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Title

A kaleidoscope of well-being to authentically represent the voices of children and young people with complex cerebral palsy: a case study series.

Abstract

Purpose

This paper authentically represents the voices of non-verbal children with cerebral palsy using a case study design. Policy suggests that children should have the right to play and leisure opportunities, however non-verbal children with cerebral palsy have fewer choices. Additionally, children with communication, learning and mobility limitations are usually excluded from research. The aim of this research was to capture the voices of non-verbal children by exploring their well-being impact in terms of their experiences and choices about their level of participation in recreational activities.

Methods

A qualitative case series study included interviews, observations, photographs and diaries. Where possible, the diaries were completed by both caregivers and children. Data were analysed thematically, and the lens of positioning theory applied.

Results

Seven children aged nine to sixteen years participated. The findings showed how equipment, people and environments enabled or hindered the children's participation. The children also advocated as champions for their own well-being. Positioning theory was applied across the data and was adapted offering a way to better understand the children's well-being responses.

Conclusion

The findings demonstrate how these children were able to self-advocate, demonstrating their well-being by their intentional behaviours from their level of participation in a recreational activity.

Main paper

Background

Children and young people with cerebral palsy (CP) aspire to participate with their peers, but they have fewer choices for recreational activities due to the need for adaptations, especially as the complexity of their disability increases [1,2]. Whilst both global and local policies promote the inclusion of these children and young people in activities for play and leisure, little is currently known about their own perceptions of their well-being in relation to their level of participation in recreational activities [3-5]. It is noticeable that when children have communication and learning disabilities, they are often excluded from research and participation in recreational activities [6,7]. This gap in existing evidence led to the study reported here which explored the views, experiences and choices of children and young people (referred to as children hereafter) with complex CP in relation to participation in recreational activities and consequent well-being effects. This paper also aims to demonstrate how the voices of non-verbal children with CP can be represented using authentic methods.

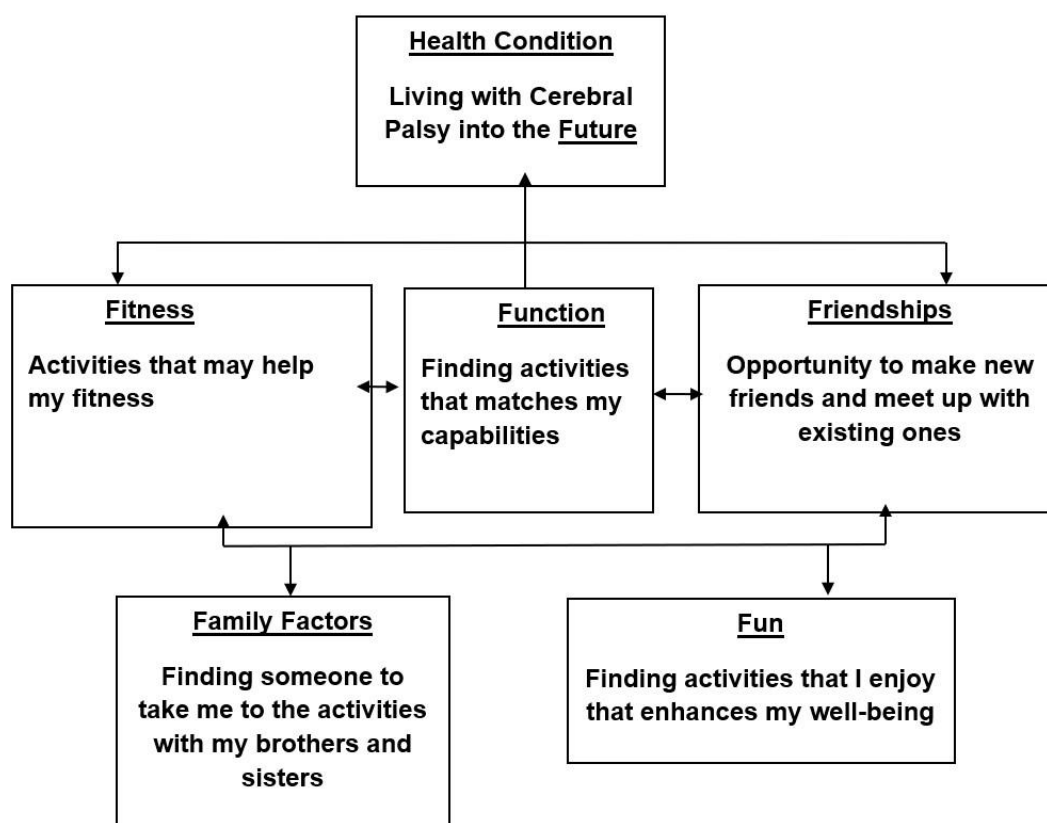
CP is a non-progressive neurological condition, presenting in early childhood, resulting in motor and sensory disorders, which can affect developmental progress [8]. It varies in presentation and this research focused on those with the greatest mobility, learning and communication limitations as defined by the Gross Motor (GMFCS) and Communication Function Classification Systems (CFCS) [9,10]. These are both five-point descriptive scales and those with the highest mobility and communication restrictions are scored at Levels IV and V. They are usually excluded from research and their experiences are currently underreported, which this study therefore sought to address.

Participation

Participation is one of the domains of the World Health Organisation's International Classification of Functioning (ICF) which targets areas for research and clinical intervention [11-15]. Rosenbaum and Gorter have proposed six complimentary 'F' words that align with each of the ICF domains, with 'Fun' aligning with participation [16]. Figure 1 illustrates how this study was mapped onto the six 'F' words of their model.

Figure 1: The 6 'F' words as adapted for this study [16]

Figure 1: The 6 'F' words as adapted for this study [Rosenbaum and Gorter 2012]



Disabled children's 'Fun' experiences have the potential to enhance their well-being. However, there are limited choices in recreational activities for children with the greatest limitations in mobility, learning and communication [17-18]. Disability studies scholars note that these inequities are due, in part, to a failure of society in recognising and validating the equitable value of disabled people's lives and can begin to be addressed by adopting an affirmation model of disability [19,20]. Imms et al have proposed a family of participation related constructs (fPRC), which includes attendance and involvement in relevant activities, to capture the participatory experiences of disabled children, including their well-being, often reported as quality of life outcomes [21]. Anaby et al [22] suggest that advocacy for improving participation for disabled children includes healthcare professionals signposting to available opportunities. Advocacy, in this research context, utilises Devakumar et al's suggestion that it is about someone speaking out on behalf of a child about their limited participation choices and acting as a catalyst for change [23]. However, the alternative voices of disabled children themselves have had limited representation in the literature to date [24,25].

Well-being

Watson et al describe emotional well-being as both a contextual and relational dynamic as well as an embodied, subjectively experienced phenomena [26]. Mpundu-Kaambwa et al's systematic review demonstrated that the patient reported quality of life measures used, which included aspects of well-being, had not

demonstrated reliability, construct validity or suitability for this population with complex CP [27]. Whilst each disabled child or young person does not exist in isolation from their family, school or community, it may be more difficult to express emotional well-being, if the child has a learning or communication disability and experiences pain, epilepsy, or fatigue [28-30]. For example, non-verbal children with CP may express their distress by intentional self-harming behaviours such as biting and hitting. They can also have spasticity, which affects their posture and reduces their comfort and well-being [31]. Behaviours that indicate well-being include having energy, being creative, engagement with others or being content on their own, good sleep and appetite. However, laughter and smiling may not be consistent indicators of well-being with this group of children; conversely, they could be having seizure activity or unable to control their facial muscles voluntarily [32]. Further, how children with CP are able to be positioned physically (e.g. in their wheelchairs or adapted equipment) can have a great impact upon their comfort, which directly impacts on their level of participation in recreational activities and well-being [33].

Research Question and Aims

Previous research has included verbal and ambulant children with cerebral palsy, demonstrating that the attitudinal, social and physical environments of disabled children influence their participation in everyday activities and social roles [34]. However, to widen potential participation in underserved groups and expand existing knowledge, the voices of non-verbal and non-ambulant children were included in the present study.

The study's research questions were: 'How do children with CP and their parents view, experience and choose their level of participation in recreational activities and how do these children demonstrate well-being during their participation?' The aims of the study were to explore the children's perceptions of their well-being and the barriers and facilitators to their participation in recreational activities.

Methods

Research approach

This was an exploratory qualitative case study series about emotional well-being with participants who have traditionally been excluded from research. A qualitative approach enabled the flexibility and creativity which are better suited to support the participation and engagement of children and young people in research, especially those with additional needs [35,36]. A case study design offers the researcher to get close to the reality of their participants, to explore the viewpoints and behaviours that characterise them as social actors [37]. A case study can comprise of documentation, archival records, interviews, direct observations, participant observation and physical artefacts. This was an interpretative study, exploring the construct of well-being, with children with CP and their caregivers from their level of participation in recreational activities. Elements of this approach and analysis are explained fully in the following sections: ethics, participants, sampling and recruitment, data collection, data analysis, research reflexivity and positioning theory.

Ethical approval

Research ethics committee (REC) approval was provided in January 2017 from the University's School of Healthcare Sciences REC Reference 358 REC. The participant information sheets were translated into Welsh. It was not necessary to obtain NHS ethical approval, as prospective participants were recruited from the third sector and special schools. The study was registered with the International Study and Clinical Trials Network Register (ISTCRN) Number:42717948 as a case study series.

Participants

Sampling and recruitment

Purposive sampling was achieved by recruiting through gatekeepers at relevant third sector groups including physiotherapists at disability sports clubs, teachers in special education schools across South Wales and parental Facebook groups. These gatekeepers reduced any potential researcher led recruitment bias from the study. The final gatekeepers were those with parental responsibility. Two distinct participant groups were recruited: (1) a 'Participatory group' (PG, defined as those who participate frequently in recreational activities) and (2) a limited participatory group (LPG, defined as those who are unable to participate regularly in recreational activities). Recruitment to the LPG required greater promotion via gatekeepers. Once the parents expressed an interest to volunteer, an initial visit was carried out at their home. This was to obtain informed consent or assent as appropriate with the parents and their child and to establish that child's interests, which informed the interview schedule.

Parental written consent was given for all children. Child assent was understood as an ongoing intention to be involved if their parents had consented. They were free to withdraw their child at any point and not give a reason why. Care was taken to look out for indicators if the researcher's presence was intrusive for them at any observation. Consent for non-identifiable photographs was given by the parents to protect their child's anonymity and confidentiality. Pseudonyms were chosen by the parents.

A case study provides depth and not breadth, so a small sample size was sufficient. The caregivers whose children had fewer opportunities, were harder to recruit into the research. However, one family support worker made an extra recruitment effort where the lead author was invited to attend a coffee morning at the special school to explain the study.

Study procedures: Case study

Each case study included two interviews, a handwritten diary completed over twelve weeks, photographs (artefacts) and an observation at one of their usual recreational activities, where field notes were written [37]. The A4 paper diary was provided with instructions asking parents to write about their child's recreational activities over the

twelve-week period following the first interview and to support this with any relevant photographs to indicate their well-being.

In order to establish the variation in the sample, demographic data were collected, including their postcode which enabled mapping onto the Welsh Index of Multiple Deprivation [38]. This index provides an indication of levels of socioeconomic deprivation, which is known to inversely reduce participation levels [39]. This scale ranks from 1-99% of deprivation indices, for example, 4% on this scale represents high socioeconomic deprivation which reduces participation levels in the community, due to low financial income and poor disabled transport facilities.

Service user involvement

Involve [40,41], a public participation charity in the UK, was approached for service users to comment on the design of the participant information sheets for two different age groups, nine to eleven and twelve to sixteen years, as well as the parental version. A parent and thirteen-year-old girl with CP (involved in the pilot study) advised on the design and, as a result, the child versions of the participant information sheets were created in an illustrated A5 booklet format.

Inclusion and exclusion criteria

Inclusion criteria were children ages nine to sixteen years. Since children in GMFCS and CFCS Levels III-V often experience decline in motor and communication function around eight years of age, children under nine years of age were excluded [42]. This enabled the prioritisation of children with more significant disability. The aim was also to recruit those with limited communication abilities, thus those at level III-V on the CFCS. It was not possible to establish their level of cognitive disability, but in these cases, the parents were interviewed by proxy.

Data collection

Data were collected between March 2017 and April 2018. Interviews were carried out at the beginning and end of the twelve-week data collection period in each case study. Two of the children who could use a communication aid were interviewed, but parental interviews were carried out with the other five participants, as it was not possible to hold a conversation that could be transcribed in the usual manner with these children, due to their limitations with verbal language expression. This tension between observing and listening to the voices of the children via their intentional behaviours and their parent's voices was a challenge. The child-based interviews utilised toys, a drawing activity and sandbox play to engage the children in their stories [43]. Figures 2 and 3 shows the interview guides with the drawing activity. One child asked the researcher in her first interview why this research was being done, which was both unexpected and reassuring that she was interested and understanding that this was a research project and not just a social chat.

Figure 2 Interview guides

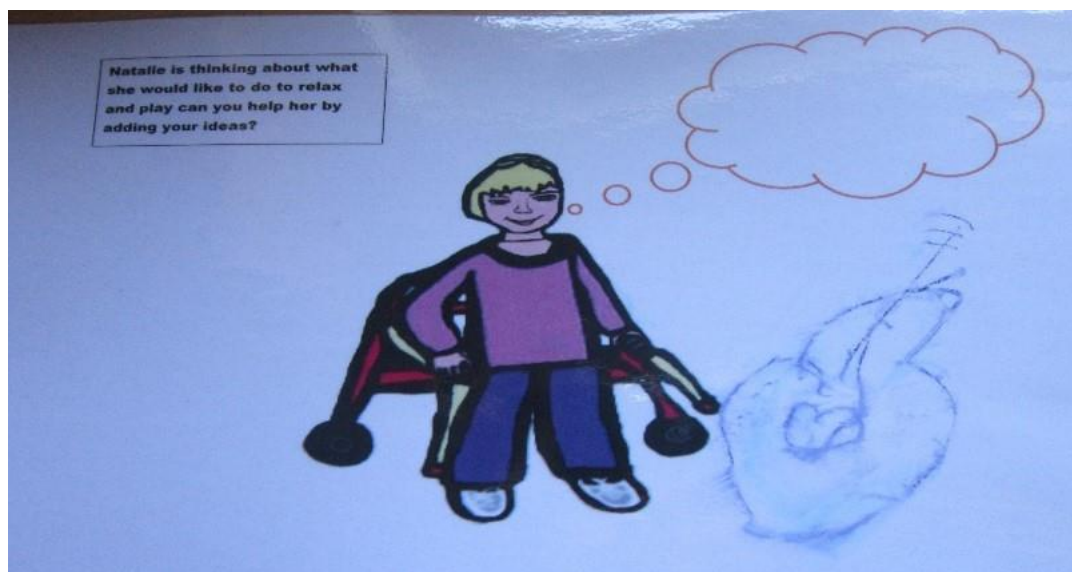
First Interview guide with parent

1. Can you tell me about your child and your family?
2. Can you tell me what they do outside of school?
3. How did you find out about any activities they can try?
4. What are the things that help or hinder them joining in recreational activities?
5. What sort of activities would you like to be developed in the future for them to join in?
6. Could you record in this diary (or on a computer if you prefer) the activities they will do over the next 12 weeks, and we can discuss this next time I come? Would it be possible for me to observe your child at one of his participatory experiences during this 12-week period?

Second Interview guide with child who used AAC

1. Recap what we talked about last time- summary of last times interview/ chat.
2. Would you like to show me your diary and tell me what you have done for the past 12 weeks?
3. Can you tell me about any fun things you have done outside of school since we last met?
4. Were there any new activities you had not tried before?
5. Do you have a favourite activity?
6. Can you tell/show me how these activities made you feel?
7. Would you like to draw on my picture (laminated)of what you think 'Natalie' might like to do to relax and play?

Figure 3 Drawing activity



Observations were carried out using conventions according to Spradley's question matrix [44] and a reflexive diary was kept, noting the researcher's feelings. Attempts were made to minimise any negative bias of researcher influence, by considering each context being observed and whether this was non-participant or participant observation. For example, when observing the adapted surfing as a participant, it was necessary to wear a wet suit and get into the water with the child. This added to his entertainment and created great hilarity for him when the waves were so strong the researcher fell over. This strengthened the bond between the participant and the researcher.

Photographs were also taken at these observations and the parents also sent additional photographs to the researcher during the twelve-week period of data collection. These photographs were used to elicit discussions in the second interview, which added to the triangulation of data sources within each case study [45]. Whilst there is some overlap in this study of photo elicited conversations, the design was an exploratory case study series and did not employ more specific photographic methods seen in other participatory research with disabled children [46]. The variety of data sources in each case, further enhanced the trustworthiness of the study's design, as each component provided depth to the analysis of the findings [47,48].

Data analysis

Braun and Clark's six stages of thematic analysis were carried out, first within each case, then across case comparisons were made [49]. The six stages started with transcription, followed by reading and familiarising with the content. Next was the first step of coding the transcripts in each case which enabled concepts of interest to be clustered into themes. Reviewing the data again enabled provisional themes to be identified with relationships between them. The last three steps were repeated in an iterative manner across the data sets. The final stage is defining and naming overall themes. Data was managed in NVIVO 11 and Microsoft word. Initial coding highlighted patterns across the data which were developed into themes and subthemes by an iterative process using the constant comparative method [48]. The visual data added meaning to the field notes and diary data, to portray their well-being effects. This was supported by triangulating the different data sources to interpret what enhanced or hindered their participation. This included some musical expressions for which the sound of intent framework was utilised, seeking to understand intentional music responses as a way of expressing well-being. This sound of intent framework developed by Ockelford [53] categorised musical expressions into reactive, proactive and interactive responses with music. This framework has been used with non-verbal children as a valid way to interpret intentional musical creations which can indicate mood and well-being and offered a way to interpret this atypical type of data.

The interpretation of the data, by the researcher, was carried out with a priori ideas about views, experiences and choices on a case-by-case basis following Braun and Clark's six stages of analysis [49]. The first author carried out all the analysis and samples of this was agreed upon by the research team to ensure depth of coding and early theme identification was agreed. Emerging thematic ideas in each case were sent back to parents for comments; these were taken into account when refining the final themes identified. This is shown in Table 1.

Table 1: Analysis based upon Braun and Clark [39]

Stages of data analysis for each case (7 in total: PG/LPG)	Researcher analysis	Research team Advisory role for extracts	Parents Confirmed
Transcribe and validate authenticity	Yes		Yes
1 Familiarise with data	Yes		
2 Generate initial codes	Yes	Yes	
3 Searching for themes	Yes		
4 Reviewing themes	Yes		
5 Defining and naming themes	Yes		Yes
6 Producing the case report	Yes	Yes	Yes
Compare cases PG/ LPG	Yes	Yes	
Draw out common themes	Yes		
Final across case themes	Yes	Yes	Yes

Researcher reflexivity

Data collection, transcription, coding and thematic identification were carried out by the first author who is a children's physiotherapist by background and was a PhD candidate. Training in interview and visual methods was provided by the university. The second and third authors (PhD supervisors) reviewed samples of data for coding agreement and refining of themes. According to Tong et al [54] the checklist of

criteria to evaluate the rigour in qualitative studies involves researcher reflexivity. A reflexive diary was therefore kept alongside the field notes from the observations, and extracts of this were shared with the supervisors [55]. The observations were a mixture of participant and non-participant observations, where the researcher considered how to make the activity less intrusive and sought to blend into the environment. Empathy was shown at these activities to support the child and caregiver. Participants in the study knew about the researcher's background but were not previously known to author one.

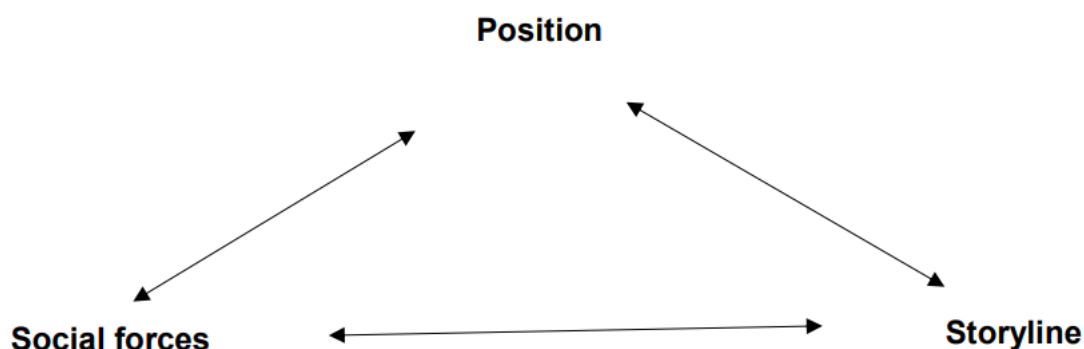
Following this analysis, the theoretical framework applied to the data was positioning theory, which offered a way to consider the children's physical and metaphorical positions, to help interpret the children's own well-being meaning, from their experiences [50]. Thus, by applying positioning theory to the findings, after analysis, it was possible to reframe the meaning of well-being with these child participants supported by their caregivers [51, 52].

Theoretical Framing: Positioning theory

Positioning theory is based upon social constructionism and is defined as the way that *"psychological and social phenomena are constructed and sustained, through discourse and activity, where individuals position themselves and others"* pg. 361 [50]. Social constructionism relates to social spaces that enable social engagement between people and objects. Positioning theory was originally developed using spoken language, however in this study it was adapted to enable the social realities of non-verbal children's experiences to be portrayed. This was illustrated via a mutually determining triad of the child's position (physical and social positions), social forces and their storylines [51,52]. The children's storylines were their expressions of their participatory experiences, that related to their well-being. In this study, positioning theory offered a way to consider the data through this lens to narrate the children's stories about their well-being. As the aim in this study was to position the children's voices centrally to their experiences, this discourse was not always through the spoken language, but by the children's social engagement and researcher observations of their intentional behaviours. This was supported by their parent's views and written diaries, including photographs.

As shown in Figure 4 this mutually determining triad illustrates the child's position, social forces, and storyline in equal measure, showing they all have an influence on the outcome. The arrows pointing both ways, shows the interaction of each of these upon each other. The triad being in equilibrium, suggests there is a relationship between position, social forces and the resulting storyline that is told from the experience. This was more than just their physical positioning (where they were placed), but also metaphorically through observations of how they chose to socially position themselves (in order to engage with people or activities that interested them), the degree to which they felt in control or empowered to be involved.

Figure 4 Mutually determining triad from Harré and Langenhove pg.18 [50]



Findings

Seven participants were recruited, four boys and three girls at Levels III-V of the GMFCS and CFCS. They lived in varying socioeconomic parts of Wales, demonstrating wide representation across the Welsh Index of Multiple Deprivation from 4-99%, supporting the notion of maximal variation in the sample [38,39]. Across the seven cases there were four (Lily-May, Clare, Matthew and Nick) in the PG and three in the LPG (Bree, James and Poppy). These enabled comparisons of their well-being to be made within and across cases. Many parents chose to write the diary in the first person, as a way of reflecting their child's identity and autonomy.

The findings were not as binary as initially anticipated between the PG and the LPG; it was more a kaleidoscope of experience with a blurring of boundaries between these groups. Three overall themes were identified: Participation enhancers, Champions for Well-being, and Hindrances to Participation. These themes will be now described and discussed, using illustrations from the cases in the form of quotes and photographs. As the child participants could not read, a visual representation and a Powtoon video were created to inform them of the findings, explained in pictures with audio embedded (<https://www.powtoon.com/s/eh8O41X6xP1/1/m>).

The details for each case can be seen in Table 2.

Table 2: Demographic detail of seven participants

Pseudonyms	Level of participation PG/ LPG	Age	Gross Motor Function Classification system [9]	Communication Function Classification System [10]: Communication Aid*	Welsh Index of Multiple Deprivation Low % = high deprivation [38]
Bree	LPG	9	III	IV	99%
James	LPG	14	V	V	52%
Poppy(male)	LPG	9	IV	IV (Eye Gaze for iPad)	96%
Lily-May	PG	16	III	IV (iPad Go Talk)	96%
Matthew	PG	14	IV	IV	4%
Nick	PG	14	IV	III	99%
Clare	PG	9	IV	III-IV (GRID3 for iPad)	29%

The main differences between the two groups, reducing their level of participation, were health issues of epilepsy and pressure sores for James and Bree and significant pain for James and Poppy. Seizures interfered with James's physical health, and he was then often not well enough to participate; pressure sores limited water-based activities such as swimming for both James and Bree; Poppy had repeated episodes of stomach cramps and frequent bowel movements that hindered his participation outside the home.

The following findings demonstrate the across case comparison analysis. The final three themes and subthemes are shown in Table 3. These reflected the exploration from the research question about the children's views, experience and choices. Additionally, this fulfilled the aims to explore the barriers and facilitators to participation, looking for evidence of their well-being from their level of participation in recreational activities.

Table 3: Final across case themes and subthemes

Theme	Subtheme
1. Participation enhancers	i. Parental advocacy ii. Innovative designs iii. Reasonable adjustments iv. Equipped volunteers
2. Champions for disabled children's emotional wellbeing	i. Expressing choices to indicate well-being-self advocacy ii. Professional advocacy
3. Hindrances to participation	i. Undermining attitudes ii. Parental views of being treated differently iii. Impact of pain on participation

The findings are reported under each theme heading. Enhancers for participation were interpreted from indicators that were observed or reported through interviews, photographs and diaries which indicated the children's' well-being. Where the children were perceived to be enjoying the activity, a smiley emoji has been used to indicate well-being and to maintain their anonymity in the photographs. Both professional staff and the children themselves were seen to advocate for their well-being by promoting their participation. The hindrances to their participation were based upon parental opinion as it was not possible to observe how the children reacted when opportunities for participation were limited.

Theme 1: Participation enhancers

Parental advocacy

Parents were the key people to advocate for the participation of their children with complex cerebral palsy. Matthew's mother also influenced other parents:

"Yeah I'm a good advocate for the Surfability (organisation that provides surfing opportunities for disabled people) and the Ice-Cool Kids Skiing Group (charity that provides skiing experiences for disabled children). Yeah 'cos I get out there and I know how much we as a family have got out of doing these things...I think more people should....Well I'm always telling people and I got alorra people into it, actually, and I think it's good for parents cos I think alorra parents get a bit down thinking, there's nothing, I can't do anything...and there is stuff, you've just got to try it..."

Matthew's mother was promoting the two key opportunities, adapted surfing and skiing that he enjoyed participating in. Lily May's mother, as well as advocating for

her needs, was an advocate for other disabled young people as she was part of a local Parent's Federation for disabled young people. They were campaigning for Changing Places toilets, which is a UK based campaign to increase accessible toilets in community and public spaces which includes an overhead tracking hoist and changing bed. The need for accessible Changing Places toilets was echoed by all participants, as the lack of these limited how long they could stay at an external recreational activity. The importance of parental advocates was central to the children's stories; physically placing the children at a recreational activity gave them the choice to participate if they so wished. Thus, their physical position was key to participation.

Innovative designs

In addition to the adapted surfing and skiing, music and cycling featured more frequently in the data. Clare had developed musical compositions that were shared during the data collection interviews. An example of Clare's creativity is shown in Figure 5 where she was playing with the beamz toy during the first interview. This created sound when Clare's hand was moved across the invisible beam. The creation of these musical sounds was a way for her to express her enjoyment in composing as the tunes that she played during the interviews demonstrated joy for her as a proactive intent [55]. This was interpreted as a positive well-being effect for Clare, based upon the sound of intent framework thought to be a valid way to illustrate intentional musical activities.

Figure 5 Clare's beamz musical toy activated by hand movements.



Music also influenced her trike riding in the community as her mother's interview quote highlighted:

"Yes, she 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, it is a bit sort of off-roading and then back to the church and then along this road or she goes that way around the park. So long as she has got music, she'll do most things."

The addition of music to the trike basket, contributed to the positive emotional well-being impact from Clare's participation in cycling, as shown by her smiley emoji in Figure 6.

Figure 6 Clare cycling with her family.



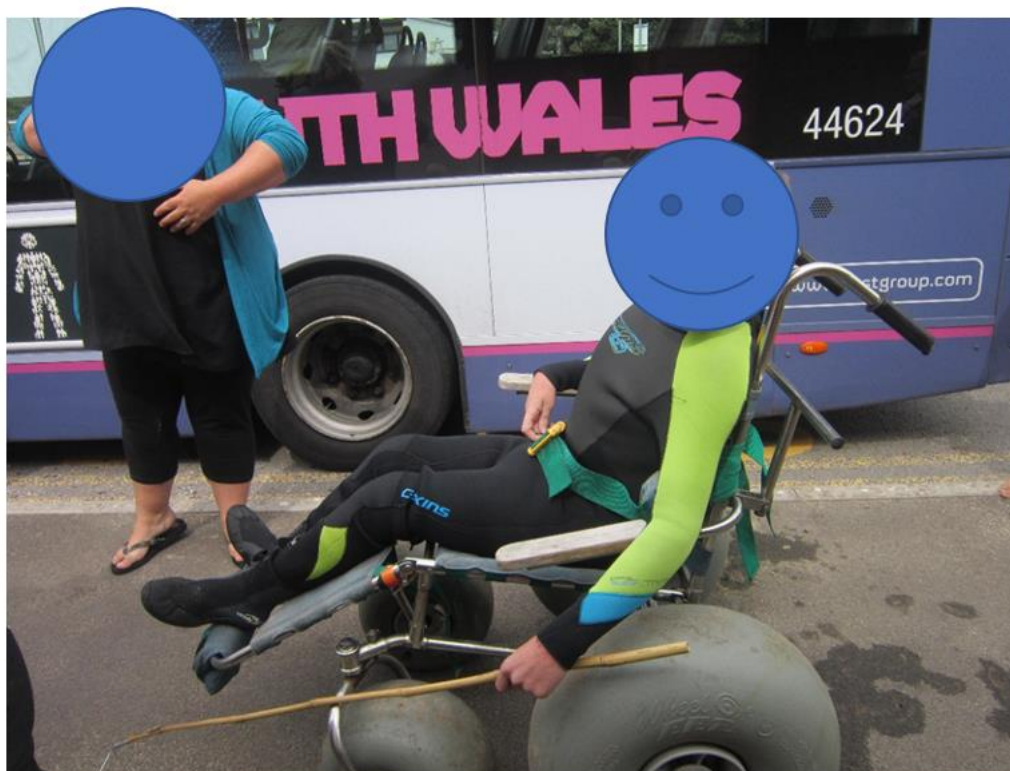
Bree also started cycling as recorded in her diary:

"My personal assistant sister, mum and I went to Pedal Power where I had an assessment for a bike. They decided a Tom Cat Trike was the best one for me I went for a ride along the caravan site and I really enjoyed it"

This was an enjoyable experience for Bree who could do this with support from her personal assistant and her family and was reported frequently in her diary as a new ongoing activity.

Matthew had been able to co-design a surfboard with a charity, which was now being used with many other disabled children, young people and adults. Matthew also had his own beach wheelchair that enabled access onto the beach, although at that time, there was no hoist or changing facility available there. This resulted in increased manual handling for his mother, putting her at risk for injury. Matthew can be seen in Figure 7 ready to surf, in his beach wheelchair, smiling in anticipation at the observation. The field notes recorded “*Matthew was visibly shaking with excitement and grunting very loudly, he became hoarse by the end of the surfing session*”. This was an example of his expression of his enjoyment and well-being.

Figure 7: Matthew in his beach wheelchair ready to surf.



Reasonable adjustments

There were musical and craft-based activities which others also found enjoyable, such as the Touch Trust (charity providing inclusive, creative, movement and multi-sensory sessions for adults and children with sensory needs) that Bree, Clare, Lily-May and James enjoyed. Also, a BBC Wales ‘relaxed’ orchestral performance was quoted as “*really good and inclusive*” by Bree’s mother:

“It 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 she could have a go with it, it was just really well thought through and organised..."

Accessible cinema showings had helped Poppy, Clare, James and Lily-May. James had fully participated in an adapted play-scheme, being gastrostomy fed outside as shown in Figure 8 from the observation.

Figure 8 James being gastrostomy fed outside at the play scheme.



His mother reported that if she fed James in a local park, she would have been stared at. Again, the limitation of a lack of Changing Places toilets restricted how long James could stay. Only one venue, Race Running (bespoke activity for CP now known as Frame Running), observed with Nick, had this facility. Thus, whilst innovative designs offer participation choices, it can still be challenging to increase the time the children can participate for, without the ability to change the children in private.

Theme 2: Champions for Well-being

Expressing choices to indicate well-being-self-advocacy

The children's behaviours appeared to show an intent to interact but the only way they could choose their recreational activity was by being given options of what they might like to do, for example, swimming or horse riding were offered to all participants. Weekly routines facilitated the children's regular participation. However, trying something different, typically involved a lot more effort and sometimes conflicted with existing family priorities. Additionally, parents were not always sure whether a new activity would be enjoyed.

Lily-May enjoyed the sandbox play used in the interview with toys to engage her on the topic. This included Lalaloopsy on the trampoline as shown in Figure 9.

Figure 9: Lily-May's story about trampolining with Lalaloopsy used in sandbox play.

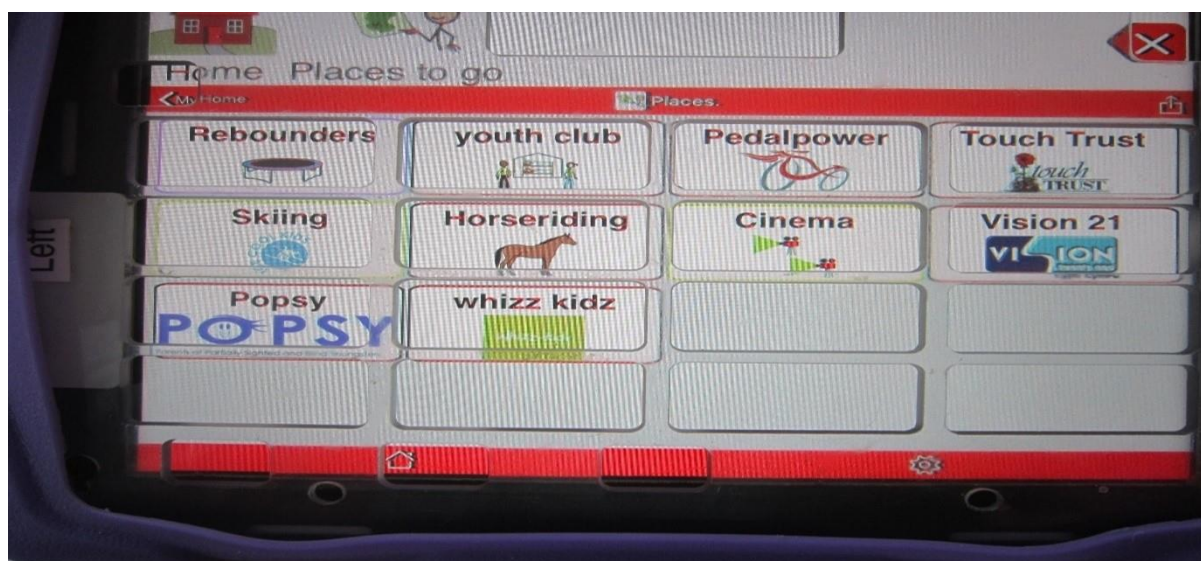


Lily-May also enjoyed being an ambassador for Whizz Kidz (charity working to transform the lives of wheelchair users across the UK, supporting them to become confident and independent young adults) which her mother recorded in the diary:

“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 Lily-May without a parent present, thus Lily-May was able to show her own self-determination by participating on her own, supported by others for her care needs. Lily May included Whizz Kidz as one of her recreational choices as shown in Figure 10.

Figure 10 Lily-Mays choices for recreational activities



Clare was creative with her stories and music making during both interviews. This was engaging for the researcher, adding confirmation about her participation in the study. Figure 11 shows a screen shot of Clare's choices, however, her finger coordination could be imprecise, making it difficult to ascertain her meaning at times.

Figure 11 Clare's recreational activity choices

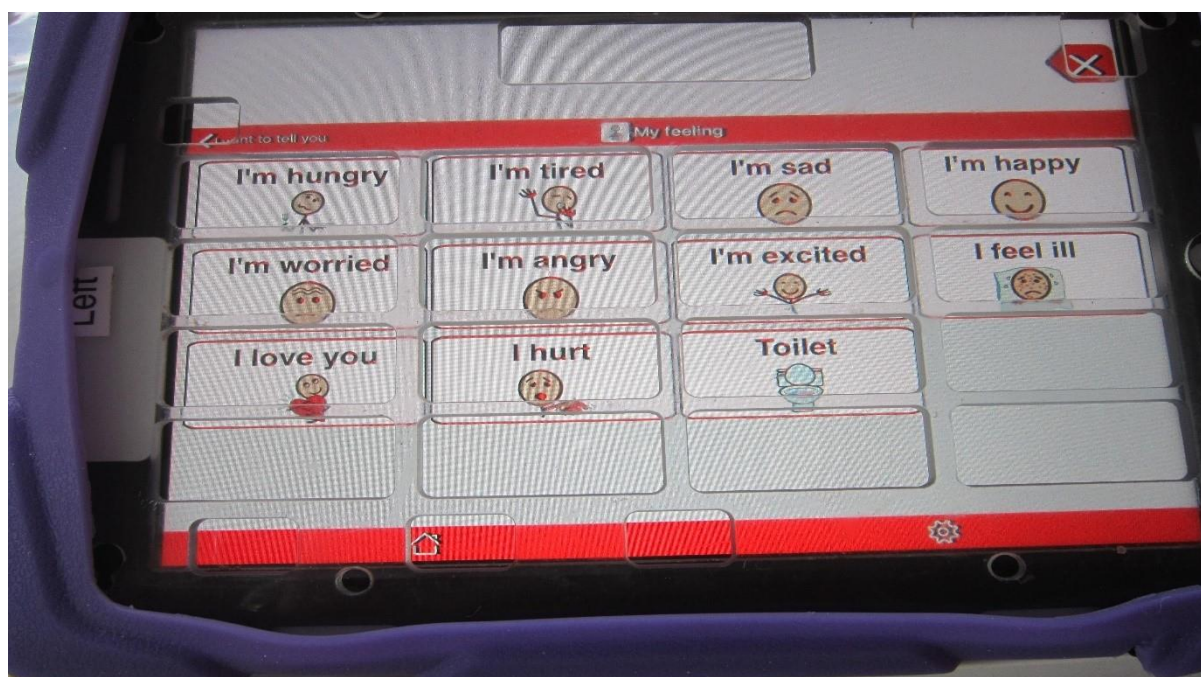


Expressing emotion

Lily-May and Clare both used their communication aids to express their choices for recreational activities. Figure 12 shows a picture of Lily May's choices of emotional responses on her touch screen, which she used during the interviews. As Lily May's fine motor control was limited, she was not always reliable in touching the correct space, despite the key guard on top of the screen. Thus, it was not always clear to the researcher what she was feeling during the interviews. Additionally, her

concentration was quite short, and she was asking what was for tea as she was hungry.

Figure 12 Lily-May's emotion grid



However, for some of the participants, staying involved in the activity was not always what they wanted to do, even when taken there, as the next section illustrates.

Choosing not to participate

Nick expressed his own choice not to participate, despite not having a physical voice. He self-advocated his wishes by his intentional behaviours, not to stay involved. For example, he was observed in the research not to engage in Frame Running but go off steering his powered chair and explore the sports hall, to watch other children playing tennis. Although Nick loved swimming, there were times he did not want to do this, even when it was available at his home, so he would drive his chair in the opposite direction. The children's parents described other ways in which their children chose not to participate in activities. For example, Poppy sometimes refused to cycle or walk, although he enjoyed these activities at other times. James closed his eyes and pretended to be asleep if he did not want to participate. Bree refused to use her walker and sit down if she did not want to participate, which was a challenge to manage outside.

Parents were able to report what their children's non-verbal cues meant related to their low well-being. This varied hugely from Poppy hitting his head, James's silent tears, Nick biting himself, Bree pulling her sister's hair, to Matthew's aggressive shouting and hitting out. Each of their expressions required a response from the parents, seeking to promote or maintain their children's well-being and reduce these harmful behaviours.

Professional advocacy

In addition to their own advocacy, parents noted some professionals supported their children through advocacy as well. Arguments had been made by Matthew's social worker, with adjustments of suitable recreational activities at his respite facility, advocating for his calmness as he had been distressed and aggressive previously when left on his own. An occupational therapist advocated for additional funding for a customized cot bed for Lily-May to improve sleep, reduce fatigue, and enable improved participation and enjoyment in her many recreational activities. Physiotherapists were reported to have previously been involved with the skiing, surfing, cycling and Frame Running groups as both initiators and volunteers.

Theme 3: Hindrances to participation

Undermining attitudes

Parents reported instances where their child's participation was hindered by unhelpful attitudes or behaviors of others. Poppy's parents perceived that even his special school did not include him as much in school trips, due to his inability to walk. Matthew's mother also reported that her son was discriminated against at a sports event, despite an advert claiming that the event was 'inclusive':

*".....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 sports event 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..."*

Clare's mother also experienced negative attitudes when seeking to enter some venues as Clare's large, powered wheelchair was placed on par with a pram. This was both at a literary festival and stately home where she was refused entry. Additionally, Nick's Dad was very disappointed with the decision that the Scout movement could not accommodate Nick. These negative attitudes highlight how the children were sometimes treated differently, as their needs had not been considered or adjusted for in the physical access.

Inaccessible environments

As disabled children need adaptations to participate in recreational activities, in this context, being treated differently was in relation to not adapting for their needs. This was highlighted for Poppy when he went to a farm that had a bat crawl, shown in Figure 13. This was difficult to get into in his wheelchair and no thought had been given as to how it could have been adapted. It was difficult to know if Poppy was aware that he was excluded from this activity, but his parents were sensitised to this oversight and were disappointed by this barrier to participation.

Figure 13: Poppy excluded from the bat crawl.



Another area that was restricted, was access to a beach. James's mother had future ambitions to get onto a beach, but the lack of hoist was a barrier to achieving this. Just having a beach wheelchair was not enough, as that involved manual handling from two or more people, increasing their risk of injury. Her interview quote highlights this issue:

"...I'd love to be able to get on the beach. Because I miss that. I like walking through the waves and things would be really nice, if we could do something like that. Because he'd get the sensory feedback about that and it's the fresh air..... There's a ramp down, but James's electric wheelchair sinks..... They have got beach wheelchairs, but they haven't got a hoist. So, I can't get him onto a beach."

Thus, beach access remained inaccessible for James during the study.

Clare had also been labelled a 'fire hazard' by the managers of an arena, when seeking to attend a pop concert. Her needs meant that she had to be treated differently for evacuation purposes. Clare's mother's interview highlights this issue:

"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".

It was clear that this risk to Clare was not one her mother was prepared to take and therefore she refused to go to the arena again, thus limiting Clare's engagement in musical events and minimising the potential positive emotional well-being impact. These examples illustrate that by not being able to be positioned at an activity, unnecessary barriers were created.

Discussion

This case study series explored the children and their parents' views, experiences and choices about their level of participation in recreational activities, by highlighting their voices authentically with the data extracts shared. The findings have described how the 'voices' of non-verbal children related to their participation may be understood through their intentional behaviours and parent- interpreted well-being responses. The children's level of participation was chosen by them once they were offered the opportunity at the recreational activity. They also highlight that these children can be their own advocates. The children chose their level of participation by engaging in the activity or not, as they preferred. However, it is important to recognise that these children's 'voices' are still subject to potentially inaccurate interpretation by parents and researchers, whereby the children's intentional meanings may be misrepresented.

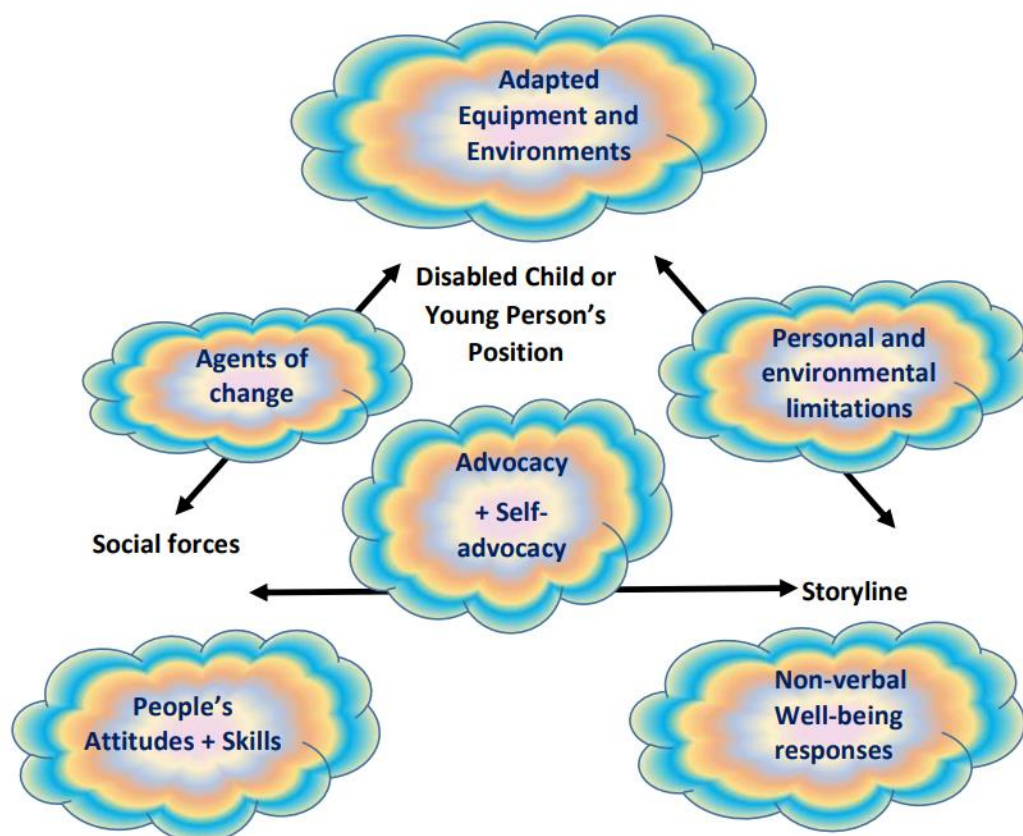
Shields et al [56,57] demonstrated that social participation was often preferred by those children with higher levels of physical disability, although those with learning disabilities were shown to lessen their level of participation as they got older. What this research adds is that if people make the reasonable adjustments for the disabled children to participate by either providing adapted equipment, suitable environments or being supportive in their attitudes, the children can choose to participate to benefit their well-being. Additionally, Lyons [31] demonstrated that if health, care and education staff attune to the needs of children with profound and multiple learning disabilities, they can interpret their comfort and discomfort, which will impact on their ability to participate in recreational activities. Whilst the interpretation of well-being can be subjective, without spoken language, the only way that people can interpret well-being from these children is by their intentional behaviours [32]. This study has offered data to illustrate aspects of the children's choices for them to indicate their well-being, from their level of participation. The two groups (PG; LPG) were distinct by the children's level of pain or epilepsy that limited participation in recreational activities, which is consistent with previous research [28-30]. This research adds to existing knowledge about the ability of non-verbal and non- ambulant children to self-advocate about their well-being, and positioning theory offers a way to explain this by including those without spoken language.

When considering positioning theory, the physical and metaphorical positions of the children, the social forces influencing their participation and their resultant storylines, the data from this study gave evidence of joy or sadness in their lives [50-52]. This

was based upon their observed behaviours and social interaction, not with a vocabulary of spoken language. Thus, this was different to how positioning theory was originally developed based upon verbal communication in nursery aged children. As the mutually determining triad was reconsidered, the idea of expressing well-being as a kaleidoscope, where the fluctuating colours representing different aspects of well-being, was developed. A kaleidoscope creates a visual multi-faceted image that can portray fluctuations in well-being. In this study, the bright colours of a kaleidoscope were illuminated from the enjoyable experiences that had enhanced the children’s well-being. This imagery also supports the idea that when participation choices were limited, the well-being ‘colours’ were diminished and duller, showing lower well-being. This kaleidoscope also related to their level of social engagement and revealed their own self-determination and control, by their intentional behaviours in choosing whether they participated or not.

This adaptation of positioning theory, not based upon spoken language, includes advocacy and self-advocacy at the centre of the triad as shown in Figure 14.

Figure 14 Kaleidoscope of Well-being adapted from Harré and Langenhove [50]

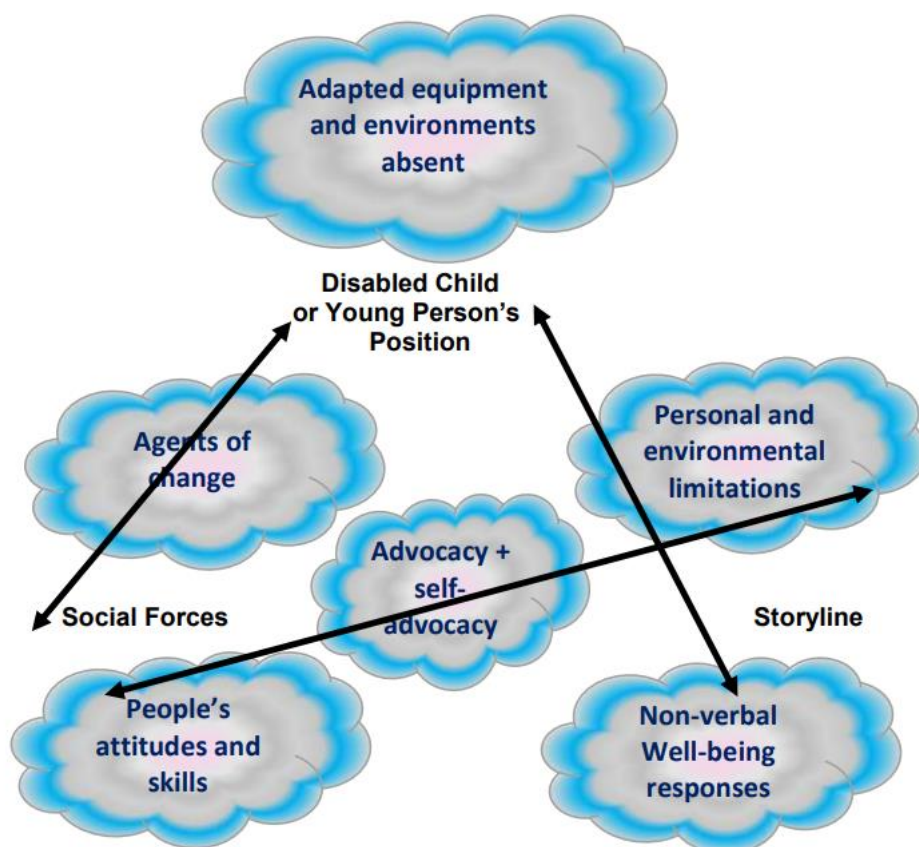


Advocacy is at the centre of this figure and child advocacy as suggested by Devakumar et al [23] proposes people acting as catalysts for change. However, the children being able to advocate for their own needs, gives greater control and

empowerment, thus acting as their own catalysts. Additionally, Tideman and Svensson [58] proposed that self-advocacy could promote a positive social identity for those with intellectual difficulties, which this study's data has shown.

Thus, the child's position is at the top of the triangle in figure 14 where equipment and environments are developed and adapted accordingly and relevant people support the children to participate. The children can then indicate their well-being from their non-verbal responses telling their own stories. The children, can become their own agents of change, supported by relevant people, who are part of the social influences that engaged the children in recreational activities. The colours highlight the vibrancy of their storylines, and their experiences can bring much fun and joy for them and their families, enhancing their well-being and supporting their social justice [34]. In contrast if any of these factors are not present the kaleidoscope can be skewed reducing the potential well-being effect and making the colours duller as shown in Figure 15. Thus, the triad is imbalanced and reflects the lack of enjoyment for the children and reduces their well-being.

Figure 15 Skewed Kaleidoscope of well-being



The change in colours and the skewing of the triangle in the kaleidoscope illustrate the intertwining of factors influencing well-being from the children's level of participation. These include a lack of suitable equipment or environments that restrict access, people's attitudes that undermine them which all reduce the child's

agency. For example, when the adapted equipment and environments are absent or relevant people do not advocate for the children's needs, they can still express their well-being, which may be diminished due to the paucity of their experiences. This can be reduced choices, if activities have not been adapted, such as the bat crawl for Poppy (Figure 13) or a lack of hoist to get into the beach wheelchair as for James. Here the adverse social influences (such as being ignored or not treated according to their needs) reduces the child's well-being potential due to a lack of participation.

Thus, this adaptation of positioning theory offers a way for their voices to be heard and promotes their well-being by observing and listening to their responses, from their intentional behaviours when choosing their level of participation in a recreational activity.

This opportunity to highlight how the children's voices can be heard, warrants further investigation as to how an observational well-being scale could be developed. Aspects observed such as comfort, engagement with others and joy for their families leads to the beginning of our understanding of well-being with this group of children. Although well-being remains a subjectively experienced phenomenon and it may not be possible to fully understand their perceptions of their well-being [32]. However, there is still the practice gap on the focus on participation, including signposting to recreational activities, which potentially reduces the well-being impact for these children.

Participation in practice

Practitioners in the United Kingdom currently demonstrate only a 30% uptake of setting participation goals and well-being is not yet as strong a focus in practice as it should become [59]. In Canada, Anaby et al [22] have now proposed a road map to facilitate bringing participation into routine clinical practice, with some emphasis on well-being. However, there is further scope for designers and policy makers to increase choices for the non-ambulant, non-verbal children. What is harder to change are people's attitudes, as that reflects wider societal values, where listening to alternative voices is not made easy. If disabled children are to be considered on an equal footing to all children, then their right to play and leisure opportunities needs addressing [3-5]. A shift is needed in how disabled children are viewed, to promote their own agency and not evoke pity. This paradigm shift has been proposed by Curran and Runswick-Cole [60-61] as a way of promoting a 'productive' childhood first. This links to the affirmation model of disability where a non-tragic view of disability is suggested, with a positive social identity as disabled [20]. Additionally, this approach has also been promoted by Gibson [19], who challenges healthcare practitioner's focus on measuring what children cannot do, rather than affirming and building on their strengths, including valuing them as people. Therefore, this research adds to expanding the disabled children's voices and their own ability to self-advocate for their well-being, promoting their social justice [6]. This is an important finding, especially in the geographic context of where this research was conducted, as the Well-Being of Future Generations (Wales) Act (2015) requires the development of well-being indicators for this marginalised group [3].

Study limitations

This case study series is a small sample restricted to Wales but has created rich data to illustrate the voices of non-verbal and non-ambulant children with CP. Given the nature of the case study design, data saturation was not expected, although a larger sample size might have facilitated this. It is not therefore expected that these findings can be generalised. However, there is potentially some transferability to other populations in the case study method, where people do not have spoken language. There was limited participation from children being able to state things in their own words, needing to rely on proxy reporting by their parents. Whilst efforts were made to reduce the researcher bias by using toys for engagement and unobtrusive observations, it was challenging to minimise the researcher's position of power. The diaries were proxy data and therefore limited in representing the child's own voice.

Areas for future research

Future research should consider how to include those without a physical voice in studies so their intentional behaviours can be given consideration to indicate their well-being. The lack of a valid and reliable measuring scale for well-being for non-verbal children remains a significant gap in knowledge. Further exploration about the domains that could inform such a scale could be based upon the data derived from this study with future consultation with interested stakeholders. This would help to include this underserved and marginalised group of children and young people, so their agency can be increased.

Conclusion

This paper has offered a way to authentically hear the voices of children and young people with cerebral palsy, from research carried out using a case study series. The data have illustrated their well-being responses from their level of participation in recreational activities, supported by relevant people who made reasonable adjustments. Whilst their choices remain limited, when appropriate adaptations were made to equipment and environments, their participation choices were enhanced and thus potentially their well-being. The proposed adaptation of positioning theory, illustrated by this kaleidoscope of well-being, promotes their ability to self-advocate, by choosing their level of involvement when attending a recreational activity. Practitioners, designers and policy makers should consider how they can promote the well-being opportunities for disabled children as their right to social justice. This can enhance their well-being and bring more fun and joy into their lives.

Conflict of interest:

The authors declare no conflicts of interest.

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