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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25th January 2014
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
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 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.

CanChild: www.canchild.ca

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The Royal Children’s Hospital, Melbourne
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 14th 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

Today I had a 20 mins bike ride with my sister and brother. In Secondary School Car Park there are loads of bends, curbs, bays and car spaces. I have come on really well considering. Me and my family thought I wouldn’t be able to achieve such a brilliant opportunity, we also thought I am going to be doing a bike test after Easter. So we have been practising weaving in and out and signals, 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’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....
“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...”

“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 buy it was to shock and
ex us ib nex we wit to masne in masne Ibon bishun nex we hab pla timu at platimi pla football nex we hab lishre
in we rit 6 a bill plasi nex we was to bush a bre we pla 6 football again nex we hab teh.
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 feedback. Every think looks OK on the sheets. I’ve got really good news. He 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 far. He now it’s 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 him and Merry Christmas and happy new year.

From
Debbie and

[Signature]
Andrew’s cycling skills

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
• Pedal Power Trustees
• 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.