SPARCLE
North of England Report

Study of Participation of Children with Cerebral Palsy
Living in Europe

European Union

Newcastle University

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Regional Maternity
Survey Office

SPARCLE: North of England Report

Acknowledgements

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Overview and Introduction

Overview and Introduction

This report is about 8-12 year old children with cerebral palsy in the North of England. Researchers visited the 116 children and their families that joined the study. The visits were part of a larger study, the Study of Participation of Children with Cerebral Palsy Living in Europe (SPARCLE), which visited 818 children with cerebral palsy across Europe.

Much information was gathered about the children's cerebral palsy but more importantly about their lives – what they did in life and what they felt about their lives.

A great deal has been learned. In particular there are important messages that children with cerebral palsy are like other children; some are happy, some less so. The children interviewed value the same things as other children; they value their families, they do not want to be bullied at school and they want to be able to participate in the activities all children do.

The study therefore has taught us much about how attitudes to disabled children must change; and about what central and local government should be doing to enable children to join in more in the normal activities of childhood.

Understanding disability

The 'social model of disability' is a relatively recent concept where disability is understood to result from the interaction between individuals and their environment rather than residing in the individual. This then requires a shift from changing the ability of an individual to changing the environment around them. To help measure disability, quality of life (QoL) and participation are two outcomes that are used. QoL is how an individual feels about their life. Participation is what the individual does in their day to day life.

It may surprise some readers that the environment around disabled individuals and the resulting QoL and participation has not always been important to researchers. SPARCLE was initiated to help us 'listen' and understand more about this issue. It is the first significant comprehensive study in terms of both sample and design.

SPARCLE is a nine-centre research study on the factors that contribute to the experience of disability in children with cerebral palsy across Europe. This report will discuss information we have gained from SPARCLE and their implications focusing on the 116 children in the study from the North of England.

SPARCLE and the North of England

The North of England has a proud record of research in disability. SPARCLE can trace its roots back to the North of England Collaborative Cerebral Palsy Survey (NECCPS), a survey of children with cerebral palsy which began in 1991. Professor Jarvis of Newcastle University was the first person to measure disability in children with cerebral palsy. Recognising these accomplishments, the European Union commissioned a wider collaboration study, SPARCLE, involving seven European countries. SPARCLE is coordinated by Professor Allan Colver of Newcastle University.

Without a doubt, the North of England has a special place in SPARCLE. We hope this report will help policy makers, healthcare professionals, parents and the public in general to understand more about the position and needs of children with disabilities in the North of England.

SPARCLE: Key facts and figures

What is SPARCLE?

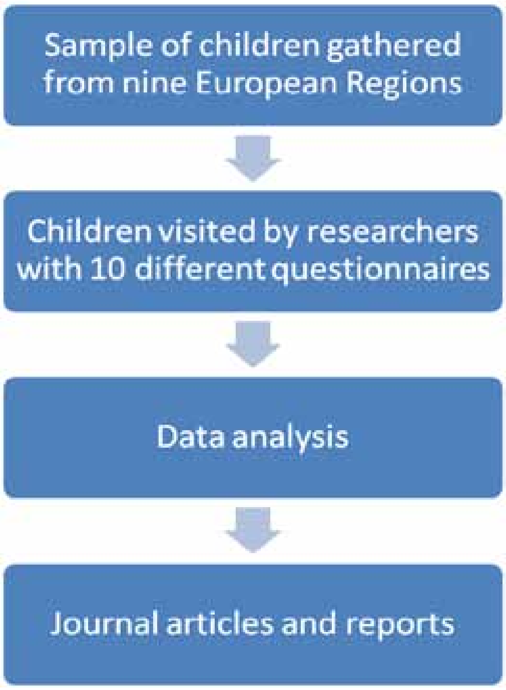
SPARCLE is a nine-centre European research study examining the relationship of participation and QoL to impairment and environment. It studies children aged 8-12 years with cerebral palsy.

What are the objectives?

The key objectives of SPARCLE are to:

- identify environmental factors contributing to QoL and participation of children with cerebral palsy
- help policy-makers and healthcare professionals understand and identify areas of improvement for the environment of disabled individuals

How was it done?



Important concepts:

Social model of disability: Disability results from the interaction between individuals and their environment rather than being a characteristic of the individual

Quality of Life (QoL): This is what children think about their lives (World Health Organisation)

Participation: This is what children do in their lives (International Classification, Functioning, Disability and Health)

SPARCLE: Key facts and figures

Who was involved?

Children aged 8-12 years with cerebral palsy.

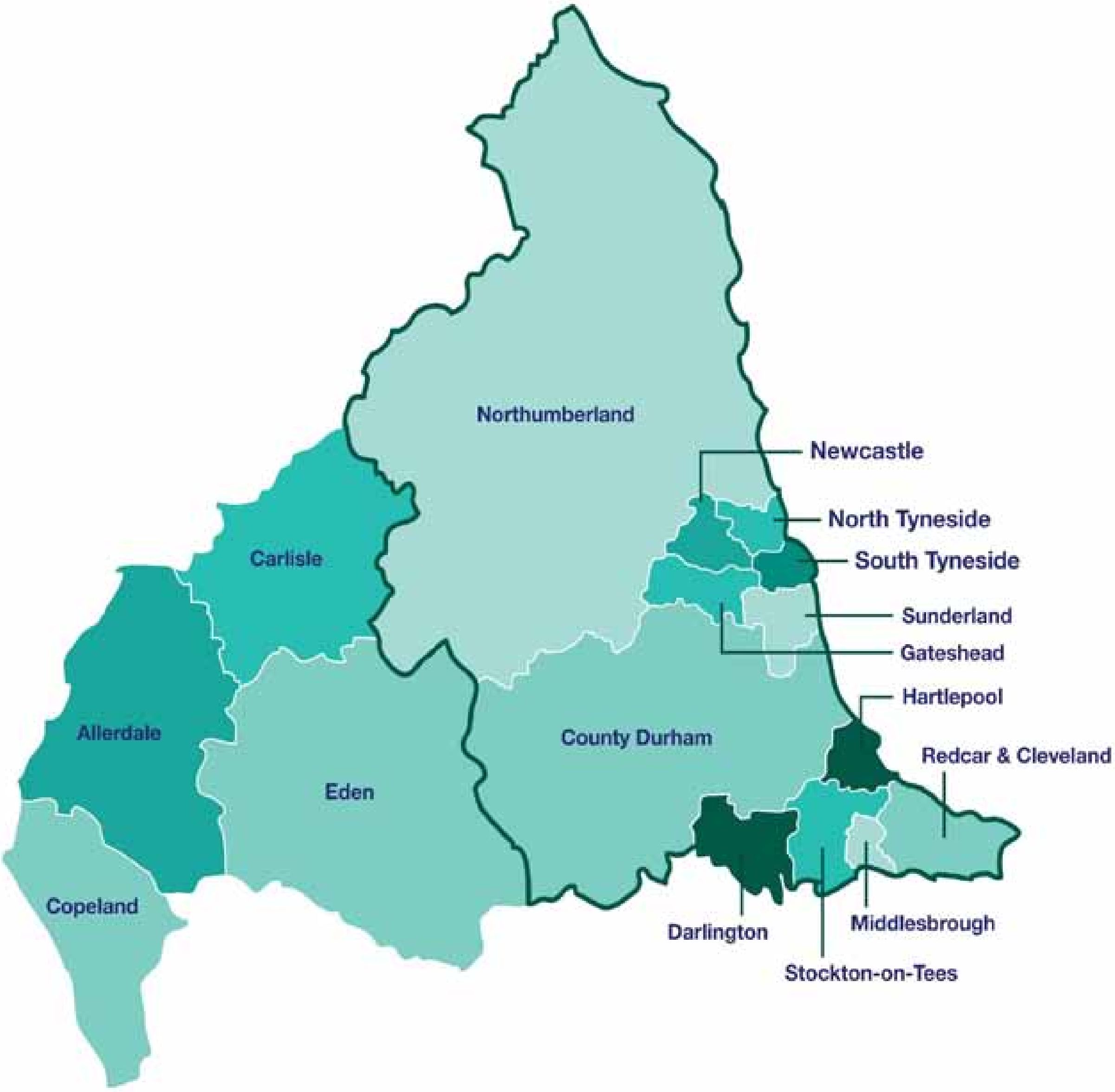
Participating regions of SPARCLE:

A United Kingdom: North of England (Co-ordinating centre)
B Sweden: Vastra Gotaland
C United Kingdom: Northern Ireland
D France: Department of Isere
E Republic of Ireland: Counties Cork and Kerry
F Denmark: Eastern Denmark
G Italy: Viterbo province
H France: Department of Haute-Garonne
I Germany: Schleswig-Holstein state

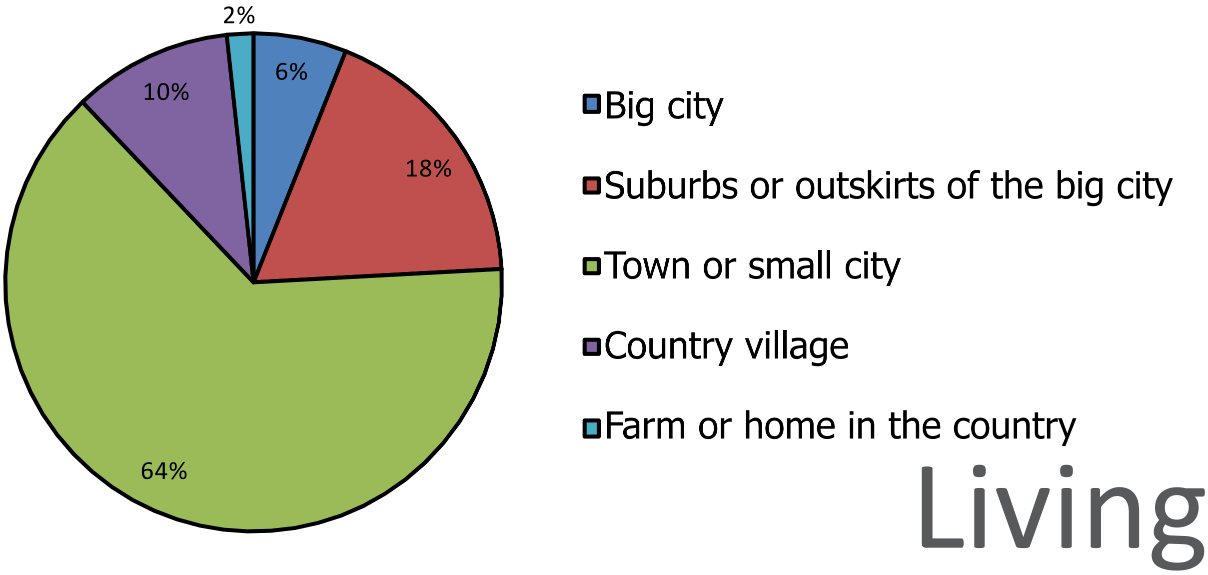
SPARCLE in the North of England: Key facts and figures

The North of England:

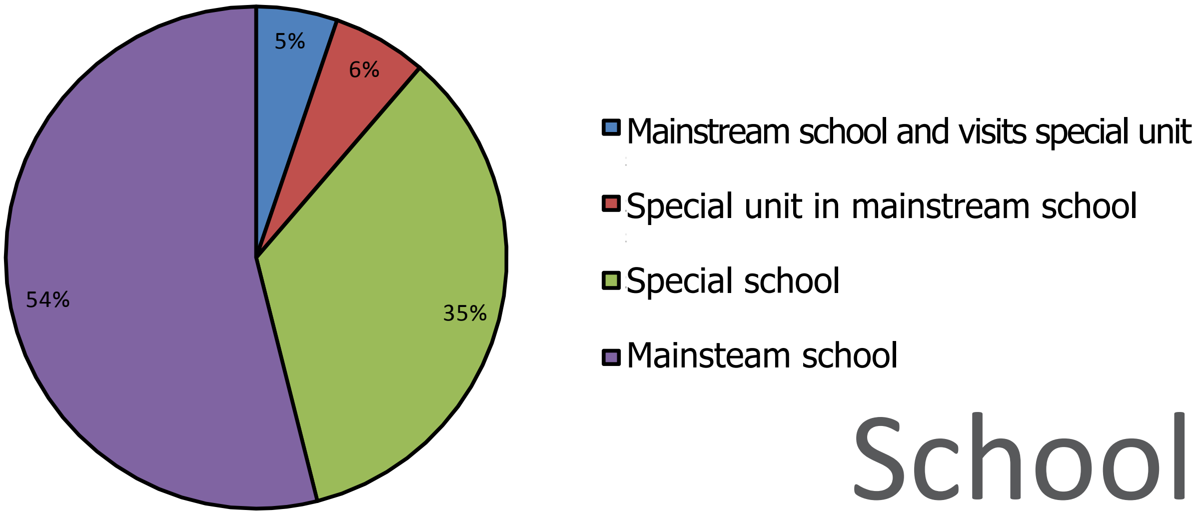
- ◇ Population (2006): 2,880,000
- ◇ Unemployment rate (2009): 8.3%
- ◇ Live births (2006): 32,660
- ◇ Children under 16 (2005): 501,000 (est.)
- ◇ Children with cerebral palsy under 16 (2008): 1,250
- ◇ Number of 8-12 year olds with cerebral palsy participating in SPARCLE: 116



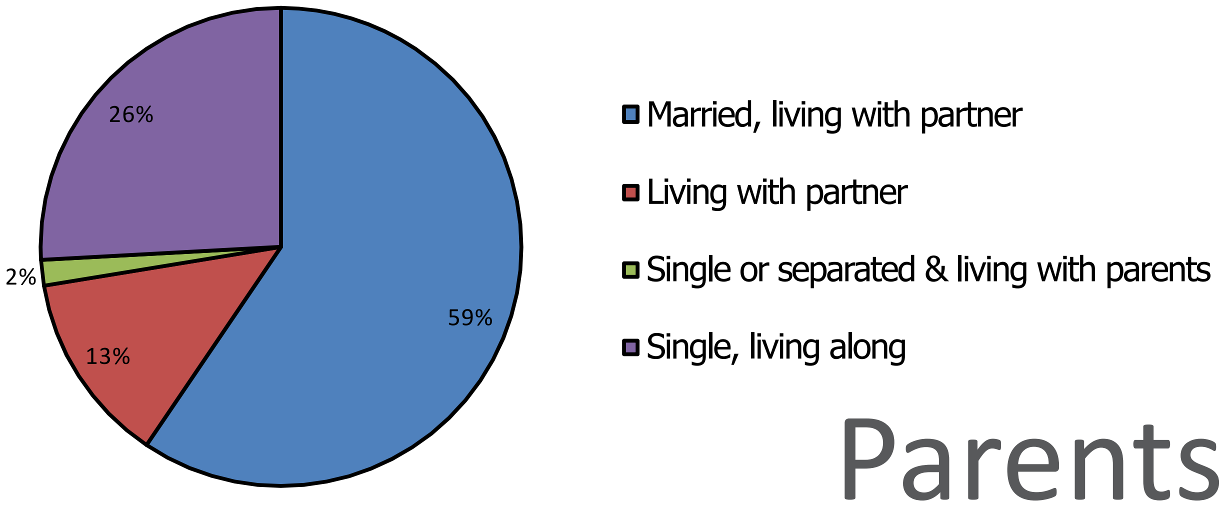
SPARCLE in the North of England:
Key facts and figures about the children & their families



Living

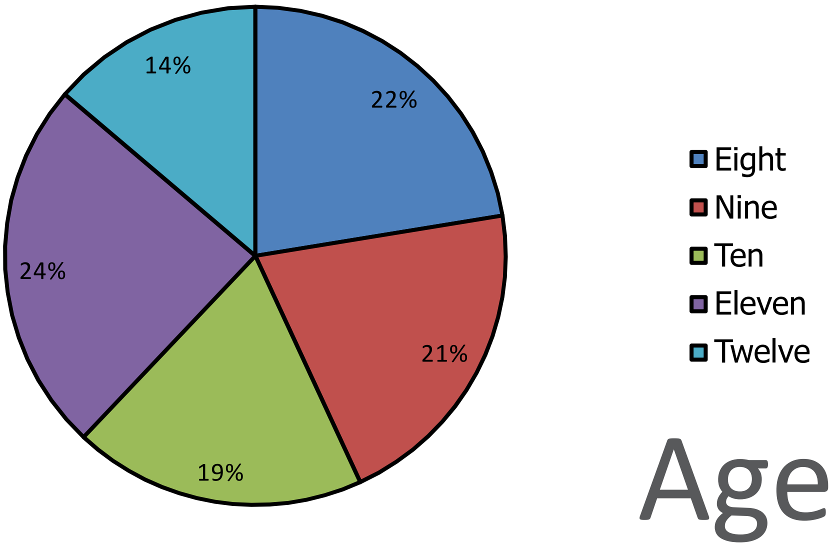


School

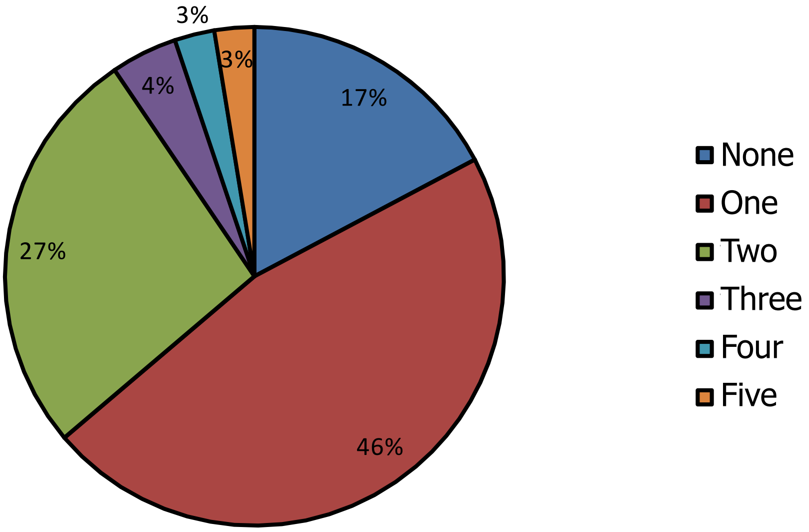


Parents

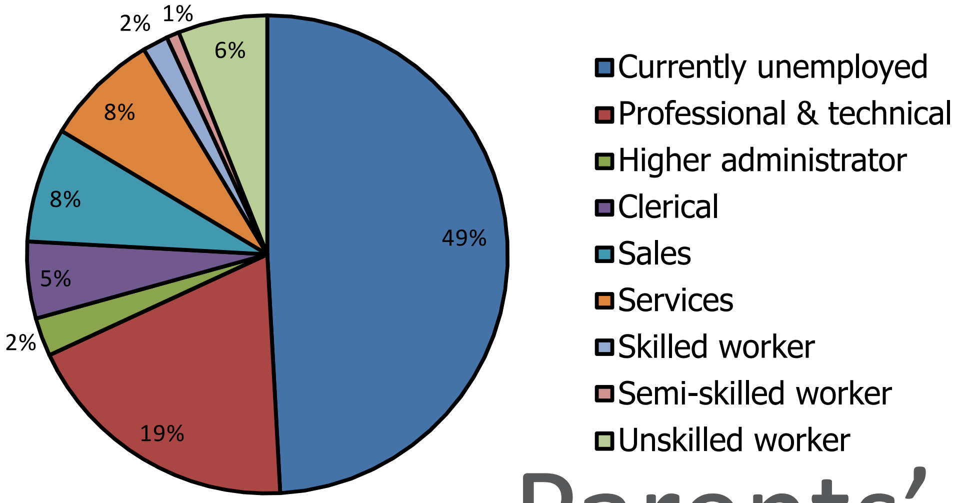
Boys 74 (64%) - Girls 42 (36%)



Age (years)



Siblings



Parents' work

Quality of Life

Quality of Life (QoL)

Everyone has the right to pursue happiness, including children with disabilities. QoL is how the individual perceives their life in relation to their expectations. A good QoL for every child is a goal society should strive for.

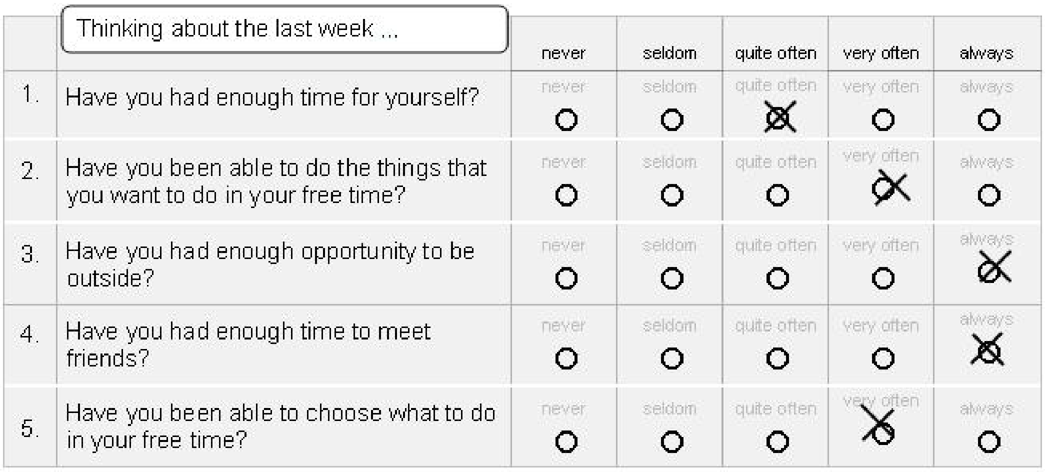
Measuring quality of life

A reliable questionnaire called KIDSCREEN was used to ask children about their QoL in ten dimensions of their lives. Who better to ask than the children themselves? Parents were also given a version of the questionnaire to see how they view the QoL of their children.

To make fair QoL comparisons, the children in the North of England were compared with Europe after adjusting for walking ability (see Table 1).

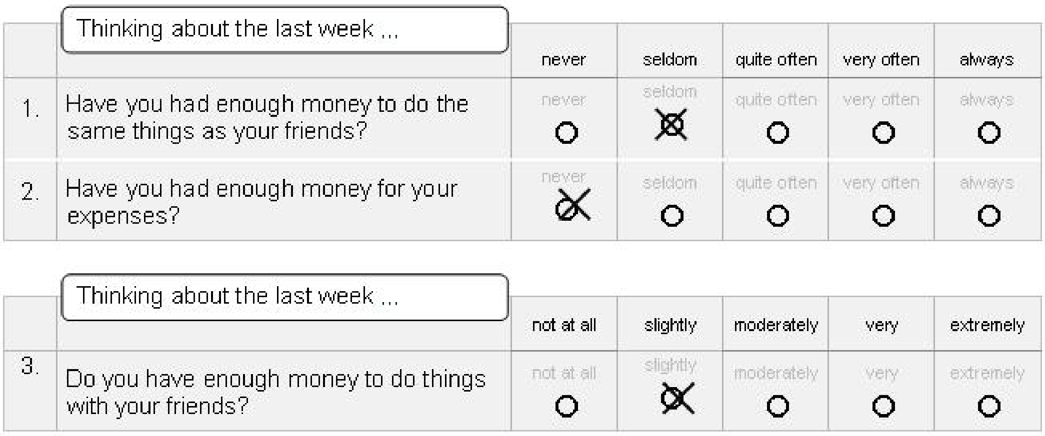
Below in Figure 1 and 2 are two samples of QoL questions asked in the questionnaire. The answers are converted to a score between 0-100 where 0 is the lowest QoL and 100 the highest.

Figure 1: Example of a high score answer for Autonomy Score: 80



	Thinking about the last week ...	never	seldom	quite often	very often	always
1.	Have you had enough time for yourself?	○	○	☒	○	○
2.	Have you been able to do the things that you want to do in your free time?	○	○	○	☒	○
3.	Have you had enough opportunity to be outside?	○	○	○	○	☒
4.	Have you had enough time to meet friends?	○	○	○	○	☒
5.	Have you been able to choose what to do in your free time?	○	○	○	☒	○

Figure 2: Example of a low score answer for Finance Score: 17



	Thinking about the last week ...	never	seldom	quite often	very often	always
1.	Have you had enough money to do the same things as your friends?	○	☒	○	○	○
2.	Have you had enough money for your expenses?	☒	○	○	○	○

	Thinking about the last week ...	not at all	slightly	moderately	very	extremely
3.	Do you have enough money to do things with your friends?	○	☒	○	○	○

Table 1: Impairment by walking ability

I	Walks and climbs stairs, without limitation
II	Walks with limitations
III	Walks with assistive devices
IV	Unable to walk, limited self-mobility

North of England Results

Child report of QoL

When compared to the general population, QoL of children with cerebral palsy was similar to the general population across all domains. The domains of the KIDSCREEN instrument are:

- Social acceptance and bullying
- School environment
- Social support and peers
- Financial resources
- Parent relationship and home life
- Autonomy
- Self perception
- Moods and emotions
- Psychological well-being
- Physical well-being

QoL in children in the North of England was very similar to that reported for Europe. However, the children with better walking ability in the North of England reported lower QoL for the relationships with parents and the home life dimensions.

Parental report of their child's QoL

Parents tend to underestimate their child's QoL. Parents scored their children's QoL lower than the children themselves in all areas, apart from the self-perception dimension where they agreed with each other. Interestingly, they disagreed strongly on social support and relationship with peers.

Comparing children with different impairments, QoL in the autonomy and physical well being dimensions was lower in the children with more severe impairment. It was particularly noticeable in the children who were unable to walk. Social support and peers domains were the same at all levels of impairment apart from children

Again, overall QoL was similar to Europe with minor differences increasing with severity. QoL in the least impaired groups (walks and climbs stairs or walks with limitations) was similar in all aspects. In the most impaired groups (walks with assistive devices or unable to walk), QoL was higher in the North of England for moods and emotions.

European-wide results

On the whole, QoL of children with cerebral palsy was similar to that of their peers in the general population in all areas except one. In school environment, disabled children reported better QoL.

Certain circumstances lead to poorer QoL in certain dimensions. Children with poorer walking disability had poorer physical well being while children with intellectual impairment had lower moods, emotions and autonomy. Those with speech difficulty had poorer relationships with their parents.

However, pain led to poorer overall QoL across all domains (see Pain chapter).

Disabled children have similar QoL to the general population

Disabled children in the North of England have the same range of happiness and unhappiness as all children. Maybe adults base their assumptions as non-disabled adults. Disabled children however may think differently. They see their disabilities as part as who they are.

Parents disagreed with the children most strongly in respect of the social support and peers dimensions. Perhaps parents think their children deserve more support from social services and health services as well as more friends.

Differences in culture and regions do not appear to have a major impact on QoL of disabled children in Europe. Children in the North of England are as happy as their peers in the rest of Europe.

We have asked our disabled children and they perceived their position in life no differently as their friends in the general population. Therefore, they should not be children for whom we give pity and sympathy. They need the support and encouragement which all children need.

Participation

Participation

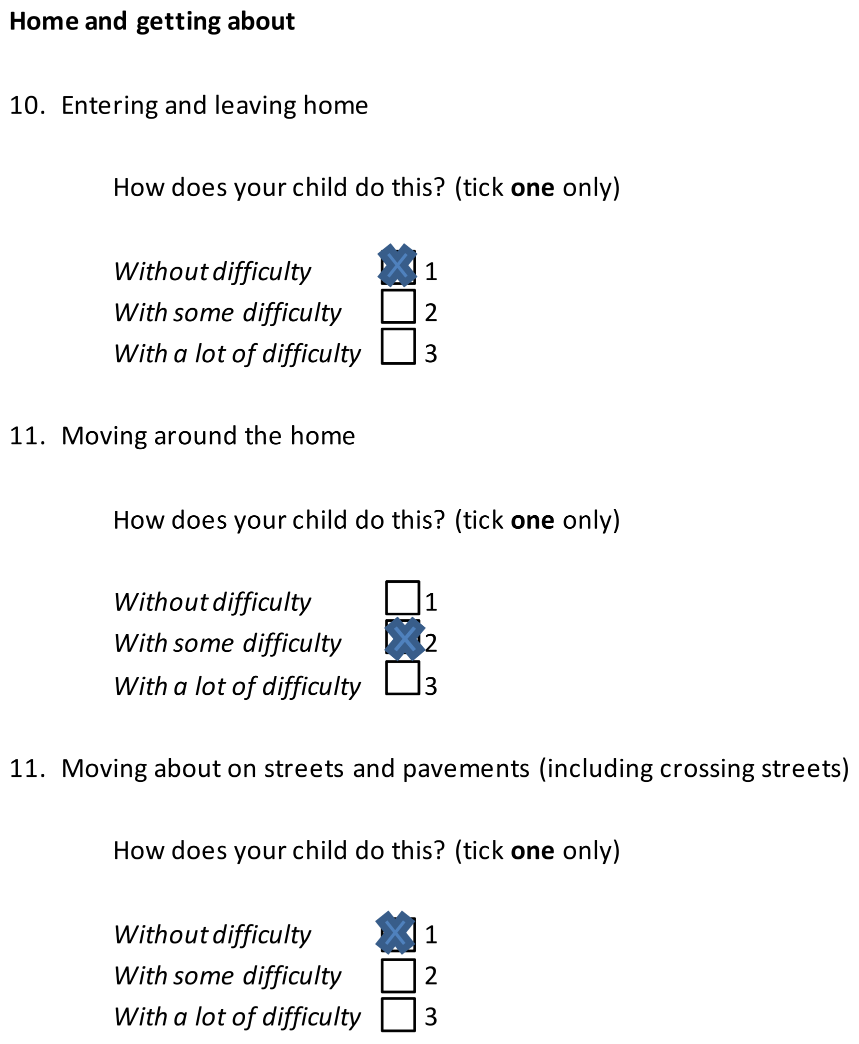
We all need to do things to stay alive and be alive. Participation is involvement in life situations, either to maintain life (non-discretionary) or to make the most out of life (discretionary). Disabled children should be able to participate as much as they possibly can.

This chapter elaborates on whether children participate and with how much difficulty.

Measuring participation

A questionnaire, Life-H, was administered to parents. The questionnaire asked parents about the extent of their children's participation in 10 areas of their lives. They were then given a score each of between 0-10, with 0 the lowest participation and 10 the highest. Sample questions are shown in Figures 3 and 4.

Figure 3: Example of a high score for Home. Score: 9.3



Home and getting about

10. Entering and leaving home

How does your child do this? (tick **one** only)

Without difficulty ☒ 1
With some difficulty ☐ 2
With a lot of difficulty ☐ 3

11. Moving around the home

How does your child do this? (tick **one** only)

Without difficulty ☐ 1
With some difficulty ☒ 2
With a lot of difficulty ☐ 3

11. Moving about on streets and pavements (including crossing streets)

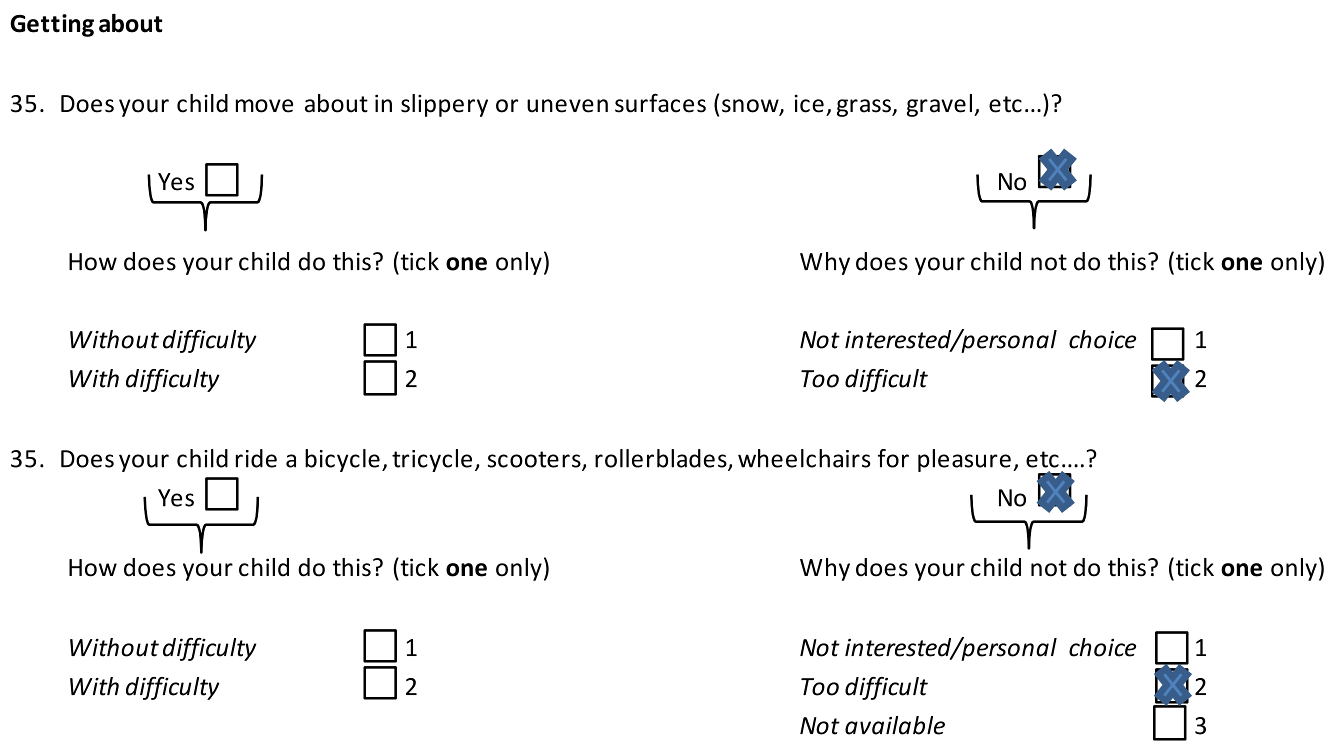
How does your child do this? (tick **one** only)

Without difficulty ☒ 1
With some difficulty ☐ 2
With a lot of difficulty ☐ 3

Table 2: Areas surveyed in Life-H

1 . Meals
2. Personal care
3. Fitness
4. Housing
5. Mobility
6. Communications
7. Responsibilities
8. Relationships
9. School
10. Recreation

Figure 4: Example of a low score for Mobility. Score: 1.1



Getting about

35. Does your child move about in slippery or uneven surfaces (snow, ice, grass, gravel, etc…)?

Yes ☐ No ☒

How does your child do this? (tick **one** only)

Without difficulty ☐ 1
With difficulty ☐ 2

Why does your child not do this? (tick **one** only)

Not interested/personal choice ☐ 1
Too difficult ☒ 2

35. Does your child ride a bicycle, tricycle, scooters, rollerblades, wheelchairs for pleasure, etc….?

Yes ☐ No ☒

How does your child do this? (tick **one** only)

Without difficulty ☐ 1
With difficulty ☐ 2

Why does your child not do this? (tick **one** only)

Not interested/personal choice ☐ 1
Too difficult ☒ 2
Not available ☐ 3

North of England results

Looking at the overall response, participation is high for housing, fitness, relationships and communication dimensions.

Apart from the relationships dimension, participation generally decreases with more severe impairment (Figure 5). Relationships consistently scored higher than all other areas and is least influenced by other factors. Participation decreases with increased severity of walking ability, hand use, feeding, communication, and IQ. Interestingly, relationship is lower in the middle IQ and feeding impairment ranges compared to the high and low range for these impairments.

Figure 6: Total participation between regions in Europe

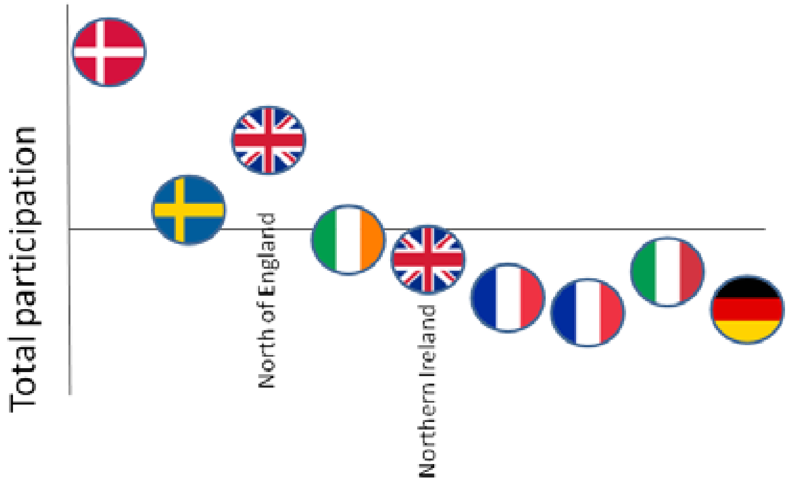
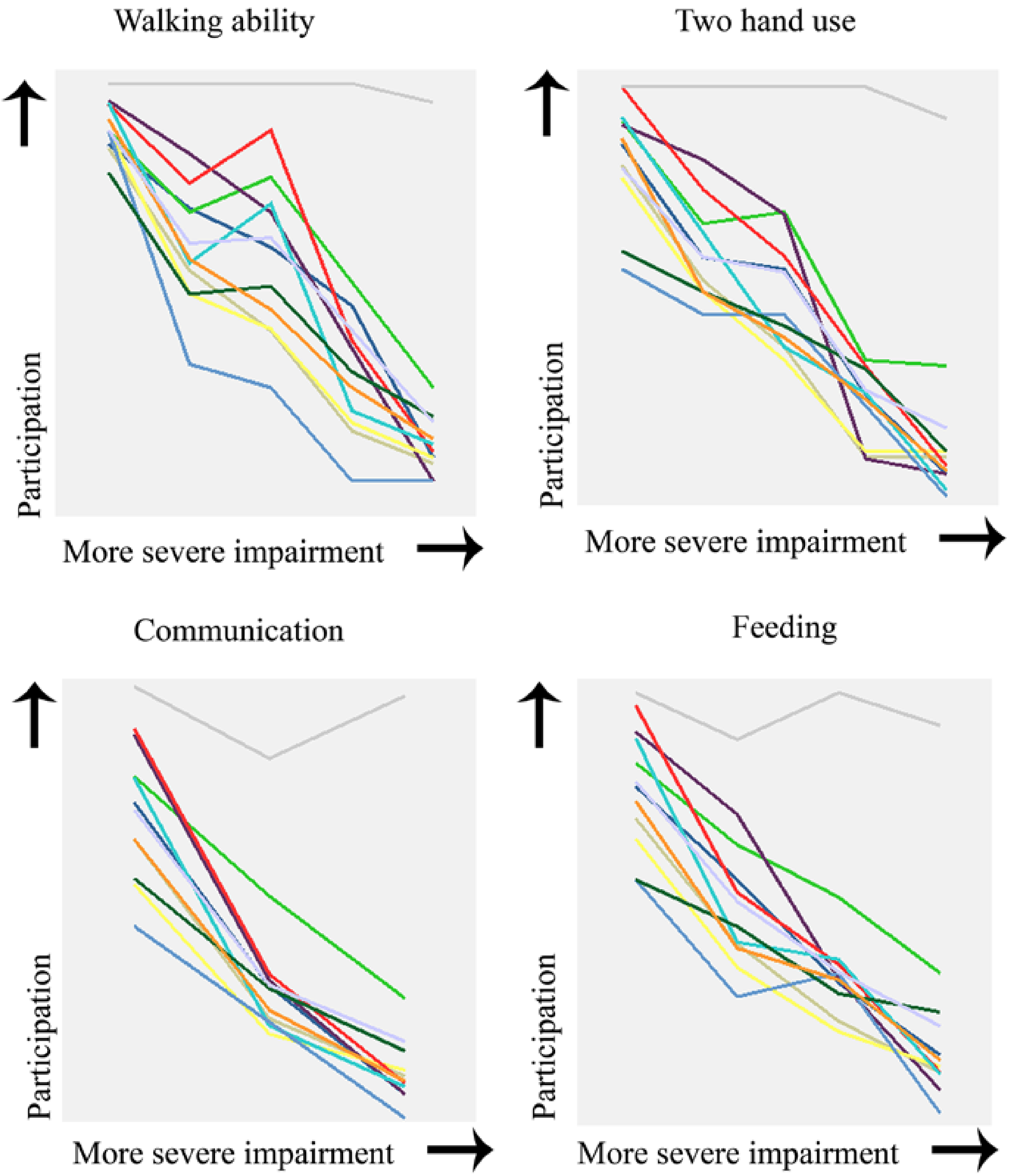


Figure 5: Participation in relation to different impairments in the North of England. Lines represent scores for the 10 areas asked. All dimensions of participation decreased with more severe impairment except relationships shown by the grey line at the high end of the graph.



Among European countries, the North of England had relatively higher participation (Figure 6). Denmark led in participation in all areas. The North of England was second in all domains apart from relationships.

European-wide results

All impairments except hearing were significantly associated with lower participation. Agreeing with the North of England results, lower participation was associated with more severe impairment of walking ability, hand use, IQ, and communication. In addition, parent report of their child's pain also was associated with lower participation. Impaired walking was the most important impairment affecting participation.

Participation varied significantly by region. Participation in East Denmark was much higher compared to other regions in Europe. West Sweden and North of England fared relatively high after East Denmark in all areas, apart from home life and relationships.

Socioeconomic background and type of school was not associated with participation.

Different children participate differently

As most people would suspect, participation decreases with severity of impairment. Impairments in walking affect children the most, underscoring the importance of mobility in improving participation.

Disabled children in the North of England, after Eastern Denmark, participated more than their counterparts in Europe. Although encouraging, the North of England could still do better.

SPARCLE highlights the importance of regions and their policies in the participation of disabled children. Public and private organisations could and should do more to improve participation of children in the North of England.

Why Denmark leads

- ◇ Advocacy groups for disabled people work with policy makers to ensure equal access
- ◇ Public system of after school clubs attended by children up to the age of 12 years regardless of whether disabled or not
- ◇ Policies emphasising social model of disability in determining access to support services
- ◇ Financial assistance to poor families in Denmark are the most generous

Pain

Pain

Pain is not unusual in children with cerebral palsy or any other form of disability. Muscle spasms, stress points and other inherent complications as well as operations and therapy may result in much discomfort.

Measuring pain

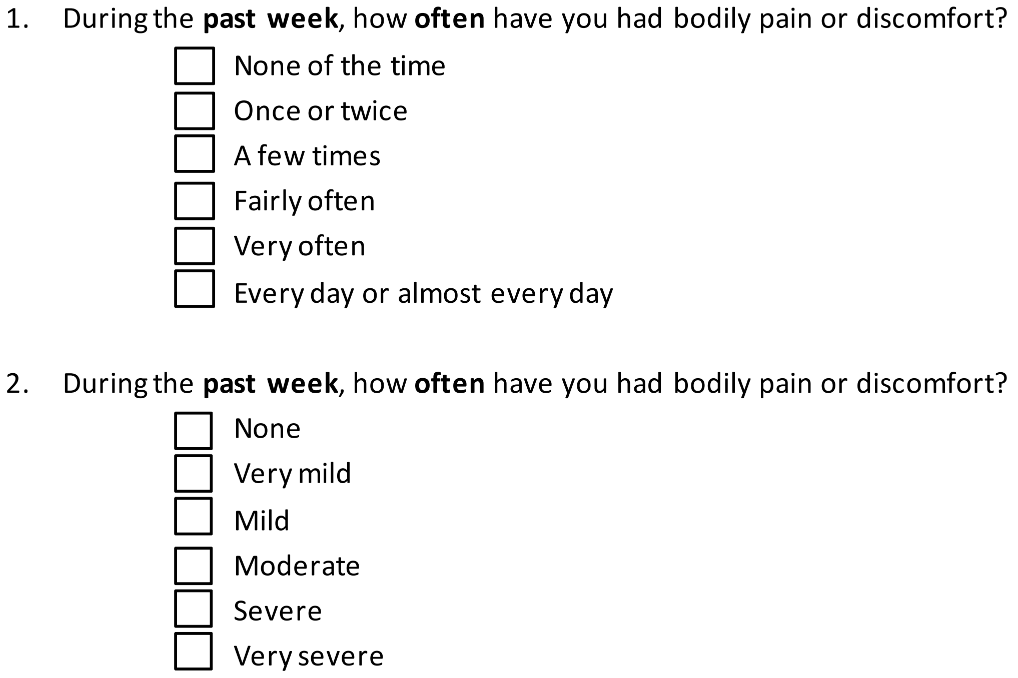
A section on pain from the Child-Health Questionnaire was completed by parents and if possible, also by children. They were asked two questions about the child's pain over the last one week. The questions are then scored between 0-10, with 0 as no pain and 10 the severest pain. Sample questions are shown in Figure 7.

North of England results

Most children in the North of England had problems with pain. Only one in three children reported no pain (Figures 8 and 9). One in three parents and close to half of children scored 1 to 4.

Parents tend to report on behalf of their children in the severest categories of walking ability and feeding impairments. They also tend to report higher pain scores.

Figure 7: Pain questionnaire



1. During the **past week**, how **often** have you had bodily pain or discomfort?
   - ☐ None of the time
   - ☐ Once or twice
   - ☐ A few times
   - ☐ Fairly often
   - ☐ Very often
   - ☐ Every day or almost every day

2. During the **past week**, how **often** have you had bodily pain or discomfort?
   - ☐ None
   - ☐ Very mild
   - ☐ Mild
   - ☐ Moderate
   - ☐ Severe
   - ☐ Very severe

Figure 8: Parental report of pain of children who could not self report
(Respondents = 35 North of England children)

Figure 9: Children who could self report.
(Respondents = 78 North of England children)

Score	Response	Key
0	No pain	☺
1-4	Once or twice, moderate pain A few times, mild pain Fairly often, very mild pain	😐
5-10	Once or twice, severe pain A few times, moderate pain Very often, very severe pain	☹

North of England results

Looking at walking abilities, pain scored higher in children who are unable to walk than those who can walk. Pain is slightly higher in children with bilateral spasticity than unilateral spasticity.

In Europe, the overall picture is similar to that of the North of England. Most children reported problems with pain. About a similar proportion of children and a slightly higher proportion of parents reported an absence of pain in Europe.

European-wide results

Pain is associated with all types of impairments including vision and hearing. In child reported pain, pain increased with age and is not associated with impairment. For parent reported pain, pain increased with severely impaired motor function, severity of seizures and parental unemployment.

Addressing pain is important

The consequences of pain extend well beyond physical discomfort. As explained in previous chapters, pain has a strong association with lowered QoL and participation.

Parents tend to report for children with severe impairments and their reported scores tend to be higher. Therefore, more attention should be paid to pain in children with severe impairments.

Pain in children with cerebral palsy was common with most children reporting some form of pain. The problem is real, prevalent and widespread. Addressing pain will make a lot of difference to children with cerebral palsy in the North of England.

Environment

Environment

We discussed the social model of disability at the start of this report. It attaches a lot of importance to the environment.

SPARCLE therefore also studied the environment. We first visited and talked to many families with children with cerebral palsy across Europe to find out the things they needed. This is to do with:

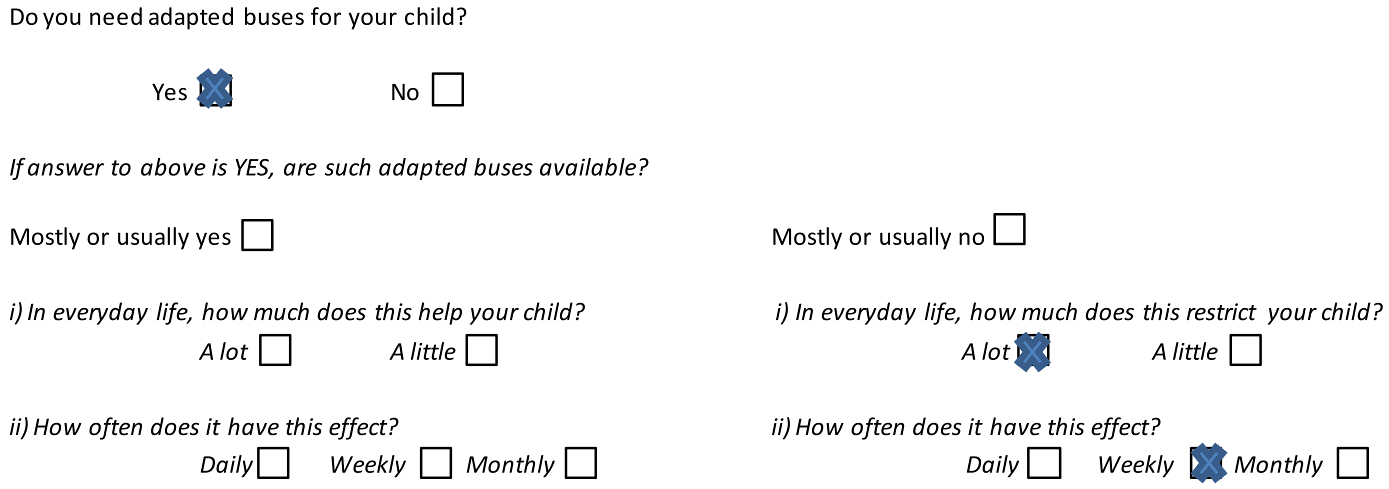
- Physical aspects like walking aids, lifts, transport
- Social aspects like financial help, assistance from people, encouragement to join clubs
- Attitudes in the family, amongst friends, at school and in the general public

Then we developed a questionnaire based on this work shown in Figure 10 below.

The questionnaire was then administered to all the 818 families in SPARCLE.

We analysed the results to see how often families had the things they thought they needed. We grouped questions together and then compared countries in respect of how many children received the things they needed. Then we did a similar graph (Figure 11) to the one on page 19 but about the environment rather than participation.

Figure 10: Example of an question on environment



Do you need adapted buses for your child?

Yes ☒ No ☐

If answer to above is YES, are such adapted buses available?

Mostly or usually yes ☐

i) In everyday life, how much does this help your child?

A lot ☐ *A little* ☐

ii) How often does it have this effect?

Daily ☐ *Weekly* ☐ *Monthly* ☐

Mostly or usually no ☐

i) In everyday life, how much does this restrict your child?

A lot ☒ *A little* ☐

ii) How often does it have this effect?

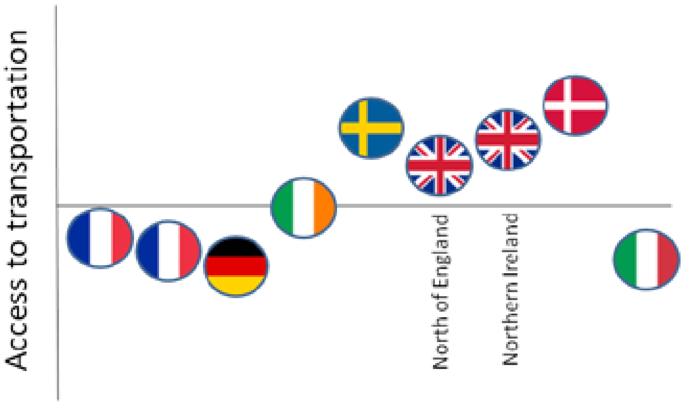
Daily ☐ *Weekly* ☒ *Monthly* ☐

To give a concrete example, consider the questions about transport. The questions are about:

- an adequate vehicle for getting your child around
- accessible car parking in public places
- adequate bus service in your area
- accessible buses for your child in your area
- accessible train services in your area
- accessible taxis for your child in your area

The results are similar but not quite the same. Denmark and the North of England still do well but the differences between countries are not as large and the pattern of difference is not so constant.

Figure 11: Physical environment between regions in Europe.



Further Reading and References

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Regional Maternity Survey Office for the North of England, http://www.nepho.org.uk

SPARCLE http://ncl.ac.uk/sparcle

Photos: NHS Photo Library, Department of Health

If you would like to be sent any of these electronically, please email Professor Colver at allan.colver@ncl.ac.uk

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