

**National Paediatric Brain Injury Conference 2022; The Royal Society of
Medicine, London**

**Breaking down barriers: Creating a fair playing field for children with acquired
brain injury.**

**Who are the champions
for well-being for
children with brain injury?**



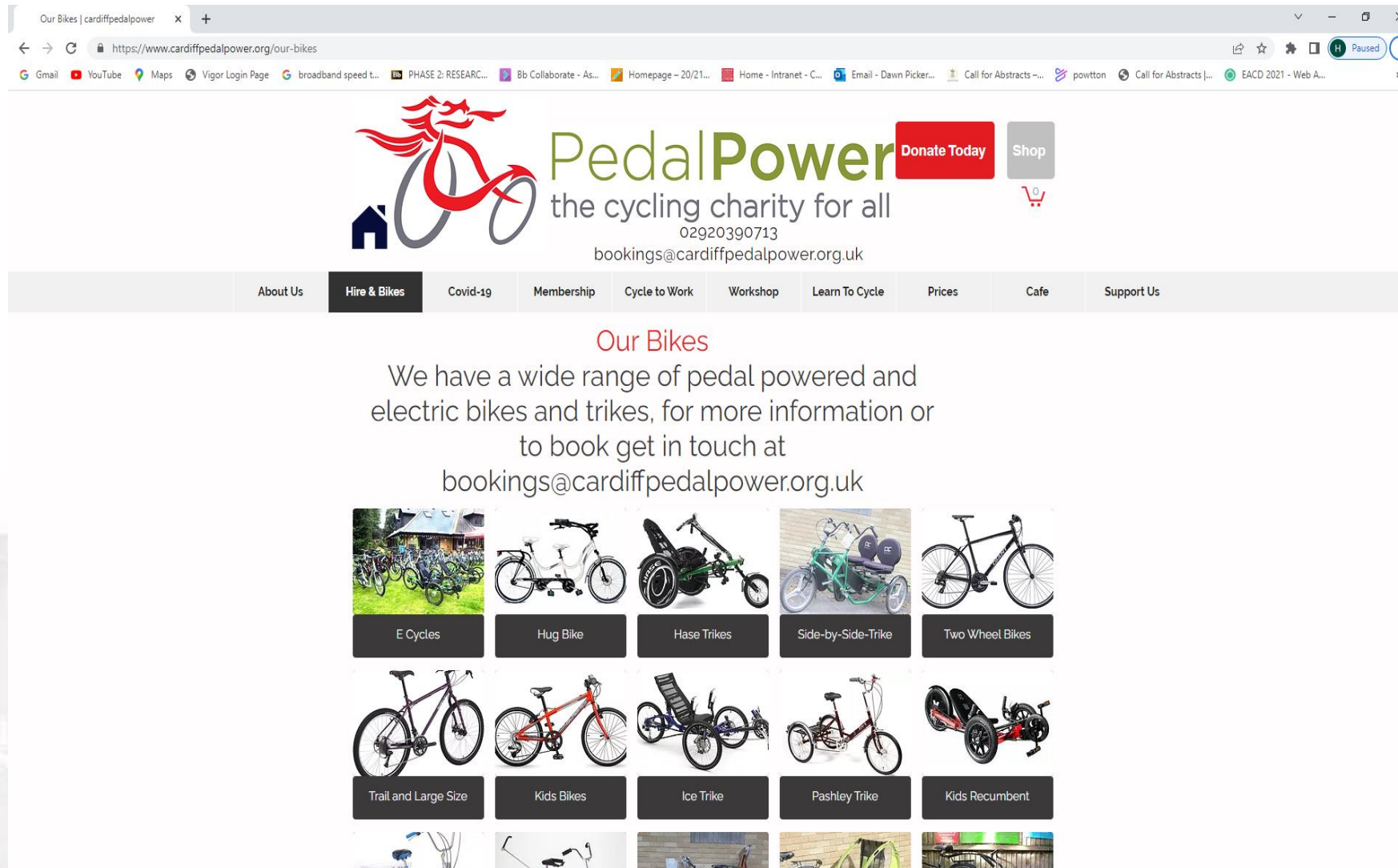
**Dr Dawn Pickering,
Physiotherapist,
Senior Lecturer,
7th October 2022**



- 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)



The screenshot shows a web browser window with the URL <https://www.cardiffpedalpower.org/our-bikes>. The website header features the Pedal Power logo, which includes a stylized red dragon and a bicycle. The text reads "PedalPower the cycling charity for all" with the phone number "02920390713" and email "bookings@cardiffpedalpower.org.uk". There are buttons for "Donate Today" and "Shop". A navigation menu includes "About Us", "Hire & Bikes", "Covid-19", "Membership", "Cycle to Work", "Workshop", "Learn To Cycle", "Prices", "Cafe", and "Support Us".

Our Bikes

We have a wide range of pedal powered and electric bikes and trikes, for more information or to book get in touch at bookings@cardiffpedalpower.org.uk
















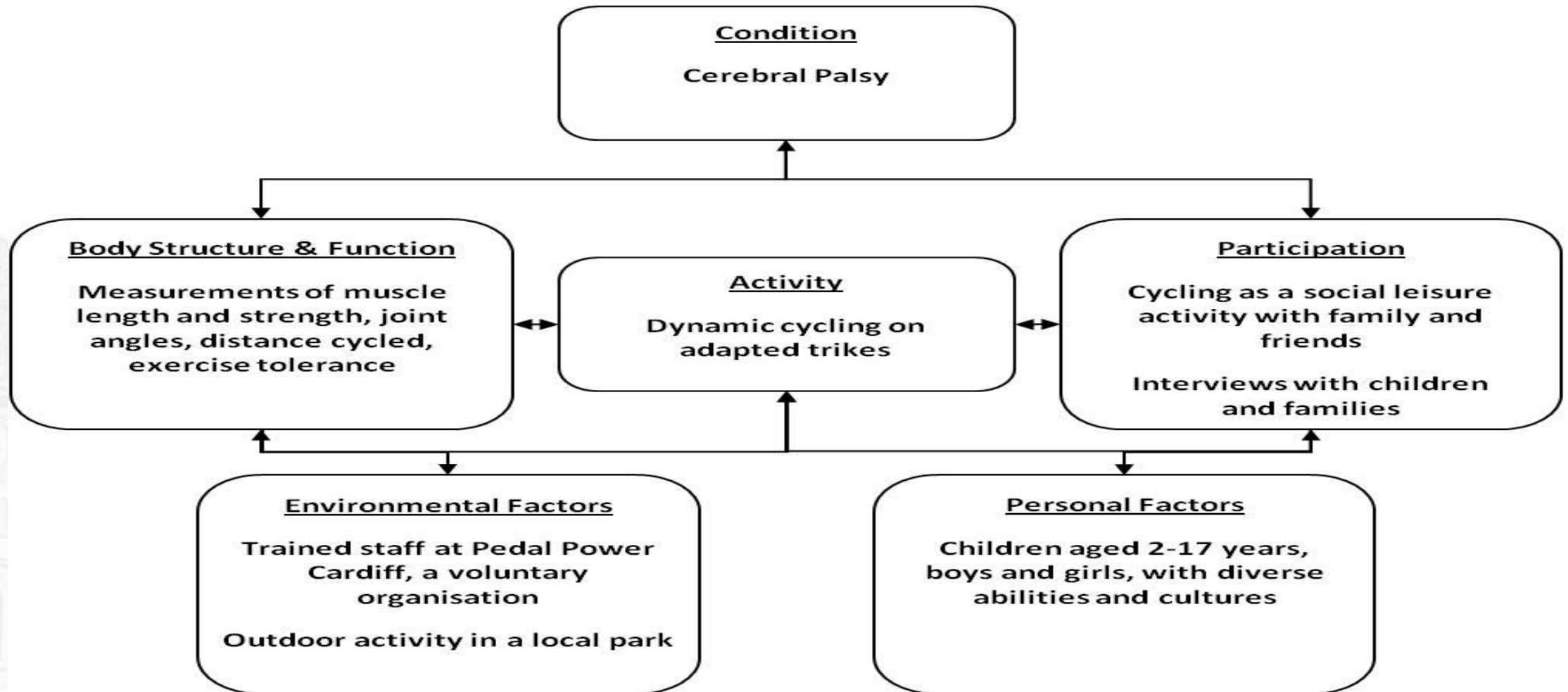
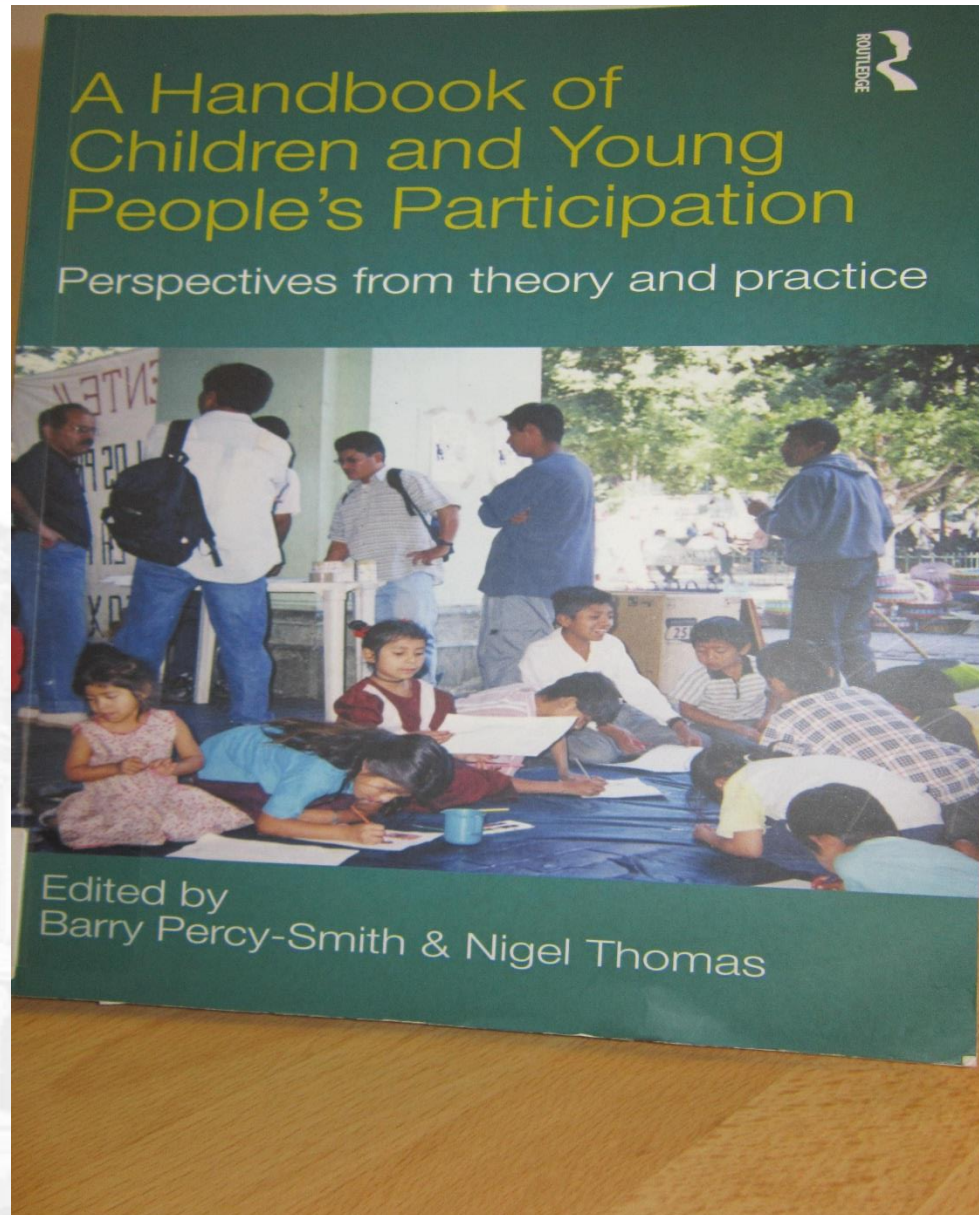
 E Cycles	 Hug Bike	 Hase Trikes	 Side-by-Side-Trike	 Two Wheel Bikes
 Trail and Large Size	 Kids Bikes	 Ice Trike	 Pashley Trike	 Kids Recumbent
				



Figure 1: Pedal Power Pilot Research Project adapted from the domains of the World Health Organisation: International Classification of Functioning





- “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

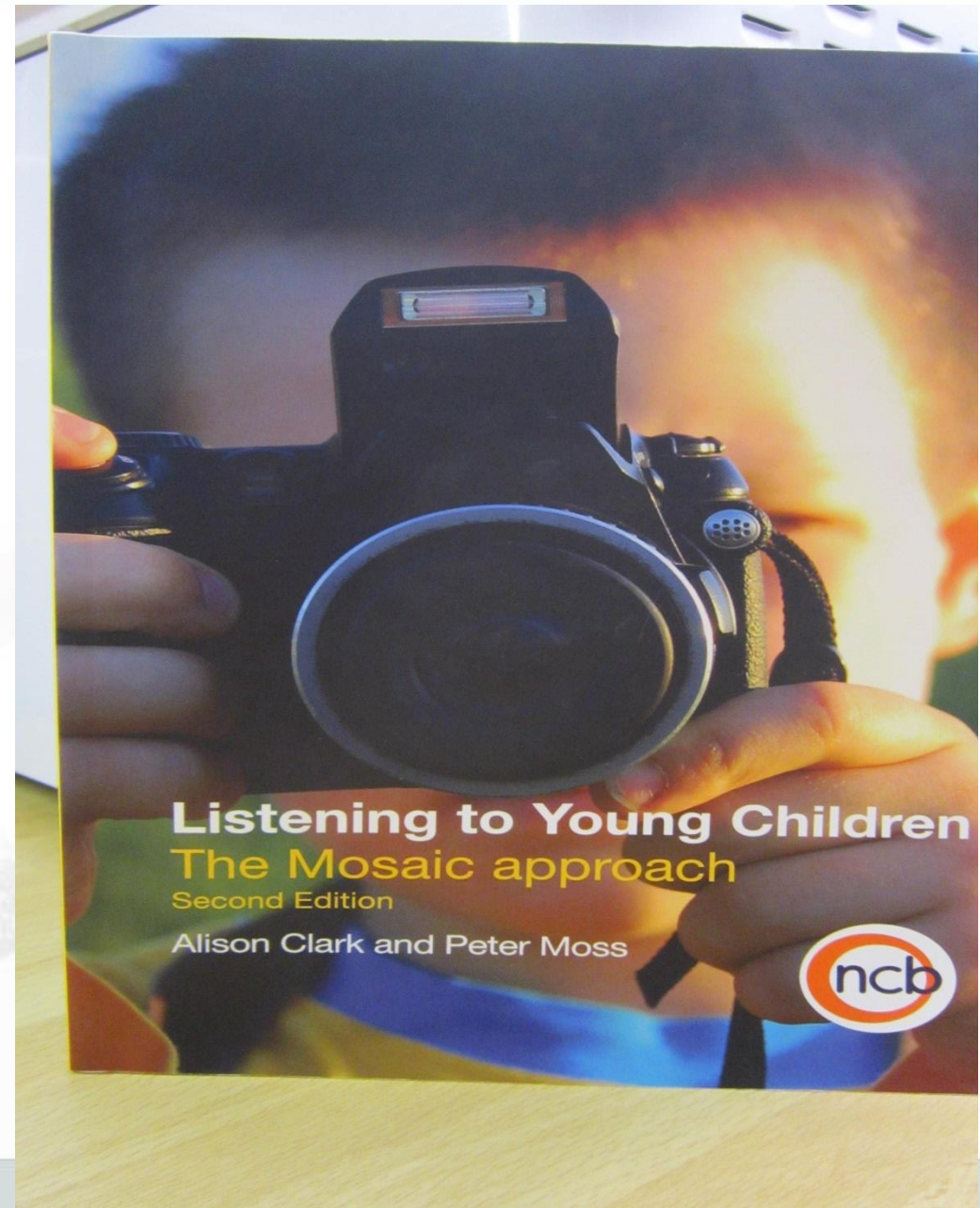
Research question

- ‘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

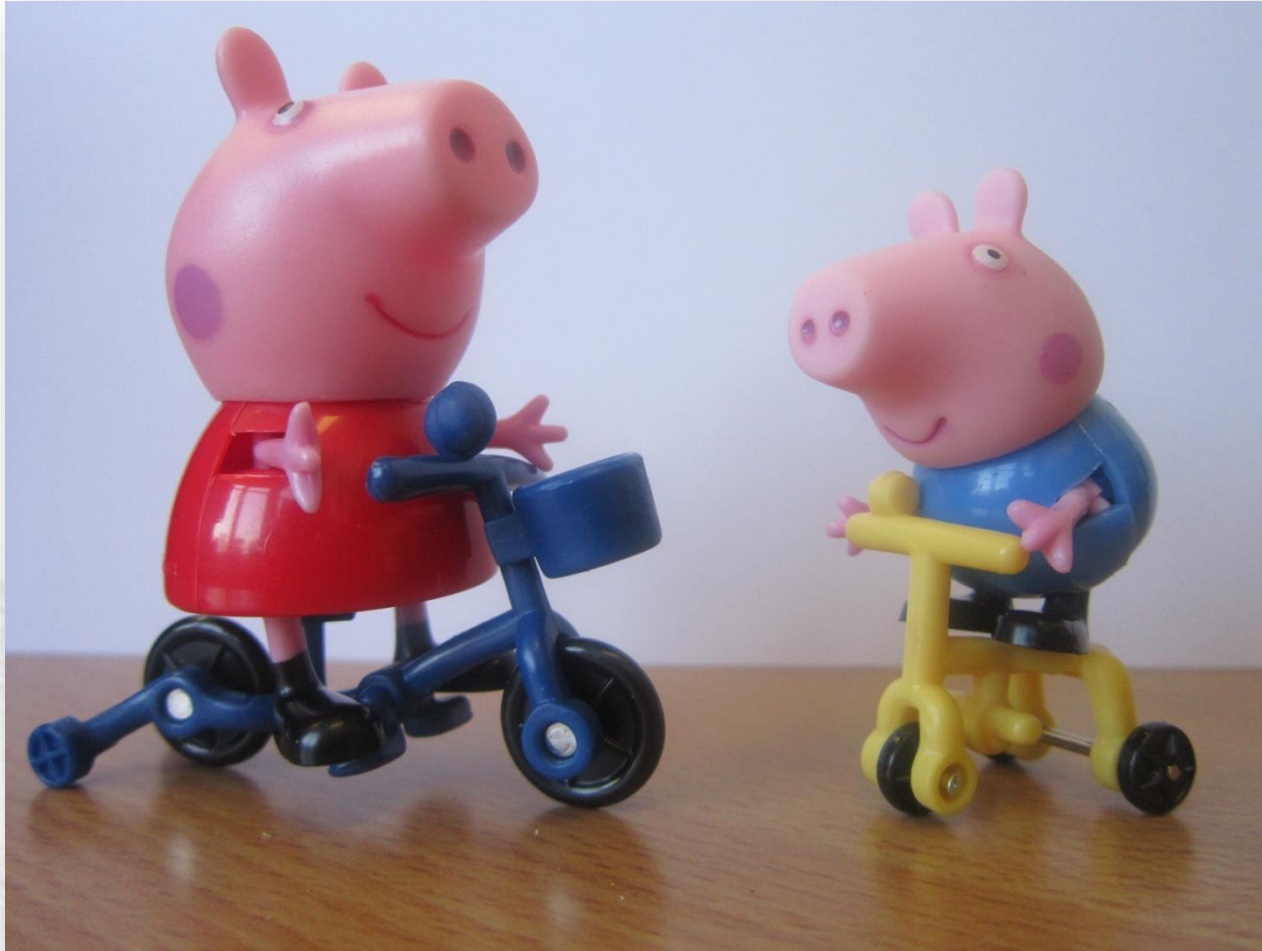




- We used a glove puppet to engage the child in measurements (muscle strength measure here) and also when doing the interviews- non-verbal children responded well to the puppet.



Story telling/ Use of toys e.g. Peppa pig goes cycling





- 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



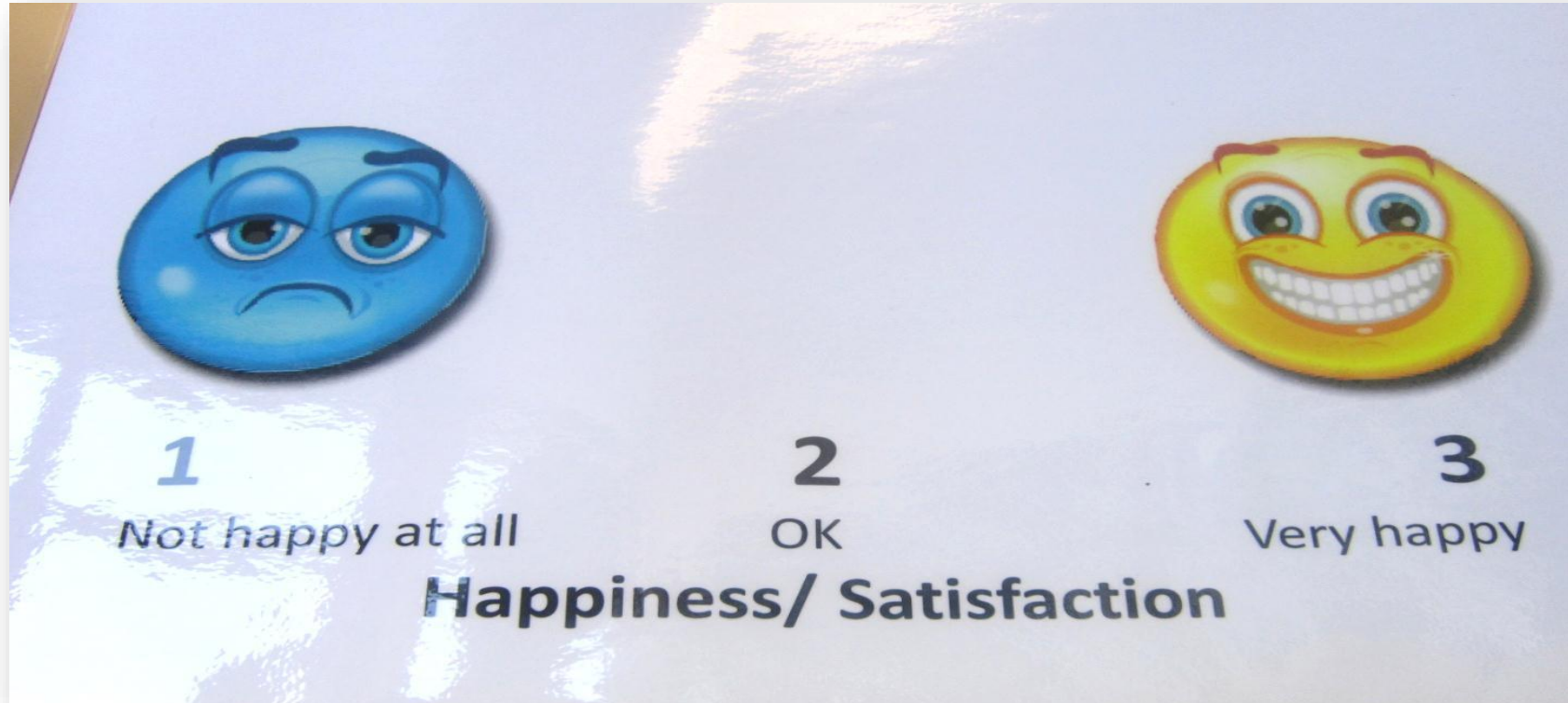
Charlie's champs



Courtesy of
John
Preston's
website

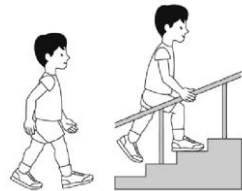


How did cycling make them feel?



- 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

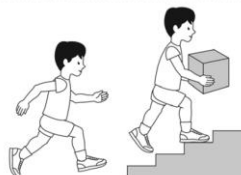


Peter's Mum: *"Gabriela put him on the Tom Cat trike, strapped his feet in and it was the first time ever he pedalled and he couldn't stop it. Everybody got so emotional, fantastic. It just shows if you've got the tools for the job, the right equipment, you can do it... This year we cycled from Bristol 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



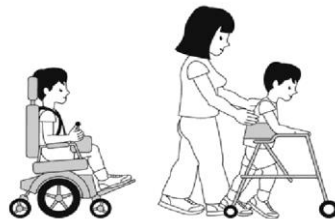
Children unable to self report

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

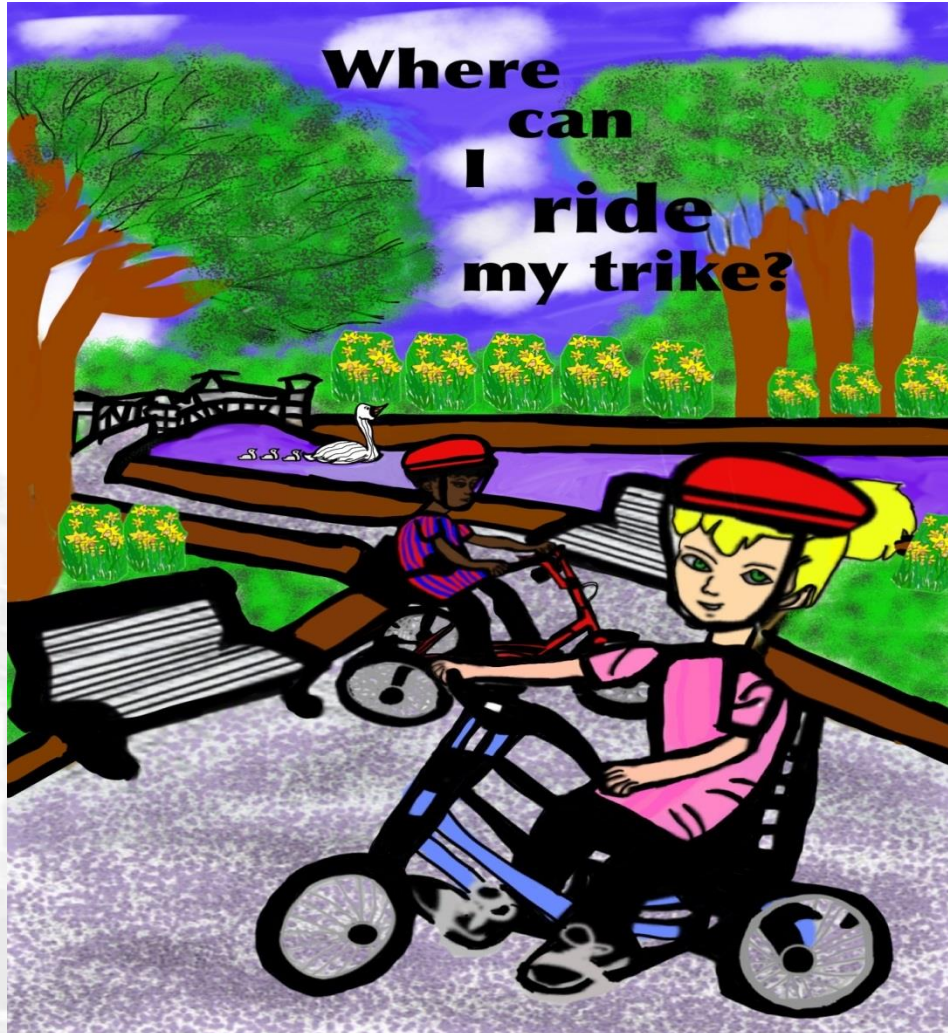
*“Throughout the cycling sessions I feel that **Rachel’s confidence has improved**. She is so happy when she is cycling and it gives her the **freedom and independence** she needs....”*



Change in cycling
activity
'Ghost' (aged 9
years)

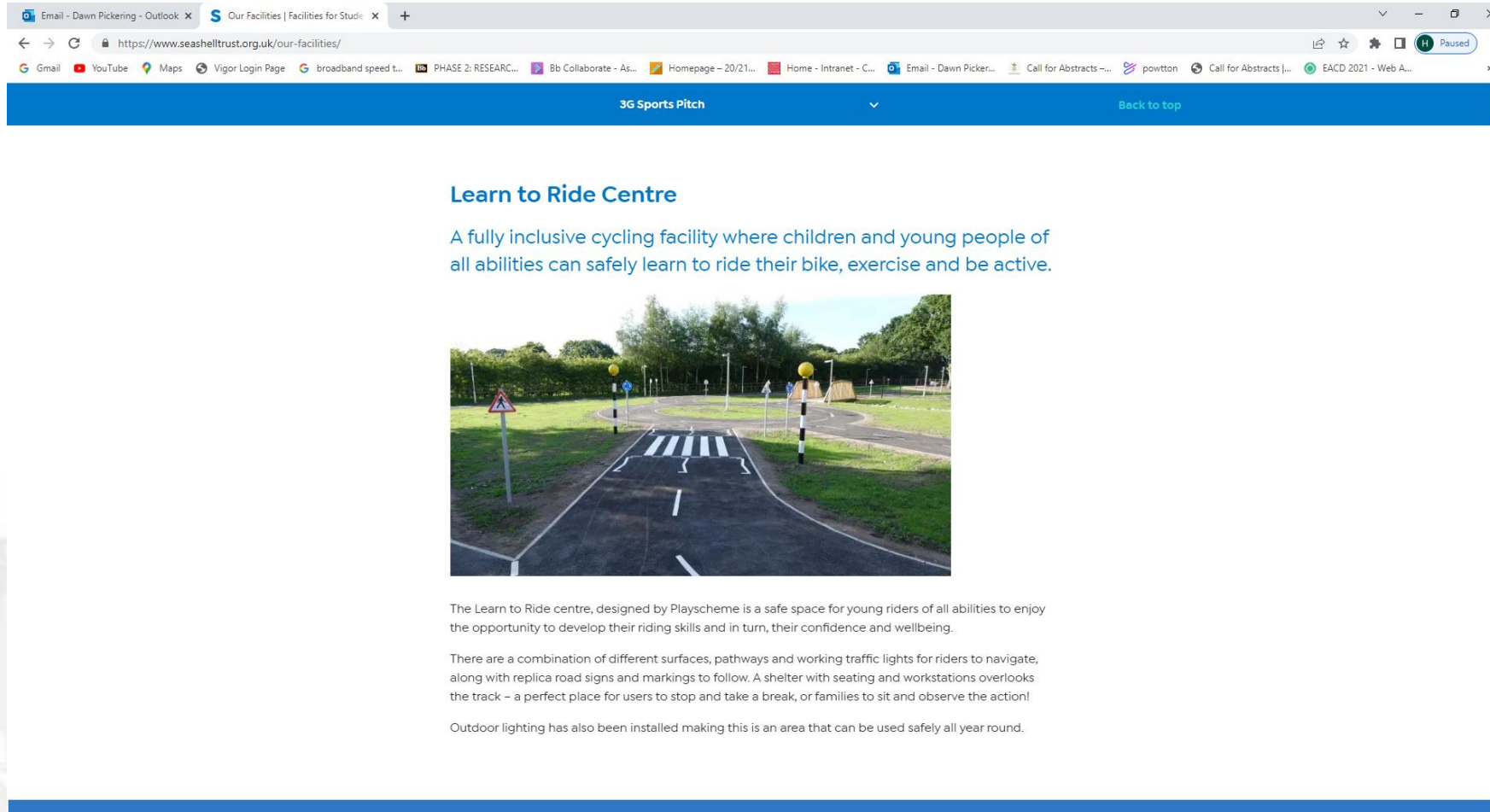
***“Didn't think he
would ever be able
to ride a bike”***

To/ Mrs D. Pickering,
thank-you for the feed back of [redacted]
every think 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 surprize.
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 [redacted]
Debbie and [redacted].



- Story inspired by the 35 children who took part
- Illustrated by Hannah Pickering






The screenshot shows a web browser window with the URL <https://www.seashelltrust.org.uk/our-facilities/>. The page has a blue header with the text "3G Sports Pitch" and a "Back to top" link. The main content area features the following text:

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 Playscheme 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 wellbeing.

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 is an area that can be used safely all year round.





The CSP Charitable Trust
Registered Charity No. 279882

Case Study design: Participatory group/ Limited participatory group; Cerebral Palsy aged 9-16 years, Levels III-V of the GMFCS

Based upon **Article 31** of the United Nations Convention on the Rights of the Child(1989)

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'



DigiCreate4u.com



- How do children and young people with cerebral palsy and their parents, view, experience and choose their level of participation in recreational activities?



2 interviews 12 weeks apart:

1st 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.

2nd 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*) by 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 Runnerand 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)



Sit ski

Surfing- Surfability - Caswell Bay (Gower) (Matthew)



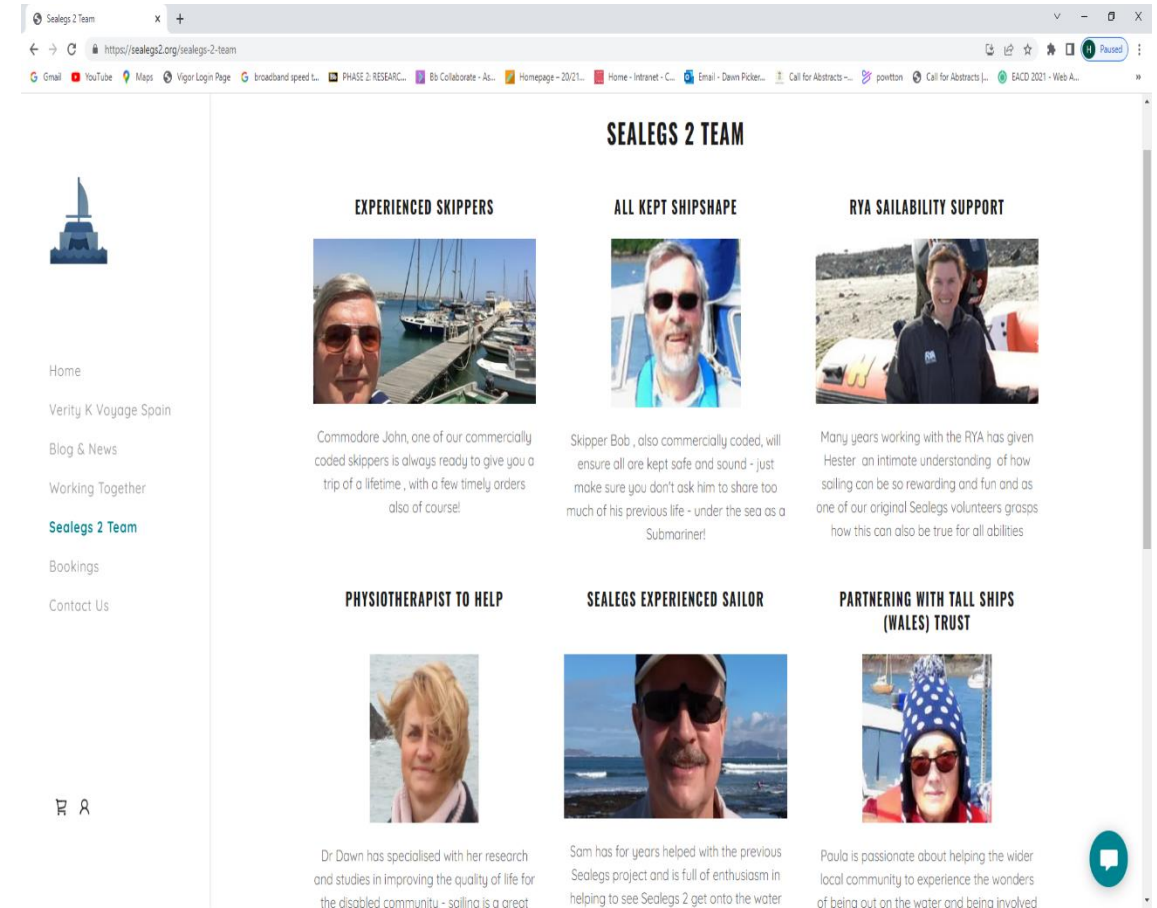
Uniformed clubs- Brownies/ Cubs (Bree/ Nick)









Sealegs2 association-Pembrokeshire

<https://sealegs2.org/>

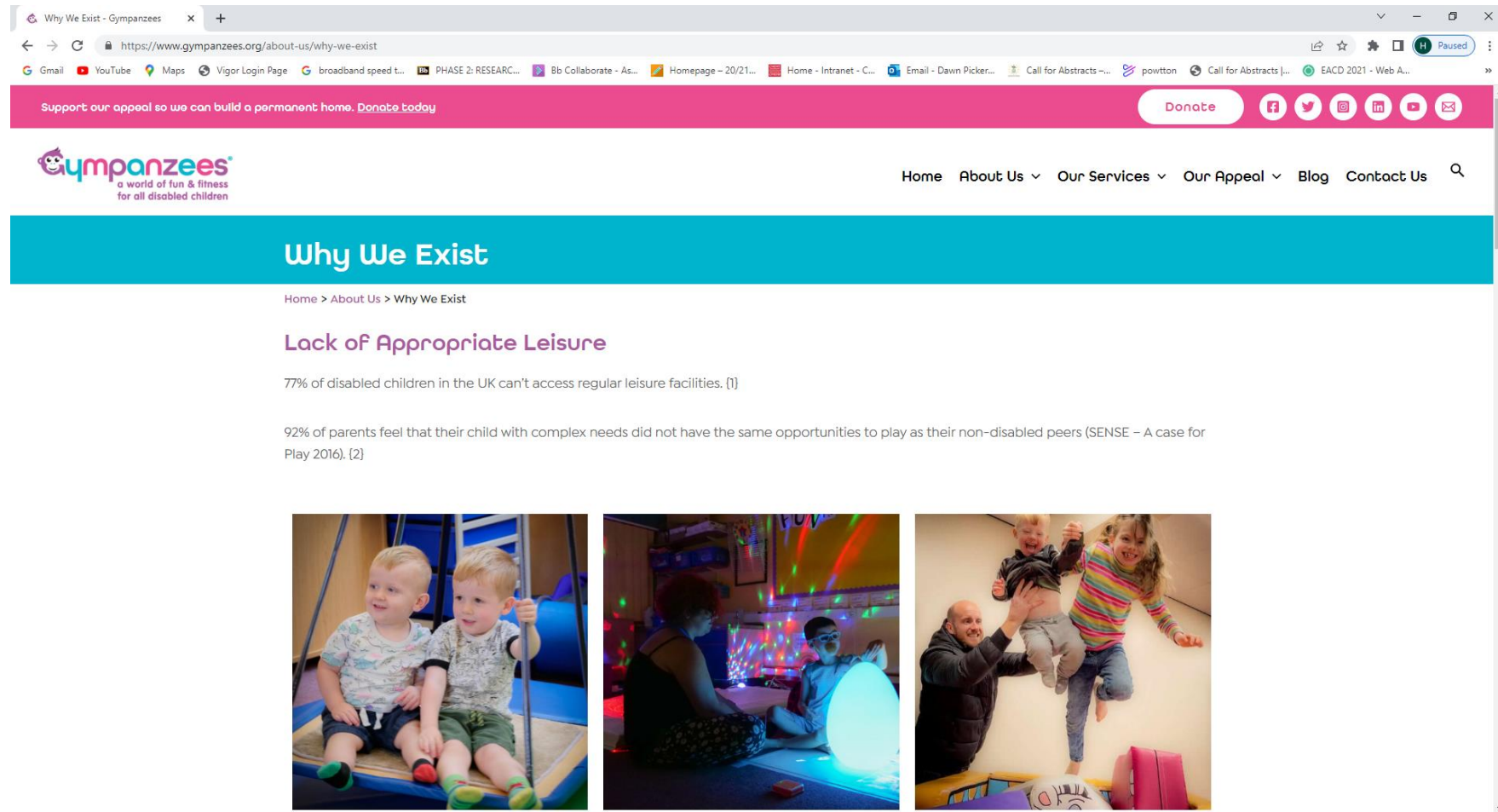
- Disability sailing experiences
- 2 boats- one wheelchair adapted



The screenshot shows the website for Sealegs 2 Team. The page features a navigation menu on the left with links to Home, Verity K Voyage Spain, Blog & News, Working Together, Sealegs 2 Team (highlighted), Bookings, and Contact Us. The main content area is titled "SEALEGS 2 TEAM" and displays six team members in a 2x3 grid. Each member has a photo and a short bio.

EXPERIENCED SKIPPERS	ALL KEPT SHIPSHAPE	RYA SAILABILITY SUPPORT
 <p>Commodore John, one of our commercially coded skippers is always ready to give you a trip of a lifetime, with a few timely orders also of course!</p>	 <p>Skipper Bob, also commercially coded, will ensure all are kept safe and sound - just make sure you don't ask him to share too much of his previous life - under the sea as a Submariner!</p>	 <p>Many years working with the RYA has given Hester an intimate understanding of how sailing can be so rewarding and fun and as one of our original Sealegs volunteers grasps how this can also be true for all abilities</p>
PHYSIOTHERAPIST TO HELP	SEALEGS EXPERIENCED SAILOR	PARTNERING WITH TALL SHIPS (WALES) TRUST
 <p>Dr Dawn has specialised with her research and studies in improving the quality of life for the disabled community - sailing is a great</p>	 <p>Sam has for years helped with the previous Sealegs project and is full of enthusiasm in helping to see Sealegs 2 get onto the water</p>	 <p>Paula is passionate about helping the wider local community to experience the wonders of being out on the water and being involved</p>

Gympanzees- pop-up leisure facility (Bristol)



The screenshot shows a web browser displaying the 'Why We Exist' page of the Gympanzees website. The browser's address bar shows the URL 'https://www.gympanzees.org/about-us/why-we-exist'. The website's header includes a pink navigation bar with a 'Donate' button and social media icons. Below the header is the Gympanzees logo, which reads 'a world of fun & fitness for all disabled children'. The main content area has a blue header with the title 'Why We Exist' and a breadcrumb trail 'Home > About Us > Why We Exist'. The text on the page states: 'Lack of Appropriate Leisure' followed by '77% of disabled children in the UK can't access regular leisure facilities. [1]' and '92% of parents feel that their child with complex needs did not have the same opportunities to play as their non-disabled peers (SENSE – A case for Play 2016). [2]'. At the bottom, there are three photographs: two young boys sitting on a blue play structure, a child sitting on a large glowing ball in a room with colorful lights, and a man holding a child up in the air while another child stands nearby.

Chamwell Centre- Gloucester

The screenshot shows a web browser window displaying the Chamwell Centre Gloucester website. The browser's address bar shows the URL <https://www.chamwellcentre.org.uk/facilities/adapted-sports-and-activities>. The website's header includes the Chamwell Centre logo with the tagline 'Overcoming disability in Gloucestershire', a navigation menu with links for HOME, OUR FACILITIES, ABOUT US, SUPPORT US, WHAT'S HAPPENING, and CONTACT US, and a pink 'DONATE' button. The main content area is titled 'Explore our Facilities' and features three cards:

- Hydrotherapy**: A photograph of a woman and a child in a pool. The text states: 'Specialist physiotherapists, qualified in aquatic therapy will prescribe and monitor programmes in the pool. Family members and carers will be offered training to support aquatic therapy and the use of changing facilities and hoists.' A pink 'DISCOVER MORE' button is at the bottom.
- Pied Piper Playground**: A photograph of a colorful playground with large, cone-shaped structures. The text states: 'The playground is suitable for all abilities. A sports area has been created for wheelchair rugby, football and basketball, in addition to Race Running. The improved campus layout enhances safety and access to the school.' A pink 'DISCOVER MORE' button is at the bottom.
- Interactive Climbing Wall**: A photograph of a person climbing a wall with illuminated holds. The text states: 'Accessible to all by overhead hoists or from wheelchairs and standers, the climbing wall hand and foot holds light up to lead users into exciting climbs and games.' A pink 'DISCOVER MORE' button is at the bottom.

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

Contact details: pickeringdm@cf.ac.uk

Twitter: @DawnMPickering

Questions/Comments

