



# Children with Cerebral Palsy

## ‘Voices’ about cycling

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# Pedal Power Research Study



- 3 year study looking at the effects of adapted dynamic cycling for children with Cerebral Palsy (CP)



# Ethics of research with children with a disability



- United Nations Convention on the Rights of the Child (United Nations, 1989)

Rights of children to participate

Article 31 ‘ children have a right to relax, play and join in a wide range of activities’

Article 23 ‘children with a disability should have special care and support so they can lead full and independent lives’

# Children and Young people's Participation Standards for Wales(2007)



## **We will:**

listen to your ideas, views  
and experiences

take you seriously and treat  
you fairly

work with you to do  
something about the  
things you tell us are  
important

work with you to help  
change things for the  
better

# Mixed methodology



Physical measurements  
of muscle strength  
and length

Interview the child and  
family about their  
experience of cycling

Diary of cycling

- Results of pilot interview data from 4 children

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

# 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 need a person to help facilitate communication [Morris, (1998)]

# Challenges of interviewing children with CP



- 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 issues to interview children with a disability under 16 years alone:

- Parents act as gatekeepers
- Some children disengage with the interview process
- 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

# Languages spoken



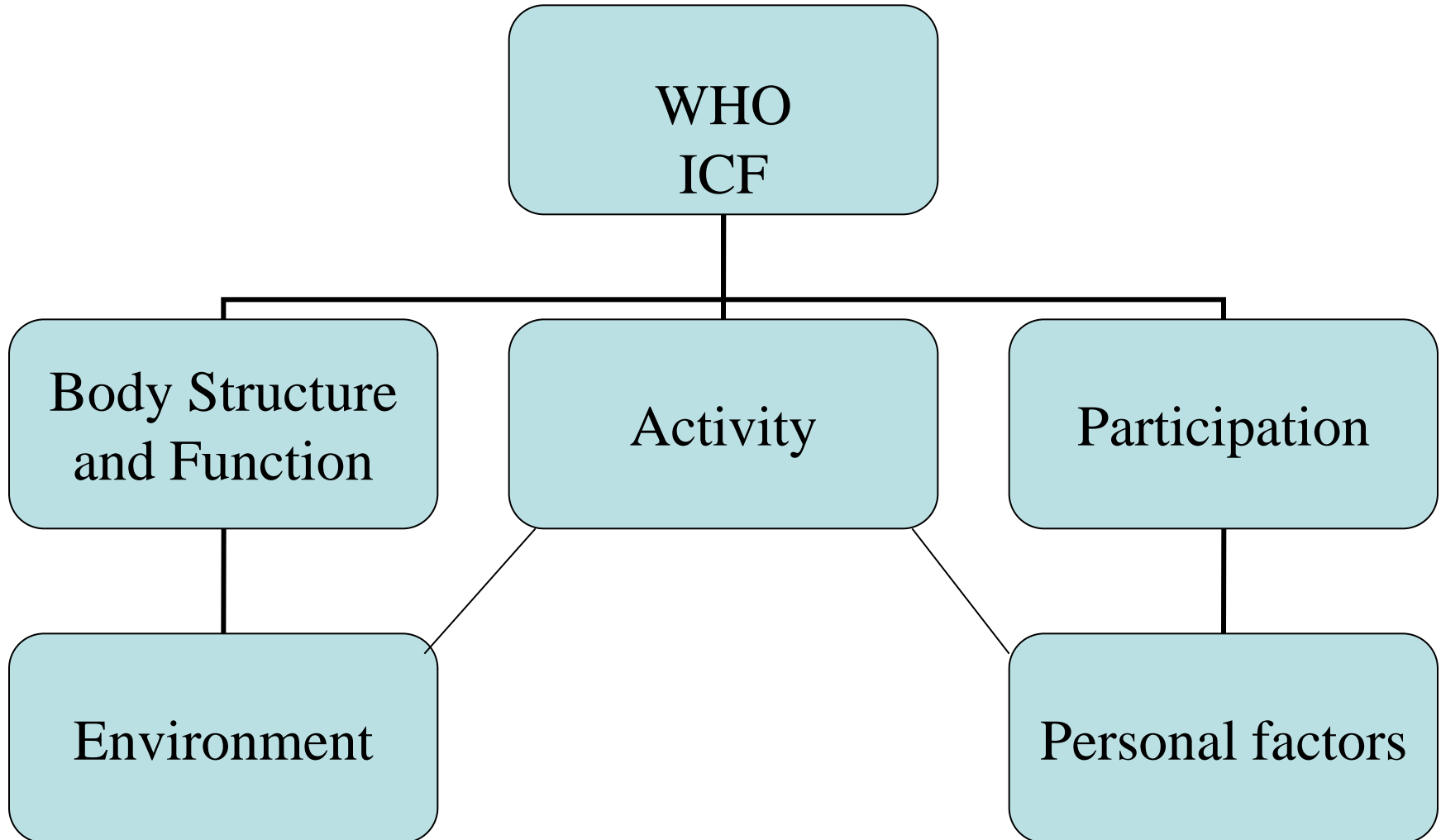
- English
  - Interviews carried out in English
- Welsh
- Urdu
  - Interpreters used where necessary

# Question design



- Clinical experience shows that there are limited opportunities for children with CP to participate in physical activities - Cycling is one activity than can be adapted
- Literature: **ASK questionnaire** (Plint, 2003)– based questions around the 5 themes here for pilot adding cycling

# World Health Organisation International Classification of Functioning model <sup>WHO(2001, 2007)</sup>



# Research schedule



- 1st measurement session – 45 minutes
- 1st interview – 40 minutes
- Cycle up to 6 sessions
- 2nd measurement session – 45 minutes
- 2nd interview – 40 minutes

# Methods



- Semi Structured Interviews take place following the first measurement session and the commencement of cycling
- Child and one parent/carer present
- Recorded with a Dictaphone/Video
- Diary kept of cycling experiences

# Interview Questions



- Style for children needed to be more direct not open ended (Booth and Booth, 1996)
- 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?

# Results of Pilot interview



- 4 children = 8 interviews
  - 3 with Dictaphone/ 1 video
- Languages spoken Welsh and English
- Interviews carried out in English



Child	Age in years	Style of Communication	Language spoken	Pseudonym
1	4	Verbal overshadowed by older sister	English	Emily
2	7	Verbal but limited concentration	Welsh and English	Peter
3	10	Makaton signing, some limited verbal	Welsh and English	Katie
4	3	Verbal	English	Jamie



# Data management



- Transcripts typed up and sent back to participants for verification
- Analysis by Themes
- Iterative- decided to narrow down onto cycling in more detail by the end of the pilot

# Emily



- *Emily's mum:*
  - *“Emily is now able to steer the bike...if the foot plates are secure she can cycle for up to an hour...however sometimes the technicians don't quite get this bit right and she gets too tired after 10 minutes ...which is a shame.....”*

# Photo from Diary entry



- Additional foot and trunk supports
- Push handle at rear



# Peter



*Mum has just described a cycling holiday where the child cycled parts of the journey from Bristol to Windsor to visit Legoland [ 90 miles].....*

INT: Peter have you got any special goals, any special things you want to do with cycling?

MUM: That's a good question, have a think . What would you **really** like to do with your cycling?

PETER           Quit!

MUM **Oh No**, you can't go on a fantastic holiday, get to Legoland. We are thinking of maybe going to Holland because it's flat, next year.....

PETER: Yes.....       **This week** ?.....

INT: What do you want to do? What's your goal with cycling?

PETER: Cycle to a hotel

INT: Cycle to a hotel! well, there you are, sounds like a good goal to me.....

# Katie



INTERVIEWER:...So I have come back to find out how that went and what you thought about it. ....

Mum: Your cousins came with you, did you like the cycling?

Katie: Yeah

INTERVIEWER: 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]

INTERVIEWER: Brilliant! .....Why do you like going fast?

**(Katie puts her thumb up, smiling)**

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

**(Katie lifts her thumb up and down)**

## Diary entry from Katie's Dad



*“After many weekends of poor weather or other activities having meant that Katie wasn’t cycling, we made it out today!.....The first 15 minutes or so were spent trying to coax Katie into cycling. It was a cold day and she seemed unhappy to move. Then when she saw a girl with 2 dogs, she was willing to cycle after them to find out their names. She then cycled to the river, along the tow path to the bridge, the horse riding stables and then back to the Pedal Power base...”*



KATIE

28<sup>th</sup> October  
2009

Interview 1

Aged 10 years

Drawing of a  
Truck



# Jamie



Int ...Let's see what we've got here shall we? This is picture number two...(shows picture of a child on bike).....What can you see? Little person on a bike? Do you know some colours?

Child Yeah

Int ...Can you tell me some colours on that picture?

Child Red

Mum What are they?

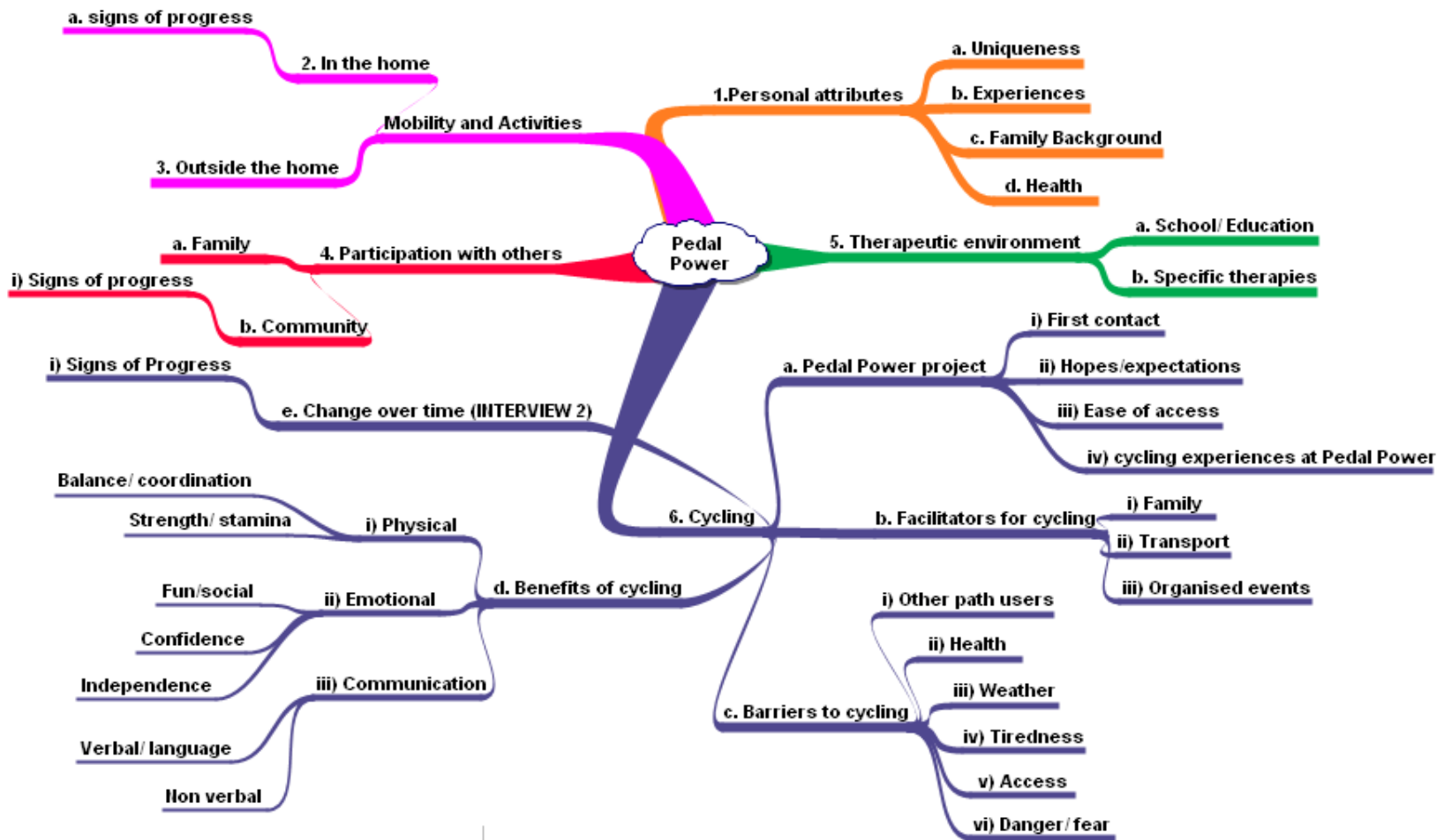
Child That's a picture, picture of one.....two, three, four, five flowers

Int You can count! What a clever boy! What colours have we got there, you talk with mummy cos I don't know which colours you know

Child Yellow, red, blue, silver, pink....

Int Well I'm impressed you know all those colours.....What colour were your trousers when you were riding this bike? (shows child a picture of himself on bike)

- E Blue.....



# Reflection



- Triangulation – asking a more experienced social science researcher to read through an interview we decided to narrow it down to asking more specific questions just about cycling
- Read about Mosaic methods (Clark and Moss, 2001)- included pictures, board game and drawing-this has limitations due to the balance and coordination difficulties.



# Researcher's interview style

Booth and Booth, 1996

- Need to build up the relationship
- Assume can understand
  - 4 possible responses –
    - » i. Don't understand
    - » ii. Cannot articulate an answer
    - » iii. Avoid answering (Chose not to answer)
    - » iv. Does not know the answer
- Creative Guesswork
- Unorthodox methods- need to be flexible and creative- 'Self Developing'

# Food for thought



- As researchers we need to explore further ways to enable children with CP to express their views.
- We need to work towards representing their views about physical activities.



# Ethical considerations

Alderson 2004

- What could the 'best outcome' be?:

*Does participation in adapted dynamic cycling affect lower limb muscle function, activity levels, and quality of life of children with Cerebral Palsy? If the findings show a positive result of either maintaining or improving these aspects then it could:*

*Reduce the harm and cost of Cerebral Palsy by encouraging children and young people to remain or become more active and promote the psychosocial benefits of adapted dynamic cycling*



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