VOCAL: Non-verbal children and young people with cerebral palsy's voices about the well-being effects from their level of participation in recreational activities.

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WARC 22nd February 2022
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Aims for this session

• To provide the context of cerebral palsy, participation and well-being

• To share my PhD findings

• To explore by discussion how to move the agenda of well-being forwards for non-verbal populations
My position

- Clinical background as a physiotherapist in the NHS

- Concern for non-ambulant and non-verbal children- are we doing enough?

- Opportunity to carry out a staff PhD part time in 2015-2021
“Cerebral Palsy describes a group of permanent disorders of the development of movement and posture, causing physical activity limitation, that are attributed to non progressive disturbances that occurred in the developing foetal 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.”

Rosenbaum et al, 2007
Participation-World Health Organisation (ICF) 2001

Health Condition
(disorder or disease)

Body Functions & Structure

Activity

Participation

Environmental Factors

Personal Factors

Contextual factors
Participation - World Health Organisation (ICF) 2001

“Right to rest, leisure, play and recreation and to take part in cultural and artistic activities”
(United Nations Children’s Fund, 1989 p.10)

Disabled children have less choices for recreational activities, thus by being overlooked their well-being is not always considered.

Play Wales, 2013
Emotional Well-Being has been defined by the Mental Health Foundation as:

“A positive sense of Well-Being, which enables an individual to be able to function in society and meet demands of everyday life; people in good mental health have the ability to recover effectively from illness, change or misfortune” (Lite 2012 p.4).

Huppert and So (2013) defined well-being as showing features of feeling and functioning behaviours, such as showing competence, emotional stability, engagement, meaning, optimism, positive emotion and relationships, resilience and vitality. These attributes can lead to empowerment, which enables an individual to be more self-determined and autonomous (Watson et al. 2012). However, this is hard for non-verbal populations to express or demonstrate their well-being.

Well-being in this context is referring to how children with CP are able to indicate they are enjoying life in their environments, using adapted equipment -‘thriving or surviving’ which directly impacts upon their perceived quality of life (whatworkswellbeing,2022).
Gap in literature about participation for non-verbal children and young people with cerebral palsy with limited mobility (Imms et al 2016).

Rosenbaum and Gorter (2012) propose that disabled children should have ‘Fun’ in their lives.

Very little is known about their perceptions of their own well-being - no current valid and reliable measure for cerebral palsy (Mpundu-Kaambwa et al 2018).
Cerebral palsy - functional classification systems

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, 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 upright position and trunk posture, and control leg and arm movement.

CFCS Level Identification Chart

Does the person consistently and effectively alternate sender and receiver roles with familiar partners?

Does the person consistently and effectively communicate with unfamiliar partners?

Is the person an effective sender AND/OR a receiver at least some of the time?

Level III
Effective Sender AND Effective Receiver with familiar partners

Level IV
Inconsistent Sender and/or Receiver with familiar partners

Level V
Seldom Effective Sender and Receiver with familiar partners

Level I
Effective Sender and Receiver with unfamiliar and familiar partners

Level II
Effective, but slower-paced Sender and/or Receiver with unfamiliar and familiar partners
Cerebral palsy

GMFCS E & R Descriptors and Illustrations for Children between their 6th and 12th birthday

**GMFCS Level I**
Children walk at home, school, indoors 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.

Cerebral palsy is a group of disorders that involve the brain and the nerves that control muscle movement and cause some or all of the following problems:

- Difficulty moving
- Difficulty keeping balance
- Problems in using hands and feet
- Speech problems
- Problems learning
- Problems with vision, hearing, or other senses
- Problems with bladder and bowels

Cerebral palsy is caused by brain damage that happens before, during, or after birth. The brain damage usually happens before the baby is born. It can happen from problems during pregnancy, delivery, or birth. It can also happen from conditions that occur at or soon after birth.
My research question explored how children and young people with cerebral palsy and their parents viewed, experienced, and chose their level of participation in recreational activities, to benefit their well-being.

- The participants were children and young people with cerebral palsy aged 9-16 years, supported by their parents.
- A comparative case-study design (Yin 2018) was developed with visual methods, with two groups, a participatory group (PG n=4) and limited participatory group (LPG n=3).
Figure 1: Mutually determining triad from Harré and Langenhove (1999 pg.18)
Consent / assent process
2 interviews: 12 weeks apart
Diary kept in between by parents
Observations of their intentional behaviours at one of their usual recreational activities during this time
Photographs (artefacts) sent by parents or taken by researcher (anonymised)
7 case studies
Reflexive diary
Seven cases were analysed utilising an interpretative approach, using Braun and Clark’s (2013) six stages of thematic analysis.
<table>
<thead>
<tr>
<th>Table of codes- mapped to research question and aims</th>
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<tbody>
<tr>
<td>‘Nick’ Data sets (PG)</td>
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<tr>
<td>Interview 1 1 hour, 5 mins, 22 seconds Dad and Mum briefly towards end.</td>
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Positive: Shows happiness by smiling and clapping (18), Spinning spinner (7).

Negative: Goes very quiet when unhappy (2), Maybe tearful or gestures (uses Makaton sign language) when unhappy (1).
## Nick’s themes and subthemes

<table>
<thead>
<tr>
<th>Theme</th>
<th>Sub-themes</th>
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<tr>
<td>Enablers for participation</td>
<td>Volunteers,</td>
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<td></td>
<td>Respite choices</td>
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<td>Well-Being indicators</td>
<td>Nick’s behaviours,</td>
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<td>Parent’s emotional responses</td>
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<td>PG/ LPG</td>
<td>Name (Pseudonym)</td>
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<tr>
<td>LPG</td>
<td>Bree</td>
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<tr>
<td>PG</td>
<td>Clare</td>
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<tr>
<td>LPG</td>
<td>James</td>
</tr>
<tr>
<td>PG</td>
<td>Lily-May</td>
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<tr>
<td>PG</td>
<td>Matthew</td>
</tr>
<tr>
<td>PG</td>
<td>Nick</td>
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<tr>
<td>LPG</td>
<td>Poppy</td>
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Findings

Three overall themes were identified from the findings:

1. Participation Enhancers

2. Champions for disabled children and young people's well-being - including self advocacy

3. Hindrances to participation

• Positioning theory was adapted to include the non-verbal children’s storylines, represented by a ‘Kaleidoscope of Well-being’.

• This proposes that well-being can fluctuate in different environments, influenced by the social forces of advocates who promote their needs, with specialist equipment. Participants also showed they could choose not to participate, showing their own agency as self-advocates. Illustrating both their attendance and involvement may vary.
Kaleidoscope of well-being

Figure 1: ‘Kaleidoscope of Well-being’ for disabled Children and Young People’s participation in Recreational Activities - adapted from mutually determining triad from Harré and Langenhove (1999 pg. 18).
1. Participation enhancers:

Interview 1

‘This is the best feeling ever, to see your child so happy, you can forget about all the worries or hospital appointments and just for that moment see him on the waves, it’s amazing’

Participation observation field notes

‘Matthew was visibly shaking with excitement and grunting very loudly, he became hoarse by the end of the surfing session’

Interview 2

“Clare loves cycling because she has a little basket on the front, we put music in the front, and she is as happy as Larry... She cycles, we do about a mile and a half she goes down, along the river path, the old railway track,...
2. Champions for Well-being

• Lily-May enjoyed being an ambassador for Whizz Kidz which her mother recorded in the diary:

  “Ambassador club! Fantastic. Wheelchair sports-dancing, tennis, table tennis, boccia. Able to leave Lily-May as has health care professionals there – much more fun for Lily-May without me there, she laughed and shouted the whole time.”

Her mother’s perception was that it was more fun for her without her present, thus Lily-May was able to show her own self-determination by participating, supported by others for her care needs.

Some practitioners also supported them: Matthew’s social worker suggested adjustments of suitable recreational activities at his respite facility, advocating for his calmness. Funding for a special cot bed for Lily-May was advocated by her occupational therapist - this reduced her fatigue, to enable her to enjoy her many recreational activities.

Physiotherapists were reported to have previously been involved with the skiing, surfing, cycling and Race Running groups, as initiators and volunteers.
Figure 2: ‘Kaleidoscope of well-being’ illustrating skewed mutually determining triad with grey clouds when factors adversely affected well-being.
3. Hindrances to participatory experiences

Unhelpful attitudes:
Clare mother’s interview about access to a music arena:

“That’s really bad, I refuse to go there now. They stick anybody in a wheelchair upstairs, you go up in a lift and I said what do you do if there is a fire? How do we come back down again and they said...oh no you don’t come back down, we lock you in a room and it’s supposed to last for 3 hours in a fire. Then the fire brigade come and rescue you...I was I’m not bloody doing that, what member of staff is going to volunteer to be locked in the room with us...none of you I should think. Are you going to rely on the fire brigade to be able to get into an inferno and get you out within 3 hours? No, I’ll be coming down the stairs with Clare, I’m not coming here again”.

He couldn't get in the bat thing because the wheelchair couldn't go under it, you know... It was really disappointing there.

Poppy’s Diary entry
Bree’s mother (July 2020): 

“It's been a nightmare!! No swimming, no touch therapy, no cycling, no brownies, no trampolining, no school, no overnight respite, no carers and in the beginning not able to travel anywhere where it was suitable to use the walking frame. Bree's behaviour steadily declined and became increasingly difficult to manage. We needed an emergency consultation with a psychologist at one point. It's slowly starting to improve, our carers have come back, cycle hire has reopened, we've had 3 overnight respite stays but I can't wait for school to reopen properly and for Bree to have a proper routine again!”
The recreational opportunities supported their well-being but are limited for disabled children with higher levels of disability. There is a need to explore how professionals perceive their role of self-advocacy from disabled children and young people to listen to their choices.

Further post-doc development is exploring how to develop a scale for well-being and involvement with non-verbal disabled children who use the Innowalk (Laevers, 2005).
The Be-Well Checklist

Helping parents, carers and professionals to reduce challenging behaviour and improve the wellbeing of people with severe learning disability and complex needs
Discussion

• Questions?
Acknowledgements

- Supervisors: Dr Paul Gill, Dr Jane Davies, Dr Carly Reagon

- Funders: Chartered Society of Physiotherapy Charitable trust fund
Play Wales. 2013. Article 31 resources [Online]. Play Wales. Available at: [Accessed: 16.06.16].