

Adapted Cycling in young children with cerebral palsy: practice and evidence of effect

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9th April 2016



<p>Conflict of interest</p>	<p>None</p>
<p>Relevant relationship with companies</p>	<p>None</p>
<ul style="list-style-type: none"> • Sponsoring or research money: £43,500 • Research partner • Integrated Research Application System approval for National Health Service recruitment in United Kingdom: South West Wales Research Ethics Committee (2010-2012) 	<ul style="list-style-type: none"> • Nancie Finnie Charitable Trust – now part of the Chartered Society of Physiotherapy, 2009-2012 • Pedal Power Cardiff • Number: 10/WMW02/25



Objectives

- Participation in recreational activities for young children with cerebral palsy (C with CP)
- Current UK practice
- Adapted cycling research study
- Voices- Interview and diary data, digital story
- Doctoral study, year 1 part time – 2 pilot cases-work in progress
- Summary

Children with Cerebral Palsy

Participating in Recreational Activities

Recreational activities-limited choices

Participation

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

Rosenbaum and Gorter, 2012;

Clark et al 2014



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.
- New sociology of childhood-Hybridity.



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

Current practice in UK

Physiotherapists remain more focussed on body structure and function.

Self management for long term conditions.

C with CP can be supported by reasonable adjustments to participate in recreational activities.

It is not known if the children perceive this could enable them to self manage their health and wellbeing as they mature into adolescence.

Prudent healthcare (Welsh Government, 2016)

Prudent healthcare

- Achieve health and wellbeing with equal partnership through co production
- Make best use of skills and resources to care for those with greatest health needs first (GMFCS IV and V)
- Do only what is needed, no more, no less and do no harm (Stop doing ineffective treatments)
- Use evidence based practices consistently and transparently to reduce inappropriate variations

Adapted cycling research 2009-2012 (Nancie Finnie Charitable Trust)

2 groups: Cycling (17), non cycling (18), N=35, Aged 2-17 years.

Muscle strength and length measures.

GFMCS I: 7, II: 12, III: 6, IV: 9, V 1

2 Interviews adapting Mosaic participatory methods (Clark and Moss, 2011)

Diary of physical activities



Research Team

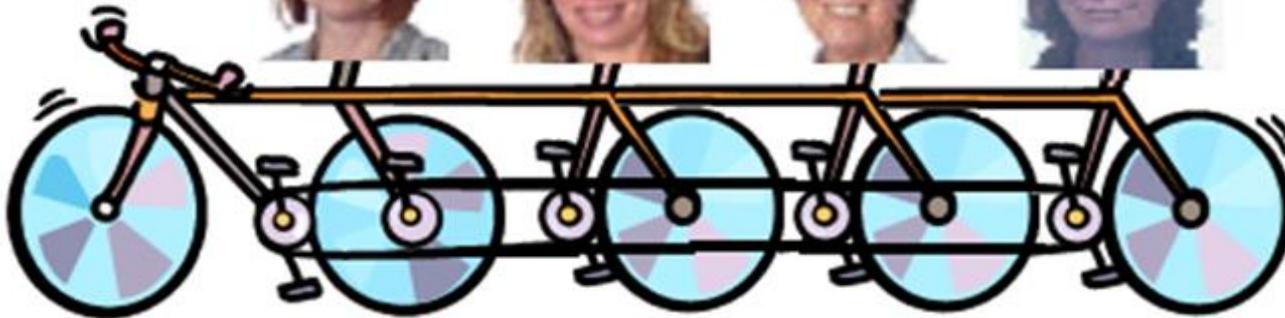


Dawn
Pickering

Karen
Visser

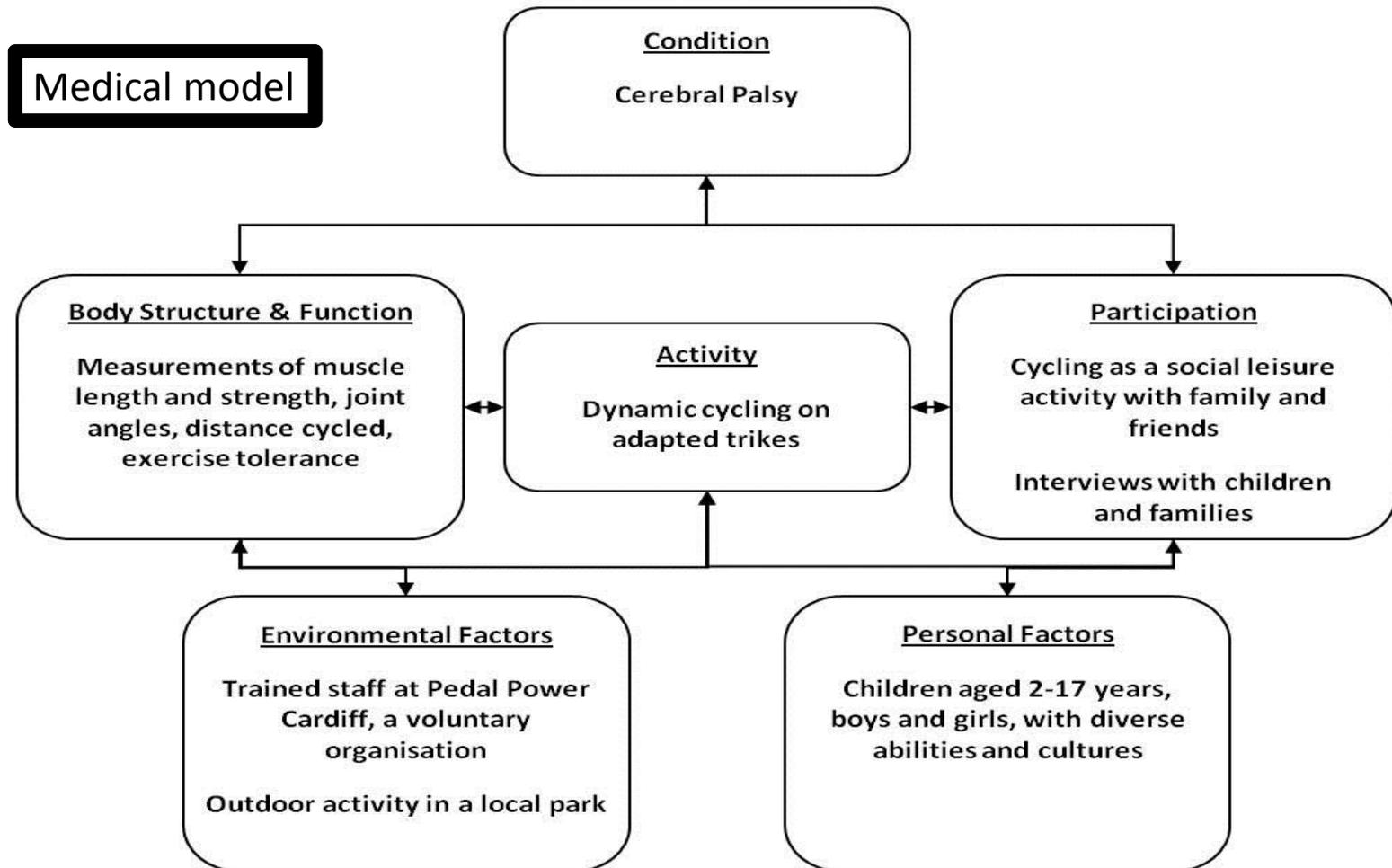
Lyn
Horrocks

Gabriela
Todd



What physiotherapists understood participation meant? Pickering et al, 2012

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



Pedal Power Cardiff -2009-2012

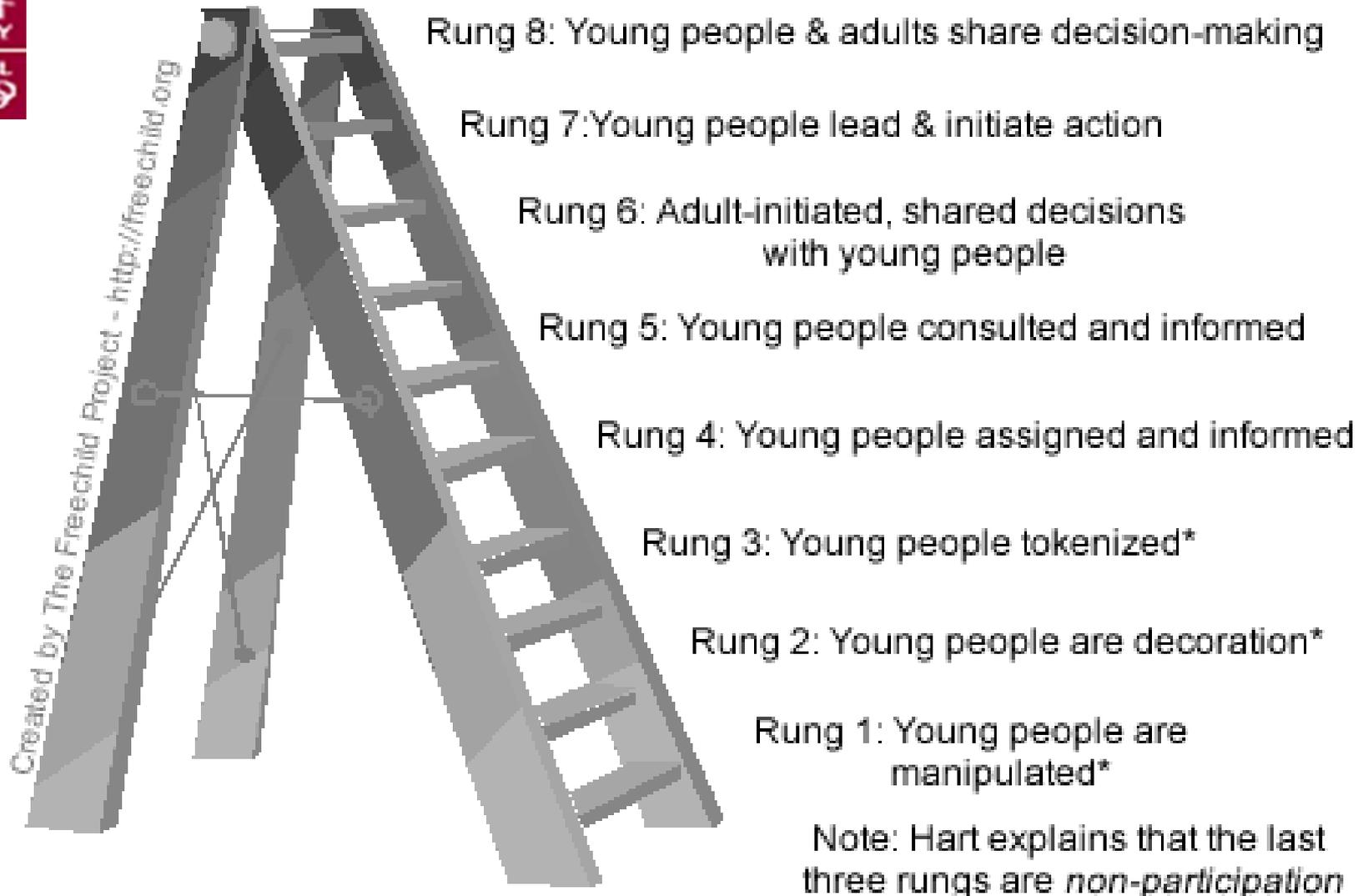


Children's Rights approach



- To enable their 'voice' to be heard:
 - United Nations Convention on the Rights of the Child(UNCRC, 1989)
 - : 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

Roger Hart's Ladder of Young People's Participation



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

Muscle strength and Length measures



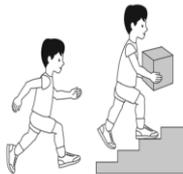


Qualitative Results

- What made it easier:
- Cycle hire centre
- Staff attitude + skills to adapt the trikes
- Family liked cycling

Aspirations

Peter's Mum: *"Gabriela put him on the 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!"

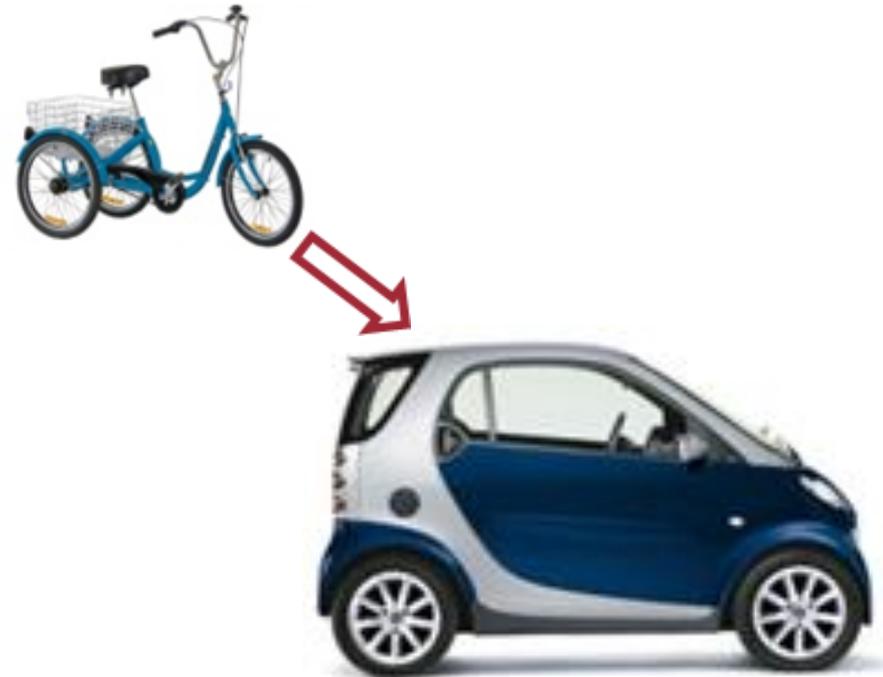
Peter aged 7 years,
GMFCS I

Barriers-environmental

Access



Transport



Barriers-physical

Fatigue

Rugby

*“After trying the trike my legs
feel aching”*



Suarez
*“My legs hurt
for 3 days after
riding the trike”*

Attitudes-low expectations

May's own Diary entry
(aged 10 years, GMFCS I)

*Today I had a 20 mins bike ride with my sister and brother.... I have come on really well considering me and my family all thought I wouldn't be able to achieve such a brilliant **opertinity**, we also thought I am going to be doing a bike *prefishinsiy* test after easter so we have been practising weving in and out and signalling left and right the right is really easy for me but the left is what I find tricky...*

May

May's 2nd interview - Barriers

Interview:

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

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

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

M: H Forest

Int: Have you been there already?

M: 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?

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

Change in cycling activity 'Ghost' (8 years, GMFCS III)



***“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 thing 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 surprise.
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 [redacted]
from
Debbie and [redacted].

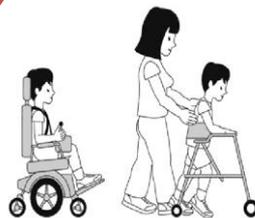
Children unable to self report

Heather, 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

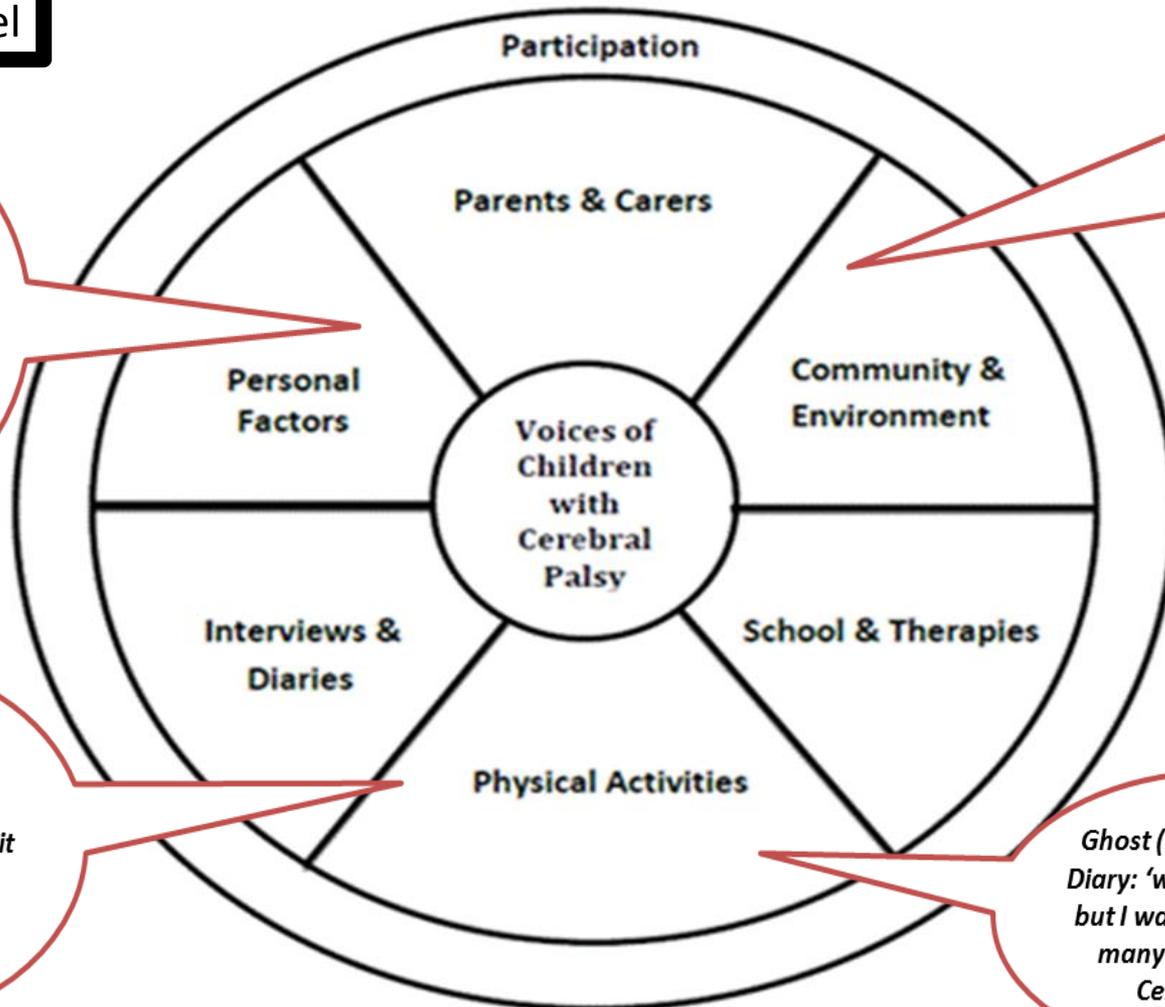
*“Throughout the cycling sessions I feel that **Rachel’s confidence has improved**. She is so happy when she is cycling and it gives her the **freedom and independence** she needs.....”*



How children's voices changed our view- 'Wheel of Participation'

Pickering et al, 2014

Social model



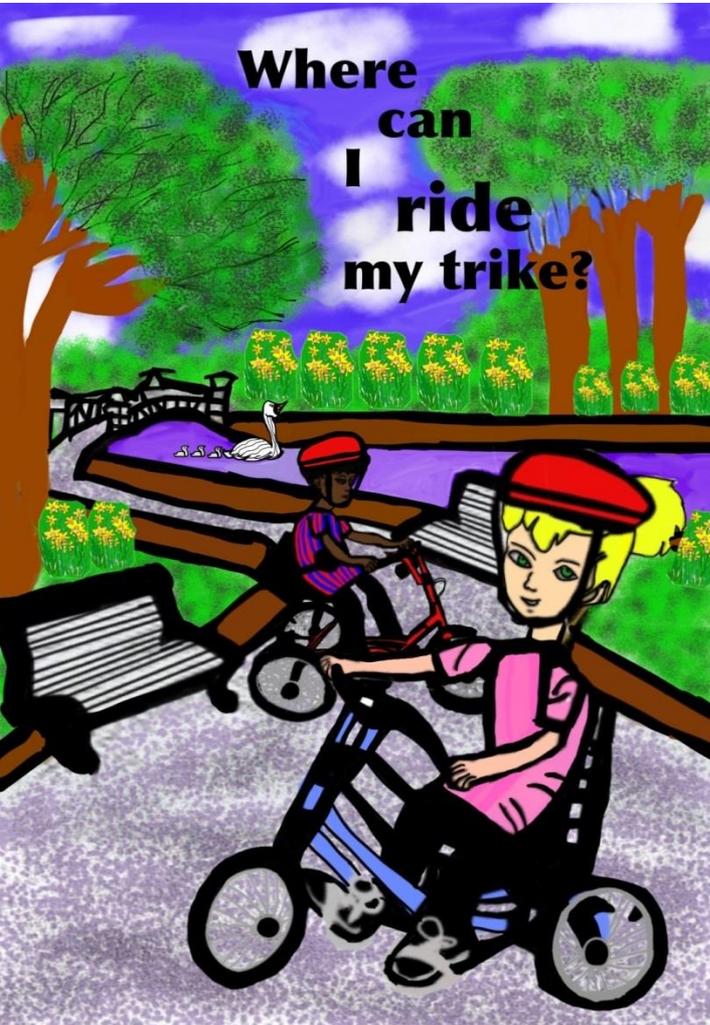
Husian (10 years/Hemiplegic):
'...I found it hard, you had to push the pedals so hard...but I got better by the third time...and I was 'wicked' at stopping...'

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'*

Children's illustrated story book 2015



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

Co-production: Digital story

- Dissemination: invite to all participants in study to co present June 2014 in Bristol.
- 1 volunteer: Consent obtained 28th April 2014:
- When asked what she enjoyed participating in she reported that

“...enjoys horse riding- especially when I’m trotting, bike riding and Brownies...”



You tube link

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

Health and wellbeing behaviours

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

Seeking a deeper understanding of the phenomena of participation

- Embodiment of children and young people living with CP and their views and experiences of participation in recreational activities as they mature into adolescence (9-16 years).

Participation

Stewart et al, 2012

Powrie et al, 2015

Social participation-
environmental
adjustments

- Evidence synthesis 12
qualitative studies: **leisure**
participation

Proposed Doctoral Title

Beyond Physiotherapy: Voices of children and young people with cerebral palsy and their carers about 'Participation' in recreationalal activities (VOCAL).

Proposed Questions

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?

What opportunities or experiences do they have?

What do they and/ or their carers think about the health and wellbeing effects of participation in recreational activities?

Aims

To use: 'Mosaic participatory' methods to capture the 'voices' of C & YP with CP in order to understand their views and lived experiences of participation in recreational activities.

To analyse: Data utilising an Interpretative Phenomenological Approach (IPA) which includes descriptive, conceptual and linguistic perspectives.

Methods

- 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 and health and wellbeing effects

- Diary of Recreational Activities kept for 12 weeks.
- 2nd interview makes reference to their diary entries.



2 pilot cases – preliminary data, not fully analysed 2015

- Girl aged 9 years:

‘Becky Lamb’ GMFCS III

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’ GMFCS II

University Student, lives away from home.

Met at a children’s physiotherapy conference November 2014.

Telephone interviews.

Becky Lamb (BL) interview 1:

56 minutes

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.



Interview 2: 47 minutes Sandbox to tell her story (Mannay, 2015)



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...'

Diary entry week 7 (week of Triathlon)

Ben helps me I work 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 a egg water stickus....'

Health and well being behaviours

Early habits established – becomes natural to get up early to do exercises before school.

Empathy with older people who find walking hard
(Future aspirations-Set up tea shop to listen to them).

Katie Tate (21 years) Telephone Interview 1:

56 minutes

'..outside of university... 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?

Katie Tate Interview 1 continued

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



Katie Tate Telephone Interview 2: 68 minutes

....So it's so beautiful, fresh air, you get to obviously run on the RaceRunnerand you can switch off that part of your brain....

What I can't do is think coherently when I walk, but I can when I Race Run.....



Never too late

Health and wellbeing behaviours can still change at an older age.

Do physiotherapists consider they have role in promoting health and wellbeing behaviour change in C and YP with CP? (Post Doc)

Summary

- Exploring this complex phenomena of participation in recreational activities with C & YP with CP seeks to research how they perceive this could help their health and wellbeing.
- Creative research methods are needed to engage C & YP with CP especially those with limited communication and mobility.
- More data from children and young people's voices can inform future healthcare practice.



Questions/Comments ?

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