The Authenticity of Visual Methods with Disabled Children and Young People who seek to Participate in Recreational Activities.

Dawn Pickering, Staff candidate,
Part time PhD student,
School of Healthcare Sciences, Cardiff University
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Myths, Methods, and Messiness
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Aim of paper

This paper will discuss the authenticity of use of visual data with non-verbal disabled children and young people to represent their ‘voice’.

• Brief background to the context will be given
• My position as the researcher
• Ethical research design: consent/assent: Anonymity and Confidentiality
• Analysis of visual data -2 case study examples -Messy process
• Representation of visual with text
• Discussion around the added value of the visual data
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 disabled 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 participated a lot in recreational activities and 3 who had limited participation.
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 the emotional well-being impact.

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 using a handheld 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 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*
Ethical position: Inclusive research (Runswick-Cole et al, 2017)

- Researching ‘with’ not ‘on’ disabled children and young people.

- Those with most severe disabilities usually excluded from research— is it a ‘Myth’ that they cannot be included?

- Pilot data: Chapter 9
  https://doi.org/10.1057/978-1-137-54446-9_9
Emotional well-being of non-verbal children and young people

• Future Generations and Well-being Act (Wales) 2015:
“For you to be able to have fun, you need lots of chances to play sport, read books, go to the theatre and go to museums” pg 2.

• Facial expression sometimes missing, other cues from interaction with equipment and environments: Intentional behaviours.

• Well-being scales that are valid and reliable for this group?

• No straightforward data collection tool
• ‘Gillick’ competency – Assent (Thackeray, 2017).

• Challenge of consent, anonymity (risk) and confidentiality- celebrate their enjoyment/ social media- ‘ethical covenant’ (Rose, 2012; Wiles et al 2012; Prosser, 2013).

• Parental consent- could retract later on if participant changes their mind, but too late if images used in publication.
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 well-being.
Each case included:

- 2 interviews (some with children and young people, some with parents) 12 weeks apart
- A written diary of recreational activities recorded by them which included some photographs sent to the researcher or printed in the diary
- An observation of an activity during this period where non identifiable photographs were taken by the researcher.
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’ UN CRC
- Design data collection protocol
- Select cases: Pilot x 2

Prepare, Collect and Analyse

- Conduct Case study 1: Participation
- Conduct case study 2: Non participation
- 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

Analysis at Jan 2019-7 cases
### Analysis: Braun and Clark’s (2013) stages of analysis

<table>
<thead>
<tr>
<th>Phases</th>
<th>Description of the process</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Familiarise yourself with your data</td>
<td>Transcribe data, reading and re-reading the data, noting down initial ideas</td>
</tr>
<tr>
<td>2. Generating initial codes</td>
<td>Code interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code</td>
</tr>
<tr>
<td>3. Searching for themes</td>
<td>Collating codes into potential themes, gathering all data relevant to each potential theme</td>
</tr>
<tr>
<td>4. Reviewing themes</td>
<td>Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic ‘map’ of the analysis</td>
</tr>
<tr>
<td>5. Defining and naming themes</td>
<td>Generating clear definitions and names for each theme</td>
</tr>
<tr>
<td>6. Producing the report</td>
<td>Producing a scholarly report of the analysis</td>
</tr>
</tbody>
</table>
27/7 Much more awake today and eaten much better. Toes are going back to normal and sitting in his chair for longer periods. Had a walk (in chair) over to Tesco in the evening—a breath of fresh air. Did some painting with his niece although he wasn't very interested.
<table>
<thead>
<tr>
<th>James/ Ruth Datasets</th>
<th>Word count TOTAL</th>
<th>Views (by proxy from Mum)</th>
<th>Experiences:</th>
<th>Choices</th>
<th>Emotional well-being indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interview 1</td>
<td>16,051</td>
<td>James has calming effect on you.</td>
<td>29th foster child (10 months) Epilepsy limits what can do- how far venture. Physically waring- ‘turmoil’, ‘absolutely shattered’.</td>
<td>Foster Mum plans to become adult carer. Hydrotherapy. When in pain can stretch him out. Enjoys food but</td>
<td>Epilepsy- cope with seizures at home. Affects level of alertness. Sleeps a lot during the day. Has a monitor for fits.</td>
</tr>
</tbody>
</table>
### Themes and Subthemes

<table>
<thead>
<tr>
<th>Theme</th>
<th>Subthemes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Internal: Personal well-being</td>
<td>Observed behaviours</td>
</tr>
<tr>
<td></td>
<td>Intentional play</td>
</tr>
<tr>
<td>External: Attitudes towards Disability</td>
<td>Behaviours in public spaces</td>
</tr>
<tr>
<td></td>
<td>Reasonable adjustments explored</td>
</tr>
</tbody>
</table>
James (14 years): ‘Behaviours in public spaces’

Gastrostomy feeding observation:

Field notes:

176 Ruth starts to give him fluids via his gastrostomy tube (Picture 12).
177 There are 2 other children being fed with a gastrostomy tube outside.
178 No one seems to be bothered about this as it is a usual activity.

– Play scheme ‘normalised’ this behaviour as other parents carrying out feeds
As James was gastrostomy fed to maintain his body weight, it was interesting at the play scheme to see him being fed outside. This would be unusual to see in a local park area, but in this space there were several families doing the same and no one was perturbed by this. This is shown in Figure 5.

Figure 5: James being gastrostomy fed (Observation field notes line 192)

James can be seen in Figure 5 enjoying the music time whilst being fed, thus participating in a meaningful activity for him.
Poppy went to Winter Wonderland, he loved going on the rides and the big Wheel. It was quite cold and there aren’t any changing facilities here so we only stayed about an hour. We have to lift Poppy onto the rides and go on them with him, but he loves them and really enjoyed his time at the fair.
• Where I chose to use an image I wrote text in the paragraph and gave a heading to guide the reader.

In fact at one of these farm events, Poppy had been unable to access a bat crawl due to fence being too low. This is illustrated by Figure 5.

**Figure 5: Poppy excluded from bat crawl (Diary entry line 55 picture 7)**

It was evident that this bat crawl activity was aimed at children who could physically crawl which Poppy found difficult and the fence was too low to enable him to get in with his wheelchair. It would appear no thought had been given to adapt this activity to view the bats.
Poppy has a trampoline, swing, slide, hot tub, tricycle, all terrain chair and walking frame, but during this process we have realised that when the nights are cold and dark we don’t use these things with him. The days seem so short and we seem to spend a lot of time playing in the house.
### Themes within case

- **Example of Poppy’s themes**

<table>
<thead>
<tr>
<th>Theme</th>
<th>Subtheme</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Intrinsic factors:</strong></td>
<td></td>
</tr>
<tr>
<td>Idiosyncratic ways to communicate well-being</td>
<td>Non-verbal communication</td>
</tr>
<tr>
<td></td>
<td>Behaviours that challenge Technology assistance</td>
</tr>
<tr>
<td><strong>Extrinsic factors:</strong></td>
<td></td>
</tr>
<tr>
<td>People’s attitudes towards disabled children</td>
<td>Being treated differently</td>
</tr>
<tr>
<td></td>
<td>Adapted equipment and environments</td>
</tr>
</tbody>
</table>
How have the visual methods added value to my data?

• Helped me with the context and recall during analysis

• Provided evidence of emotional well-being for me to analyse

• Provided discussion around the myth of excluding disabled children

• Triangulation of different data sources added to the rigour/trustworthiness of the study
I have socially constructed their stories by including the visual to provide context of equipment and environments that affected their level of participation. This rich data has added value to the interviews and written diaries.

It remains a challenge how to understand and represent their emotional well-being as their cues are not always the same as typically developing children-only 1 child had evidence of an observational emotional well-being scale: Leuven scale.

It is essential to have someone who knows them well to give evidence on their behalf—in my case this was their parents and a foster parent.
VOCAL ‘Visual’ Dissemination for non verbal children and young people
Questions?

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Supervisory team: Dr Paul Gill, Dr Carly Reagon and Dr Jane Davies
Dawn Pickering, Staff PhD Candidate,
Cardiff University’s School of Healthcare Sciences; pickeringdm@cf.ac.uk,
Twitter: @DawnMPickering