Who are the champions for well-being for children with brain injury?
Aim of my talk

• To showcase recreational opportunities for children with significant brain injury where walking and talking are limited from 2 research studies: ‘Pedal Power’ and ‘VOCAL’.
• To signpost families to adapted activities which promotes the children’s health and well-being.
• To highlight how the children can be their own advocates.
Context for 3 year study: Pedal Power Cardiff (2009-2012)
Figure 1: Pedal Power Pilot Research Project adapted from the domains of the World Health Organisation: International Classification of Functioning.

**Condition**
- Cerebral Palsy

**Body Structure & Function**
- Measurements of muscle length and strength, joint angles, distance cycled, exercise tolerance

**Activity**
- Dynamic cycling on adapted trikes

**Participation**
- Cycling as a social leisure activity with family and friends
- Interviews with children and families

**Environmental Factors**
- Trained staff at Pedal Power Cardiff, a voluntary organisation
- Outdoor activity in a local park

**Personal Factors**
- Children aged 2-17 years, boys and girls, with diverse abilities and cultures
Participation

• “Involvement in meaningful activities” World Health Organisation, ICF 2001

• Kellet, 2014 ‘Act of doing and being involved’

• Combining these two different constructs by redefining participation as the ‘act of doing and being involved in meaningful life situations’, The agency of a disabled child can be included more actively.
Children and Young People’s Participation Standards for Wales (2007)

Having a voice, having a choice-7 standards: we offered that we would:
listen to their ideas, views and experiences,
take them seriously and treat them fairly,
work with them to do something about the things they told us were are important,
work with them to help change things for the better
Research question

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

• Mixed methods quantitative and qualitative
• ‘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.
We used a glove puppet to engage the child in measurements (muscle strength measure here) and also when doing the interviews—non-verbal children responded well to the puppet.
Story telling/ Use of toys e.g. Peppa pig goes cycling
Laminated pictures

- Different contexts for cycling were presented to the children in picture format to explore where they might like to cycle in the future:
- Photo elicited responses - not always verbal - eye-gaze, pointing
Different trikes available

Charlie’s champs

Courtesy of John Preston’s website
How did cycling make them feel?

1. Not happy at all
2. OK
3. Very happy

Happiness/ Satisfaction
• 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- ..

• Diary drawing

Diane, 10 years
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
Children unable to self report

**Julia, 14 years**

“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**

“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.....”
Change in cycling activity
‘Ghost’ (aged 9 years)

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

- Story inspired by the 35 children who took part

- Illustrated by Hannah Pickering
Learn to Ride Centre

A fully inclusive cycling facility where children and young people of all abilities can safely learn to ride their bike, exercise and be active.

The Learn to Ride centre, designed by Playcentre is a safe space for young riders of all abilities to enjoy the opportunity to develop their riding skills and in turn, their confidence and well-being.

There are a combination of different surfaces, pathways and working traffic lights for riders to navigate, along with replica road signs and markings to follow. A shelter with seating and workstations overlooks the track – a perfect place for users to stop and take a break, or families to sit and observe the action!

Outdoor lighting has also been installed making this an area that can be used safely at any time of the day.
Case Study design: Participatory group/ Limited participatory group; Cerebral Palsy aged 9-16 years, Levels III-V of the GMFCS


which states that all children and young people:

‘Have the right to rest, leisure, play and recreation and to take part in cultural and artistic activities’
• How do children and young people with cerebral palsy and their parents, view, experience and choose their level of participation in recreational activities?
Method Case study design (Yin 2018)

2 interviews 12 weeks apart:

1\textsuperscript{st} interview structured around the 6 themed ‘F’ words: Fun, Fitness, Family, Friends, Function and Future in relation to recreational activities (Rosenbaum and Gorter, 2012)

Direct and participant observations at one of their usual recreational activities, looking for evidence of their well-being - photographs taken

Diary of Recreational Activities kept for 12 weeks - photographs added by parents.

2\textsuperscript{nd} interview made reference to the diary entries.
Interview 2
‘...the medal with the orange ribbon was for the Super Tri I did in March...it’s got one star, two stars, three stars, four stars, five stars, six stars, seven stars....I’m a winner...

Int: What did you have to do?
....Three things...swimming, riding my bike and walking 100 miles...

Diary entry week 7
Ben helps me I walk for 400M with my frame....I did two lengths (swimming) bye my own....Ida came two help riding by bike, I did two times round the cycle track.....the end of my Triathlon everyone cheers for me!....I had a medal and a bag with a egg water sticker....’
So it's so beautiful, fresh air, you get to obviously run on the Frame Runner ....and you can switch off that part of your brain. I think motor function just uses more - because we've got less maybe - we've got damaged brains so the bits that are alive are working 100 fold more than they're meant to, it might be the fact that somehow they can switch off and you can start thinking. What I can't do is think coherently when I walk, but I can when I Frame Run.
Frame Running
Frame Running (International sport)

International Athletics stadium, House of Sport, Cardiff
Fridays 5-7pm
Contact Physiotherapist, Gabriela Todd 0780 377 0962
Trike riding-Clare

Diary entry

• “I have been for lots of bike rides with ‘D’ my dog”
Touch Trust (Cardiff with outreach groups in Wales)
Sensory- music and movement (Bree)
Skiing- Ice Cool Kids- Pembrey (Matthew)
Uniformed clubs- Brownies/ Cubs (Bree/ Nick)
Sealegs2 association - Pembrokeshire

https://sealegs2.org/

- Disability sailing experiences
- 2 boats - one wheelchair adapted
Gympanzees - pop-up leisure facility (Bristol)
Chamwell Centre- Gloucester
Local contacts

• Disability Sports Officers in local authorities

• Health Boards in Wales- now employ: “Health disability activity practitioners”
Who are the champions?

- **You** all are able to promote your children’s health and well-being needs- the children’s voices are the most powerful to advocate change
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Questions/Comments