Bore da- Greetings to 2021 CPISRA conference from Wales, UK

Dr Dawn Pickering, Cardiff University, UK
Children and youth with cerebral palsy’s voices (GMFCS III-V) about the well-being effects from their level of participation in recreational activities

Dr Dawn M Pickering
Senior Lecturer
Physiotherapy
School of Healthcare Sciences
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pickeringdm@cf.ac.uk
Twitter@DawnMPickering
Children and youth with cerebral palsy with mobility, communication and learning disabilities are underrepresented in the literature.

This PhD research focussed on the well-being impact for children and young people aged 9-16 years from their level of participation in recreational activities.

There is not currently a well-being measure for this group (Mpundu-Kaambwa et al. 2018) and yet Rosenbaum and Gorter (2012) have proposed they should have ‘Fun’ in their lives.
The research question was: How do children and young people with cerebral palsy and their parents view, experience, and choose their level of participation in recreational activities, to benefit their well-being?

Two aims were to explore their perceived barriers and facilitators and the well-being effects.

A comparative case-study design (Yin 2018) was developed.
Inclusion criteria

Gross Motor Functional Classicisation System - Expanded and Revised (CanChild, 2021)

Communication Function Classification System (Hidecker, 2011)
‘Mosaic’ of individual data sources to make up each single case study

2 interviews: 12 weeks apart
Diary kept in between
Observations of their intentional behaviours at one of their usual recreational activities during this time.
Photographs sent by parents or taken by researcher (anonymised)
7 case studies
Reflexive diary
Offered a way to socially construct their stories without spoken language

Imms et al (2016) have proposed the Family of participation related constructs (fPRC) where attendance and involvement are the two key factors determining their level of participation.

Position was interpreted as both where they were placed as their physical positions and their metaphorical positions in how involved they chose to be at the activity.
Positioning theory: Harre and Langenhove 1999

Figure 1: Mutually determining triad from Harré and Langenhove (1999 pg.18)
Findings

Seven cases were analysed utilising an interpretative approach, using Braun and Clark’s (2013) six stages of thematic analysis.

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

<table>
<thead>
<tr>
<th>Pseudonyms</th>
<th>Level of participation</th>
<th>Age</th>
<th>Gross Motor Function Classification system</th>
<th>Communication Function Classification System: Communication Aid*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bree</td>
<td>LPG</td>
<td>9</td>
<td>III</td>
<td>IV</td>
</tr>
<tr>
<td>Clare</td>
<td>PG</td>
<td>9</td>
<td>IV</td>
<td>III-IV*</td>
</tr>
<tr>
<td>James</td>
<td>LPG</td>
<td>14</td>
<td>V</td>
<td>V</td>
</tr>
<tr>
<td>Lily-May</td>
<td>PG</td>
<td>16</td>
<td>III</td>
<td>IV*</td>
</tr>
<tr>
<td>Matthew</td>
<td>PG</td>
<td>14</td>
<td>IV</td>
<td>IV</td>
</tr>
<tr>
<td>Nick</td>
<td>PG</td>
<td>14</td>
<td>IV</td>
<td>III</td>
</tr>
<tr>
<td>Poppy (male)</td>
<td>LPG</td>
<td>9</td>
<td>IV</td>
<td>IV (Eye Gaze)</td>
</tr>
</tbody>
</table>
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).
Participation enhancers:

Interviews

“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”

“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,...

Participation observation field notes

‘Matthew was visibly shaking with excitement and grunting very loudly, he became hoarse by the end of the surfing session’
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.
Music and sensory based activities were important

Bree’s mother: “The relaxed orchestral performance was brilliant, that was really good … she loves music and I think they should do more…everything from start to finish and they had somebody signing for those kids that needed signing, it was just so inclusive….they had pupils come on from one of the valley’s special schools who play instruments, they had been practicing with members from this orchestra. That was amazing, that was really lovely to see that, and you could get up, you could dance at the end they sort of came into the audience with some of these musical instruments so Bree could have a go with it, it was just really well thought through and organised…”
Choosing not to participate

Nick showed his own agency by removing himself from Frame Running and went to watch the tennis, his father seemed unconcerned. It was a pivotal moment in the data collection that challenged my misconceptions about participation and led to further reflection about my researcher’s position.

Image taken from Frame Running website [20.10.21]
3. Hindrances to participation

The children in the limited participation group had less choices and these were influenced by pressure sores, pain and epilepsy. The lack of “Changing places toilets” was also a limitation to how long the children could stay at the activity. Their well-being was reduced by these lack of choices, additionally some attitudes were perceived as unhelpful.
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

Poppy’s Diary entry

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

Unhelpful attitudes/lack of personal care support:
Matthew's Mum

“…..you need to have a nice little paragraph underneath where you say you are inclusive for everyone, because you're not inclusive for everyone… …They took it by putting on their Facebook page, which really, really infuriated me 'cos it was aimed at me…to say that don’t forget that next week is our all-inclusive sport’s things but we need to tell you that we cannot provide one-to-one services for personal care… it was kind of that’s for me that was and I was really, really annoyed by that…because Matthew is in a wheelchair he is automatically written off...”
The recreational opportunities supported their well-being, but are limited for disabled children with higher levels of disability.

Further post-doc development is exploring the development of an observational well-being scale in different recreational contexts.
References


Play Wales. 2013. Article 31 resources [Online]. Play Wales. Available at: [Accessed: 16.06.16].

