

What will we do next?

We still have some more analysis to do. We will then tell the European Parliament and Governments in each country what we have found out. After all they gave us the money for the research so we could advise them about what helps and is available in different countries.

Also our work should help change attitudes so that politicians realise disabled children are children first and foremost with a right to participate, not a group to feel sorry for.

We would like to visit you and your child again when they are 5 years older. Nearly all of you said it would be all right to contact you again; you can then decide if you want to join the next part of the study. We think it will be very interesting because your child will then be a teenager and will have new ideas about life and what they want to do.

We are applying for money to do this follow up study. So once again, many thanks for your help with SPARCLE. Its success is due to the helpfulness of the families who generously gave their time to the study.

If you would like to know more, please visit the project website or phone Allan Colver.

Allan Colver and Kathryn Parkinson

**Sir James Spence Institute,
Newcastle University,
Royal Victoria Infirmary,
Newcastle upon Tyne, NE1 4LP**

**Tel (0191) 219 6672
Website: <http://www.ncl.ac.uk/sparcle>**

THE SPARCLE STUDY



March 2008

Summary of results, written for parents

Your family took part in SPARCLE in 2004/2005 and you may remember we wrote to you last year about how it was going; 116 families in the north of England took part and another 702 families throughout Europe. We have nearly finished analysing all the information you gave us and are confident it will help the governments in Europe to continue develop best practice for disabled children.

A key feature of SPARCLE is that wherever possible we asked the children themselves about their lives. Often in the past children were not consulted. We have shown that if suitable questionnaires are used, it is quite possible for many children to report about their own life.

We want to say thank you; and tell you the results of the research. We have prepared a separate summary for your child which we enclose. We realise you may be a parent of a child who was not able to understand the visit and would not understand their summary— however we decided still to enclose it.

We have a website www.ncl.ac.uk/sparcle. If you want to read the research papers where the results are published, you can download them from here.

Some findings may not apply to you but they do apply to most families.

Your child's Quality of Life (QoL)

QoL is what a person feels about their life. For children who can report their own QoL, there is no difference between those with cerebral palsy and the general population of children of the same age. This was a surprise to some people who thought people with cerebral palsy would be unhappy or would not feel good about themselves. Naturally, children with cerebral palsy may not be happy all the time or always have as many friends as they want; but that is the same for children who do not have cerebral palsy.

Pain is commoner than expected and reduces a child's QoL.

When we compared the child's report of their QoL with what their parents said it was, parents usually underestimated their child's QoL.

Doctors and therapists should not make assumptions about the lives of disabled children, but must listen to the child. Doctors are well placed, for example, to ask about and treat pain which could improve a child's quality of life.

We rely on parents' reports for children who can not report their QoL. Pain is still important and limited mobility reduces physical well being and autonomy. However limited mobility and learning difficulty were associated with better QoL in areas such as mood, emotions and relationships.

Your child's participation

Participation is what children do. Children with cerebral palsy participate much less than the general population – especially those with severe cerebral palsy.

Children with cerebral palsy do some things as often or more than other children such as eating out or using a computer. However they do most things less often, such as playing sports, watching sports events or doing housework.

Children in some countries do more things than those in other countries. Why is this? The children are the same and their parents love them just as much; it seems some countries are better at making sure disabled children can do as much as other children. We can say this to the European Parliament.

Stress

Children with cerebral palsy have more psychological problems than the general population, and it is often the children with milder cerebral palsy.

Parents of children with cerebral palsy report being more stressed than parents in general – especially if the cerebral palsy is severe.

Environment

The laws, regulations and social provision made for disabled children vary a lot in European countries. The differences are summarised in a SPARCLE report. We also assessed if families get the help they need. We found that children with fewer needs are more likely to have what they need; and there are certain things such as wheelchairs which are more likely to be provided than say communication aids. We have not completed the analysis but it seems children participate more if they have the adaptations, access to buildings, transport etc they need.