

Participation in recreational activities: views, experiences and choices from children and young people with cerebral palsy.

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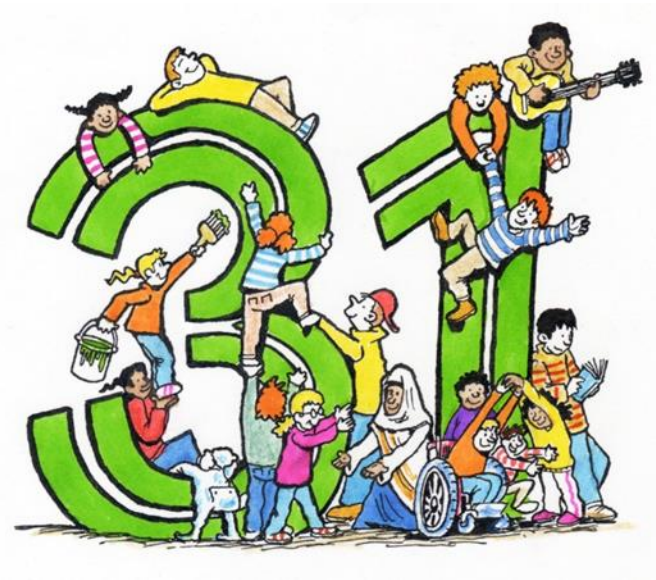
Objectives

- My position as a healthcare professional
- Health and Wellbeing : Children's rights- Article 31
- Adapted cycling research study
- 'Voices' Interview and diary data, digital story
- Doctoral study: 'VOCAL' year 2 part time –case study-work in progress- examples of data yet to be fully analysed

Children's Rights approach

To enable the 'voices' of CYP with cerebral palsy to be heard:

- United Nations Convention on the Rights of the Child (UNCRC, 1989): Article 31
- Rights of Children and Young Persons (Wales) Measure 2011



<http://www.playwales.org.uk/eng/>

'All children and young people have the right to rest, leisure, play and recreation and to take part in cultural and artistic activities'

Physical Health and Emotional Wellbeing Benefits

- Participation in recreational activities can improve physical health and emotional 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 (usual expectation from physiotherapy)
- Some activities may take place in school but many are after school and extra curricula

Well-being

- National Institute for Health and Care Excellence (NICE) 2013
- World Health Organisation (WHO), 2014
- Social Services and Well-being (Wales) Act 2014

Feeling valued as a person, realising own potential:

3 aspects; Emotional, Psychological, Social

Children with Cerebral Palsy

Participating in Recreational Activities

Participation

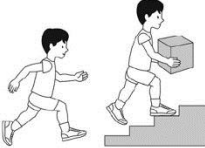
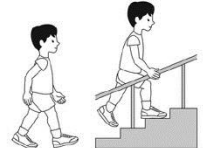



‘The act of doing and being involved in meaningful life situations’

Recreational activities-sport's bias



Gross Motor Function Classification System (GMFCS)

GMFCS E & R Descriptors and Illustrations for Children between their 6th and 12th birthday

	<p>GMFCS Level I</p> <p>Children walk at home, school, outdoors and in the community. They can climb stairs without the use of a railing. Children perform gross motor skills such as running and jumping, but speed, balance and coordination are limited</p>
	<p>GMFCS Level II</p> <p>Children walk in most settings and climb stairs holding onto a railing. They may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas or confined spaces. Children may walk with physical assistance, a hand-held mobility device or used wheeled mobility over long distances. Children have only minimal ability to perform gross motor skills such as running and jumping.</p>
	<p>GMFCS Level III</p> <p>Children walk using a hand-held mobility device in most indoor settings. They may climb stairs holding onto a railing with supervision or assistance. Children use wheeled mobility when traveling long distances and may self-propel for shorter distances.</p>
	<p>GMFCS Level IV</p> <p>Children use methods of mobility that require physical assistance or powered mobility in most settings. They may walk for short distances at home with physical assistance or use powered mobility or a body support walker when positioned. At school, outdoors and in the community children are transported in a manual wheelchair or use powered mobility.</p>
	<p>GMFCS Level V</p> <p>Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements.</p>

GMFCS descriptors copyright © Palisano et al. (1997) Dev Med Child Neurol 39:214-23 CanChild: www.canchild.ca

Illustrations copyright © Kerr Graham, Bill Reid and Adrienne Harvey, The Royal Children's Hospital, Melbourne

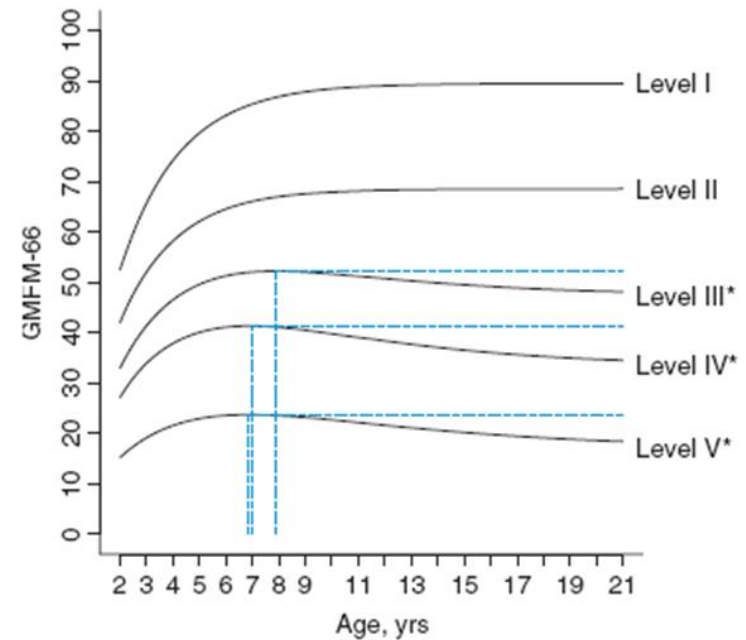


Figure 1: Predicted Gross Motor Function Measure (GMFM-66) motor scores as a function of age by Gross Motor Function Classification level. *GMFCS levels with significant average peak and decline. Dashed lines illustrate age and score at peak GMFM-66.

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.

GMFCS:

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

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

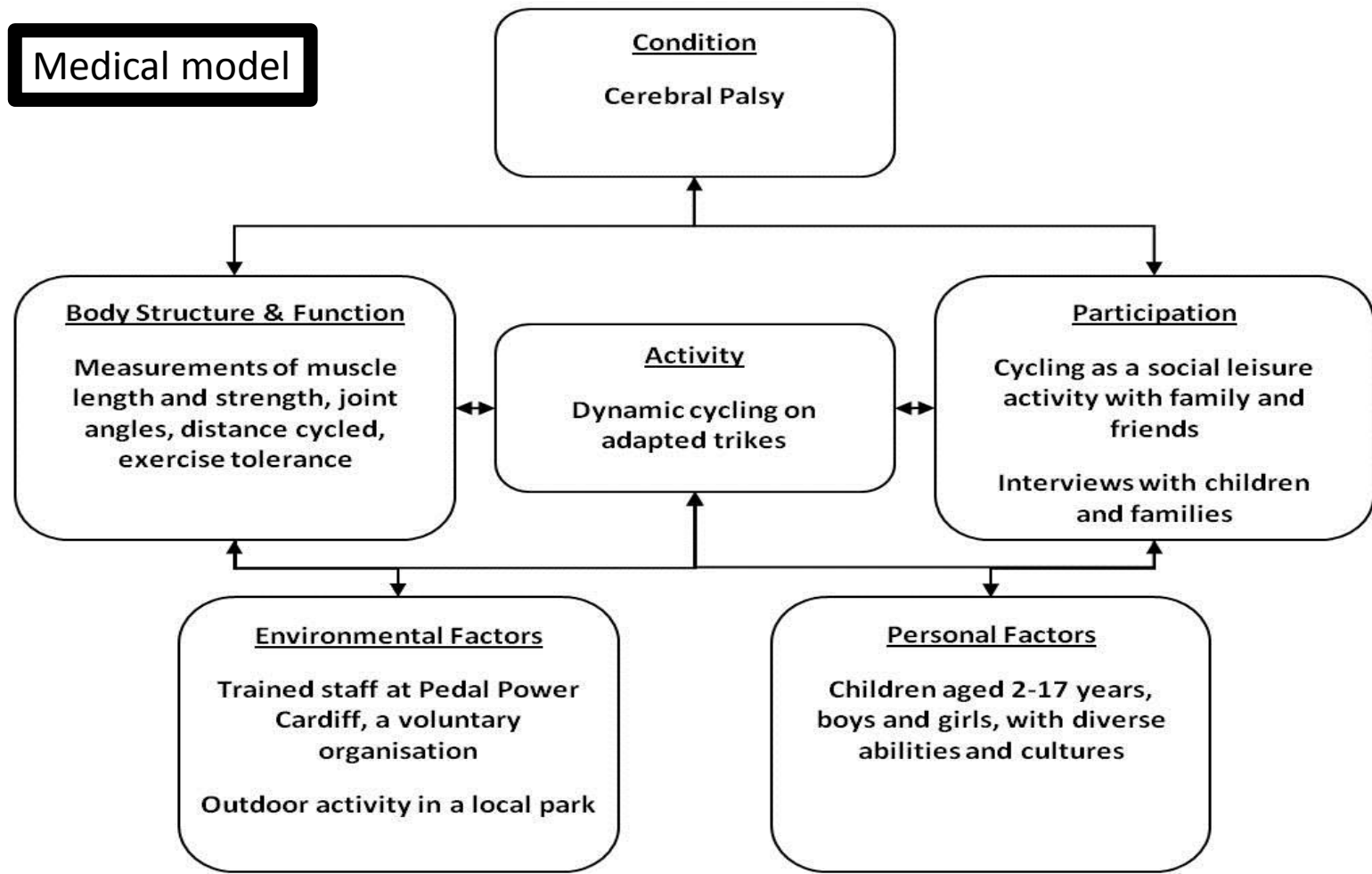
Diary of physical activities



What physiotherapists understood participation meant? Pickering et al, 2012

World Health Organization –International Classification of Functioning (ICF), 2007

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



Muscle strength + Length measures

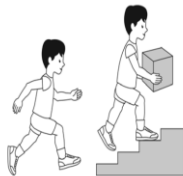


Qualitative Results

- 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 (2009),
GMFCS I

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 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
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

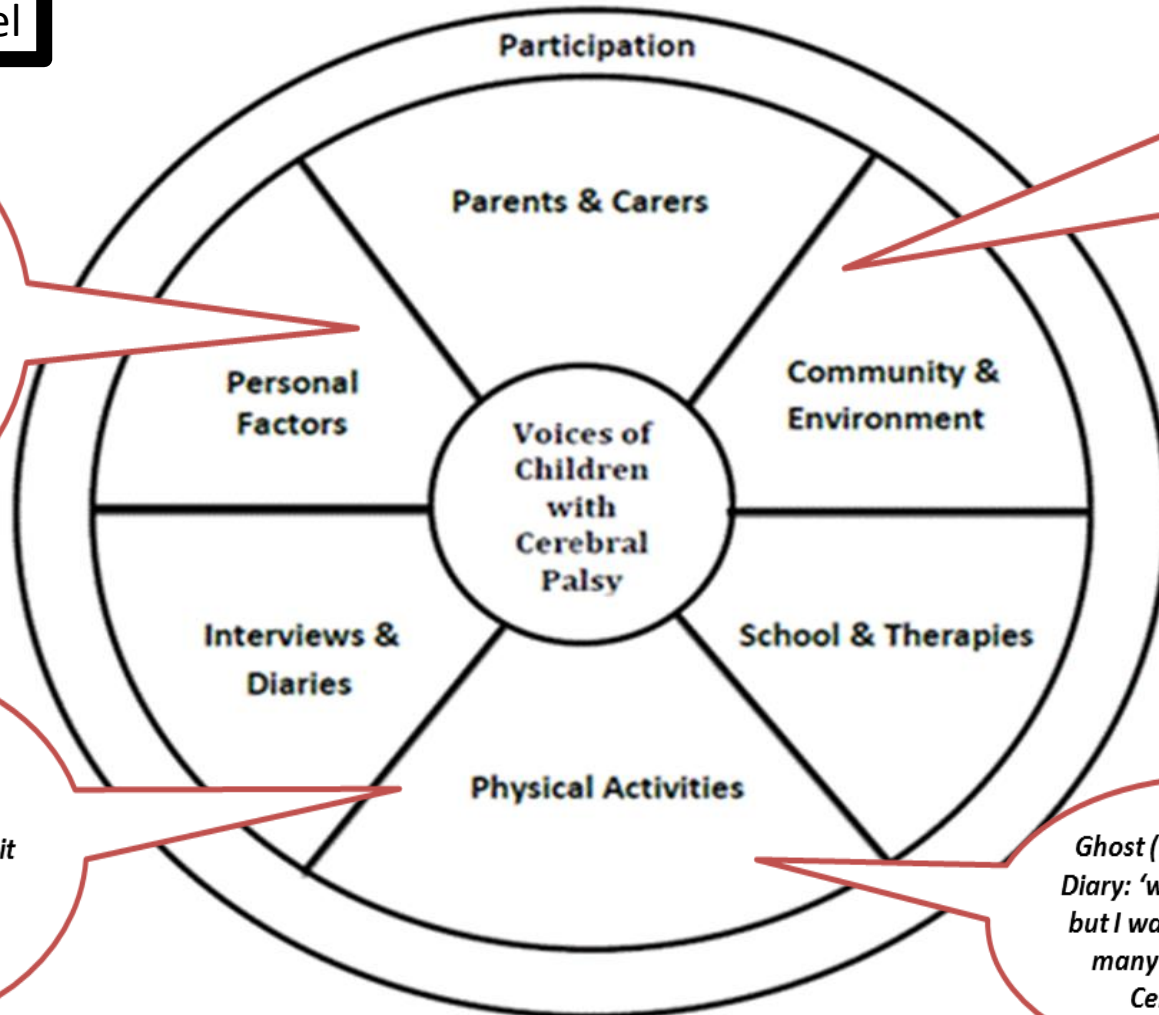
*“Throughout the cycling sessions I feel that **Rachel’s confidence has improved**. She is so happy when she is cycling and it gives her the **freedom and independence** she needs.....”*



GMFCS IV

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...'

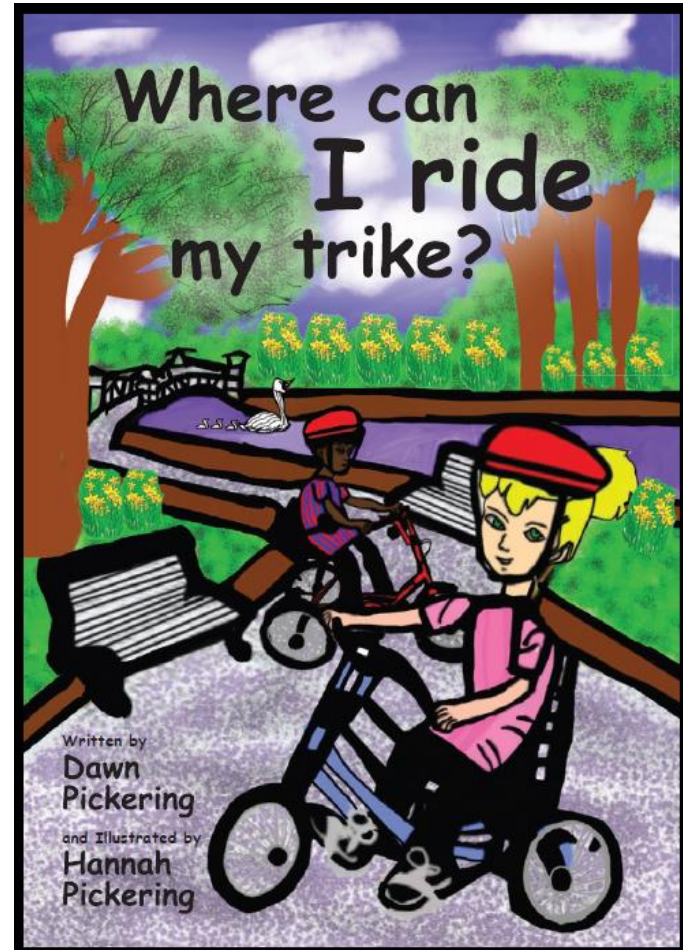
Rugby (11 years/Diplegic):
'...I was a bit nervous going on the bike....but it made me feel a bit stronger...but my legs ached afterwards...'

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
- Aimed at typically developing children learning to read to consider what disabled children can do

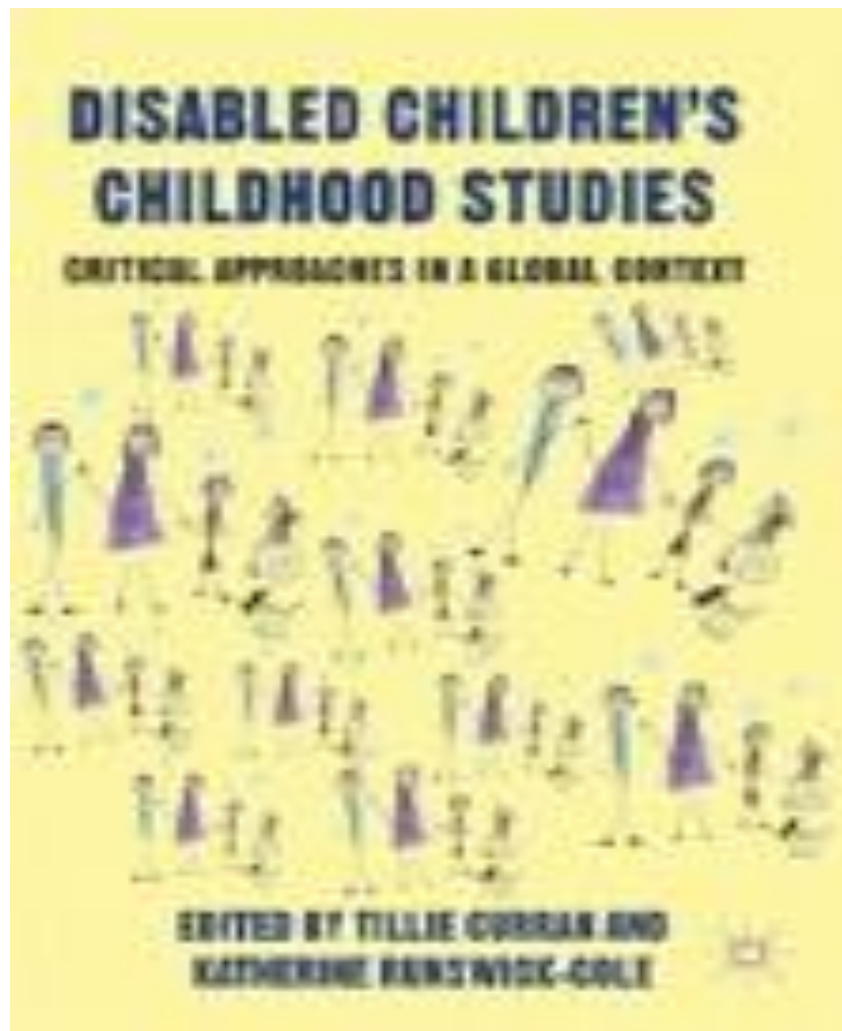


New activity: Race Running

- <https://www.racerunningdragons.org/info>



Disabled Children's Childhood Studies, 2013



Co-production: Digital story

- Dissemination: invite to all participants in study to co present June 2014 in UWE, Bristol at Child, Family and Disability conference.
- 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>

Research network

Regional network formed

- 2 day Conference hosted in Cardiff 2016:

‘Telling Our Own Stories:
Disabled and non-Disabled
Children and Young People
Shaping Change’

Marginalised CYP- LACE/
illness/ disabilities

Health and Social care/
hospice/ Voices from care



Doctoral Title

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

*Supported by the Chartered Society of
Physiotherapy: Research award PRF NP/15/03*

Research Question

How do children and young people with cerebral palsy and their carers perceive their level of participation in recreational activities affects their emotional wellbeing?

Aims

The aims of the study are to explore participants':

- Views, experiences and choices for the child or young person's level of participation in recreational activities, including barriers and facilitators.
- Perceptions of the effect of their level of participation upon the child or young person's emotional wellbeing.

Methods

- Case study design: Participatory group (4) and a Non participatory group (4) N=8.
Aged 9-16 years. GMFCS III-V
- 2 interviews 12 weeks apart:
- 1st interview getting to know you
- Observation of their usual recreational activities if unable to take part in an interview
- Diary of usual recreational activities kept for 12 weeks
- 2nd interview makes reference to their diary entries.



Consultation young people, Collage activity, May 2016



Jugs aged 19 years



Dora aged 23 years- by proxy

Case studies – preliminary data

Pseudonym	Age	GMFCS level	Communication style
Becky	9 years	III	Verbal
Katie	21 years	II	Verbal
Mary	9 years	II	Verbal
Captain America	16 years	I	Verbal
Clare	9 years	IV	Communication aid
Lily May	16 years	III	Communication aid
Matthew	14 years	IV	Non verbal
Nick	14 years	IV	Non verbal

Becky interview 1 :

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

B:.....Bike.....

Dad: What did we do this morning before school?

B: 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?

B: Yes..

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

B: Peanut ball

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

B: err.... Treadmill

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

B: 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?

B: I don't know....

Dad: It's too cold at the moment.



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...'

<https://www.youtube.com/watch?v=kE4oUW7FJN0>

Diary entry week 7 (week of Triathlon)

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....'

Becky's Sandbox activity



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).

Mary's aspirations

“someone should step up (voice getting louder) and say this is our rights... this is what we should do...this is what we want to do....this is our time to say to people.....would you like it if you had cerebral palsy and you had to travel all the way to Cardiff? It's quite a long way from my village....someone should step up and say 'we want a club'..... but there should be other places that gives you the chances to actually do something...disability people can have...cos they are limited, limited to what they can do... and that is just out of our hands....that's what we should stand up and say 'we want a club that can give us no limits whatsoever'.”

Mary's Diary example



Tuesday 21st September 2016

Friends

I have a lot of friends because I am nice and help people when there lonely. I have told them that I do have Cerebral Palsy. We play a lot of Pokémon games and spy ones so you could say we are the best of friends. They do understand that I can't run as fast as they can. We love to play in my school field because it's so big and especially when its summer. It helps when you have got friends because they help you through times.

Communication aid

Clare aged 9 years GMFCS IV



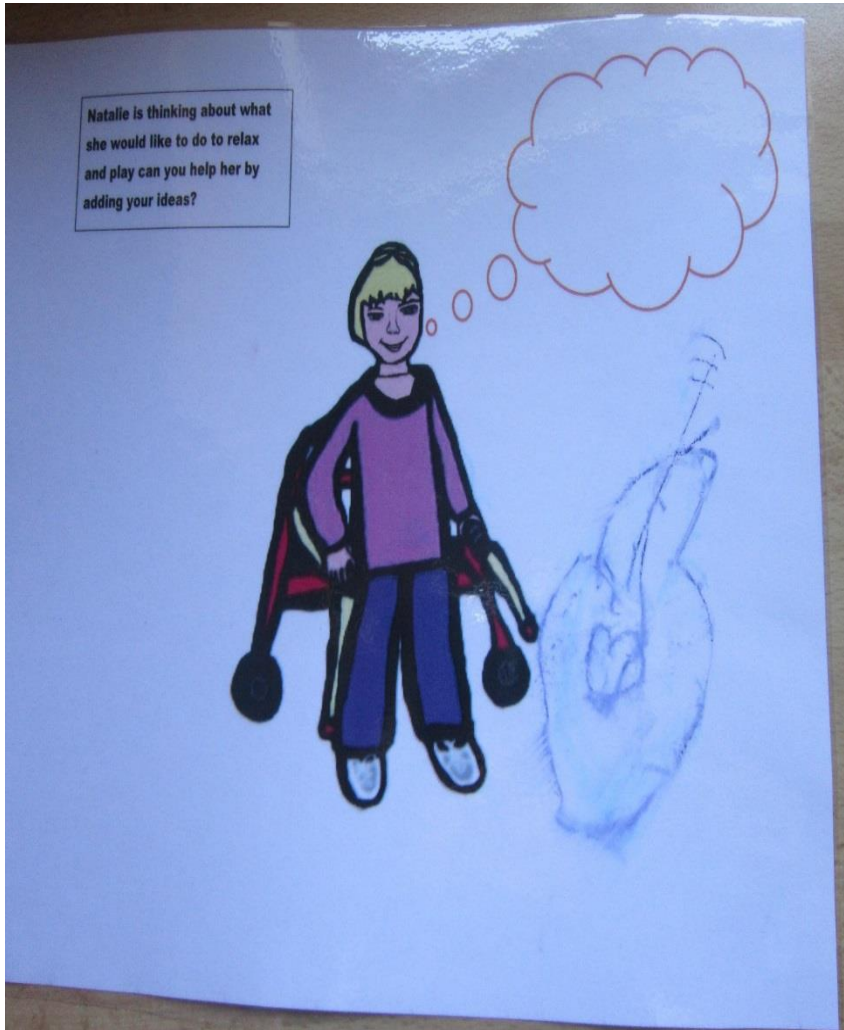
Mum: Yes, what do you like doing the BEST?
....Have a proper think about it. All of those things, what do you like to do the most?
Clare: Playing my beams.

INT: What are your beams? You'll have to tell me about that?

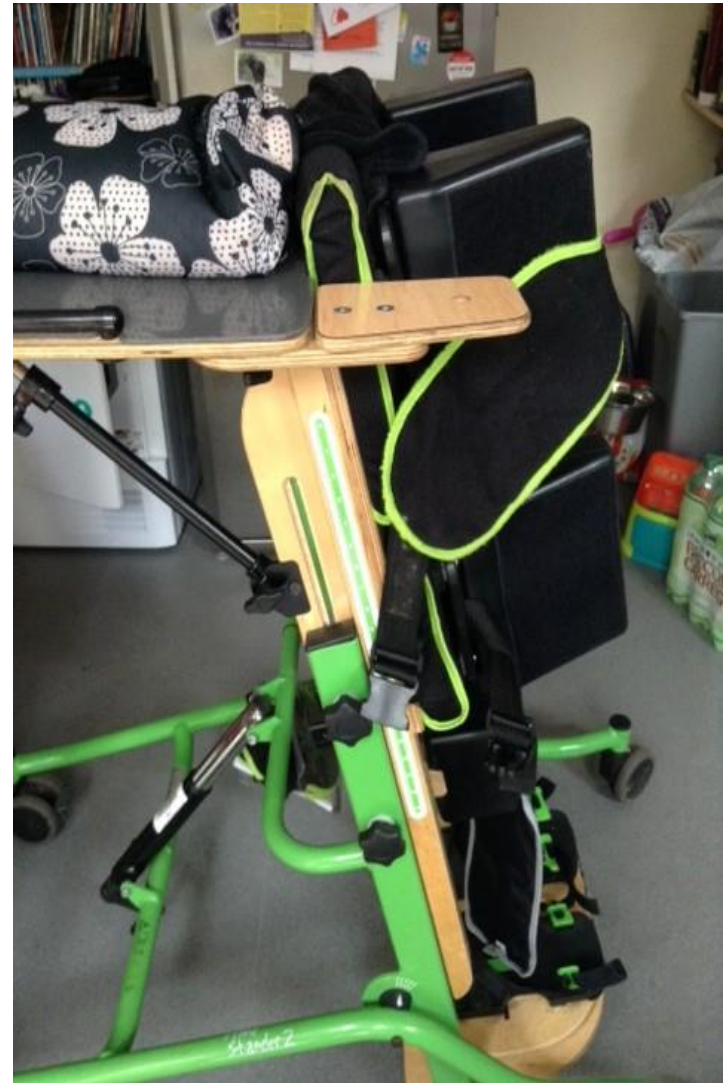


beamz

Specialist equipment



Clare's drawing of guitar using special pen holder



Standing frame

Interview Lily May

Interview 1

- MUM: Do you want to ask Dawn some questions?
- LILY MAY: I want to tell you.....My feelings.
- INT: Good, you're going to tell me how do you feel at the moment?
- LILY MAY: I am happy.
- INT: That's good, really good [*Lily May clapping*] that's very good. That's lovely to know that you're happy today.

i pad with key guard



Interview 1 January 2017

'Lily MAY' INT 1

- iPad used to communicate . vocalising + clapping

<u>FAMILY</u>	<u>FRIENDS</u>	<u>ACTIVITIES</u>	
Mum	Boys +	TV shows - Xfactor	CHARITY GROUP - TRIPS
Sister	Girls at	Voice	HORSE RIDING
Dog	School	CYCLING	MUSIC TRUST
Cat	+ activities	SWIMMING	CINEMA
Nanny	Really enjoys	- HYDROTHERAPY	ARTS + CRAFT
Grampy	Social time	TRAMPOLINE	DAY CENTRE
Cousins	+ meal times	LAZY SPA	SLEEPOVER
Auntie	Bridesmaid	SWING	BAKING
		SKIING	'SAND BOX' - Music + Toy figures
		HOLIDAYS	MEDALS
		YOUTH CLUB	Physical Programme (School)
		RESPIRE	- standing frame
		ZIP WIRE	- walking aid
		SAILING	- bike
		PANPER - RELAXING	DANCING on feet +
			BUS TRIPS wheelchair

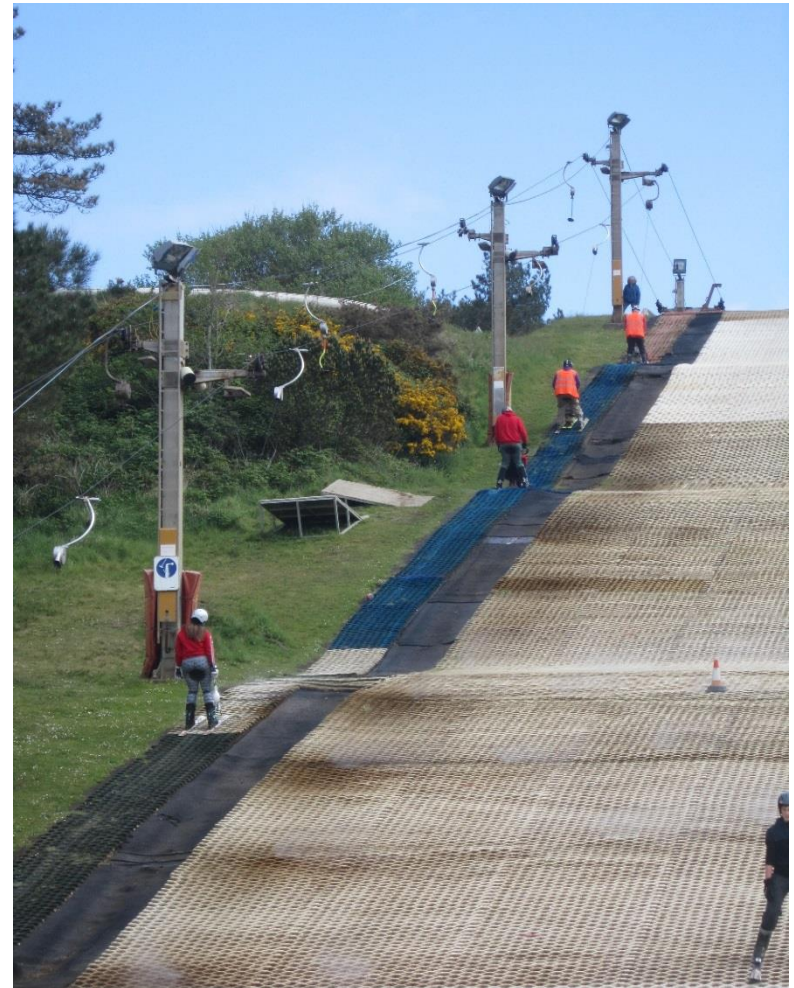
BARRIERS

- Not catering for siblings
- Getting tired

'I AM HAPPY'

Matthew's Mum

- *Yeah, yeah, we didn't do the bike riding for a couple of months but then he got back on it, so school P.E. , so he does it in school every week...He's doing swimming now...so last term now he did the bikes and now this term he's doing swimming.*
- Non participant Observation of skiing

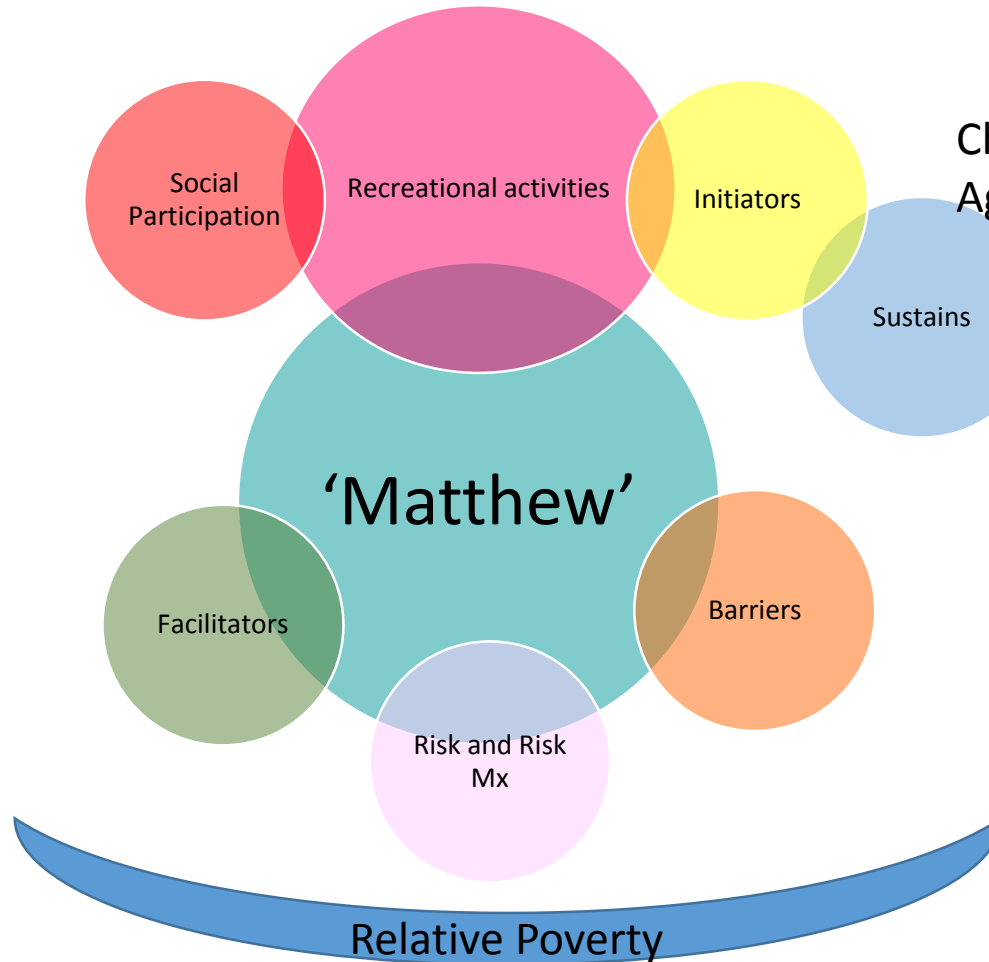


Emotional Well-being

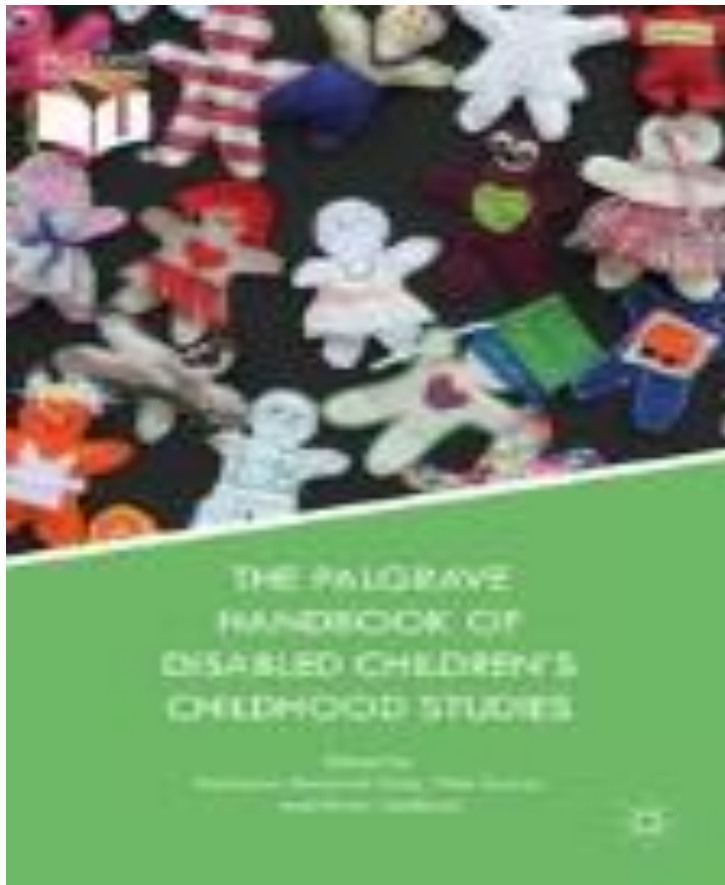
8.6.17

Good behaviour=
Happy

Challenging behaviour=
Aggressive/ Unhappy



Book chapter: August 2017



Dawn Pickering

- Shared perspectives

'The Embodiment of disabled children and young people's voices about participating in recreational activities':

Summary

- Creative research methods are needed to engage CYP with CP especially those with limited communication and learning difficulties.
- More data from children and young people's voices can inform future practice.
- I am still finding where my voice fits in the research world: Health/ Social Sciences?
- ? Future Publication journals to target

Questions/Comments ?

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