Both the Quality of Life and the Participation of adolescents with cerebral palsy are predicted by the pain, psychological difficulties and parenting stress experienced when the adolescents were 8-12 years old

Implications:

Help to the younger child and their family will not only make life easier at the time but will also have long term benefits for adolescence.

Some European countries provide environments which enable children with cerebral palsy to participate much more in life than children in other countries

We took two approaches to assessing how much the environment affected disability.

In the first we used a questionnaire to examine directly how easily families and children could access the environment they needed. We found:

Children with more severe cerebral palsy needed more adjustments to the environment; and what they needed was less likely to be available. Their access to transport and buildings was less good; the social support that they needed was less widely available; and there was a suggestion that attitudes of wider family and friends were less positive. However attitudes of teachers and therapists were similar for children with all severities of cerebral palsy.

There was much variation between countries in the availability of environmental features that disabled children needed; and this was for children with mild or severe cerebral palsy. Some countries consistently provided better access to most aspects of the environment that disabled children needed.

The availability of needed features was broadly similar when the young people reached adolescence; and the four best performing countries and the four worst performing countries were the same countries at both ages.

In the second approach we collated national policies about the environment relevant to children with cerebral palsy; these included how countries varied in their equality and anti-discrimination legislation, their education and social security policies, the provision of support and care services, the availability of assistive technology and legislation and regulation about the physical environment such as transport, access to buildings and toilet design. We found for example one country has after school clubs for all children and there is state provided transport to take children to them. Also a parent of a disabled child can go part time to look after their child but continue to be paid their full salary. Another country provides low financial assistance to families of disabled children compared to other countries.

Implications:

There is much that could be done to improve the environment for disabled children and their families. Countries should aspire to the environments provided in those countries that best promote Participation. This is in line with the United Nations Conventions discussed at the beginning of this brochure.

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SPARCLE

A Study of Participation and Quality of Life of Children with Cerebral Palsy Living in Europe

Denmark, France, Germany, Ireland, Italy, Sweden, England and Northern Ireland

Two United Nations Conventions set out the rights of disabled children. For example:

- Convention on the Rights of the Child (1989) Article 12 'Children's views must be taken into account in all matters concerning them.'
- Convention on Rights of Persons with Disabilities (2006). Article 23 'Children with disabilities should be able to participate on an equal basis with others in family life, health maintenance, education, public life, recreational, leisure and sporting activities.'

This brochure summarises the results of a research study about children with cerebral palsy in Europe, first visited at 8-12 years of age and then at 13-17. 818 children of all abilities and their families from nine European regions joined the first visits and 667 the second visits.

Individuals with cerebral palsy have difficulty with movement due to injury to their brain. They were chosen for this study as they are representative of a wide range of disabled children because, as well as their movement difficulty, children with cerebral palsy may have associated learning difficulty, communication difficulty, epilepsy and hearing or visual impairments.

The key findings were:

- Children and young people with cerebral palsy experience **much pain**, more than their peers in the general population and more than had been appreciated before the study
- Children and young people with cerebral palsy are more likely to have **psychological problems** than their peers in the general population
- Parents of children with cerebral palsy are more likely to experience **significant stress** than parents of children in the general population
- Children and young people with cerebral palsy who can self-report have **similar Quality of Life** to other children of their age – both at age 8-12 years and at 13-17 years, except that at 13-17 years, the young people experienced lower Quality of Life concerning 'social support and relationships with peers'
- For children and young people with **severe learning difficulties**, we rely on parents to report what they think is their child's Quality of Life. In general Quality of Life was reported to be good unless the child had much pain or psychological problems or the parents were very stressed
- Children and young people with cerebral palsy take part in **fewer activities** than their peers; and the activities they do take part in are usually engaged in less often
- Quality of Life and Participation of young people with cerebral palsy **are predicted** by their Quality of Life and Participation when they were 8-12 years old; but they are also predicted by pain, psychological difficulties and parenting stress when the young people had been 8-12 years old.
- **Some European countries** provide environments which enable children and young people with cerebral palsy to participate much more in life than children in other countries

More information on the study and its published research papers are on the SPARCLE website: **http://research.ncl..ac.uk/sparcle**

Separate summaries have been sent to the parents and young people in the study.

Understanding disability

In the 'social model of disability' disability is understood to result from the interaction between individuals and their environment rather than residing in the individual. It implies that disability can be reduced by changing the environment around the person rather than changing the person. We used two indicators to assess disability: Quality of Life and Participation.

Quality of Life or subjective well being is how an individual feels about their life. Participation is what the individual does in their day to day life.

It may seem surprising that the environment around disabled children and their Quality of Life and Participation have only recently become important to researchers. SPARCLE was the first large, comprehensive study that was planned to help understand these issues better.

Asking children directly

SPARCLE showed that 8-12-year-old children with cerebral palsy can be asked directly about their lives; parents do not need to report for them. At the first visit 500 children self-reported. For the second visits at age 13-17 years, 431 young people self-reported.

The parent's viewpoint is different but is also important. Furthermore, children with severe learning difficulties cannot self report so we have then to rely on parents' reports of their children's lives. This applied to 318 children at the first visit and 236 at the second.

Implications:

Doctors, teachers and therapists should talk directly to the child, rather than through parents, wherever possible

Children and young people with cerebral palsy experience much pain

We found that pain was commoner in children and young people with cerebral palsy than previously thought; also more pain led to lower Quality of Life and less Participation.

Implications:

Children should be asked whether they have pain by their parents and their therapists or doctors. A child, thinking their pain to be "normal" because he/she had always had pain, may not mention it unless asked about it.

Treatments should be developed for pain. Common headaches and tummy pains may respond to psychological approaches. Pain due to cerebral palsy itself needs trials of medication or other treatments to deal satisfactorily with it.

Some therapy treatments for cerebral palsy may actually cause pain. These treatments should be carefully reconsidered to make sure they do really help the children.

Children and young people with cerebral palsy are more likely to have psychological problems than their peers

A quarter of children with cerebral palsy have symptoms that make it likely they need psychological help. We do not understand well the reasons for this, though they may be:

Altered brain networks associated with cerebral palsy may affect the child's ability to learn and regulate their behaviour and emotions

Parents may react to and manage their child differently to their non-disabled siblings – due to the increased stress families experience in bringing up a disabled child or due to feeling very protective towards their child

Some children with cerebral palsy may have unrecognised subtle learning difficulties which make many situations difficult for them to cope with

Implications:

Guidance should be available for parents of preschool children with cerebral palsy; children with cerebral palsy should experience the same boundaries and consistency as all children.

Where difficulties persist, then psychological services should be readily available to help families.

Parents of children with cerebral palsy are more likely to experience significant stress than parents of children in the general population

A quarter of parents of children with cerebral palsy experience very high stress associated with caring for their child and require help from professional services. Only 5% of parents of children in the general population experience similar levels of stress.

Parental stress is more likely if their child has pain, learning problems or communication difficulties. Parental stress is less likely if their child has more severe movement difficulties.

Implications:

Parents' stress should be minimised by ensuring they have sufficient additional income and support to care for a disabled child; and that they can easily obtain the services and schools they need for their child

Professionals should not make assumptions about the impact of caring for a child with cerebral palsy based on the severity of the child's movement difficulties.

A family centred approach to the care and management of children with cerebral palsy could help to ensure that parents' needs are considered along with the child's needs for care and support, especially of any communication difficulties.

Children and young people with cerebral palsy who can self report have the same Quality of Life as other children of their age; both at 8-12 years and 13-17 years

We looked at how the children felt about their life in areas such as physical health, self esteem, emotional life, relationships, and life at school.

There were three main findings:

1. Children with cerebral palsy who can self-report have similar Quality of Life to children in the general population of the same age from the same country. The results are the same when they are aged 13-17 years, except that adolescents with cerebral palsy reported a lower Quality of Life concerning 'social support and relationships with peers'.
2. If a child experiences much pain, this affects all aspects of their Quality of Life - not just one or two such as physical health or school.
3. The severity of the child's cerebral palsy and their associated impairments, such as communication or epilepsy, did not in general affect the child's Quality of Life. However children who could not walk had a poorer perception of their physical health, children with learning problems had lower self-esteem and children with communication problems had poorer relationships with their parents.

Implications:

At time of diagnosis, parents can be reassured that children and young people with cerebral palsy, who can self-report, will experience similar Quality of Life to that of other children of their age.

Children with cerebral palsy who can self-report are like all children; some are happy, some less so. They value the same things as other children; they value their families, they want considerate peers and they want to be able to participate in everyday activities.

Recognition of the well-being, autonomy and emotional life of disabled children strengthens arguments for social and educational policies which ensure their right as citizens, rather than as disabled children, to participate as fully in society as other children.

Attitudes to disabled children should continue to change. Most western European countries encourage acceptance and integration of disabled children. However many people still feel sorry for disabled children and this attitude also needs to change. Disabled children are not more or less happy than other children, so pity is not appropriate. Rather, disabled children need the same opportunities as other children to lead a full a life.

For children and young people with severe learning difficulties, we rely on parents to report what they think is their child's Quality of Life

In general Quality of Life of those with severe learning difficulties was reported to be good unless the child had much pain or psychological problems or the parents were stressed. Quality of Life in the more 'emotional' domains tend to be higher in those with severe learning difficulties than in those without.

Implications:

Further research is needed in this area as we are not confident our instruments are the right ones for children and young people who cannot self-report.

Children and young people with cerebral palsy take part in fewer activities than other children of their age

Although Participation was lower in most domains, using digital media and going out for meals with family were undertaken to a similar extent in disabled and able bodied children. Participation was lower if children and young people experienced more pain and if they had more severe movement difficulties and associated impairments. When we compared countries, children with the same severity of cerebral palsy participated much more in some countries than others.

Implications:

These findings are quite different to those about Quality of Life, which was broadly similar between children with cerebral palsy and the general population.

In order to promote Participation healthcare providers care need to treat and improve, where possible, a child's movement and other impairments. But also essential, and more realistic given our very limited number of effective treatments, is the need to alter the environment around a child. This needs to be done at national level (eg ensuring adequate financial benefits), at local level (eg ensuring lifts in buildings and easy access to public transport) and at the level of the child (ensuring enough time to do things, or adapting household appliances).