



# The benefits of cycling: What children and young people with cerebral palsy say

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Time for Change: Child, Youth and Disability conference

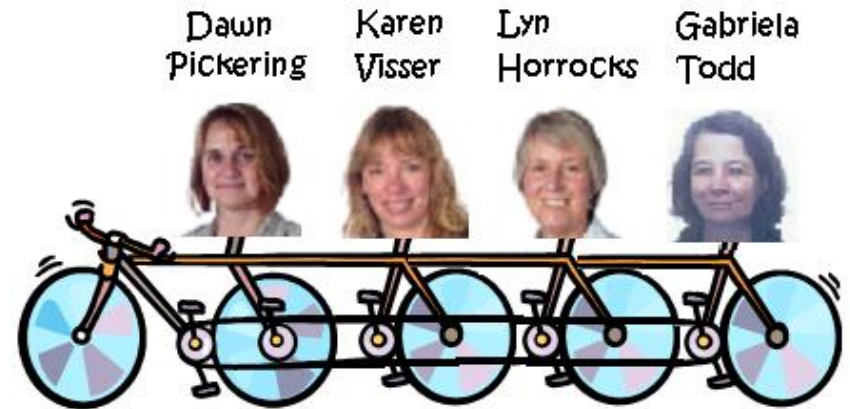
Manchester

# Background

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

Physical activities need adapting and support provided to access them

- Physiotherapy clinical practice with Cerebral Palsy (CP)

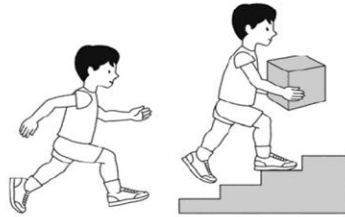


# Cerebral Palsy- consensus definition

Rosenbaum et al 2007

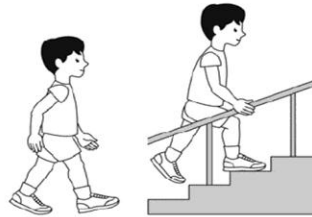
‘...describes a group of permanent disorders of the **development of movement and posture causing activity limitations** that are attributed to non-progressive disturbances that occurred in the developing fetal or Infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances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

# GMFCS E & R Descriptors and Illustrations for Children between their 6<sup>th</sup> and 12<sup>th</sup> birthday



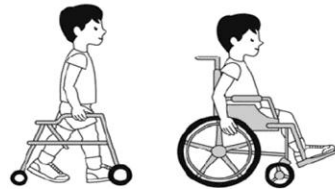
## GMFCS Level I

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) Video



# 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 (families travelled up to 50 miles to hire the trike)
- 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

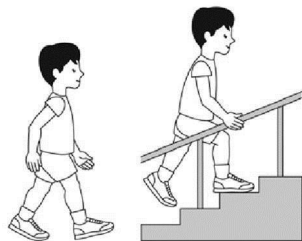
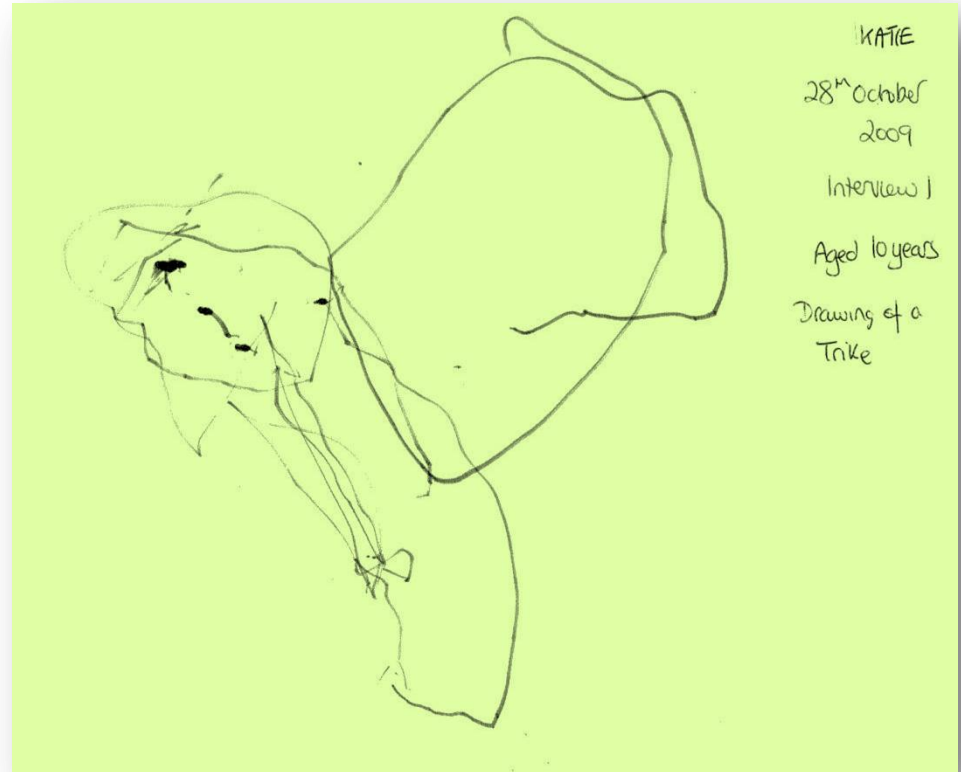
- To enable their 'voice' to be heard
  - United Nations Convention on the Rights of the Child: Articles 12, 23 and 31:
    - All children have the right to say what they think
    - If disabled to have support to lead full and independent lives
    - to relax and play and to join in a wide range of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

# Mosaic Methods Clark and Moss (2001, 2011)

- *'Unhurried listening'*

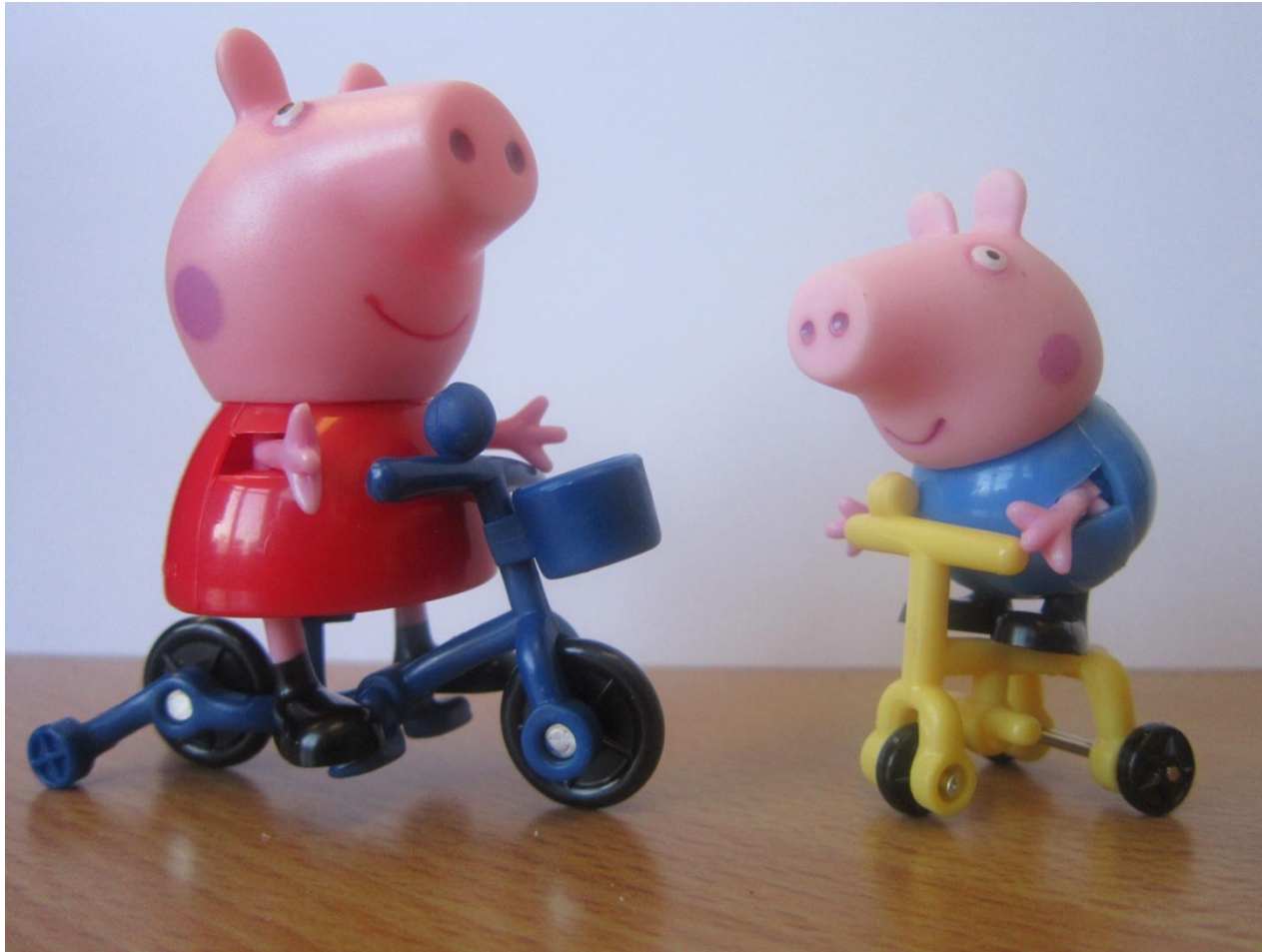
Attempted to use creative methods such as stickers/ drawing / ink pad printing/ game card matching, but several children had limited cognitive and manipulative Skills.

Photographs were used but many children were unable to take these themselves



Katie was 10, GMFCS II, Ataxic ,Quadriplegia

# 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:

City Park

Countryside

Seaside

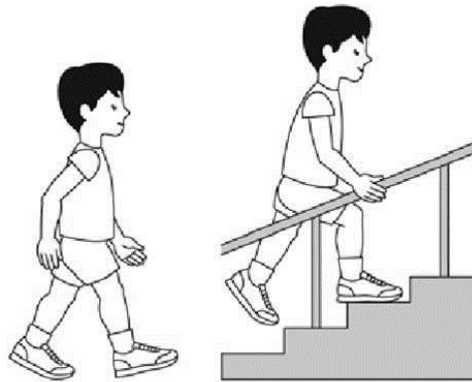
With family and friends

# 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*

# Interviews and Diaries

- Some children could self report
- However, when they were not able to self report, the diaries set the agenda for the conversations either with the children or the adult present at the interview.

# Data management

- NVivo
- 2 researchers- 4 children pilot methods
- Transcripts typed verbatim
- Participant validation
- Analysis 3 stages- pilot/rest of cycling group/  
non cycling group
- Double analysis of  $\frac{1}{3}$  data

# 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

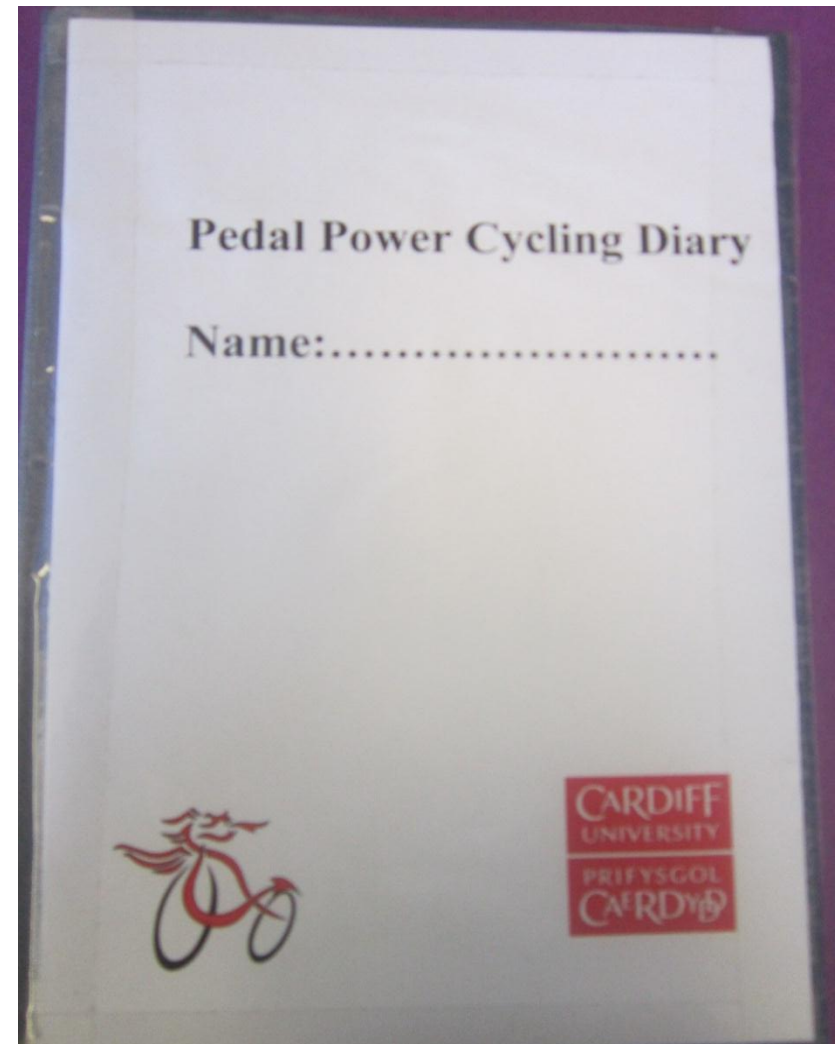
4 self reported

3 mixed

15 parents completed

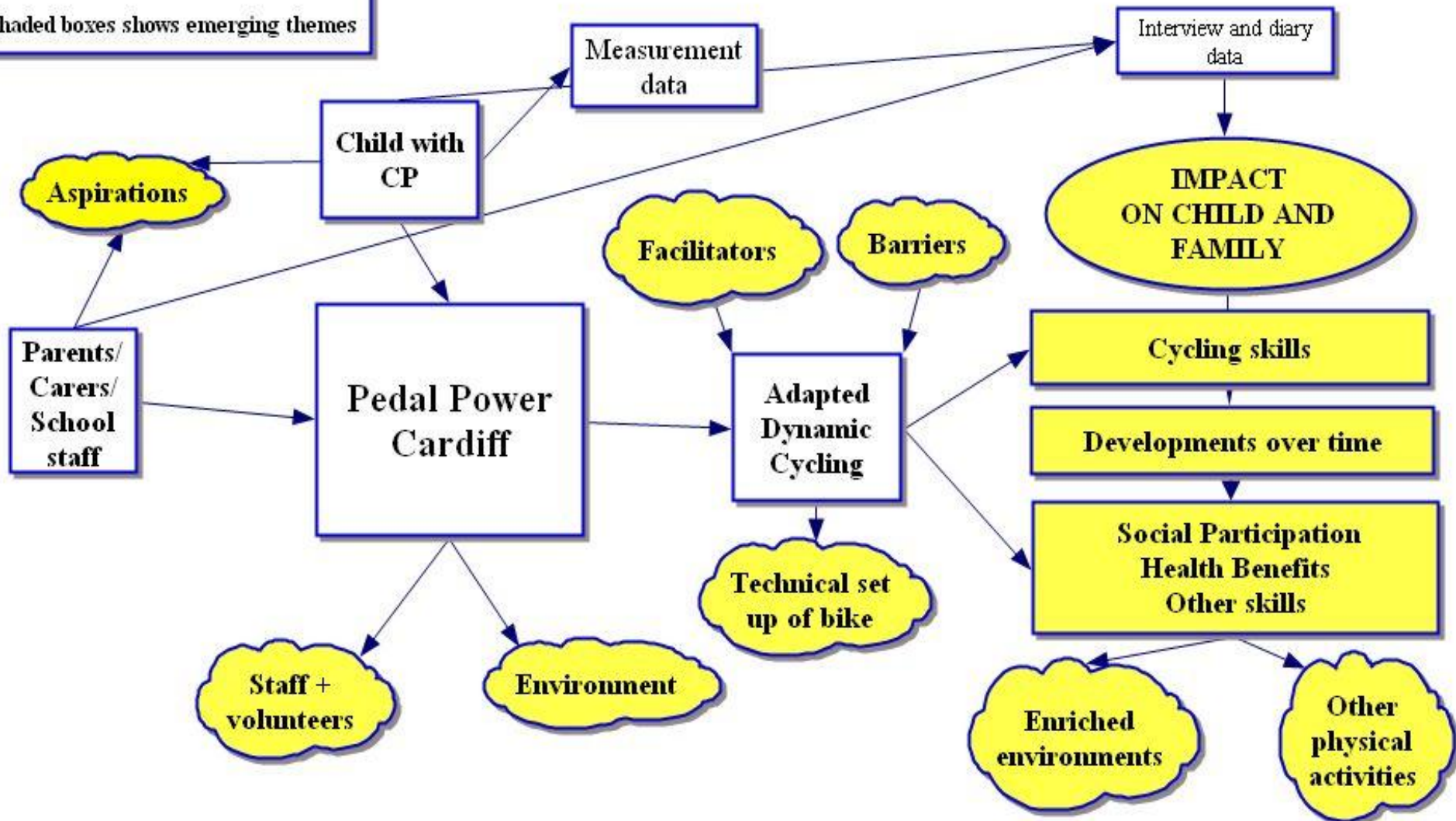
[ photographs included]

Diaries set the interview agenda



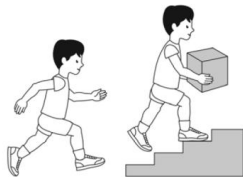
# Cycling Group Thematic analysis Pickering et al, 2012b

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



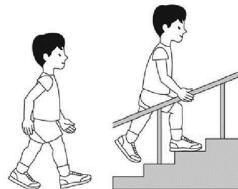
# Social Participation

Publication pending, 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

Saturday 11<sup>th</sup> 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



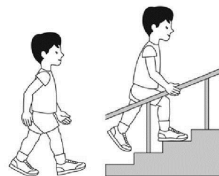


# Andrew's cycling skills

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...**”*

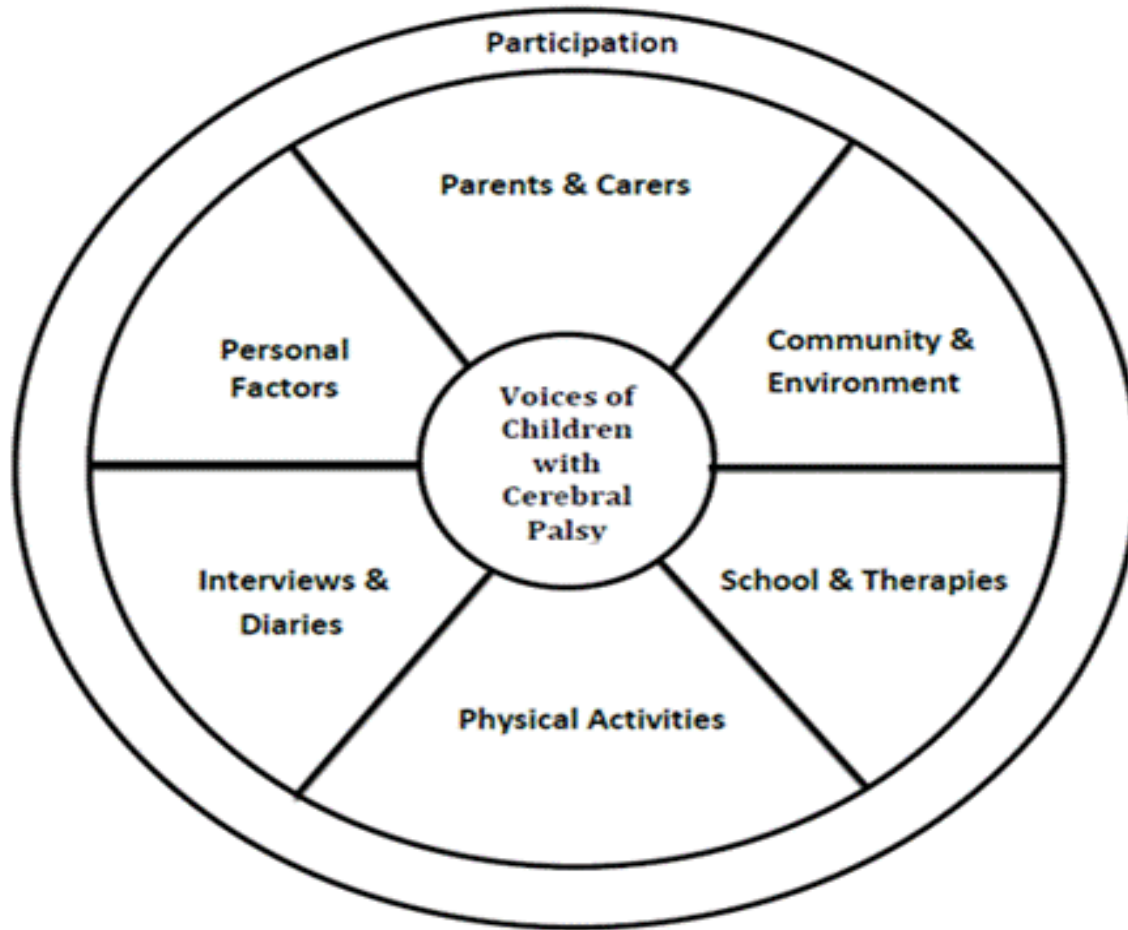
Rachel, 8 years, GMFCS IV

*“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.....”*



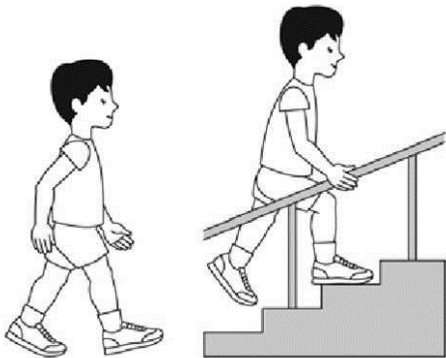
# Non cycling group analysis- physical activities + cycling

## Wheel of Participation



# May's 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 my sister and brother to [redacted] 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 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..*

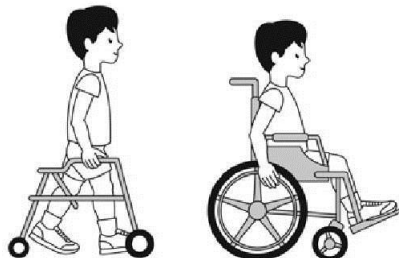
*Int: So you didn't do any pedalling at all?*

*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'

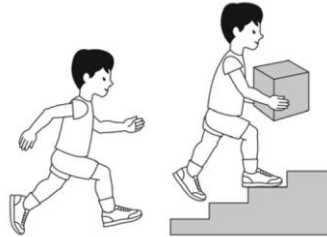
***' Didn't think  
he would ever  
be able to  
ride a bike'***

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 New Year  
from  
Debbie and [redacted]

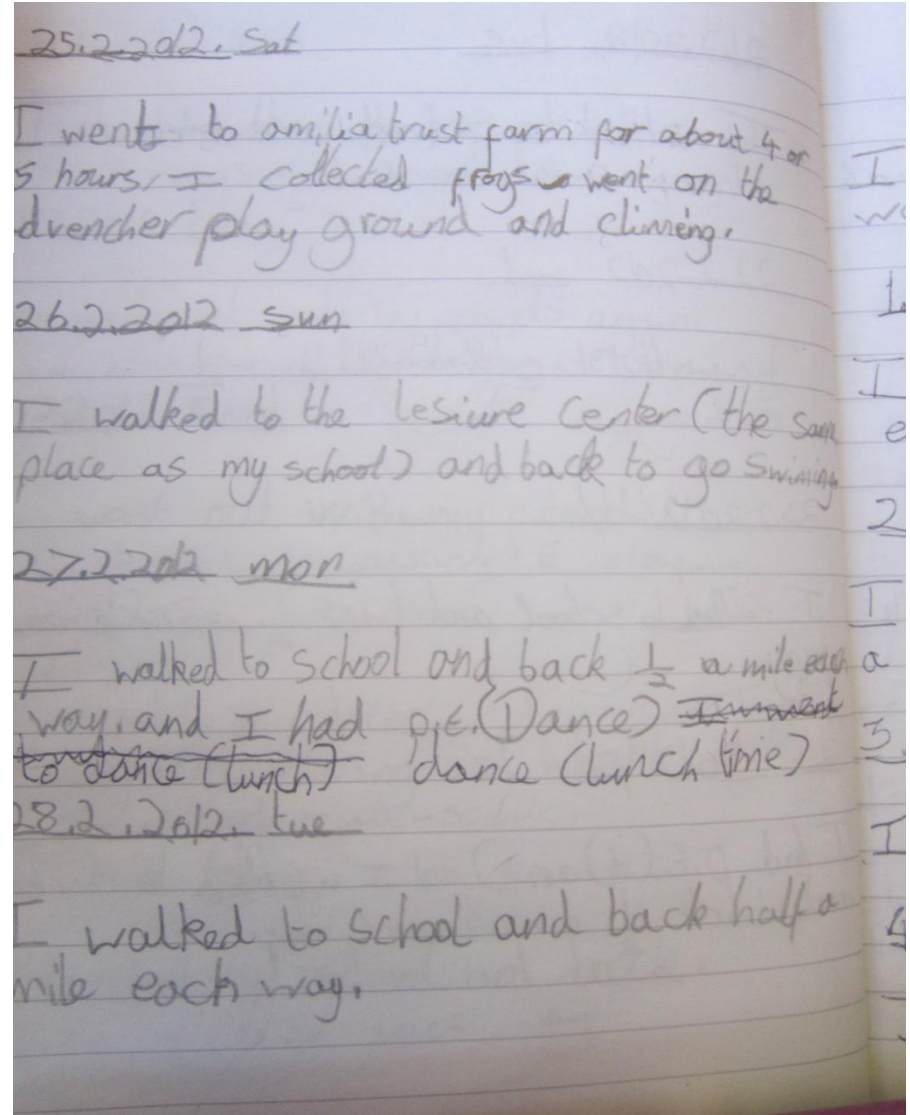


# Choices

- 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..'**



# 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'**

# 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
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- Jenx Ltd
- Polar
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