

Pedal Power Final Report for Nancie Finnie Charitable Trust

Introduction:

This final report will summarise the findings of the three year funded study from the Pedal Power research team based in the School of Healthcare Studies at Cardiff University. The study was funded from May 2009 until April 2012. The objective was to explore this research question: **‘Does participation in adapted dynamic cycling affect lower limb muscle function, activity levels, and quality of life of children with Cerebral Palsy (CP)?’** We consider that adapted dynamic cycling does have an effect in a beneficial way for muscle strength and length. It increases activity levels for children and young people with CP, enabling their participation in the community. This improved their sense of ‘well being’ and contributes in a positive way to their enhanced quality of life. It will be illustrated by 2 individual anonymised cases, one case from the cycling group and one from those who had not started cycling. The dissemination achievements and future plans will be outlined and the strategy for further research in this area proposed.

Recruitment:

The cycling group were recruited as they participated in adapted cycling at Pedal Power, Cardiff. Seventeen children volunteered in this cycling group. Their involvement in the research study was over and above this cycling activity. This was an extra commitment on top of their already very busy lives. Recruitment for the control group was via 6 NHS Organisations in England and Wales and the voluntary sector. Organisations such as Contact a family, Scope, Bobath Children’s therapy centre for Wales and Cerebra all helped by advertising the research study through their networks. Eighteen children volunteered in this group.

Data Management:

The data has remained secure at Cardiff University and will be stored for a further two years in line with the University’s Data Protection Policy. The quantitative data was coded and analysed using SPSS 18. The qualitative data was managed with NVivo and children chose a pseudonym to protect their identity.

Data analysis:

Thirty five children were recruited in total; three children were not able to complete the study after volunteering. The first withdrew after the first data sets were collected. A second child became distressed and we could not gain consent for participation. The third child had previously developed a hip dislocation which meant participation in adapted cycling was not safe until this had been corrected surgically.

Quantitative Data: There were 32 complete sets of measurement data however all available data for all 35 participants were included in the final data analysis.

Participant Descriptive Results:

Table 1 presents the age ranges, means and standard (Std.) deviations for the children in each group: cycling group and control group. Cycling group ages ranged from 2 – 17 years while the control group ages ranged from 2 – 13 years.

Table 1: Age Descriptive Statistics

| AGE: | n | Minimum | Maximum | Mean | Std. Deviation |
|---------------|----|---------|---------|------|----------------|
| Cycling Group | 17 | 2 | 17 | 7.12 | 4.69 |
| Control Group | 18 | 2 | 13 | 7.67 | 3.41 |

Children were classified on the Gross Motor Function Classification Scale (GMFCS) to provide an indication of their motor functional abilities. The scale is rated from I – V with the most able-bodied child being at level I and the most severely limited in functional mobility, at level V. Both groups of children ranged from I – IV on the GMFCS, with no child being at level V. Table 2 presents GMFCS descriptive frequencies for each group.

Table 2: GMFCS Frequencies

| GMFCS: | Cycling Group (n=17) | Control Group (n=18) |
|--------|----------------------|----------------------|
| I | 4 | 3 |
| II | 4 | 8 |
| III | 2 | 4 |
| IV | 7 | 3 |

As can be seen from Table 2, the cycling group appear to be more limited in gross motor function ability when compared to the control group, as defined by the GMFCS. This seems to be further confirmed when comparing the mean strength measures at baseline (pre-intervention) for each group. The strength of the control group was markedly more at baseline than that of the cycling group and is demonstrated in Table 3.

Strength Measures:

Table 3: Baseline Mean Strength Measures and Standard (Std.) Deviations

| Group | (R) Quadriceps | (L) Quadriceps | (R) Hamstrings | (L) Hamstrings |
|---------------|-----------------------------|--------------------|--------------------|--------------------|
| Cycling Group | 39.73 Newtons (N) ±22.78 | 33.41 N ± 17.06 | 33.77 N ± 18.44 | 33.69 N ± 15 |
| Control Group | 60.56 N ± 30.03 | 59.74 N ± 34.57 | 45.16 ± 21.07 | 48.76 N ± 25.54 |

An independent T-Test tested each muscle group, to determine whether the differences between Quadriceps and Hamstrings at baseline, were significantly different between groups. There was no significant difference in Hamstring baseline measures between groups; however Quadriceps baseline measures were significantly different;

(R) Quadriceps: $t=-2.183$, $p=0.037$, (L) Quadriceps: $t= -2.731$, $p= 0.012$

Change scores between baseline measures and post intervention measures, within each group, were calculated to look for differences between variables within groups.

Table 4 and Table 5 present mean strength change scores for Quadriceps and Hamstrings in both groups respectively. There appears to be a trend for the cycling group to have increased in strength while the control group decreased in strength.

Table 4: Quadriceps Strength Changes

| | Right (R) Leg | Std. Deviation | Left (L) Leg | Std. Deviation |
|---------------|----------------------|----------------|---------------------|----------------|
| Cycling Group | Increased by 12.14 N | ± 6.5 | Increased by 15.6 N | ± 13.87 |
| Control Group | Decreased by 3.62 N | ± 4.73 | Decreased by 0.14 N | ± 1.4 |

Table 5: Hamstring Strength Changes

| | (R) Leg | Std. Deviation | (L) Leg | Std. Deviation |
|---------------|---------------------|----------------|---------------------|----------------|
| Cycling Group | Increased by 5.19 N | ± 3.5 | Increased by 4.23 N | ± 5.94 |
| Control Group | Decreased by 1.03 N | ± 006 | Decreased by 1.05 N | ± 3.05 |

Popliteal Angle (PA) Measures:

Bilateral PA measures, as a measure of Hamstring muscle length, were taken before and after the intervention period (Table 6).

Table 6: Baseline and Post-Intervention Mean Bilateral PA measures for both groups.

| Groups | (R) Baseline | (R) Post-Intervention | (L) Baseline | (L) Post-Intervention |
|---------------|-------------------|-----------------------|-------------------|-----------------------|
| Cycling Group | 44.87° ± 14.47 | 44.21° ± 9.95 | 39.64° ± 13.57 | 42.2° ± 10.32 |
| Control Group | 50.53° ±9.06 | 49.57° ±10.64 | 49.14° ±12.72 | 46.73° ±11.83 |

An unpaired samples T-Test revealed no significant difference between group baseline PA measures (R: $t = -1.220$, $p = 0.233$; L: $t = -1.911$, $p = 0.067$). As can be seen from Table 6, the cycling group reduced PA by 0.66° on the right and increased by 2.36° on the left; while the control group decreased by 0.96° on the right and by 2.41° on the left.

These few degrees are unlikely to be clinically relevant or significant. Research evidence suggests that the Hamstring muscles are shortened if the PA is $\geq 50^\circ$. Both groups are close to this with the control group hamstrings appearing shorter than the cycling group.

Inferential results: Testing for differences between before and after measurements between groups and within groups for each variable

For those variables where group baseline measures were not significantly different (Hamstring strength and PA measures) a repeated measures ANOVA was carried out, significance level $p < 0.05$. Results demonstrated no significant difference in bilateral PA measures or hamstring strength changes between groups.

(R) PA: $t = -0.335$, $p = 0.741$; (L) PA $t = -1.109$, $p = 0.279$

(R) Hamstrings: $t = -.218$, $p = 0.830$; (L) Hamstrings: $t = -.212$, $p = 0.834$

For those variables where group baseline measures were significantly different (Quadriceps strength) an ANCOVA was carried out. The ANCOVA looks for difference in post intervention measures, taking into consideration differences in baseline (pre-intervention) measures; averaging baseline measures for both groups. Results demonstrated no significant difference between groups; (R) Quadriceps: $p = 0.088$, $f = 3.15$; (L) Quadriceps: $p = 0.079$, $f = 3.364$.

Despite a lack of significant changes in strength between the groups, ANCOVA analysis demonstrated an overall, similar and interesting trend in strength changes, as previously noted. With ANCOVA, both groups' averaged baseline measures for (R) Quadriceps was 52.16 N. The cycling group then increased from 52.16 N to 61.70 N, while the control group decreased from 52.16 N to 50.51 N. Both groups' averaged baseline measures for (L) Quadriceps was 48.83 N. The cycling group then increased from 48.83 N to 64.92 N, while the control group increased by only 0.33N, from 48.83 N to 49.16 N. Therefore, the cycling group (R) quadriceps appears to have got stronger while the control group (R) quadriceps got weaker, over the intervention period. Similarly, the cycling group (L) Quadriceps got stronger while the control group (L) quadriceps increased minimally (0.33N).

Testing for differences between before and after strength measurements within groups

Changes in quadriceps and hamstring strength were also analysed within groups using the paired samples t test, significance level $p < 0.05$ (data being normally distributed in histograms). Bilateral quadriceps changes in the cycling group were significant, while all other strength changes for both groups were not. Table 7 illustrates strength change significance levels for each group.

Table 7:

| Strength Changes | Cycling Group | Control Group |
|------------------------|-----------------------|-----------------------|
| (R) Quadriceps Changes | p=0.03 (t= -2.420) | p=0.72 (t= 0.358) |
| (L) Quadriceps Changes | p=0.04 (t= -2.382) | p=0.90 (t= -0.120) |
| (R) Hamstring Changes | p=0.30 (t= -0.968) | p=0.47 (t= -0.744) |
| (L) Hamstring Changes | p=0.49 (t= -0.711) | p=0.8 (t= -0.222) |

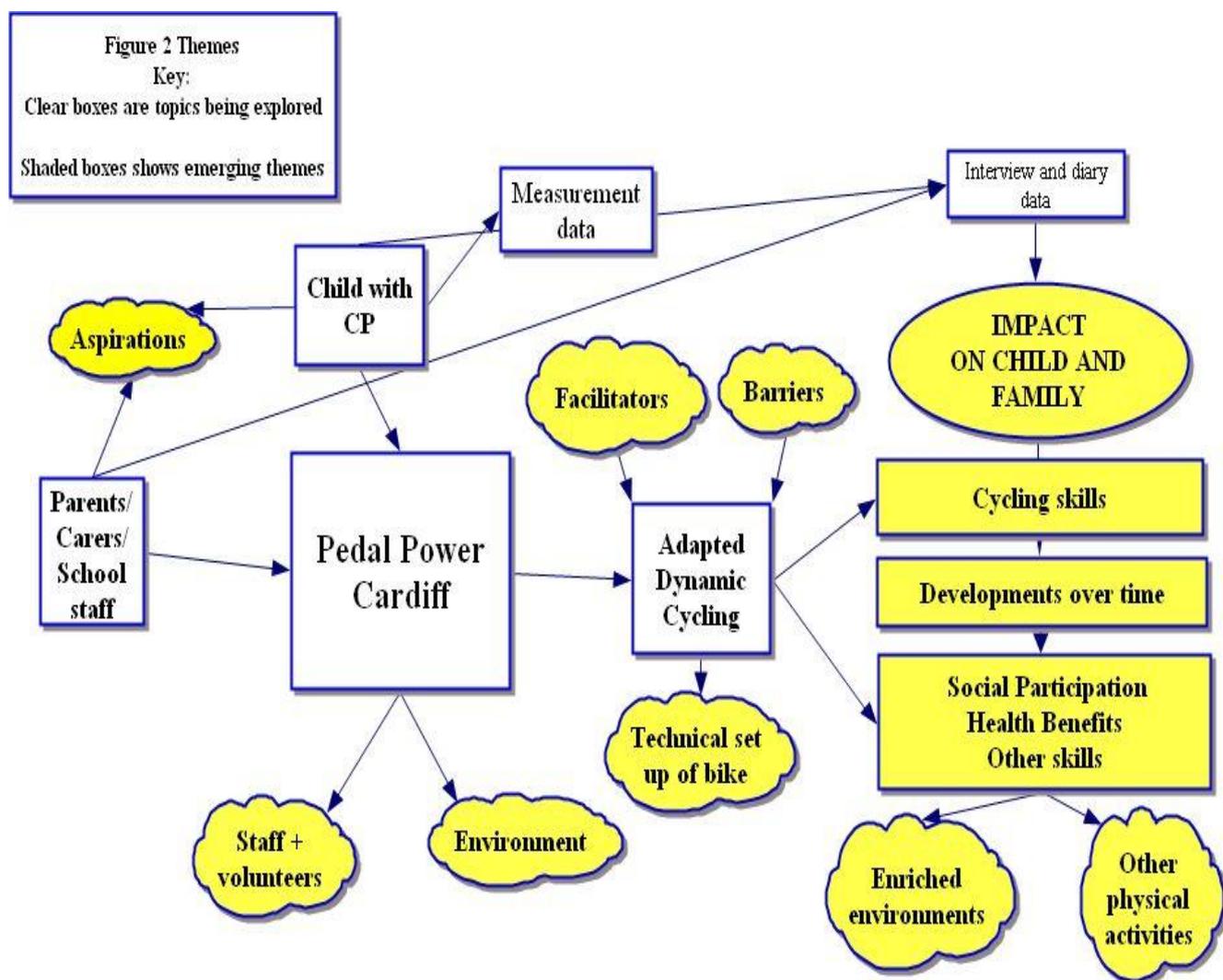
Cycling Measurements:

Cycling pedometers and heart rate monitors were applied to cycles and children where possible. Unfortunately, the heart rate monitors proved fairly invasive for the children, when on a fun outing in a social setting, as these had to be placed under the clothes next to the skin. Consequently many children did not wear them. Further the cycle pedometers were manufactured for traditional two wheel cycles and inventive ways had to be found to apply them to trikes with special adaptations. As a consequence of the fact that the pedometers and their accessories were not manufactured to be applied to adapted trikes, many potential cycle recordings were not able to be obtained. For the future, quick, easy to use tools that can be reliably applied and are

robust in nature should be used to obtain reliable cycling data when using adapted trikes.

Qualitative Data:

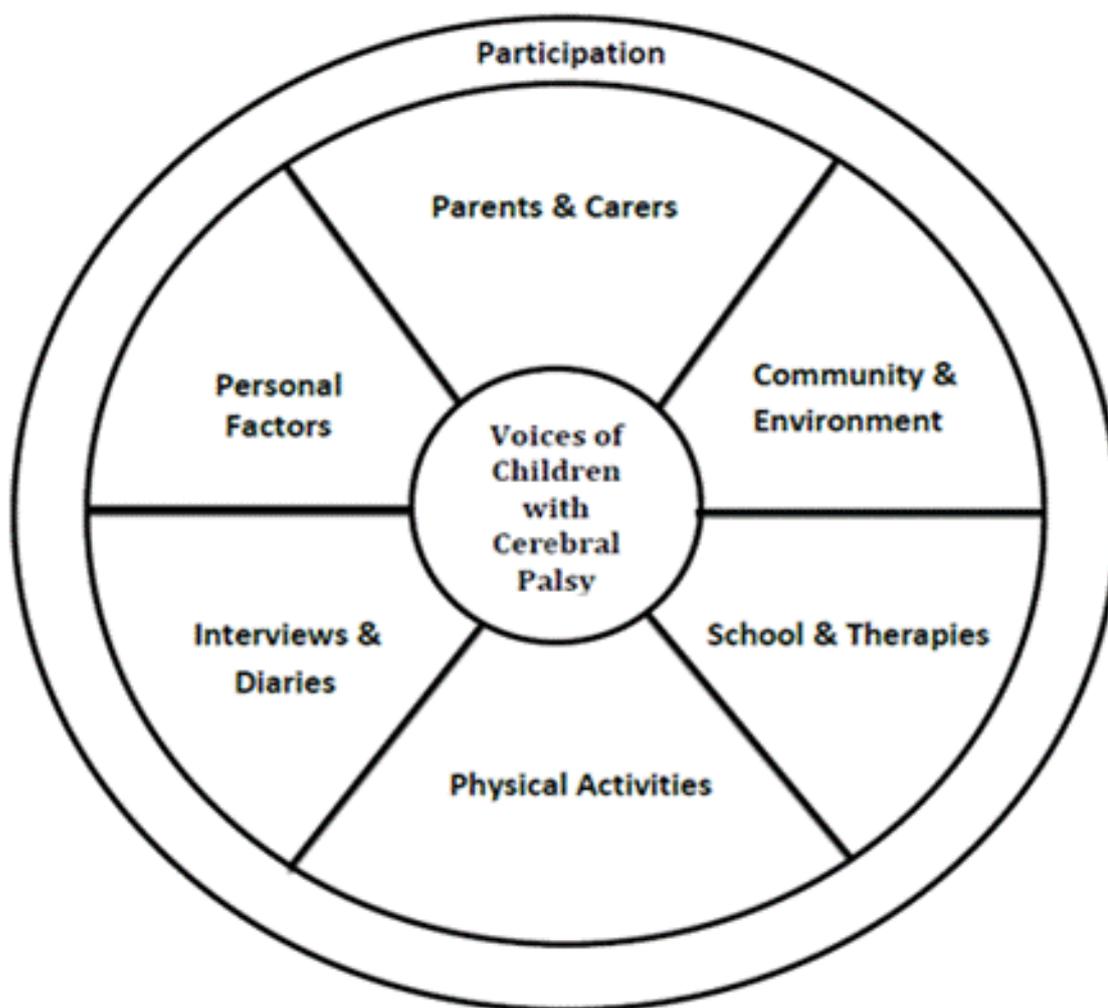
In total the 35 children data sets resulted in 43 interviews and 23 diaries. The cycling group's data had been analysed and aspects have been published from this in Disability and Rehabilitation: Assistive Technology. The illustration of the themes which emerged, are shown in the figure below in yellow:



It was very clear that the children learnt cycling skills in terms of speed and control of the bike. The need for an assessment and technical bike set up was evident from the interview and diary data. Their confidence and social participation were additional benefits that demonstrated their sense of 'well

being'. The access to an affordable adapted cycle hire facility was key to their achievements.

The control group's thematic analysis was completed in August 2012 prior to the retirement of Lyn Horrocks. The themes which emerged from this analysis show the wider participation of physical activities of children and young people with Cerebral Palsy. These have been illustrated in a 'wheel' to show the relationship of wider influences that impact on participation. We would aim to enable the children's 'voices' to be heard to a wider audience. The "wheel" is illustrated in the figure below.



Wheel to represent thematic analysis phase 2

The plan for publishing these findings is to explore Qualitative research journals such as Children and Society and Qualitative Health Research. We consider we have gained a unique perspective from children and young people with CP about their participation in physical activities. A factor that was described here relates to 'fatigue' and this requires deeper exploration to

understand the balance between activity and rest, to maximise performance and function.

The children and young people have been sent their individual reports with the option to comment on their results and be involved in a consultation event to explore future research ideas. An anonymised sample of these is provided at the end of this document in Appendix 1. As the children in the non cycling group had got weaker we did not want to emphasise this in the results sent back to them, so a positive slant was given on 'no change' in their hamstring muscle length measures.

Limitations:

Whilst the data did not show statistical significance, it still has clinical relevance. The numbers were low to achieve statistical significance, therefore if a larger sample size had been used, this may have been achieved. The children who cycled did get stronger in their quadriceps, whilst those who did not cycle, got weaker or increased very little. It is therefore logical to suggest that if specific muscles are targeted in an activity that muscle strength changes can be achieved. Six sessions is a relatively low number; however muscle strength changes were detected. This could be done over a longer period to see if these are maintained.

The hamstring length did not change in either group between the 6 sessions/weeks; this requires further exploration over a longer period. This short time period would not account for growth, so any achievements from cycling to maintain the length might be counteracted by a growth spurt.

Conference presentations since last report:

Health Enhancing Physical Activity (HEPA) 8th European Symposium, Cardiff, September 2012- Getting to the grass roots- using the 'green' environment to promote physical activity. Karen Visser and Gabriela Todd: Free paper: **'Young people with cerebral palsy's experiences of adapted dynamic cycling.'**

Association of Paediatric Chartered Physiotherapists Conference London, 2012 Pickering DM, Horrocks LM, Visser KS and Todd GL. Free paper **'Participation in adapted dynamic cycling- children and young people with Cerebral Palsy's experiences- a work in progress'**

Publications:

Visser et al, 2012 **'Pedal power pilot study: adapted dynamic cycling for children with cerebral palsy'** *Clinical Rehabilitation* 2012 26(3) 280–287 DOI: 10.1177/0269215511425764.

Pickering DM, Horrocks LM, Visser KS and Todd GL (2012) **Adapted Bikes- what children and young people with cerebral palsy told us about their**

participation in adapted dynamic cycling *Disability and Rehabilitation: Assistive Technology*, Early Online 1-8 © Informa UK,Ltd (26th April 2012)

'The transition from practitioner to researcher: physiotherapists undertaking research with disabled children' Chapter 10 Pickering DM, Horrocks LM, Visser KS and Todd GL in Fleming J and Boeck T(Ed.s) 'Involving children and young people in Health and Social care research' 2012 by Routledge.

Papers out for review:

'Every picture tells a story' Interviews with children with cerebral palsy about adapted cycling. Pickering et al, Australian Journal of Paediatrics and Child Health submitted Nov 2012

Abstracts submitted pending a decision:

Physiotherapy Research Society, Cardiff, April 2013: Free paper **'Children and Young People Participation in Adapted Dynamic Cycling: A Pilot Study'**

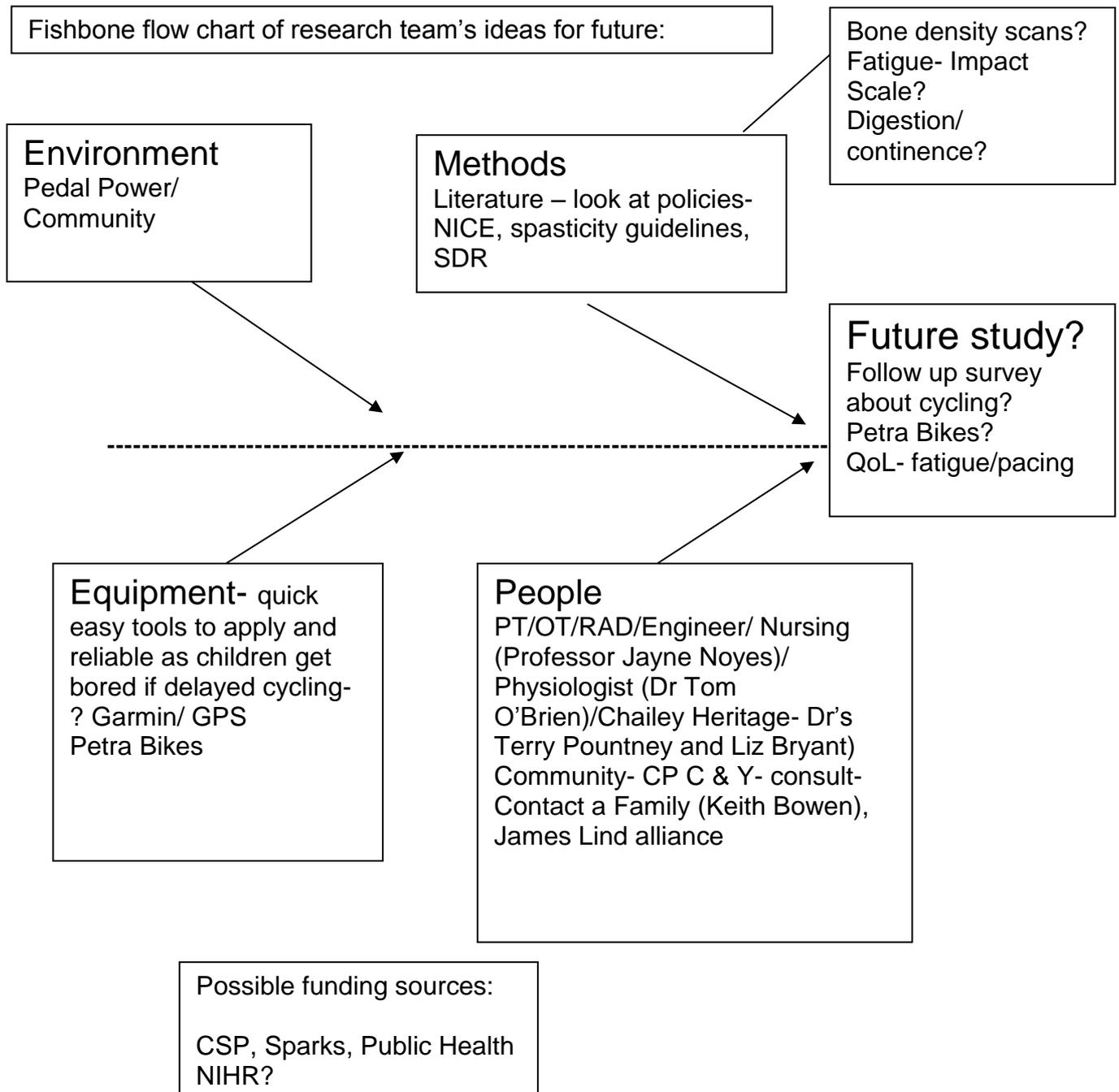
British Association of Childhood Disability, Birmingham, March 2013. Poster **'Children with Cerebral Palsy's participation in physical activities, including adapted cycling: interview and diary data'**

Future presentations:

The UK Disabled Children's research network is to be held in Newcastle in June 2013 with a theme of 'Citizenship'. Dawn Pickering will present some case studies from the research data entitled: **'Social participatory benefits of adapted dynamic cycling: voices from Children and Youth with Cerebral Palsy'**.

Where next?

The research team carried out an exercise to explore where this research could develop in the future. This is illustrated below in the fishbone flow chart. As the participants respond to their personal results, we aim to carry out a consultation event with families, children and young people. The aim of this would be to explore further research into aspects of participation that they feel are important. This will then be combined with the team's ideas to explore research funding streams to secure further funding. As we acknowledge that the Nancie Finnie Charitable trust is being taken over by the Chartered Society of Physiotherapy this will be one source that will be pursued.



Acknowledgments:

Dawn Pickering

We would like to thank the trustees of the Nancie Finnie Charitable Trust for investing in this study. The experience we have been through has taught us so much and we hope that the families have benefitted from their participation. We acknowledge that we need to understand more about Cerebral Palsy, but aim to contribute towards the knowledge about factors which affect 'participation'. We would aim to increase participation opportunities to enable these children and young people to be valued as citizens in our society.

Appendix 1 Information sent to individual families

January 2013

Dear Parents, Children and Young People,

Re: Pedal Power research study

Thank you for participating in this research study. I am pleased to enclose your individual report from the findings. It may have been a long time for some of you since you last heard from us; we started the study in May 2009 and completed our data collection in May 2012. It has taken us a while to analyse the complete data but we now have the full results.

We have enjoyed this opportunity to explore the research question we set out to investigate: **'Does participation in adapted dynamic cycling affect lower limb muscle function, activity levels, and quality of life of children with Cerebral Palsy?'** We consider we have some answers outlined below, but you are the best judge of the impact of such an opportunity on your quality of life.

Thirty five children and young people volunteered to take part, seventeen in the cycling group and eighteen in the group who had not started cycling. Some of the data was not complete but we have reported all that we found. Those in the cycling group developed stronger muscles in their thighs; the Hamstring muscle length did not change. Many of you were physically active and many of you really enjoyed the cycling experience. For some there were factors that needed to be overcome, in order to achieve regular successful cycling. A few individuals did not like cycling but did other enjoyable activities. The opportunity to participate in community activities was beneficial for all, from a social development perspective.

Some of you have already expressed an interest in participating in a follow up study should we secure further funding. Once you have read your individual report, if you would like to complete the sheet overleaf where you can add comments then you could return this to me in the enclosed stamped addressed envelope. Alternatively, please feel free to email or telephone me.

Thank you again for your participation,

Dawn Pickering

Nancie Finnie Final Report February 2013

Dawn Pickering

Principal Investigator: Dawn Pickering (pickeringdm@cf.ac.uk, Tel 02920 687741), Karen Visser, Lyn Horrocks and Gabriela Todd (Research team)

Dawn Pickering

Comments on Pedal Power data results

Name of participant

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Email address for future correspondence:

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Comments:

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We would be interested in a follow up study or future study
.....Yes/No

**Would you be interested in attending an event to explore future research
with Cerebral Palsy children and young people?**

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Cardiff Pedal
Power

Pedal Power Pilot Study:

This study included 35 children with Cerebral Palsy: 17 children who participated in regular cycling sessions at Pedal Power; and 18 children who had not yet participated in cycling. Families, children and young people with Cerebral Palsy helped us find out about participation in cycling and other physical activities, as well as about potential changes to lower limb muscle strength and length.

Why did we do the study?

Participation in leisure and recreation activities is fun and a way of interacting with family and friends in the community, as well as staying fit and healthy. Cycling is a fun recreational activity that can increase fitness and has the potential to affect lower limb muscle length and strength. Children and young people with Cerebral Palsy may have difficulty accessing cycling activities, find it difficult to move, and can have problems increasing or maintaining muscle length and strength. Our purpose was to learn more about the effects of cycling on muscle length and strength and about participation in cycling and other physical activities, for children and young people with Cerebral Palsy.

How was the information gathered?

Families, children and young people completed two interviews, before and after participating in 6 cycling sessions at Pedal Power; while those who did not cycle completed one interview. Diaries were kept of cycling and other physical activities. Quadriceps and Hamstring (thigh) muscle strength in both legs was measured using a "Hand-held Dynamometer". This measured the force the muscles produced when moving the leg against the physiotherapist's resistance as they held the hand-held dynamometer. Hamstring muscle length was measured by placing markers on 3 bony points

on the leg, and then the knee was straightened as far as possible, while children and young people lay on their back. This was video recorded and the knee angles measured using a computer package called "Silicon Coach".

What did we learn?

Adapted cycling requires a thorough assessment of needs, suitable equipment and technical expertise at every cycling opportunity. This allows children, young people and families to enjoy participating in a recreational activity in the community. Participation in adapted dynamic cycling allows the learning of new skills that encourage independence, for example: controlling speed of cycling, steering and self-perception within the outdoor environment. Overall, those who participated in cycling got stronger, while there was little change in the group that did not cycle. Those who cycled had a significant increase in their quadriceps strength. All children maintained their hamstring muscle length.

Where do we go from here?

We would like to gain a better understanding of the factors that affect families, children and young people with Cerebral Palsy, regarding their participating in regular physical activities; including cycling. We are keen to consult with you and all the families, children and young people about future research ideas in this area. If you wish to be involved, please do fill out the enclosed document and return it in the stamped, addressed envelope (provided).

Sample Case study 1: Cycling group

Phase 1 children feedback. There were 17 children who took part between May 2009 and November 2011. Some of you chose alternate names, if not, we chose one for you- these are written after your own name in brackets. If we publish or present your quotes, this is the name we will use. Any actual quotes are written in *'italics'*.

'Andrew' aged 17 years

When you and your Dad took part in an interview with us, you told us that you did the following physical activities:

Used to go swimming, now bowling, listen to music on i pod, doing cleaning and recycling at school, hoping to go to college. Went on an activity weekend in West Wales, did swimming and quad bikes.

In your diary we learnt about your cycling:

You rode a recumbent trike and cycled with your Dad, the school staff and you progressed to cycling with a carer. You book the trike hire on your own mobile phone. Your control of the gears improved and you no longer needed the footplates. You were able to go up and down ramps and slopes. You learnt to control the speed of the trike on different terrains, keeping both feet on the pedals, controlling the brake and keeping to the left. You achieved cycling independently and took part in a sponsored cycle ride where you won a medal.

There was one activity that you told us about that no one else in the study did:

Changed gears with your trike

Your muscle strength improved and you did really well to achieve so much with your cycling. We hope you continue to enjoy physical activities in order to stay happy and healthy.

Please contact Pedal Power should you wish to review your cycling progress. Contact: Gabriela Todd Tel: 07594 554 158, Email:gabriela.todd@cardiffpedalpower.org

'Andrew'



Following 6 cycling sessions your right Quadriceps muscle strength had increased by 100% and your left by 50%.

Right Quadriceps:

Strength *before* cycling = 30.8 Newtons
Strength *after* cycling = 70.4 Newtons
You could straighten your knee with a force of over 7 kilograms

Left Quadriceps:

Strength *before* cycling = 44 Newtons
Strength *after* cycling = 66 Newtons
You could straighten your knee with a force of over 6 kilograms

Your Left Hamstring muscle strength increased by 43% and your Right Hamstring muscle strength remained unchanged

Left Hamstrings:

Strength *before* cycling = 44 Newtons
Strength *after* cycling = 63.8 Newtons
You could straighten your knee with a force of over 6 kilograms

Right Hamstrings:

Strength *before* cycling = 63.8 Newtons
Strength *after* cycling = 63.8 Newtons
You could straighten your knee with a force of over 6 kilograms

Sample Case study 2: Non cycling group

Phase 2 children feedback. There were 18 children who took part between December 2010 and May 2012. Some of you chose alternate names, if not, we chose one for you- these are written after your own name in brackets. If we publish or present or your quotes this is the name we will use.

'Ghost'- aged 10 years

When you did an interview with us you told us that you did the following physical activities:

Fairground rides but joining in with these was limited by your CP, football, swimming, walking short distances, Adventure Park - climbing, walk to school and physio exercises.

You told us '*you have to keep stopping for rests*' after any activity.

You described doing regular exercises at school in the early morning, but you were bored with these after 2 years.

In your diary to told us about:

Your mum wrote in this, in your own words, you also drew some robot and football pictures. You described your legs as '*killing you*' and having to stop after walking short distances as you get '*leg cramps*'. You described being in your wheelchair when your legs are cold or tired but not liking being different from other children who '*stare at me*'.

There was one activity that you told us about that no one else in the study did:

Lazer Tag

In terms of cycling you:

You were thinking about a tag along bike for your Dad's bike. Your mum wrote to me after the study had ended to tell me you were now cycling to school.

What an amazing achievement, well done. Keeping up a range of physical activities is likely to help maintain your muscle strength and length.

'Ghost'



This is a picture of you having your hamstring muscles (back of the thigh) stretched. The stretch was video recorded and the video placed into the computer software package Silicon Coach. The software package Silicon Coach helped us measure how far you could straighten your knee (the knee popliteal angle). We did this on two occasions to see whether your hamstring muscles got shorter.

**YOUR KNEE MUSCLES STAYED LONG
AND DID NOT GET SHORTER!**

**YOU ALSO SAT ON A BENCH AND STRAIGHTENED YOUR KNEES
AND BENT THEM AS STRONGLY AS YOU COULD, WHILE WE
MEASURED HOW STRONGLY YOU COULD DO THIS, WITH OUR
HAND-HELD MUSCLE STRENGTH MEASURING MACHINE!**