Cerebral Palsy Registers

The Cerebral Palsy Register for Scotland is one of 3 Cerebral Palsy registers in the UK. The others are in the North of England, and surrounding counties, and Northern Ireland. The registers collect and hold information about cerebral palsy that is used for research into the condition. This research looks at clinical issues as well as causes and trends.

United Kingdom Cerebral Palsy Collaboration

The United Kingdom Cerebral Palsy Collaboration (UKCP) has brought the registers together to provide a basis for the research. The research is important in medico-legal settlements and also for determining needs and planning services.

The information held by all the registers has been put into a single database because the numbers of children born each year with cerebral palsy is low- about 2 children per 1000 births. Although the data held by the registers does vary, they all collect basic information such as:

- year of birth
- sex
- birth weight
- gestational age (how long the pregnancy lasted)
- type of cerebral palsy
- associated difficulties
- severity of motor, intellectual and sensory impairments.

This meant it was possible to combine the information held by all the registers into a single database. This was done with a grant from the Medical Research Council. The database contains confidential information about 6910 children born from 1960-1997.

Information from the joint database shows that:

- more males than females have cerebral palsy. For every 100 girls born with cerebral palsy, there are 135 boys
- the number of children born each year with cerebral palsy has increased over the past few decades, but this is now stabilising and may even be decreasing
- children born prematurely have an increased risk of having cerebral palsy, although the majority of children with cerebral palsy were actually born at full term (37 or more weeks).
This is because only a relatively small number of babies are born prematurely

- the proportion of children with a severe learning disability has decreased over time.

**Measuring the effects of cerebral palsy**

Measuring the effects of cerebral palsy on the lives of children, adults and families can be done in a limited way by looking at what individuals are not able to do such as dressing or feeding themselves. Using this approach it has been discovered that:

- over 66% of children with cerebral palsy are able to walk, but many need walking aids
- about 66% of children with cerebral palsy are able to carry out manual tasks such as dressing or feeding themselves
- about 75% of children with cerebral palsy born in the 1990’s don’t have a learning disability
- hearing and visual impairments are less common. About 1 in 50 children with cerebral palsy are deaf and 1 in 11 is blind.

**Life expectancy study**

Information from the UKCP database and the National Health Service Central Registers of births and deaths for Scotland, England and Wales, and the Central Health Index for Northern Ireland has shown the following:

- Children who are only mildly affected by cerebral palsy will have a life expectancy similar to that of the general population
- Children affected more severely or profoundly may have a life expectancy below that of the general population. This can be due to the associated complications that occur from immobility or deformity
- Respiratory disorders and infections are common in children with severe mobility difficulties.

**Further Information**

The life expectancy study results can be found in the following publications:

More detailed information on the results obtained from the life expectancy project can be found at: www2.warwick.ac.uk/fac/sci/statistics/staff/academic/hutton/scope4.pdf

Further work from the UKCP collaboration is available from the following website: www.liv.ac.uk/PublicHealth/ukcp/UKCP.html or through the UKCP coordinator:

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Our Advice Service
Advice Service Capability Scotland is a national disability advice and information service. We specialise in information on cerebral palsy.

We offer:
• information on Capability Scotland services
• advice on cerebral palsy
• general advice on disability issues

We also have a small lending library with resources about cerebral palsy and children’s books about disability.

You can get in touch with us by calling, e-mailing, dropping in or writing a letter.

This Factsheet can be made available in other formats e.g. audio, large print