

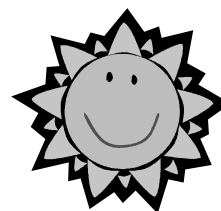
Cerebral Palsy Register *for* Scotland

A joint project between Napier University and NHS Scotland

Issue 6

July 2006

Welcome to the 6th issues of the Cerebral Palsy Register for Scotland (CRPS) newsletter. The register has been actively growing over the last 6 months, and working with health boards across Scotland to maintain a steady increase in registrations.



The first piece of specific research has also got underway, and I've had the opportunity to meet some of the parents and young people involved with the register through the 'Moving Schools' project - more details on page 4.

Many thanks for the continued support you give to the register.

I hope you enjoy the issue!

Abbi Green
Health Services Researcher



In this issue:

	Page
New Advice Worker at Capability Scotland	3
CPRS News: Moving Schools project	4
Scottish Parliament Disability Inquiry	5
Cerebra CP day	5
CPRS Update	6-7
Contact details	8

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New Cerebral Palsy Advice Worker at Capability Scotland

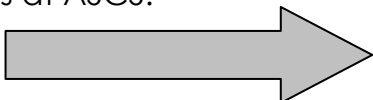
I'm Katerina Vasiliou. I joined the **Advice Service Capability Scotland- (ASCS)** in February. I am one of two advice workers. ASCS provides free and confidential advice and information on a range of disability and cerebral palsy issues.

The post has been created to enhance Capability Scotland's cerebral palsy focus. I will be updating ASCS's information on cerebral palsy including the booklet **"What is cerebral palsy?"** and expanding the range of cerebral palsy fact sheets which we currently produce. I will also be giving advice and information to enquirers and working to build stronger links with other cerebral palsy organisations.

Capability Scotland is the country's leading disability organisation working for a just Scotland. We work with children, adults and families living with disability to support them in their everyday lives. We have a wide range of services for disabled people.

At ASCS we have a library with over 3500 resources, which are available for loan without charge. The library has a large number of books on cerebral palsy, as well as publications on specific issues. You can view our library catalogue online. At the moment we have cerebral palsy fact sheets on the following subjects: Ageing and Cerebral Palsy, an Introduction to Therapy, Bobath Therapy, Challenging Behaviour, Conductive Education, Dolphin Therapy, Drooling and Cerebral Palsy, Lycra Dynamic Splinting, Medical and Surgical Treatments for Spasticity, Sleep Problems in Children and lastly Pregnancy and Parenthood.

If you would like to receive the revised **"What is cerebral palsy?"**, be put on our mailing list or require any information you can contact us at ASCS:



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CPRS NEWS

Moving School's Project

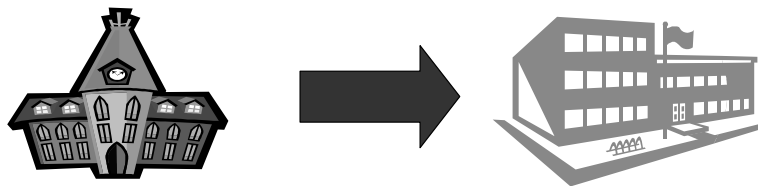
The first part of the moving school's project has just come to an end. This project is looking at the move young people make from primary into secondary school, and the support they and their families receive during this time.

Part 1:

This part of the project involved collecting the experiences of young people between the ages of 14 to 16 years, and their parents or carers. As part of the project we were able to meet mums, dads, and young people and hear their experiences, both the good and the bad. Now we need to start looking at the information we've collected and see what it was that made some transitions go well, and others not so well.

The families involved had a range of both mainstream and special school experiences, and the young people had a range of levels of severity. It was interesting to hear the different issues that came up which were linked to severity, but also that there were issues common to all families. Many parents commented that the most important thing was for their child to be happy, and this was a deciding factor when choosing a school.

Another excellent opportunity was meeting some of the young people from the register as part of the project. We made sure that every young person who wanted to be part of the project were given the opportunity, and every young person we spoke to made an important contribution to the work.



What's happening next?

The next task now is for the researchers to start looking at all these different experiences, and to gather together the important factors that contribute towards a positive transition.

We expect this might take some time, but we will keep posting updates on the website and in the next newsletter.

You can still be part of the project:

For this part of the study we were only able to speak to a small number of parents and young people. We really think it's important that the project represents everyone on the register between 14 to 16 years old, and so we plan to produce a questionnaire once we've finished studying the data.

This questionnaire will ask parents and young people in this age group if they agree or disagree with the things that we've found, this way we'll be able to say that the project reflects the experiences of everyone.

Part 2

We hope to start the second part of the project in 2007. For this next part we will talk to parents and young people just before they make the move into secondary school, and again once they've made the move.

These young people will be making the transition under the new Additional Support for Learning Act, and we will be able to see if this new act had made a difference to the experiences of the young people through comparing their experiences with those in the first group.

We will be contacting families* with children in the appropriate age group to invite them to participate in early 2007.

Scottish Parliament Disability Inquiry

Back in the summer of 2005 a representative from the CPRS was invited to attend a disability inquiry into 'removing barriers and creating opportunities' held by the **Equal Opportunities Committee of the Scottish Parliament**. This gave us the opportunity to put forward some of the experiences we'd been told about by you.

The Equal Opportunities Committee have now produced a **draft report of recommendations** that they would like to propose, and members who attended the meeting have been invited to comment on these.

The recommendations are on a range of areas, such as education, leisure activities, transport, information provision, and access to work.

Recommendations include such things as:

- Improving career guidance for young people with disabilities.
- Making sure there's a system in place for transitions, in particular the move out of school.
- Providing information in accessible formats.
- Ensuring a consistent approach to accessing leisure services throughout Scotland.

These are just some of the recommendations that aim to ensure that young people with disabilities have the same opportunities as those without disabilities.

The CPRS will comment on this draft report, and we will keep you updated with any progress through the website and newsletters.

Cerebra CP Event

Cerebra, the charity who fund the register held a study day for professionals working with children with CP at the end of June 2006.

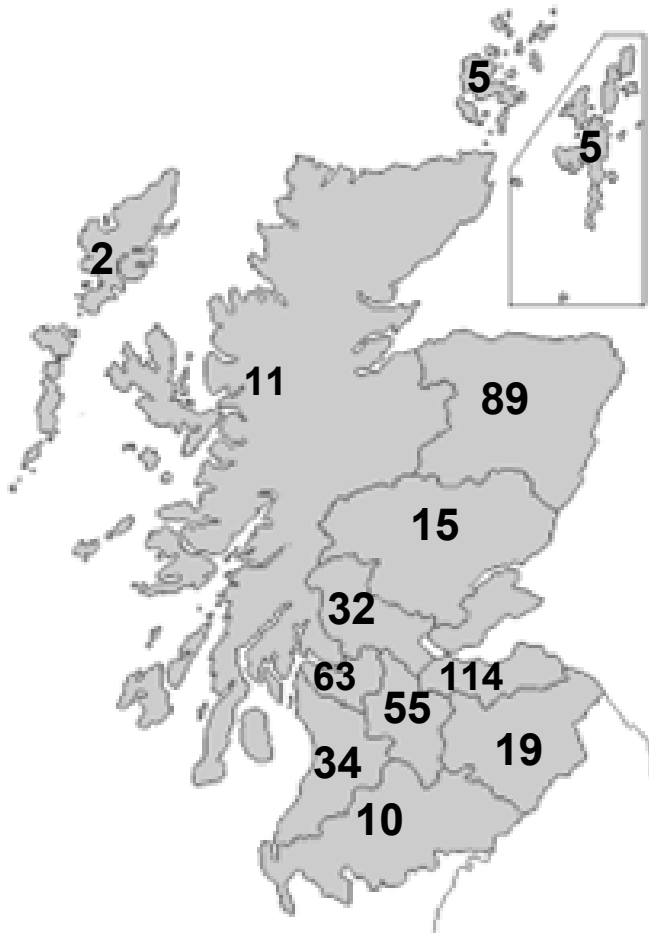
The day aimed to raise awareness about the register, and also to bring together professionals with an interest in CP to talk about current issues. A range of professionals attended, including paediatricians, occupational therapists, speech and language therapists, and physiotherapists.

Along with discussions about the register there were a number of presentations on a range of issues, such as; management of CP, CP in twins and singletons, European study of CP, and participation of children with CP.

The day was a real success, and helped inform professionals about the register, which means that they'll now be able to tell more parents about the CPRS, and give those parents the opportunity to be part of it.

Cerebra plan to post details of the day, and the presentations, on their website (www.cerebra.org.uk) in the near future.





Children on the register

Children from the whole of Scotland are represented on the register.

How does CP impact on the everyday life of children and young people, and their families?

Through the green **Lifestyle Assessment Questionnaire** we send you when your child is over 4 years old we can start to answer this question.

For most families we've found that there is an impact, and the parts of their life they find CP causes the most problems (severe impact) are within 'physical independence' and 'mobility'. Both of these areas involve moving around, lifting and being lifted, and doing physical things for yourself.

Social parts of life, such as going out after school, going on holiday, or getting support from local people, can also be affected by CP for some families. Most families tell us that this area is affected.

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Do you agree?

All parents/carers are invited to complete the questionnaire, and we would really like as many parents as possible to do so, then we can say our findings represent everyone on the register. If you haven't received a copy, or have misplaced your copy, please contact the CPRS office (details on the back cover) and we'll happily send you out another one.

For more information about the green questionnaire (LAQ) please see the website, and newsletter 2, which is available online or through contacting the CPRS office.

Clinical Information...

CP Types

Paediatricians inform us that most children on the register have a diagnosis of Spastic CP, with **Spastic Diplegia being the most common**. Following this Ataxia is the next most common type of CP represented on the register, followed by Dyskinesia.

Related Disorders

Medical information about the children also tell us that many of them have other disorders as well as their CP. The 8 most common are shown opposite.

Most
Common

Related Disorders

1. Visual Impairment
2. Learning Disabilities
3. Speech and Language problems
4. Epilepsy
5. Feeding problems
6. Developmental delay
7. Hearing impairment
8. Behaviour problems

Services

Most children on the register have been offered physiotherapy, and have made use of this service.

Occupational therapy and Speech and Language therapy are the second and third most common services offered and used by families.

Service	Offered to
Physiotherapy	94% of families
Occupational Therapy	82% of families
Speech and Language Therapy	68% of families

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