Social participatory benefits of adapted dynamic cycling: voices from children and youth with Cerebral Palsy

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Background

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

Choice of activities limited—requires some adaptation and support

• 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 6th and 12th 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.

Palisano et al, 1997; Reid et al, 2011
Adapted bikes

- Cost
- Charity Funding
- Trike Hire opportunities limited
Context for 3 year pilot study (2009-2012)
Cycle route
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

3 year study Funded by Nancie Finnie Charitable Trust
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 (travelled up to 50 miles to access this hire facility)

• 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
Block printing

- Many children could not press hard enough to make an impression with the block
Puppets

• We used a glove puppet to engage the child in measurement and also when doing the interview- non verbal children responded well to the puppet
Games

Picture matching

- Some children enjoyed participating in this game and talking about their cycling experiences.
- Not all could manipulate the cards themselves.
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:
  – Park in a City
  – Countryside
  – Seaside
  – With family and friends
How did cycling make them feel?

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

Happiness/Satisfaction
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
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, 2012

Figure 2 Themes
Key:
Clear boxes are topics being explored
Shaded boxes shows emerging themes

Child with CP

Measurement data

Interview and diary data

Aspirations

Parents/Carers/School staff

Pedal Power Cardiff

Facilitators

Barriers

IMPACT ON CHILD AND FAMILY

- Cycling skills
- Developments over time
- Social Participation Health Benefits Other skills

Enriched environments

Other physical activities

Staff + volunteers

Environment

Technical setup of bike

Adapted Dynamic Cycling
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 Pickering et al, 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
Saturday 14th 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

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....’

Andrew 17 years and GMFCS level II with diplegia, athetosis and autism

Recumbent Trike steered from side
Children unable to self report

Julia, 14 years, GMFCS IV
Rachel, 8 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...”

“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

- Participation
- Parents & Carers
- Personal Factors
- Interviews & Diaries
- Physical Activities
- Community & Environment
- School & Therapies

Voices of Children with Cerebral Palsy
May’s Mum cycling perspectives

Mum: “Cycling in itself is something that I didn’t think May would ever achieve, not that I have ever told her that. But I actually applied for a grant from Cerebra for a trike, I didn’t even knew that trikes existed for …you know…..for an older child……and it’s really taken from there using the trike and getting her confidence…

Int: What age was she when she had the adapted trike?
Mum: erm….7 I would say …yeah..and that gave her the confidence and ability to feel less anxious ....in control of a moving object and then took on 2 wheels down the field with a little slope and we’ve taken it from there. She’s many, many years behind her brother ...  
Int: That’s doesn’t matter does it?
Mum: No, it doesn’t matter, but it something that she’s achieved  
Int: I think that video of her cycling on a two wheeler is fantastic” [shown prior to interview on mobile phone]
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

Today I had a 20 mins bike ride with my brother and cousin. In Secondary School Car Park there are loads of bends, curbs, bays and car spaces. I have done on really well considering me and my family thought I wouldn’t be able to achieve such a brilliant opportunity. We also thought I am going to be doing a bike fitness in my test after Easter. So we have been practising moving 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’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 prefishinsiy test after easter so we have been practising waving 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’

“So didn’t think he would ever be able to ride a bike”
Timothy

‘Whoosh’
Lack of physical activity
‘Murray’ aged 4 years, Diplegia GMFCS III

- no physical activity
- some walking at nursery
- no real physical activity
- some walking at nursery
- some walking at nursery
- short walk to local shops
- swimming in 3m
- soft play in pm
- lots of walking at school
- very little physical activity
Fatigue

Rugby 11 years
GMFCS IV: “After trying the trike my legs feel aching”

Ghost 10 years
GMFCS III
“My legs was killing me after 15 minutes of lazer tag”

Wayne 7 years
GMFCS II
“Legs get too tired after riding a bike so don’t do it very often”

Suarez 8 years
GMFCS III
“My legs hurt for 3 days after riding the trike”
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..”
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.
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Goodbye