

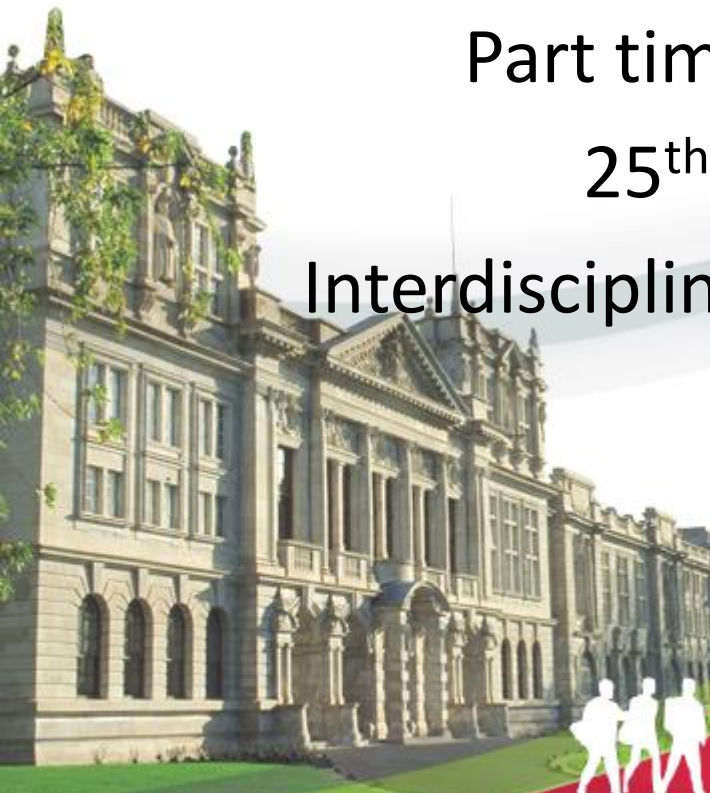
Participatory methods to explore the 'Lifeworld' and views of children and young people with cerebral palsy about 'Participation' in recreational activities.

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Part time PhD student

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Interdisciplinary Graduate Event



Objectives

- Define 'Participation' in relation to health and wellbeing outcomes of recreational and leisure activities for children and young people with cerebral palsy.
- Present a pilot case study using participatory methods.

Lifeworld

- Embodiment of being a child/ young person living with Cerebral Palsy (CP):
 - Where is their voice?
- Childhood different:
 - How different?
 - Pain and Fatigue are known factors which impact on health and wellbeing.

Stereotypes

- Why should the disabled child's experiences of recreational activities be limited to what adults have constructed?
- What choices do they have?
- Hybridity of childhood (Prout, 2011) - information technologies (eye gaze technology), surgery, psychopharmaceuticals (drug management)

Participating in Recreational Activities as a child/ young person with CP

Participation

‘The act of
doing and
being involved
in meaningful
life situations’

Rosenbaum and
Gorter, 2013;
Clark et al 2014



Recreational activities

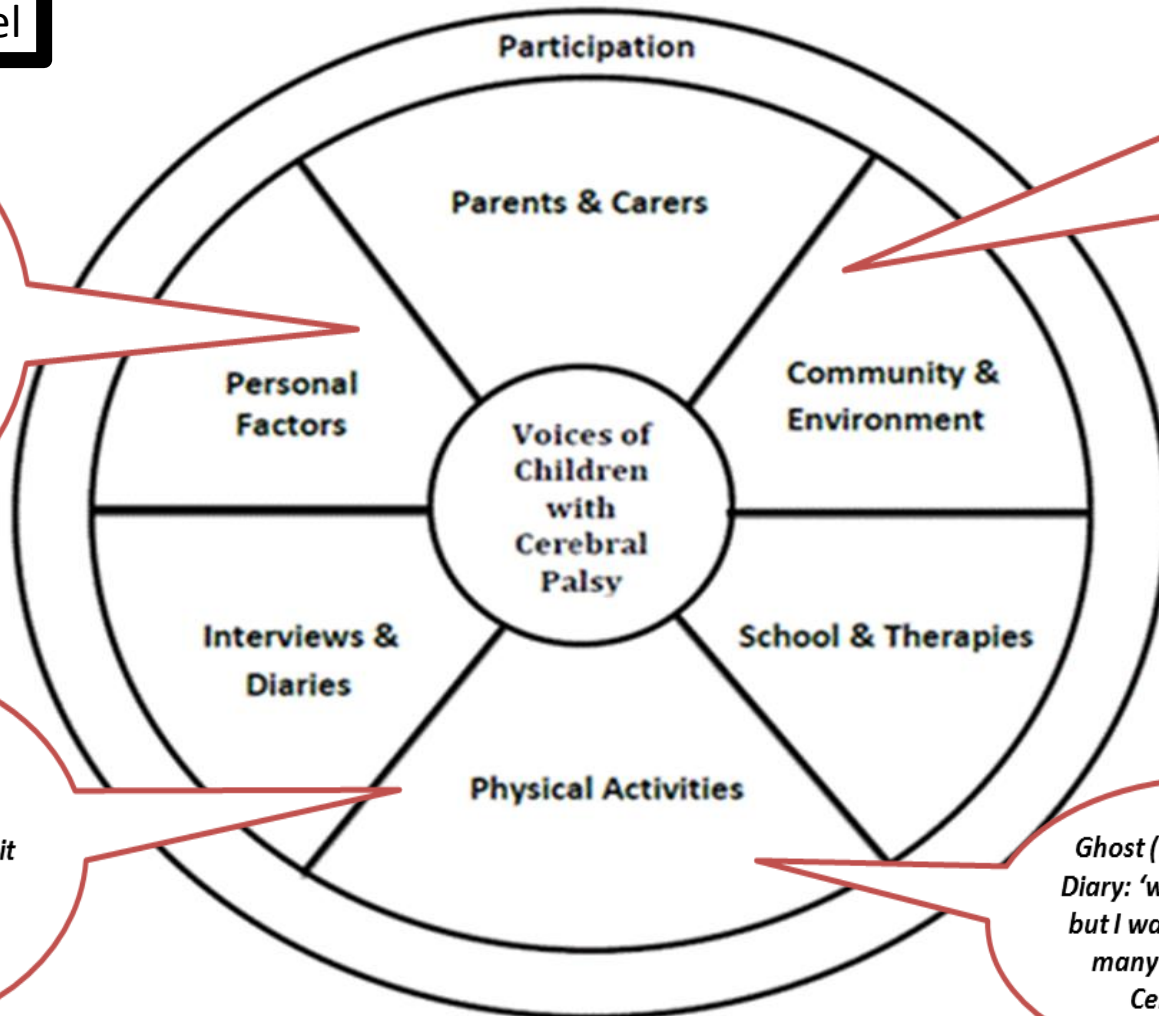


Pedal Power Cardiff study 2009-2012



How children's voices changed our view- 'Wheel of Participation' Pickering et al, 2014

Social model



Husian (10 years/Hemiplegic):
'...I found it hard, you had to push the pedals so hard...but I got better by the third time...and I was 'wicked' at stopping...'

Rugby (11 years/Diplegic):
'...I was a bit nervous going on the bike....but it made me feel a bit stronger...but my legs ached afterwards...'

Lizzie (11 years/Hemiplegic)
'..I just don't like riding a bike...I don't like falling off...I don't feel scared about my balance I just don't like it..'

Ghost (7 years/Diplegic) Diary: *'we went to the pier but I wasn't able to go on many rides due to my Cerebral Palsy'*

Dissemination for children



Physical Health and Emotional Wellbeing Benefits

- Participation in recreational activities can improve physical health and wellbeing.
- Activities can be competitive or non-competitive, group or individually based.
- Can be sedentary or solitary activities
- Joining in can give a 'sense of belonging' however may not change abilities



Wellbeing

- National Institute for Health and Care Excellence (NICE) 2013
- World Health Organisation (WHO), 2014

Feeling valued as a person, realising own potential:

3 aspects; Emotional, Psychological, Social

Health and wellbeing behaviours

- What helps or hinders adoption of health and wellbeing behaviours for children with cerebral palsy?
- How do children with cerebral palsy perceive the value of recreational activities to support their own health and wellbeing as they mature into adolescence?

Proposed Research question

- 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?

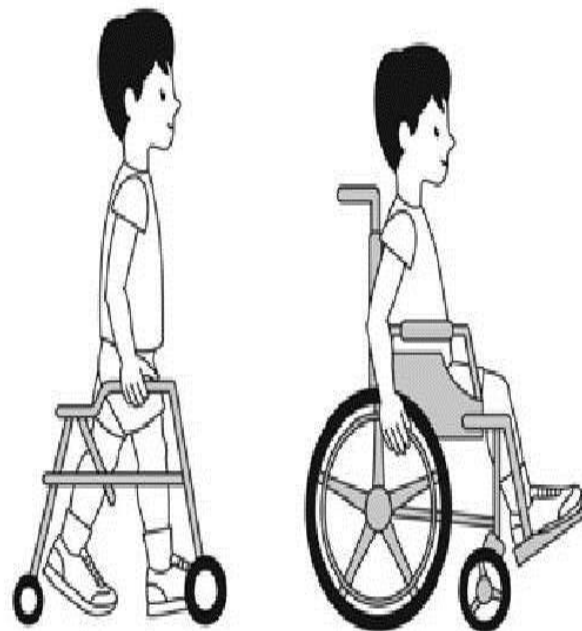
Methods

- Initial meeting to gain consent/ assent
- 2 participatory interviews 12 weeks apart.
- 1st interview structured around the 6 themed 'F' words Fun, Fitness, Family, Friends, Function and Future (Rosenbaum and Gorter, 2013)
- 2nd interview makes reference to the diary entries.
- Diary of Recreational activities kept for 12 weeks.



Pilot case study

- Girl aged 9 years:
'Becky Lamb'
Attends mainstream
primary school, lives with
both parents and younger
brother.
Prior research relationship
since 2009: (6 years)

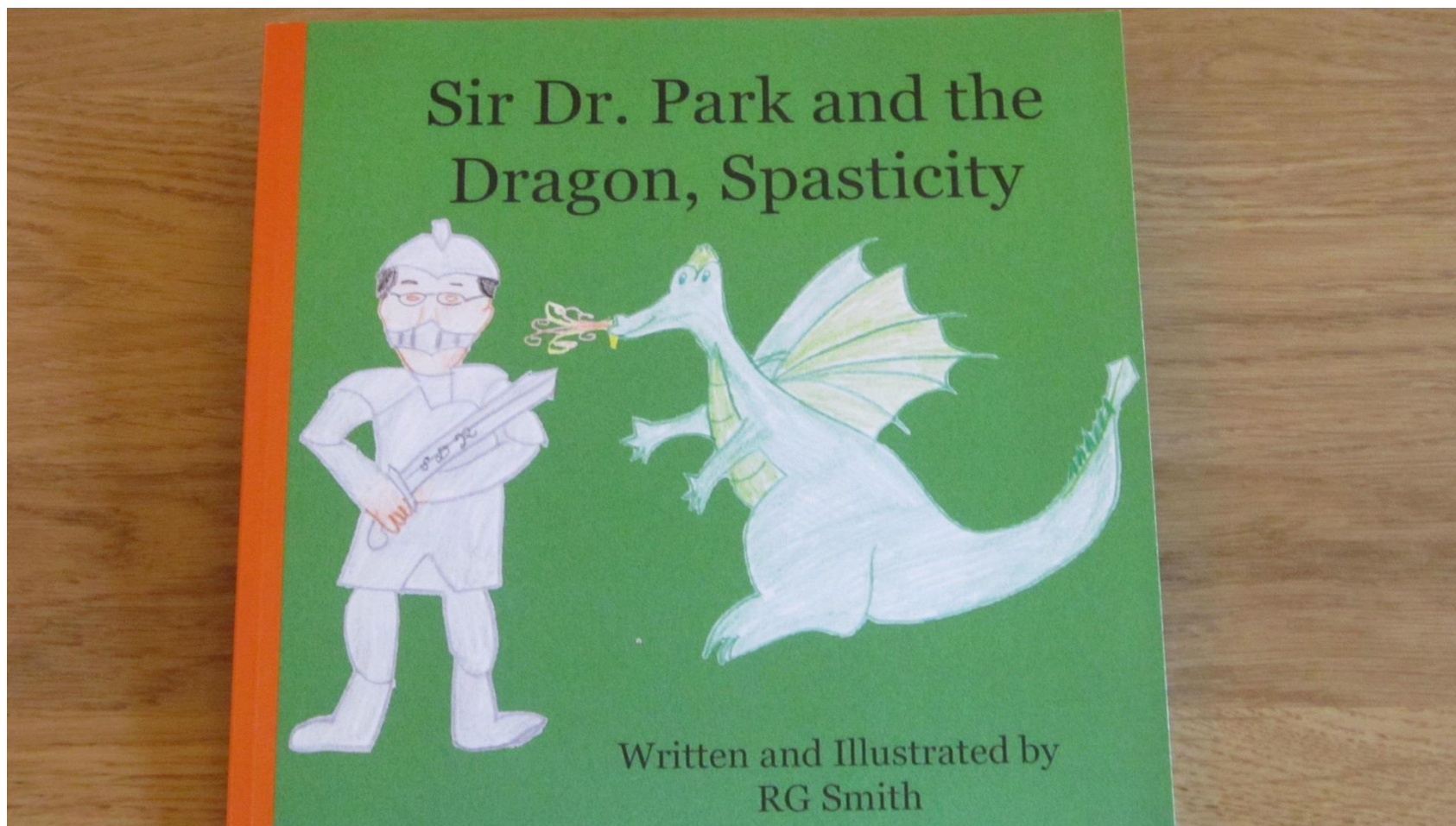


GMFCS Level III

Build relationship

- Previous research relationship helped me to understand what was important to Becky to know what ideas/ laminated cards to include.

Stiffness in muscles



Becky Lamb Interview 1 (55 minutes) (Feb 15)

Becky described the activities she enjoys which includes singing in a choir, playing the violin in an orchestra, reading, cycling, swimming and horse riding: Here is her story about what is Fun, told with laminated card figures:

'...Cos friends have fun....so first there's a family.....then they have their friends, then they played for a little bitand then we go horse riding together...then we play...then... we go on our bikes, then we play in the walker.....'

Becky Lamb Interview 1

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



Becky Lamb (BL) interview 1:

INT: So here is a picture of fitnessSo what things do you like to do that keep you fit?

BL:.....Bike.....

Dad: What did we do this morning before school?

BL: Hip stretches....I need to do what is important which is the hip stretch

INT: A hip stretch....is that something you do every morning?

BL: Yes..

Dad: What else do we use in the mornings for exercise?

BL; Peanut ball

Dad: What did we do this morning, do you know?

BL: err.... Treadmill

INT: You went on the treadmill? How long do you do that for?

BL: 10.... minutes before school....I don't do my training every day....only on Tuesdays and Thursdays.

INT: That's really good. So, how often go on bike at the moment?

BL: I don't know.... Dad: It's too cold at the moment.



Sandbox (Mannay, 2015)



Becky Lamb Interview 2

47 minutes(May 15)

Sandbox to tell her story

BL speaks to her 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.'



Interview 2: Sandbox story

'...the medal with the orange ribbon was for the Super Tri I did in March...it's gotseven stars....I'm a winner...

Int: What did you have to do?

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

Own diary entry week 7 (week of Triathlon Mar 2015)

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

Observation

- Invited to see Super triathlon Dec 2015- walked 400 metres round track twice
- Field notes- Dad – *‘Its amazing what the motivation of a crowd cheering can do....’*



Photo used from Big Moose SuperTri 2 web page



Questions/Comments ?

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