ISRCTN42717948 https://doi.org/10.1186/ISRCTN42717948

Voices of children and young people with cerebral palsy about participation in recreational activities

Submission date
11/04/2018

Registration date
02/05/2018

Last Edited
26/06/2024

Recruitment status
No longer recruiting

Overall study status
Completed

Condition category
Nervous System Diseases

☐ Prospectively registered
☐ Protocol
☐ Statistical analysis plan
[X] Results
☐ Individual participant data

Plain English summary of protocol
Background and study aims
There is a strong evidence base that participation in physical activity improves both physical health and emotional well-being. Children and young people who are growing up and living with long term disabilities, such as cerebral palsy, can find participation difficult. Especially those who need assistance to walk, are non-ambulant or have difficulty with learning and communication. Cerebral palsy is a non-progressive neurological condition described by five levels of motor ability with one being the highest and five being the lowest. Those with levels three to five can have the more complex levels of disability. In order to participate they require reasonable adjustments for their physical limitations. Physiotherapists originally thought that by building the child's physical capacity, it would lead to an increase in participation, but this has now been shown not to be the case. In fact, the gradual decline of physical abilities during adolescence for those less ambulant children and young people, also contributes to less participation.
It is now known that changing the environment plays a significant role in increasing participation, such as providing accessible transport, ramps and toilets. However, if the construct of participation is understood more widely to include engagement, the lack of physical participation does not necessarily mean less emotional wellbeing. Whilst the evidence base supports the physical health benefits, less is known about the emotional wellbeing effects of participation in recreational activities for those with cerebral palsy. Recreational activities are wider than sporting activities and include culture, music and the arts.
In Wales, although investment in adapting sporting activities has increased for disabled children and young people, wider participation in recreational activities remains limited. This lack of choice for meaningful participation can lead to less participation in adulthood. This is then thought to negatively affect physical health and emotional wellbeing and reduce their quality of life. However, the emotional wellbeing is not known, as there are currently no valid and reliable measures for emotional wellbeing specifically for children with complex disabilities, such as cerebral palsy. In order to investigate this topic of emotional wellbeing, an observational case study design will be used to answer the following research question:
How do children and young people and their carer's view, experience and choose their level of participation in recreational activities?

The study has two exploratory aims, firstly to find out the participants' views, experiences and choices from their level of participation in recreational activities. Secondly, to find how they think their level of participation affects their emotional wellbeing.

Who can participate?

Children and young people with cerebral palsy and their parents. Boys and girls can participate. The age range is 9-16 years and they need to either use walking aid or be unable to walk. This will be referred to as one of levels three, four or five on the Gross Motor Function Scale. Additionally, if they have learning and speaking difficulties, adjustments will be made to include them in the study.

What does the study involve?

There will be two groups of participants, those who do participate in recreational activities outside the home and those who do not. The study involves participants taking part in two interviews twelve weeks apart, keeping a diary and at least one observation of their usual participation activities. Photographs will be taken during these observations, but later made non identifiable to ensure no one can recognise the participants. Additionally, participants will be asked to keep a written diary record of their activities during the twelve week period. The diary and observations will be discussed at the second interview to explore if the participants can explain the importance to their emotional well being. Participants can choose a false name to protect their identity in order that confidentiality and anonymity are maintained.

What are the possible benefits and risks of participating?

This group of disabled children and young people's views are usually not included in research studies as it is difficult to engage them. By asking, listening and observing their behaviours more can be learnt to improve their quality of life. Therefore the benefits will be for future children and young people with cerebral palsy and similar complex disabilities. By finding out about their possible emotional wellbeing indicators, future children and young people can be included in recreational activities, to meet their needs. There potentially is more harm done by not asking for their views, experiences and choices as the impact upon their emotional wellbeing will remain unknown.

The risk of taking part for the participants is minimal as they are not being asked to do anything additional, other than keep a record of their usual activities over the 12 week research period. The risk of any disclosure during the interviews would be supported by following the Safeguarding Procedures for Wales. If any participants expressed a topic of concern to the researcher related to their emotional state, this would be followed up with their General Practitioner or Paediatrician by agreement.

Where is the study run from?

Cardiff University, School of Healthcare Sciences (Wales)

When is the study starting and how long is it expected to run for?

October 2015 to September 2020

Who is funding the study?

This study is part funded by the Chartered Society of Physiotherapy's Charitable trust and supported by Cardiff University's School of Healthcare Sciences.

Who is the main contact?

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Contact information

Type(s)
Public

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Additional identifiers

EudraCT/CTIS number

IRAS number

ClinicalTrials.gov number

Secondary identifying numbers
NP/15/03

Study information

Scientific Title
Beyond Physiotherapy: Voices of children and young people with cerebral palsy and their carers about ‘Participation’ in recreational activities

Acronym
VOCAL

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

Ethics approval required
Old ethics approval format

Ethics approval(s)
School of Healthcare Sciences Ethics committee, Cardiff University,25/01/2017, ref: 358REC

Study design
Observational case series

Primary study design
Observational

Secondary study design
Case series

Study setting(s)
Community

Study type(s)
Other

Participant information sheet
This is not available in web format - please contact the author for details

Health condition(s) or problem(s) studied
Cerebral Palsy

Interventions
A multiple case study design is being used. Each case study comprises 2 interviews, a diary and observations at their usual recreational activity over 12 weeks. This includes some visual data. The aims are to explore how children and young people with cerebral palsy and their carers view, experience and choose their level of participation in recreational activities and how they think this affects their emotional well-being.

Intervention Type
Other

Primary outcome measure
1.How children and young people with cerebral palsy and their parents view, experience and choose their level of participation in recreational activities. This is assessed for the duration of the 12 weeks at varying times and frequencies using qualitative approaches. Surfing, Brownies. Spradley's (2016) checklist of observations was adapted to observe emotional wellbeing (Spradley, J. P. 2016. Participant observation. Waveland Press). Field notes and photographs were taken to provide context at these observations. Behaviours such as smiling, refusal, biting or hair pulling were recorded.

Secondary outcome measures
1.How participants perceive participation in recreational activities affects their emotional well being. This is assessed by interviews conducted at week 1 and week 12, observations and assessing diary entries.

Overall study start date
01/10/2015

Completion date
30/09/2020

Eligibility

Key inclusion criteria
1.Parent or carer of child with cerebral palsy
2.Cerebral palsy levels III, IV and V as specified by Gross motor function classification system

Participant type(s)
Mixed

Age group
Child

Sex
Both

Target number of participants
8

Total final enrolment
7

Key exclusion criteria
1.Cerebral palsy level I and II as specified by Gross motor function classification system

Date of first enrolment
01/04/2017

Date of final enrolment
31/03/2018

Locations

Countries of recruitment
United Kingdom

Wales

Study participating centre
Cardiff University, Wales, UK
School of Healthcare Sciences
Ty Dewi Sant, Heath Park
Cardiff, UK
United Kingdom
CF14 4XN

Sponsor information

Organisation
The Chartered Society of Physiotherapy Charitable Trust

Sponsor details
14 Bedford row
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Sponsor type
Charity

Website
http://www.csp.org.uk/professional-union/research/research-funding/prf-awards

ROR
https://ror.org/04sn78z72

Funder(s)

Funder type
Not defined

Funder Name
The Chartered Society of Physiotherapy Charitable Trust award; Cardiff University

Results and Publications

Publication and dissemination plan
Planning to publish an article in an open-access journal.

2017 pilot data published in: https://doi.org/10.1057/978-1-137-54446-9_9

Intention to publish date
01/04/2022

Individual participant data (IPD) sharing plan
The participant level data is not expected to be available.

IPD sharing plan summary
Not expected to be made available

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Results article		29/10/2023	22/01/2024	Yes	No
Other publications	A kaleidoscope of well-being to authentically represent the voices of children and young people with complex cerebral palsy: a case study series	26/04/2023	26/06/2024	Yes	No