



Social participatory benefits of adapted dynamic cycling: voices from children and youth with Cerebral Palsy

**UK Disabled Children Research Network,
Newcastle**

27th June 2013

Dawn Pickering: PickeringDM@Cardiff.ac.uk

Equality and Diversity Coordinator

School of Healthcare studies

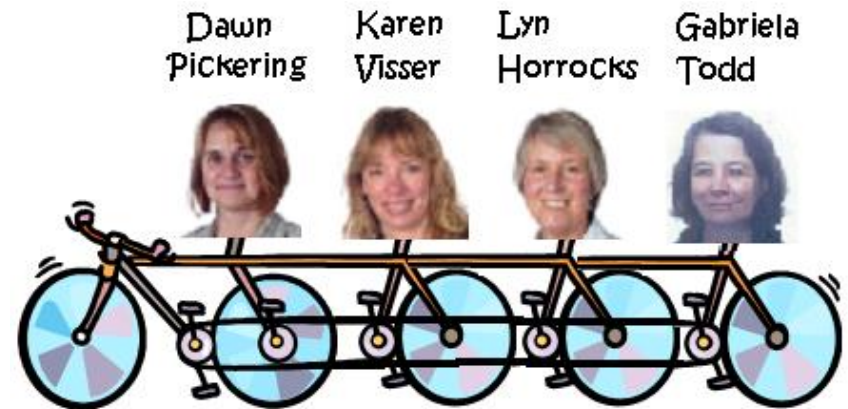
Cardiff University

Background

Lack of participation opportunities for CP
Fowler et al, 2009;
Fauconnier et al, 2009;
McConachie et al, 2006;
Mihaylovat et al 2004

Choice of activities limited-
requires some adaptation and
support

- Physiotherapy clinical practice with Cerebral Palsy (CP)

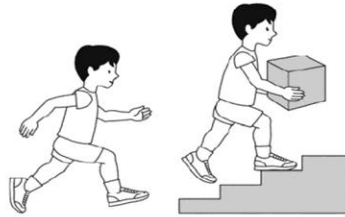


Cerebral Palsy- consensus definition

Rosenbaum et al 2007

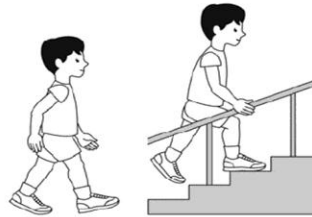
‘...describes a group of permanent disorders of the **development of movement and posture causing activity limitations** that are attributed to non-progressive disturbances that occurred in the developing fetal or Infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances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

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



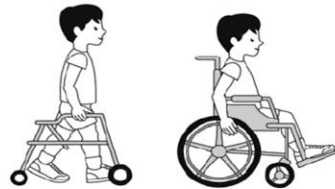
GMFCS Level I

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.

Adapted bikes

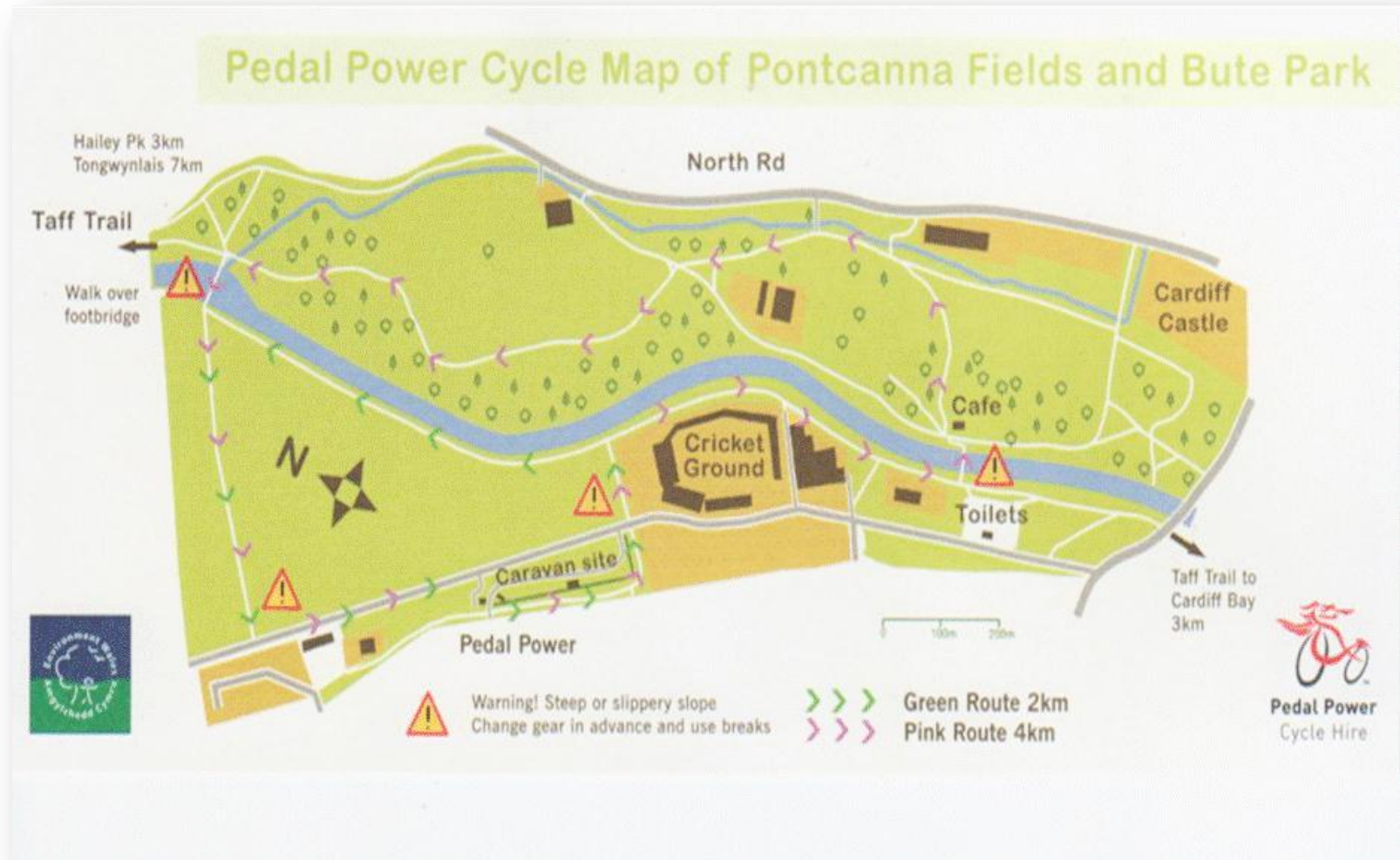
- Cost
- Charity Funding
- Trike Hire opportunities limited



Context for 3 year pilot study (2009-2012)



Cycle route



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?

Quality of life Aims were

- To find out about their experiences of adapted cycling/physical activities
- To introduce adapted cycling information to a non cycling group to explore if this is an activity they would consider for the future

Quality of life measures

KIDSCREEN questionnaire, HRQoL (Young et al, 2007)
Recreational activities not covered

Activity Scale for Kids (Young et al, 2000)

Not specific or sensitive to explore cycling- Piloted with questions based upon ASK, after analysis of these 4 children, changed to develop Mosaic methods

2 groups of children and youth with CP

- Adapted dynamic cycling
- 17 recruited from Pedal Power (travelled up to 50 miles to access this hire facility)
- Non cycling group – weren't currently participating in adapted dynamic cycling
- 18 recruited from NHS and voluntary organisations

Interview schedule

Cycling group: First interview at beginning. Diary kept about their cycling experiences (only 8 returned).

Second interview after 6 sessions of cycling (not all were able to achieve 2 interviews)

Non cycling group: Information given about adapted cycling in their area (limited for children) at first measurement session. Diary kept about physical activities (14 returned).

One interview at second measurement session 6 weeks later.

Children's Rights approach

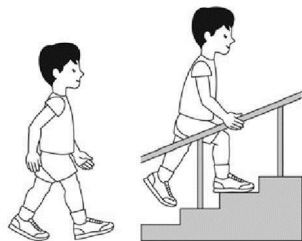
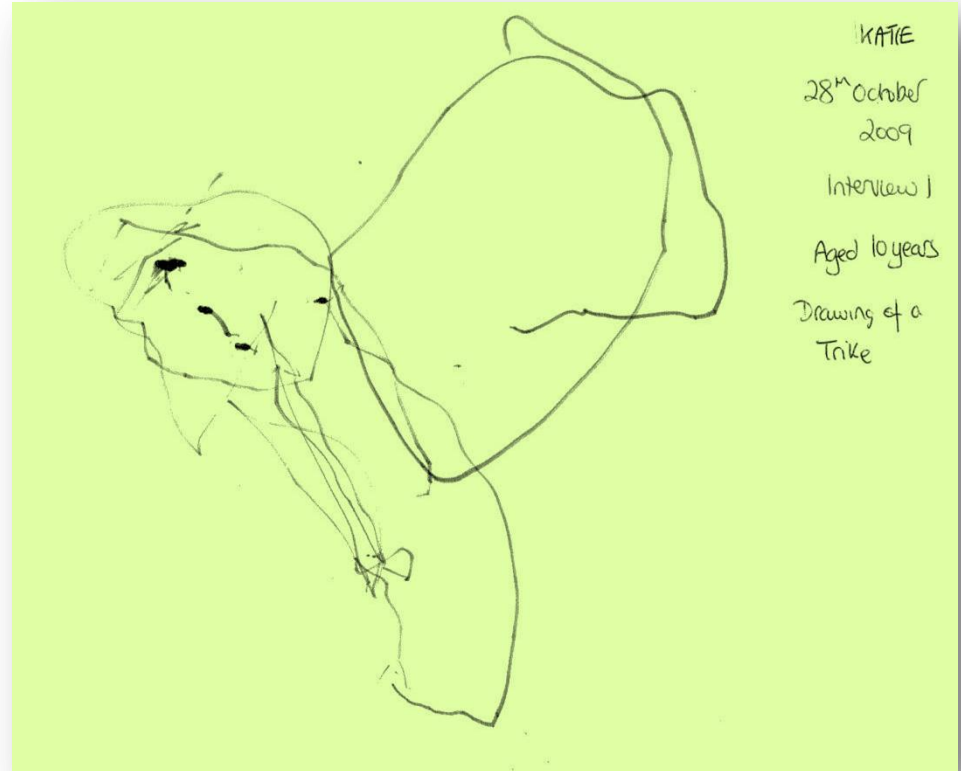
- To enable their 'voice' to be heard
 - United Nations Convention on the Rights of the Child: Articles 12, 23 and 31:
 - All children have the right to say what they think
 - If disabled to have support to lead full and independent lives
 - to relax and play and to join in a wide range of activities
(UNCRC, 1989)
 - Hart's participation ladder (Hart, 1992)

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, Ataxic ,Quadriplegia

Block printing



- Many children could not press hard enough to make an impression with the block

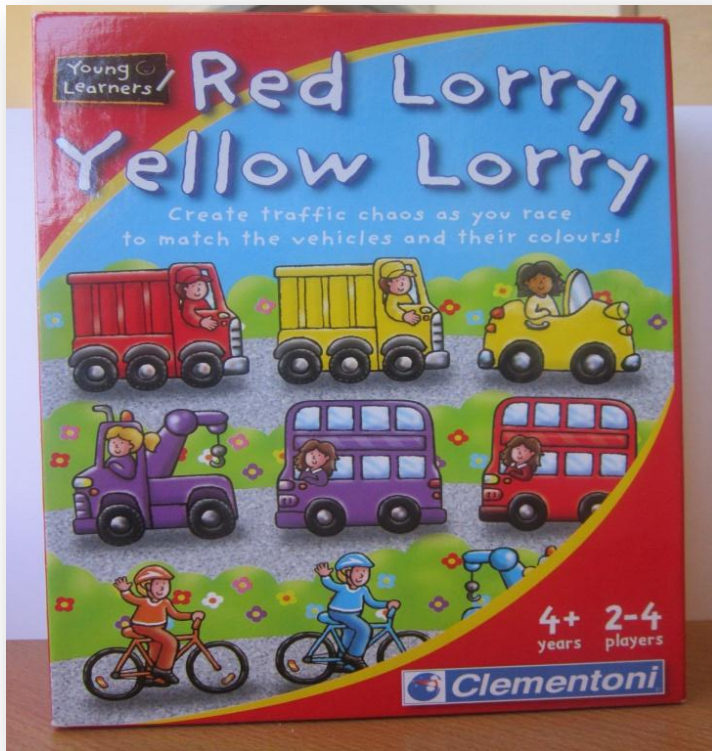
Puppets



- We used a glove puppet to engage the child in measurement and also when doing the interview- non verbal children responded well to the puppet

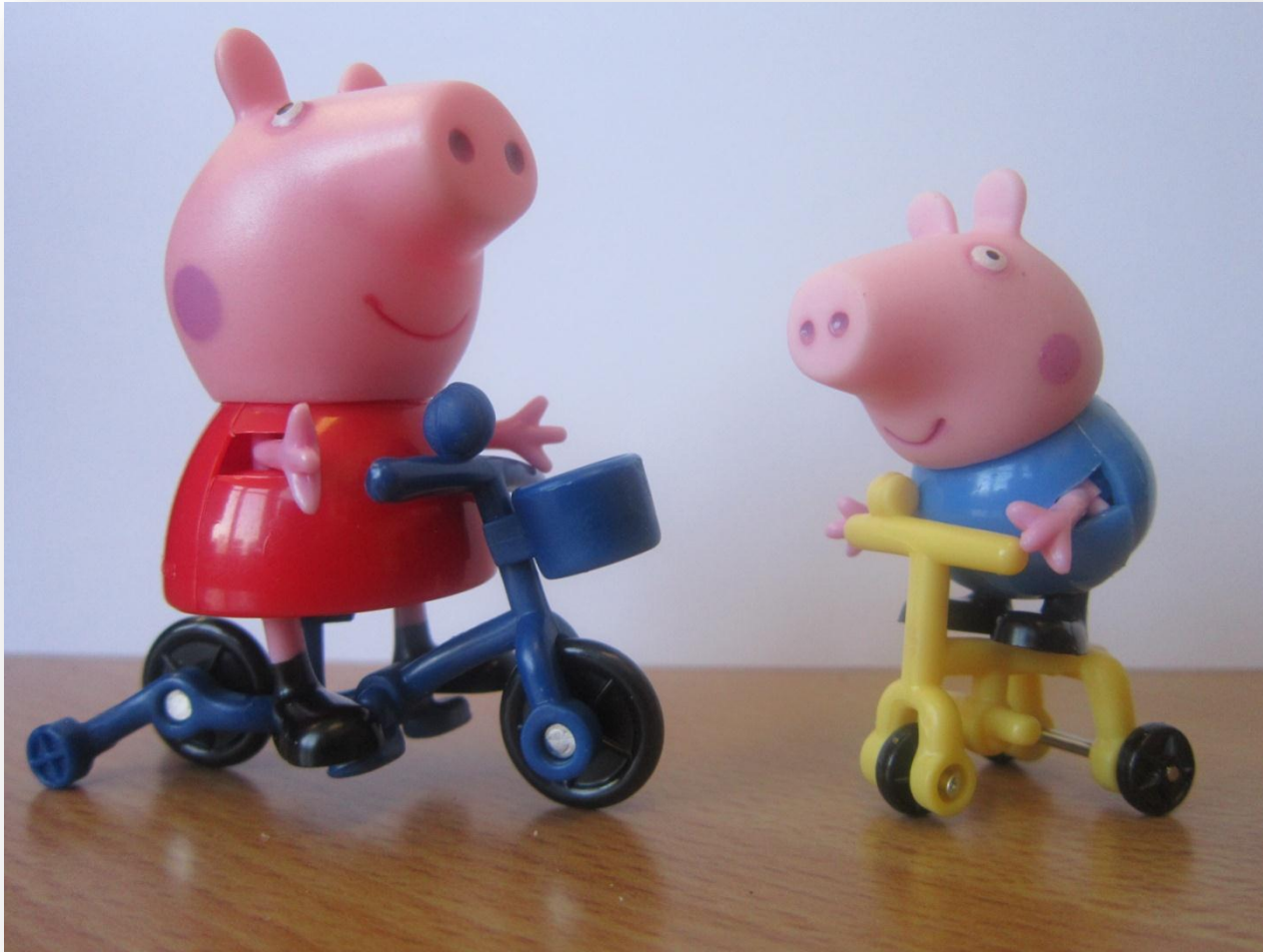
Games

Picture matching



- Some children enjoyed participating in this game and talking about their cycling experiences.
- Not all could manipulate the cards themselves

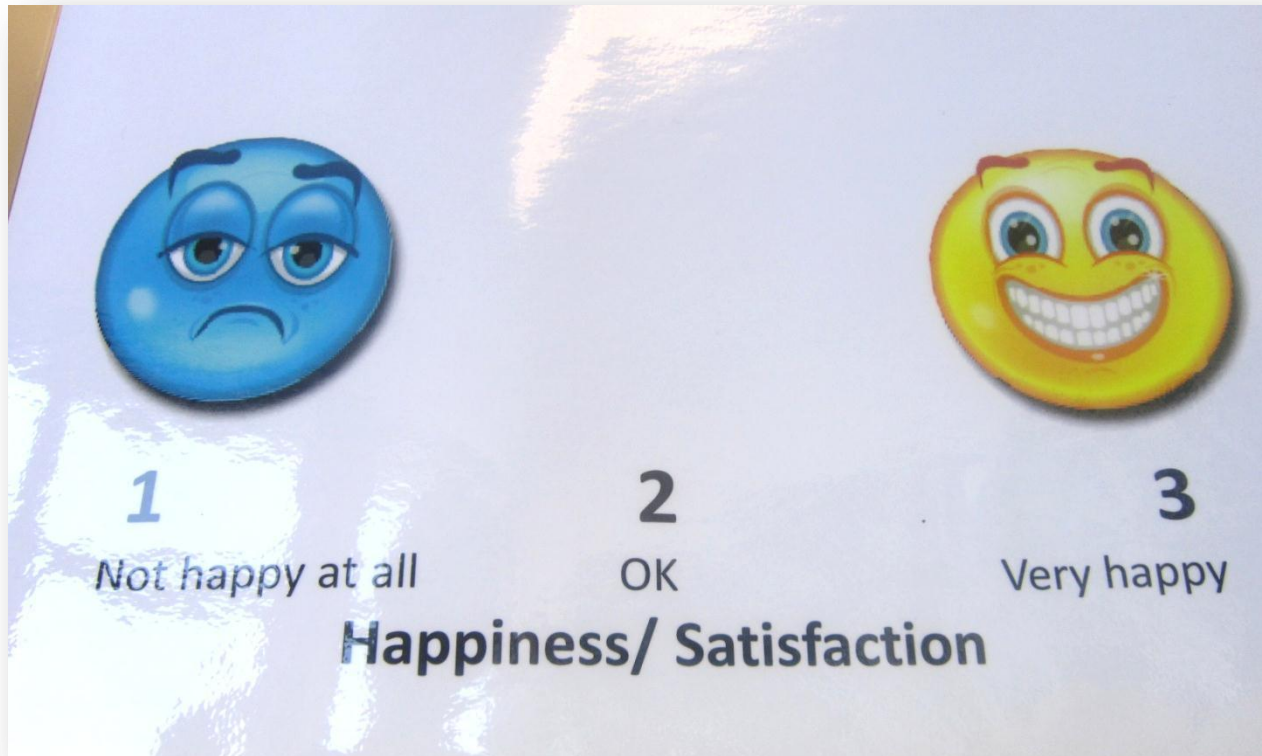
Story telling/ Peppa pig goes cycling



Laminated pictures

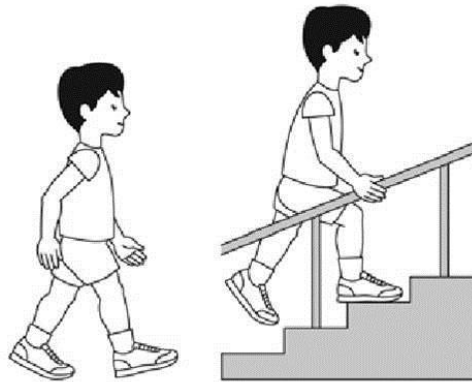
- Different contexts for cycling were presented to the children to explore where they might like to cycle in the future:
 - Park in a City
 - Countryside
 - Seaside
 - With family and friends

How did cycling make them feel?



Example of methods in action

- Timothy (GMFCS II, 5 years, hemiplegia, limited verbal communication) was energetic and jumping around the room:



- Attempts were made to engage him in conversation with the use of his diary photographs, the laminated pictures and where he might like to cycle in the future

Mum: *"Is Timothy happy on the bike?"*

T: *No (points to sad face)*

Int: *"I think you are kidding us...you don't look sad in this Photo"*

(shows diary)

T: *Once Timothy was sad and after was happy (gestures with 2 hands...handle bar sign for cycling a bike...)*

...shown laminated cycling pictures....

T: *"Is he happy after?"*

Int : *"Are you happy when you go on the bike?"*

T: *Sad (but smiling) points to sad face*

Results: 35 recruited: Voices from 32 children and youth with Cerebral Palsy

43 Interviews

15 carried out own interview

10 Joined in with parent

7 Parent/carer reported

22 Diaries

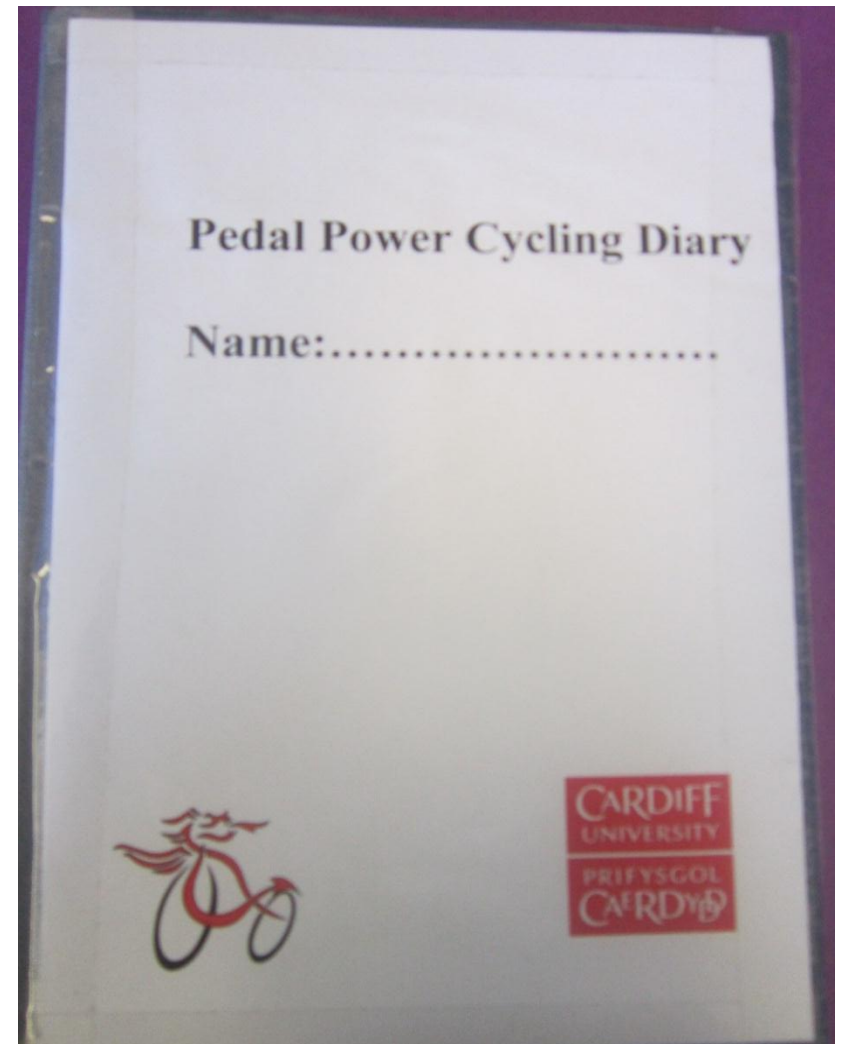
4 self reported

3 mixed

15 parents completed

[photographs included]

Diaries set the interview agenda



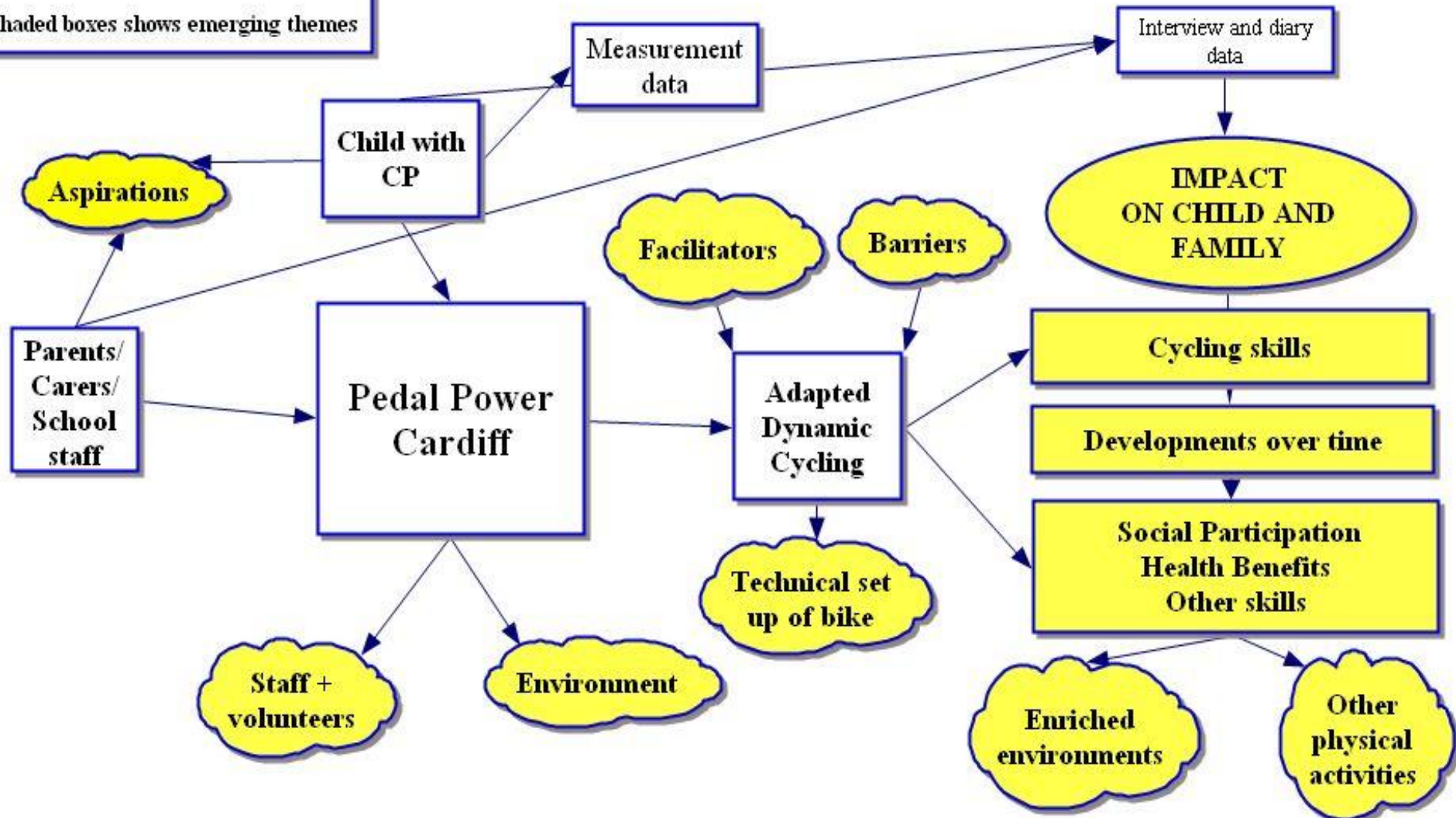
Cycling Group Thematic analysis Pickering et al, 2012

Figure 2 Themes

Key:

Clear boxes are topics being explored

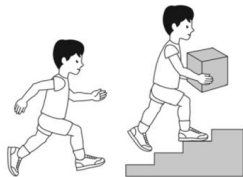
Shaded boxes shows emerging themes



Aspirations

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...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!"



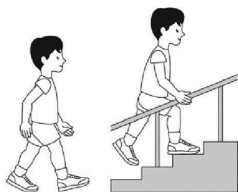
Peter aged 7 years Diplegia, High tone, GMFCS I

Social Participation Pickering et al, 2013

- 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 was 10, GMFCS II and has Diplegia

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

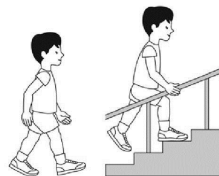


Andrew's cycling skills

Recumbent Trike steered from side



Andrew 17 years and GMFCS level II with diplegia, athetosis 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....'***

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...**”*

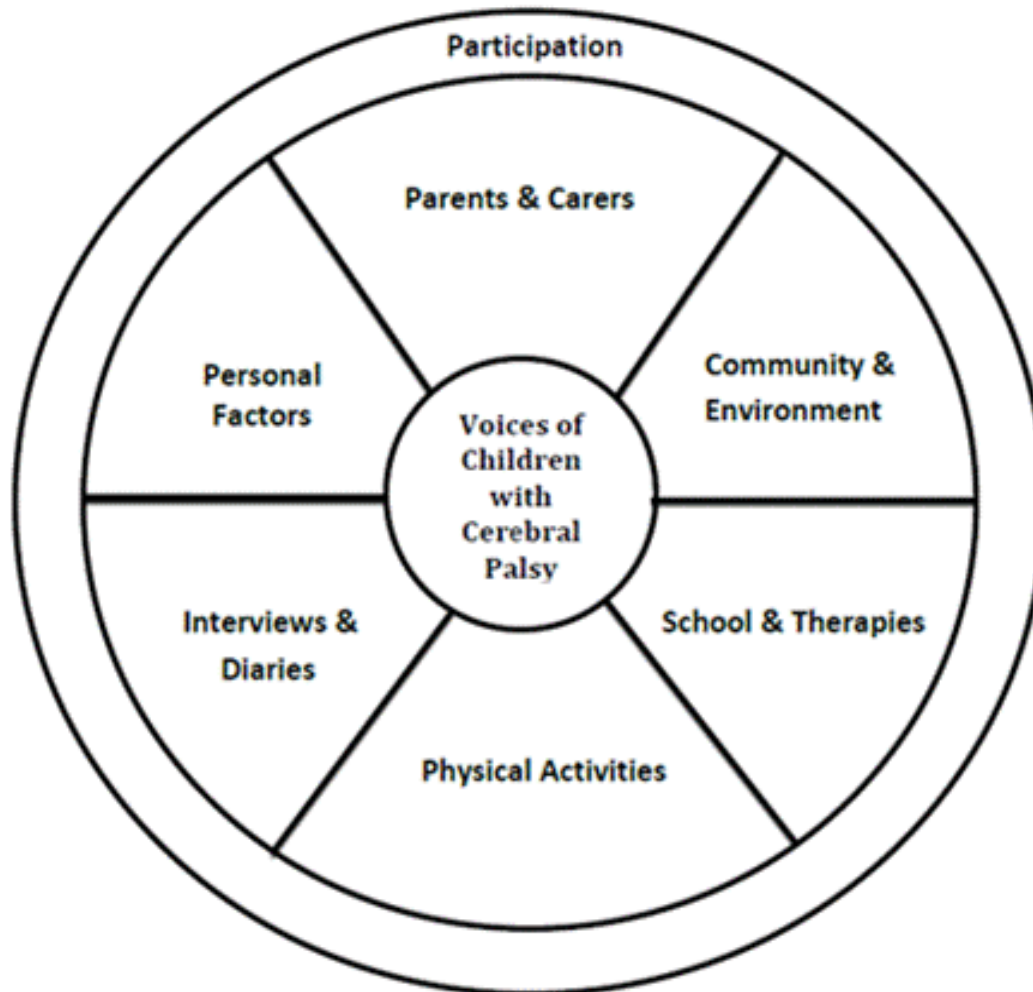
Rachel, 8 years, GMFCS IV

*“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.....”*



Non cycling group analysis- physical activities + cycling

Wheel of Participation



May's Mum cycling perspectives

*Mum: “Cycling in itself is something that I didn't think May would ever achieve, not that I have ever told her that. But I actually applied for a grant from Cerebra for a trike, I didn't even know that trikes existed for ...you know.....for an older child.....and it's really taken from there using the trike and **getting her confidence...***

Int: What age was she when she had the adapted trike?

*Mum: erm....7 I would say ...yeah..and that gave her the **confidence and ability to feel less anxious** ..._in control of a moving object and then took on 2 wheels down the field with a little slope and we've taken it from there. She's many, many years behind her brother ...*

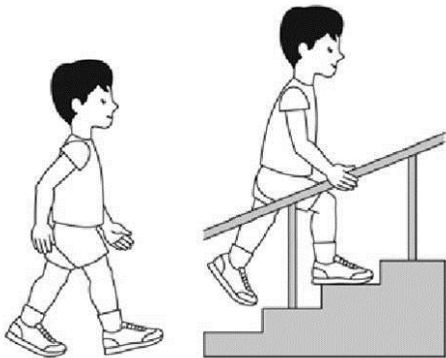
Int: That's doesn't matter does it?

*Mum: No, it doesn't matter, but it something that **she's achieved***

*Int: **I think that video of her cycling on a two wheeler is fantastic**” [shown prior to interview on mobile phone]*

May's diary entry

May is GMFCS II and has underdeveloped organs, dystonia and hemiplegia due to prematurity and having a stroke



Sunday 1st of April 2012 (2)

Today I had a 20 mins bike ride with m - ister and brother to 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 Cycling Ambitions

May 's own Diary entry (aged 10 years)

*Today I had a 20 mins bike ride with my sister and brother to RK 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 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 signalling 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

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..

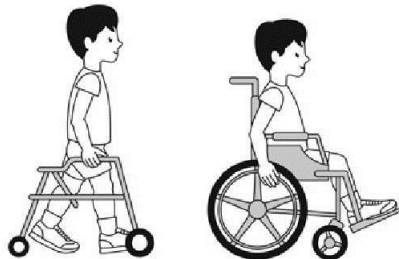
Int: So you didn't do any pedalling at all?

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

Ghost's interview (GMFCS III)

*'I walk most of the time but its just like those few days when I'm not very active and I need the Wheelchair..the kids in school say **'why are you in a pram'?**'*

*'We tried to go on the bumper cars... I've been on them before...but the man asked my mum if I was disabled and he said **we don't really have people with disabilities on here....'***



Ghost's engagement with cycling

Int: Have you thought any more about cycling since we gave you the information?...

G: Well, I looked at the photo of the thing , there's like a bike with three wheels.... I'm thinking of hiring that one....

Mum: I think we could attach this to Andrew's bike, like a tag along, so he could pedal at the back as much as he liked.....

Change in
cycling
activity
'Ghost'

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

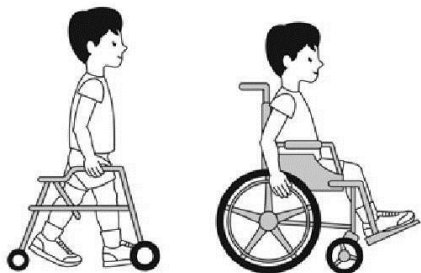
To/ Mrs D. Pickering,
Thank-you for the feed back of [redacted]
every thing looks o.k on the sheets,
I've got really good news [redacted] has
learnt to ride a bike only a little way
down hill or flat roads,
can't ride up hill yet. But we are
all really excited didn't think he
would ever be able to ride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

Timothy



'Whoosh'

Lack of
physical
activity
'Murray'
aged 4
years,
Diplegia
GMFCS III



- 19/4 - no physical activity
- 20/4 - some walking @t nursery.
- 21/4 - no real physical activity.
- 22/4 some walking at nursery.
- 23/4 some walking at nursery
- 24/4 short walk to local shops
- 25/4 no physical activity
- 26/4 swimming in am
soft play in pm.
lots of walking at school
- 27/4 lots of walking at school.
- 28/4 very little physical activity

Fatigue

Rugby 11 years
**GMFCS IV: "After trying
the trike my legs feel
aching"**

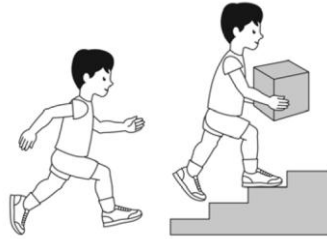
Wayne 7 years
GMFCS II
**"Legs get too
tired after
riding a bike so
don't do it very
often"**

Ghost 10 years
GMFCS III
**"My legs was
killing me after
15 minutes of
lazer tag"**

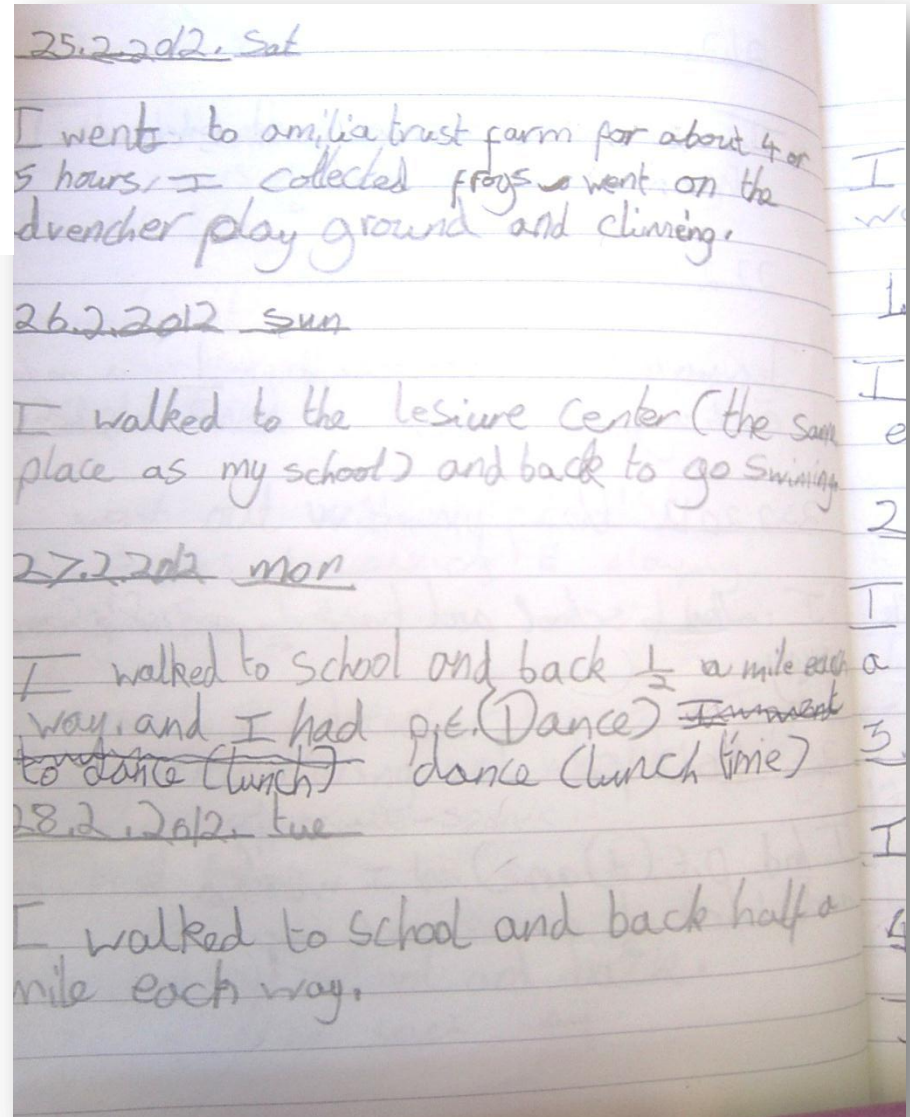
Suarez 8 years
GMFCS III
**"My legs hurt for
3 days after
riding the
trike"**

Choices

- Lizzie



Lizzie
(11 years/GMFCS I
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..”



Change in behaviour

- 11 of the 18 children started cycling during or after the study was completed

Implications for practice

- **Quality of life** - The children who participated in adapted cycling told us they enjoyed this experience and it improved their sense of well being, independence, achievement and confidence.
- Some children chose other activities to participate in, fatigue was a factor in this.
- **Policy makers** should consider offering adapted cycle hire within a 50 mile radius.



Acknowledgements



- Nancie Finnie Charitable Trust
- Children, families and carers who took part
- Pedal Power Trustees, 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.

