child from taking part in the things you want to do (physical, social, attitudinal)? (See check list above)
Questionnaire

Home

- Is your child/young person able to get into all the rooms in the house you live in? If not why not?
- Does your child/young person need help with everyday activities such as washing and dressing? If they do who or what helps them?
- Is there any piece of equipment (e.g. adapted cutlery/specialist seating) that has been of particular help to you?
- Is there any piece of equipment that you would like to have but do not? If there is why do you not have it?
- Is there any service you have found particularly helpful when thinking about your child/young person’s physical independence?

Education

- How close to your child/young person’s school do you live?
- How does your child/young person get to school?
- Do they have any problems getting to school?
- Can your child/young person physically get around school (e.g. can they get into the classrooms/toilets etc)? If they cannot what are the difficulties?
- Does your child/young person receive any help or support in the classroom if they need it?
- Is there anything your child/young person would like to do at school but is unable to, and why?
- Does your child/young person experience any social problems in the school (e.g. bullying)? If they do can you give any reason as to why this happens?

Transport

- Do transport problems influence the number of times you go out with your child/young person?
- Are there any places you would like to visit with your child/young person, but cannot, because there are problems with access or the facilities are not suitable? (e.g. swimming baths, cafes). Why are they not suitable?
- Do you use any type of public transport when going out with your child/young person? If you do can you identify the good and bad points of the transport you use?
- If your child/young person uses a wheelchair do you have any problems when going out with them?
- How many times has your child/young person gone outside the house in the last week (other than to school)? Why were these journeys made and what transport was used?
Health Related Services

- How often has your child/young person attended the doctor’s surgery, dentist, and hospital appointments in the past year?
- How far is it to these places, and what type of transport do you use?
- Is the surgery and hospital adapted to suit your child/young person’s needs if it is required?
- Do you receive the support you need from staff when your child/young person attends surgery and hospital appointments?
- Are you satisfied with the services your child/young person receives from hospital? (e.g. Physiotherapy, Occupational Therapy, Speech & Language Therapy). If not why not? If you are satisfied with the service what are the reasons for this?
- In your opinion is there any part of the Health Service you think could be improved upon, that would make it easier for you and you child to use? This could include physical access, organising appointments, staff attitude etc.
- Are there some health services your child receives which have stopped or restricted the things they want to do? (e.g. plaster casts).

Social Environment

- What does your child/young person do in their spare time?
- Is what you and your child/young person do in their spare time affected by where you live, the amount of help they need, the length of time it takes to do something, or another reason?
- Are you able to use Local Services when you go out with your child/young person (e.g. shops, libraries, leisure facilities, clubs)? If not, why not?
- Is there something your child/young person would like to do but cannot (e.g. a particular leisure activity/attend a special event)? What are the reasons for not being able to do so?
- Does your child/young person go out socially in a group, by themselves, or do they need to have someone to assist them?
- Is going out socially important to your child/young person? How would you rate it on a score of 0-10?
- When was your last holiday with your child/young person? What was it like?
- Does your child/young person need any special help when they go out (e.g. Communicator/Support Worker)?
- Do you feel that people understand what help your child/young person needs when you go out?
Financial Circumstances

- Does your child/young person receive any benefits as a result of their disability? If so did you have any problems in getting the benefits and why?
- If your child/young person receives any special equipment or adaptations have been carried out to your house, did you receive any financial help towards paying for them?
- Have you had any other financial costs in the past year as a result of your child/young person’s disability (e.g. special diet, clothing, shoes)?
- Do you think having a disabled child places more of a financial burden upon you (e.g. extra transport costs)? If you do what are the reasons for this?
- Are you or anyone in your home in full or part time employment?
- Are there ways in which you or your partner are prevented from taking on paid work?

Thinking about all the different environments/services discussed, what in your experience might help you and your child/young person to use them?

Thinking about all the different environments/services discussed what in your experience might stop you and your child/young person from using them?

Has being able to use (or not use) a service or have access to a place made a difference to you and your child/young person’s life?

Can you think of any change in legislation or policies that would improve how you and your child/young person take part in activities or services?

Optional Questions

- Are you aware of any recent laws or policies, which have made a difference to the way in which you use services or have improved the environment (physical, social, attitudinal) for you and your child/young person (e.g. Disability Discrimination Act, Childrens Act, CSDP Act)?

- Do you know where to go to find out more about the laws and policies, which might affect the services, you and your child/young person use?
• How do you think getting this information to families could be improved?

• Can you suggest any changes that could be made to make it easier for you and your child/young person to take part in any activity you want to or use any service you require?

• Who do you think should be responsible for removing the existing barriers, which stop you and your child/young person from taking part in the things you/they, want to do?

• Is there any way in which you could contribute to removing the barriers, which stop or hinder you and your child/young person from taking part in the things you/they, want to do?