



Children with Cerebral Palsy- How can we hear their voice?

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Research question



Pedal Power

Does participation in adapted dynamic cycling affect lower limb muscle function, activity levels, and quality of life of children with Cerebral Palsy?

How did children with Cerebral Palsy find the experience of Adapted Dynamic Cycling with “Pedal Power”?

Nancie Finnie Charitable Trust

'Adapted dynamic cycling'



Expensive costs between £800-£2,500



Pedal Power Research Study



- 3 year study looking at the effects of adapted dynamic cycling for children with Cerebral Palsy (CP)
- Mixed methods – quantitative measuring muscle strength and knee joint angles
- **Qualitative interviews and diaries**
- Cycling(hired bike costs £3.00 per hour)

Cerebral Palsy

Rosenbaum et al 2006



- *‘a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non progressive disturbances that occurred in the developing foetal 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’ (pg 9)*

Clinical experience



- The 4 researchers were all physiotherapists who had worked with children with CP - Clinical experience and literature shows that there are limited opportunities for children with CP to participate in physical activities

(McConachie et al, 2006)

Cycling is one activity than can be adapted

- The 2 interviewers had not previously carried out research with children

(Fleming and Boeck, 2012)

Children's' Rights approach

- To enable their voice to be heard
 - United Nations Convention on the Rights of the Child
 - Hart's participation ladder

Research team



Dawn
Pickering



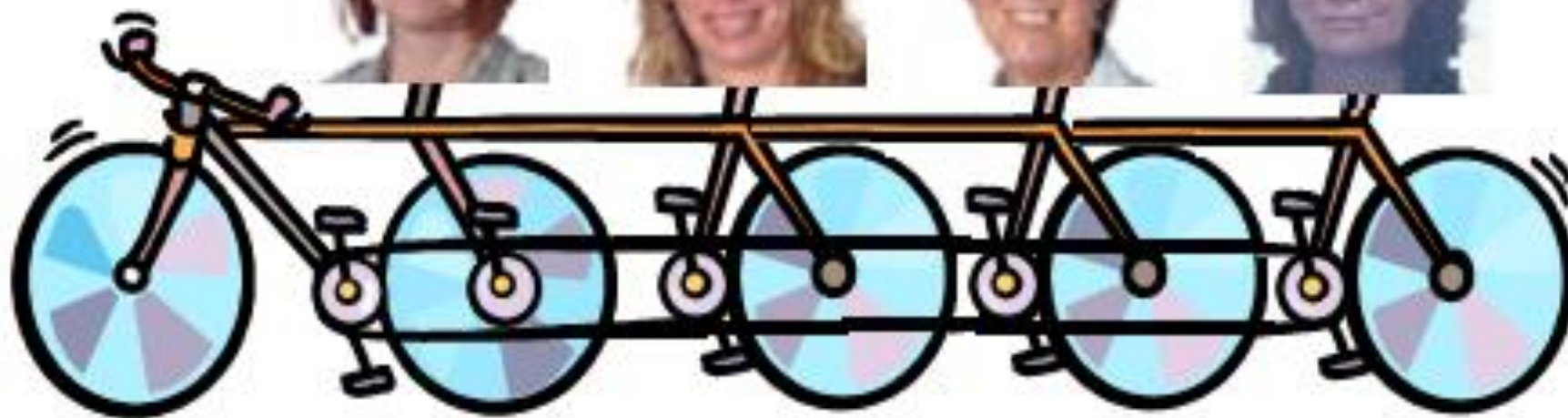
Karen
Visser



Lyn
Horrocks



Gabriela
Todd



Limited literature base



- Connors and Stalker (2003) interviewed disabled children and their siblings to obtain their view and experiences
- The whole family were invited to participate including siblings, however they interviewed the child, siblings and parents both separately and together
- Due to the variation of the presentation of CP we considered this too difficult for novice researchers- we needed a person to help facilitate communication (Morris, 1998)

Challenges of interviewing children with CP



- Age range between 2 – 17 years
- Some children fully conversant
- Some children use augmentative forms of communication- eye pointing/signing/ gesture
- Some children use alternate forms of communication- communication boards
- Some children use PECS- picture recognition to make choices

Interviewing children with a disability



Consent/Assent issues to interview children
with a disability under 16 years alone:

- Parents act as gatekeepers
- Children may disengage with the interview

“Does he take sugar?”



- How do we obtain the child’s voice?
 - To gain their consent/assent to participate?
(Morris, 1998)
 - To obtain their views?
(Renold et al, 2008)
- Hard to separate out child’s from parents/siblings views- speak for them

Question design



- Activity Scale for Kids (ASK) (Plint et al, 2003) – questionnaire
 - Used themes from ASK for 4 pilot interviews about capacity and performance
- Iterative – questions developed more about cycling rather than capabilities

Mosaic Methods Clark and Moss (2001)

- Attempted to use creative methods such as stickers/ drawing / ink pad printing/ game card matching, but several children had limited cognitive and manipulative skills



KATIE
28th October
2009
Interview 1
Aged 10 years
Drawing of a
Trike

Creative methods

Physical measurements: Dynamometer

- Age appropriate creative methods to engage the child eg puppetry



Methods



- Semi Structured Interviews took place following the first measurement session and the commencement of cycling and again after the 6th session (2 interviews per child)
- Recorded with a Dictaphone
- Diary kept of cycling experiences- used as a prompt for 2nd interview in cycling group

Researcher's interview style



Booth and Booth,(1996), Minkes et al, (1994)

- Need to build up the relationship
- Assume they can understand
- Creative Guesswork
- Unorthodox methods- needs more thought and to be flexible and creative- 'Self Developing' (trial and error)

Interview Questions



- Semi Structured style –
 - Tell me about the cycling you have done at Pedal Power?
 - What colour is the bike? Helmet?
 - Who else has gone with you?
 - How far have you cycled?
 - What do you hope to achieve from cycling?

Languages spoken



- Languages spoken by the families Welsh, Urdu and English
- Interviews carried out in English
- Interpreters used where necessary
- Always an adult present who was familiar with the child and their communication style-are we hearing the children's voices?

Adaptation of interview questions



- Style for children needed to be more direct not open ended (Booth and Booth, 1996)
- Closed questions when vocabulary limited so the child could answer yes/no with gesture or nod/shake
- Made it hard to allow the child to lead the interview- more directed by interviewers

Use of pictures



- Different laminated pictures of cycling were used to engage with and generate a response from the child.
- Happy/ sad faces were used for children to point to if they were not able to vocalise their response- this could be finger/hand pointing or eye pointing

Diaries

Some children had drawn pictures and stuck photographs in in their diaries which were used as a prompt during the second interview



Data management



- Transcripts typed up and sent back to participants for verification (usually parents)
- Data managed with NVIVO⁸
- Analysis by Themes using InspirationTM mind mapping- 2 researchers

Results



- 17 children in the cycling group=
26 interviews and 8 diaries
- 7 children used additional forms of
communication than verbal



‘The lens of children’s physiotherapists’

- Stiles(1999) suggests that:

‘investigators use their imperfect empathic understanding of participants inner experiences.....interpretations are tentative and bound by context’

Themes

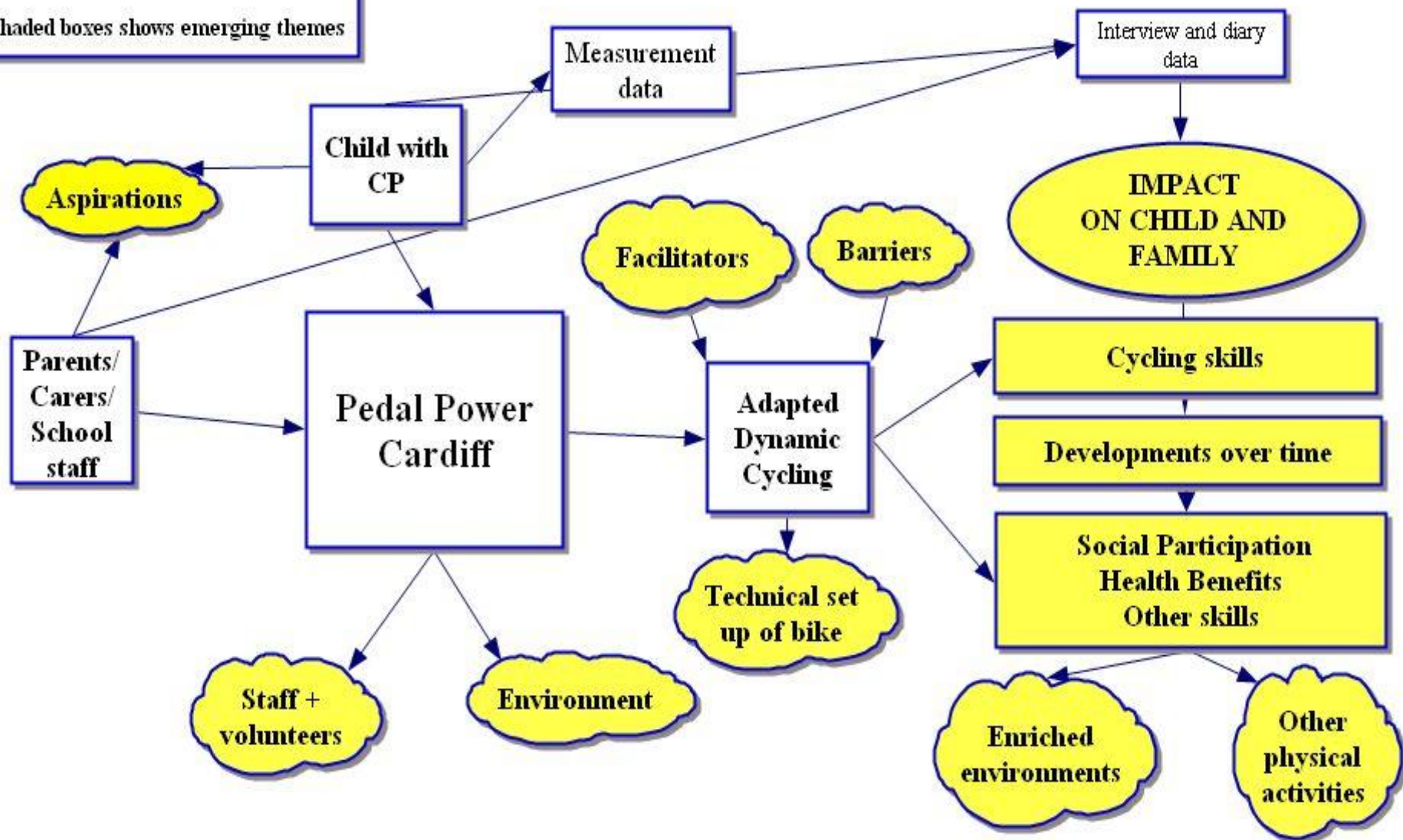
Pickering et al, 2012



- Learning a new skill- cycling
- Impact on child and family
- Social participation
- Future cycling aspirations

Themes

Figure 2 Themes
Key:
Clear boxes are topics being explored
Shaded boxes shows emerging themes



*Peter(aged 7 years): I did cycling
.....it was wicked !*



- **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'

Learning a new skill



Int: Did you like the cycling?

*Katie: **Yeah***

INT: Did you?Tell me what was good about it then ?.....

Mum: Was it because it was you went very, very slowly?

*Katie: **No [shakes head]***

Mum: Did you go very, very fast?

*Katie: **Yeah!.....***

Mum: Do you like going fast?

*Katie: **Yeah!** [really enthusiastic here]*

INT: Brilliant!Why do you like going fast?

[Katie puts her thumb up, smiling]

INT: Was it good? Is it, yeah?....What do you enjoy about it?

[Katie lifts her thumb up and down]

Katie (Aged 10, Ataxia)

Gesture



- Use of gesture as a way of expressing- should I have mirrored this and not asked the open questions?
- Use of Katie's Mum who was engaged in the interview was very helpful, however did I get to Katie's truth?

Impact on wider family



- Andrews muscle strength had increased by 100% and he progressed to going cycling with a support worker rather than just his Dad during the 6 sessions:
‘...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...’

Andrew (17 years Athetosis/Autism)

Other family participation



- Emily's (4 years, ataxia) Grandma went cycling for the first time and Husain's (10 years, Hemiplegic) Mother from an African country.

- ***“we went on a picnic and we explored and we went to look for the ‘Gruffalo’”***
(Julia Donaldson)...

{Emily used playing at making a picnic during the interview with a toy bike}



Suitability

- **Becky's (4 years) Mother** *“Pedal Power is brilliant and it would have been very useful for us had it provided children's assessments earlier (prior to 2009). I just wish..... we had it before.....rather than spend £800 of our own money on her own bike, rather something which would have been better for her”*

Social participation



“I: So, what’s it like if you haven’t got a bike when you are with your friends at the caravan?

Diane: ***I normally tag along, walk for a while, ponder my thoughts, get bored.... The bike’s great, easier to get around than walking. Clever, clever invention whoever invented it I want to thank them....”***

Diane (10 years, Hemiplegia)

Participation in school



- 5 children participated in cycling at school
- Becky's Diary entry:

"It's bike day at (mainstream) school. All of the children are taking their bikes....."

..apparently she had another good session, cycling enthusiastically and proudly on her bike (not sure how long- should think it was a good hour)."

Future aspirations



Father of Katie: *“I think also you know, in the long term, it's access to a leisure opportunity.....But like, one not just leisure as in a pastime, but one which strengthens and improves her health and also her general bodily functions, and the co-ordination, the sense of braking, the sense of taking care. She's usually so dependent, so she can experience a sense of danger, you know ?”*

Future aspirations



- Going on a cycling holiday with family and friends
- Going to the Velodrome with brother
- Some families had applied for charitable funding and had bikes on order, others had decided due to lack of storage and not living in a flat area that they would continue to hire bikes at Pedal Power.

Take home messages



- This opportunity improves the well being for children with CP
- Is an assessment and technical set of adapted bikes available locally?
- Careful consideration should be given before families purchase an adapted bike due to the need for outside storage, transporting the bike and living in a relatively flat area.

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