

'Qualitative Research: Children's Perspectives, Cerebral Palsy'

4th Baltic and North Sea Conference on
Physical and Rehabilitation Medicine,

Riga, Latvia

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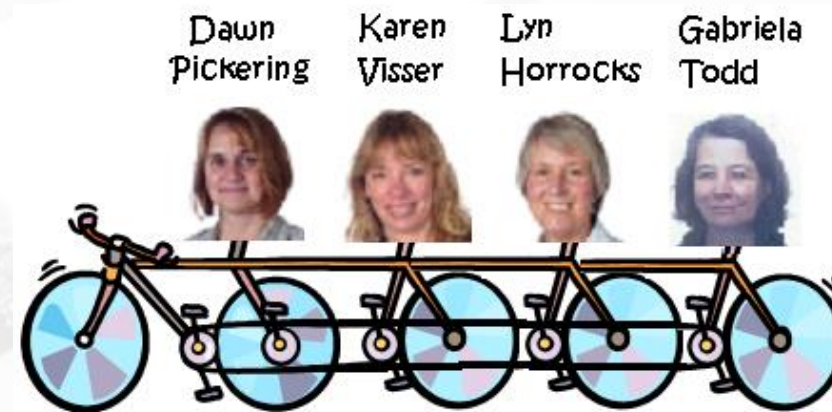
- Data from 2 different studies will be used to show the additional value of qualitative data:
 - 1. 'Pedal Power'- 35 children and young people with Cerebral Palsy: Interviews + diary.
 - 2. Proposed Doctoral study 'VOCAL'– Lifeworld- using Interpretative Phenomenological Analysis.



Lack of participation opportunities for CP
Fowler et al, 2009;
Fauconnier et al, 2009;
McConachie et al, 2006;
Mihaylovat et al 2004

Choice of activities limited-
requires some adaptation
and support

- Physiotherapy clinical practice with Cerebral Palsy (CP)- team approach.



Context for 3 year study: Cardiff (2009-2012)



- Research question: Does participation in adapted dynamic cycling affect lower limb muscle function, activity levels and quality of life in children with Cerebral Palsy.
- Quality of life aims:
 1. To find out about their experiences of adapted dynamic cycling/physical activities.
 2. To introduce a non cycling group to information about adapted dynamic cycling, to explore if this is something they would consider for the future.



- Adapted dynamic cycling
- 17 recruited from Pedal Power (travelled up to 50 miles to access this hire facility)
- Non cycling group –weren't currently participating in adapted dynamic cycling
- 18 recruited from NHS and voluntary organisations



Cycling group: First interview at beginning. Diary kept about their cycling experiences (only 8 returned).

Second interview after 6 sessions of cycling (not all were able to achieve 2 interviews)

Non cycling group: Information given about adapted cycling in their area (limited for children) at first measurement session. Diary kept about physical activities (14 returned).

One interview at second measurement session 6 weeks later.



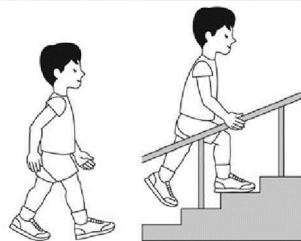
- To enable their 'voice' to be heard
 - United Nations Convention on the Rights of the Child:
Articles 12, 23 and 31:
 - All children have the right to say what they think
 - If disabled to have support to lead full and independent lives
 - to relax and play and to join in a wide range of activities
(UNCRC, 1989)
 - Hart's participation ladder (Hart, 1992)



- *‘Unhurried listening’*

Attempted to use creative methods such as stickers/ drawing / ink pad printing/ game card matching, but several children had limited cognitive and manipulative Skills.

Photographs were used but Many children were unable to take these themselves



Katie was 10, GMFCS II, Ataxic ,Quadriplegia

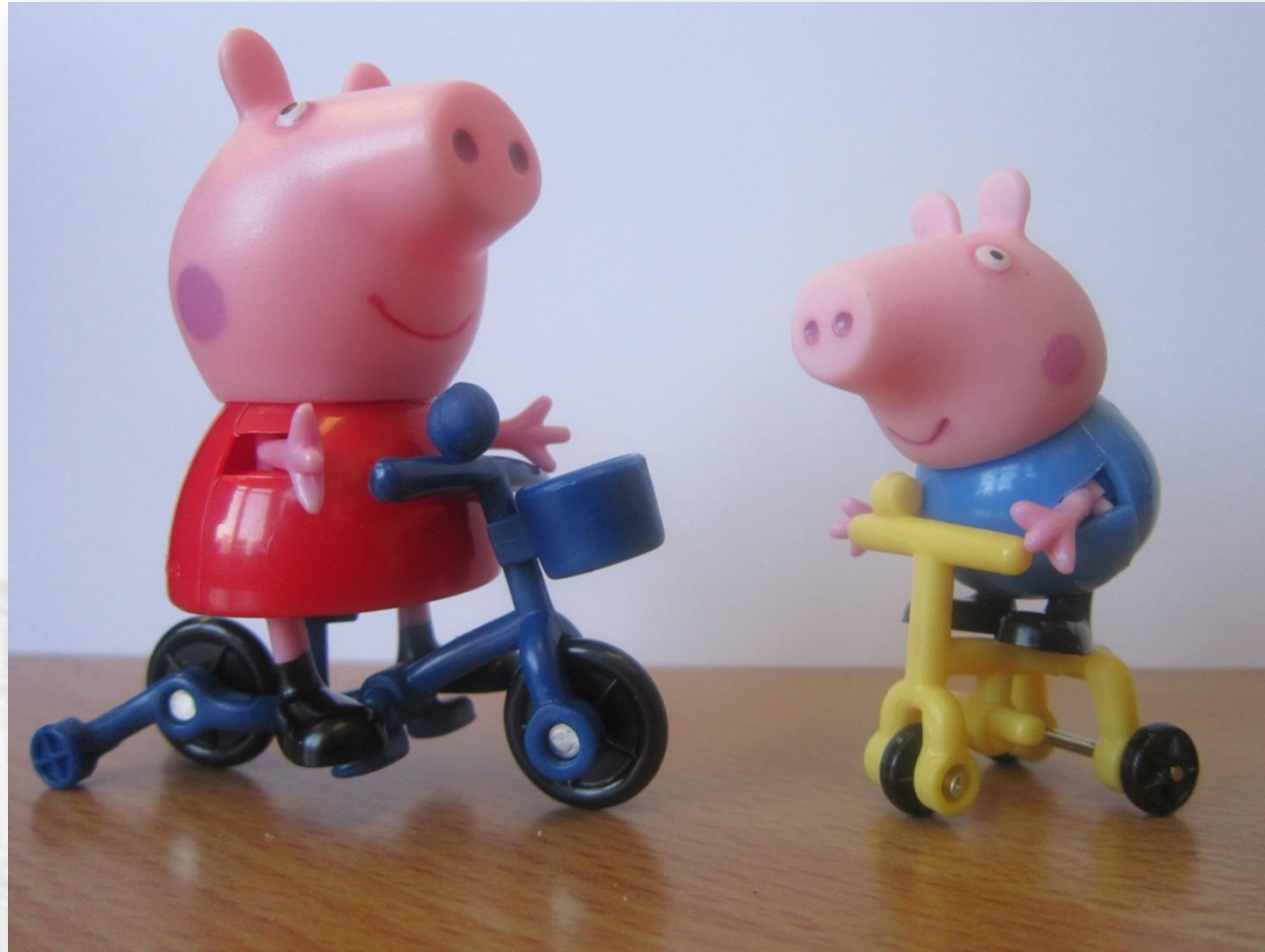




- We used a glove puppet to engage the child in measurement and also when doing the interview- non verbal children responded well to the puppet



Story telling/ Peppa pig goes cycling



- Different contexts for cycling were presented to the children in picture format to explore where they might like to cycle in the future:
 - Park in a City
 - Countryside
 - Seaside
 - With family and friends



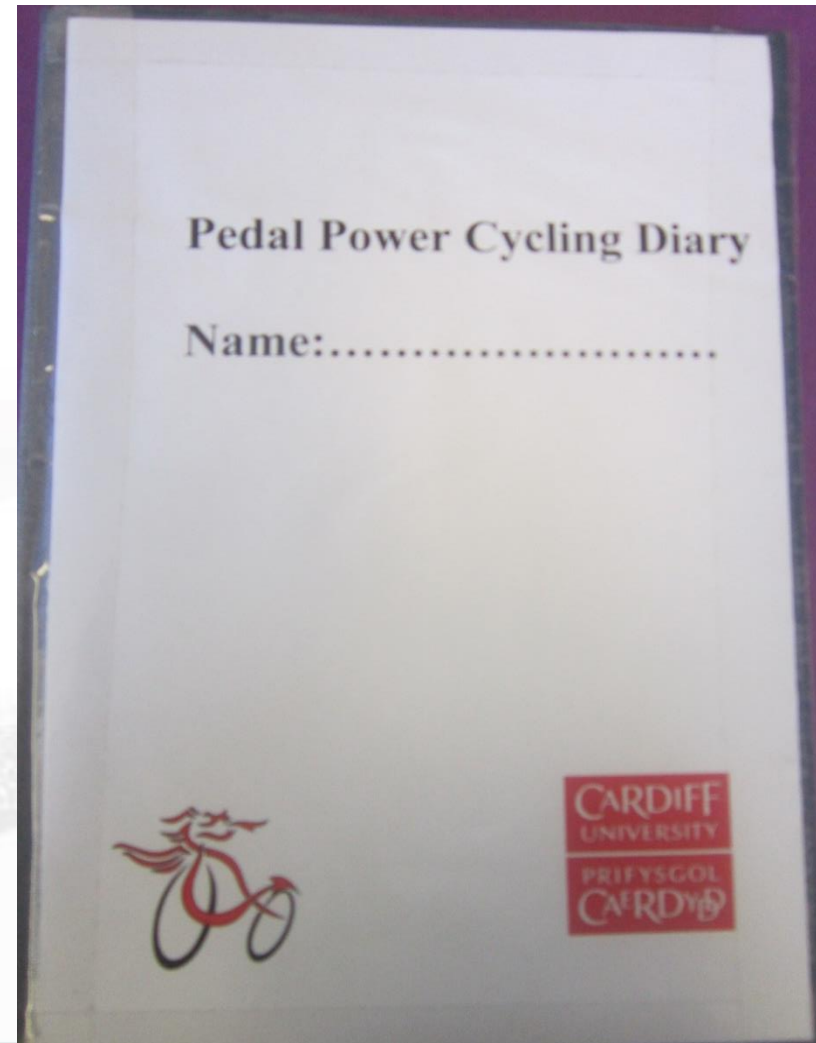
43 Interviews

- 15 carried out own interview
- 10 Joined in with parent
- 7 Parent/carer reported

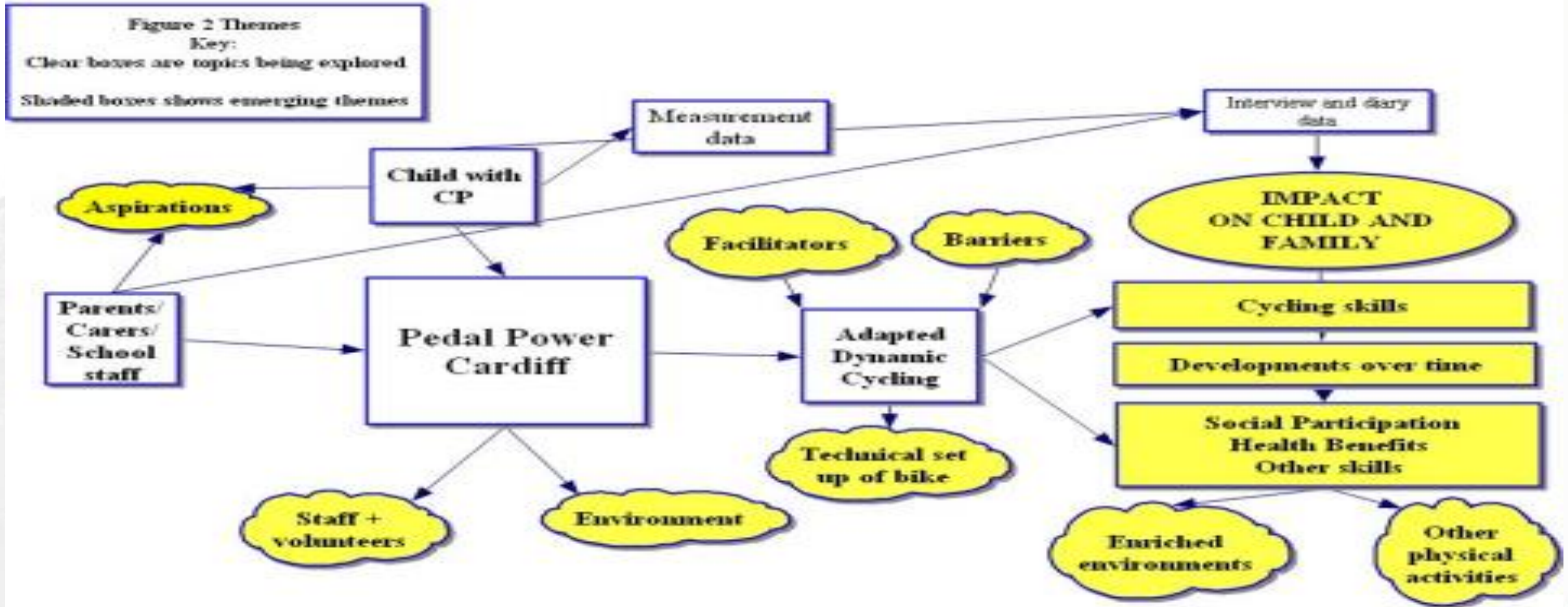
22 Diaries

- 4 self reported
- 3 mixed
- 15 parents completed
[photographs included]

A5 Diaries set the interview agenda

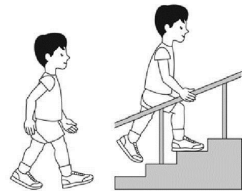


Cycling Group Thematic analysis Pickering et al, 2012



- Interview

*“..at the caravan park it was much easier than walking ...I cycled quickly with my friends and we chased each other on bikes and went to buy sweets at the village **shop...we cycled on our own without Mum and Dad to the ‘lagoon’[see drawing]...when I don’t have my bike I tag along with others for a while..ponder my thoughts... get bored... in the city there aren’t enough **safe places to cycle** but at the caravan its easier to get around- **it’s a clever ,clever invention whoever invented it I want to thank them.....”*****



- Diary drawing

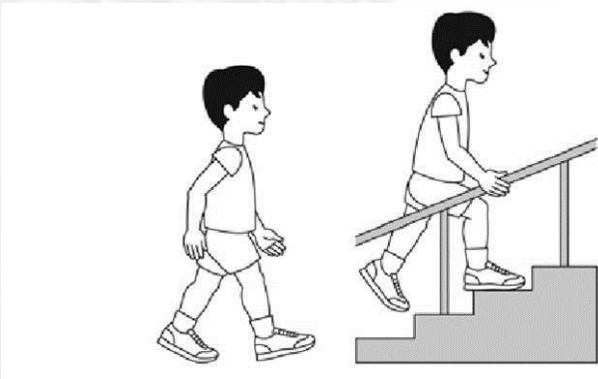


Diane was 10, GMFCS II and has Diplegia



May's diary entry

May is GMFCS II and has underdeveloped organs, dystonia and hemiplegia due to prematurity and having a stroke



Sunday 1st of April 2012 (2)

Today I had a 20 mins bike ride with my sister and brother to [redacted] Secondary School Car park there are loads of bends, curbs, bays and car spaces. I have gone on really well considering me and my family all thought I wouldn't be able to achieve such a brilliant opportunity, we also thought I am going to be doing a bike proficiency test after easter so we have been practising weaving in and out and straight, left and right the right is really easy for me but the left is what I find tricky and I am also learning that I have to ride on the left on the road. ~~May~~ - May.



Interview:

Int: ... So assuming you pass your cycling proficiency test, what do you hope to do with your cycling?

May: ...to get better and better at it.

Int: Where would you like to go with your bike?

May: H Forest

Int: Have you been there already?

May: Yeah but I had to go on a 'stupid tandem' because my teacher kind of forced me...another Dad pedalled..

Mum: ...It was sort of an ice cream basket on the back..

Int: So you didn't do any pedalling at all?

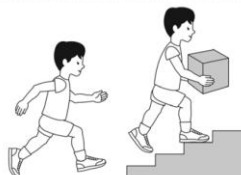
May: No which was really, really, really disappointing...cos all my other friends were like riding a bike and I was lonely....



Peter's Mum: *"Gabriela put him on the Tom Cat trike, strapped his feet in and it was the first time ever he pedalled and he couldn't stop it. Everybody got so emotional, fantastic. It just shows if you've got the tools for the job, the right equipment, you can do it... This year we cycled from Bristol towards Windsor because we could hire the special trike.... I think completely independently he cycled not far off 40 miles..."*



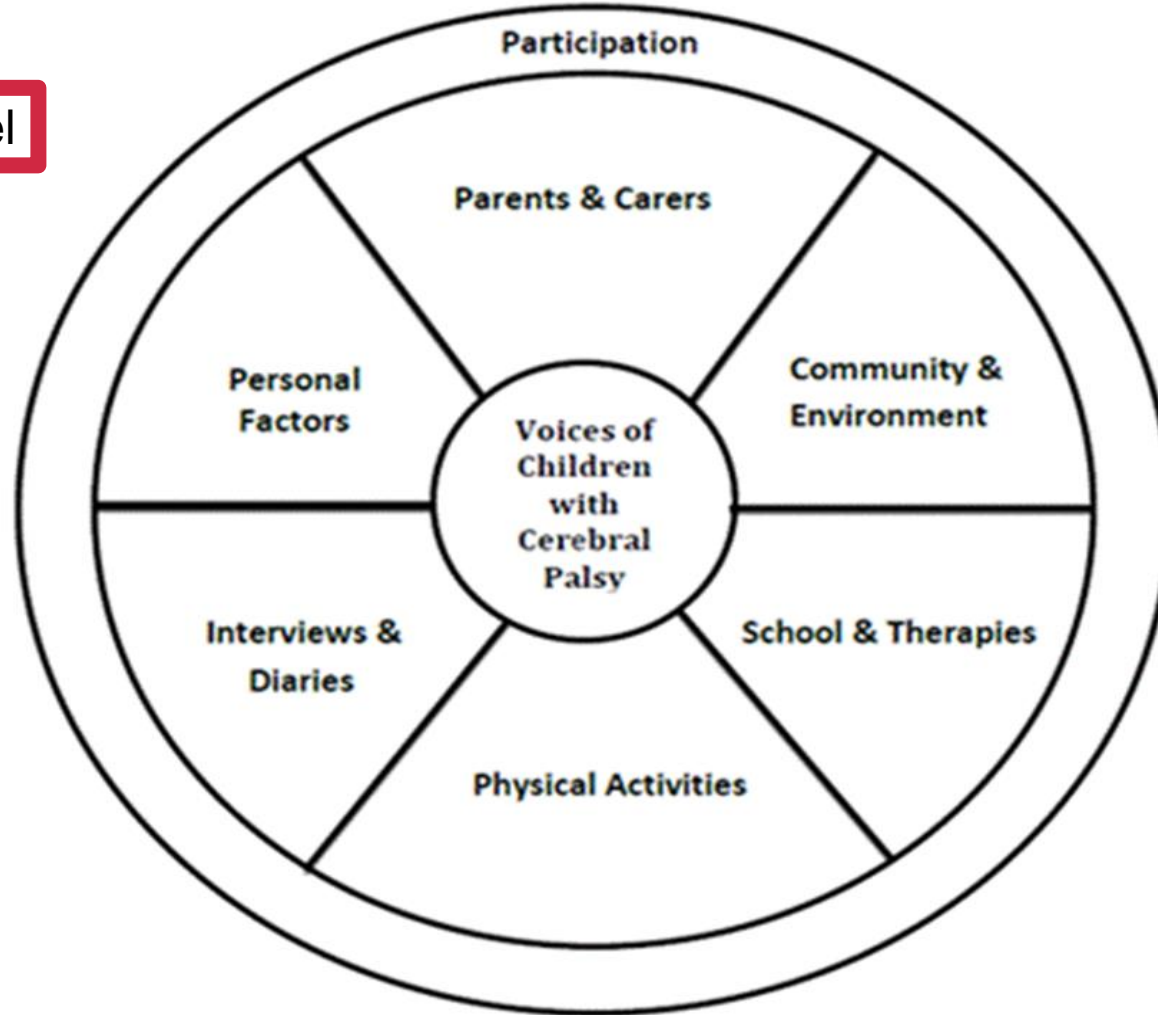
"I did cycling and it was wicked!"

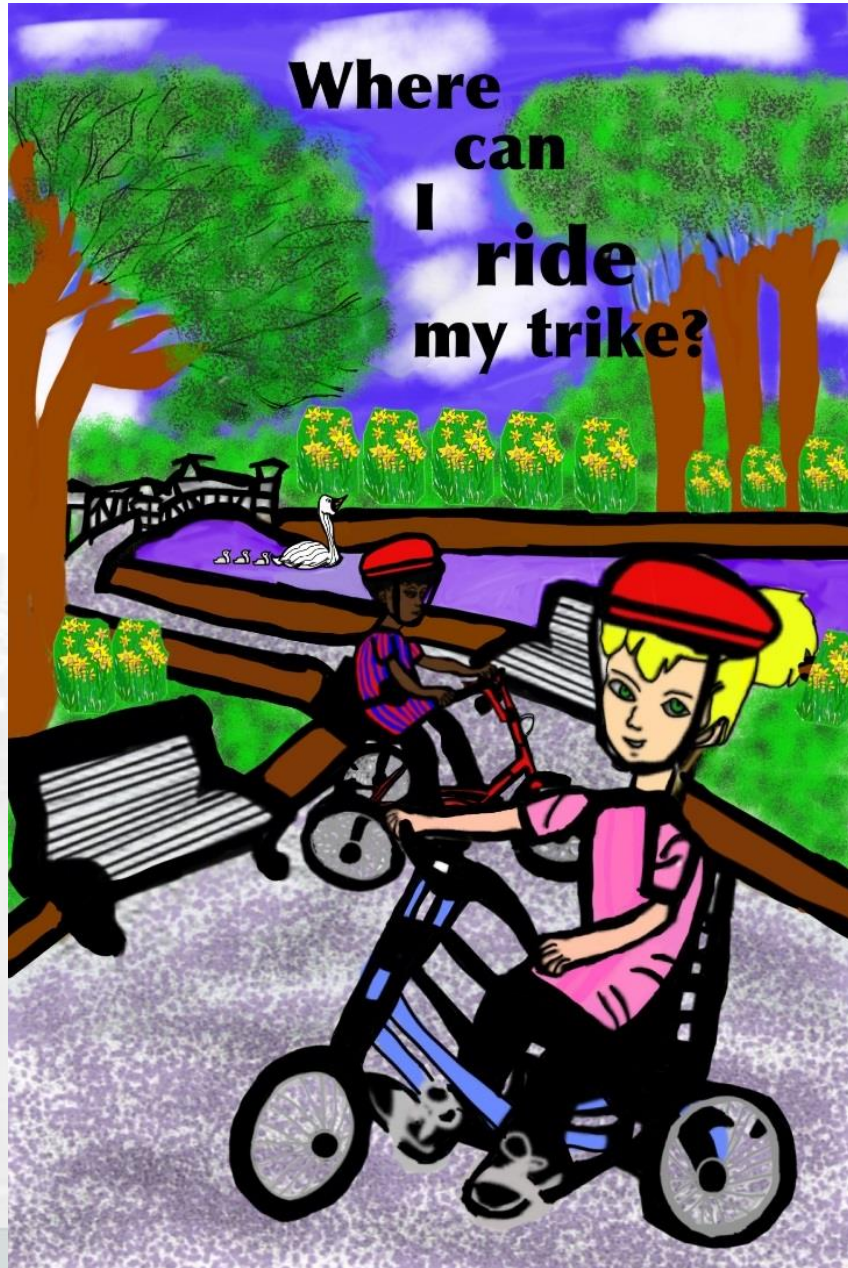


Peter aged 7 years Diplegia, High tone, GMFCS I



Social model





- Story inspired by the 35 children who took part
- Illustrated by Hannah Pickering



2. Proposed Doctoral study: 2015 onwards

- Individual study- more in depth qualitative.
- Interpretative Phenomenological Analysis: Human lived experience
3 components
 - 1. Phenomena-show/reason – both perceptual and analytical
 - 2. Hermeneutic- interpretation- sense making process. non-linear
 - 3. Idiographic- particular- single case analysis provides insight– series of cases.

Explores embodied, cognitive, affective and existential- double hermeneutic-explores empathy/ suspicion. Use of metaphors by participants.



- Beyond Physiotherapy:
Voices of children and young people with cerebral palsy and their carers about 'Participation' in recreational activities.



- What is the 'Lifeworld' and the views of Children and Young People with Cerebral Palsy (C & YP) and their carers about 'Participation' in recreational activities?



- 2 interviews 12 weeks apart:
- 1st interview structured around the 6 themed 'F' words: Fun, Fitness, Family, Friends, Function and Future in relation to recreational activities
- 2nd interview makes reference to the diary entries.
- Diary of Recreational Activities kept for 12 weeks.



- Girl aged 9 years:

‘Becky Lamb’

Attends mainstream primary school, lives with both parents and younger brother.

Prior research relationship since 2009: (6 years)

- Young adult female aged 21 years:

‘Katie Tate’

University Student, lives away from home.

Met at a children’s physiotherapy conference November 2014.

Telephone interviews.

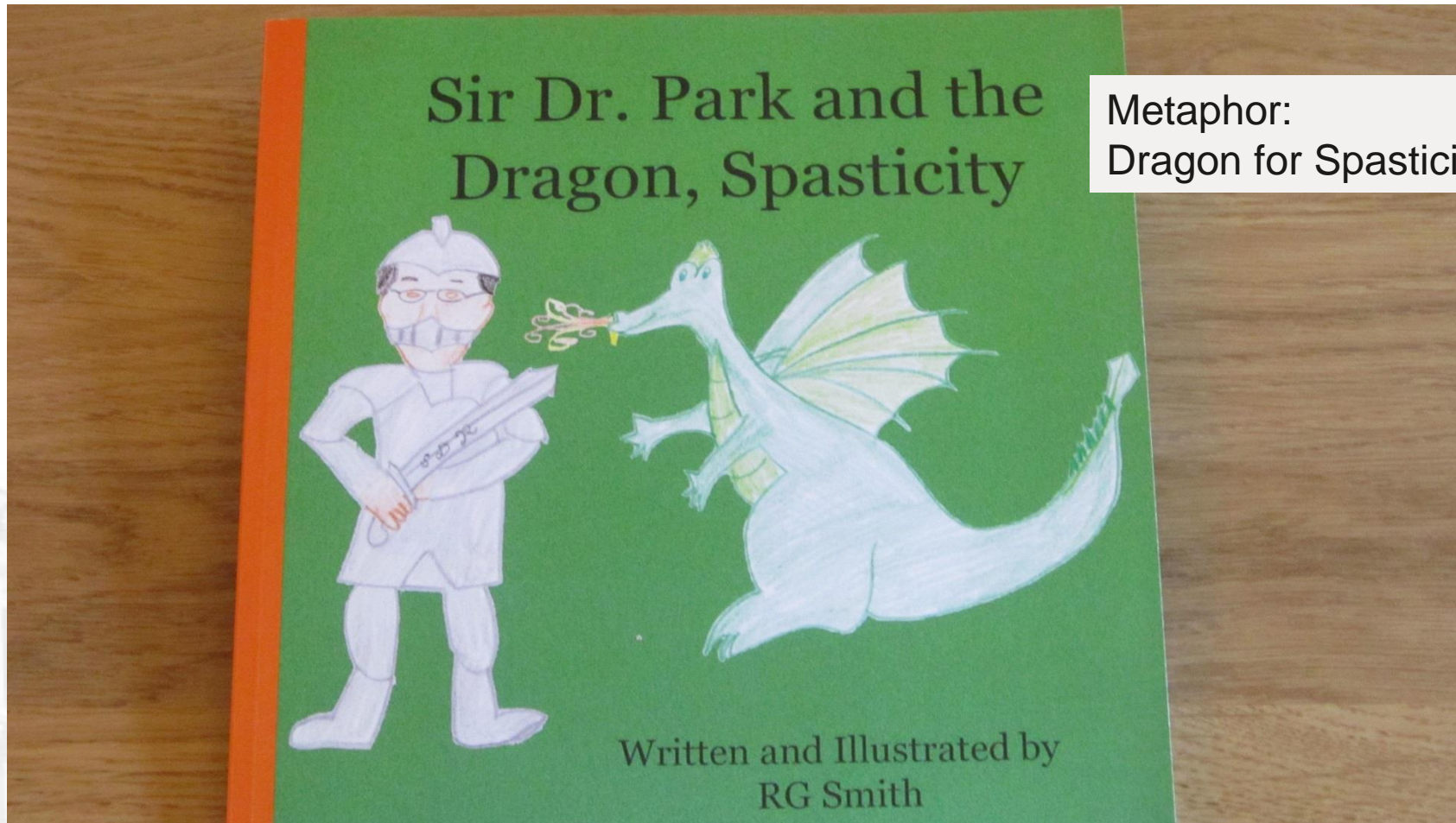


- Descriptive: describes what participant said.
- Conceptual: engages at a more interrogative and conceptual level. Interpretative.
- Linguistic: focusses on the specific use of language by the participant, sometimes metaphors used.



- <https://www.youtube.com/watch?v=2jYXHdMoEgg>

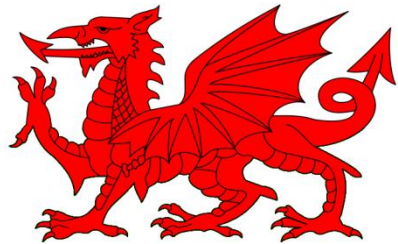




Metaphor:
Dragon for Spasticity



‘The dragon story is about Dr Park...he did an operation on the boy.....and it made the fires...that made my legs to cross, it flighted it away...’



BL speaks to father who arrives at the end of the interview and sees the sandbox:

'That's me. I'm the smiley one in the pink dress.'



Sandbox (Mannay, 2015)



Interview 2

'...the medal with the orange ribbon was for the Super Tri I did in March...it's got one star, two stars, three stars, four stars, five stars, six stars, seven stars....I'm a winner...

Int: What did you have to do?

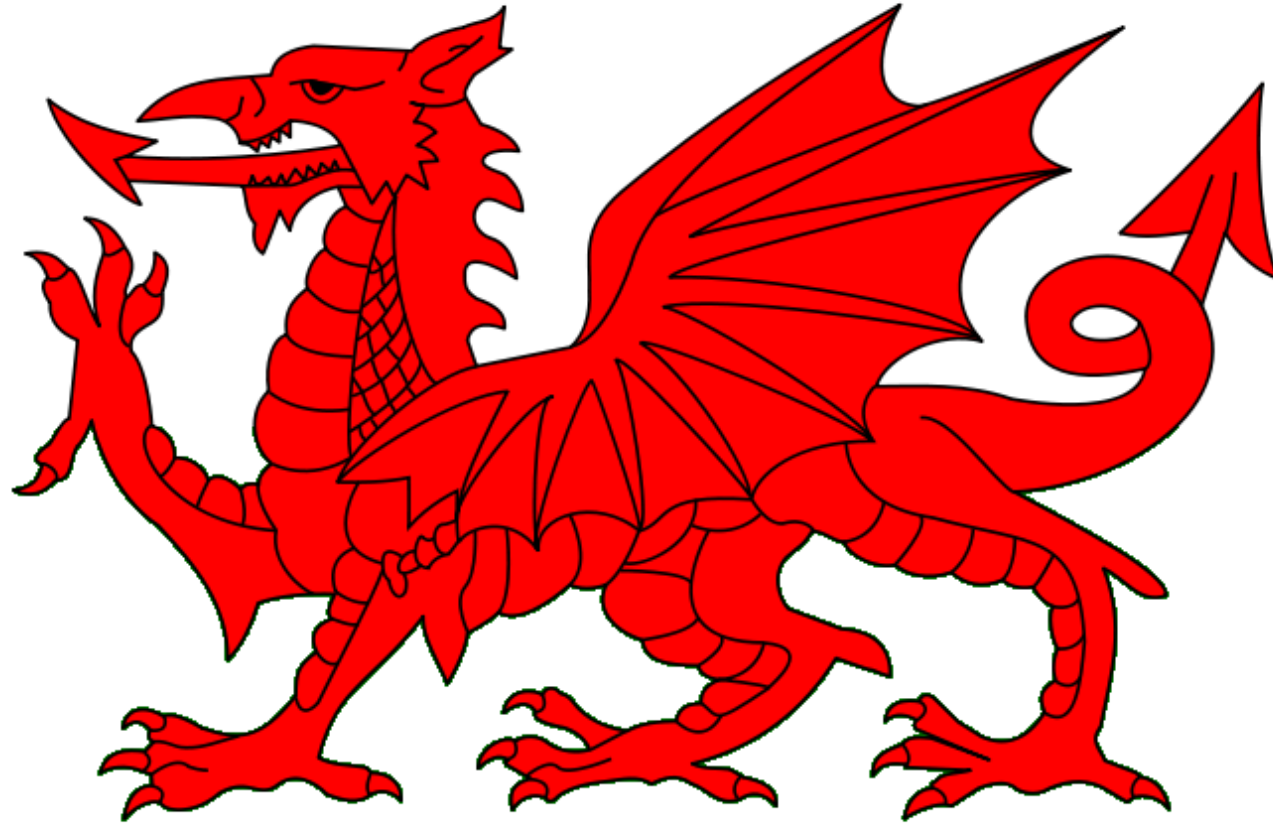
....Three things...swimming riding my bike and walking 100 miles

Diary entry week 7

Ben helps me I walk for 400M with my frame....I did two lengths (*swimming*) by my own....Ida came to help riding by bike I did two times round the cycle track....the end of my Triathlon everyone cheers for me!....I had a medal and a bag with an egg water stickus....'



Dragon – gone



2:Katie Tate Telephone Interview 1:56 minutes

'..outside of university...I don't have a job...so outside of that I do mainly sporting activities: mainly working out which is part of my role as a development trainer, it varies from week to week but I do 15 hours of physical activity a week, I do cycling on a trike and also stretching and then also strength and conditioning.'

INT: So, has this always been your experience that you do 15 hours per week?

'No.....I was never an active person..... I was what I would describe as a 'couch potato' all the way up until 19 years of age and I'm 21 now. I was very sedentary, and I hated working out..'

INT: What was it that changed your experience?



- *‘It was an introduction to a cerebral palsy specific sport called RaceRunning...it was just so freeing, even though I looked ridiculous, despite everything it was just amazing!..... My activities were very short and staggered, I would never really raise my heart rate or get into an easy motor pattern. Gravity and my CP is what made my walking pattern so disjointed- the need to stay upright against gravity with muscles which co-contract at the faintest hint that I might fall. So at first the RaceRunner gave me the experience of what walking must be like without cerebral palsy- using motor patterns which come naturally and easily..... Of course, I understand that some people truly cannot use the RaceRunner or can but won't enjoy it or it is too much hassle to get one. You can get the mentality of sport even if you aren't doing exercise, I mean people who play Boccia in their electric wheelchairs, that does not necessarily have a health effect but it does help mentally in the same way as RaceRunning.*



Race Running



....So you go (Race Running on a University Running track) and it's so beautiful, fresh air, you get to obviously run and because - obviously every movement, even driving, is very much concentrating, trying to do it right, not to fall over and then you get on to RaceRunner and you don't have - you can switch off that part of your brain. I think motor function just uses more - because we've got less maybe - we've got damaged brains so the bits that are alive are working 100 fold more than they're meant to, it might be the fact that somehow they can switch off and you can start thinking. **What I can't do is think coherently when I walk, but I can when I Race Run.**

Obviously loads of people, able-bodied people talk about how much they can think when they run and it's beautiful and they become more creative, so it might be something to do with that but I'm not sure.....



What have I learnt so far?

- Both participants described the activities they consider **fun**, they have self awareness about the importance of their own **fitness** levels.
- It is important to address capacity building as this has an impact on their **functional** levels determining choices of recreational activity and can affect their concentration, mental and emotional well-being due to fatigue and pain levels.
- The **future** is unclear as the present NHS seeks to accommodate for the diverse needs of a developing child and young person with cerebral palsy. It is clear that opportunities to participate in RA builds self awareness, confidence and self esteem. New literature is suggesting **Freedom** and **Fulfilment** are also important. Further research is need to hear more 'voices' of disabled children and youth to understand their Lifeworld.



Questions/Comments ?

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