



Children with Cerebral Palsy's participation in physical activities, including adapted cycling – interview & diary data



Pickering DM^{1A} (PickeringDM@cf.ac.uk), Horrocks LM^{1A}, Visser KS¹ and Todd GL^{2*}

School of Healthcare Studies¹, Cardiff University. Pedal Power² www.cardiffpedalpower.org

Cardiff Pedal Power is a charity providing adapted cycles and cycling opportunities for all ages and abilities. This three year study was carried out in partnership with Cardiff University and explored the effects of participation in 6 sessions of adapted cycling for children and young people with Cerebral Palsy (CP). This was compared with a control group of Children and Young People with CP who had not yet had this opportunity.

Background

There is limited research to explore the concept of participation for Children and Young People (C & YP) with Cerebral Palsy (CP)^{1,2}. The lack of participation in healthy leisure activities can have a negative impact on long term health and well being. Adapted cycling is one activity that enables C & YP with CP to participate in the community. However, these trikes are expensive, costing between £400 and £3,000 to purchase and requires a careful analysis of their needs to make the correct choice of cycle.

Methods

Participants were recruited from the voluntary project, Pedal Power, by the physiotherapist employed for children and young people*. C & YP were invited to take part in an interview about their cycling experiences, prior to starting 6 sessions of cycling and again after completing 6 sessions. They also kept a diary about these experiences. The control group of children with CP were recruited via the NHS and the voluntary sector. The facility to hire an adapted trike was not available in the areas where they were recruited from. Information about adapted cycling was given to them at this first meeting. They were also asked to write in a diary about their general physical activities during this time. They participated in one interview at the end of the 6 week period.

The C & YP with CP had a variety of communication styles where communication aids, picture boards or symbols, as well as gestures and sign language, were used. This resulted in the 2 researchers^A adapting their communication style to mirror the needs of the individual. Interviews were conducted with C & YP and an accompanying adult, familiar with their communication style. Pictures were used to encourage a dialogue about cycling. Closed questions were developed with images of happy or sad faces, to capture more feeling about the experiences when spoken language was not possible. Observation of their non verbal communication was essential. The data transcripts were verified by the accompanying adult and analysed using a template approach. The themes were sent back to the participants for comments. The data were managed by NVivo⁸ and analysed for emergent themes.

Results

In total, thirty five C & YP took part which resulted in 43 interviews and 23 diaries. All children were given a pseudonym. Seventeen children took part in the **cycling group** and data analysis showed that many families, C & YP perceived improvements in pedalling skills, control of cycling speed and steering. Many felt this was good for their muscle strength, balance and endurance. This outdoor participatory opportunity had opened up a new community environment, which enhanced their choice of activities. The cycle hire facility made this an affordable, accessible activity. Six children reported cycling at school. All the C & YP enjoyed their cycling experiences, expressing this in a variety of communication styles. This was represented by their diverse range of verbal and non verbal means of expression and is published elsewhere⁴.

Acknowledgements

Children and families; The Nancie Finnie Charitable Trust; Pedal Power Staff and volunteers; BBC Children In Need; Jenx Ltd; Polar Cycling Equipment

References

1. Fauconnier J, et al (2009) Participation in life situations of 8-12 year old children with cerebral palsy: cross sectional European study /bmj.b1458 BMJ;338;b1458/ doi:10.1136 .
2. Fowler EG, et al (2007) Promotion of Physical Fitness and Prevention of Secondary Conditions for Children With Cerebral Palsy: Section on Pediatrics Research Summit Proceedings ; Section on Pediatrics Research Summit Participants, Section on Pediatrics Research Committee Task Force Physical Therapy 87:1495–1510 .
3. McConachie H, et al (2006). Participation of disabled children: how should it be characterised and measured? *Disability and Rehabilitation*, September 2006; 28(18): 1157 – 1164.
4. Pickering DM, et al (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).

Eighteen C & YP took part in the control group. The themes which emerged from the **control group (non cycling)** are illustrated by Figure 1. A wide variety of activities were reported in their diaries, such as, steel drumming, ball and computer games, wheelchair karate and basketball, animal care, swimming, fishing, horse riding and trampolining. The majority of these C & YP were considering adapted cycling, however, two children did not like cycling, one preferring her electric scooter. Once they had received the adapted cycling information 9 children had participated in adapted cycling during this study. Following completion of the study, two further parents reported their child had now started cycling. Families in both groups had applied for charity funding or done fund raising for the trikes.

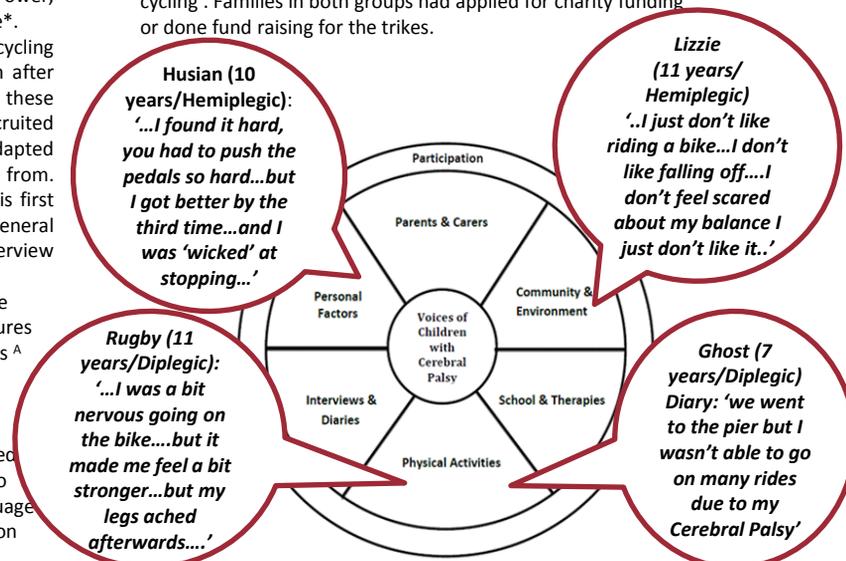


Figure 1: Themes from the control group of Children and Young People with CP

Discussion

Those C & YP who had the opportunity to cycle had enjoyed the social participation and learning to control the trike. Children who had not yet had the opportunity were keen to try, but access was limited. The cost was prohibitive in the short term, until funding was available. It was encouraging that 11/18 (61%) children in the control group were now participating in adapted cycling, following involvement in the research study. This increase in participation in a leisure activity with potential health benefits was a positive trend. However, it is clear that both groups of C & YP with CP had a variety of opportunities which provided enjoyment and facilitated their participation in the community.

Implications

The continuation of support for C & YP with CP to participate in community leisure activities needs ongoing investment. Therapists, educators and policy makers should consider providing adapted cycle hire facilities for C & YP with disabilities, as an option for increasing their participation with potential health benefits.