

The quality of life of children with cerebral palsy:

the SPARCLE study



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The SPARCLE study

- Study of **P**ARTicipation of Children with cerebral palsy Living in **E**urope

- 9 centres in 7 countries :
 - UK: N Ireland, N England
 - SW Ireland
 - France: S West , S East
 - West Sweden
 - East Denmark
 - Central Italy
 - NW Germany



- CP registers in 8 of 9 centres
- Conducted between 2004/2005
- Involved 818 children with CP aged 8 to 12

www.ncl.ac.uk/sparcle/

The SPARCLE regions



- 1= North England,
- 2= Västra Götaland, West Sweden,
- 3= Northern Ireland,
- 4= Isère, South East France,
- 5= Cork and Kerry, South West Ireland,
- 6= Sealand, Fynen and Islands, East Denmark,
- 7= Central Italy,
- 8= Haute-Garonne, South West France,
- 9= Schleswig-Holstein, North West Germany.

Aim and Hypothesis

- To identify environmental factors that influence the child participation and quality of life of children with cerebral palsy and their families
- Children with similar severity of impairment experience variation of participation and quality of life due to environmental factors.

Quality of life

- Increasingly recognised as important **determinant of health**
- Essential to go beyond **objective** measures to try and capture the child's **subjective** appreciation of his/her life.
- **Multi-dimensional** construct
- Every effort should be made to obtain children's own opinion on their QoL → **self-reported** if possible
- Difficulties in measurement of QoL for children with intellectual impairment → **proxies used** in children with severe disability

Aims

- Assess QoL of *all* children with CP
 - regardless of the severity of impairment
 - using self-report wherever possible
- Study child, parent and professional reports
- Examine determinants of disagreement between respondents

Quality of life measure

- **KIDSCREEN-52** (Ravens-Sieberer et al, 2001)
- **Generic** QoL questionnaire (child and proxy versions)
- Based on **focus groups with children** and parents from several European countries
- 52 items grouped into **10 domains**
 - Physical well-being
 - Autonomy
 - Psychological well-being
 - Moods and emotions
 - Self-perception
 - Parent relations/home life
 - Peers and social support
 - School life
 - Bullying (social acceptance)
 - Financial resources
- Domain scores from **0 to 100** (0=worst QoL, 100=best QoL)

Physical well-being

Explores the level of the child's physical activity, energy and fitness

Psychological well-being

Examines the psychological well-being of the child, including positive emotions and satisfaction with life

Moods and emotions

Covers how much the child experiences depressive moods and emotions, and stressful feelings

Self-perception

Explores whether the child perceives his/her bodily appearance positively or negatively; body image is explored by questions concerning satisfaction with looks as well with clothes and other accessories

Autonomy

Looks at the child's opportunities to create leisure and social time

Parental relations

Examines relationships with parents and atmosphere at home

Social support and peers

Examines the nature of the child's relationships with other children

School environment

Explores the child's perceptions of their cognitive capacity, learning and concentration and their feelings about school

Social acceptance (bullying)

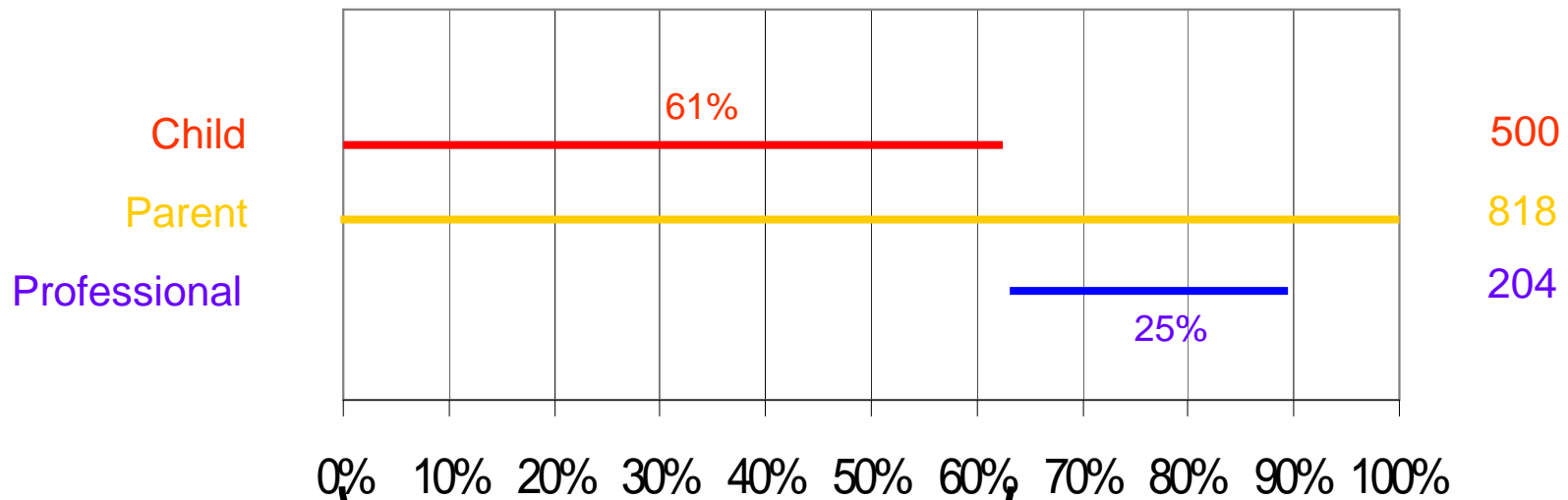
Covers the aspect of feeling rejected by peers

Financial resources

Assesses the child's perceptions of their financial resources

QoL reports in SPARCLE

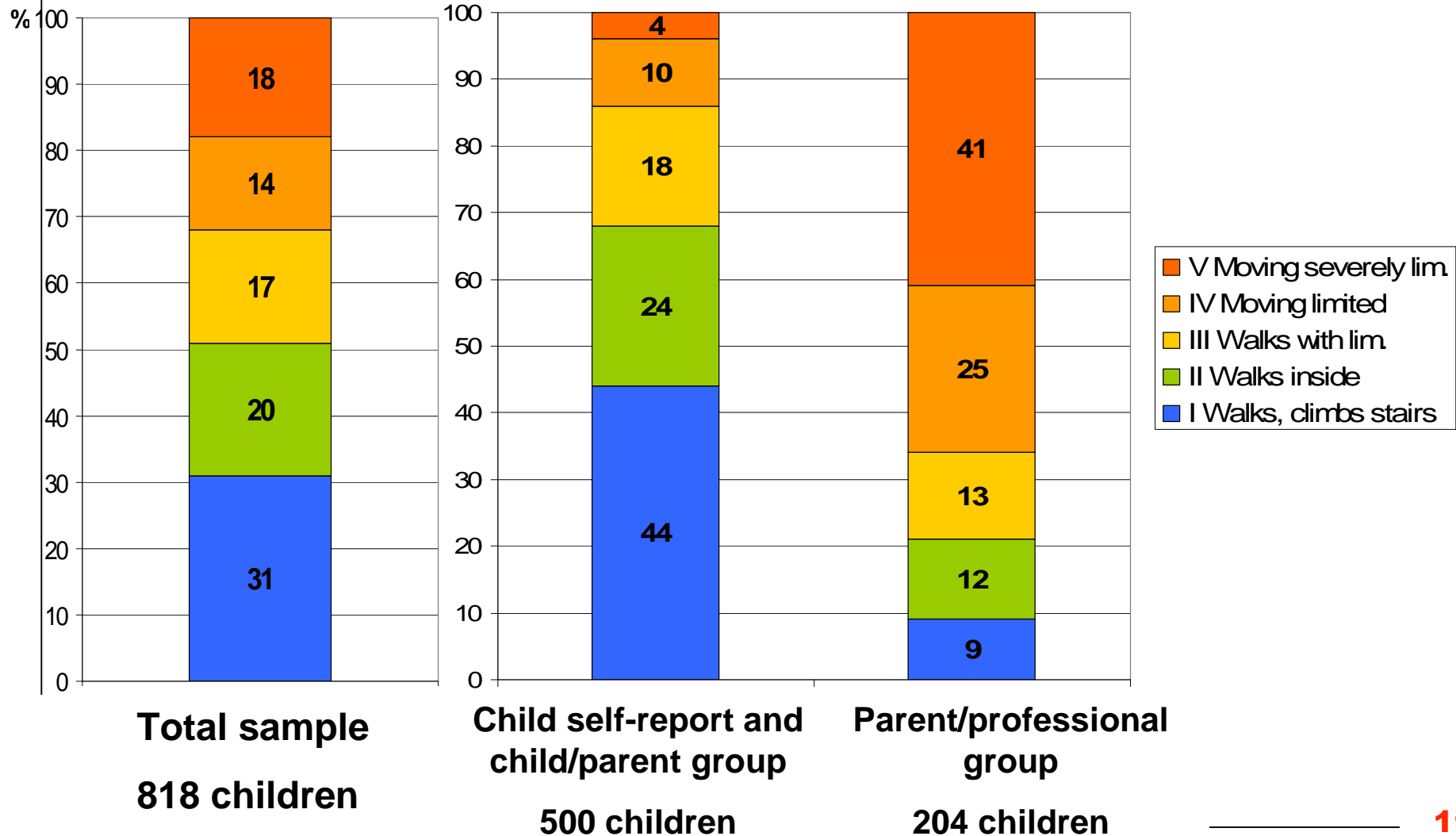
- Child self-reports as often as possible (formal competency assessment)
- Parent reports should be obtained for all children
- Obtain reports from another informant for non self-reporting children
→ professionals (teachers, carers, therapists)



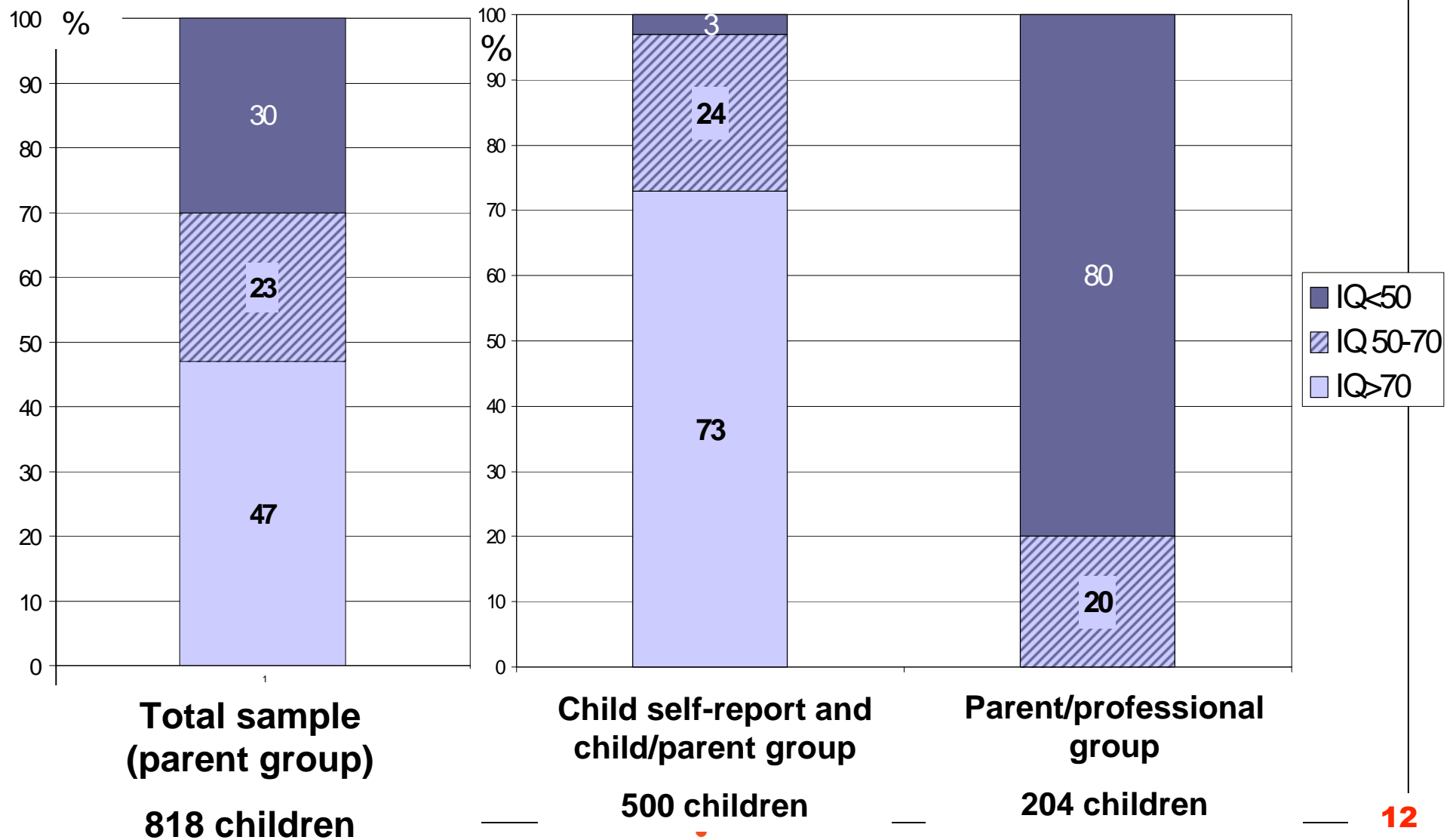
- Child self-report study (500 observations)	- Parent reports of child (818 observations)	- Professional comparison (204 pairs)
- Child/parent comparison (500 pairs)		

Walking ability in each group

Gross motor function (GMFCS)



Intellectual impairment in each group (IQ)



Papers on QoL

- Preliminary paper

- White-Koning. **Subjective quality of life in children with intellectual impairment – how can it be assessed?** *DMCN* 2005; 247: 281–285

- Papers of results

- Arnaud. **Parent-Reported Quality of Life of Children With Cerebral Palsy in Europe.** *Pediatrics* 2008;121;54-64
- Dickinson. **Self-reported quality of life of 8–12-year-old children with cerebral palsy: a cross-sectional European study.** *Lancet* 2007; 369: 2171–78
- White-Koning. **Determinants of Child-Parent Agreement in Quality-of-Life Reports: A European Study of Children With Cerebral Palsy.** *Pediatrics* 2007;120;e804-e814
- White-Koning. **Parent and professional reports of the quality of life of children with cerebral palsy and associated Intellectual impairment.** *DMCN* 2008, 50: 618–624

Child self-reported QoL (1)

- Aims :
 - describe QoL of children with CP as reported by the children themselves
 - identify factors that affect QoL
 - compare with QoL of children in the general population

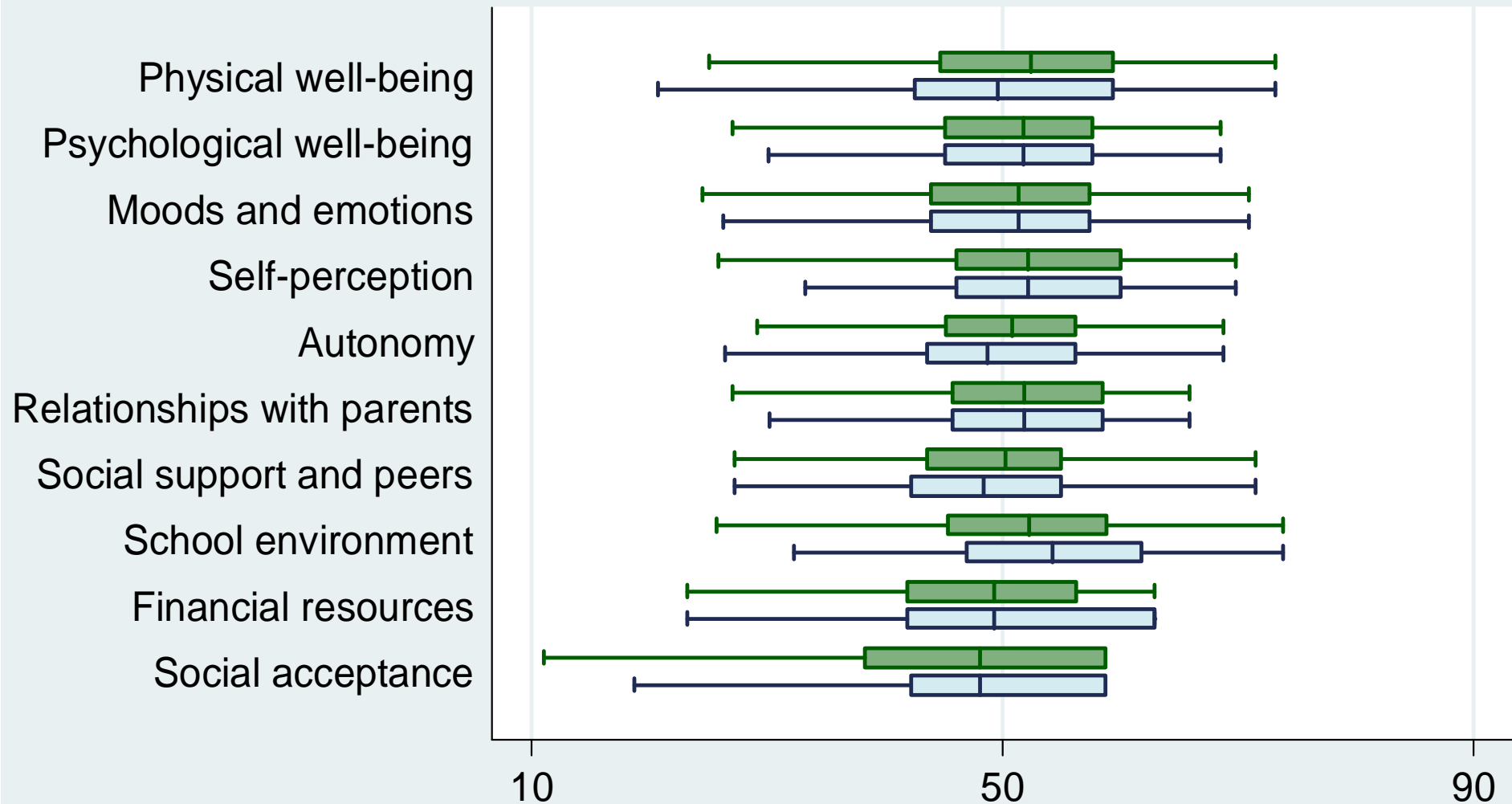
Number of children in the group : **N=500**

Dickinson *et al.*, 2007, Lancet

Child self-reported QoL (2)

- QoL of self-reporting children with CP similar to QoL of children in general population
 - except for the *School environment domain* (explores the child's perceptions of their cognitive capacity, learning and concentration and their feelings about school) where children with CP reported a significant better QoL
 - *Physical well-being* domain not formally analyzed: slight modification to one item for children with CP
- Perspective of the child
 - sense of self from birth incorporates their impairment
 - lives as most children

KIDSCREEN quality of life scores by domain



Children in general population
Children with cerebral palsy

Median, inter-quartile range and adjacent values are shown

Child self-reported QoL (3)

- Specific impairments associated with poorer QoL (4 domains)
 - poorer walking ability with poorer *Physical well-being*,
 - intellectual impairment (IQ<70) with poorer *Moods and emotions* and with less *Autonomy*
 - speech difficulty with poorer *Relationships with parents*
- In most aspects, QoL not associated with impairments: likely to be determined by social and environmental factors
 - cross-sectional study design
 - BUT improvement in physical function, speech or communication might enhance QoL

Child self-reported QoL (4)

- Children who reported pain tended to have lower QoL in all domains
 - significant association in *Physical well-being, Moods and emotions, Self-perception, Autonomy, Relationships with parents* and *School environment*.
 - 54% experienced pain/discomfort in the previous week (> general population)
-
- Important and consistent association
 - BUT
 - Source of the pain not studied
 - Children with poor QoL might perceive pain differently or report emotional distress as pain

Parent-reported child QoL (1)

Aim:

- **Determine** whether the type and severity of the child's motor and associated impairments, as well as the family context (socio-economic factors and parental stress), influence the child's QoL as reported by the parents

Number of children in the group : **N=818**

Arnaud *et al.*, 2008, Pediatrics

Parent-reported child QoL (2)

Domains	Responders	Median	IQR
Physical well-being	97%	55	40 - 70
Autonomy	95%	65	50 - 75
Psychological well-being	96%	75	63 - 83
Mood and Emotions	94%	82	75 - 93
Self perception	93%	80	70 - 90
Parent relations and home life	96%	79	67 - 92
Peer and social support	93%	50	33 - 67
School life	95%	75	63 - 83
Bullying (social acceptance)	94%	92	75 - 100
Financial resources	79%	75	50 - 92

Parent-reported child QoL (3)

Factors associated with poor QoL (scores <25^e p)

- **Motor function**

- QoL worsens in the *Physical* and *Autonomy* domains as severity of motor impairment increases
- **BUT** children with least motor impairment have worst QoL at *School* and for *Social acceptance*

	Physical	Autonomy	School	Bullying
Motor function				
Walks, stairs	1	1	1	1
Walks inside	2.2	0.8	0.6	0.7
Walking limited	3.4	2.1	0.4	0.4
Moving limited	4.7	1.6	0.3	0.2
Moving sev. lim.	12.4	2.6	0.4	0.1

Parent-reported child QoL (4)

Factors associated with poor QoL (scores <25^e p)

- **IQ level**

- QoL in the *Social support* domain decreases as severity of intellectual impairment increases
- **BUT** children with IQ<50 have better QoL in terms of *Moods and Emotions* and *Self-perception* than less impaired children

	Moods	Self-percep.	Soc. supp.
IQ level			
>70	1	1	1
50-70	0.7	0.6	1.7
<50	0.3	0.3	2.7

- **Pain** (parent reports, p=70%) increases risk of poor QoL in the *Physical, Psychological WB* and *Self-perception* domains

Parent-reported child QoL (5)

Family and environment factors

- Parents with **higher levels of stress** were more likely to report poor QoL for their child *in all domains*

Cause or consequence ?

Importance of considering mothers (both parents) well-being

- Parents with **high educational qualifications**: increased risk of poor QoL in the *Parental relations*

Higher expectations for their child, differences between expectations and reality negatively influence their assessment

- Those living in **single parent households** had poor QoL in the *Mood and emotions* domain

Discussion (1)

- SPARCLE: **large population-based study** of children with CP across full spectrum of disability
- Most children (including those with moderate intellectual impairment) can and should **self-report QoL**, using instruments which are
 - **Generic**: same universal standards of QoL
 - **Subjective and objective**
 - Based on **children's perspective**
 - Preceded by **assessment of child's ability** to understand and use Likert scales
- 500/818 children self-reported including 134 with intellectual impairment

Discussion (2)

- **Child pain:** most important factor associated with child QoL according to all respondents
 - Need more detailed information concerning location and cause
 - Efforts should be made to evaluate and alleviate pain in CP children
- **Children, parents and professionals have different perspectives**
 - Need **multiple informants** for valid assessment of child QoL
- **Child/parent and parent/professional comparisons**
 - Children rate their QoL higher than their parents
 - Parents and professionals disagree but no consistent pattern
- Take **parental stress** into account
 - in **research** → as affects parents' reports of child QoL
 - in **practice** → pay attention to parent's well-being

SPARCLE in adolescence

- **Objectives**

- To describe the evolution of QoL and participation of adolescents with CP at the period of transition from childhood to adulthood
- To study the type and intensity of evolution (improvement or decline) of these factors and the links with the environmental factors.

- **Others topics (French centres)**

- Social support
 - to evaluate the role of perceived social support, especially family support (in particular the siblings' role in the support network) in relation to the QoL and Participation
 - to study whether the teenager seeks social support, reflecting his/her capacities of adaptation and his/her degree of autonomy
- Bullying (HBSC questions)

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<http://www.ncl.ac.uk/sparcle/>



Study of Participation of Children with Cerebral Palsy Living in Europe

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Funding

Welcome to this site about a research study called SPARCLE which aims to discover the best ways of promoting the quality of life and participation of children with cerebral palsy in Europe.

SPARCLE stands for the Study of PARTICipation of Children with cerebral palsy Living in Europe.

"The individual is rarely going to be altered very much whereas the environment slowly but surely can"

Tom Shakespeare