

Action on Disability

Enable Ireland

The SPARCLE Project

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



SPARCLE 1 South-West Ireland Local Report

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1. Introduction

Enable Ireland became involved in the SPARCLE project through its membership of the Surveillance of Cerebral Palsy in Europe (SCPE) collaborative group. The Research Department at Enable Ireland Cork & Kerry Services is responsible for the management of the Southern Ireland Cerebral Palsy Registry (SICPR), which is a population-based registry of all people born with cerebral palsy (CP) in counties Cork and Kerry. Along with 13 other CP registries in Europe, the SICPR contributes data to the common database annually and participates in epidemiology and public health projects funded by the European Community.

Research projects conducted by the SCPE collaborative group are mainly epidemiological in nature, concerned with matters such as prevalence and causal factors of CP, as well as some important clinical work, for instance the invaluable work on developing a standardized tool for the diagnosis and classification of CP (Gainsborough et al., 2008).

When a number of participating centres expressed an interest in researching important health outcomes such as participation and quality of life, it was decided to use the SCPE network to recruit centres to participate in a multi-centre “Study of **P**ARTicipation and quality of life of **C**hildren with cerebral palsy **L**iving in Europe” (**SPARCLE**).

1.1 Cerebral Palsy

Cerebral palsy describes a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy, and by secondary musculoskeletal problems (Rosenbaum et al. 2007).

The prevalence of cerebral palsy is between 1.5 and 2.2 per 1000 live births (SCPE, 2002) making it the highest cause of physical disability in childhood, and the second highest cause of physical disability in adults (multiple sclerosis is the leading cause) (Doyle et al, 2009). According to SICPR data for the birth years 1990-1999, the prevalence of cerebral palsy in counties Cork and Kerry is 2.2/1000 live births.

CP may be classified into spastic, dyskinetic or ataxic clinical sub-types and unilateral or bilateral distributions (Cans et al 2007). Severity of motor impairment is commonly classified using tools such as the Gross Motor Classification System (GMFCS) (Palisano et al 2007) and the Manual Ability Classification System (MACS) (Eliasson et al 2006).

About 70–80% of the causes of CP are ascribed to prenatal factors, including low gestational age, low birthweight, intrauterine infections, multiple pregnancies, brain malformations, vascular events, chorioamnionitis and metabolic disorders (Reddihough and Collins, 2003; Jarvis et al, 2003). Birth asphyxia accounts for <10%, and postnatal events, such as infections, injuries and metabolic disturbances, comprise the

remaining 10–20%. Prenatal causes are less likely in children born at term (Himmelman et al, 2005). The risk of cerebral palsy is some fivefold higher in twins and about 15-fold higher in triplets than in singletons (Pharoah et al, 2002; Scher et al, 2002; Topp et al, 2004). The risk is even higher for twins whose co-twin had died (Pharoah, 2005). Post-neonatally acquired cerebral palsy is mainly due to infection, both non-CNS and CNS (meningitis/encephalitis) (Cans et al, 2004).

1.2 Description of the SPARCLE Project

International Classification of Functioning, Disability and Health (ICF)

In 2001, the World Health Organisation published the International Classification of Functioning, Disability and Health (ICF). The ICF focuses on the “components of health” rather than on the consequences of disease, which was the primary problem with its predecessor, the International Classification of Impairments, Disability and Handicap (ICIDH – World Health Organisation [WHO] 1980). The ICF provides a standard language and framework for the description of health and health-related states and is the conceptual basis for the definition, measurement and policy formulations for health and disability (WHO, 2002).

The ICF classification encompasses functioning as universal human experience that can be conceptualized and classified at three different planes or dimensions: body function and structure, the performance of personal activities and participation in communal life. The facilitating or restricting role of the environment at each of these planes is recognized and can also be classified (Simeonsson et al. 2003) (Fig 1.1).

In the context of CP, the new ICF model of functioning and disability provides many more “points of entry” for people seeking to enhance the participation of children whose functional wellbeing is at risk (Rosenbaum and Stewart, 2004). Some important applications of the ICF are as follows:

- ◆ Provides a conceptual framework for interventions that aim to enhance a person’s social participation;
- ◆ By encouraging a ‘biopsychosocial’ approach it acts as a bridge between the social and medical models of healthcare;
- ◆ Provides a framework for structuring outcome measures at the levels of body function/structure, activity (execution of a task) and participation (involvement in a life situation) and;
- ◆ Incorporates values such as person-centredness and modern theories of motor learning such as ‘dynamical action theory’ by acknowledging the important contributions of personal and environmental factors towards functioning and health.

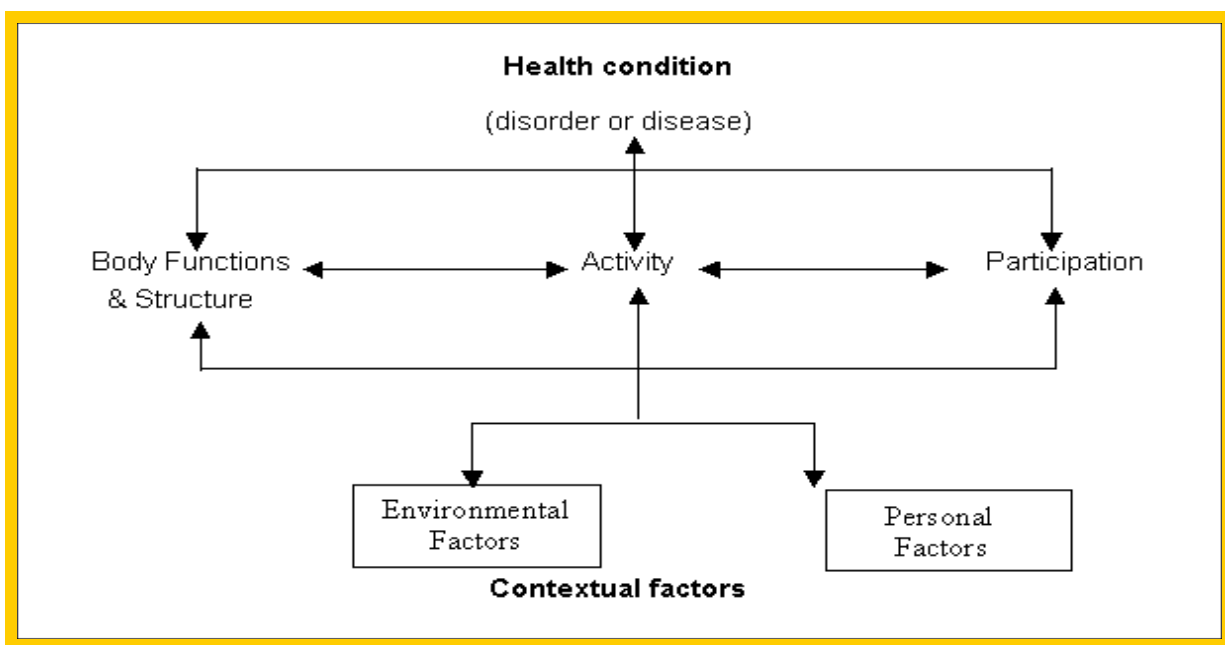


Fig 1.1 Model of disability that is the basis for ICF (WHO, 2001)

Social Model of Disability and the Concepts of Participation and Quality of Life

The ICF takes account of the social model of disability (Oliver, 1990), which considers disability to result from the interaction between individuals and their environment, rather than being a characteristic of the individual. The ICF introduces Environmental Factors into its classification, defining them as the physical, social and attitudinal environment in which people live and conduct their lives. These factors include arrangements for educational provision, social attitudes and norms, legislation on access to buildings, anti-discrimination legislation, transport design, rehabilitation, therapeutic services and assistive technology.

The ICF introduced the concept of Participation, defining it as involvement in life situations, with the following domains: learning and applying knowledge, general tasks and demands, communication, mobility, self-care, domestic life, interpersonal interactions and relationships, major life areas and community, social and civic life. The concept of Participation replaced that of handicap, introduced by the ICIDH, which was rarely used in childhood because it was too medical and did not take sufficient account of the social construction of disability (Shakespeare, 1992).

The WHO defines quality of life (QoL) as an individual's perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns (WHOQOL, 1998). In particular it is a person's self reported, subjective account of their QoL across a number of dimensions. This is sometimes called health related quality of life (HRQoL), with health referring to the WHO definition as a state of complete physical, mental and social wellbeing. HRQoL also distinguishes it from concepts which include factors external to the person such as poverty, living in a police state, and wider environmental factors such as pollution (Berntsson, 2001). HRQoL is also distinct from concepts such as

functional disability or handicap (Gill and Feinstein, 1994) which a decade or more ago were sometimes called QoL.

Research on children's QoL used to rely on their parents' or other proxies' perceptions, but it is now appreciated that the child's view should, where possible, be sought directly rather than being inferred from proxy reports. Measurement of QoL in children has lagged behind that in adults because of concern about the reliability of children's self reports, and the different values they place on particular health states as compared to adults (Jenney et al, 1995; Jenney and Campbell, 1997). Early work developed measures for specific diseases such as cancer (Eiser et al, 1995) and asthma (Christie et al, 1993) for the purpose of contributing to the evaluation of medical interventions, but there is now the need for generic measures which allow comparisons not only across children with different diseases states but also across children with and without impairments.

The SPARCLE Hypothesis

The principal hypothesis in SPARCLE is that children with similar severity of impairment experience variable outcomes, in terms of Participation and QoL, due to variation in Environmental Factors. As some Environmental Factors are consistent across a country but vary between countries, the study design allows the identification of those Environmental Factors which, if improved, yield the greatest benefits for children and their families. Such knowledge is invaluable in informing EU policy in the health, educational and social sectors.

Funding

The source of funding for the SICPR is Enable Ireland Cork/ Kerry services. The European Commission Research Framework 5 Programme-Grant number QLG5-CT-2002-00636 funded the SPARCLE 1 Research Programme.

1.3 Background Information

Description of Population

Eight centres in the SCPE collaborative group joined the SPARCLE project: North England, West Sweden, Northern Ireland, South-East France, South-West Ireland, East Denmark, Central Italy, South-West France. A further centre in North-West Germany joined the study after the start and followed all study protocols; however its sample could not be drawn from a validated population database and was constructed from referrals from clinicians, statutory and voluntary bodies working with children with CP in a defined geographic area (Fig 1.3.).

In order to maximize numbers in the smaller centres, children with dates of birth between 31/7/1991 and 01/04/97 inclusive (i.e. between 7 years 3 months and 12 years 11 months on 1st July 2004) were included with the oldest being approached immediately and the youngest not until near their eighth birthday. As milder cerebral palsy is more common, in the centres with sufficient numbers we sought similar numbers of children at each severity level by grouping children into four strata by walking ability and selecting a random sample from each stratum.

- 1-North England, UK
- 2- West Sweden
- 3-Northern Ireland
- 4- South-East France
- 5-South-West Ireland
- 6-East Denmark
- 7-Central Italy
- 8-South-West France
- 9- North-West Germany

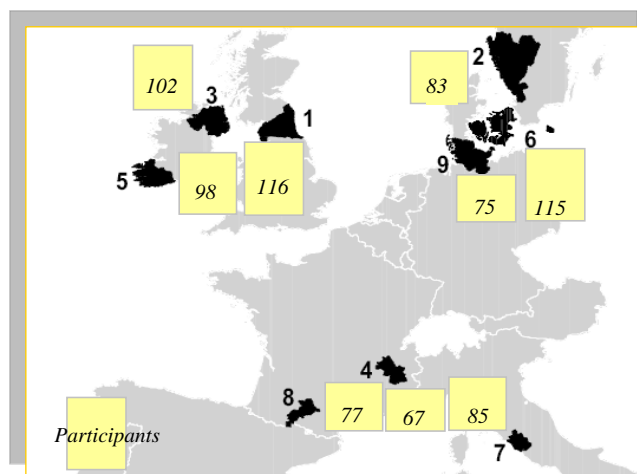


Fig. 1.3 SPARCLE 1 Participating Centres

More males than females comprised the sample in the study, ranging from 64% male in North England to 53% male in West Sweden. South-West Ireland reported a sample of 54% male. The median age ranged from 10.1 (2.8) in North-West Germany to 10.6 (2.4) in South East France. South-West Ireland reported a median age of 10.2 (2.3) in their sample.

Table 1.4. outlines the clinical features of the Total Sparcle 1 participants across all centres with the participants in South-West Ireland centre only. Broadly speaking, South-West Ireland participants are quite similar to their European counterparts. The most striking differences are in the cerebral palsy type whereby 34% and 52% of the total sample comprised of Spastic Unilateral and Spastic Bilateral respectively, whereas the South-West Ireland sample comprised of 50% and 37.8% of Spastic Unilateral and Spastic Bilateral respectively. Also, there is quite a significant difference between the samples on gross motor function, GMFCS IV in particular, the local sample contains 12.1% of its participants at this level, whereas the total sample has 34% of its participants at this level. Finally, there is quite a substantial difference in those participants who have an intellectual disability in South-West Ireland, at almost 44% whereas the European sample stands at 23%.

Table 1.1. Comparison of characteristics of Total Sparcle participants with Irish only participants

Characteristics	Total Sparcle 1 N (%)	Ireland N (%)
<i>Gross Motor Function</i>		
I Walks and climbs stairs, without limitation	257 (31)	37 (37.8)
II Walks with limitations	164 (20)	22 (22.4)
III Walks with assistive devices	139 (17)	11 (11.2)
IV Unable to walk, limited self mobility	113 (34)	12 (12.1)
V Unable to walk, severely limited self mobility	145 (18)	16 (16.3)
<i>Fine Motor Skills</i>		
I Without limitation	281 (34)	45 (45.9)
II Both hands limited to fine skills	205 (25)	33 (33.7)
III Needs help with tasks	131 (16)	
IV Needs help and adapted equipment	91 (11)	20 (20.4)
V Needs total human assistance	110 (13)	

Characteristics	Total Sparcle 1	Ireland
<i>Cerebral Palsy Type</i>		
Spastic Unilateral	279 (34)	49 (50.0)
Spastic Bilateral	423 (52)	37 (37.8)
Dyskinetic	86 (11)	6 (6.1)
Ataxic	29 (4)	6 (6.1)
<i>Intellectual Impairment</i>		
None or Mild (IQ > 70)	385 (47)	54 (55.1)
Moderate or Severe (IQ ≤ 70)	186 (23)	43 (43.9)
<i>Communication</i>		
Normal Speech	463 (57)	66 (67.3)
Difficulty but uses speech	133 (16)	8 (8.2)
Uses non-speech for formal communication	98 (12)	13 (13.1)
No formal speech	123 (15)	11 (11.2)
<i>Vision</i>		
Has useful vision	759 (93%)	96 (91.8%)
Blind or no useful vision	59 (7%)	8 (8.2%)
<i>Hearing</i>		
Does not need hearing aids	799 (98%)	96 (98%)
Needs hearing aids (>70 decibel lost)	18 (2%)	2 (2%)
<i>Seizures</i>		
No seizures in previous year	650 (79%)	82 (83.6%)
Seizures in previous year	167 (20%)	16 (16.4%)
<i>Feeding</i>		
No problems	583 (71%)	73 (74.5%)
Feeds orally with difficulty, or by tube	234 (29%)	25 (25.5%)

Training and visits

Training of the research associates from the different countries together was essential for quality control. They had to speak sufficient English to be able to take advantage of the training workshops, which included instruction in administering questionnaires, engaging children, disability issues and the rationale for the study. Following this, each research associate carried out up to five pilot visits in their own country; they all then met together again for the second training workshop at which difficulties and dilemmas were discussed and clear decisions made about how these should be resolved. Children and families were therefore visited by researchers trained both to administer questionnaires to parents and to engage children for completion of their questionnaires.

The visits usually took place in the child's home, lasting between 90 and 120 minutes. When the parents allowed it and the child agreed, the child completed the QoL instrument in private with the researcher. Children with communication difficulties were included by ensuring assistance from a parent, teacher or therapist as necessary.

It was realised that some children with learning difficulties might not be able to report their QoL. A literature review was undertaken (White-Koning et al, 2005a) to establish how to assess whether such children could self report their QoL and how to interpret proxy responses from a parent or other person who knew the child well. The review showed that studies of assessment of QoL in children have never addressed the issue of self-report in children with intellectual impairment. Based on this review, we introduced a procedure to assess ability to respond to QoL questionnaires and in particular children's understanding and use of Likert scale. The procedure, described by Cummins (1997) for adults with intellectual impairment, was adapted for children (White-Koning et al, 2005b). The child is asked to order 3 real wooden cubes according to size; then to match each cube to a picture scale; then to mention things they dislike, like a bit and like a lot; then to match these to the picture scale. If successful the procedure is attempted with 5 levels.

2. Participation

2.1 Definition and Description of Concept

The ICF defines Participation as involvement in life situations. It is understood to be a consequence of a dynamic interaction between a person and environmental factors rather than a direct consequence of illness. The 9 domains of participation described in the ICF are shown in Figure 2.1.

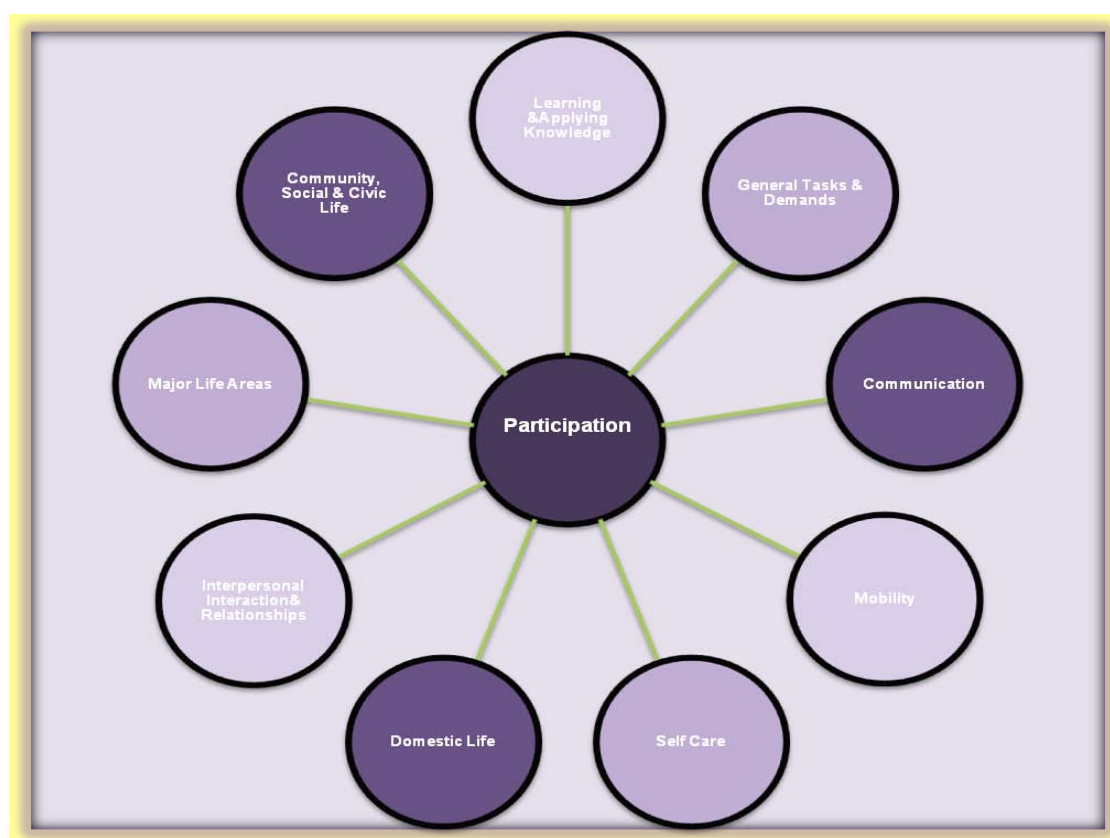


Fig 2.1. ICF Activity & Participation Domains

Disabled children experience difficulty in participating across a wide range of discretionary and non-discretionary domains. Non-discretionary aspects of participation that are essential to daily life, such as eating, sleeping, and toileting, whereas discretionary aspects of participation are what children can choose to do, rather than what is required of them by families and society. For example, whether children are able to achieve discretionary aspects of participation successfully may be mediated by the availability of appropriate assistive technology, environmental modification or personal assistance, and therefore it is particularly for discretionary participation that it is relevant also to indicate degree of assistance and choice.

2.2 Questionnaire Information

In the SPARCLE project we used the **Assessment of Life Habits (Life-H)** questionnaire to measure participation. The Life-H consists of 62 items grouped into 11 domains which cover both daily activities and social roles (Fig 2.2).

The Life-H asks if an activity is achieved, if it is achieved with or without difficulty, and whether aids and adaptations are required. The scoring system scores participation as lower not only if the child has greater difficulty in participation but also if more assistance is needed.

We were interested in participation levels of children, even if this required extensive environmental adaptation. Therefore, our main analysis ignored the questions about assistance, as the availability of required environmental adaptations is measured separately (see Environmental Considerations section).

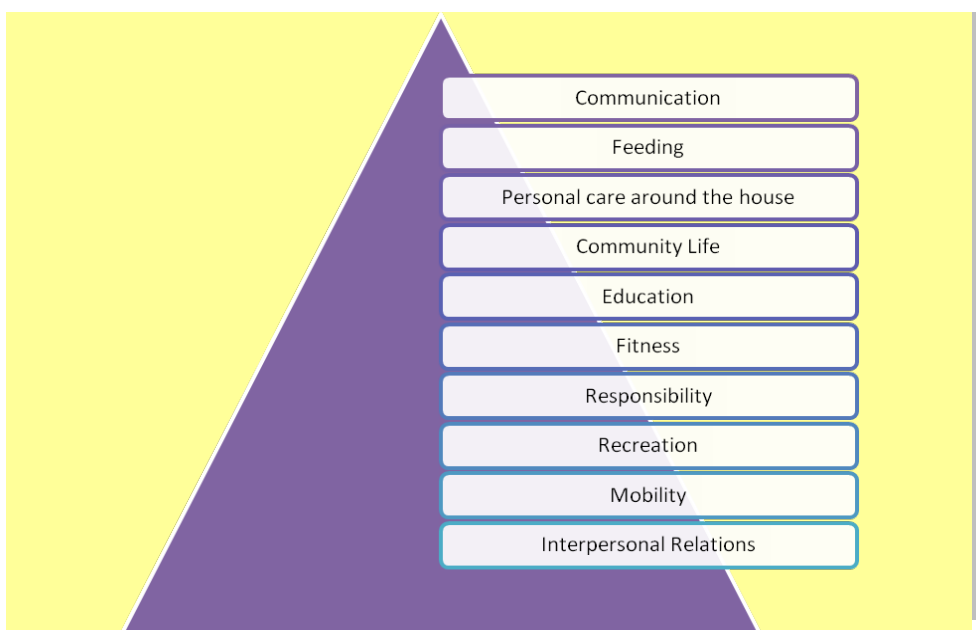


Fig. 2.2 LIFE-H domains

2.3 Results

Statistical Methods

Non-discretionary items were coded as binary variables (with/without difficulty); discretionary items were coded as ordinal variables (performed without difficulty, performed with difficulty, not performed because too difficult). Each Life-H domain was analysed separately. Non-discretionary items were also grouped together to facilitate comparison between countries, as non-discretionary participation may be less subject to cultural variation.

Main Findings

In general, reduced participation was associated with impairment of motor function (walking ability or fine motor skills, or both), intellectual impairment, communication difficulties, and pain.

When non-discretionary items were analysed together, participation was associated with pain, impairment of walking ability, impairment of fine motor skills, and communication limitations/restrictions. There was a clear trend of lower participation being associated with greater impairment of walking ability and more pain, and impaired walking ability was the most important impairment in reducing participation.

None of the socio-demographic factors considered were significantly associated with participation on any domain or with non-discretionary participation. After adjustment for the child's impairment, the type of school attended was not associated with participation on any domain. Table 2.1 and Table 2.2 summarise the level of participation with the characteristics of the sample.

All domains of participation – except relationships - showed significant variation between regions ($P < 0.001$) (tables 2.1 and 2.2). Figure 2.3 shows the mean level of the children's participation in each region, after adjustment for impairment and pain. The average level of participation of children in east Denmark was much higher than that of children in other regions on all domains except relationships, generally by 1-2 SD.

For all domains except relationships, the variation in participation between regions was substantial compared with the overall variation in participation (tables 2.1 and 2.2): it accounted for about a third of the total variation for personal care, communication, home life, school, recreation, and non-discretionary participation (Fig 2.3.) and was even higher for mobility (63%), mealtimes, and health hygiene (51%).

Children in South-West Ireland had consistent levels of participation which were about average when compared with other regions. Highest scores were obtained in the domains of home-life, responsibilities and school-life, with lowest scores in recreation and non-discretionary items grouped together. This latter point is significant, as variation in non-discretionary items is thought to represent the most valid differences between regions (environmental factors), as these aspects of participation are less subject to cultural variation.

Table 2.1 Multilevel, multivariable regression models, relating participation for each LIFE-H domain in daily activities to type and level of impairment and pain of 799 children with cerebral palsy. Figures are odds ratios (95% confidence intervals) unless otherwise stated.

	Mealtimes	Health hygiene	Personal Care	Communication	Home life	Mobility
% Change in log likelihood due to P for heterogeneity between regions	0.16	0.09	0.07	0.14	0.16	0.08
Variance between regions as % of	<0.001	<0.001	<0.001	<0.001	<0.001	<0.001
	0.51	0.51	0.27	0.33	0.36	0.63
Gross motor function						
I Walks and climbs stairs without	1	1	1	NS	1	1
II Walks inside	1.4 (1.0 to 2.1)	2.3 (1.7 to 3.2)	3.1 (2.1 to 4.6)	NS	3.4 (2.2 to 5.3)	4.0 (2.9 to 5.5)
III Walks with assistive devices	1.9 (1.2 to 2.8)	3.7 (2.7 to 5.2)	5.4 (3.6 to 8.3)	NS	14.8 (9.0 to 24)	5.5 (3.9 to 7.8)
IV Unable to walk, limited self-	2.4 (1.5 to 3.9)	5.3 (3.7 to 7.6)	7.9 (4.8 to 13)	NS	17.6 (10 to 31)	5.2 (3.5 to 7.6)
V Unable to walk, severely limited self	3.6 (2.0 to 6.5)	7.7 (5.1 to 12)	9.1 (4.7 to 18)	NS	20.5 (10 to 41)	7.6 (4.8 to 12)
Fine motor skills						
I Without limitation	1	NS	1	1	1	NS
II Both hands limited in fine skills	3.4 (2.3 to 4.8)	NS	3.4 (2.4 to 4.9)	1.9 (1.3 to 2.7)	2.0 (1.3 to 2.9)	NS
III Needs help with tasks	3.2 (2.1 to 4.8)	NS	4.0 (2.6 to 6.2)	2.1 (1.4 to 3.1)	2.6 (1.7 to 4.1)	NS
IV Needs help and adapted	3.5 (2.0 to 6.2)	NS	4.6 (2.5 to 8.5)	2.2 (1.3 to 3.7)	4.3 (2.3 to 8.1)	NS
V Needs total human assistance	5.0 (2.6 to 9.7)	NS	3.1 (1.5 to 6.3)	2.9 (1.7 to 5.0)	4.1 (2.0 to 8.4)	NS
Intellectual impairment						
> 70	1	NA	1	1	1	1
50-70	1.7 (1.2 to 2.3)	NA	1.5 (1.0 to 2.0)	4.3 (3.1 to 5.9)	1.7 (1.1 to 2.4)	1.7 (1.3 to 2.3)
<50	4.8 (3.4 to 6.7)	NA	2.3 (1.6 to 3.3)	14.2 (9.5 to 21)	2.9 (1.9 to 4.5)	1.7 (1.2 to 2.4)
Communication						
Normal speech	NS	1	NS	1	1	1
Difficult but uses speech	NS	2.3 (1.7 to 3.1)	NS	5.2 (3.6 to 7.5)	1.8 (1.2 to 2.7)	1.8 (1.3 to 2.5)
Uses non-speech for formal	NS	1.4 (1.0 to 2.0)	NS	8.8 (5.4 to 14)	1.1 (0.7 to 1.9)	0.9 (0.6 to 1.4)
No formal communication	NS	2.1 (1.5 to 3.1)	NS	31.4 (17 to 57)	2.6 (1.4 to 4.8)	1.8 (1.1 to 3.0)
Type of cerebral palsy						
Spastic unilateral	NS	NS	NS	1	1	NS
Spastic bilateral	NS	NS	NS	1.2 (0.9 to 1.5)	1.9 (1.4 to 2.7)	NS
Dyskinetic	NS	NS	NS	1.5 (1.0 to 2.4)	2.0 (1.2 to 3.4)	NS
Ataxic	NS	NS	NS	4.1 (2.2 to 7.7)	2.0 (1.0 to 4.1)	NS
Feeding						
No problems	1	NS	NS	NS	NS	NS
Orally with difficulty	1.8 (1.3 to 2.6)	NS	NS	NS	NS	NS
Partial or complete feeding by tube	3.5 (2.0 to 6.3)	NS	NS	NS	NS	NS
Vision						
Has useful vision	NS	NS	NS	1	NS	NS
No useful vision	NS	NS	NS	2.8 (1.7 to 4.6)	NS	NS
Parental report of pain						
None of the time	NS	1	1	NS	1	1
Once or twice or a few times	NS	1.4 (1.1 to 1.8)	1.5 (1.2 to 2.1)	NS	1.8 (1.3 to 2.4)	1.5 (1.2 to 2.0)
More often	NS	2.3 (1.7 to 3.1)	2.6 (1.8 to 3.7)	NS	2.4 (1.6 to 3.5)	1.9 (1.4 to 2.6)

Table 2.2 Multilevel, multivariable regression models, relating participation for each LIFE-H domain in social roles and non-discretionary to type and level of impairment and pain of children with cerebral palsy. Figures are odds ratios (95% confidence intervals) unless otherwise stated.

	Responsibility	Relationship	School	Recreation	Non-discretionary
% Change in log likelihood due to impairment and P for heterogeneity between regions	13% <0.001	5% 0.009	4% <0.001	8% <0.001	4% <0.001
Variance between regions as % of total residue	15%	5%	34%	35%	38%
Gross motor function					
I Walks and climbs stairs without limitation	NS	NS	1.0	1.0	1.0
II Walks inside	NS	NS	2.3 (1.6 to 3.4)	2.5 (1.7 to 3.7)	3.4 (2.3 to 5.1)
III Walks with assistive devices	NS	NS	3.0 (2.0 to 4.4)	3.6 (2.3 to 5.5)	6.4 (4.1 to 10)
IV Unable to walk, limited self-mobility	NS	NS	3.3 (2.1 to 5.3)	2.5 (1.5 to 4.2)	9.6 (5.5 to 17)
V Unable to walk, severely limited self mobility	NS	NS	3.5 (2.1 to 5.8)	2.6 (1.3 to 5.1)	9.6 (4.5 to 20)
Fine motor skills					
I Without limitation	1.0	NS	NS	1.0	1.0
II Both hands limited in fine skills	2.4 (1.6 to 3.6)	NS	NS	1.9 (1.3 to 2.7)	2.5 (1.7 to 3.7)
III Needs help with tasks	2.6 (1.6 to 4.2)	NS	NS	2.8 (1.8 to 4.4)	3.3 (2.1 to 5.2)
IV Needs help and adapted equipment	1.9 (1.0 to 3.6)	NS	NS	2.7 (1.4 to 5.1)	4.0 (2.0 to 8.2)
V Needs total human assistance	3.1 (1.5 to 6.3)	NS	NS	4.0 (1.9 to 8.5)	2.7 (1.2 to 6.3)
Intellectual impairment					
> 70	1.0	1.0	1.0	1.0	NS
50-70	6.3 (4.2 to 9.4)	1.9 (0.8 to 4.2)	1.6 (1.1 to 2.2)	2.3 (1.6 to 3.2)	NS
<50	26.2 (15 to 44)	4.6 (1.7 to 12)	2.3 (1.5 to 3.5)	5.6 (3.6 to 8.7)	NS
Communication					
Normal speech	1.0	1.0	1.0	1.0	1.0
Difficult but uses speech	2.5 (1.5 to 3.9)	3.3 (1.3 to 8.2)	2.0 (1.4 to 3.0)	1.8 (1.2 to 2.7)	3.0 (2.0 to 4.6)
Uses non-speech for formal communication	4.4 (2.3 to 8.2)	2.4 (0.8 to 6.9)	1.4 (0.8 to 2.3)	1.3 (0.8 to 2.2)	1.6 (1.0 to 2.8)
No formal communication	16.0 (7.4 to 35)	7.9 (2.6 to 24)	2.9 (1.6 to 5.4)	2.7 (1.5 to 5.1)	2.4 (1.3 to 4.4)
Type of cerebral palsy					
Spastic unilateral	NS	NS	NS	NS	NS
Spastic bilateral	NS	NS	NS	NS	NS
Dyskinetic	NS	NS	NS	NS	NS
Ataxic	NS	NS	NS	NS	NS
Feeding					
No problems	NS	NS	NS	NS	NS
Orally with difficulty	NS	NS	NS	NS	NS
Partial or complete feeding by tube	NS	NS	NS	NS	NS
Vision					
Has useful vision	1.0	NS	NS	1.0	NS
No useful vision	5.2 (2.5 to 11)	NS	NS	3.0 (1.8 to 5.1)	NS
Parental report of frequency of child pain in previous four weeks					
None of the time	NS	1.0	NS	1.0	1.0
Once or twice or a few times	NS	1.8 (0.9 to 3.6)	NS	1.6 (1.2 to 2.2)	1.6 (1.1 to 2.2)
More often	NS	5.2 (2.2 to 12)	NS	2.5 (1.7 to 3.6)	2.7 (1.8 to 4.1)



Figure 2.3 Mean level (with 95% confidence intervals) of children's participation in each region, adjusted for impairment and pain. Higher scores indicate higher participation. Mean adjusted participation is zero and each unit is 1 SD of residual variation between children.

3. Frequency of Participation

3.1 Definition and Description of Concept

This aspect of the study was developed by the SPARCLE group in order to acknowledge the importance of frequency of participation in a social context, as opposed to just measuring whether and with how much difficulty participation is achieved. The importance of frequency of participation is emphasised by McConachie et al (2006), who bridge the gap between the ICF components of 'Activity' and 'Participation', by focusing on the 'Activity Performance' qualifier. Activity performance describes what an individual does in their real lives, which is influenced by the environment and personal factors such as choice, and it is performance in terms of frequency which is fundamental to the measurement of participation, although additional information (level of choice, enjoyment, assistance required) is required in order to make meaningful interpretation of frequency differences

3.2 Questionnaire Information

The Life-H questionnaire was used as a conceptual and content framework from which to develop the Frequency of Participation Questionnaire (FPQ). The FPQ has 14 questions, each with six response options for different frequencies (from never to a few times a week). Parents completed the questionnaire. The FPQ was also administered to the general population to obtain normative data.

3.3 Results

Statistical Methods

Responses to each FPQ question were dichotomised into "high" or "low" participation at the median of the combined general and CP population.

For children with CP, multivariable logistic regression was used to assess whether high/low participation on each item was related to age, gender, type and level of impairment, pain, socio-economic and demographic variables and region.

For children in the general population, multivariable logistic regression was used to assess how high/low participation on each item was related to their region of residence, after adjusting for age, gender and family affluence score.

Frequency of Participation of children with CP at each GMFCS level was compared with that of children in the general population by constructing a dummy variable with one category for each level of GMFCS and assignment of children in the general population to the reference category.

Multivariable logistic regression was then used to assess how high/low participation on each item was related to GMFCS, after adjusting for age, gender and region. A similar logistic regression was performed to compare the participation of children with CP at each level of IQ with that of children in the general population. Finally,

multivariable logistic regression was used to compare the participation of children with CP with that of children in the general population within each region, after adjusting for age and gender.

Main Findings

When comparing the CP population and the general population (Table 3.1) there were both positive and negative findings. From a positive perspective, doing crafts was the only area where children with CP participated as often as children from the general populations in all regions.

Figure 3.1. compares the frequency of participation with walking ability (GMFCS) and IQ. It shows that children with mild to moderate motor or intellectual impairment used a computer and played non-sporting games more often than children in the general population. Children with CP of all severities participated as much or more than children from the general population in pursuits organised by their school.

From a negative viewpoint, children with CP in most regions participated less frequently than children from the general populations in playing sports, watching sports events, eating out, shopping, helping with housework, and joining in tourist pursuits and community groups.

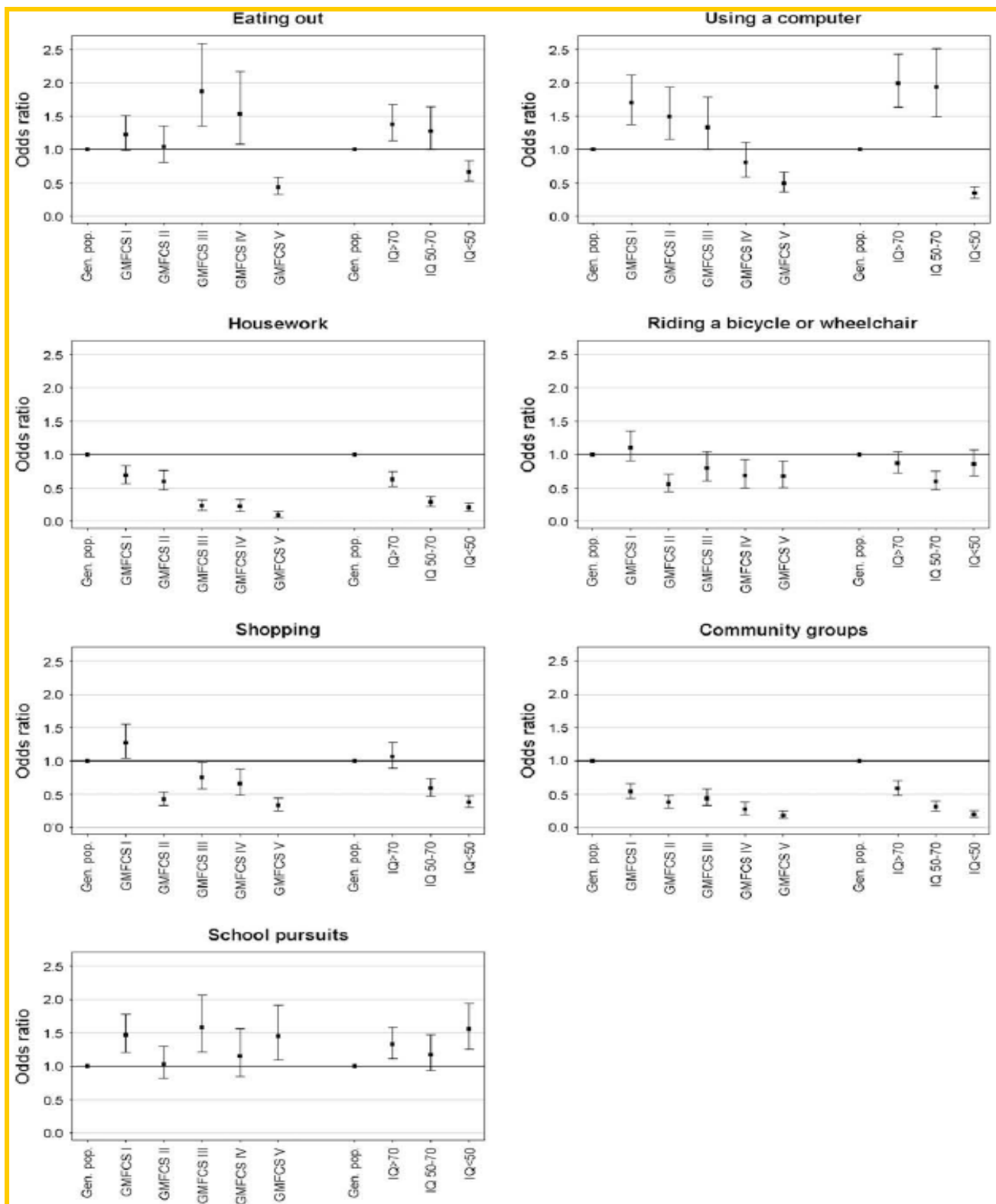
Within the CP population, a number of interesting trends were observed. Frequency of Participation decreased with increasing severity of motor and intellectual impairment in most areas of everyday life. Older children more often used a computer; whilst younger children more often participated in craft pursuits, sport or outdoor games, community groups, cycling or housework. Boys more often watched sport events, played non-sporting games or used a bicycle or wheelchair for fun, whereas girls more often participated in craft pursuits or shopping. After adjustment for severity of impairment, children in special schools or special classes participated less frequently in eating out, shopping, playing sports and watching sport events compared with children in mainstream schools. The presence of pain in the previous month was associated with lower participation in areas of community groups and those arranged by the school.

When comparing the CP population by European region, Denmark was the only country where children with CP participated as often as or more than children from the general population in the same country in most domains assessed. In addition, children with CP in North-West Germany, North England, West Sweden and central Italy participated as often as children from the general populations in some domains.

Activity	Group of children	>Once/ week	Once/ week	Once/ fortnight	Once/ month	<Once/ month	Never	Unknown
1. Eating out	With CP:	5%	15%	16%	30%	26%	7%	1%
	General population:	2%	12%	16%	32%	32%	5%	<1%
2. Relaxing leisure pursuits	With CP:	90%	6%	1%	<1%	1%	1%	1%
	General population:	93%	4%	1%	1%	1%	<1%	<1%

3. Using a computer	With CP:	60%	17%	3%	2%	4%	13%	1%
	General population:	50%	23%	9%	6%	6%	5%	1%
4. Housework	With CP:	26%	18%	6%	6%	8%	34%	1%
	General population:	50%	28%	7%	6%	6%	4%	<1%
5. Riding a bicycle or wheelchair	With CP:	43%	15%	5%	6%	6%	23%	1%
	General population:	53%	18%	8%	7%	9%	4%	1%
6. Shopping	With CP:	15%	23%	8%	8%	9%	37%	1%
	General population:	19%	29%	14%	12%	14%	12%	1%
7. Community groups	With CP:	21%	21%	2%	3%	5%	48%	1%
	General population:	34%	23%	2%	3%	7%	30%	1%
8. School pursuits	With CP:	6%	10%	6%	21%	50%	6%	2%
	General population:	7%	9%	3%	18%	54%	6%	4%
9. Sports	With CP:	33%	25%	4%	5%	8%	24%	1%
	General population:	66%	21%	3%	2%	4%	5%	1%
10. Non-sporting games	With CP:	57%	13%	5%	4%	3%	17%	1%
	General population:	63%	19%	7%	4%	4%	3%	1%
11. Watching sports	With CP:	2%	8%	4%	9%	22%	54%	1%
	General population:	17%	14%	4%	9%	25%	31%	1%
12. Craft pursuits	With CP:	31%	26%	5%	4%	7%	25%	1%
	General population:	43%	27%	6%	5%	9%	11%	1%
13. Watching cultural events	With CP:	<1%	2%	6%	32%	43%	16%	1%
	General population:	1%	3%	8%	34%	48%	5%	1%
		>Once/ month	Once/ 3 months	Once/ 6 months	Once/ year	<Once/ year	Never	Unknown
14. Tourist pursuits	With CP:	13%	18%	24%	29%	9%	5%	2%
	General population:	9%	23%	24%	21%	17%	5%	1%

Table 3.1 Frequency of participation in areas of everyday life of children with CP & general population



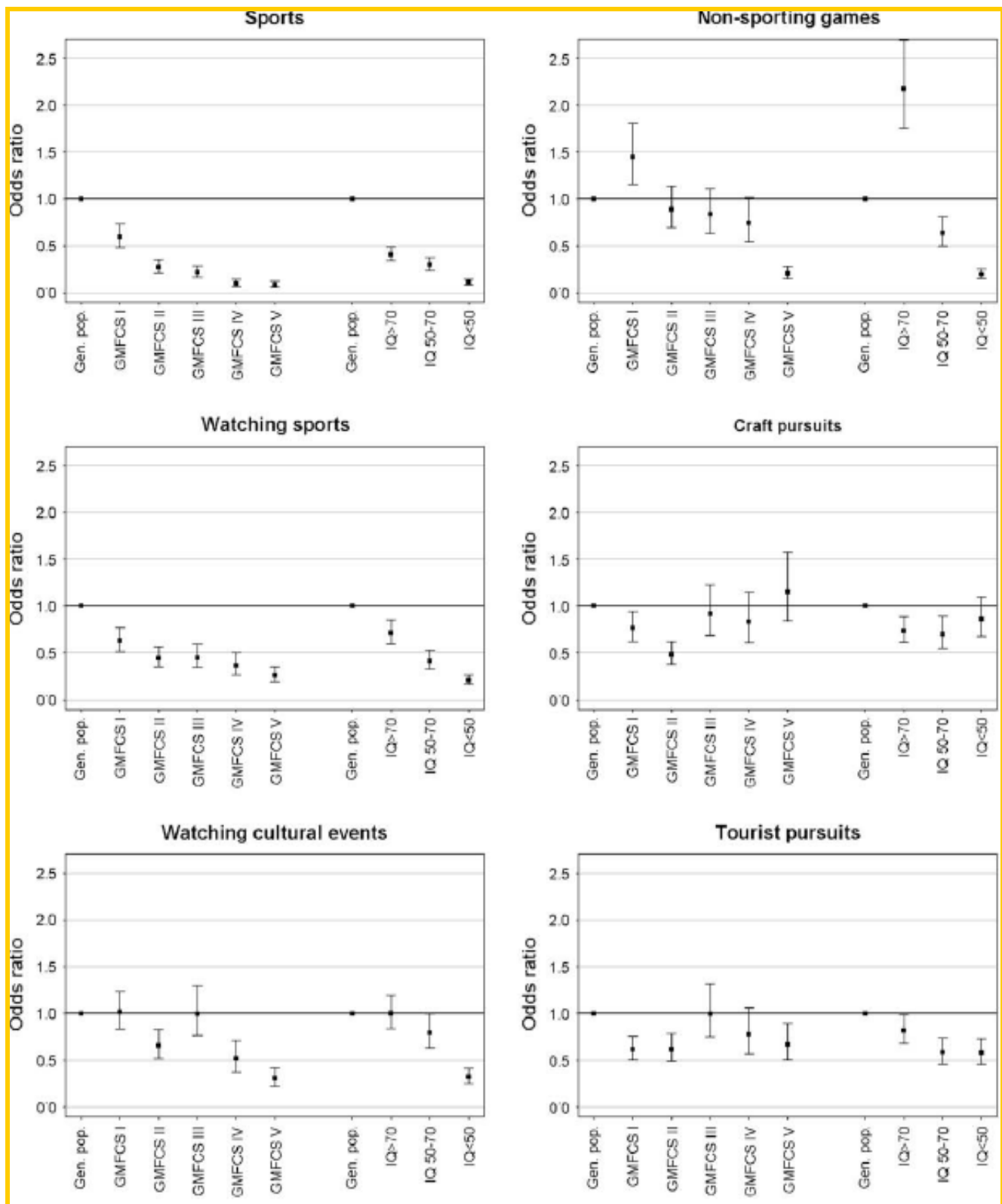


Figure 3.1 Frequency of high participation in 13 areas of everyday life, by level of walking ability (GMFCS) and IQ. The figures show odds ratios and 95% confidence intervals for high participation in children with various levels of severity of CP compared with children in the general population, adjusted for age, gender and region. GMFCS and IQ were analysed separately.

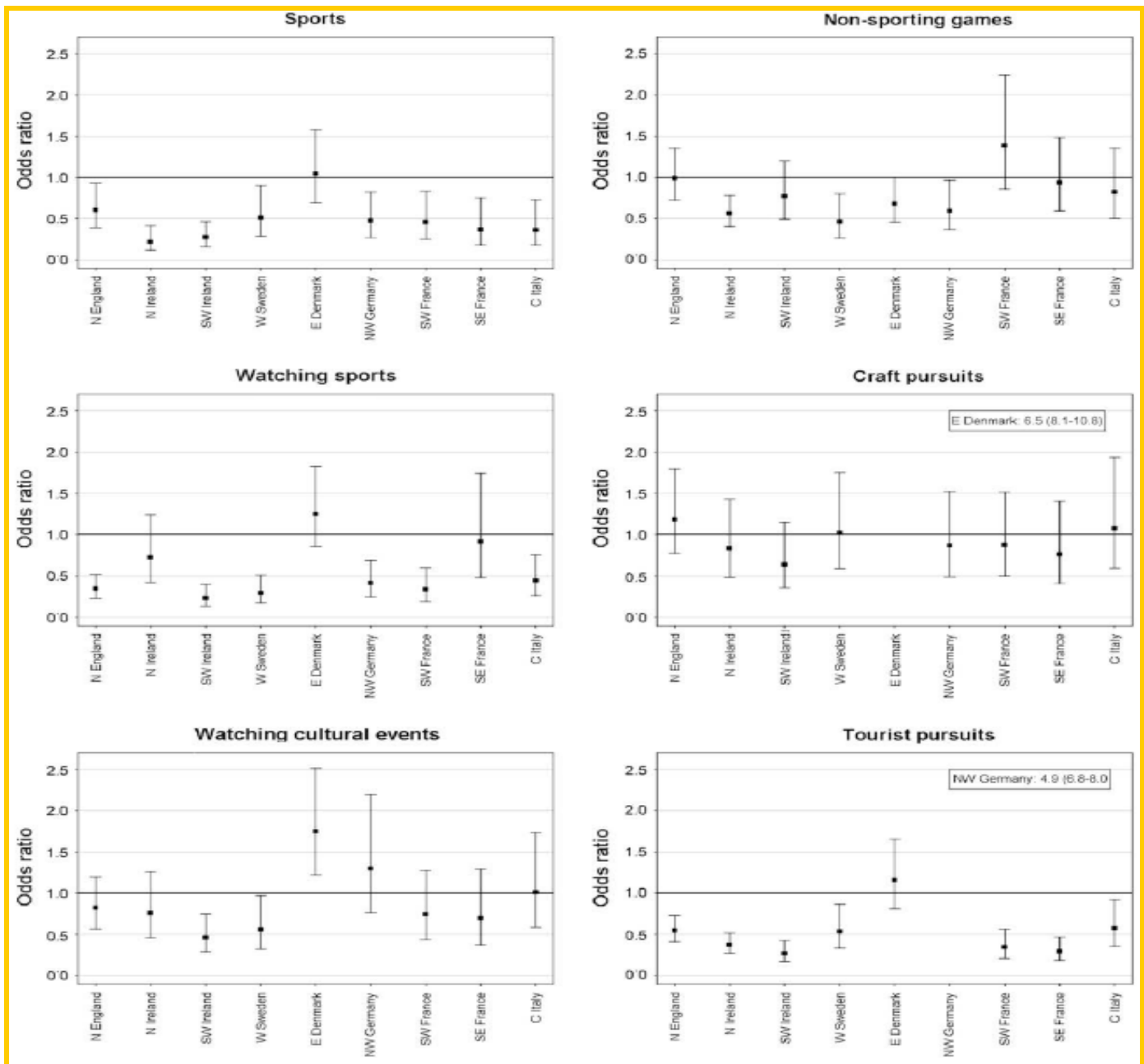


Figure 3.2. Frequency of high participation in 13 areas of everyday life, by region. The figures show odds ratios and 95% confidence intervals for high participation in children with CP compared with children in the general population, adjusted for age and gender.

4. Quality of Life

4.1 Definition and Description of Concept

The UN Convention on the Rights of the Child (UNCRC), to which all European Union countries are signatories, states that children's views must be taken into account in all matters concerning them (article 12) and that disabled children are entitled to a "full and decent life" (article 23). Article 7 of the 2006 UN Convention on the Rights of Persons with Disabilities (UNCRPD) emphasises the right of disabled children to express their views.

QoL is a key outcome for the individual child and is what society wants for all children. QoL is defined by WHO as "an individual's perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns". QoL is therefore subjective and so must be reported by the individual concerned whenever possible.

There is much supportive evidence that children can self-report QoL reliably, provided their emotional development, cognitive ability, and reading level are taken into account. However it may not be possible to obtain reliable information from children with severe intellectual impairments or significant communication problems and the use of parental proxies for the assessment of QoL in such children are necessary.

(a) Child Self-reported Quality of Life

4.2 (a) Questionnaire Information

Self-reported QoL in the previous week was assessed using the KIDSCREEN questionnaire, a modern instrument with excellent psychometric properties, which uses questions derived from focus-group work with children across Europe to assess the QoL of children and young people. The ten domains of QoL measured by KIDSCREEN are shown in Table 4.1. Comparative data for children in the general population were available from the developers of KIDSCREEN for children aged 8–12 years in five countries in the SPARCLE study: Ireland, France, Germany, Sweden and the UK.

4.3 (a) Results

Statistical Methods

Regression models were used to relate each domain of children's QoL to socio-demographic characteristics, pain, and impairments. All models were adjusted for region (children with CP) or country (general population).

We first assessed how QoL of children in the general population varied with socio-demographic characteristics. Next, we assessed how QoL of children with CP varied with impairments and pain. For each KIDSCREEN domain, we used regression to relate QoL to pain, impairments, and the additional sociodemographic characteristics available only for disabled children (type of school, siblings, and area of domicile), considering each factor separately. We adjusted these regressions for the sex and age of the child, family structure, and parental employment and educational qualifications using the relations estimated from the general population

(external adjustment using off sets), and we made additional internal adjustment for region. Final multivariable models were developed and were checked for interactions, influence and sensitivity analyses were undertaken, and plots of residuals were examined.

To investigate whether pain mediated a relation between impairments and QoL, we used logistic regression to relate pain to impairments, adjusting for region.

Finally, we compared QoL of children with CP with that of children in the general population of the five countries in SPARCLE for which general population data were available. For each domain, multivariable regression was used to compare QoL in children with CP with that in the general population, both unadjusted and adjusted for country and for socio-demographic characteristics that were significant in the general population.

Main Findings

500 (61%) of the 818 children in the SPARCLE study self-reported their QoL. The QoL of children with CP was, on average, similar to that of children of the same age in the general population in all domains except for the school environment, in which it was better. However, sensitivity analysis indicated that there might be little difference in the school domain, and that autonomy might be lower in the disabled children than in the general population.

Impairments were not significantly associated with QoL on six domains: psychological wellbeing, self-perception, social support and peers, school environment, financial resources, and social acceptance. Specific impairments were associated with poorer QoL for only four domains. Poorer walking ability was associated with poorer physical wellbeing, intellectual impairment was associated with poorer moods and emotions and with less autonomy; and speech difficulty was associated with poorer relationships with parents.

Pain was significantly associated with poorer QoL for these four domains and also for the self-perception and school domains, although children who reported pain in the previous week tended to report a lower QoL on all ten domains.

Table 4.1 Description of each KIDSCREEN domain and the associations of QoL in each domain with sociodemographic characteristics for children in the general population

	Measured perceptions of these aspects of life	Groups that reported poorer QoL compared with other children
Physical wellbeing (5)	Physical activity, energy, and fitness	Girls, older children, and children whose parents had a lower employment status
Psychological wellbeing (5)	Positive emotions and satisfaction with life	Older children, children living with one parent, and children whose parents had higher educational status

Moods and emotions (7)	Negative moods, boredom, and stress	Girls and children whose parents had a lower employment status
Self-perception (5)	Self, bodily appearance, and body image	Girls and older children
Autonomy (5)	Freedom of choice and self-determination in leisure time	Children whose parents had higher educational qualifications
Relationships with parents (6)	Interactions and relationships with parents and the socioemotional atmosphere at home	Older children and children whose parents had higher educational qualifications
Social support and peers (6)	Social support available from friends and peers	Boys
School environment (6)	Learning and feelings about school and teachers	Boys, older children and children living with one parent
Financial resources (3)	Adequacy of pocket money relative to peers	Younger children and children living with one parent
Social acceptance	Social acceptance of rejection by peers, including bullying	Children living with one parent and children whose parents had lower educational qualifications

Table 4.2 Percentage of variation explained by univariable and multivariable linear regression models relating KIDSCREEN domains to impairment and pain in children with cerebral palsy.

	r2 impairment*	r2 pain*	r2 region*	r2 total**
Physical wellbeing	2%	7%	8%	17%
Moods and emotions	3%	4%	3%	9%
Self-perception	NA	3%	6%	8%
Autonomy	2%	6%	8%	14%
Relationships with parents	3%	3%	6%	11%
School environment	6%	6%	8%	11%

NA=not applicable because QoL on this domain was not significantly associated with impairment.

*r2 is % variance explained by impairment, pain, and region in separate univariable models.

**r2 is % variance explained jointly by impairment, pain and region in multivariable models

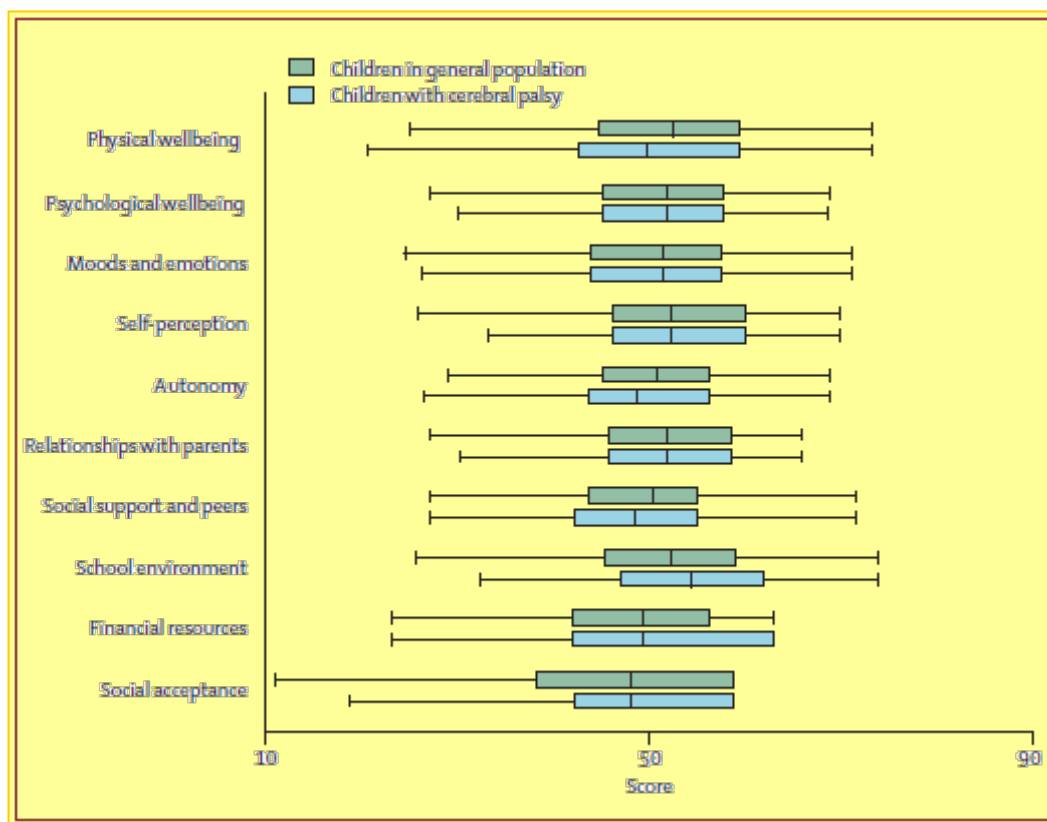


Figure 4.1 Box and whisker plots of KIDSCREEN quality of life scores by domain for children with cerebral palsy and in the general population

(b) Parent Proxy-reported Quality of Life

4.2 (b) Questionnaire Information

Because one third of the children were unable to self-report, valid comparisons of QoL across the spectrum of children with CP must be based on proxy reports for the whole population. The KIDSCREEN questionnaire has a parent/proxy version with 52 items covering the same 10 dimensions as the child version.

4.3 (b) Results

Statistical Methods

To determine the factors associated with poor QoL, scores for each domain were dichotomized by using the lowest quartile as a cutoff point. Our clinical decision to focus on the children whose QoL was lowest led to the use of logistic regression rather than linear regression.

For each domain, we performed a multivariate, multilevel (clustering the children within the regions), logistic regression analysis. Children's impairments and pain, family structure, socioeconomic status, and Parenting Stress Index scores were included as covariates in the initial multivariate model if they were related to QoL scores at the 20% significance level in the univariate multilevel analysis. A backward procedure was then used to remove variables from the model (1% significance level).

Regression analyses excluded children who had missing values for any of the variables considered in the initial model. We tested for interactions between impairment and other variables in the final model. Models were reanalyzed by excluding the most influential observations to check stability.

Main Findings

Children with severely impaired motor function were more likely to have poor QoL in the physical well-being and autonomy domains. Similarly, children with lower IQ were at higher risk of having a poor QoL in the social support domain. However, greater severity of impairment was not always associated with poorer QoL.

The risk of poor QoL in terms of social acceptance and school environment decreased with increasing severity of gross motor impairment. Similarly, children with an IQ of <50 were less likely to have poor QoL in the moods and emotions and self-perception domains than were other children.

Among the children's associated difficulties, parents tended to perceive children suffering from seizures more than once per month as having significantly poorer QoL in the social support domain. Pain was associated with poor QoL in 3 domains, namely, physical well-being, psychological well-being, and self-perception.

Children whose parents had high educational qualifications had increased risk of poor QoL in the parental relations domain, whereas those living in single-parent households had poor QoL in the mood and emotions domain. Parents with higher levels of stress were more likely to report poor QoL for their child in all domains.

Table 4.3 Adjusted Odds Ratio for Covariates Affecting Parents' Reports of Their Children's QoL in Each Domain

Domains	Covariates		OR	95%CI	p
Physical well-being (n=761)	Gross motor function	(I) walks, climbs stairs	1		<0.001
		(II) walks inside	2.2	1.2-4.2	
		(III) walks with limitation	3.4	1.8-6.5	
		(IV) moving limited	4.7	2.5-9.0	
		(V) moving severely limited	12.4	6.5-23.5	
	Pain/discomfort	none	1		<0.001
		moderate	2.5	1.4-4.3	
		severe	5.2	2.7-9.7	
	Parental Stress Index	normal	1		<0.001
		borderline abnormally high	1.9 3.5	1.1-3.4 2.1-6.0	
Psychological well-being (n=754)	Pain/discomfort	none	1		<0.001
		moderate	1.6	1.02-2.4	
		severe	2.9	1.7-4.9	
	Parental Stress Index	normal	1		<0.001
		borderline abnormally high	2.6 5.6	1.6-4.2 3.6-8.9	
Mood and Emotions (n=744)	IQ level	>70	1		<0.001
		50-70	0.7	0.4-1.1	
		<50	0.3	0.2-0.5	
	Family structure	married /living w. partner	1		0.01
		single	1.6	1.1-2.4	
	Parental Stress Index	normal	1		<0.001
		borderline	3.1	1.9-4.9	
		abnormally high	6.9	4.1-11.4	
	IQ level	>70	1		<0.001
		50-70	0.6	0.4-0.9	
		<50	0.3	0.2-0.5	
	Pain/discomfort	none	1		<0.001
		moderate	1.8	1.2-2.7	
		severe	2.7	1.6-4.4	
	Parental Stress Index	normal	1		<0.001
		borderline abnormally high	1.8 2.4	1.2-2.6 1.6-3.7	
Autonomy (n=750)	Gross motor function	(I) walks, climbs stairs	1		<0.001
		(II) walks inside	0.8	0.5-1.3	
		(III) walks with limitation	2.1	1.3-3.3	
		(IV) moving limited	1.6	0.9-2.6	
		(V) moving severely limited	2.6	1.6-4.3	
	Parental Stress Index	normal	1		<0.001
		borderline	1.7	1.1-2.6	
		abnormally high	3.2	2.1-4.9	
	Parental qualification	none/lowest qualification	1		<0.001
		below university university degree	1.6 4.1	0.99-2.5 2.3-7.4	
Parent relations and home life (n=753)	Parental Stress Index	normal	1		<0.001

		borderline	3.1	1.9-5.0	
		abnormally high	7.0	4.3-11.3	
Financial resources (n=630)	Parental Stress Index	normal	1		<0.001
		borderline	1.8	1.1-2.7	
		abnormally high	3.3	2.1-5.4	
Social support and Peers (n=728)	Seizures	no seizures last year	1		<0.01
		seizures <1/month last y.	1.5	0.8-2.9	
		seizures >1/month last y.	2.3	1.3-4.1	
	IQ level	>70	1		<0.001
		50-70	1.7	1.05-2.8	
		<50	2.7	1.6-4.3	
	Parental Stress Index	normal	1		<0.001
		borderline	1.9	1.2-3.2	
		abnormally high	3.3	2.0-5.4	
School environment (n=751)	Gross motor function	(I) walks, climbs stairs	1		<0.001
		(II) walks inside	0.6	0.3-0.9	
		(III) walks with limitation	0.4	0.3-0.7	
		(IV) moving limited	0.3	0.1-0.5	
		(V) moving severely limited	0.4	0.2-0.8	
	Parental Stress Index	normal	1		<0.001
		borderline	2.6	1.6-4.1	
		abnormally high	4.5	2.8-7.1	
Social acceptance (bullying) (n=744)	Gross motor function	(I) walks, climbs stairs	1		<0.001
		(II) walks inside	0.7	0.5-1.2	
		(III) walks with limitation	0.4	0.2-0.7	
		(IV) moving limited	0.2	0.1-0.4	
		(V) moving severely limited	0.1	0.1-0.2	
	Parental Stress Index	normal	1		<0.001
		borderline	1.8	1.2-2.8	
		abnormally high	2.7	1.7-4.3	

5. Pain

5.1 Definition and Description of Concept

Pain is common in children with neuromuscular and neurodevelopmental problems such as spina bifida, juvenile arthritis and CP (Parkinson et al, in press; Houlihan et al, 2004). Children with CP are exposed to many types of pain. Acute and chronic pain can be experienced through increased frequency of medical procedures, an increased exposure to accidental pain (falls), pain of gastrointestinal origin (reflux and constipation), muscle spasms, and chronic pain as a consequence of secondary musculoskeletal problems which occur with growth, such as joint subluxations/dislocations and spinal scoliosis.

Using age appropriate instruments (Zonneveld, 1997), children rather than their parents should report the child's pain whenever possible. In children with CP, many of whom are unable to reliably self-report due to immaturity, intellectual impairments and/or communication limitations/restrictions, pain is increasingly recognized as being difficult to assess, yet hugely important in terms of its impact on physical functioning, participation and quality of life (Russo et al., 2008; Castle, Imms and Howie, 2007). Therefore, aspects of pain requiring assessment are type, location, severity and frequency, as well as pain-related interference with biopsychosocial functioning.

5.2 Questionnaire Information

The two items from the 'Bodily Pain and Discomfort' scale of the Child Health Questionnaire (parent-reported CHQ-PF50 and child-reported CHQ-CF87) (Landgraf et al, 1999) were used to capture pain. Each question has a 6 point response scale asking about bodily pain or discomfort experienced over the preceding four weeks: one focusing on frequency of pain (none of the time; once or twice; a few times; fairly often; very often; every or almost every day); and the other on severity (none; very mild; mild; moderate; severe; very severe).

We asked parents to report their child's pain so that we had a common metric for all children. However, we also sought where possible a child's own report of their pain over the past week; this time period was chosen because the children were also asked about their quality of life in the previous week.

5.3 Results

Statistical Methods

The six possible responses for frequency and severity of pain were treated as ordinal variables and used proportional odds ordinal regression to relate them to the child's impairments and socio-demographic characteristics. These models allowed the estimation of odds ratios (ORs) and their 95% confidence intervals comparing the odds of pain among children in a specific group (e.g. defined by type and severity of impairment) with the odds of pain in a reference group (e.g. the least impaired children). All models were stratified by region.

Univariate analyses were performed, relating frequency and severity of pain to each type of impairment and each socio-demographic characteristic in turn. Forwards stepwise regression, followed by a backwards step, was then used to select covariates to include in a multivariable model.

Goodness-of-fit of the final multivariable models was assessed by calculating a fit statistic comparing the observed and expected number of children with pain in ten quantiles of risk of pain.²⁸ Sensitivity analyses were performed excluding children with the largest residuals.

Main Findings

Parent-reported pain was available for 806 children and 490 children reported their own pain. Self-reporting children tended to be less severely impaired than other children in terms of walking ability, bimanual fine motor function, feeding and communication ability and IQ.

Table 5.1 summarises the severity and frequency of self-reported and parent-reported pain, both overall and by walking ability.

Although the distribution of self-reported pain varied little between children of different walking ability, parents tended to report more frequent and more severe pain if their child was more severely impaired, in particular if the child could not walk.

56% of self-reporting children experienced some pain in the previous week and 72% of parents of all children (i.e. those who could and could not self-report) said that their child had some pain in the previous four weeks.

In the univariable analysis, frequency and severity of self-reported pain did not vary significantly with impairment, but younger children and those living in a village or the countryside tended to report less frequent and less severe pain (Table 5.1). As younger children were more likely than older children to live in a village or the countryside, only frequency of pain remained significantly ($p<0.01$) associated with age in multivariable analysis (Table 5.2).

In the univariable analysis, parents tended to report a higher frequency and severity of pain if the child was more severely impaired in terms of walking ability, hand function, seizures, feeding and communication difficulties, intellect and CP sub-type or if the child was a girl or attended a special school or a special unit in a mainstream school (Table 5.1). Parents also tended to report more child pain if only one parent worked part-time or neither parent worked. In multivariable analysis (Table 5.2), only walking ability, seizures and parental unemployment were significantly associated with frequency of pain.

Table 5.1 Odds ratios (OR) from univariable ordinal regression models, relating child pain to impairment and socio-demographic characteristics. All models were stratified by region and used weights that allowed for the sampling design and for non-response. Children with missing data on pain outcomes were excluded.

	Self reported (n=490) pain in previous week							Parent - reported (n=806) pain in previous 4 weeks								
Impairments	No.	%	OR*	Frequency 95% CI	p	OR	Severity 95%CI	p	No	%	OR*	Frequency 95% CI	p	OR	Severity 95%CI	p
					0.68			0.54					<0.0001			<0.0001
Gross motor function																
I Walks without limitation	215	44	1.0			1.0			256	32	1.0			1.0		
II Walks with limitation	118	24	0.8	(0.4 to 1.4)		1.0	(0.6 to 1.7)		164	20	1.7	(1.0 to 2.7)		1.5	(1.0 to 2.3)	
III Walks with assistive devices	89	18	0.9	(0.5 to 1.5)		1.1	(0.7 to 1.7)		132	16	1.3	(0.8 to 2.1)		1.3	(0.8 to 2.1)	
IV Unable to walk, limited self-mobility	49	10	1.5	(0.7 to 3.2)		1.9	(0.9 to 4.1)		112	14	2.2	(1.4 to 3.5)		1.7	(1.1 to 2.7)	
V Unable to walk,severely limited self mobility	19	4	1.5	(0.6 to 3.7)		1.4	(0.6 to 3.7)		142	18	3.7	(2.3 to 6.0)		3.8	(2.4 to 6.1)	
Bimanual fine motor function					0.43			0.29					<0.0001			<0.0001
I Few restrictions	237	48	1.0			1.0			280	35	1.0			1.0		
II Mild restrictions	143	29	1.0	(0.6 to 1.6)		0.9	(0.5 to 1.4)		201	25	1.7	(1.1 to 2.5)		1.8	(1.2 to 2.7)	
III Moderate restrictions	74	15	1.0	(0.5 to 1.9)		0.8	(0.4 to 1.5)		128	16	1.9	(1.2 to 3.2)		2.2	(1.4 to 3.4)	
IV Severe restrictions	28	6	1.8	(0.8 to 4.3)		1.8	(0.9 to 3.6)		88	11	1.7	(1.0 to 2.9)		2.2	(1.3 to 3.9)	
V Very severe restrictions	8	2	1.2	(0.5 to 2.9)		1.1	(0.4 to 2.8)		109	14	4.6	(2.9 to 7.3)		4.5	(2.8 to 7.1)	
Seizures (in last year)					0.45			0.32					<0.0001			<0.0001
No seizures, not on medication	421	86	1.0			1.0			571	71	1.0			1.0		
No seizures,on medication	27	6	0.7	(0.3 to 2.1)		0.7	(0.3 to 1.5)		72	9	1.1	(0.6 to 1.9)		0.9	(0.6 to 1.5)	
Seizures less than once a mth	26	5	1.3	(0.7 to 2.6)		2.0	(0.8 to 5.1)		61	8	1.7	(0.9 to 3.3)		1.7	(1.0 to 3.0)	
Seizures between once a mth&once a wk	11	2	1.9	(0.3 to 10.5)		1.4	(0.3 to 5.9)		47	6	2.6	(1.4 to 4.8)		3.2	(1.6 to 6.2)	
Seizures more than once a wk	5	1	0.1	(0.0 to 0.9)		0.1	(0.0 to 0.8)		54	7	3.9	(2.2 to 6.7)		3.4	(1.9 to 6.3)	
Feeding					0.19			0.17					<0.0001			<0.0001
No problems	437	89	1.0			1.0			577	72	1.0			1.0		
Feeds orally with difficulty	50	10	1.0	(0.5 to 1.9)		1.1	(0.6 to 2.3)		171	21	1.6	(1.1 to 2.4)		1.7	(1.2 to 2.5)	
Feeds by tube, partially/completely	3	1	8.5	(3.5 to 20.5)		6.8	(3.2 to 14.6)		57	7	4.4	(2.4 to 8.1)		4.2	(2.4 to 7.4)	
Communication					0.15			0.15					<0.0001			<0.0001
Normal	402	82	1.0			1.0			460	57	1.0			1.0		
Difficulty but uses speech	63	13	1.3	(0.6 to 2.5)		0.7	(0.4 to 1.3)		130	16	0.8	(0.5 to 1.2)		0.9	(0.6 to 1.4)	
Uses non-speech for formal communication	25	5	2.2	(0.8 to 5.9)		1.5	(0.7 to 3.4)		96	12	1.6	(1.0 to 2.5)		1.5	(0.9 to 2.3)	
No formal communication	0	0							119	15	2.4	(1.5 to 3.7)		2.6	(1.7 to 4.1)	
Vision					0.02			0.07					0.07			0.14
Has useful vision	486	99	1.0			1.0			748	93	1.0			1.0		
Blind or no useful vision	4	1	6.6	(2.4 to 17.7)		3.5	(1.1 to 11.3)		58	7	1.7	(0.9 to 3.2)		1.7	(0.9 to 3.2)	
Hearing					0.31			0.85					0.24			0.24
Normal	486	99	1.0			1.0			787	98	1.0			1.0		
Needs hearing aids	4	1	2.2	(1.1 to 4.6)		0.2	(0.0 to 1.9)		18	2	2.2	(0.6 to 7.3)		1.4	(0.5 to 3.8)	
Intellect					0.55			0.88					0.00			0.00
None or mild (IQ >70)	357	73	1.0			1.0			384	48	1.0			1.0		
Moderate (IQ 50-70)	117	24	1.3	(0.8 to 2.2)		1.2	(0.7 to 2.0)		183	23	1.1	(0.7 to 1.6)		1.1	(0.8 to 1.6)	
Severe (IQ < 50)	13	3	0.8	(0.4 to 1.8)		1.0	(0.3 to 3.3)		235	29	2.0	(1.4 to 2.9)		2.0	(1.4 to 2.9)	
Cerebral palsy sub-type					0.28			0.51					0.01			0.15
Unilateral spastic	216	44	1.0			1.0			278	34	1.0			1.0		
Bilateral spastic	231	47	1.0	(0.7 to 1.5)		1.3	(0.9 to 2.0)		413	51	1.4	(1.0 to 2.0)		1.3	(1.0 to 1.9)	
Dyskinetic	30	6	1.5	(0.7 to 3.3)		1.5	(0.7 to 3.1)		85	11	1.1	(0.7 to 1.7)		1.1	(0.7 to 1.8)	
Ataxic	12	2	3.0	(1.1 to 8.0)		1.0	(0.2 to 4.0)		29	4	1.8	(0.7 to 4.4)		2.5	(1.1 to 5.7)	

Sociodemographics

	No.	%	OR*	Frequency 95% CI p	OR	Severity 95%CI p	No	%	OR*	Frequency 95% CI p	OR	Severity 95%CI p
Gender				0.09		0.08				0.04		0.04
Boys	286	58	1.0		1.0		477	59	1.0		1.0	
Girls	204	42	1.4	(1.0 to 2.1)	1.4	(1.0 to 2.2)	329	41	1.4	(1.0 to 1.9)	1.3	(0.9 to 1.8)
Age in years				0.007		0.02				0.93		0.98
7-8	104	21	1.0		1.0		181	22	1.0		1.0	
9	105	21	1.0	(0.5 to 2.0)	1.0	(0.6 to 1.9)	158	20	1.2	(0.8 to 1.8)	1.2	(0.8 to 1.9)
10	89	18	1.8	(1.0 to 3.2)	2.0	(1.1 to 3.4)	164	20	1.2	(0.8 to 1.9)	1.2	(0.8 to 1.9)
11	103	21	2.2	(1.2 to 3.9)	1.9	(1.0 to 3.6)	156	19	1.4	(0.9 to 2.2)	1.3	(0.8 to 2.1)
12-13	89	18	2.2	(1.2 to 4.0)	1.9	(1.0 to 3.7)	147	18	1.1	(0.6 to 1.7)	1.1	(0.7 to 1.8)
Family structure				0.84		0.5				0.11		0.07
Married or living with partner	398	81	1.0		1.0		653	81	1.0		1.0	
Single	92	19	0.8	(0.5 to 1.3)	0.9	(0.5 to 1.5)	153	19	1.6	(1.1 to 2.3)	1.6	(1.1 to 2.3)
Siblings				0.35		0.21				0.56		0.52
None	84	17	1.0		1.0		155	19	1.0		1.0	
One or more, none disabled	339	69	1.1	(0.6 to 1.9)	1.0	(0.6 to 1.7)	555	69	0.9	(0.6 to 1.4)	0.9	(0.6 to 1.3)
One/more, one/more disabled	58	12	0.7	(0.3 to 1.6)	0.6	(0.3 to 1.4)	83	10	1.0	(0.5 to 1.8)	0.8	(0.4 to 1.5)
Area of domicile				0.01		0.02				0.93		0.81
City	78	16	1.0		1.0		117	15	1.0		1.0	
Town or suburbs	238	49	0.8	(0.4 to 1.3)	0.7	(0.4 to 1.2)	403	50	0.9	(0.6 to 1.4)	1.0	(0.6 to 1.5)
Village or countryside	172	35	0.4	(0.2 to 0.8)	0.5	(0.3 to 0.9)	284	35	0.9	(0.6 to 1.4)	1.0	(0.6 to 1.6)
Schooling				0.25		0.68				0.0004		0.0002
Mainstream	284	58	1.0		1.0		314	39	1.0		1.0	
Mainstream&visits special unit	64	13	0.5	(0.3 to 0.9)	0.8	(0.3 to 2.0)	109	14	1.7	(1.0 to 3.0)	1.7	(1.0 to 2.9)
Special unit in mainstream	45	9	1.2	(0.6 to 2.3)	1.2	(0.6 to 2.4)	66	8	0.9	(0.5 to 1.6)	1.1	(0.6 to 1.9)
Special school	95	19	1.8	(0.9 to 3.6)	1.4	(0.7 to 2.8)	303	38	2.1	(1.5 to 3.1)	2.2	(1.6 to 3.1)
Parent educational qualifications				0.66		0.46				0.45		0.53
Above university entrance	125	26	1.0		1.0		201	25	1.0		1.0	
Intermediate	252	51	1.4	(0.8 to 2.3)	1.5	(0.9 to 2.5)	409	51	1.0	(0.7 to 1.5)	1.1	(0.7 to 1.6)
Lowest formal qualification/none	110	22	1.3	(0.7 to 2.5)	1.6	(0.8 to 3.2)	190	24	1.3	(0.8 to 2.1)	1.4	(0.9 to 2.3)
Parental employment				0.73		0.92				0.0005		0.001
At least one parent works full-time	125	26	1.0		1.0		224	28	1.0		1.0	
Intermediate	257	52	0.8	(0.8 to 2.3)	1.0	(0.6 to 1.5)	397	49	0.8	(0.6 to 1.2)	0.9	(0.6 to 1.3)
One parent works part-time/neither	106	22	0.7	(0.7 to 2.5)	1.0	(0.5 to 1.9)	183	23	1.9	(1.2 to 3.0)	1.7	(1.1 to 2.7)

Table 5.2 Odds ratios (OR) from multivariable ordinal regression models, relating child pain to the type and level of impairment and socio-demographic characteristics. All models were stratified by region and used weights that allowed for the sampling design and for non-response. Children with missing data, either on pain outcomes or on factors included in the model, were excluded.

	Self-reported pain in previous week			Parent-reported pain in previous 4 weeks					
	Children who could self-report (n=490)			All children (n=799):					
	Frequency		Severity	Frequency		Severity			
	OR*	(95% CI)	p†	OR*	(95% CI)	p†	OR*	(95% CI)	p†
Gross motor function						<0.0001			<0.0001
I. Walks without limitation				1.0	-		1.0	-	
II. Walks with limitation				1.5	(1.0 to 2.3)		1.3	(0.9 to 2.0)	
III. Walks with assistive devices				1.2	(0.7 to 1.9)		1.2	(0.7 to 1.9)	
IV. Unable to walk, limited self-mobility				2.0	(1.2 to 3.3)		1.6	(1.0 to 2.6)	
V. Unable to walk, severely limited self-mobility				2.8	(1.6 to 4.7)		3.0	(1.8 to 5.0)	
Seizures (in previous year)						0.0008			0.0003
No seizures, not on medication				1.0	-		1.0	-	
No seizures, on medication				0.8	(0.5 to 1.5)		0.7	(0.4 to 1.1)	
Seizures less than once a month				1.6	(0.8 to 3.1)		1.6	(0.9 to 2.9)	
Seizures between once a month & once a week				2.0	(1.1 to 3.8)		2.4	(1.2 to 4.5)	
Seizures more than once a week				2.4	(1.3 to 4.2)		2.1	(1.1 to 4.0)	
Age in years			0.007			0.003			0.007
7-8	1.0	-							
9	1.0	(0.5 to 2.0)							
10	1.8	(1.0 to 3.2)							
11	2.2	(1.2 to 3.9)							
12-13	2.2	(1.2 to 4.0)							
Parental employment									
At least one parent works full-time professionally (or equivalent)				1.0	-		1.0	-	
Intermediate				0.8	(0.6 to 1.2)		1.0	(0.6 to 1.4)	
One parent works part-time or neither parent works				1.8	(1.1 to 2.9)		1.6	(1.1 to 2.5)	
p-value from goodness-of-fit deciles of risk test	0.32			0.76		0.55			
* ORs greater than 1.0 indicate a higher level of pain in that group than in the reference group									
† p-values are from likelihood ratio test statistic (LRTS) comparing models with and without the corresponding factor; these models did not use sampling weights.									

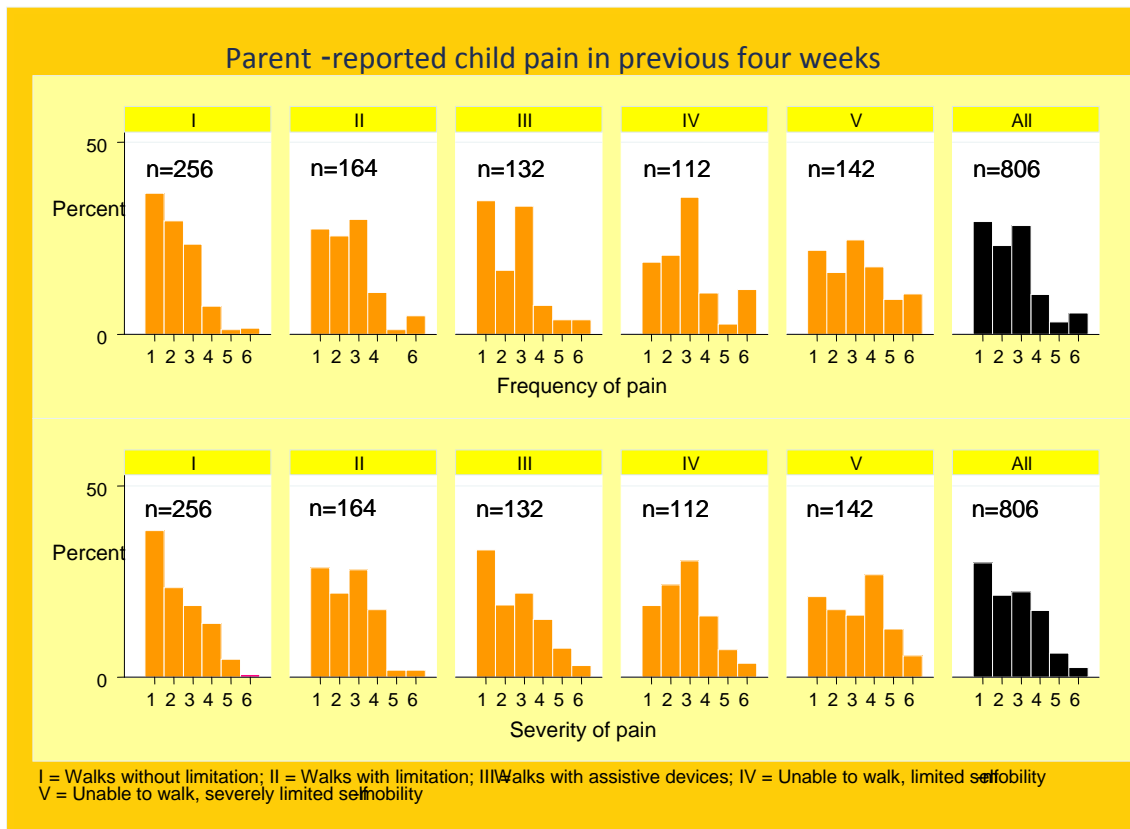


Figure 5.1 Severity and frequency of self-reported and parent-reported pain, both overall and by walking ability

6. Child Psychological Factors

6.1 Definition and Description of Concept

In the last decade it has become apparent that, in developed Western countries, approximately 20% of young people under the age of 18 encounter mental health difficulties and 8% meet the criteria for a mental disorder (WHO, 2004). In Ireland, there is a lack of research into the prevalence of such disorders in young people, although a study by Lynch and colleagues (2006) found that of the 723 adolescents between the ages of 12 and 15, 19.4% were identified as being 'at risk' of psychiatric disorder.

Disabled children are at an even higher risk than those in the general population (Goodman, 2002), which may be partly attributable to the association between brain and behaviour (Goodman and Graham, 1996) or social difficulties such as maintaining friendships or bullying (Yude & Goodman, 1999).

As CP is one of the leading causes of physical disability in children and young people, the purpose of this part of the study was to investigate psychological problems in children aged 8-12, the predictors of these symptoms, and their impact on the individual and on their family.

6.2 Questionnaire Information

The Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997) measures emotional and behavioural symptoms suitable for children aged between 4 and 16 and uses a six month reference period. The 25 item scale yield a total difficulties score (TDS) across the four symptom scales of conduct, hyperactivity, emotion and peer problems. According to the author (Goodman, 1999), a TDS score above 16 is reasonably accurate in symptomatic cases. For the purpose of this study, the parent version was administered. The Impact Supplement of the SDQ provides additional information regarding the impact of any difficulties on the individual and the family.

6.3 Results

Statistical Methods

Prevalence (expressed as proportions with 95% confidence intervals) was estimated using sampling weights which took account of the sampling strategy (Dickinson et al., 2006). Prevalence estimates excluded children in North-West Germany, as their children were not identified from a population-based register.

The determinants of children's symptoms (as measured by the total difficulties score dichotomised into normal/borderline versus abnormal) were studied using multilevel, multivariable logistic regression. Multilevel modelling was used as it was considered likely that children from the same region would be more similar than children from different regions.

Initially, multilevel univariate logistic regression was performed, considering each covariate in turn. Covariates associated below the 20% significance level in the univariable analysis were then entered into the multivariable analysis using forward stepwise regression, and included in the final model if they were significant below the 5% significance level. All variables significant in the multivariable analysis were tested for removal with a backwards step at each stage. Where significant, categories within variables were collapsed after including the factor in the model if the 95% confidence intervals overlapped substantially.

The final multivariable model excluded children with missing values on the included covariates, explaining why the model was based on 774 out of the possible 818 subjects. Goodness-of-fit was adequate. Models were rerun excluding influential observations and found to be stable. The reduction in deviance resulting from the multivariable model was used as an indicator of the variation explained by the model.

Main Findings

As illustrated in Table 6.1, 23.9% of children were categorized as being in the abnormal range when considering their TDS. In terms of the four symptom scales, problems with peers were most prevalent (32%), whereas problems with conduct were the least reported (15%). Problems with emotion and hyperactivity were also high (27% and 28% respectively).

Table 6.1 Mean, standard deviation (SD), median, inter quartile range (IQR), % normal, borderline and abnormal (using established "cut-offs" on SDQ domains (total sample) (n=818)

SDQ domains	n (%)	Mean (SD)	median (IQR)	n (%) normal	n (%) borderline	n (%) abnormal
Emotion	808 (99)	3.1 (2.3)	3 (1-5)	497 (61.5)	92 (11.4)	219 (27.1)
Conduct	802 (98)	1.9 (1.6)	2 (1-3)	543 (67.7)	138 (17.2)	121 (15.1)
Hyperactivity	806 (98)	4.8 (2.7)	5 (3-7)	489 (60.7)	95 (11.8)	222 (27.5)
Peer problems	807 (99)	2.7 (2.1)	2 (1-4)	420 (52.1)	126 (15.6)	261 (32.3)
TDS	799 (98)	12.4 (6.0)	12 (8-16)	466 (58.3)	142 (17.8)	191 (23.9)
Prosocial	796 (97)	7.2 (2.7)	8 (6-9)	604 (75.9)	65 (8.2)	127 (15.9)
Impact score	810 (99)	1.9 (2.4)	1 (.3)	361 (44.6)	123 (15.2)	326 (40.2)

Table 6.2 Parent reported behavioural and emotional symptoms of children with cerebral palsy (Southwest Ireland (n=98)

Domains	Number of items	Response rate		Non missing scores				Floor effect	Ceiling effect
		n	%	Mean	SD	median	IQR**	%	%
Emotion	5	94	92	3.2	2.4	3	2-5	13.8	2.1
Conduct	5	91	89	2.0	1.8	2	1-3	20.9	1.1
Hyperactivity	5	93	91	4.7	2.9	5	2-7	10.8	5.4
Peer Problems	5	95	93	2.5	2.2	2	.0-4	26.3	1.1
Total difficulties	20	90	88	12.1	6.4	12	7-17	1.1	1.1
Prosocial	5	92	90	7.5	2.9	9	6-10	5.4	34.8
Impact scores	8	95	93	1.3	2.0	.0	.0-2	55.8	1.1

**IQR = interquartile range

The factors pertaining to a TDS score of >16 were also examined and Table 6.3. illustrates the results. The factors that greatly increased the likelihood of the child having a score above this threshold were those children with a hearing impairment, intellectual impairment, more pain, those with no siblings or disabled siblings, those children attending special schools or special units in mainstream schools and children living in urban areas such as a town or city. The factors that were associated with a lower TDS score were those with a GMFCS level of IV and V.

Table 6.3 Multilevel, univariate logistic regression model of TDS >16 in relation to child and family characteristics (ORs > 1 indicate a higher risk of symptomatic cases in that group)

Characteristics	n	OR	95% CI
Gender			
Boys	471	1	
Girls	328	1.2	.6-1.2
Age (yrs)			
7/8	178	1	
9	157	1.0	.6-1.6
10	161	1.1	.6-1.8
11	153	.9	.5-1.5
12	150	1.0	.6-1.6
GMFCS			
I (no limitation)	256	1	
II	164	1.3	.8-2.0
III	138	.9	.6-1.5
IV	109	1.0	.6-1.7
V (total assistance)	132	.5	.3-0.8
BFMF			
I (no limitation)	280	1	
II	205	1.2	.8-1.8
III	131	1.3	.8-2.1
IV	84	.8	.4-1.5
V (total assistance)	99	.6	.3-1.2
Vision			
Has useful vision	748	1	
Blind or no useful vision	51	.9	.4-1.8
Hearing			
Does not need hearing aids	782	1	
Needs hearing aids	16	3.3	1.2-9.1
Seizures			
No seizures, no medication	569	1	
No seizures, with medication	72	.9	.5-1.7
Seizures < 1/month	61	2.4	1.4-4.2
Seizures >= 1/month < weekly	46	1.0	.5-2.1
Seizures > = 1/week	50	1.5	.8-2.9
Feeding			
No problems	579	1	
By mouth with difficulty	166	1.2	.8-1.8
Tube feeding	53	.6	.3-1.4

Communication			
Normal	462	1	
Difficulty but uses speech	132	1.8	1.2-2.8
Alternative formal methods	96	1.0	.6-1.8
No formal communication	108	.9	.5-1.5
Intellectual impairment			
None-mild (IQ >70)	385	1	
Moderate-severe (IQ <= 70)	428	3.0	2.1-4.2
CP subtype			
Spastic unilateral	279	1	
Spastic bilateral	407	.7	.5-1.0
Dyskinetic	83	.6	.3-1.1
Ataxic	29	1.2	.5-2.8
Pain (parents report on CHQ)			
None (score=100)	224	1	
Moderate (score=50-90)	426	1.3	.9-2.0
Severe (score 0-40)	139	2.0	1.2-3.2
School type			
Mainstream	315	1	
Mainstream&visits special unit	109	1.5	.8-2.8
Special unit in mainstream	67	2.1	1.0-3.8
Special school	297	1.6	1.0-2.3
Siblings			
One/more,none disabled/ill	548	1	
One/more,one/more disabled/ill	83	2.7	1.7-4.4
None	158	1.9	1.2-2.8
Family structure			
Married, living with partner	564	1	
Living with partner	82	1.5	0.9-2.6
Single/separated living with parents	18	1.4	0.8-2.3
Single alone	134	1.5	1.0-2.4
Parent qualifications (median)			
University degree	113	1	
Above lowest qualification but below University degree	494	1.4	0.8-2.3
None/lowest formal qualification	187	1.8	1.0-3.3
Parent occupation			
Full-time professional	223	1	
Full-time trade, trade/professional	394	1.5	1.0-2.3
Part-time trade/professional	63	1.6	0.9-3.1
Neither partner working	116	1.5	0.8-2.5
Area of living			
Big city or its suburbs	243	1	
Town or small city	286	1.7	1.1-2.5
Village, farm/home in the country	286	1.0	0.7-1.5

However, as several of these factors were correlated, it was necessary to test some of the more significant variables in a multivariable model that would allow for these correlations. Table 6.4 illustrates the results from this model. The variables of moderate-severe intellectual impairment, no siblings or disabled siblings, higher pain, or living in a small town or city were most significantly associated with higher TDS scores. The more functionally impaired the child was, the greater the likelihood that they had a lower TDS score.

Having allowed for the covariates described above, variance between regions was low (3% of total variance) but statistically significant ($p = .02$), suggesting country-specific differences in the psychological well-being of children with cerebral palsy.

Table 6.4 Multilevel, multivariable logistic regression model of predictors of TDS >16 by child and family characteristics (n=774)

Characteristics	n=774	OR	95%CI
GMFCS			
I (no limitation)	252	1	
II	160	.9	.6-1.5
III	127	.6	.3-1.1
IV	106	.4	.2-.8
V (total assistance)	129	.2	.1-.3
Intellectual impairment			
None-mild (IQ >70)	376	1	
Moderate-severe (IQ ≤ 70)	398	3.2	2.1-4.8
Siblings			
One/more, none disabled/ill	542	1	
One/more, one/more disabled/ill	79	2.7	1.6-4.6
None	153	1.8	1.2-2.8
Pain (parents report on CHQ)			
None (score=100)	222	1	
Moderate (score=50-90)	414	1.4	.9-2.1
Severe (score 0-40)	138	2.7	1.5-4.6
Area of living			
Big city or its suburbs	233	1	
Town or small city	273	1.8	1.1-2.8
Village/farm/home in the country	268	.9	.6-1.5

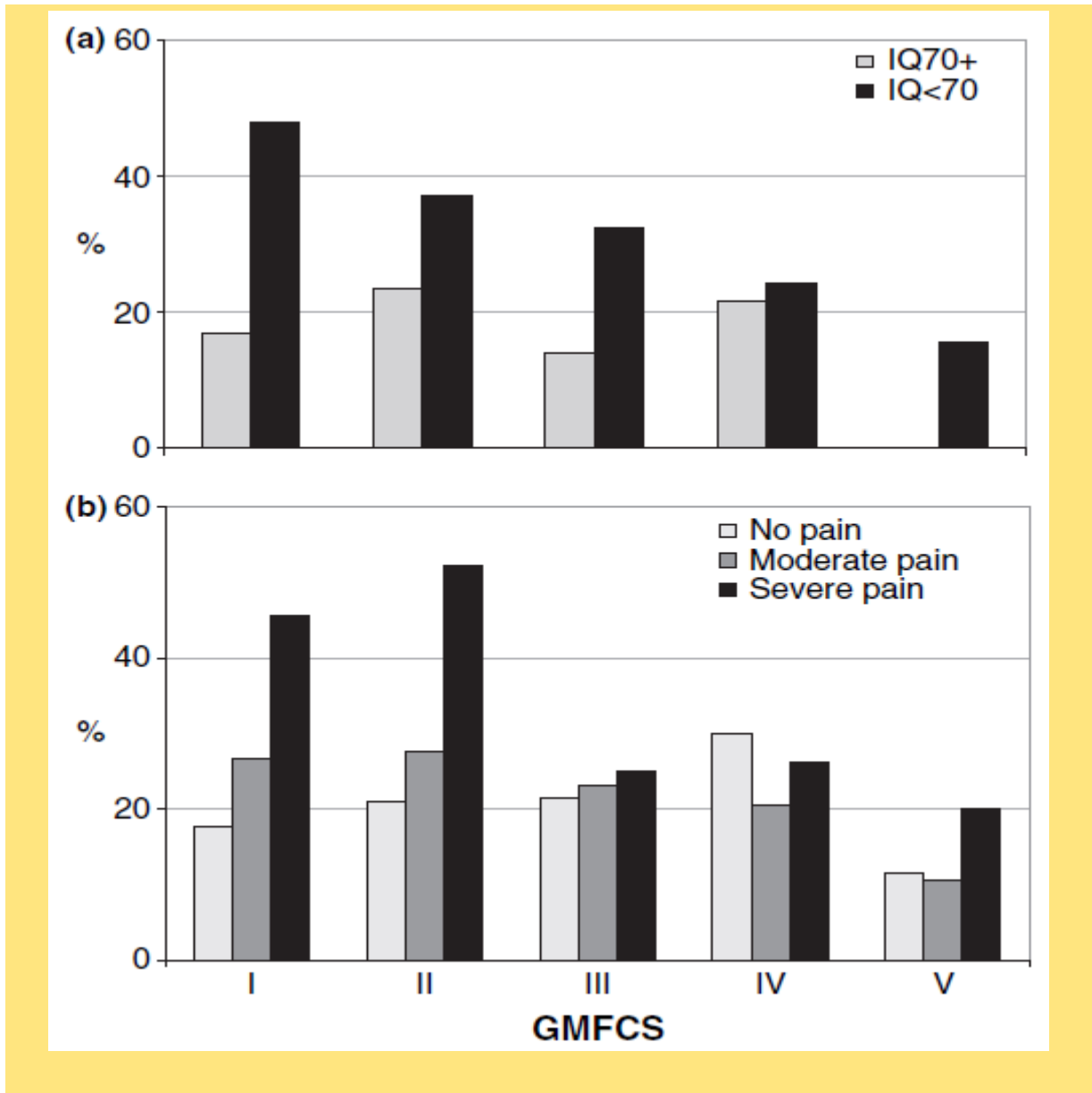


Figure 6.1 Proportion of children with TDS > 16 by GMFCS and intellectual impairment (1a) and by pain (1b) (n = 774)

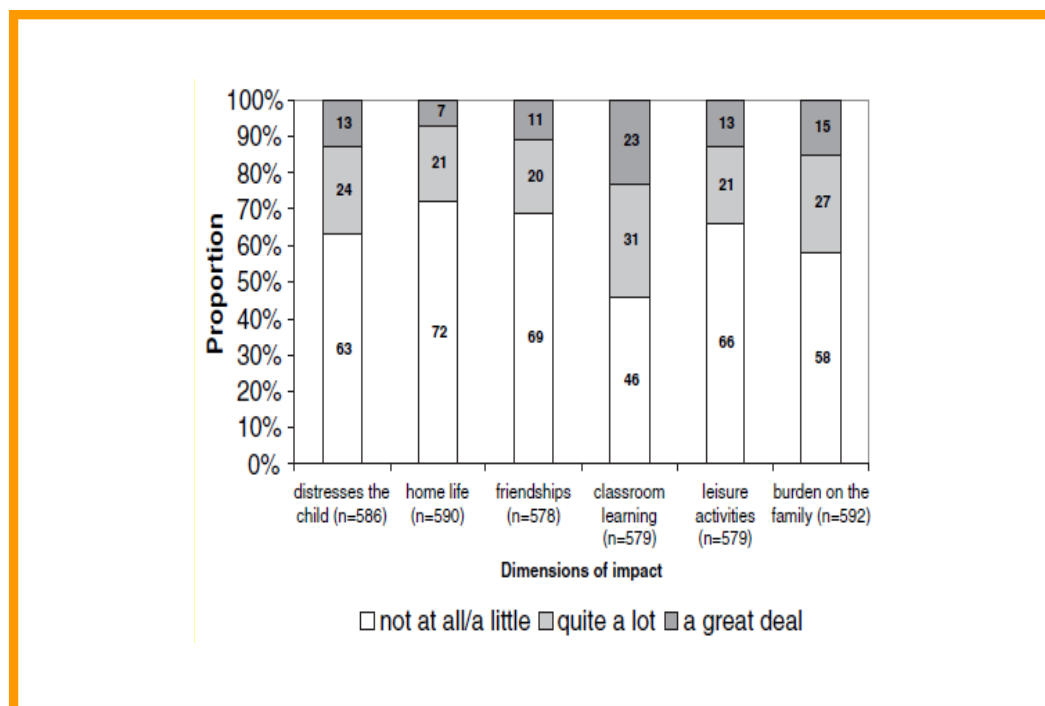


Figure 6.2 Impact of parent perceived difficulties on the child (social impairment) and the family (burden) (n =594)

In relation to the impact of all of these psychological difficulties, 40% of the population were classified as abnormal. Those parents reporting minor difficulties or worse on the impact question were asked for how long their child's difficulties were present and 95% said over a year. The extent to which these difficulties upset the child and family and impacted on their everyday life is summarised in Figure 6.2. Parents perceived the child's classroom learning to be the most disrupted aspect of the child's life and their home life the least disrupted. Forty-two percent of parents reported the child's difficulties burdened the family at least 'quite a lot'.

7. Parental Impact/Stress

7.1 Definition and Description of Concept

Caring for a child with a disability can often be stressful for the caregiver, and this elevated stress may have several consequences such as maladaptive parenting styles (Haskett et al., 2006), poorer QoL, and may even pose as a risk factor for psychopathology in the child and the parent (Reitman, Currier & Stickle, 2002)

Researchers (Cohen and Lazarus, 1979, Pearlin and Schooler 1978) have defined coping as efforts, both cognitive and behavioural, used to lessen demands that put a strain on an individual's resources (as cited in Trute and Hiebert-Murphy, 2002) or essentially to deal with stress (Taanila et al., 2002). Miller and Kaiser (2001) reports that numerous studies in the last few decades have consistently illustrated those parents of disabled children experience more stress than parents of non disabled children.

In physical terms, inability to cope may conduce to poorer caregiver health which can subsequently result in more frequent hospitalization, or out of home placements for children with disability (Murphy et al 2007, Whitley et al 2001 as cited in Taylor et al 2007) or affect the services the disabled person receives (Brannan et al 2003, Brannan and Heflinger 2005). Psychologically, it may also lead to increased parental stress which is associated with maladaptive parental styles, lack of warmth, in extreme cases abuse of the child (Haskett et al 2006), and specifically relative to disability, a heightened risk of depression or a poorer parent-child bond (Kim et al 2003). If families are coping well, the child's development is enhanced and stress is evaded for all members of the family (Crnic, 1983). Knussen and Sloper (1992) concede that while there is a lack of research into the level of parental stress experienced by parents of children the evidence that does exist (Brehaut et al 2004, Sloper and Turner 1992) found higher than average levels of stress than those parents with non disabled children.

7.2 Questionnaire Information

The Parental Stress Index Short Form (PSI-SF (Abidin 1995) is a 36 item questionnaire assessing the perceived stress experienced by parents.

The measure yields a total stress score which is derived from the three scales of:

- (i) Parental Distress: which indicates the distress a parent is experiencing and relates to items such as inter-parental conflict and levels of social support. This scale in particular has been found to be correlated with psychological symptomology (Reitman et al 2002);
- (ii) Parent-Child Dysfunctional Interaction: which focuses on the parent's expectations of the child and the bond between the parent and child; and
- (iii) Difficult Child: this concentrates on the behavioral attributes of the child, such as compliance and temperament.

Parents rate the items on a five point Likert scale, ranging from strongly agree to strongly disagree. The scores for each scale range from 12 to 60, whereas the Total Stress Score (TSS) ranges from 36 to 180. The higher the score, the higher the perceived level of stress. A TSS Score of above 90 is indicative of clinical levels of stress (Abidin 1995).

Additionally, SPARCLE 1 employed the 19 item Life Stress scale which is taken directly from the full version of the PSI but can also be used as an independent measure as a contextual basis for the parents stress. This accounts for stressful situations outside the realm of parental control as well as stress outside the parent-child relationship.

7.3 Results

Statistical Methods

The internal consistency of the TSS was assessed by Cronbach's alpha, both overall and within each level of each type of impairment. All nine types of impairment had values above 0.8 indicating very good reliability estimate of the instrument (Armitage & Colton, 1998).

We first evaluated whether the distribution of TSS was similar in parents of children with different levels of impairment and in different categories of each socio-demographic factors. In order to determine which factors were associated with the high levels of parental stress, taking account of a possible effect of the country in which the child lives, we used multivariable logistic regression (with correction for centre cluster data).

For the logistic regressions, the dependent variable was 'high parental stress', defined as TSS above the 75th centile. The 75th percentile was chosen as a cut-off value as this was related to socio-demographic factors (the child's age, gender, number of siblings and type of school attended; and the parent's educational qualifications, type of employment and area of residence) and the type and level of the child's impairments (gross motor function, fine motor skills, intellectual impairment (IQ), vision, hearing, seizures, feeding, communication and CP sub-type).

Unadjusted and adjusted odds ratios (and their 95% confidence intervals) are reported as measures of the association between high parental stress and the socio-demographic factors and impairments.

In the multivariable regression, the variable selection strategy was a combination of non automatic forward (enter criteria: $p < 0.3$) and backward (exclusion criteria: $p > 0.1$) selection. The comparison among nested models was made using the likelihood-ratio test. Vision and hearing were not included in the final multiple logistic regression model because few children had impaired vision or hearing.

Main Findings

785 parents completed the PSI/S questionnaire. The TSS Scores for the sample ranged from 71 to 90 (median). As illustrated by Table 7.1 and Figure 7.1, the South-West Ireland had a relatively modest score according to the TSS, with parents in Denmark experiencing the least amount of stress, and those in South-East France having the highest amount of stress.

As illustrated by Table 7.2, stress level's increase as the child's gross and fine motor impairments, intellectual impairment, feeding, seizures, vision, hearing and communication needs/dependency increases. Also, stress levels are higher for those parents with children who are ataxic, bilateral spastic or dyskinetic, compared with those children who are unilaterally spastic.

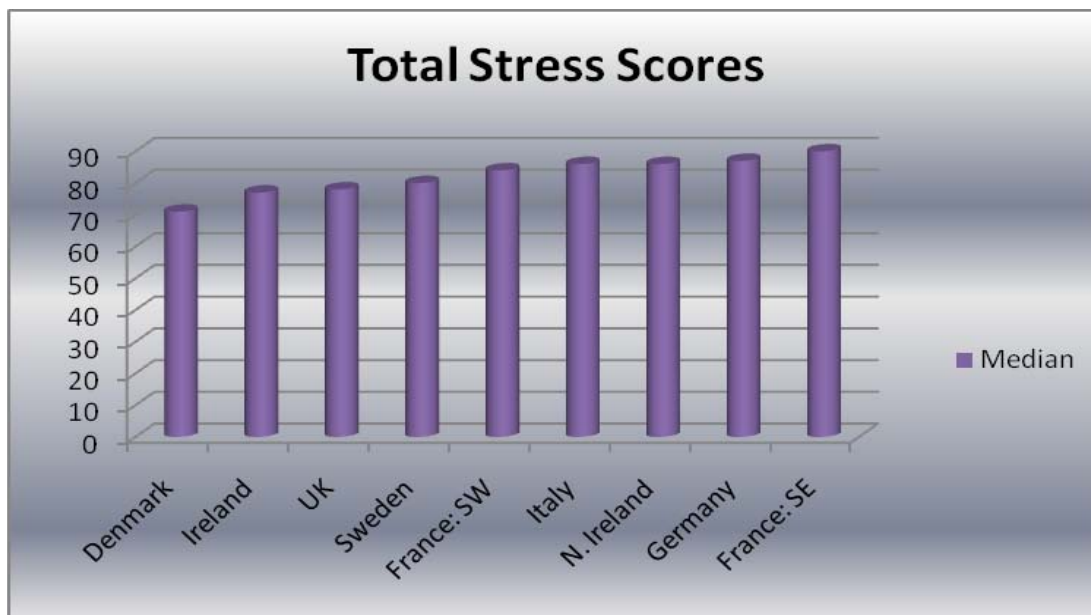


Figure 7.1 Total Stress Score by Sparcle Centre

Table 7.1. Number and percentage of responders and median of total Parent Stress Index by type and level of impairment of child.

	PSI/SF total score				
	N	(%)	Median	(IQR*)	p**
Gross motor function					0.0001
I Walks and climbs stairs, without limitation	249	(32)	75	(58-90)	
II Walks with limitations	160	(20)	81	(65-100)	
III Walks with assistive devices	134	(17)	85	(73-97)	
IV Unable to walk, limited self-mobility	109	(14)	85	(70-99)	
V Unable to walk, severely limited self-mobility	133	(17)	86	(73-101)	
Fine motor skills					0.0001
Without limitation	271	(35)	74	(58-90)	
Both hands limited in fine skill	201	(26)	85	(68-100)	
Needs help with tasks	127	(16)	84	(72-97)	
Needs help and adapted equipment	85	(11)	83	(69-96)	
Needs total human assistance	101	(13)	90	(76-104)	
Intellectual impairment					0.0001
None or mild (IQ>70)	377	(48)	75	(58-86?)	

Moderate (IQ 50-70)	176	(22)	84	(72-98)	
Severe (IQ<50)	228	(29)	92	(76-105)	
No information available	4	(1)	98	(86-110)	
Vision					0.0009
Has useful vision	735	(94)	80	(66-96)	
Blind or no useful vision	50	(6)	91	(75-104)	
Hearing					0.002
Does not need hearing aids	767	(98)	80	(66-96)	
Needs hearing aids; profound or severe loss >70 decibels	17	(2)	100	(82-111)	
No information available	1	(0)	121	-	
Seizures					0.0001
No seizures and not on medication in previous year	555	(71)	78	(64-94)	
No seizures and on medication in previous year	70	(9)	85	(71-97)	
Seizures less than once a month in previous year	59	(8)	84	(72-101)	
Seizures more than once a month and less than once a week in previous year	45	(6)	88	(77-98)	
Seizures more than once a week in previous year	55	(7)	95	(74-111)	
No information available	1	(0)	68	-	
Feeding					0.0001
Feeds by mouth with no problems	564	(72)	78	(64-95)	
Feeds by mouth but with difficulty	169	(22)	85	(73-101)	
Partial or complete feeding by tube	51	(6)	90	(71-103)	
No information available	1	(0)	68	-	
Communication					0.0001
Normal communication	451	(57)	76	(62-90)	
Problem but communicates with speech	127	(16)	88	(72-103)	
Uses alternative formal methods to communicate	94	(12)	85	(73-101)	
No formal communication	112	(14)	91	(75-105)	
No information available	1	(0)	68	-	
Cerebral palsy subtype					0.01
Unilateral spastic	268	(34)	77	(60-91)	
Bilateral spastic	410	(52)	83	(70-98)	
Dyskinetic	79	(10)	82	(67-98)	
Ataxic	27	(3)	85	(60-103)	
No information available	1	(0)	96	-	
All children	785	(100)	81	(66-97)	

* IQR: inter-quartile range

** p-value from Kruskal-Wallis test

8. Environmental Considerations

Definition and Description of Concept

Article 13 of the 2006 UNCRPD asserts the obligation of states "to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications". The ICF considers disability to result from an interaction between a person's intrinsic impairment and their physical, social and attitudinal environment (WHO, 2001); this is consistent with the Social Model of Disability (Oliver, 1990). It is therefore of interest to assess the availability to disabled children of the environmental items that they need

Questionnaire Information

The European Child Environment Questionnaire (ECEQ) was specifically developed for SPARCLE to investigate the child's surroundings (i.e. at home, at school and in the community) relevant to their impairment (Colver & Parkinson, personal communication). Its sub-domains are: transport, mobility and independence of the child, assistance to the child and the family, attitude and bureaucracy. There are 60 items, with one score per item, and these items were organised on a conceptual rather than statistical origin (Parkes et al 2008). Validity and reliability work on the instrument is ongoing (Parkes et al 2008)

In developing the instrument, and the concepts that should be included, a literature review, a qualitative study and a consultation process (i.e. focus groups were conducted). Recent research in the area, such as Mitchell and Sloper (2000), reported that parental carers of children with more profound impairment wanted information on service and resource provision, rights, housing, leisure activities, and support and relationship issues. Beresford and Sloper (1999) found that young people wanted information on dealing with emotions, parents, peers, coping, planning for the future, and managing at school and in social situations.

Examination of qualitative and exploration studies (e.g. McManus et al 2006, Mihaylov et al 2004) revealed items relating to physical, social and attitudinal environment. Additionally, policy and legislative documents were consulted in the development of the instrument, such as the UNCRC, the UN Standard Rules and the ICF (Tisdall, 2006)

Results

Main Findings

Children with more severely impaired walking ability generally had significantly lower access than less impaired children to aspects of the physical environment and social support that they needed, not only at home but also at school and in the community.

Likewise, children with more impaired walking ability had less access to transport, and experienced less favorable attitudes among family and friends. Additionally, children with greater intellectual impairment tended to have less access to the physical and social support they needed at home; children with bilateral cerebral palsy tended to have less access to the physical environment in the community; and children with

communication difficulties tended to have less access to the social support they needed in the community. Attitudes of teachers and therapists did not show significant association with any impairment; attitudes of classmates tended to be less favorable towards children with greater intellectual impairment.

All domains of the ECEQ showed significant variation between regions ($p<0.001$) (Figure 8.1). In comparison to other countries, South-West Ireland scored well on physical environment at school and in the community, social support at home and in the community, attitudes of family and friends and teachers/therapists and not so well on physical environment at home, transport and attitudes of classmates.

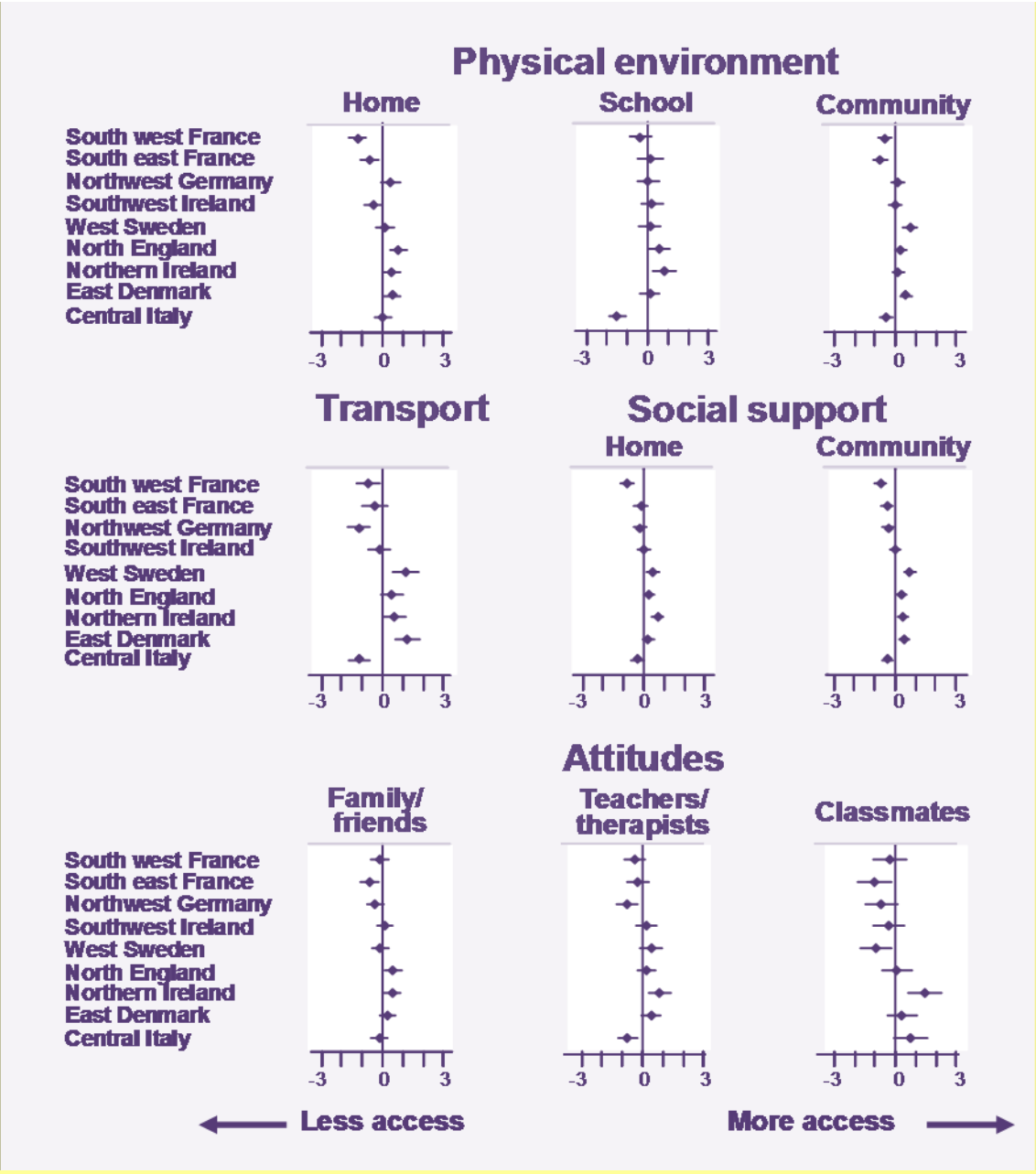


Fig 8.1 Mean level (with 95% confidence intervals) of child's access in each region, adjusted for impairment (the scale was chosen so that the mean adjusted access was zero)

		Physical environment						Transport		Social support				Attitudes					
		Home		School		Community				Home		Community		Family and friends		Teachers and therapists		Classmates	
Items	n	1 2 3 17 18 19		47, 48, 49, 50		4, 5, 6, 8, 9, 10, 11, 12		13, 14, 15, 16		20, 21, 22, 23, 36		24, 29, 33, 34, 35, 38, 39, 42		26, 28, 31, 37, 41, 44		30, 46, 51, 52, 53, 55, 60		54, 56, 59	
		807		818		817		818		813		817		818		818		813	
p for heterogeneity between regions		<0.0001		<0.0001		<0.0001		<0.0001		<0.0001		<0.0001		0.0001		<0.0001		0.0001	
Intra-class correlation coefficient**		0.16		0.21		0.16		0.18		0.18		0.21		0.07		0.09		0.08	
		OR*	(95% CI)	OR*	(95% CI)	OR*	(95% CI)	OR*	(95% CI)	OR*	(95% CI)	OR*	(95% CI)	OR*	(95% CI)	OR*	(95% CI)	OR*	(95% CI)
Impairments																			
Gross motor function																			
I Walks and climbs stairs, without limitation		1.00	-	1.00	-	1.00	-	1.00	-	1.00	-	1.00	-	1.00	-				
II Walks inside		0.27	(0.15 to 0.47)	0.24	(0.13 to 0.45)	0.24	(0.17 to 0.36)	0.42	(0.22 to 0.81)	0.36	(0.26 to 0.50)	0.44	(0.34 to 0.58)	0.47	(0.29 to 0.76)				
III Walks with assistive devices		0.07	(0.04 to 0.11)	0.15	(0.08 to 0.28)	0.08	(0.05 to 0.12)	0.08	(0.04 to 0.14)	0.24	(0.17 to 0.33)	0.37	(0.26 to 0.49)	0.39	(0.24 to 0.63)				
IV Unable to walk, limited self-mobility		0.04	(0.02 to 0.06)	0.13	(0.07 to 0.24)	0.05	(0.03 to 0.08)	0.05	(0.03 to 0.11)	0.18	(0.12 to 0.27)	0.34	(0.24 to 0.47)	0.22	(0.13 to 0.36)				
V Unable to walk, severely limited self-mobility		0.07	(0.04 to 0.12)	0.34	(0.17 to 0.66)	0.06	(0.04 to 0.09)	0.07	(0.04 to 0.14)	0.23	(0.16 to 0.34)	0.37	(0.25 to 0.54)	0.19	(0.12 to 0.30)				
Intellectual impairment																			
>70		1.00	-							1.00	-							1.00	-
50-70		0.54	(0.36 to 0.81)							0.66	(0.49 to 0.88)							0.40	(0.18 to 0.86)
<50		0.51	(0.34 to 0.77)							0.67	(0.50 to 0.91)							0.18	(0.09 to 0.38)
Communication																			
Normal speech												1.00	-						
Difficulty but uses speech												0.62	(0.48 to 0.81)						
Uses non-speech for formal communication												0.65	(0.47 to 0.90)						
No formal communication												0.67	(0.47 to 0.96)						
Type of cerebral palsy																			
Spastic unilateral						1.00	-												
Spastic bilateral						0.52	(0.38 to 0.71)												
Dyskinetic						0.54	(0.35 to 0.84)												
Ataxic						0.55	(0.29 to 1.06)												
Socio-demographic characteristics																			
Parental employment																			
At least one parent works full time professionally (or equivalent)		1.00	-																
One parent works full time (or equivalent)		0.65	(0.45 to 0.94)																
One parent works part-time		0.43	(0.24 to 0.79)																
Neither parent works		0.85	(0.50 to 1.43)																
Gender																			
Boys														1.00	-				
Girls														1.75	(1.27 to 2.42)				

* Odds ratios are from latent regression Rasch models (see appendix)

** The intra-class correlation coefficient is the proportion of the residual variance that is between regions

Fig 8.2. Odds ratios relating environmental accessibility for each ECEQ domain to walking ability and IQ

Table 8.1. ECEQ Support category (Southwest Ireland n=98)

Categories	Not needed		Needed and how much it is needed								Missing		Total	
			yes a little		yes a lot		no a little		no a lot					
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Benefit Information on time	12	12	10	10	33	34	25	26	15	15	3	3	98	100
Practical help public	50	51	7	7	19	19	16	16	4	4	2	2	98	100
Teachers etc listen	0	0	9	9	72	73	3	3	12	12	2	2	98	100
Specialised therapy services	6	6	16	16	62	63	6	6	6	6	2	2	98	100
Professional co-ordination	0	0	7	7	62	63	9	9	13	13	7	7	98	100
Social services co-ordinate	59	60	3	3	20	20	6	6	7	7	3	3	98	100
Child care for few days	63	64	1	1	19	19	10	10	4	4	1	1	98	100
Helper at home	64	65	0	0	13	13	11	11	9	9	1	1	98	100
Family/friends care for child for few hours	31	32	3	3	39	40	11	11	13	13	1	1	98	100
Parent support groups in area	48	49	5	5	7	7	24	24	10	10	4	4	98	100
Counselling available	49	50	4	4	3	3	23	23	12	12	7	7	98	100
Public positive attitude	0	0	11	11	62	63	12	12	10	10	3	3	98	100

Table 8.2. ECEQ Physical accessibility & equipment category (Southwest Ireland n=98)

Categories	Not needed		Needed and how much it is needed								Missing		Total	
			yes a little		yes a lot		no a little		no a lot					
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Enlarged rooms at home	49	50	2	2	16	16	10	10	20	20	1	1	98	100
Adapted WC	62	63	1	1	15	15	6	6	12	12	2	2	98	100
Modified home kitchen	69	70	2	2	2	2	11	11	12	12	2	2	98	100
Ramps in public places	55	56	4	4	17	17	6	6	16	16	17	17	115	117.3
Adapted public WC s	66	67	0	0	14	14	4	4	12	12	2	2	98	100
Lifts in public places	41	42	6	6	27	28	9	9	15	15	0	0	98	100
Escalators in public	62	63	8	8	17	17	4	4	6	6	1	1	98	100
Suitable doorways in	48	49	3	3	27	28	6	6	14	14	0	0	98	100
Room to move in public	47	48	5	5	22	22	4	4	19	19	1	1	98	100
Smooth town pavements	22	22	5	5	32	33	6	6	33	34	0	0	98	100
Walking aids	52	53	9	9	34	35	1	1	0	0	2	2	98	100
Hoists at home	69	70	5	5	5	5	8	8	10	10	1	1	98	100
Communication aids at	79	81	3	3	7	7	3	3	6	6	0	0	98	100
Grants or free	49	50	4	4	41	42	0	0	2	2	2	2	98	100
Home modification	55	56	2	2	10	10	6	6	23	23	2	2	98	100
Grants for holidays	40	41	7	7	19	19	13	13	15	15	4	4	98	100
Local leisure facilities	0	0	21	21	35	36	13	13	25	26	4	4	98	100
Wheelchair/buggy	57	58	2	2	35	36	2	2	1	1	1	1	98	100

Table 8.3. ECEQ Educational provision (*Southwest Ireland n=98*)

Categories	Not needed		Needed and how much it is needed								Missing		Total	
	n	%	A little		A lot		A little		A lot		n	%	n	%
Ramps of benefit at school	55	56	1	1	33	34	2	2	1	0	6	6	98	100
Adapted toilets at school	60	61	4	4	24	24	2	2	3	0	5	5	98	100
Lifts for child at school	75	77	1	1	6	6	8	8	3	0	5	5	98	100
Communication aids at school	67	68	5	5	22	22	0	0	0	0	4	4	98	100
Special staff in school	22	22	2	2	69	70	1	1	0	0	4	4	98	100
Extra time for child at school	20	20	2	2	56	57	2	2	4	0	14	14	98	100
Encouragement from teachers etc at school	0	0	8	8	83	85	0	0	2	0	5	5	98	100
Encouragement from classmates at school	0	0	2	2	62	63	11	11	8	0	15	15	98	100
Emotional support at school from teachers etc.	0	0	4	4	76	78	2	2	2	0	14	14	98	100
Emotional support from classmates	0	0	6	6	59	60	11	11	8	0	14	14	98	100
Practical help from teachers etc at school	0	0	6	6	63	64	2	2	0	0	6	6	77	79
Positive attitude teachers etc at school	0	0	2	2	86	88	0	0	2	0	8	8	98	100
Classmates positive attitude towards child	0	0	5	5	70	71	3	3	6	0	14	14	98	100
Teachers sufficient medical understanding of child	0	0	4	4	70	71	7	7	6	0	8	8	95	97

Table 8.4. ECEQ Transport category (*Southwest Ireland n=98*)

Categories	Not needed		Needed and how much it is needed								Missing		Total	
	n	%	Yes a little		yes a lot		no a little		no a lot		n	%	n	%
Adequate family vehicle	21	21	3	3	64	65	3	3	6	6	1	1	98	100
Accessible car parking	45	46	6	6	34	35	5	5	8	8	0	0	98	100
Adequate bus service	58	59	7	7	12	12	9	9	11	11	1	1	98	100
Accessible bus service	64	65	2	2	11	11	11	11	8	8	2	2	98	100
Accessible train service	75	77	7	7	3	3	3	3	8	8	2	2	98	100
Accessible taxis	67	68	8	8	9	9	9	9	4	4	1	1	98	100

Table 8.5. ECEQ Family & Friends category (Southwest Ireland n=98)

Family and friends Categories	Not needed		Needed and how much it is needed								Missing		Total	
			Yes needed a little		yes needed a lot		no needed a little		no needed a lot					
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Family emotional support	0	0	21	21	91	93	1	1	0	0	4	4	117	119
Emotional support wider family	0	0	10	10	79	81	3	3	2	2	4	4	98	100
Physical help from family	17	17	7	7	73	74	0	0	0	0	1	1	98	100
Physical help from wider family	22	22	12	12	39	40	14	14	8	8	3	3	98	100
Child extra time encourage independence at home	18	18	9	9	64	65	4	4	4	4	3	3	102	104
Positive attitude from family members	0	0	5	5	88	90	1	1	0	0	4	4	98	100
Positive attitude wider family	0	0	2	2	92	94	0	0	1	1	3	3	98	100
Encouragement from family members	0	0	2	2	92	94	0	0	1	1	3	3	98	100
Encouragement from wider family	0	0	9	9	77	79	3	3	5	5	4	4	98	100

9. Discussion & Implications for Service Development

9.1 Summary of Main Findings

Quality of Life

- ◆ For children able to report their QoL, there is no overall difference between those with CP and the general population of children of the same age. However, the factors that influence QoL may be different in children with CP and the general population.
- ◆ Pain reduces QoL across all domains.
- ◆ Walking ability (physical well-being), intellectual impairment (moods/emotions and autonomy) and speech difficulties (relationship with parents) reduce QoL in specific domains.
- ◆ When the child's report of their QoL is compared with what their parents think it is, parents in general underestimate their child's QoL. This difference is greater when parents are experiencing much stress.
- ◆ Children with CP in South-West Ireland do not self-report QoL as being any higher or lower than children with CP in other European countries.

Participation

- ◆ The participation of children with CP is considerably reduced when compared to the general population.
- ◆ Reduced participation is associated with severity of motor impairment (walking ability and/or fine motor skills), intellectual impairment, communication difficulty and pain.
- ◆ Impaired walking ability is the most significant factor in reducing participation.
- ◆ Children with CP in South-West Ireland participate less often in non-discretionary aspects of daily life, such as mealtimes, personal care, communication and mobility, than children in most other European countries.
- ◆ Children with CP in South-West Ireland participate well in discretionary items such as relationships, responsibilities and school-life, but not so well in recreational and leisure in the wider community, such as sports and cultural activities, attending sports or cultural events, or participating in tourist pursuits.

Pain

- ◆ Pain is very common in children with CP and is associated with lower QoL and participation.
- ◆ Reporting of severity and frequency of pain does not vary between levels of impairment.
- ◆ Children with CP in South-West Ireland do not report any more or less pain than children with CP in other European countries.

Parental Stress

- ◆ Parents of children with cerebral palsy experience more stress than parents in general.
- ◆ Parent stress tends to be greater for parents whose children have more severe impairments.
- ◆ Parental stress is associated with poorer reported child QoL across all domains.
- ◆ Parents of children with CP in South-West Ireland do not report higher levels of stress than parents in other European countries, excluding Denmark.

Child Psychological Factors

- ◆ Children with CP have more psychological problems than those children in the general population.
- ◆ Children with CP in South-West Ireland do not have any more or less psychological problems than children with CP in other European countries.
- ◆ Psychological problems are more common in those children with intellectual impairment and mild physical impairment.

Environmental Factors

- ◆ When compared with children with CP in most other European countries, children with CP in South-West Ireland generally do:
 - ✓ Have good access to their physical environment at school and in the community;
 - ✓ Have good access to social support at home and in the community;
 - ✓ Experience positive attitudes of family and friends and teachers/therapists.
- ◆ When compared with children with CP in most other European countries, children with CP in South-West Ireland generally do not:
 - ✗ Have good access to their physical environment at home
 - ✗ Have good access to transport,
 - ✗ Experience positive attitudes of classmates in school.

- ◆ Children with severely impaired walking ability have reduced access to aspects of the physical environment, transport and social support that they need, at home, school and in the community, and they generally experienced less favourable attitudes among family and friends.
- ◆ The only environmental domain not associated with impairment level was the attitudes of teachers and therapists.

9.2 Implications for Service Development

Person-centredness and Individualised Approach

Based on the self-reported QoL findings, we should treat children with CP as we would children from the general population. However, the findings this is based on are specific to an 8-12 year-old population of children with CP, and we should be aware that this may change during the transition to adolescence.

Pain Management

Pain is very common and a consequence of secondary musculoskeletal problems in children with CP. Pain should be assessed early and often, and should be treated as an important and preventable secondary musculoskeletal problem in children with CP.

Coordinated individual pain prevention programmes are required as part of a child's overall management and more research is required to determine the causal pathways and optimal treatment strategies for pain in children with CP.

Service users and families require information and education regarding the development and management of pain in children with CP.

Applied Skill Sets

Children with CP in Ireland require increased intervention and support to participate in non-discretionary aspects of daily life, such as mealtimes, personal care, communication and independent mobility. This support should include interventions aimed at enhancing applied skills sets (functional abilities) and addressing environmental barriers, such as access to the physical environment at home.

We should be aware that person-centred goals to improve specific areas of function, such as mobility, communication, learning, etc., may also target specific aspects (domains) of a child's QoL.

Child Support Services

There is much evidence of the need for psychological intervention in a significant number of children with CP. Assessment and early identification of those children at-risk of developing psychological problems (i.e. those children with both intellectual impairment and mild motor impairment) may be beneficial in terms of prevention of these problems.

Children with more severe motor impairment require enhanced social and emotional support at home, school and in the community.

Family Support Services

Professionals who work with families of children with CP should be aware that parents who are under stress may perceive their child's quality of life as lower than the child themselves. This may lead to negative experiences for the child, and possible exacerbation of stress for the parent.

Family support services should be developed with consideration given to those parents of children with more severe impairments, and should primarily target the information and education needs of the family.

Environmental Access and Adaptation

When compared with most other European countries, there is much evidence of the need in Ireland to physically adapt the home to the needs of the individual and for more availability of accessible transport.

Community Participation and Social Inclusion

Children with CP require more social support from their peers in school, which can be achieved through disability awareness training and addressing the information and education needs of the school and wider community.

Children with CP in Ireland require augmented intervention and support to participate in recreation and leisure activities. This support should include information and education, personal assistance and transport. Local research is required into the availability of accessible recreation and leisure activities in the community and the specific environmental barriers to participation in these activities.

10. Next Steps - SPARCLE 2

10.1 Research

SPARCLE 1 Dissemination

The SPARCLE Research Team has been very productive in disseminating the findings of SPARCLE 1 through academic publications and conference presentations.

To date, articles have been published in highly respected professional journals, such as

- ✓ Lancet,
- ✓ British Medical Journal,
- ✓ Pediatrics,
- ✓ European Journal of Paediatric Neurology,
- ✓ Disability and Rehabilitation,
- ✓ Developmental Medicine and Child Neurology,
- ✓ Archives of Disease in Childhood,
- ✓ Child: Care, Health and Development,
- ✓ Journal of Child Psychology and Psychiatry,
- ✓ Journal of Paediatric Psychology

SPARCLE 2

Given the success of the SPARCLE project to date, all participating centres agreed that it would be very interesting to conduct a follow-up longitudinal study of key outcomes for the SPARCLE participants into the adolescent period (13–17 years), and it was decided to call this second phase of the project SPARCLE 2.

A Plenary Workshop was held in Luebeck in January 2008, where the second phase of the project was discussed in terms of research questions, methodology and potential funding sources. The European Commission Research Framework 7 Programme was researched, but found to be unsuitable to our needs. Each participating centre then agreed to research potential funding sources in their own country. All centres have been successful in doing so, with the Wellcome Trust (UK-Grant number WT086315MA) providing funding for the centres in the UK and Ireland.

As in SPARCLE 1, Research Associates have been recruited in each participating centre to conduct data collection via home visits. The SPARCLE 2 Research Associate for Enable Ireland Cork/Kerry is Ms. Laura O'Connell, MSc (Psych). Data collection will be completed by April 2010 and preliminary results available by December 2010.

SPARCLE 2 Sub-Projects

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 domains of the impact 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.

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 a 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.

The PYPPA Project

The PYPPA Project 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.

PYPPA employs a mixed method design of a population-based survey (Children's Assessment of Participation and Enjoyment [CAPE] and Preferences for Activities of Children [PAC] questionnaires) 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. The PYPPA project aims to explore this reduced participation in more depth: describing the availability and location of various types of activities in the regional community; outlining specific preferences of young people with CP for physical activities; and exploring what young people perceive as the main barriers/facilitators to their participation.

10.2 Service Development & Delivery

Enable Ireland Core Values and Corporate Strategy

Enable Ireland's main Core Value is the Social Model of Disability, which states:

"Enable Ireland focuses on all aspects of an individual's life, particularly in the context of the community and society. We promote the idea that society and the environment must recognise and accommodate individual needs."

The SPARCLE findings can be used to articulate the Social Model of Disability in more depth, describing key aspects of society and the environment which can be altered to promote community participation and social inclusion.

Enable Ireland's Strategic Plan 2009-2011, 'Promoting Inclusion, Enabling Independence', describes 5 Strategic Priorities for improving the lives of our service users:

1. Enhance quality of living for service users through a person-centred approach;
2. Support service users in achieving inclusion and independence within their communities;
3. Provide timely, accurate and accessible information to service users and other stakeholders;
4. Work in partnership with all stakeholders;
5. Support service delivery through continuous improvement.

These Strategic Priorities inform the Operational Plans for our services for the same period.

Enable Ireland Children's Services

Enable Ireland offer a range of services to over 3000 children and their families in the home, school, local community, and from over 20 service centres. Our teams are committed to working in partnership with children and families, using a key-worker system to ensure that our services are responsive and flexible to meet changing needs. With a greater focus on working with children and families at times of transition, we will place an emphasis on supporting them as they progress from childhood to adolescence, and on to adulthood.

The SPARCLE findings can be used to pro-actively plan services which support children and their families as they face these life transitions. Evidence from SPARCLE and other research projects has been used to develop the Enable Ireland Children's Services Operational Plan 2009-2011, which describes the organisation's approach to achieving this. The main Strategic Goals for Children's Services are described below, and are further illustrated by specific examples from Cork and Kerry Services.

1. 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:
 - ◆ We will work in partnership with children and their families through an inter/trans-disciplinary team approach;
 - ◆ We will support every child and their family to make informed choices about their needs, which may be met in a variety of settings. This may include schools, pre-schools and other community settings.
 - ◆ This approach reflects the Life Needs Model of Service Delivery, which is being incorporated into local services in order to facilitate a common approach to preparation of service users and families for important life transitions, and to address the information and education needs of the child, family and wider community.
2. 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:
 - ◆ We will develop an individual service plan (ISP) for every child in partnership with them and focused on agreed outcomes. A major focus will be put on long-term outcomes such as participation and quality of life through the incorporation of the ICF and Life Needs Model into local services.
 - ◆ We will ensure that every child's plan will facilitate their development at each transitional stage in their life as they grow up and in preparation for the adult world;
 - ◆ We will assign a key-worker to every child and their family;
 - ◆ We will provide every child and their family with access to a range of appropriate services which focus on improving activity performance, capability to participate, and quality of life:
 - Postural Management to prevent secondary musculoskeletal problems and pain
 - Assistive Technology to support communication, mobility, education and leisure activities
 - Eating, drinking and swallowing management

- Holiday and respite breaks and family support services
3. We will deliver services to children and their families, and will plan for all periods of transition in preparation for adulthood
- ◆ We will support all children and their families to make informed choices that will maximise each child's opportunities for well-being, inclusion and independence;
 - ◆ We will support children and their families to access a range of community-based educational and other learning opportunities;
 - ◆ We will actively support children to participate in a wide range of leisure activities including cultural, artistic, sporting and other community activities to enrich their experience of childhood;
 - ◆ We will support all children and families advocating for age-appropriate participation in a range of setting in both mainstream and specialist services.

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