

# Audio and visual data to represent the emotional well-being from disabled children and young people's participation in recreational activities.

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This paper will discuss the findings of audio and visual data with non-verbal disabled children and young people to represent their 'voices'.

- Analysis of within and across case study data
- Representation of audio and visual within the text
- Early ideas around theories which might fit in how I represent the findings



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

- Article 31 of UNCRC: Rest, leisure, play and recreation and to take part in cultural and artistic activities.
- Method-Comparative 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 in recreational activities and 3 whose participation was limited.



- **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.



**'Mosaic' of individual data sources to make up single case study over 12 weeks**





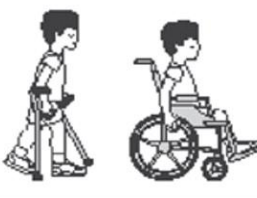


7 children and young people were recruited via schools, charities and community groups.

Age range 9-16 years, Levels III-V Gross Motor and Communication Function Classification Systems: 2 at III, 4 at IV, and 1 at V; 4 boys, 3 girls

4 who participated (PG) and 3 whose participation was limited (LPG).

Their pseudonyms were (PG) Clare, Lily-May, Nick, Matthew;  
(LPG) James, Bree and Poppy.

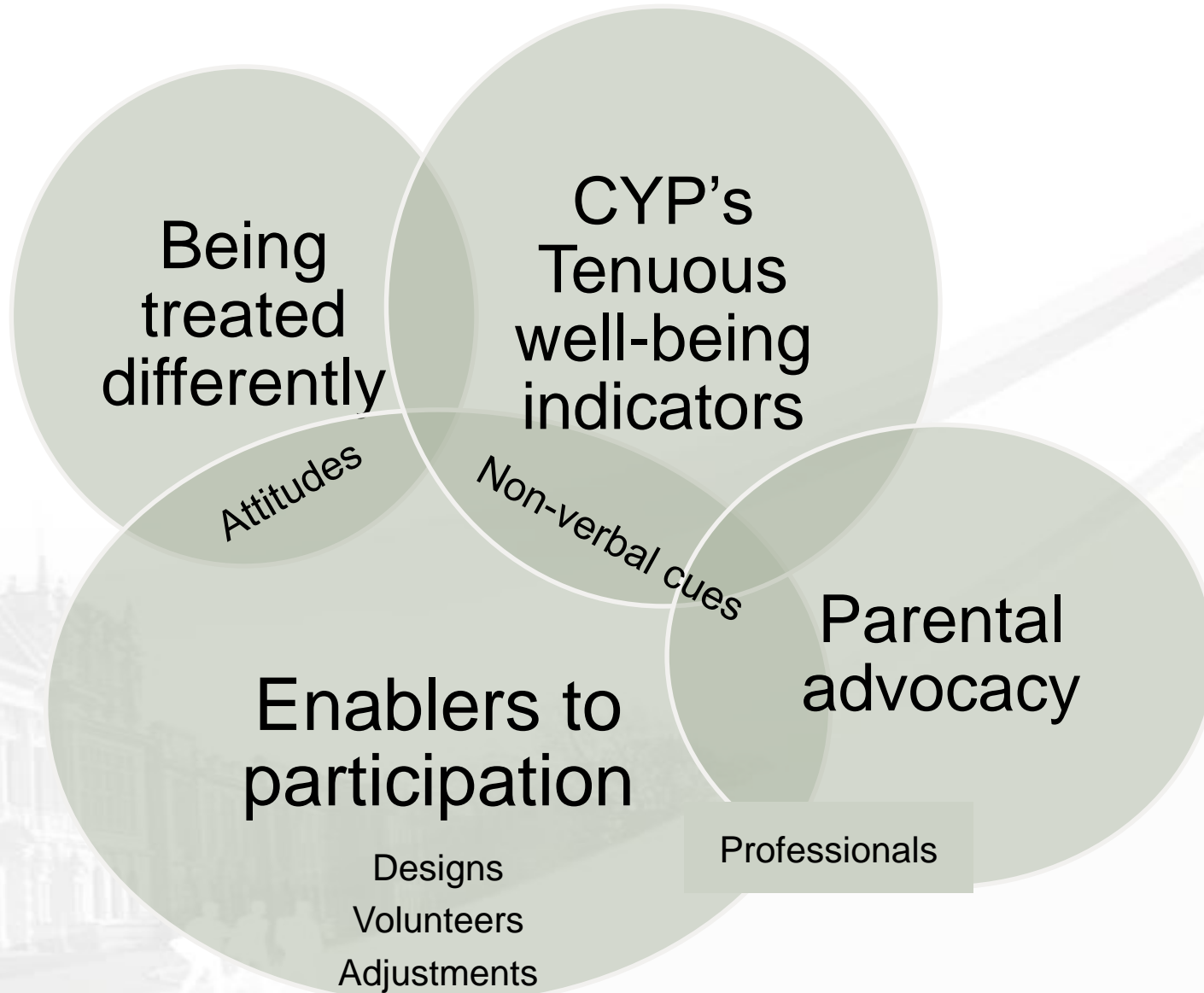
GMFCS for children aged 6–12 years:  
Descriptors and illustrations

|                                                                                       |                                                                                                                                                                                                                                                                                                  |
|---------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|    | <b>GMFCS Level I</b><br>Children walk indoors and outdoors and climb stairs without limitation. Children perform gross motor skills including running and jumping, but speed, balance and co-ordination are impaired.                                                                            |
|    | <b>GMFCS Level II</b><br>Children walk indoors and outdoors and climb stairs holding onto a railing but experience limitations walking on uneven surfaces and inclines and walking in crowds or confined spaces.                                                                                 |
|    | <b>GMFCS Level III</b><br>Children walk indoors or outdoors on a level surface with an assistive mobility device. Children may climb stairs holding onto a railing. Children may propel a wheelchair manually or are transported when traveling for long distances or outdoor on uneven terrain. |
|   | <b>GMFCS Level IV</b><br>Children may continue to walk for short distances on a walker or rely more on wheeled mobility at home and school and in the community.                                                                                                                                 |
|  | <b>GMFCS Level V</b><br>Physical impairment restricts voluntary control of movement and the ability to maintain antigravity head and trunk postures. All areas of motor function are limited. Children have no means of independent mobility and are transported.                                |



# Venn diagram of ideas for across case themes

Stigma  
Being Rejected



Being Valued  
Accepted



# James's case study: Behaviours in public spaces Stigma/Acceptance?

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.





- *“....Matthew, he always looked normal, not special needs, he has an infectious laugh, people wanted to spend time with him, they wanted him to go and do things...like the physios...cos I always went to things and I always carried out my physio, the physios wanted to help. So anything that came up I would be the kind of first person they would ring-do you want to go and try this? So you know, I think we were just really fortunate you know.... (Int1: 139-145)..... everyone always thought that about Matthew, cos the way he looked, so handsome, he never looked as if he had a disability and he was so cheeky, so I think alorra things have come his way by his personality I think, who he is...”(Int2:444-447)*



# Enablers to participation: Matthew skiing and surf board that he co-designed





*“Pottery at X Farm. We were a bit disappointed with this activity, we were sat just inside the doorway which wasn't very wide and had a big lip to get his chair over. We weren't offered an apron as the other children were. We felt very rushed and Poppy wasn't given very much time to do the activity in his own time. We were rushed out of the room before the activity had actually ended whilst everyone else carried on with their pottery.... Poppy did however enjoy the very brief pottery class (Diary entry:40-52).*

*...it was really disappointing” (Int 2:243).*



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.



# Emotional well-being indicators: Clare's expression of enjoyment: Steel drum



[https://cf-my.sharepoint.com/:u:/g/personal/ferridayr\\_cardiff\\_ac\\_uk/EcliAuLDjrdDu7kbJ1H0Te4BPwNfQ4IN-pZPtxgDRpbfqg?e=2gQj7o](https://cf-my.sharepoint.com/:u:/g/personal/ferridayr_cardiff_ac_uk/EcliAuLDjrdDu7kbJ1H0Te4BPwNfQ4IN-pZPtxgDRpbfqg?e=2gQj7o)





- *“Yes she loves cycling because she has a little basket on the front, we put music in the front and she is as happy as Larry... She cycles, we do about a mile, a mile and a half she goes down, down along the river path the old railway track, it is a bit sort of off-roading and then back at the church and then along this road or she goes that way around the park. ....so long as she's got music she'll do most things (laughs)”*



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# How have the audio and 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 in research
- Triangulation of different data sources has added to the rigour/trustworthiness of the study





‘Auteur theory’ to apply to the visual images (Lash, 1992)

Bourdieu’s (1984) view of practice: ‘Cultural capital’- how are these participants valued when they have no physical voice and limited participation?

Gibson (2016) Rehabilitation: Ethic of openness- interconnectivity.



# Questions ?



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