



The transitional journey from practice to research to hear the 'Voices' of children and youth with Cerebral Palsy about adapted cycling

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Objectives

- Explain physiotherapy practice and cerebral palsy, specifically postural alignment.
- Draw on examples of significant emotional moments in the research process.
- Draw on some case studies to hear their 'voices' for the emotional impact of the research output.

Physiotherapy with Children



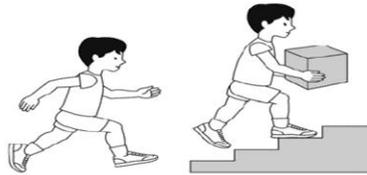
Cerebral Palsy- consensus definition

Rosenbaum et al 2007

‘...describes a group of permanent disorders of the **development of movement and posture causing activity limitations** that are attributed to non-progressive disturbances that occurred in the developing fetal or Infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy, and **by secondary musculoskeletal problems.**’

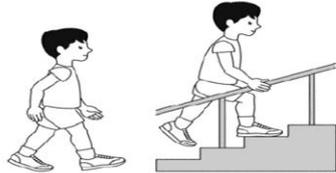
GMFCS

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



GMFCS Level I

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



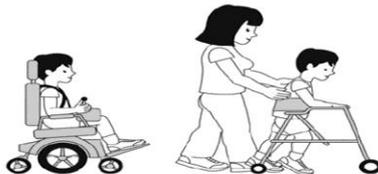
GMFCS Level II

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.



GMFCS Level III

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.



GMFCS Level IV

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.



GMFCS Level V

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.

Posture

- Good postural alignment enables safe functional activities and communication- eye contact gesture, verbal / non-verbal expression

Adapted Dynamic Cycling



Interview ? Suitable Chair



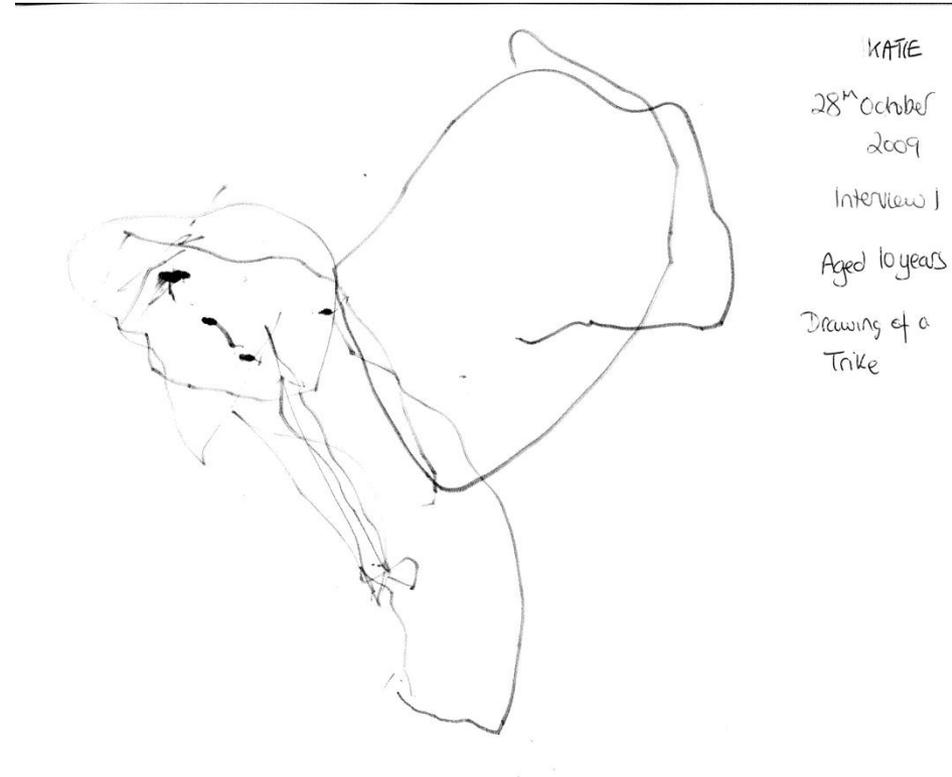
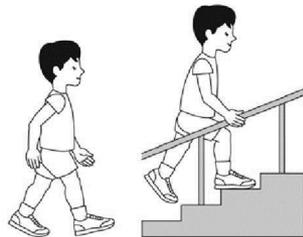
Poor seating

- Child fell out of the chair and banged her head
- Lack of postural support means pencil control can be poor and speech volume lower

Mosaic Methods Clark and Moss (2001, 2011)

- *'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

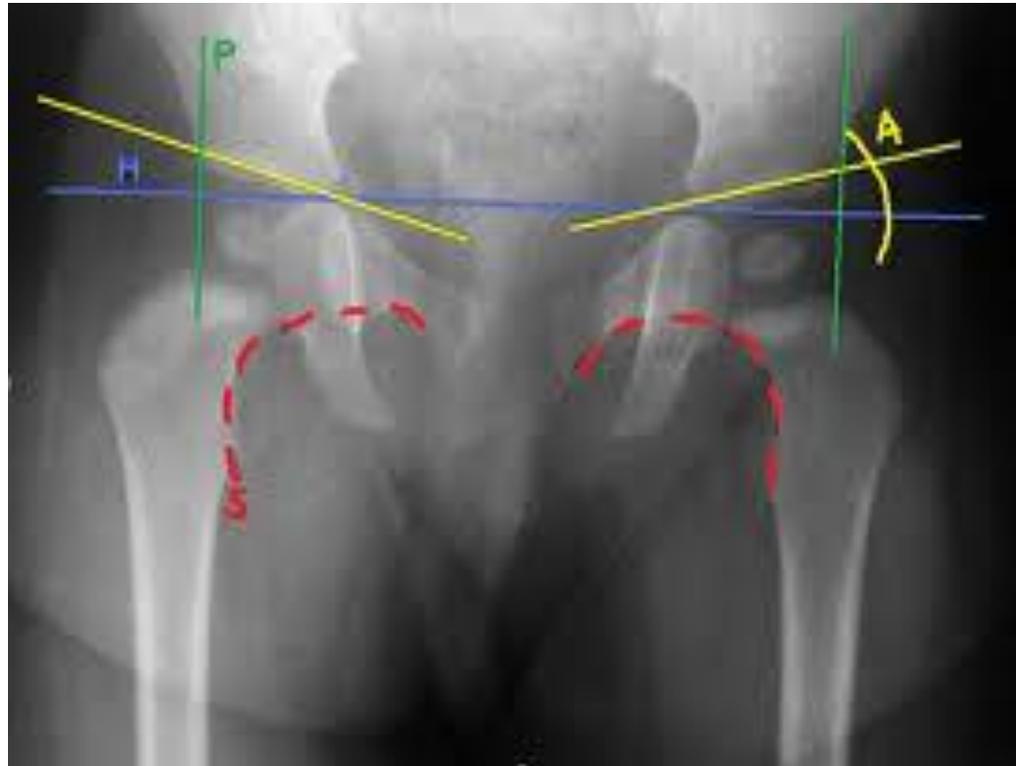


Katie was 10, GMFCS II

Avoid 'W' Sitting



Prevention of dislocated hips



Conflict

- 2 children chose to do their interviews 'W' sitting on the floor. Do I mention the obvious?
- As a researcher my role was different- chose to mention it afterwards/ off record.
- Many parents wanted school and surgical advice.

Recording the interview

- Dictaphone used
- For those with limited verbal responses tried a video camera
- That had a negative impact and the family withdrew from the study.

Reflect on what makes a 'good interview'?

- *Something that matters has been discussed*
- *An intimacy has been shared*
- *Something disclosed or worked through*
- *Person said something of significance- immediately translates into an 'on the page quotation'*

*Abbott D Ch 6 in
Disabled Children's Childhood studies Ed.s
Curran T and Runswick-Cole K (2013)*

Case examples of their 'Voices'

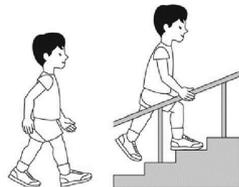
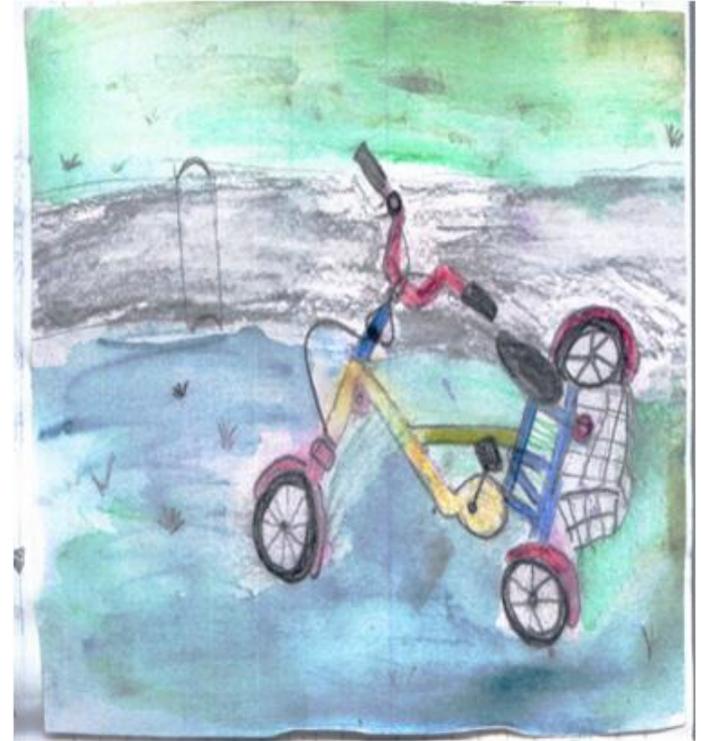
- Diane- verbal/written / illustration
- May- verbal/written/ photos
- Julia and Rachel- non verbal- carer/ parent report
- Ghost- mother wrote/verbal/ illustrations
- Andrew-verbal/ father report

Diane 10 years, GMFCS II

- 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

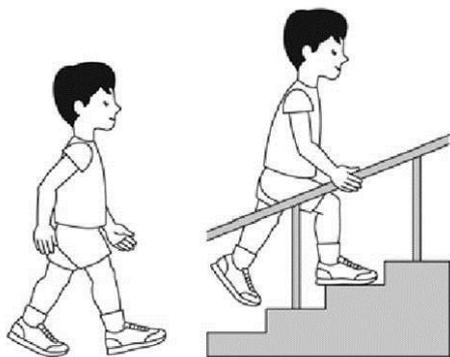


Diane's Diary entry- cycling skills

Saturday 11th August
My dad brought his camera
down this weekend and he took
some photos of me on my bike.
He was very surprised how well
I could ride it. The photo below
is me with my dog Dylan



May's diary entry



Sunday 1st of April 2012 (2)

Today I had a 20 mins bike ride with my sister and brother to a 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 spiralling 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.

May's (10 years, GMFCS II)

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....***

Children unable to self report

Julia, 14 years, GMFCS IV

*“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...**”*

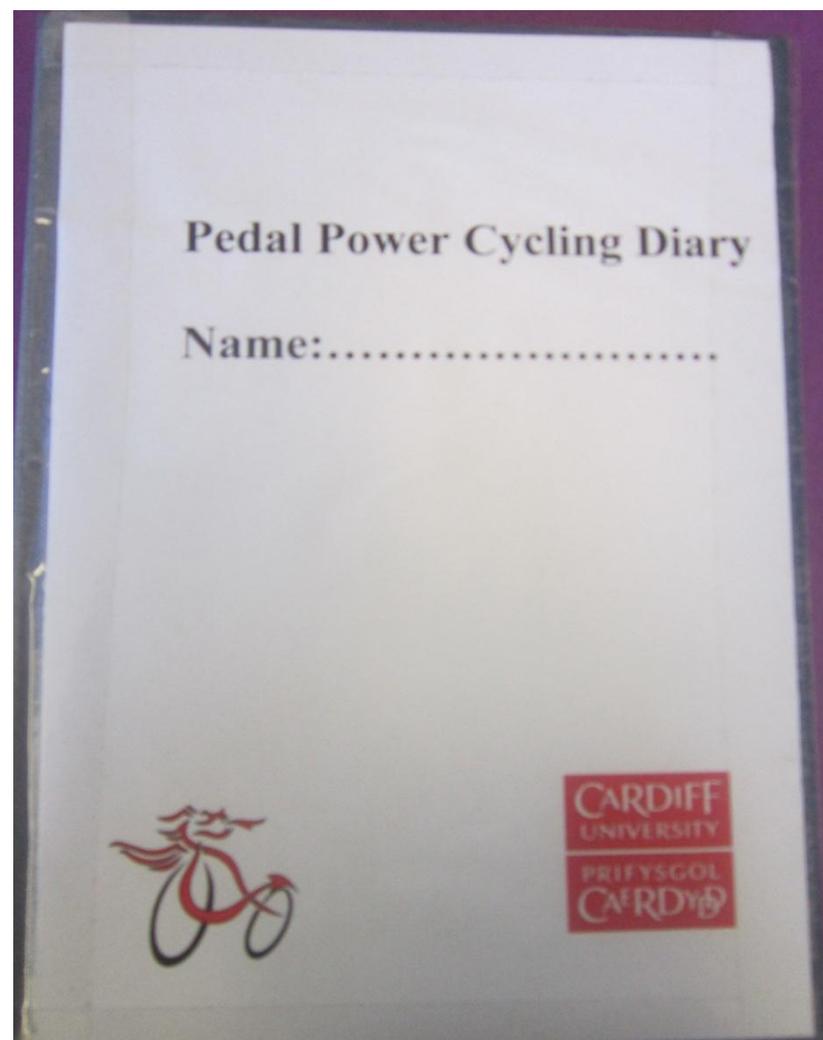
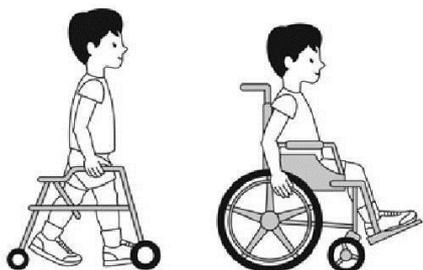
Rachel, 8 years, GMFCS IV

*“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.....”*



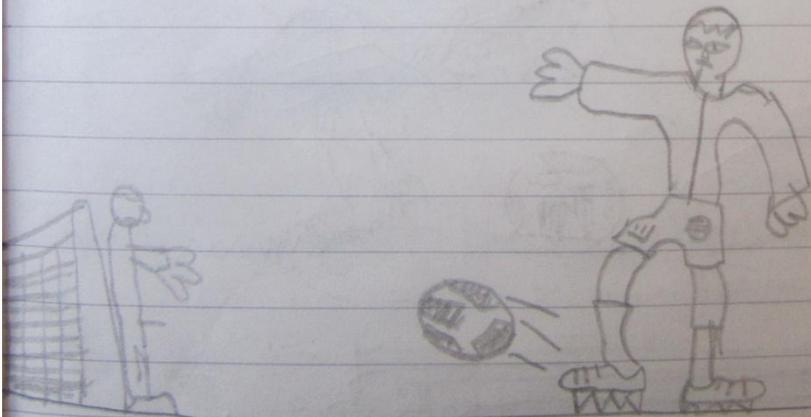
'Ghost', 10 years (GMFCS III)

- Ghost, aged 10 years was thrilled to be given a diary- he had always wanted one



I find writing hard work so
mum is going to write this book
for me but in my own words

to bay ei was to shock and
ex us it nex we wit to masne
in masne I bun bsishun nex we
hab pla timu at pla tim I pla
footdall nex we hab lishre
in we ritb a b llt Plasi
nex we was to lush a dre
we pla b footdall a gan
nex we hab rten



Change in cycling activity 'Ghost'

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

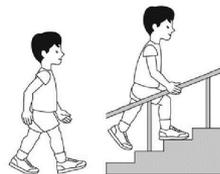
To/ Mrs D. Pickering,
Thank-you for the feed back of [redacted]
every thing looks o.k on the sheets,
I've got really good news [redacted] has
learnt to ride a bike only a little way
down hill or flat roads,
can't ride up hill yet. But we are
all really excited didn't think he
would ever be able to ride 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]

Andrew's cycling skills

Recumbent Trike steered from side



Andrew 17 years and GMFCS level II and autism



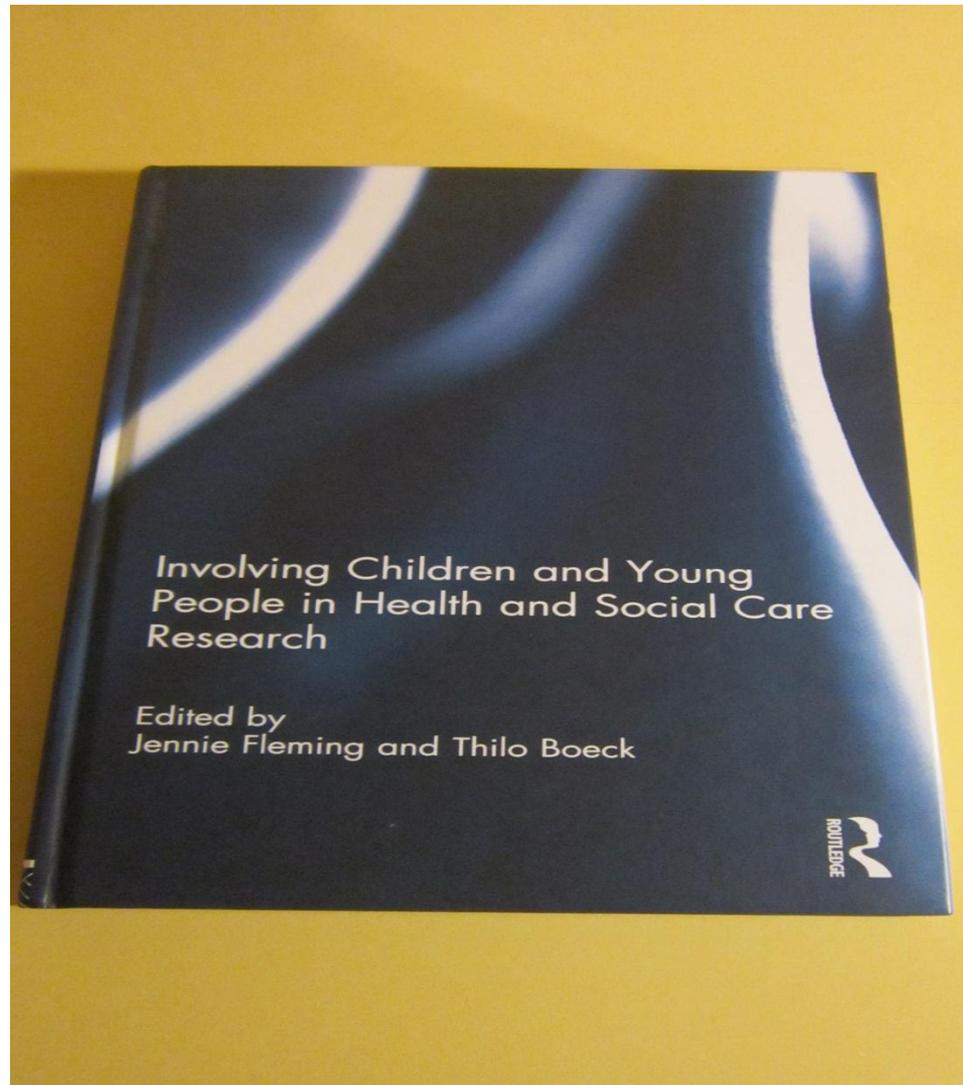
Andrew was able to describe his cycling experiences: *'...when I pedal it's like I'm there and I am enjoying it...we cycle in the park and I go down the slope...and then I change it.... you know... I put into **3 (gears)** and it makes me fast...'*

Dad describes his progress *'...he loves biking, **obviously it gives him that independence**...they've taken the footplates away..'*

Andrew progressed to going cycling with a carer (Bethan)

Dad: *'...Bethan actually cycles with Andrew and **they now do four circuits rather than the one or two he did before....'***

Book chapter



Acknowledgements



- Nancie Finnie Charitable Trust
- Children, families and carers who took part
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- Bike-shed staff and volunteers
- BBC Children in Need
- Jenx Ltd
- Polar
- NHS physiotherapists in England and Wales who helped us recruit to control group, as well as Contact a Family, Cerebra and Scope.

Where next?

- PhD- Interpretative Phenomenological Analysis- small sample exploring the 'lived experiences' of children and young people who participate in recreational activities including cycling.