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

Dawn Pickering, Staff candidate, Senior Lecturer, Physiotherapy, Part time PhD student (Year 4 of 5), School of Healthcare Sciences, Post Graduate Research Symposium, Cardiff University 10th April 2019
Aim of this paper

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

• Brief background to the context of cerebral palsy
• My position as the researcher
• Ethical research design: consent/assent: Anonymity and Confidentiality
• Analysis of visual data -2 case study examples
• 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

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

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

- Little known yet about the emotional well-being impact

Palisano et al, 1997; Reid et al, 2011

Inclusion criteria: Ages 9-16 years
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

• 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

• Likely Theme identified so far: “Tenuous well-being indicators”
• ‘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.
Construction of case study

• 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

• Where possible 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’ UNCRC
- Design data collection protocol
- Select cases: Pilot x 2

Prepare, Collect and Analyse

- Conduct Case study 1: Participation
- Write individual case report
- Draw within case conclusions

- Conduct case study 2: Non participation
- Write individual case report
- Draw within case conclusions

- Conduct remaining Case studies (8 total) in total
- Write individual case reports

Analyze and Conclude

- Intuiting: Draw cross case conclusions
- Develop theory, new knowledge
- Develop Policy Implications
- Write cross case report
### 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>
Findings: Diary data – Stage 2 coding James

47  27/7 Much more awake today and eaten much better toes are going 
48  back to normal and sitting in his chair for longer periods. Had a walk (in 
49  chair) over to Tesco in the evening- a breath of fresh air. Did some 
50  painting with his niece although he wasn’t very interested.

[Image] James painting 1

47  27/7 Shower this morning and open air theatre in the afternoon to see 
48  Aladdin (Burial) 
49  29/7 Watch a pattern taster session 
50  2/8 Went to museum to see dinosaur exhibition with friends. Lift not 
51  working so needed to ring and be admitted through staff entrance.
<table>
<thead>
<tr>
<th>James/ Ruth Data sets</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></td>
<td>26,975</td>
<td>James has calming effect on you.</td>
<td>29th foster child (10 months) Epilepsy limits what can do- how far venture. Physically warping-'tumour', '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>
<tr>
<td>Interview 1</td>
<td>16,051</td>
<td>Was fading prior to scoliosis surgery-now well.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### James: Stage 3: 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.
In fact at one 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.

Commented [DP59]: Trampoline, swing, slide, hot tub, tricycle, all terrain chair and walking frame- but in winter months don’t use them- mainly plays in house
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 excluding disabled children who have communication and learning difficulties
- Triangulation of different data sources has 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.
VOCAL ‘Visual’ Dissemination for participants
Questions?

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Next presentation: Poster, Sept 2019: American Academy of Cerebral Palsy and Developmental Medicine: 73rd Annual conference in Anaheim, California, USA. This is a shared conference with the Alliance of Academics in Childhood Disability.