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

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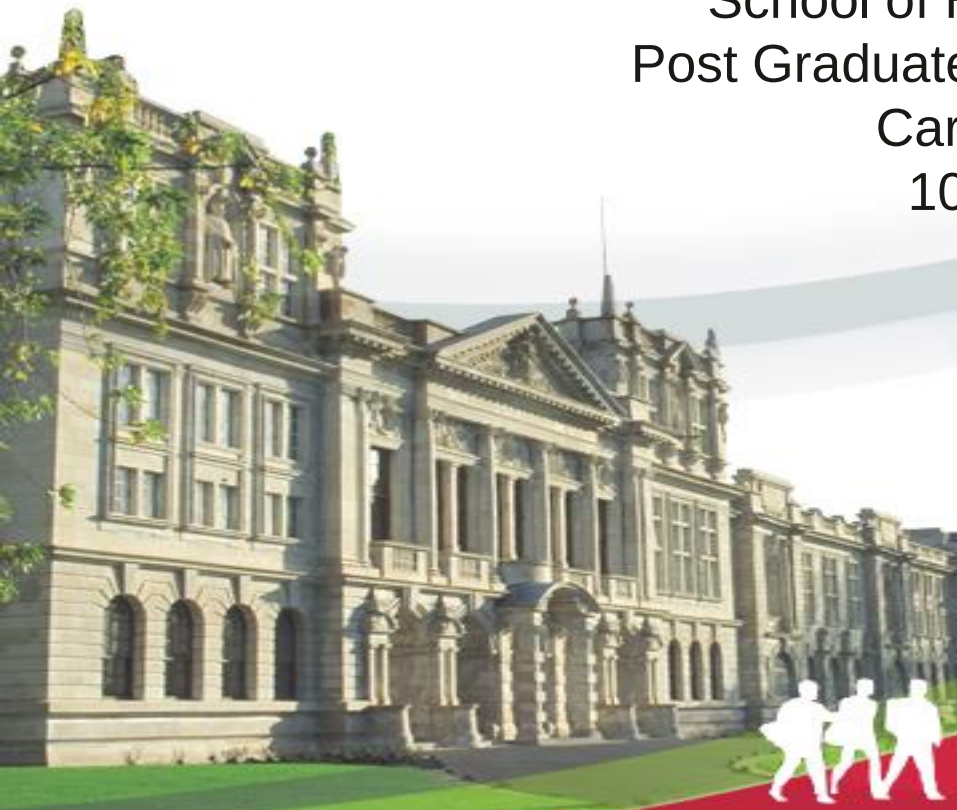

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Aim of this paper

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

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."**

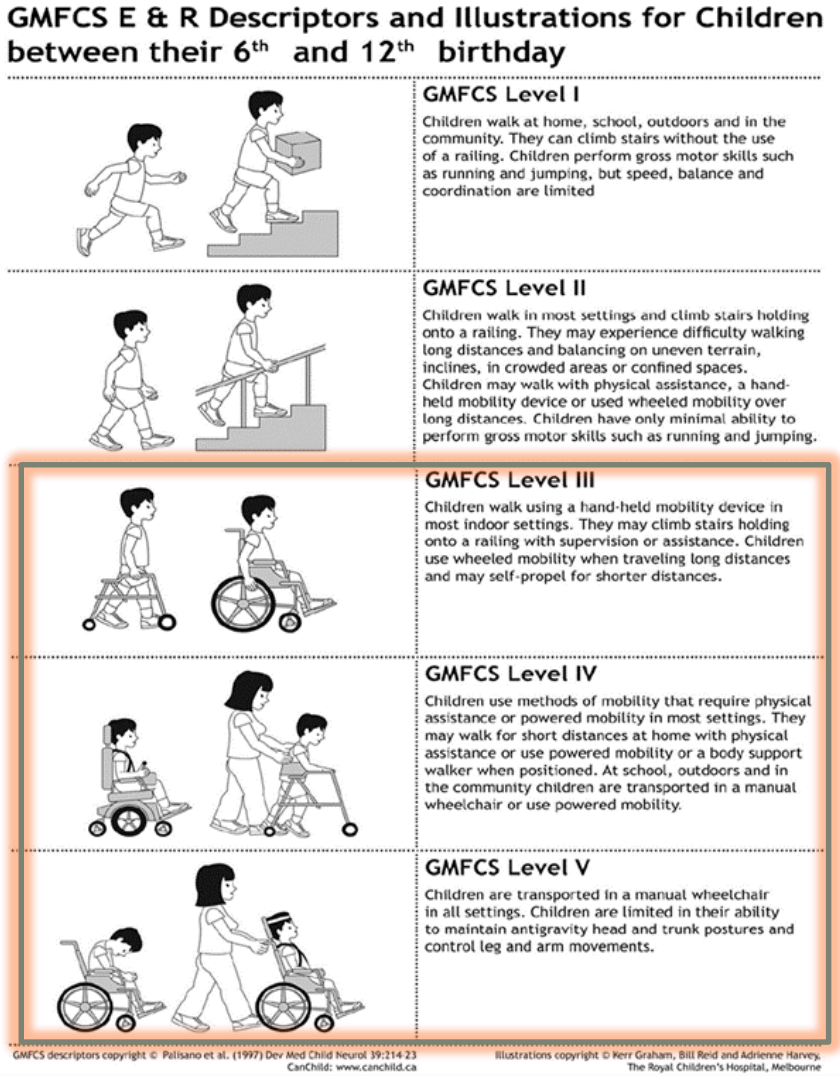
- My position as a former children's physiotherapist- voices of disabled children often missing in treatment choices-'Rights'.

- **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

Predictive Graph of Gross Motor Function decline (Hanna et al. 2009) pg 299

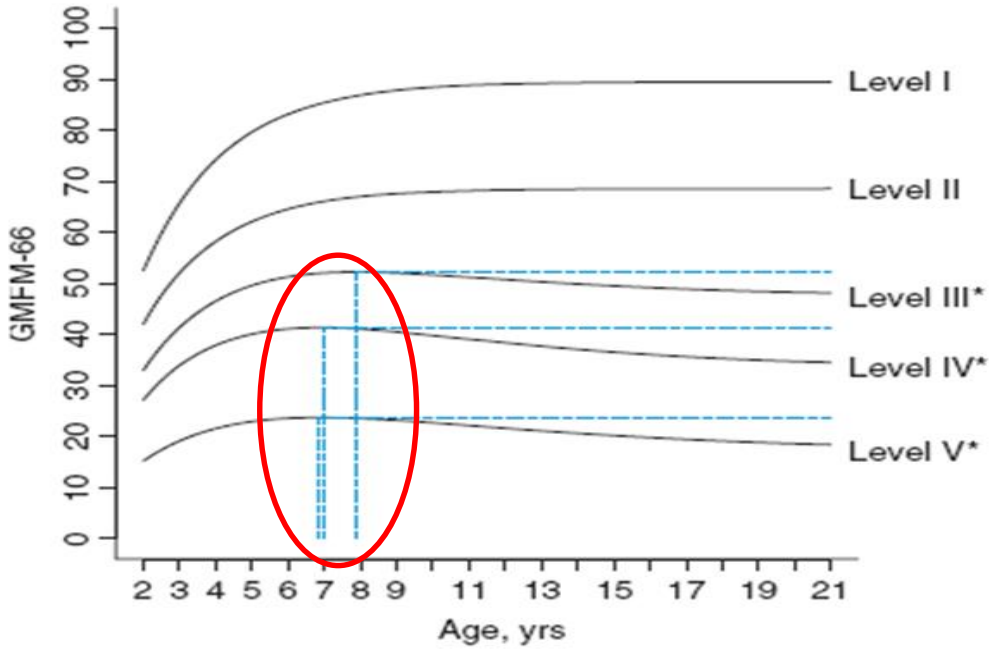


Figure 1: Predicted Gross Motor Function Measure (GMFM-66) motor scores as a function of age by Gross Motor Function Classification level. *GMFCS levels with significant average peak and decline. Dashed lines illustrate age and score at peak GMFM-66.

Inclusion criteria: Ages 9-16 years

Hanna, et al (2008) Reference curves for the Gross Motor Function Measure: percentiles for clinical description and tracking over time among children with cerebral palsy. *Physical therapy* 88 (5) 596-607.

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

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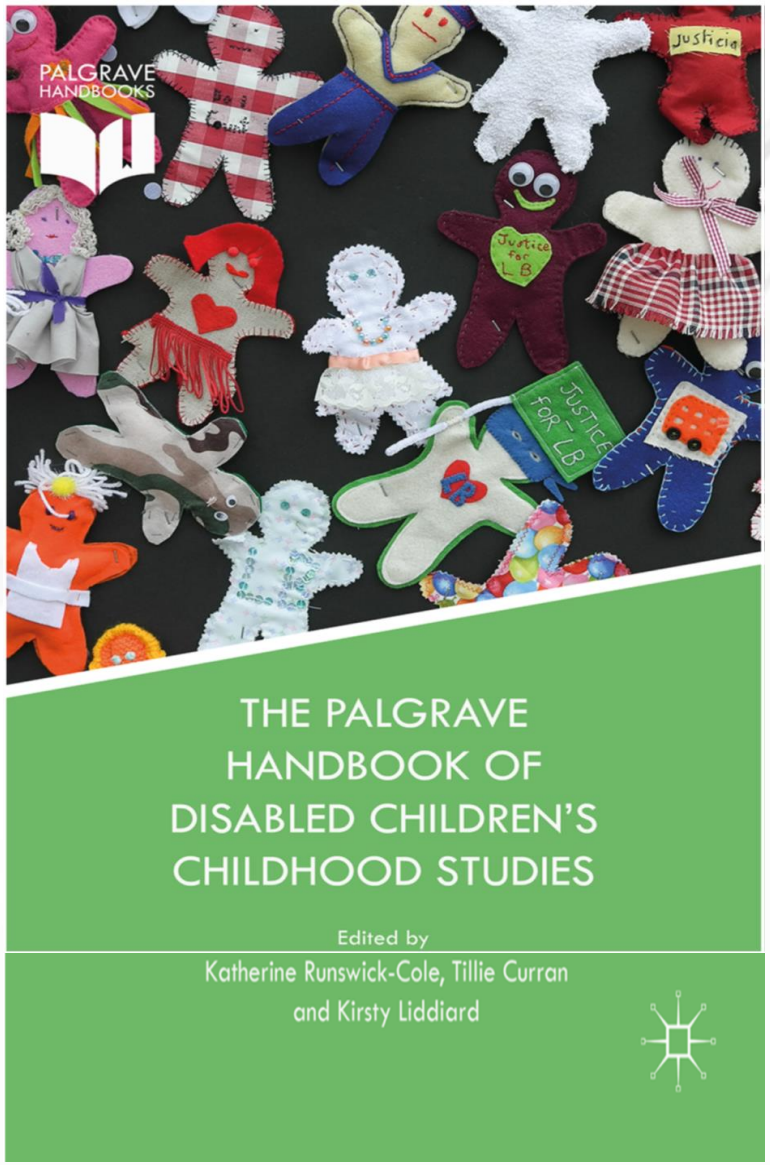


Emotional well-being of non verbal children and young people

- 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"

Disabled Children's Consent: Visual data

- ‘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:

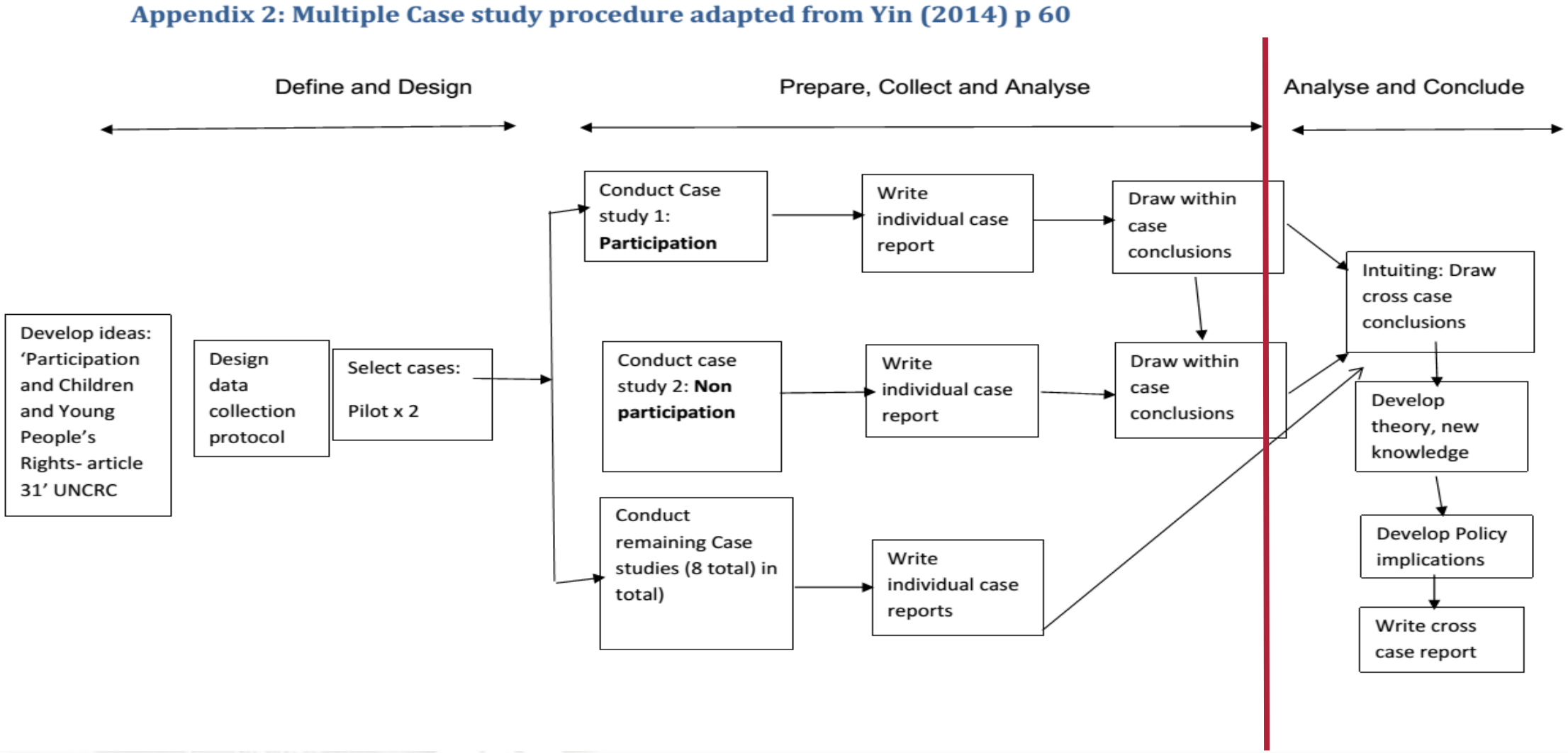
- **Research question**
  - How do children and young people with cerebral palsy and their carer's view, experience and choose their level of participation in recreational activities?
- **Study Aims**
  - The 2 aims of this study were to explore participants':
  - Views, experiences and choices for their 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.

Case study flow chart

Analysis at April 2019-6/7 cases

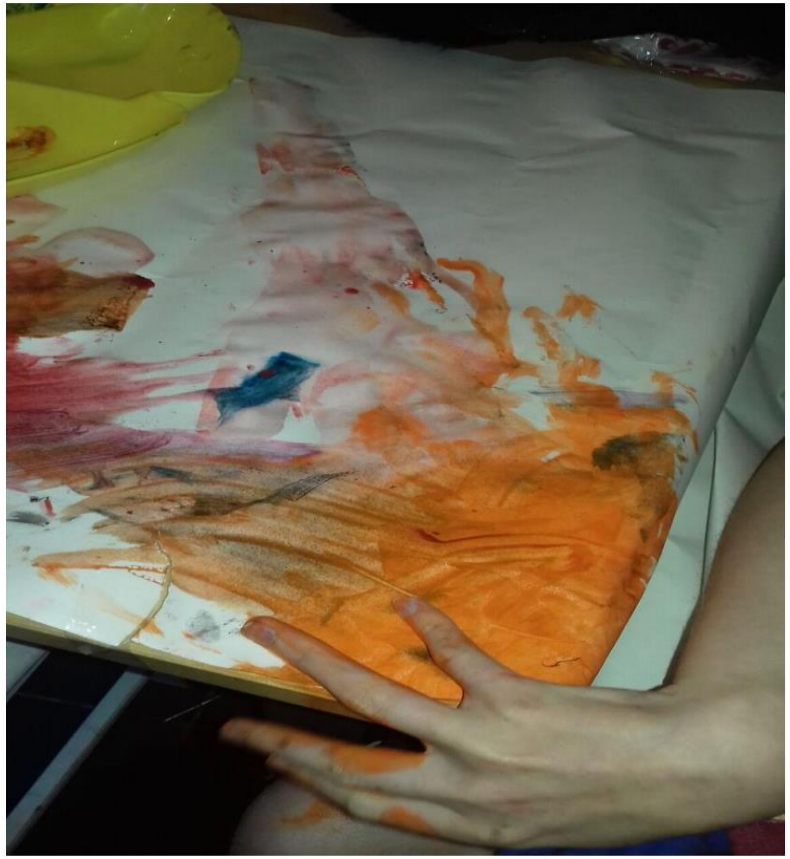


Analysis: Braun and Clark's (2013) stages of analysis

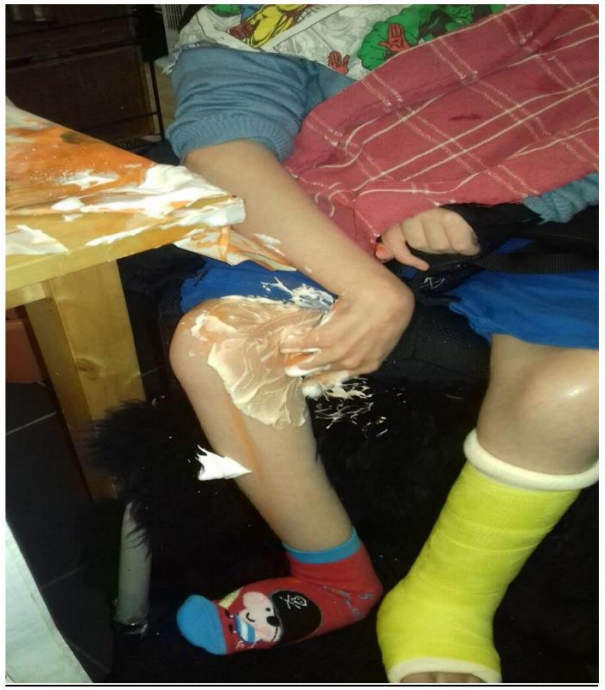
Phases	Description of the process
1. Familiarise yourself with your data	Transcribe data, reading and re-reading the data, noting down initial ideas
2. Generating initial codes	Code interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code
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

Findings: Diary data – Stage 2 coding James

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.



James painting 1



James painting 2

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

29/7 Cwtch a pattern taster session.

2/8 Went to museum to see dinosaur exhibition with friends. Lift not 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 26,975	Views (by proxy from Mum)	Experiences:	Choices	Emotional well-being indicators
Interview 1	16,051	James has calming effect on you. Was fading prior to scoliosis surgery- now well.	29th 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.

James: Stage 3: Themes and Subthemes

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

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

Extract from James's case study: Behaviours in public spaces

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: Visual views of what participant's could see

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

Messy data

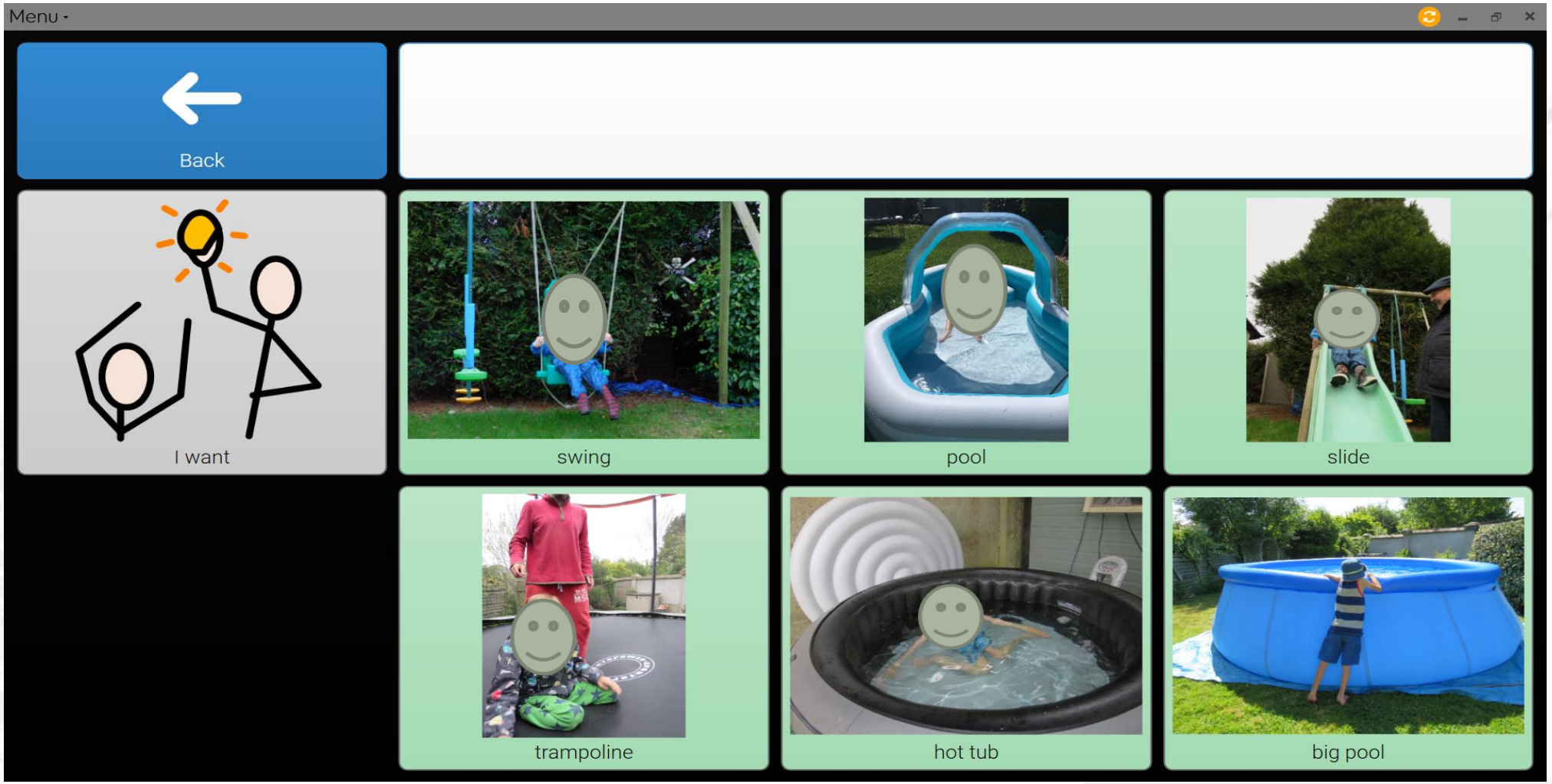
- Where I chose to use an image I wrote text in the paragraph and gave a heading to guide the reader

In fact at one 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.

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

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

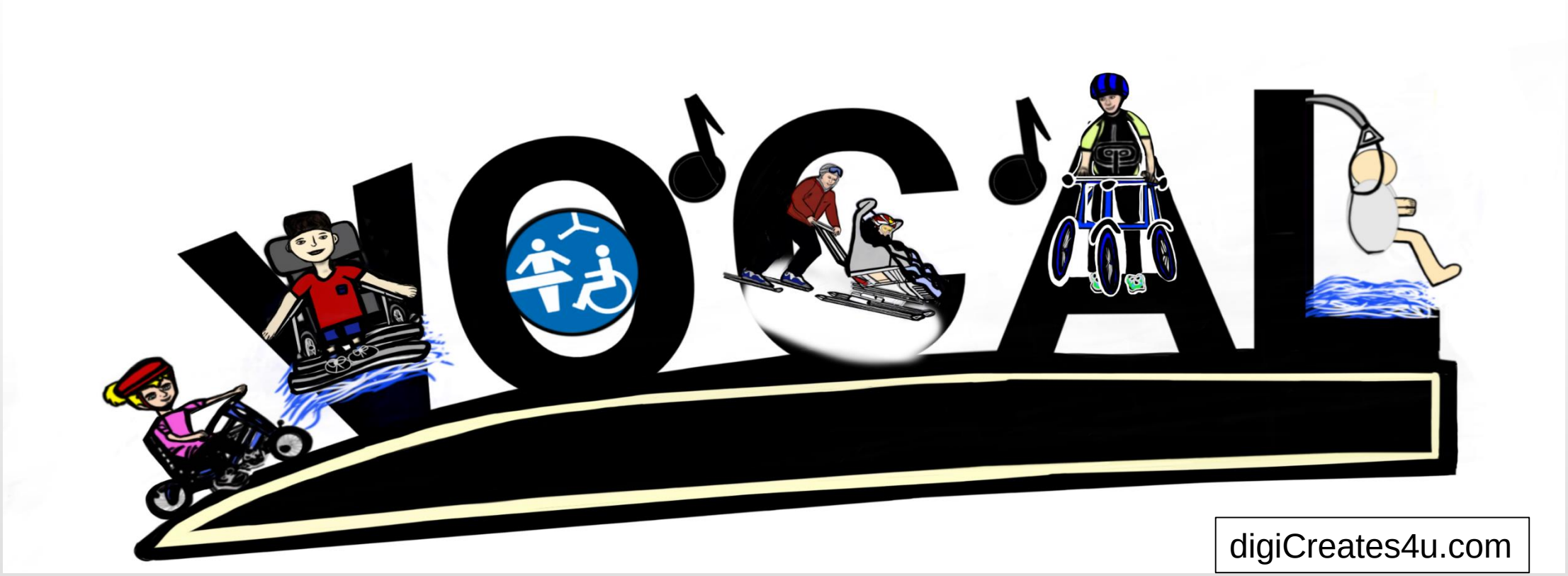
Authenticity

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.