

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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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



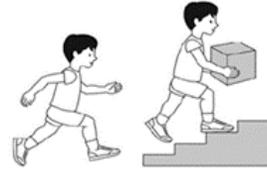
PhD : ‘VOCAL’ study title- “**Beyond Physiotherapy: Voices of children and young people with cerebral palsy and their parents about ‘Participation’ in recreational activities.**”

- 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.



- 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, outdoors 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 hand-held mobility device or used 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 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, outdoors 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.

GMFCS descriptors copyright © Palisano et al. (1997) Dev Med Child Neurol 39:214-23
CanChild: www.canchild.ca

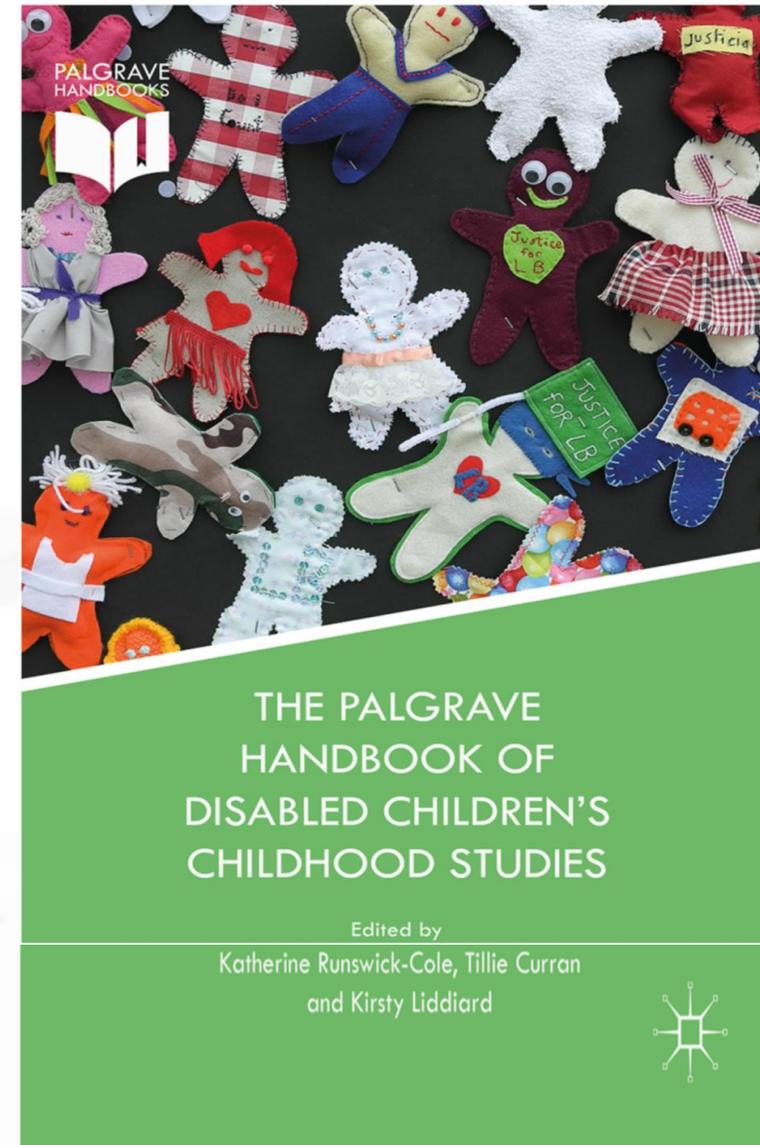
Illustrations copyright © Kerr Graham, Bill Reid and Adrienne Harvey,
The Royal Children's Hospital, Melbourne

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



- 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**

- 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.

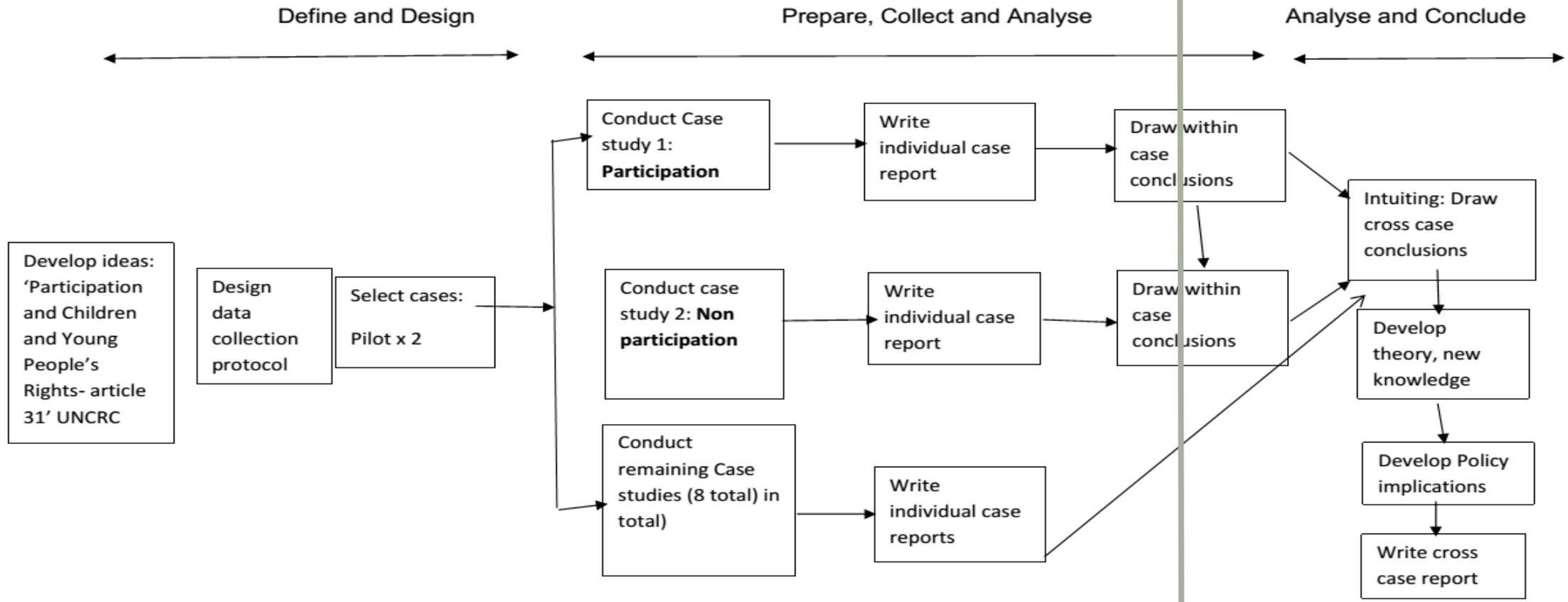


- Each case included:
- 2 interviews (some with children and young people, some with parents)
12 weeks apart
- A written diary of recreational activities recorded by them which included some photographs sent to the researcher or printed in the diary
- An observation of an activity during this period where non identifiable photographs were taken by the researcher.



Appendix 2: Multiple Case study procedure adapted from Yin (2014) p 60

Analysis at Jan 2019-7 cases

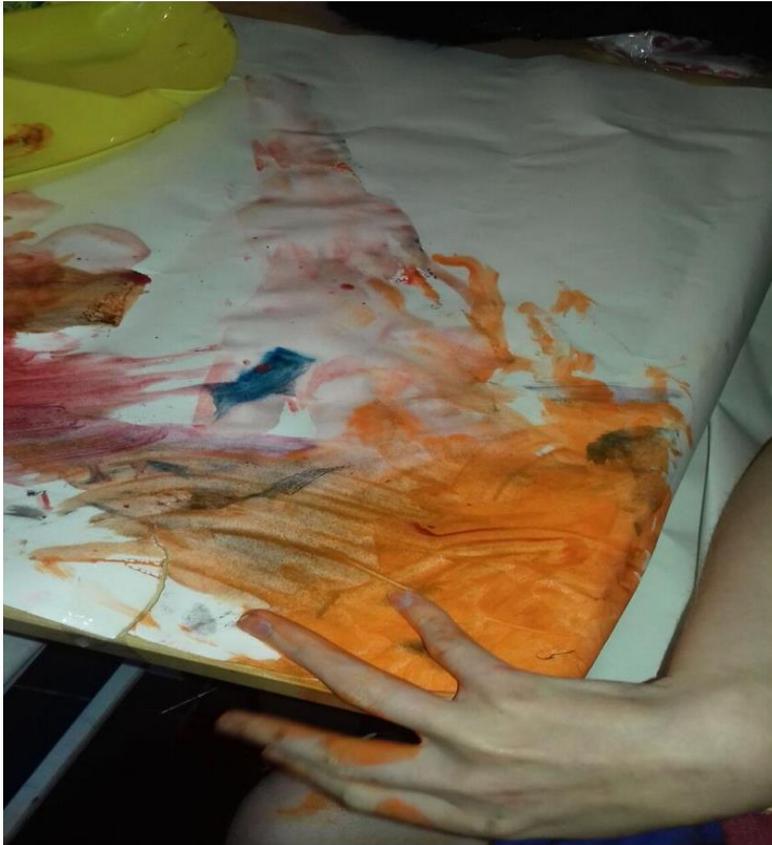


Analysis: Braun and Clark's (2013) stages of analysis

Phases	Description of the process
1. Familiarise yourself with your data	Transcribe data, reading and re-reading the data, noting down initial ideas
2. Generating initial codes	Code interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code
3. Searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme
4. Reviewing themes	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
5. Defining and naming themes	Generating clear definitions and names for each theme
6. Producing the report	Producing a scholarly report of the analysis

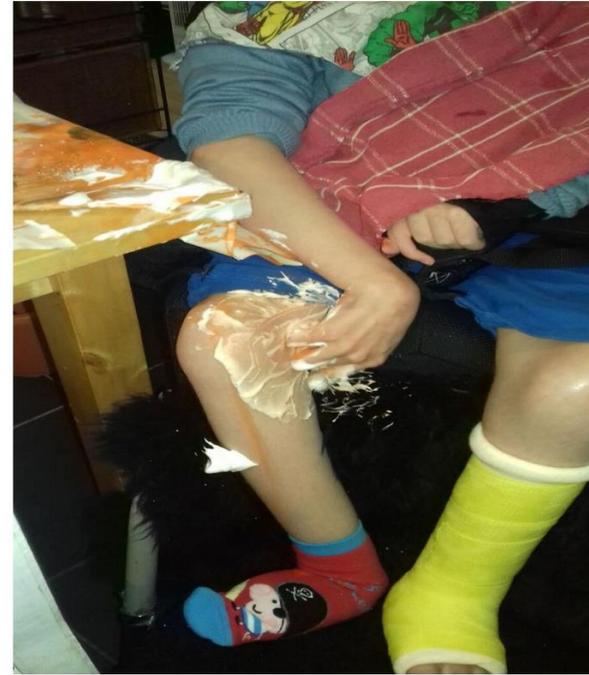


47 27/7 Much more awake today and eaten much better toes are going
48 back to normal and sitting in his chair for longer periods. Had a walk (in
49 chair) over to Tesco in the evening- a breath of fresh air. Did some
50 painting with his niece although he wasn't very interested.



51

52 James painting 1



54

55 James painting 2

56 28/7 Shower this morning and open air theatre in the afternoon to see
57 Aladdin Sunair.

58 29/7 Cwtch a pattern taster session.

59 2/8 Went to museum to see dinosaur exhibition with friends. Lift not
60 working so needed to ring and be admitted through staff entrance.

Commented [DP30]: Painting shaving foam- left ankle surgery evidence here with plaster

Commented [DP31]: Shower and open air theatre

Commented [DP32]: Cwtch pattern taster session

Commented [DP33]: Museum lift not working- ring for assistance – staff entrance



Data management: Stage 2 Coding/Ideas Table

James/ Ruth Data sets	Word count TOTAL	Views (by proxy from Mum)	Experiences:	Choices	Emotional well-being indicators
	26,975				
Interview 1	16,051	James has calming effect on you. Was fading prior to scoliosis surgery- now well.	29 th foster child (10 months) Epilepsy limits what can do- how far venture. Physically waring- 'turmoil', 'absolutely shattered'	Foster Mum plans to become adult carer. Hydrotherapy. When in pain can stretch him out. Enjoys food but	Epilepsy- cope with seizures at home. Affects level of alertness. Sleeps a lot during the day. Has a monitor for fits.
Photographs	28 images	Photo of ankles in blow up splints. Tambourine and lights. Space blanket Steering wheel Operant controlled powered wheelchair. James with various musical instruments.	Picture of James on a bed with shark costume on, Eating ice cream x2, View of lake, Finger painting x2, Dinosaur exhibition x2 Techniquest view-glass lift. Bowling participation. Gastrostomy feeding.	Intentional behaviours X9 pictures Surviving X2 Absorbing X5	Not sure what he sees but mum took photos of what he might see. Bowling participation good. Ice cream cone plastered in it and couldn't get enough of it-likes tubs also- sensory experience. Tolerates cold better now. Picture of tambourine. Maraca, wind chimes, drum.



Theme	Subthemes
Internal: Personal well-being	Observed behaviours Intentional play
External: Attitudes towards Disability	Behaviours in public spaces Reasonable adjustments explored





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.



Diary entry: Big Wheel, Winter Wonderland



248 7th January 2018

249 Poppy went to Winter Wonderland, he loved going on the rides and the big Wheel. It
250 was quite cold and there aren't any changing facilities here so we only stayed about
251 an hour. We have to lift Poppy onto the rides and go on them with him, but he loves
252 them and really enjoyed his time at the fair.

Commented [DP49]: Lack of changing facilities limits participation

Commented [DP50]: Enjoyed winter wonderland

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)

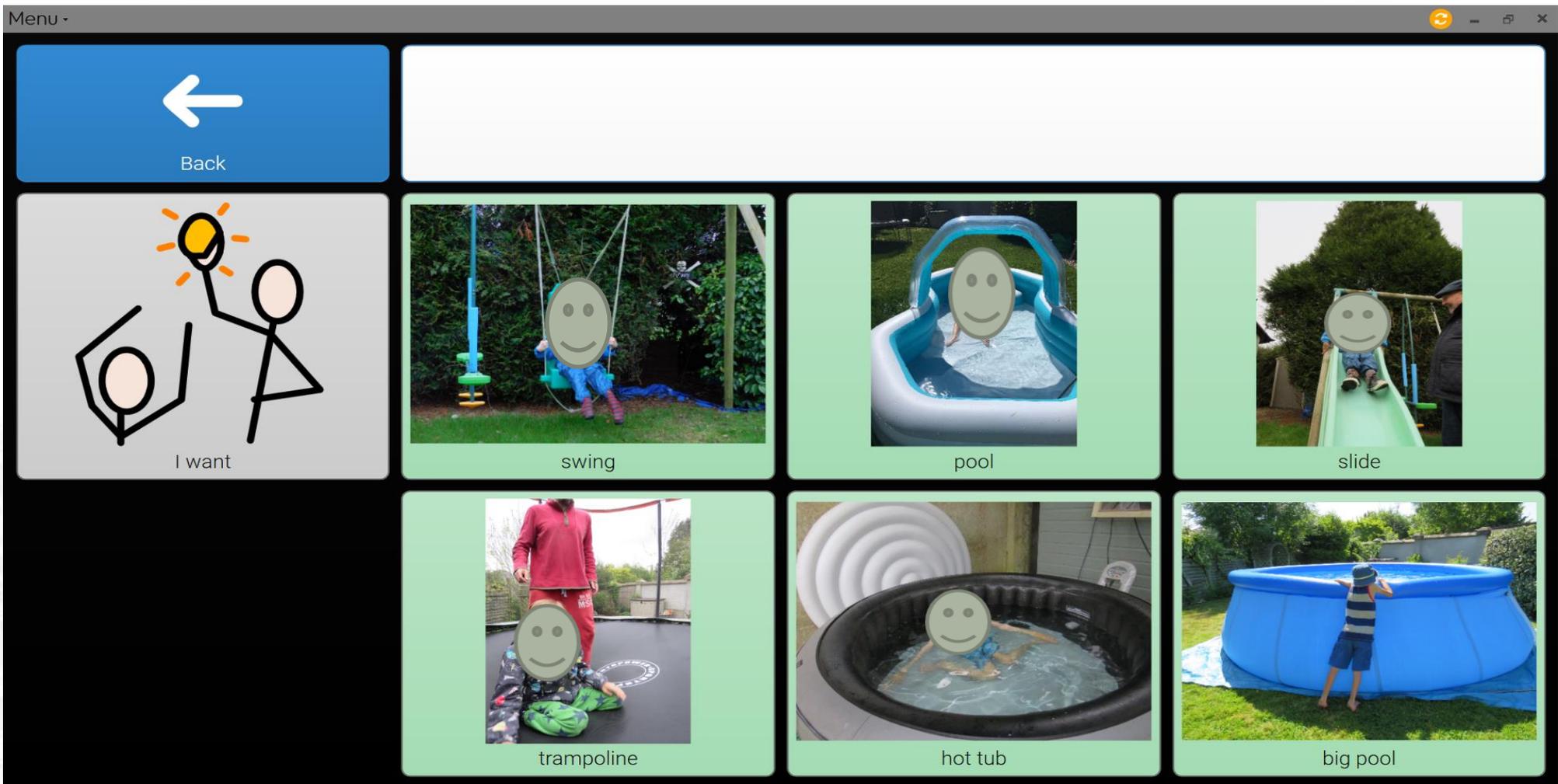
- Where I chose to use an image I wrote text in the paragraph and gave a heading to guide the reader



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.



Technology Assistance: Eye Gaze technology –pre-linguistic choices ‘Poppy’ (9 years) Observational visit to school/ Diary entry 14th Jan 2018



268 Poppy has a trampoline, swing, slide, hot tub, tricycle, all terrain chair and walking
269 frame, but during this process we have realised that when the nights are cold and
270 dark we don't use these things with him. The days seem so short and we seem to
271 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



- Example of Poppy's themes

Theme	Subtheme
Intrinsic factors: Idiosyncratic ways to communicate well-being	Non-verbal communication Behaviours that challenge Technology assistance
Extrinsic factors: People's attitudes towards disabled children	Being treated differently Adapted equipment and environments



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





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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