

# Enable Ireland

## The SPARCLE Project

Study of **P**ARticipation and quality of life of **C**hildren with cerebral palsy **L**iving in **E**urope



### SPARCLE 1 South-West Ireland Local Report Lay Summary

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*Mr. Alan Lyons, MISCP MSc (Physio) PG Dip (ClinTher)  
Clinical Researcher*

*Ms. Laura O' Connell, MSc (Psych)  
Research Associate*

## Introduction and Description of SPARCLE Project

Over eight hundred (818) children and their parents took part in a large European project on participation and quality of life in 2004. One hundred of these children live in Cork and Kerry, most of whom attend Enable Ireland Children's Services. The study investigated the influence of the environment on the quality of life and involvement in life situations of children with cerebral palsy.

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.

## Summary of Main Findings

### *Quality of Life*

Quality of life is the term used to describe how a person sees themselves in terms of their relationships, school or work life, and general health. For children with cerebral palsy it is very important to measure how well they are supported by friends, family and professionals so we know what areas need to be improved. The best way to do this is to ask the children themselves.

For 8–12 year-old children who can report their own quality of life, we found 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 that people with cerebral palsy would be unhappy or would not feel good about themselves.

When we compared a child's report of their quality of life with what their parents said it was, parents usually underestimated their child's quality of life. Naturally, children with cerebral palsy may not always be happy, or always have as many friends as they want, but that is the same for children who do not have cerebral palsy.

### *Participation*

Children with cerebral palsy participate in every day life activities much less than the general population – especially those with severe cerebral palsy.

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

Participation in everyday life is affected to a small degree by intrinsic impairments in the children (walking, fine-motor, speech and intellectual abilities).

Pain is strongly associated with reduced participation.

Children with cerebral palsy in Ireland participate less often in activities of daily living such as mealtimes, personal care, communication, mobility, and in recreational activities such as sports and culture, when compared with children in most other European countries. However, our children participate well in relationships, responsibilities and school-life, when compared to our European counterparts.

### *Pain*

When asked, almost one third of the children in our study experienced pain on a weekly basis, which is more common than expected.

Pain reduces a child's participation and quality of life. Not having pain was the most important factor that contributed to a feeling of a better quality of life.

Parents and professionals should understand that pain is a common problem in children with cerebral palsy. Children should be asked about pain more often, and existing pain prevention treatments should be evaluated and improved.

### *Child Psychological Problems*

Children with cerebral palsy have more psychological problems than the general population. Psychological problems are more common in those children with both intellectual impairment and mild physical impairment. Irish children with cerebral palsy have no more or less psychological problem than children in most other European countries.

### *Parental Stress*

Parents of children with cerebral palsy report being more stressed than parents in general – especially if their child has severe cerebral palsy.

In Ireland, 31% of parents of children with cerebral palsy have significant levels of stress, compared with 10% of parents of children in the general population. The child's level of communication is the factor which most effects stress.

30% of parents stated a need for counselling, but only 12% received it.

### *Environment*

The laws, regulations and social provision made for disabled children vary a lot in European countries. This has a strong influence on children's participation and quality of life.

Children who are wheelchair-users have reduced access to all aspects of their environment, and they generally experienced less favourable attitudes among family and friends.

When compared with children with cerebral palsy in most other European countries, children with cerebral palsy in Ireland generally have good physical access to school, but not to their home environment; have good social support at home and in the community, but not in school; and have poor access to transport in the community.

## **Next Steps**

### *SPARCLE 2*

The second phase of SPARCLE (SPARCLE 2) is currently in progress, with follow up of SPARCLE 1 participants into their adolescent years.

It will be very interesting to discover if the important outcomes from SPARCLE 1 change during the transition from childhood to adolescence.

The home visits are almost complete and analysis of all the information will begin over the summer months.

### *Participation of Young People with cerebral palsy in Physical Activities (PYPPA)*

The PYPPA project is about the involvement of young people with physical disabilities in recreational physical activities in Cork and Kerry. We are all aware of the health and social benefits of being physically active, and we want to help our service users to get active in their communities.

We know from SPARCLE that young people with cerebral palsy in Ireland participate less than their European peers. The PYPPA project aims to explore this in more depth: describing

the availability of various types of activities, young people's specific preferences for activities, and what young people think prevents them from being more active in the community.

### *Service Development*

The SPARCLE findings have been used to plan services which support children and their families as they face important life transitions.

Each child will be supported to reach his or her potential, by promoting well-being, independence, social inclusion and choice in education and future life choices. This will be achieved through partnership with families, an inter-disciplinary team approach, and through working in a variety of settings, such as schools, pre-schools and community setting.

Using a child and family-centred approach, we will work in partnership with children and their families to ensure that every child and family is offered a clearly defined pathway of service. We will support each child through transitional stages of life to reach his or her full potential. This will be achieved by using an Individual Service Plan focused on preparation for transitions and long-term outcomes of participation and quality of life, a Key-worker system.

We will provide specialised services such as Postural Management to prevent secondary musculoskeletal problems and pain; Assistive Technology to support communication, mobility, education and leisure activities; Eating Drinking and Swallowing Services; Respite Breaks; and Family Support Services

We will deliver services to children and their families, and will plan for all periods of transition in preparation for adulthood. This will be achieved by supporting children and their families to access community-based and age-appropriate education, recreation and leisure opportunities.