

# Local News

Spring 2010

Our mission is to support shared learning and service development through research activities and translation of knowledge in partnership with all Enable Ireland stakeholders and external agencies.

## Introduction

Welcome to the first newsletter produced by the local Research & Service Development Department at Enable Ireland Cork/Kerry Services. The aim of this newsletter is to raise awareness of our research activities to all Enable Ireland stakeholders nationally.

There are a number of projects ongoing at a European, national and local level. We would like to present these projects under the following headings:

- Research & Ethics Committee
- Community Participation and Social Inclusion
- Public Health and Epidemiology
- Child and Family Support Services
- Effectiveness of Clinical Services

## Contact Details

**Alan Lyons** (Research Coordinator)  
**Laura O'Connell** (Research Associate)

Research & Service Development Department,  
Enable Ireland Cork/Kerry Services,  
Lavanagh Centre,  
Ballintemple,  
Cork.

Tel: 021 4294803 (ext 254)

Email: [alyons@enableireland.ie](mailto:alyons@enableireland.ie)  
[loconnell@enableireland.ie](mailto:loconnell@enableireland.ie)

## Enable Ireland Research & Ethics Committee

The Research Department coordinates the activities of the national Enable Ireland Research & Ethics Committee (REC). Any research involving Enable Ireland staff or service users must initially be approved by the local Director of Services in the area concerned, and subsequently by the Enable Ireland REC. The REC Application Form and Guidance Notes are available from the Enable Ireland website:

<http://www.enableireland.ie/publications-and-research/research>

In addition to the studies described in this newsletter, the following REC Applications were approved by the Enable Ireland REC in 2009:

- Building a Sustainable Wheelchair Mobility & Seating Community – A Soft Systems Approach (University of Limerick and SeatTech)
- INFORM Intranet – Its usage and implications for communication in Enable Ireland (Kilkenny Services)
- The effectiveness of a six week physiotherapy group programme on balance and function in children with hemiplegia (Kilkenny Services)

Please contact Alan Lyons (Enable Ireland REC Coordinator) for further information.

## Community Participation & Social Inclusion

### **SPARCLE - Study of Participation of Children with Cerebral Palsy Living in Europe**

The first phase of SPARCLE (SPARCLE 1) commenced in 2004 with 818 children 8 - 12 year-old children participating from nine CP registries in seven European countries. Of these, 98 children were from the Cork/Kerry region. Results specific for this region were recently compiled and the SPARCLE 1 Local Report will be published on the Enable Ireland intranet INFORM in April 2010, with access also available on [www.enableireland.ie](http://www.enableireland.ie) and hard-copies in local Enable Ireland centres.

Some of the main findings were:

- Children with CP did not perceive their quality of life as significantly different from their non-impaired peers;
- Most children with CP experienced pain on at least a weekly basis;
- Children with CP participated in activities less often than their non-impaired peers.

The second phase of SPARCLE (SPARCLE 2) is now being implemented, with follow up of SPARCLE 1 participants into their adolescent years. Data collection is almost complete and analysis will begin over the summer months. There are numerous outcomes such as participation, quality of life, pain, parental stress/coping which, coupled with environmental, impairment and socio-demographic information, will provide us with useful information for future service development.



### **PYPPA - Participation of Young People with Cerebral Palsy in Physical Activities**

This study is exploring the participation of young people with physical disabilities in recreational physical activities in Cork and Kerry.

As a leading disability service provider, we are all aware of the valuable health and social benefits of participation in physical activities, and we want to demonstrate how we can be more effective in assisting our service users to get active in their communities.

The study employs a mixed method design of a population-based survey and semi-structured interviews with a representative sample of service users.

We know from SPARCLE 1 that young people with cerebral palsy in Ireland participate less often in recreational physical activities than their European peers. This project aims to explore this reduced participation in more depth, describing:

- Availability and location of various types of activities in the regional community;
- Specific preferences of young people with CP for physical activities; and
- What young people perceive as the main barriers or/and facilitators to their participation.

The data collection stage is now complete, with data analysis underway, and the PYPPA Project Report will be published in Summer 2010.

## Public Health & Epidemiology

### **Southern Ireland Cerebral Palsy Registry (SICPR)**

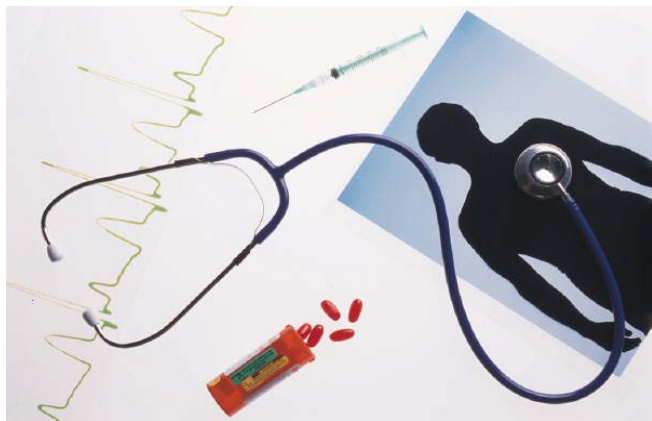
It is important to survey the trends of CP in the population in order to identify any potential risk factors and to plan services based on population-based need.

The SICPR keeps an account of all the cases of cerebral palsy in the Cork/Kerry region. This anonymised data is then sent to the Surveillance of Cerebral Palsy in Europe (SCPE) collaborative network, who collate the data and conduct valuable epidemiological research based on large

populations. We are currently preparing the data for the registration years 1999 and 2000.

In addition, it is planned that SICPR 1990-1999 Report will be published later this year, so watch this space.

There are also ongoing plans to expand to an Irish Cerebral Palsy Registry in the future, in partnership with other existing registries in the Western and Eastern regions.



### Surveillance of Cerebral Palsy in Europe (SCPE)

#### What is SCPE?

In 1998, a collaborative network of cerebral palsy registries was formed between 14 centres in 8 countries across Europe. The overall aim of the SCPE network was to develop a central database of children with cerebral palsy. Specific objectives were to monitor trends in birth-weight specific rates; to provide information for service planning; and to provide a frame-work for collaborative research.

SCPE have recently received funding from the **European Community 2nd Programme of Community Action in the Field of Health (2008-2013)** for **SCPE-NET**, a Project entitled: "SCPE: Best Practice in Monitoring, Understanding Inequality and Dissemination of Knowledge".

SCPE-NET consists of a number of elements addressing the following topics:

- **Exchanging knowledge on CP with professionals and families: SCPE open access website on CP**
- Variations in access to healthcare and outcome of healthcare in children with CP in Europe

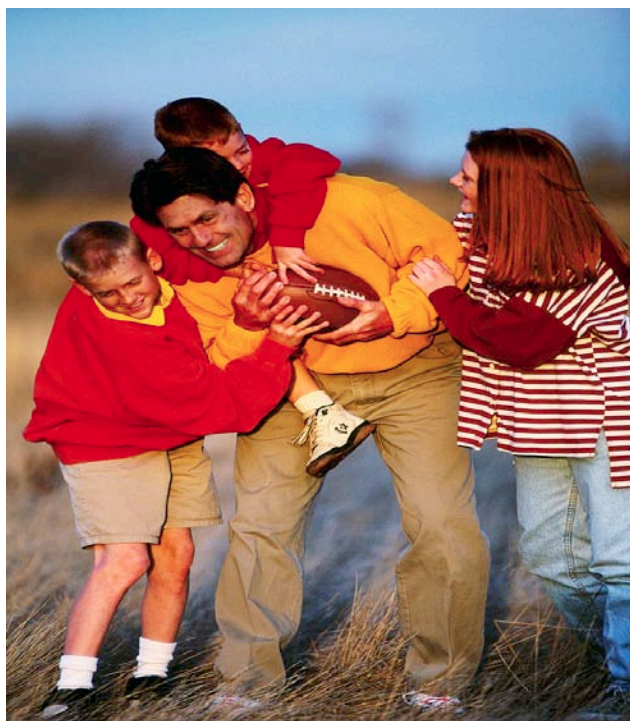
- SCPE network as a reference tool for monitoring early childhood impairments
- Harmonisation and dissemination of best practice and clinical information

## Child & Family Support Services

### Mental Health in Young People with Cerebral Palsy – Improving the Identification of Risk Factors

The main focus of this study is to provide a reliable account of psychological problems experienced by young people with cerebral palsy in the Cork/Kerry region, and is part of collaboration with our SPARCLE partners from the Northern Ireland centre in Belfast. SPARCLE 2 includes an instrument which measures psychological problems in young people: the Strengths and Difficulties questionnaire (SDQ). It is now established that when the SDQ is administered to multiple sources, including the young person's teacher, it provides more reliable information than when administered to a single source.

Data collection from all sources (parent, young person and teacher) is almost complete and a report on the incidence of psychological problems in young people with cerebral palsy will be available by the end of 2010.



### **Coping Strategies in Parents of Young People with Cerebral Palsy**

The aim of this research project is to investigate the coping patterns used by parents of young people with cerebral palsy, and to examine the relationship between parent and young person characteristics, parental stress levels, and the coping strategy employed.

The 28-item Brief COPE questionnaire has been incorporated into SPARCLE 2, and comprises of 14 scales, such as venting, acceptance and self-blame. Data collection will be completed in April 2010 and a report will be available in late 2010.

### **Family Impact of Childhood Disability**

The impact of childhood disability on the family unit is a reasonably well-researched concept, in the domains of internal and external family relationships, material resources, and physical and psychological health. However, little is known on the mechanisms whereby these domains may further affect the quality of life and participation of the disabled young person.

Various aspects of the impact of disability on the family unit can exacerbate the young person's existing environmental barriers, leading to a reduced capability to engage in social roles. This study, in collaboration with our SPARCLE partners from the French centres of Toulouse and Grenoble, has three main objectives:

1. To study the impact of disability on parents of young people with cerebral palsy in Europe;
2. To assess the consequences on the young person's quality of life and participation; and
3. To identify environmental factors associated with these consequences.

## **Effectiveness of Clinical Services**

### **Evaluation of Early Intervention Team (EIT) Initial Assessment Process**

The EIT Initial Assessment is one of the first experiences a family have when referred to our services, and can be a traumatic and difficult time. The team recently decided to conduct a service evaluation and designed an appropriate

questionnaire with the support of the Research Department. Data collection will be completed by March 2010 and a Report will be available in June 2010.



### **Lymed Study**

Lymed external pressure garments are orthotic supports used to improve function in children with movement disorders, through the provision of mechanical (three-dimensional pressure) and sensory (proprioceptive) input.

In conjunction with the primary PTs and OTs in Enable Ireland Cork Children's Services, the Lymed Study aims to investigate the influence of Lymed pressure garments on postural alignment and performance of the tasks involved in daily activities in children with cerebral palsy.

Musculoskeletal and activity capacity outcomes are being measured using a standardized Body Function & Structure Assessment, the Gross Motor Function Measure (GMFM) and the Assisting Hand Assessment (AHA); whilst child and parent perception of Activity Performance is being measured using Goal Attainment Scaling. Further information on the positive and negative experiences of using Lymed garments is also being collected from participants using a Child & Parent Feedback Form.

Data collection is almost complete and data analysis will focus on outcomes in homogenous groups of children, categorized by age, sub-type and distribution of cerebral palsy, and severity of motor impairment. A Report will be available by December 2010.