Quality of life and participation of 8-12 year old children with cerebral palsy

Introduction to SPARCLE study

Allan Colver
Professor of Community Child Health
Outline of my presentation

- Concepts
- SPARCLE study - methods
Social model of disability

Individual
- Personality
- Impairments of different severities

Environment

Participation

Quality of Life
The “social model of disability” regards disability as resulting from the interaction between individuals and their respective Environments, rather than as something intrinsic to or residing in the individual. The individual is “disabled” by society. Why I use disabled child rather than child with disability.

Where society does not provide sufficient environmental adjustment ensure good QoL and full participation, then this is discrimination against a minority group and a denial of their human rights.
Baby

To give and example, a normal newborn baby has very many impairments or restrictions compared to an independent adult – he is incontinent, he can not speak, he can not move about etc. But society and the environment make great adjustments. Mothers spend much time with the baby. Grandparents and neighbours help. Parents are allowed time off work. Special clothes and milks and foods are available on every high street. So a baby is impaired but is not disabled because society and the environment adjust to meet his needs. This often does not happen for a person with cerebral palsy.
Social model of disability

The disablement or disadvantage experienced by people with impairments concerns their:

Restricted Participation

and

Reduced Quality of Life
International Classification of Functioning, Disability and Health - WHO 2002

Body structure and function
Activity
Participation
Context

Environmental factors
Personal factors
Some areas of children’s participation

Responsibilities: money, shopping, helping others, helping at home

Maintaining relationships: parents, siblings, friends, teachers

Community life: clubs, church, charity work

Education: getting to school, getting about school, homework

Recreation: sport, films
The term Participation has replaced Handicap

- Concept applies to all, not just disabled people
- Positive rather than negative connotations
- Difficulties do not reside in the individual - rather in the interaction between the individual and their environment
## Environmental factors

### Attitudinal
- Positive attitudes
- Encourage independence
- Inclusiveness
- Attitudes of
  - Family
  - Peers
  - Teachers
  - Therapists
  - Strangers
  - Services

### Social
- Inclusiveness
- Emotional support
- Physical support
- Communication
- Time
- Service co-ordination

### Physical
- Adaptations
- Access
- Toilets
- Transport
- Aids
- Finances
- Services
WHO Definition of Quality of Life

Quality of Life is the 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.
Quality of Life domains

Perception of:
- Emotional wellbeing
- Interpersonal relations
- Material wellbeing
- Physical wellbeing
- Self esteem
- Self determination
United Nations

- UN Convention on Rights of the Child 1989
  Article 12. Children's views must be taken into account in all matters concerning them

- UN Convention on Rights of Persons with Disabilities 2006
  Article 7. Disabled children have the right to express their views
Like Participation, QoL is a concept which applies to all people.

Both concepts apply to all people.

Inherent biases in both coming from especially doctors and therapists.

Also results must be interpreted in context of general population data.
Review of studies

In respect of QoL, the results of studies are contradictory. In some, type and severity of impairment is strongly associated with QoL, in others it is not. But nearly all these studies are problematic:
Similar contradictory results when comparisons are made between children with cerebral palsy and the general population of children of that age
Small sample, convenience samples, 30 – 60 children
Wide age range 4-18, Usually parent reported
Instruments like CHQ and PedsQL do not really measure QoL – rather health status and function. Function will usually be reduced and therefore by definition QoL would be

whereas results on Participation do not
Review of studies

Results of studies of QoL conflict

whereas results on Participation do not
For disabled children:

- Unavoidable participation is more difficult and needs much assistance.
- Frequency (intensity) of discretionary participation is broadly similar to that of the general population. Some participation occurs less often, some as often or more. Participation decreases with age in all children.
- Diversity of discretionary Participation is reduced.
- Informal discretionary participation is achieved better than formal.
Study of PARticipation of Children with cerebral palsy Living in Europe

www.ncl.ac.uk/sparcle/

1.4 million euros
European Union Grant QLG5-CT-2002-00636
<table>
<thead>
<tr>
<th>Centre</th>
<th>Partner</th>
<th>Research Associates</th>
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<tbody>
<tr>
<td>Newcastle</td>
<td>Allan Colver</td>
<td>Kathryn Parkinson, Heather Dickinson, Kerry Anderson</td>
</tr>
<tr>
<td>Goteborg</td>
<td>Eva Beckung</td>
<td>Malin Carlsson</td>
</tr>
<tr>
<td>Belfast</td>
<td>Jackie Parkes</td>
<td>Ann Madden</td>
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<tr>
<td>Grenoble</td>
<td>Jerome Fauconnier</td>
<td>Ondine Pez</td>
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<tr>
<td>Cork</td>
<td>Formerly Vicki McManus,</td>
<td>Louise Gibson</td>
</tr>
<tr>
<td></td>
<td>Now Alan Lyons</td>
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<tr>
<td>Copenhagen</td>
<td>Susan Michelsen</td>
<td>Eva Eriksen</td>
</tr>
<tr>
<td>Viterbo/Rome</td>
<td>Giorgio Schirripa (deceased), Marco Marcelli</td>
<td>Barbara Caravale, Jude Canute</td>
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<tr>
<td>Toulouse</td>
<td>Catherine Arnaud</td>
<td>Melanie White-Koning, Delphine Fenieys</td>
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<tr>
<td>Lübeck</td>
<td>Ute Thyen</td>
<td>Bettina Gehring, Heidi Kiecksee</td>
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Title of SPARCLE study

The influence of Environmental Factors on the Participation and Quality of Life of 8-12 year old children with cerebral palsy in 7 EU countries
Main hypothesis

Children with similar severity of cerebral palsy will experience variable outcomes in different countries due to variation in environmental factors.
Methods

Year 1
• Instrument choice and translation
• Ethics approval
• Appoint and train research associates
• Development of instrument for local environmental factors

Year 2
• Visits to children and their families

Year 3
• Analysis
## Number of children in study

<table>
<thead>
<tr>
<th>Centre</th>
<th>No. of children</th>
<th>No. (%) of males</th>
<th>Median age in years (IQR)</th>
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<tbody>
<tr>
<td>North England, UK</td>
<td>116</td>
<td>74 (64)</td>
<td>10.5 (2.5)</td>
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<tr>
<td>West Sweden</td>
<td>83</td>
<td>44 (53)</td>
<td>10.5 (2.1)</td>
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<tr>
<td>Northern Ireland, UK</td>
<td>102</td>
<td>63 (62)</td>
<td>10.3 (2.3)</td>
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<td>Southeast France</td>
<td>67</td>
<td>38 (57)</td>
<td>10.6 (2.4)</td>
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<tr>
<td>Southwest Ireland</td>
<td>98</td>
<td>53 (54)</td>
<td>10.2 (2.3)</td>
</tr>
<tr>
<td>East Denmark</td>
<td>115</td>
<td>73 (63)</td>
<td>10.5 (2.9)</td>
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<tr>
<td>Central Italy</td>
<td>85</td>
<td>47 (55)</td>
<td>10.4 (2.5)</td>
</tr>
<tr>
<td>Southwest France</td>
<td>77</td>
<td>48 (62)</td>
<td>10.3 (3.1)</td>
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<tr>
<td>Northwest Germany</td>
<td>75</td>
<td>43 (57)</td>
<td>10.1 (2.8)</td>
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<tr>
<td><strong>Total</strong></td>
<td><strong>818</strong></td>
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Results

• Publications can be downloaded from:

www.ncl.ac.uk/sparcle

Main ones so far are in Lancet, Pediatrics, Journal of Child Psychology and Psychiatry, Developmental Medicine and Child Neurology, Paediatric Psychology
Results are robust because:

– large sample
– population based
– randomly selected
– many countries
– home visits
– high quality statistical analysis
– general population comparisons