



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 report is about 8-12 year old children with cerebral palsy in Europe. 818 children of all abilities and their families from nine European regions were visited by researchers.

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

The key findings were:

- **Children with cerebral palsy experience much pain**
- **Children with cerebral palsy are more likely to have emotional and behavioural difficulties than children 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 with cerebral palsy who can self report have the same Quality of Life as other children of their age**
- **Children with cerebral palsy take part in fewer activities than other children of their age**
- **Some European countries provide environments which enable children 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: www.ncl.ac.uk/sparcle/.

Separate summaries have been sent to the parents and children 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 objective, what the person does in their day to day life.

It may be surprising that the environment around disabled children and their Quality of Life and Participation have only recently become important to researchers. SPARCLE is the first large, comprehensive study that was planned to help us 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. Children can be consulted directly and SPARCLE has shown how effective this can be. In SPARCLE, 500 children self-reported.

The parent's viewpoint is different but it 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 in SPARCLE.

Implications:

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

Local government and health and social care agencies should consult more with children before deciding how to change services.

Children with cerebral palsy experience much pain

We found that pain was commoner in children with cerebral palsy than previously thought; also that more pain was associated with worse Quality of Life and less Participation.

Implications:

Children should be asked whether they have pain by their parents and professionals. Perhaps a child, thinking their pain was "normal" because he/she had always had pain, does not mention it.

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

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

Children with cerebral palsy are more likely to have emotional and behavioural difficulties than children in the general population

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 pathways or 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 non-disabled siblings – because of the increased stress families experience in bringing up a disabled child or due to feeling overprotective towards their child

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

Implications:

Adequate resources should be available for assessment of psychological function.

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

Parents of children with cerebral palsy are more likely to experience high 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 and support from professional services. Only 5% of parents of the general child 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:

Parent stress should be minimised by ensuring they have sufficient additional income and support to care for a disabled child; and that they 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.

Children with cerebral palsy who can self report have the same Quality of Life as other children of their age

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:

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

If a child is experiencing much pain, this affects their Quality of Life on all the aspects of their Quality of Life - not just one or two such as physical health or school

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 with cerebral palsy, who can self-report at age 8-12 years, will experience similar Quality of Life to that of other children of their age.

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.

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.

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 perhaps 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.

We are often asked "would the results be the same for teenagers?" We do not know but we have just completed data collection on the same children as teenagers and have started to analyse these data.

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

When we examined Participation – what children actually did in their lives – we found that children with cerebral palsy participated much less than other children. Their Participation was even lower if they 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.

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

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 from 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.

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:

There was considerable variation between countries in the availability of environment items 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. 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 the paper.

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