



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

This **Summary** is 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 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. *This finding was unexpected but has now been confirmed by studies elsewhere. The SPARCLE study was the first study to draw attention to the importance of pain in cerebral palsy.*
- 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 on the domain of

‘social support and peer relationships’. This finding was also unexpected and has subsequently been confirmed by other studies. Again the SPARCLE study has helped all members of society to appreciate that we should not feel sorry for disabled children and young people – they have the same range of happiness and unhappiness as all children.

- 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. *So this is the main area in which action is needed. Children and young people with cerebral palsy have quality of life similar to that of the general population but their participation in society is much reduced.*
- 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>