An ethical dilemma: How can we authentically represent the voices of disabled children and young people about their views, experiences and choices for participation in recreational activities?

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Nottingham, June 2018
Aim of paper

• To explore issues around the authentic engagement and representation of disabled children and young people in research.
• Describe how visual methods were used, as part of a multiple comparative case study design.
• The need to anonymise the visual data can lead to a loss of meaning, whilst still revealing some real aspects of their lives.
VOCAL study

PhD : ‘VOCAL’ study title- “Beyond Physiotherapy: Voices of children and young people with cerebral palsy and their parents about ‘Participation’ in recreational activities.”

- My position as a former children’s physiotherapist- voices of children often missing in treatment choices-‘Rights’.
- Method-Case study design using creative, visual and participatory approaches with disabled children and young people, aged 9-16 years, with walking communication and learning disabilities.
- 7 Case studies, 4 who did participate and 3 who did not.
- Each case included: 2 interviews (some with children and young people, some with parents), 12 weeks apart, a diary of recreational activities recorded and an observation of an activity during this period where non identifiable photographs were taken.

• Disabled children’s childhood studies demands **ethical research practices** that position disabled children and young people at the centre of the inquiry outside of the shadow of the perceived ‘norms’: Re-imagining their futures. Researching ‘with’ not ‘on’ disabled children and young people.

• Those with most severe disabilities usually excluded from research.

‘Have the right to rest, leisure, play and recreation and to take part in cultural and artistic activities’

http://www.playwales.org.uk/eng/
Research Question and Aims:

• **Research question**
  - How do children and young people with cerebral palsy and their carer’s view, experience and choose their level of participation in recreational activities?

• **Study Aims**
  - The 2 aims of this study were to explore participants’:
    - Views, experiences and choices for their level of participation in recreational activities, including barriers and facilitators.
    - Perceptions of the effect of their level of participation upon their emotional wellbeing.
Background: Cerebral Palsy

- Cerebral Palsy - long term condition affecting motor and sensory control

- Gross Motor Function Classification System (GMFCS) - 5 levels of ability

- Seeking to explore their views, experiences and choices about meaningful participation in recreational activities - less choices

- Little known yet about their emotional wellbeing.

GMFCS E & R Descriptors and Illustrations for Children between their 6th and 12th birthday

**GMFCS Level I**
Children walk at home, school, outside and in the community. They can climb stairs without the use of a railing. Children perform gross motor skills such as running and jumping, but speed, balance and coordination are limited.

**GMFCS Level II**
Children walk in most settings and climb stairs holding onto a railing. They may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas or confined spaces. Children may walk with physical assistance, a handheld mobility device or use wheeled mobility over long distances. Children have only minimal ability to perform gross motor skills such as running and jumping.

**GMFCS Level III**
Children walk with a hand-held mobility device in most indoor settings. They may climb stairs holding onto a railing with supervision or assistance. Children use wheeled mobility when traveling long distances and may self-propel for shorter distances.

**GMFCS Level IV**
Children use methods of mobility that require physical assistance or powered mobility in most settings. They may walk for short distances at home with physical assistance or use powered mobility or a body support walker when positioned. At school, outdoor and in the community children are transported in a manual wheelchair or use powered mobility.

**GMFCS Level V**
Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements.

Palisano et al, 1997; Reid et al, 2011
Justification of inclusion criteria

- Levels III-V of the Gross Motor Function Classification System (GMFCS) - natural decline

- Children and young people (CYP) with cerebral palsy aged 9-16 years

Hanna et al., 2008
Appendix 2: Multiple Case study procedure adapted from Yin (2014) p 60

Define and Design

- Develop ideas: ‘Participation and Children and Young People’s Rights- article 31’ UNCRC
- Design data collection protocol
- Select cases: Pilot x 2

Prepare, Collect and Analyse

- Conduct Case study 1: Participation
  - Write individual case report
- Conduct case study 2: Non participation
  - Write individual case report
- Conduct remaining Case studies (8 total in total)
  - Write individual case reports

Analyse and Conclude

- Draw within case conclusions
- Intuiting: Draw cross case conclusions
- Develop theory, new knowledge
  - Develop Policy Implications
  - Write cross case report

- Challenge of consent, anonymity and confidentiality - celebrate their enjoyment/ social media- ‘ethical covenant’ (Prosser, 2013).

- Facial expression sometimes missing, other cues from their interaction with equipment and environments.

- Parental consent.

- Data collected from March 2017-March 2018
Method: Interviews using Symbolic play and Drawings

Symbolic and sensory play to engage in story

Drawings (Pickering and Pickering, 2015)
Method: Interactive interviews with Children and young people: iPad

Lily May 16 years: Experiences and choices

How I feel

I was asked ‘why I am doing this research?’ via the iPad with a key guard
Method: Computer communication

Clare 9 years (GMFCS IV): Experiences and choices: I want to ride my bike……

Limitation:
‘Views’ difficult to explore further when participants using a communication aid.
“….That was a really amazing day (aged 2 years) because I suddenly thought wow she can cycle, if you've got the right equipment, you can do practically anything as long as you can find the right equipment. Because up until then I kind of thought it's such a small world, you can't do anything and then suddenly I thought, right if we've got the right equipment, the world’s our oyster we can do it…..”

Anonymity: Unable to see joy on her face
Method: Observation (field notes): some Visual data

Matthew (14 years): Skiing -
www.icecoolkids.org

Surfing - www.surfabilityukcic.org/
Race Runner used by Nick

Would the spinner toy identify him?
Eye Gaze technology – pre-linguistic choices ‘Poppy’ (9 years)
Participation ‘on own’
Bree: Touch Therapy/ Brownies
Music as a language - creativity - each instrument played in interview 2
James (14 years): Gastrostomy feeding observation: Surviving

- Gastrostomy feeding in public places - surviving
- Play scheme ‘normalised’ this behaviour as other parents carrying out feeds
Interactive museum: Sensory experiences
Thriving- James (14) enjoying ice cream and cone, bowling
Visual views of what participants can see: James and Poppy

- Big Wheel, Winter Wonderland
- Transparent lift in indoor museum
- Heights of fences
I have socially constructed their stories by including the visual to provide context of equipment and environments that support their participation: Innovation

Is the way I have utilised the visual data authentic to represent their views, experiences and choices? Could I have described the event to portray the same meanings?

Working with analysis of data to explore theoretical ideas.
Questions?

Acknowledgments to the School of Healthcare Sciences and the Chartered Society of Physiotherapy for part funding this PhD: NP/15/03; ISTCRN number: 42717948.

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