

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



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Children and youth with cerebral palsy's voices (GMFCS III-V) about the well-being effects from their level of participation in recreational activities



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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.

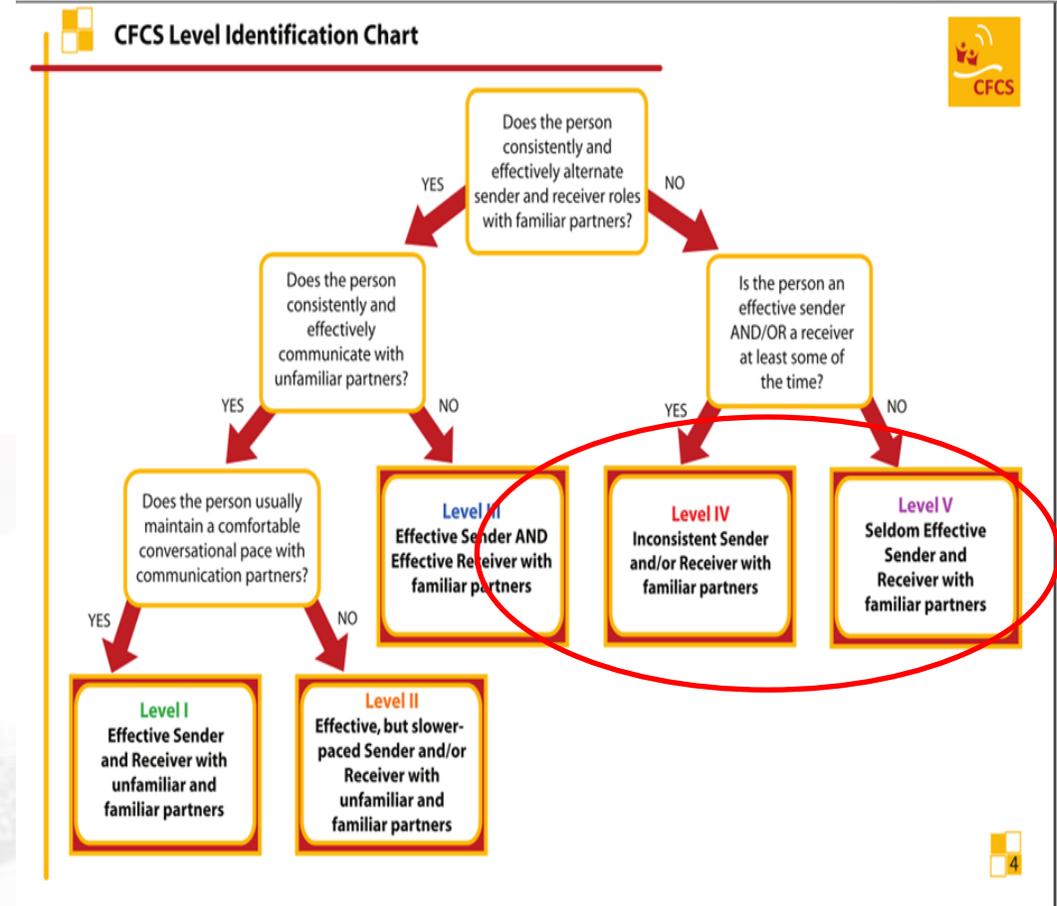
A comparative case-study design(Yin 2018) was developed.



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

GMFCS E & R between 6th and 12th birthday: Descriptors and illustrations

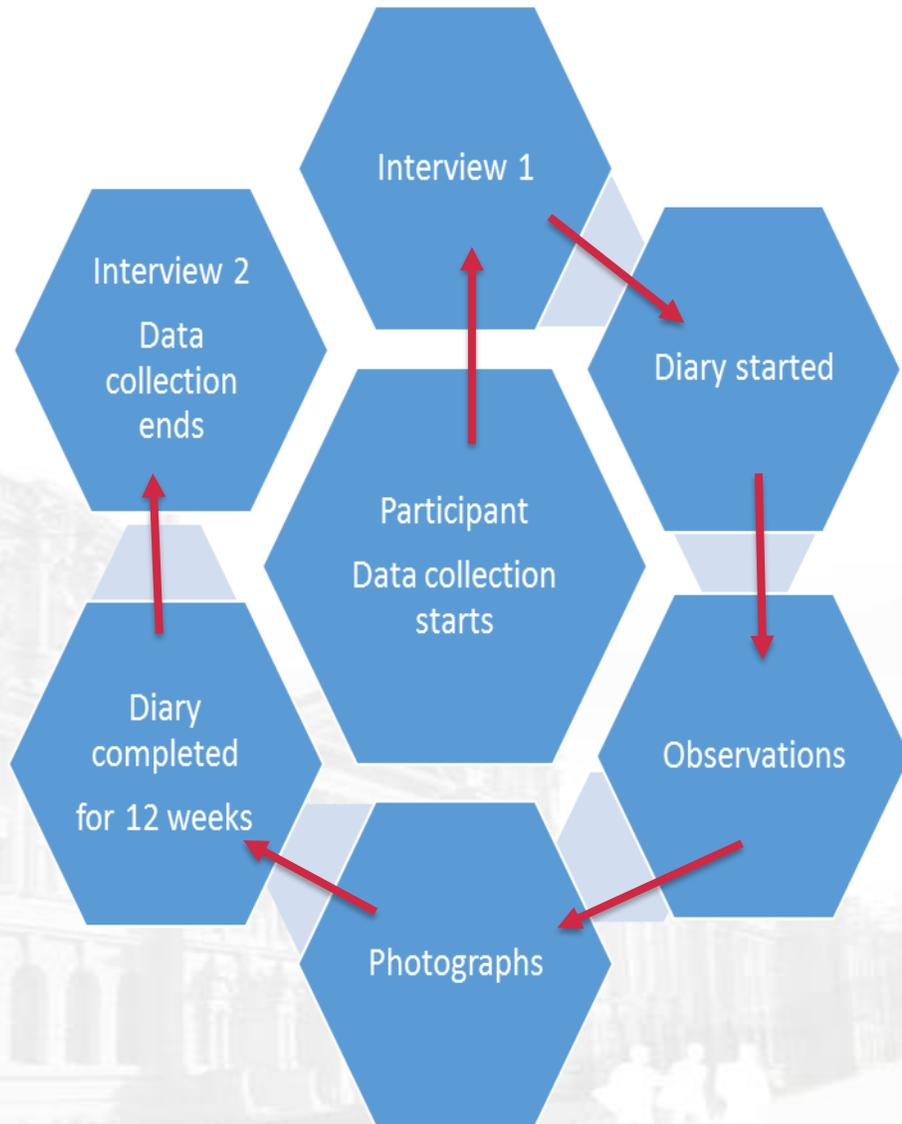
	<p>GMFCS Level I Children walk at home, school, outdoors and in the community. They can climb stairs without the use of a railing. Children perform gross motor skills such as running and jumping, but speed, balance and coordination are limited.</p>
	<p>GMFCS Level II Children walk in most settings and 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.</p>
	<p>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.</p>
	<p>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.</p>
	<p>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 posture and control leg and arm movements.</p>



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.



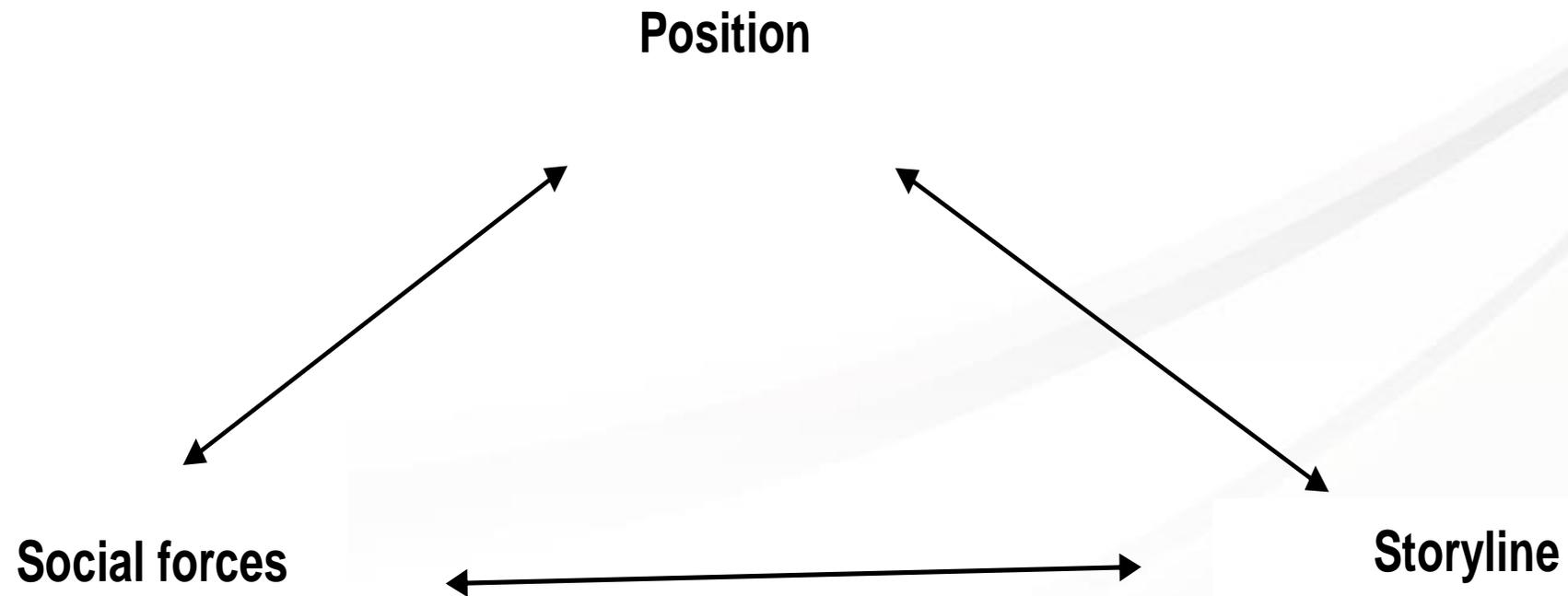


Figure 1: Mutually determining triad from Harré and Langenhove (1999 pg.18)



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**

Pseudonyms	Level of participation Participatory group (PG)/ Limited Participatory group (LPG)	Age	Gross Motor Function Classification system	Communication Function Classification System: Communication Aid*
Bree	LPG	9	III	IV
Clare	PG	9	IV	III-IV*
James	LPG	14	V	V
Lily-May	PG	16	III	IV*
Matthew	PG	14	IV	IV
Nick	PG	14	IV	III
Poppy(male)	LPG	9	IV	IV (Eye Gaze)



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.



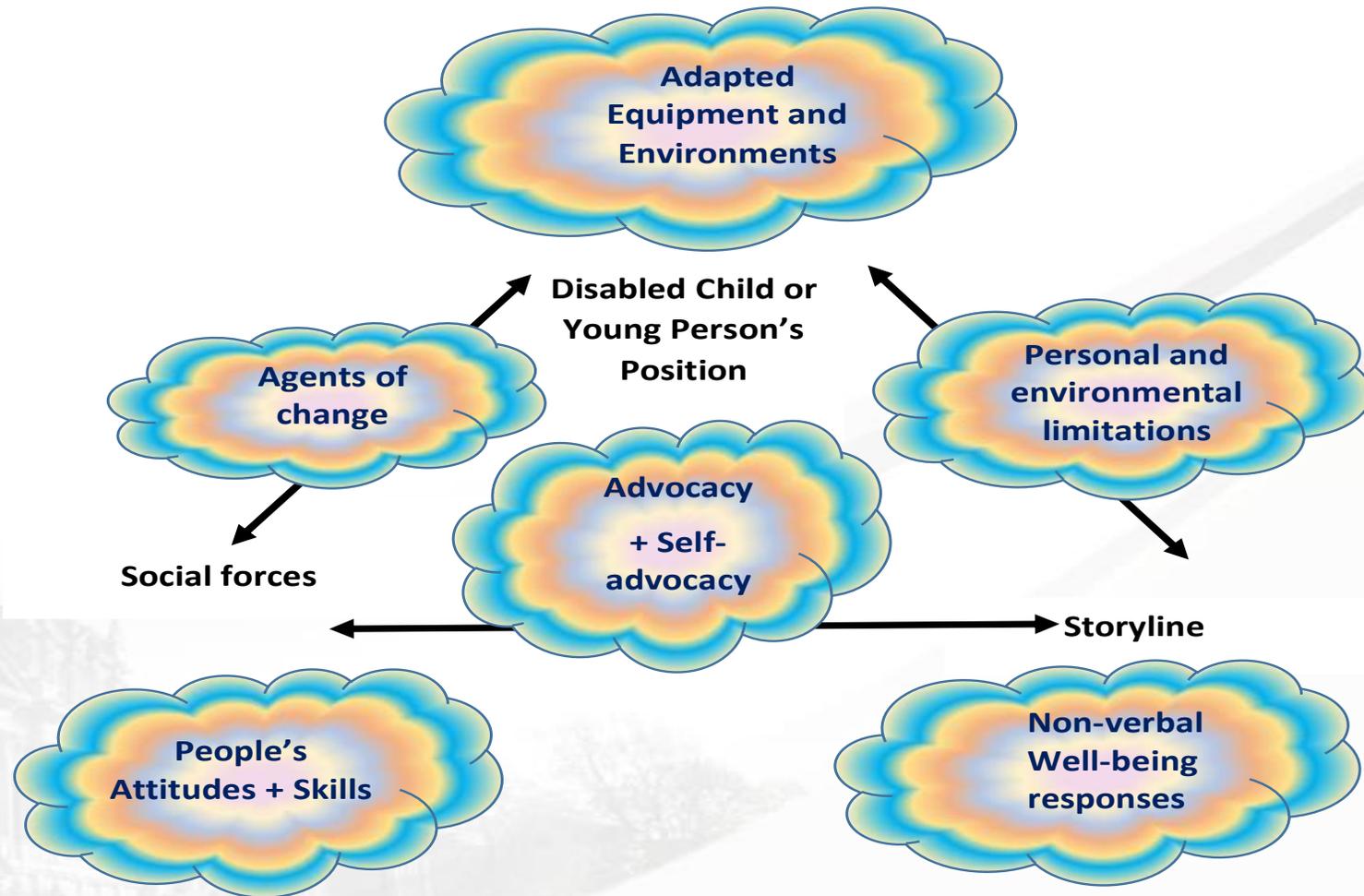


Figure 1: 'Kaleidoscope of Well-being' for disabled Children and Young People's participation in Recreational Activities - adapted from mutually determining triad from Harré and Langenhove (1999 pg. 18).



1. Participation enhancers:

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'



Participation observation field notes

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

"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,..."

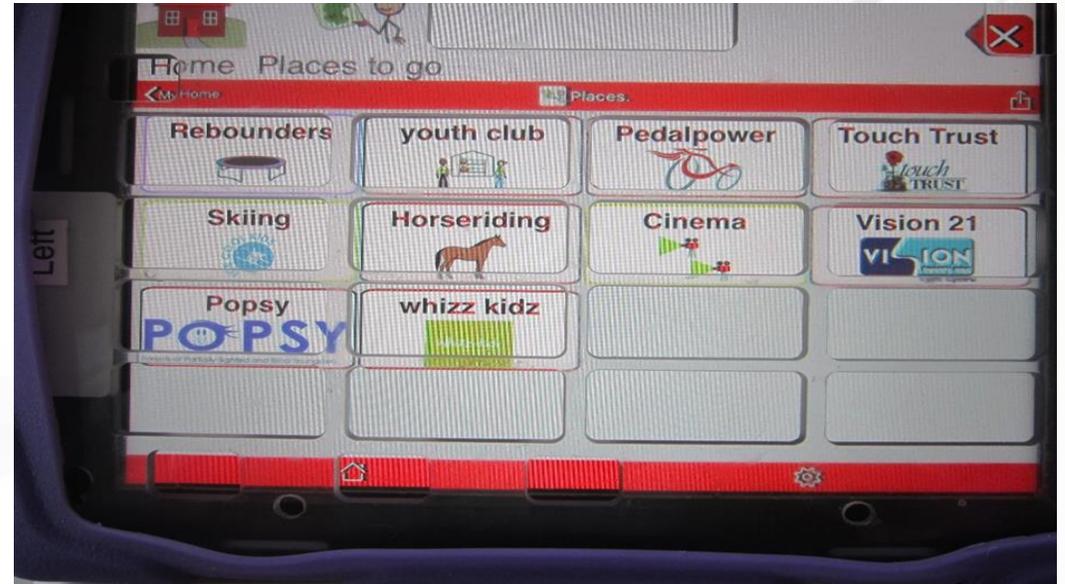


2.Champions for Well-being

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.



Lily May’s communication aid



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..."*



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.



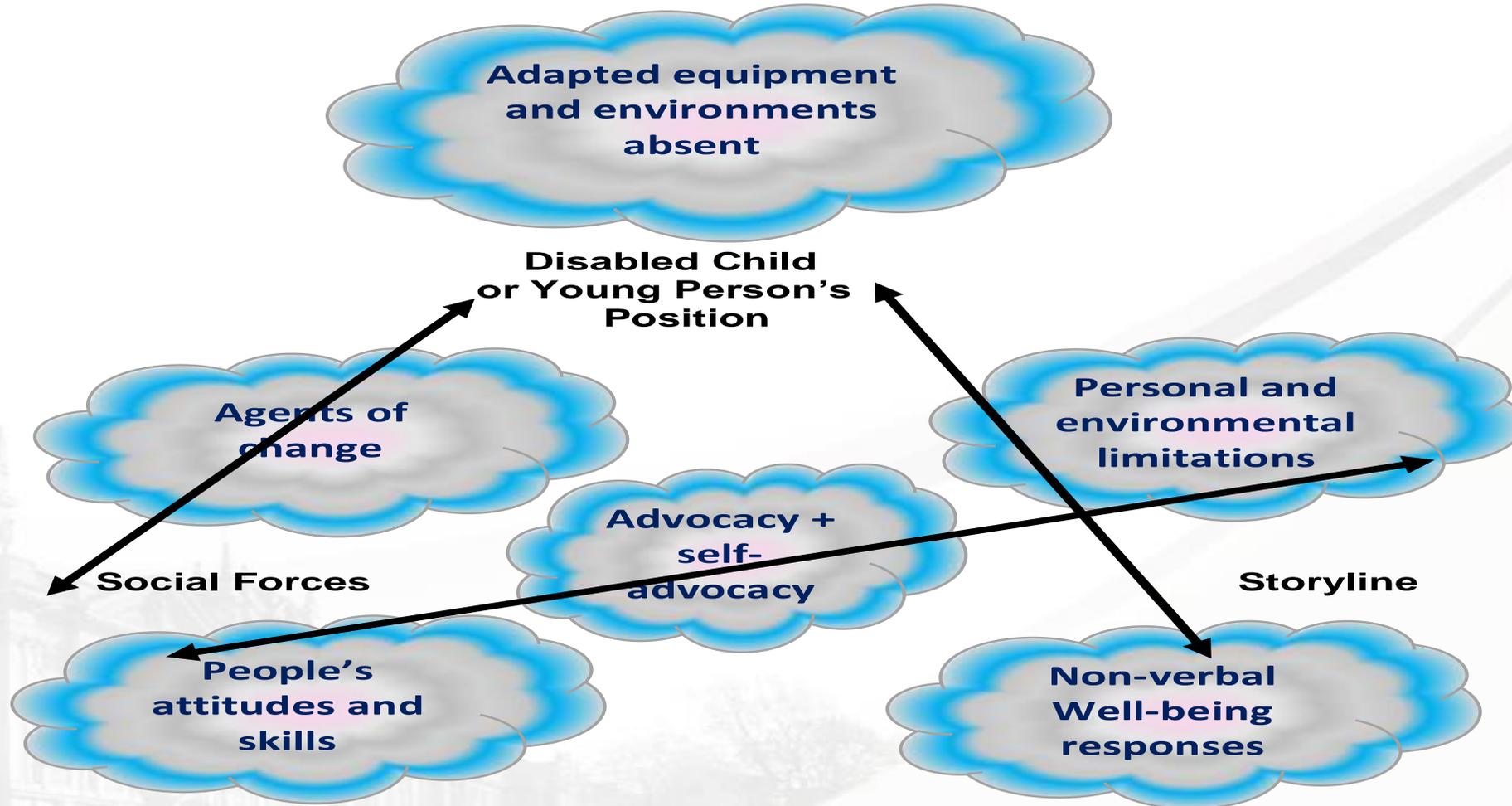


Figure 2: 'Kaleidoscope of well-being' illustrating skewed mutually determining triad with grey clouds when factors adversely affected well-being.



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.

Likert scale	1	2	3	4	5
	Poor	Low	Usual	Good	Excellent
Appetite level					
Bowel Movements					
Calmness					
Comfort					
Creativity					
Engagement with other people					
Expressing joy					
Involvement in activities					
Sleep quality					
Self-harming behaviours					



- Braun V. and Clarke V. 2013. Successful qualitative research: A practical guide for beginners. Los Angeles: Sage.
- CanChild (2021) Gross Motor Function Classification system- Expanded and Revised
<https://canchild.ca/en/resources/42-gross-motor-function-classification-system-expanded-revised-gmfcs-e-r>
- Curran T. and Runswick-Cole K. 2013. Disabled Children's Childhood Studies: Critical Approaches in a Global Context. Basingstoke: Palgrave Macmillan.
- Harré, R. and Langenhove, L. 1999. Positioning theory: moral contexts of intentional action. Malden, Mass.: Oxford
- Hidecker, M. J. et al. 2011. Developing and validating the Communication Function Classification System for individuals with cerebral palsy. Dev Med Child Neurol 53 704-710.
- Imms, C. et al. 2016. 'Participation': a systematic review of language, definitions, and constructs used in intervention research with children with disabilities. Developmental Medicine & Child Neurology 58(1), pp. 29-38. 30(2), pp. 175-186.
- Laevers, F. (1996) The Leuven scale of WB and involvement available from:
<https://www.earlylearninghq.org.uk/earlylearninghq-blog/the-leuven-WB-and-involvement-scales/>
- Mpundu-Kaambwa, C. et al. 2018. A review of preference-based measures for the assessment of QoL in children and adolescents with cerebral palsy. Quality of Life Research 27(7), pp. 1781-1799.
- Play Wales. 2013. Article 31 resources [Online]. Play Wales. Available at: [Accessed: 16.06.16].
- Rosenbaum, P. and Gorter, J. W. 2012. The 'F-words' in childhood disability: I swear this is how we should think! Child Care Health Dev 38(4), pp. 457-463.
- United Nations Children's Fund. 1989. United Nations Convention on the Rights of the Child [Online]. New York: UNICEF. Available at: http://www.unicef.org/crc/files/Rights_overview.pdf pg.10 [Accessed: 24.02.16].
- Yin, R. 2018. Case study Research: designs and methods. 6th ed. Los Angeles: Sage Publications.

