

Children in Wales conference, Cardiff: Promoting and Empowering the Rights of Disabled Children and Young People

Utilizing participatory methods to hear the voices of disabled children and young people who participate in recreational activities



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11th November 2015

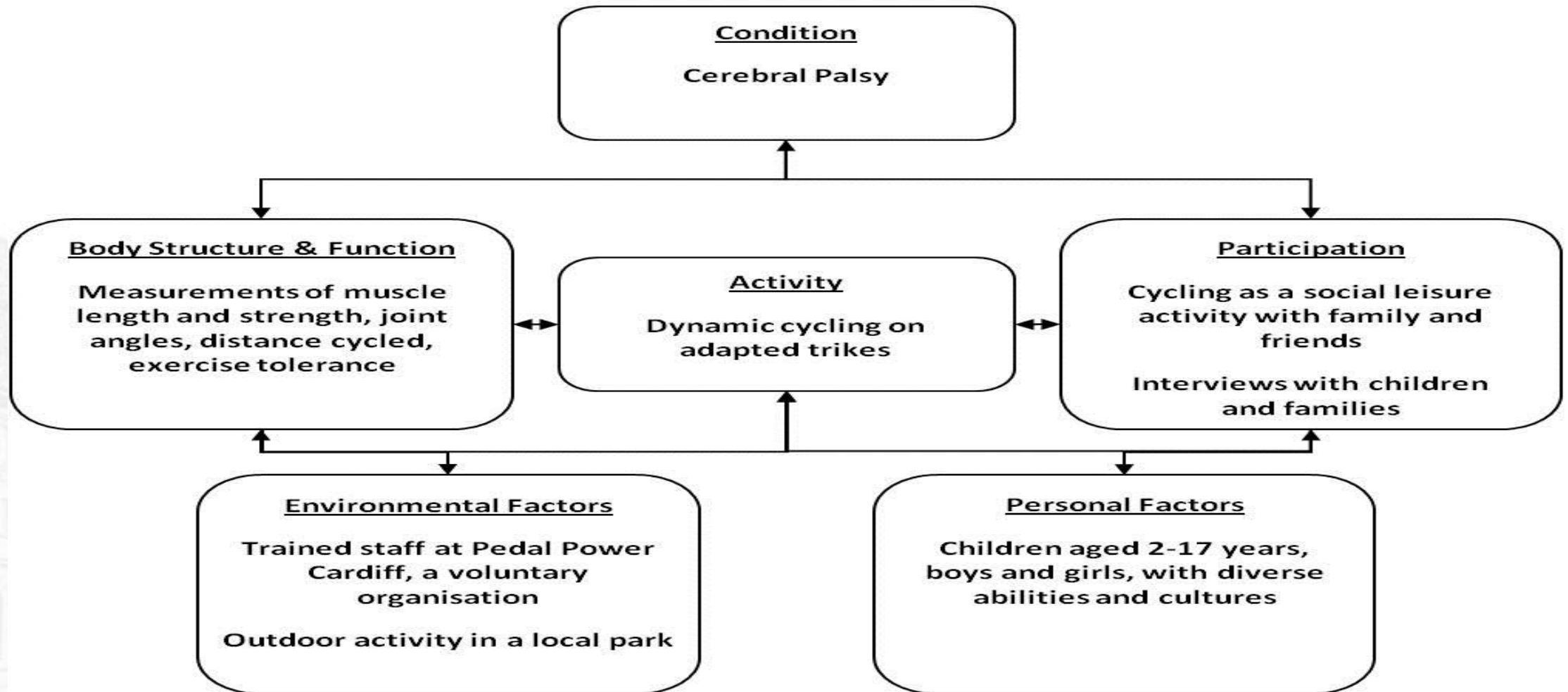
- Data from 2 different studies will be used to show the additional value of participatory methods:
 - 1. 'Pedal Power'- 35 children and young people with Cerebral Palsy: Interviews + diary.
 - 2. Doctoral study 'VOCAL'– Lifeworld- using Interpretative Phenomenological Analysis.



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



Figure 1: Pedal Power Pilot Research Project adapted from the domains of the World Health Organisation: International Classification of Functioning

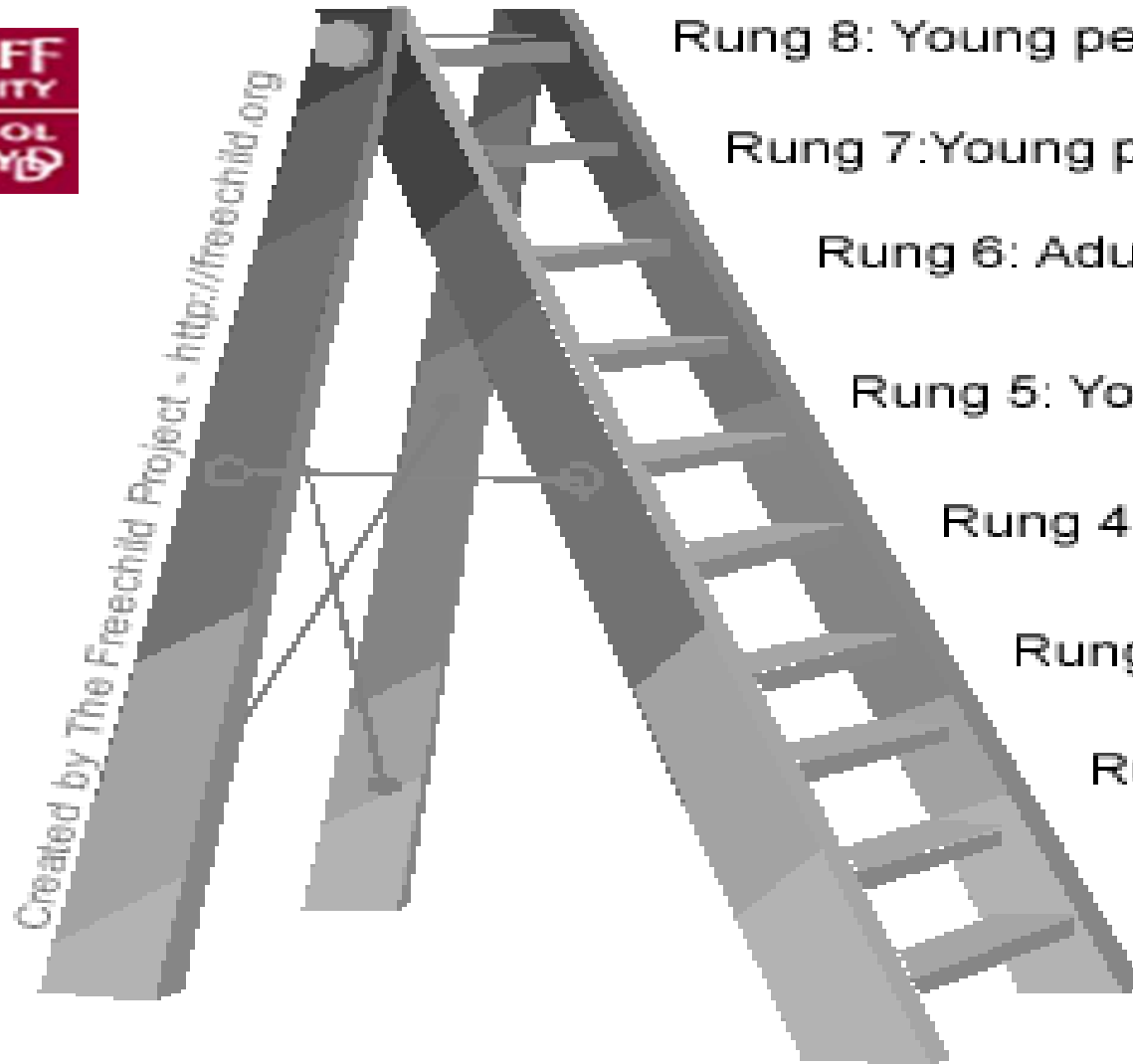


- To enable their 'voice' to be heard
 - United Nations Convention on the Rights of the Child: Articles 12, 23, 24 and 31:
 - All children have the right to say what they think
 - If disabled to have support to lead full and independent lives
 - Best quality healthcare
 - to relax and play and to join in a wide range of activities

(UNCRC, 1989)



Roger Hart's Ladder of Young People's Participation



Rung 8: Young people & adults share decision-making

Rung 7: Young people lead & initiate action

Rung 6: Adult-initiated, shared decisions with young people

Rung 5: Young people consulted and informed

Rung 4: Young people assigned and informed

Rung 3: Young people tokenized*

Rung 2: Young people are decoration*

Rung 1: Young people are manipulated*

Note: Hart explains that the last three rungs are *non-participation*

Adapted from Hart, R. (1992). *Children's Participation from Tokenism to Citizenship*. Florence: UNICEF Innocenti Research Centre.

Children and Young People's Participation Standards for Wales(2007)



Having a voice, having a choice-

7 standards: we offered that we would:

listen to your ideas, views and experiences

take you seriously and treat you fairly

work with you to do something about the

things you tell us are important

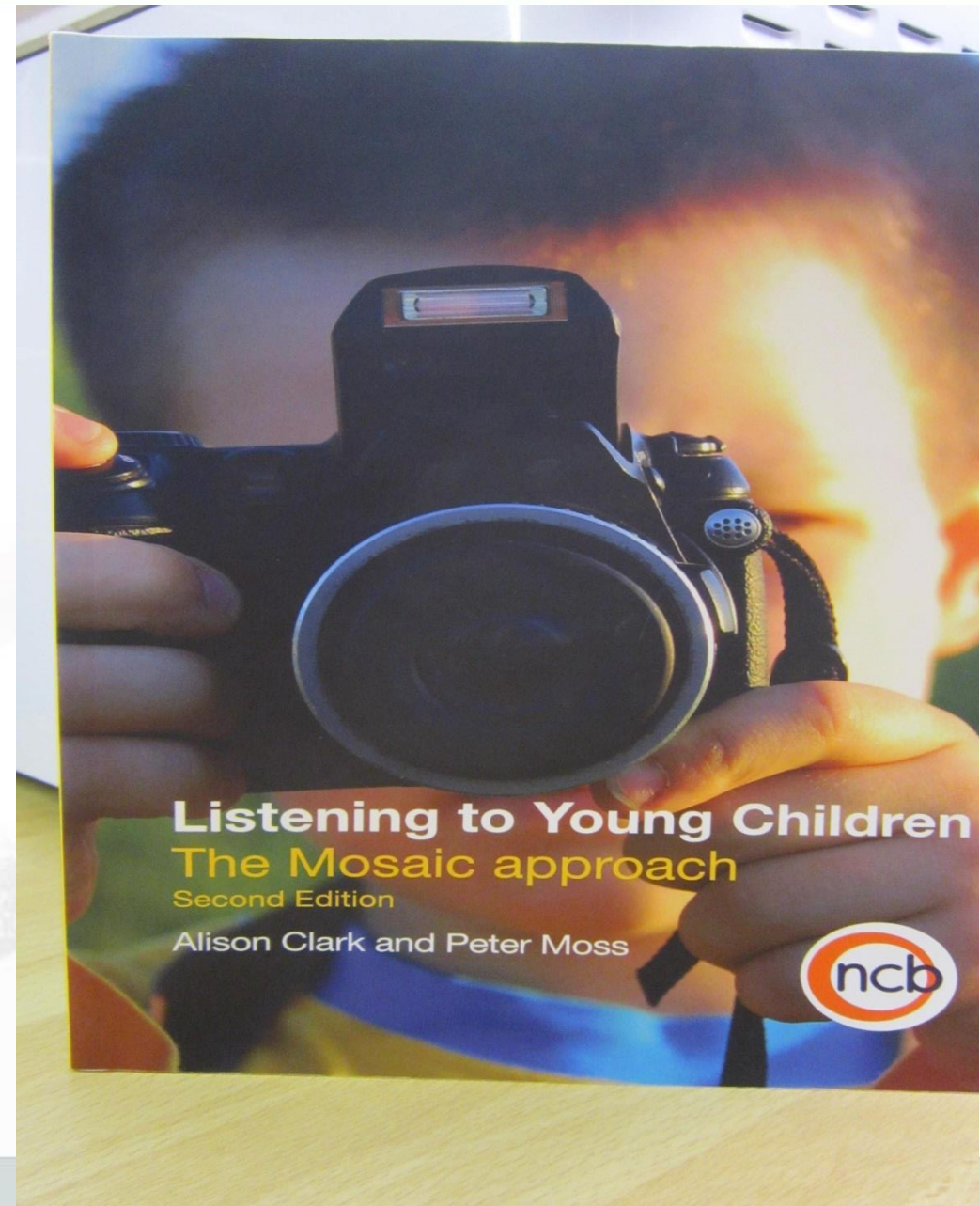
work with you to help change things for the

better

- *'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

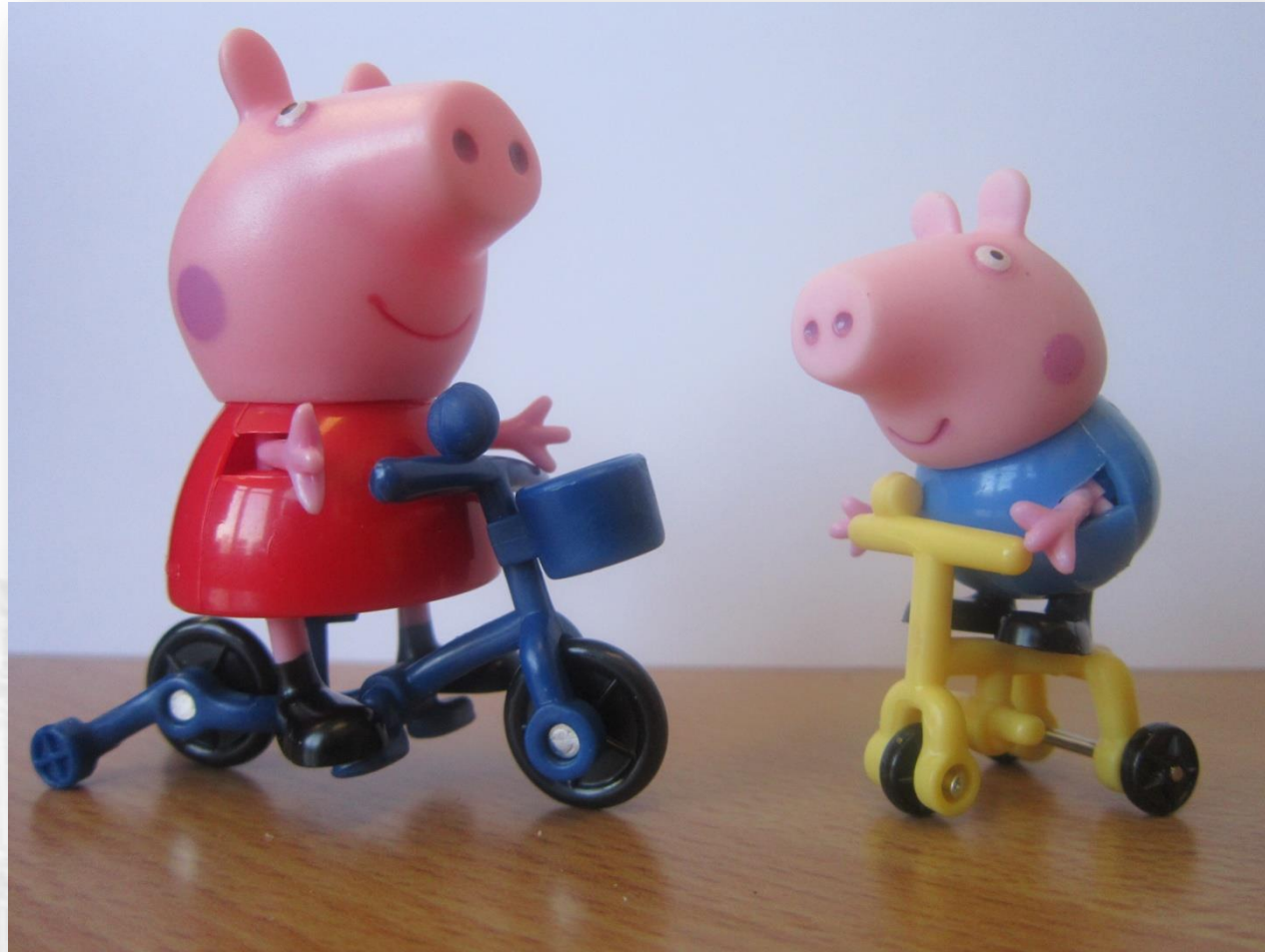




- We used a glove puppet to engage the child in measurements (muscle strength measure here) and also when doing the interviews- non verbal children responded well to the puppet.



Story telling/ Peppa pig goes cycling

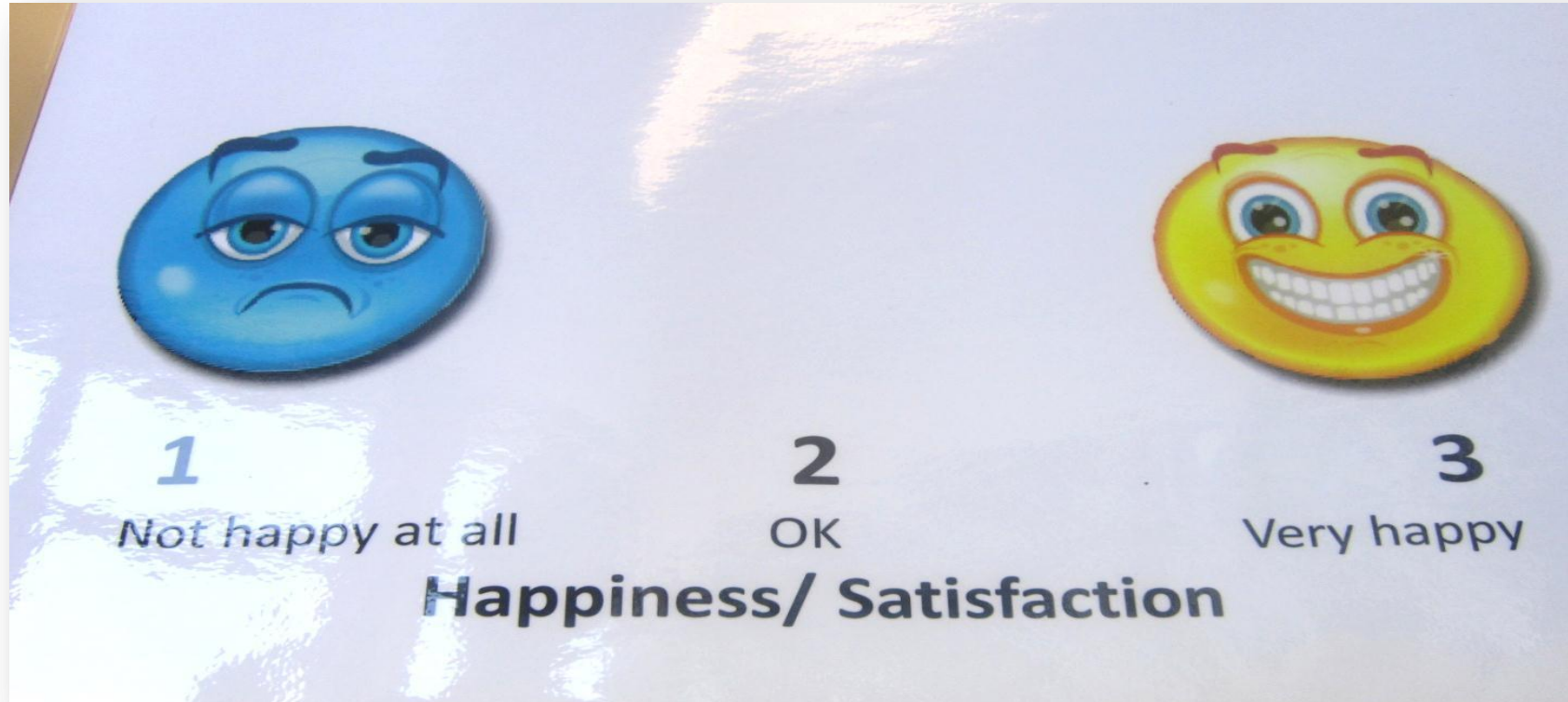




- Different contexts for cycling were presented to the children in picture format to explore where they might like to cycle in the future:
- Photo elicited responses- not always verbal

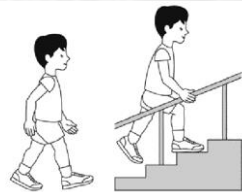


How did cycling make them feel?



- 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- ..***



- Diary drawing



Diane, 10 years

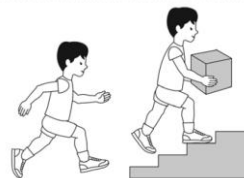


Peter's Mum: *"Gabriela put him on the Tom Cat trike, strapped his feet in and it was the first time ever he pedalled and he couldn't stop it. Everybody got so emotional, fantastic. It just shows if you've got the tools for the job, the right equipment, you can do it... This year we cycled from Bristol 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



Children unable to self report

Julia, 14 years

*“You can just see **the joy** in her face when she’s on her bike yeah!....Um, I mean if it’s straight, you know, you can virtually sort of let go and she’ll just go by herself until she starts veering off course.....**she definitely enjoys it...**”*

Rachel, 8 years

*“Throughout the cycling sessions I feel that **Rachel’s confidence has improved**. She is so happy when she is cycling and it gives her the **freedom and independence** she needs....”*

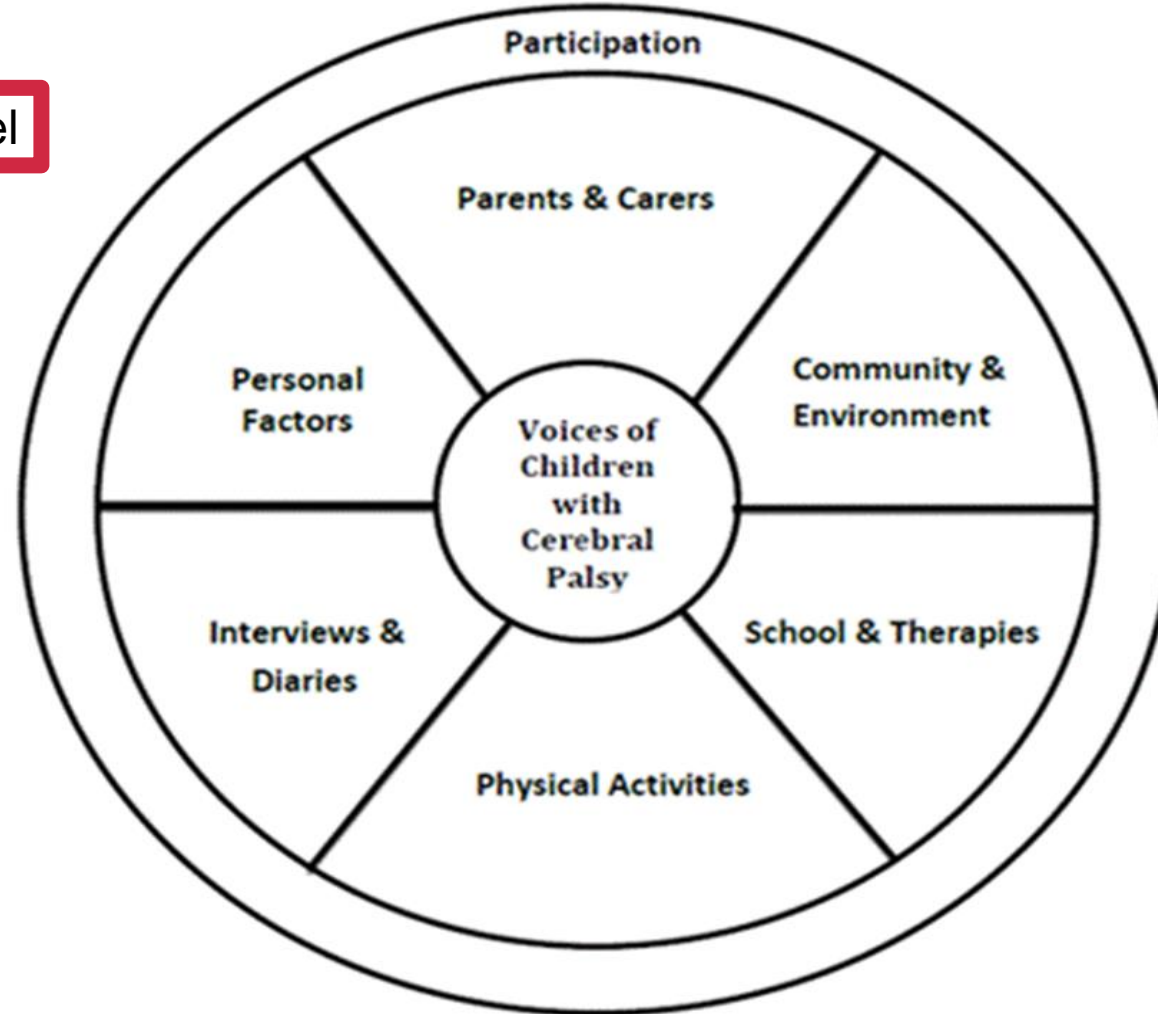


Change in cycling activity 'Ghost'

***“Didn't think he
would ever be
able to ride a
bike”***

To/ Mrs D. Pickering,
thank-you for the feed back of [redacted]
every think looks o.k on the sheets,
I've got really good news [redacted] has
learnt to ride a bike only a little way
down hill or flat roads,
can't ride up hill yet. But we are
all really excited didn't think he
would ever be-able to ride a bike,
so he's got one for christmas as a
special surprize.
He has also learnt to swim a little
But not gone too take him now its
winter cause his legs plays him up
too long in cold water.
And also just to say thank-you for all
the work you've done with [redacted]
and merry christmas and happy new year
from [redacted]
Debbie and [redacted].

Social model



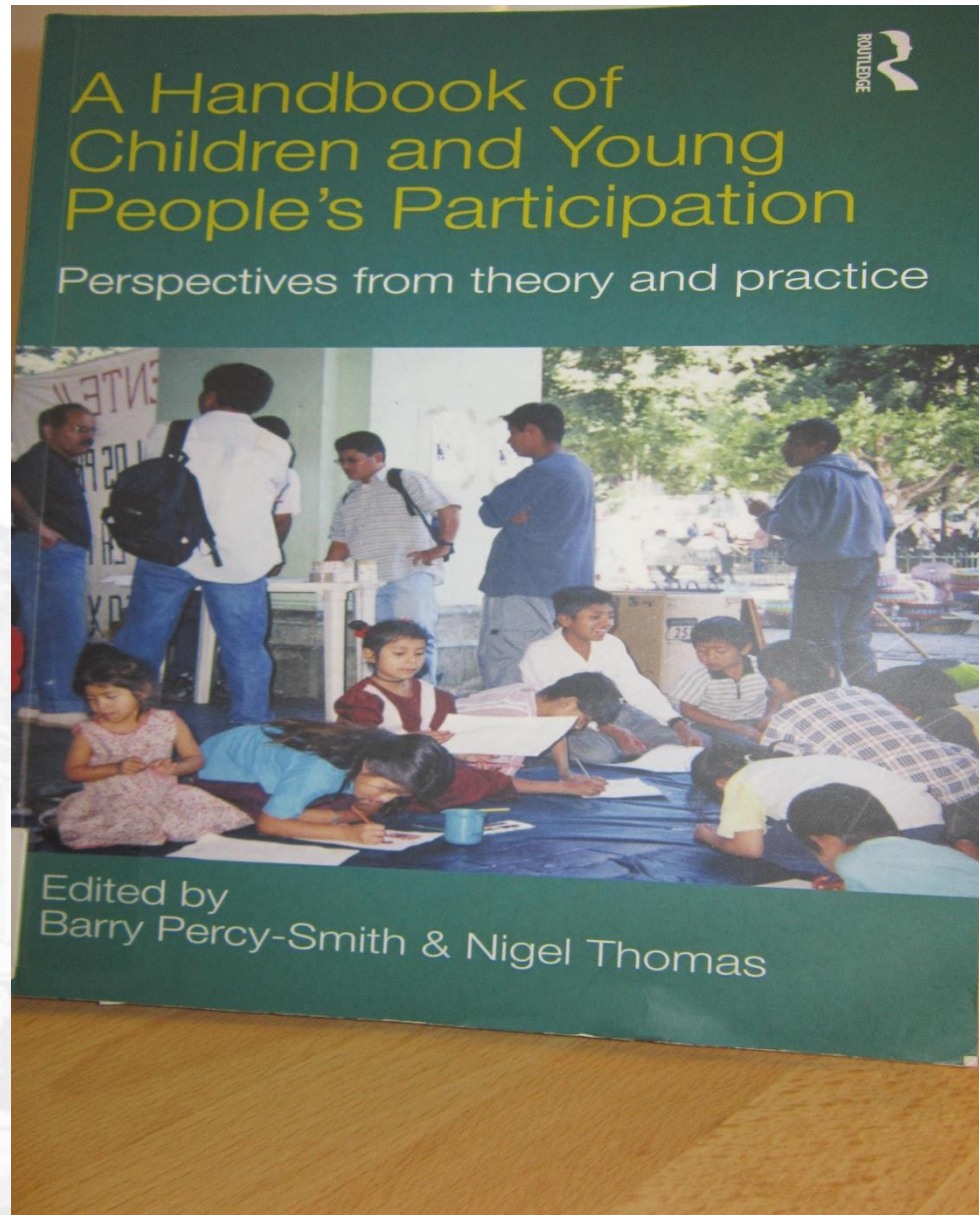
Links to
Treseder's
Circle of
participation,
1997





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





- “Involvement in meaningful activities”
WHO, ICF 2001
- Kellet, 2014 ‘Act of doing and being involved’
- Combining these two different constructs by redefining participation as the **‘act of doing and being involved in meaningful life situations’**, the agency of a disabled child can be included more actively.

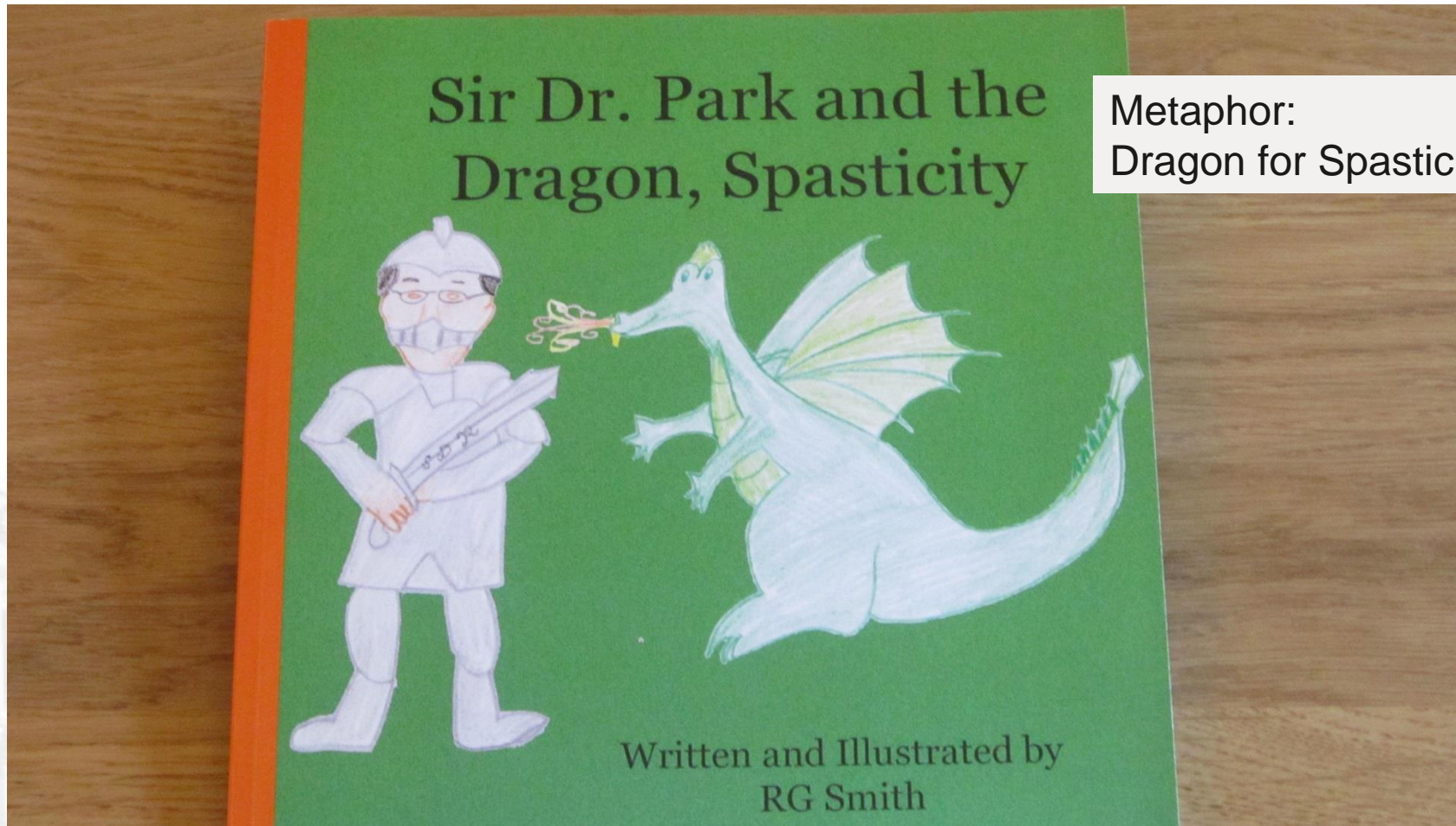


- What does participation mean to you?

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

Co-production,
Bristol, 2014





Metaphor:
Dragon for Spasticity



- 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.

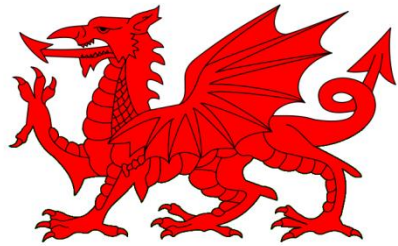
Telephone interviews.



- 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.



‘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...’



Becky Lamb Interview 2 47 minutes Sandbox to tell her story (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 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 medal and a bag with a egg water stickus....'



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 outit 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?



Race Running



- *'It was an introduction to a cerebral palsy specific sport called RaceRunning...it was just so freeing....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.....*



*.....So it's so beautiful, fresh air, you get to obviously run on the RaceRunnerand 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.***



What can participatory methods in research offer?

- Engagement with disabled children and young people
- Takes more time but gives depth
- Fun
 - Listen
 - Hear their views and experiences
 - Learn what helps or hinders their experiences
 - Represent their voices



Race Running

International Athletics stadium,
House of Sport, Cardiff
Fridays 5-7pm
Contact Physiotherapist,
Gabriela Todd 0780 377 0962



Questions/Comments ?

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