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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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- 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



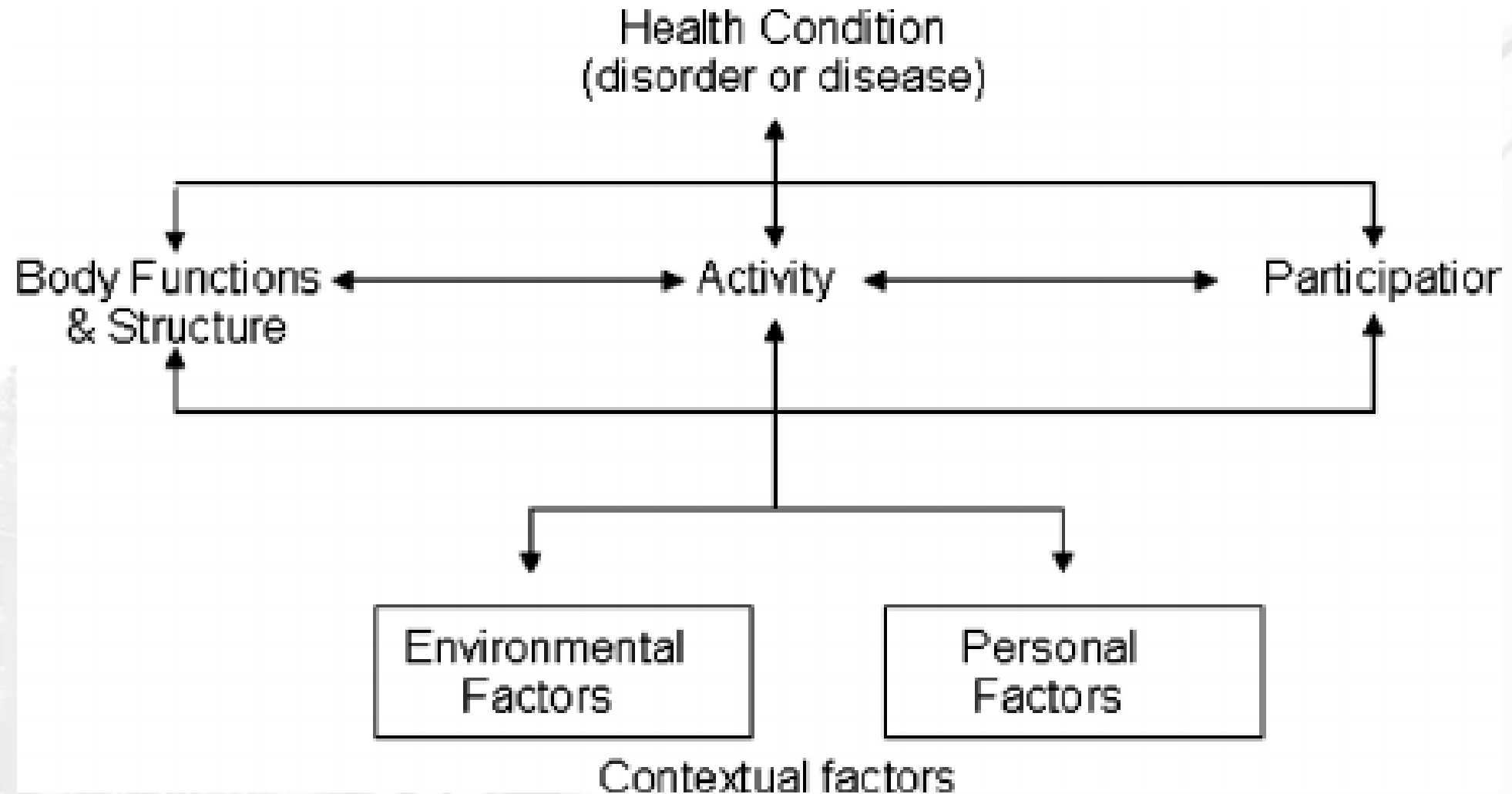
- Clinical background as a physiotherapist in the NHS
- Concern for non-ambulant and non-verbal children- are we doing enough?
- Opportunity to carry out a staff PhD part time in 2015-2021

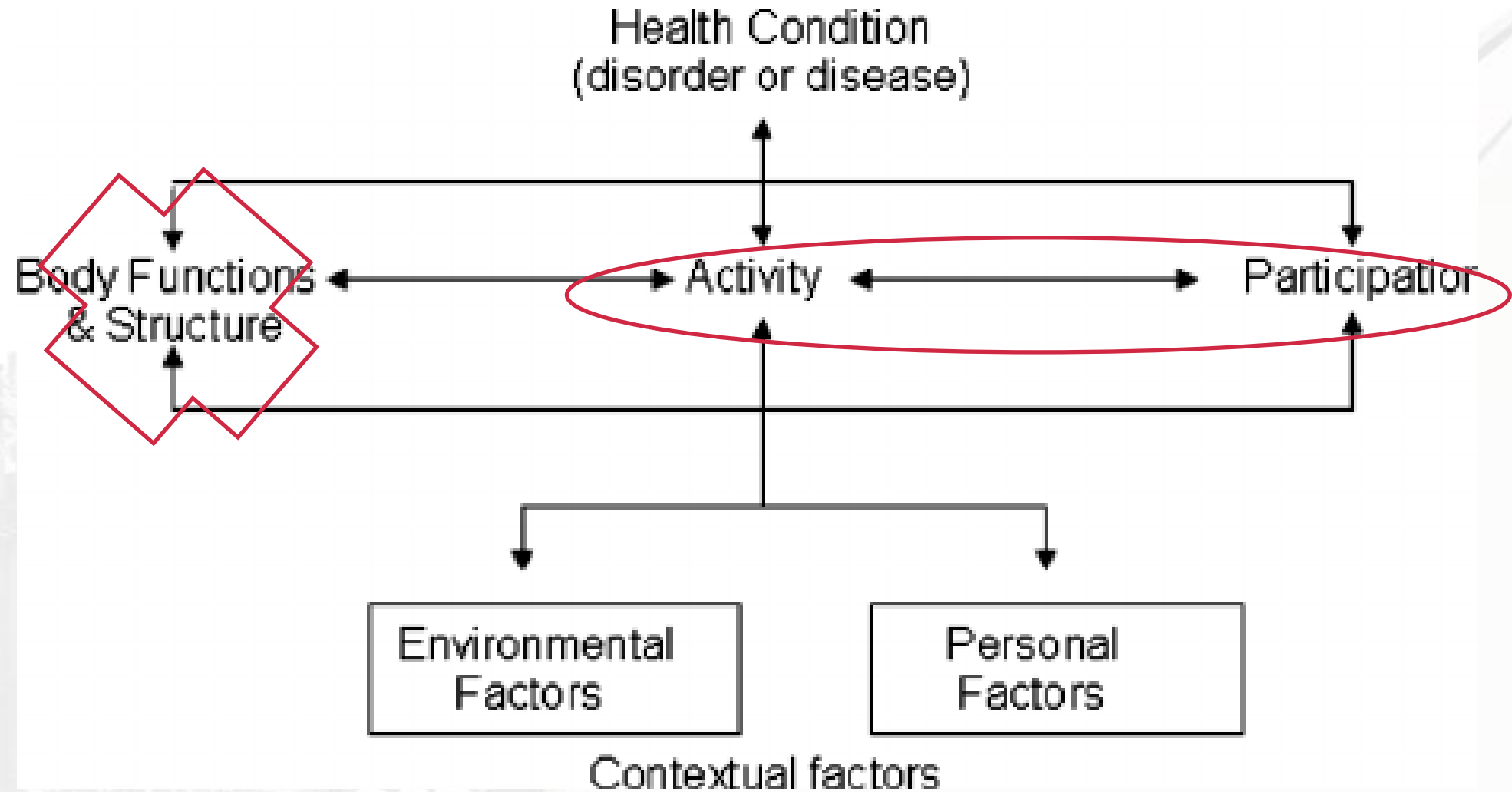


“Cerebral Palsy describes a group of permanent disorders of the development of movement and posture, causing physical activity limitation, that are attributed to non progressive disturbances that occurred in the developing foetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy, and by secondary musculoskeletal problems.”

Rosenbaum et al, 2007







“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).

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)

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



Cerebral palsy- functional classification systems

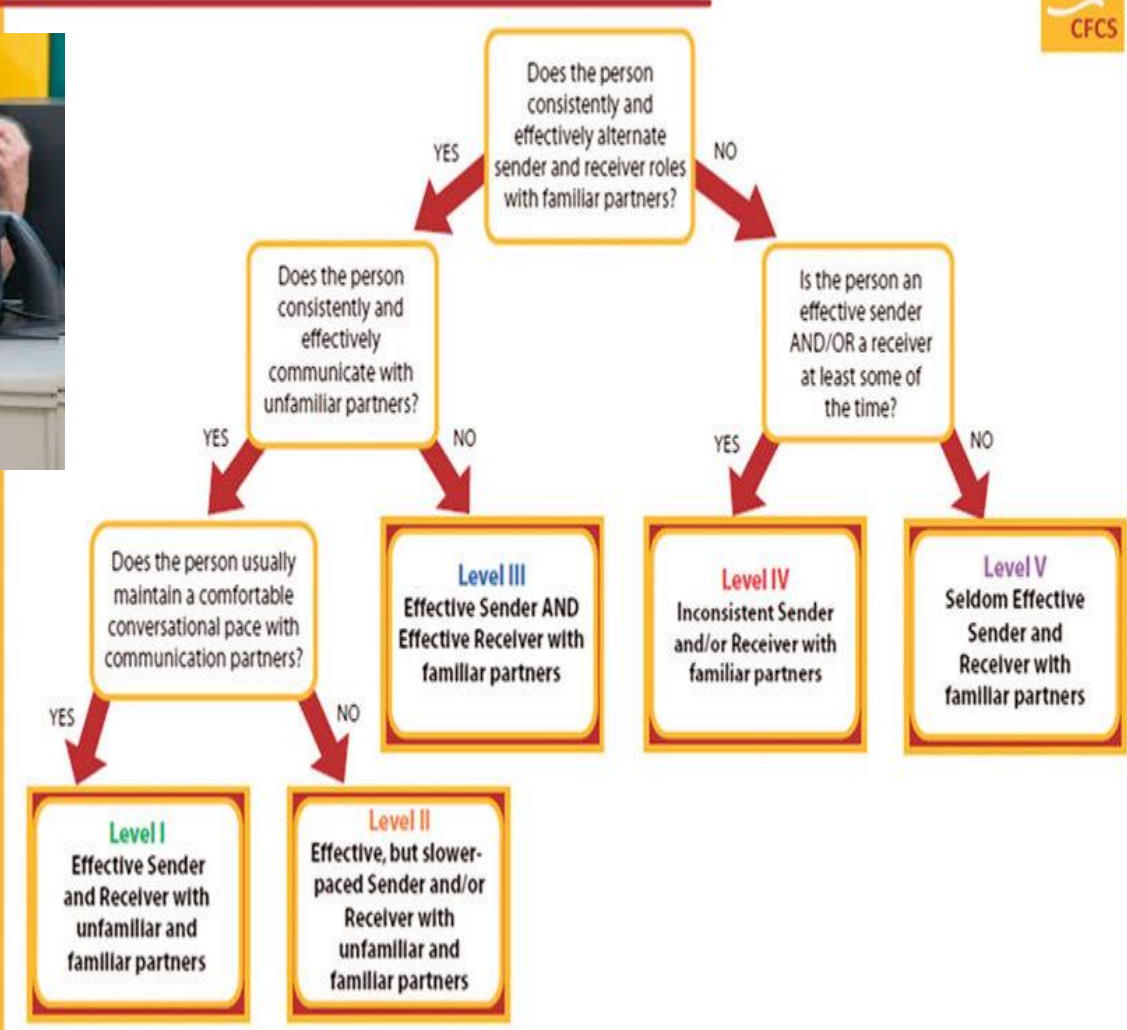
GMFCS E & R Descriptors and Illustrations for Children between their 6th and 12th birthday

	<p>GMFCS Level I</p> <p>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</p> <p>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</p> <p>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</p> <p>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</p> <p>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.</p>

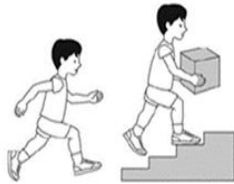
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CFCS Level Identification Chart

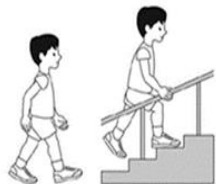


GMFCS E & R Descriptors and Illustrations for Children between their 6th and 12th birthday



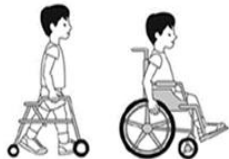
GMFCS Level I

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



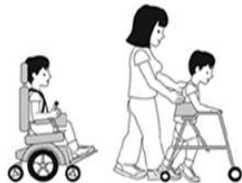
GMFCS Level II

Children walk in most settings and climb stairs holding onto a railing. They may experience difficulty walking long distances and balancing on uneven terrain, 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.



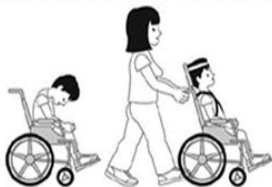
GMFCS Level III

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 travelling 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

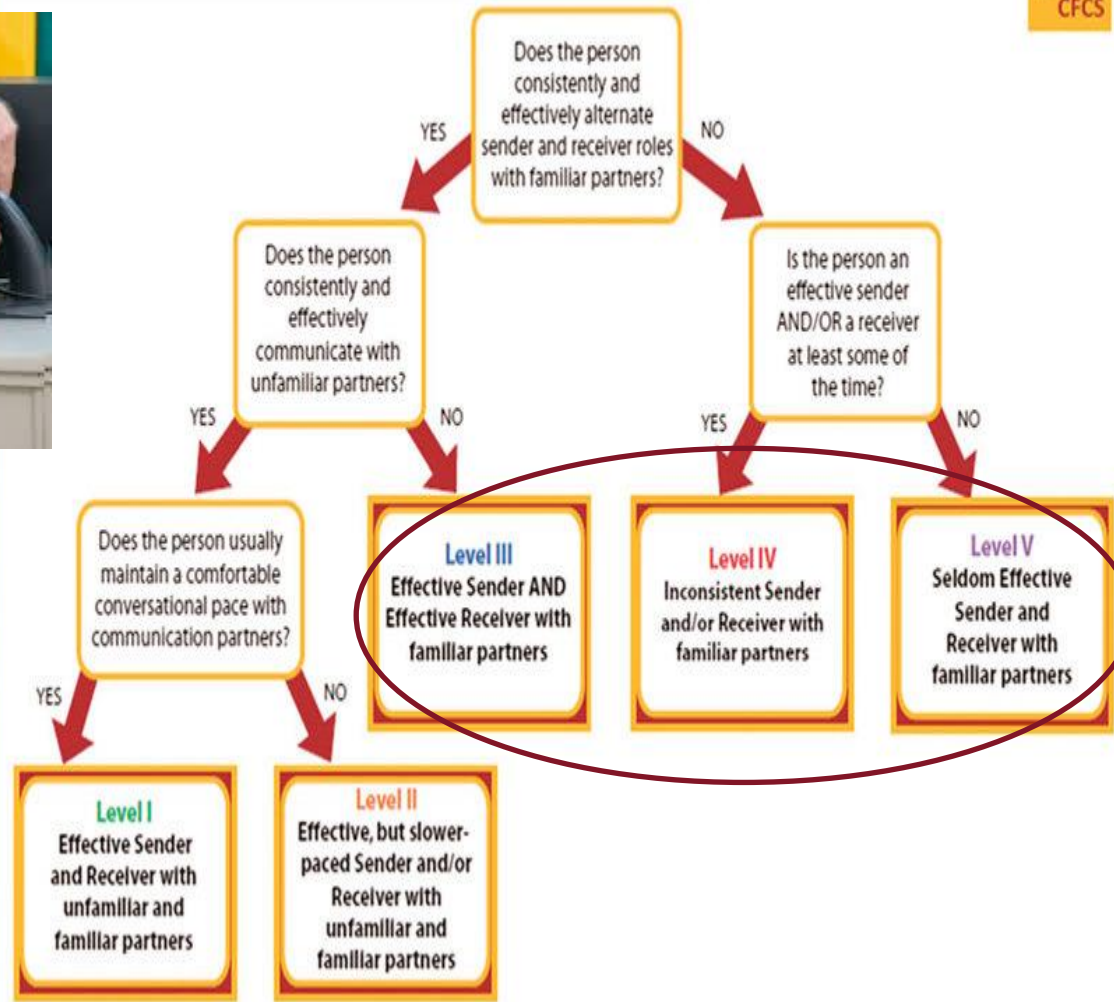
Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements.

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CFCS Level Identification Chart



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).



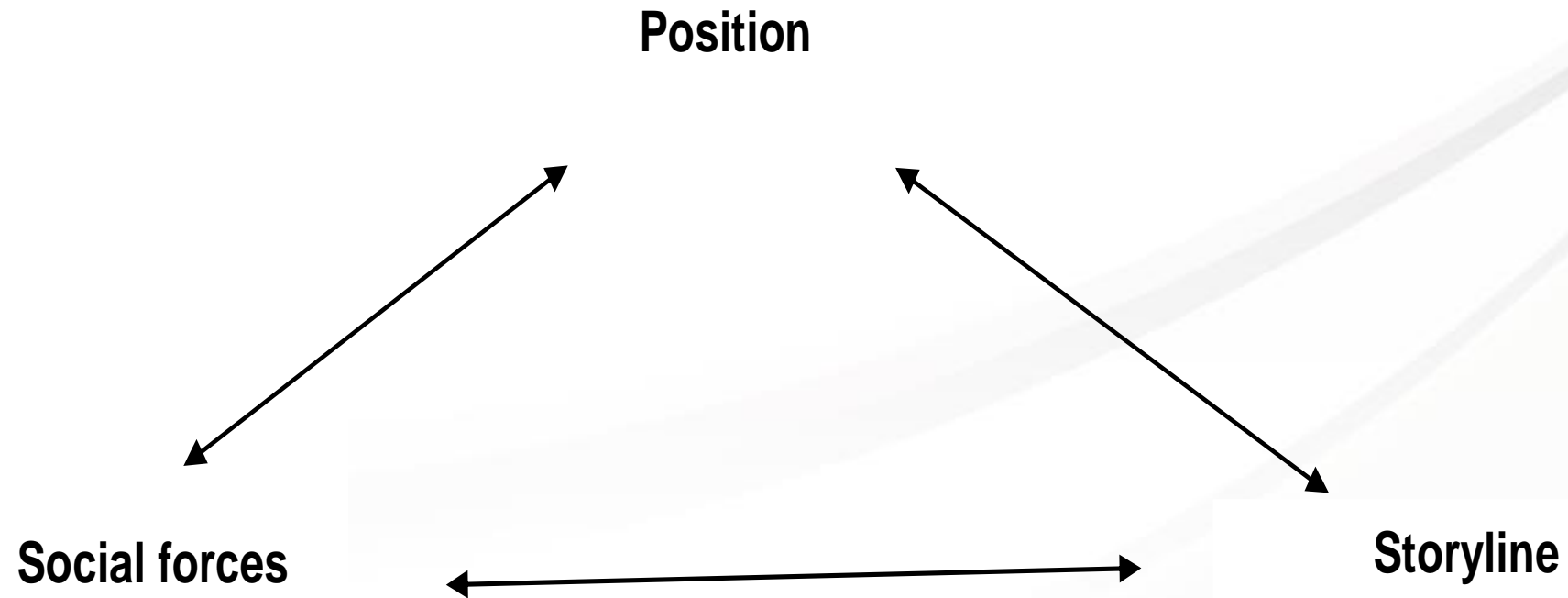


Figure 1: Mutually determining triad from Harré and Langenhove (1999 pg.18)



'Mosaic' of individual data sources to make up each single case study

Consent / assent process

2 interviews: 12 weeks apart

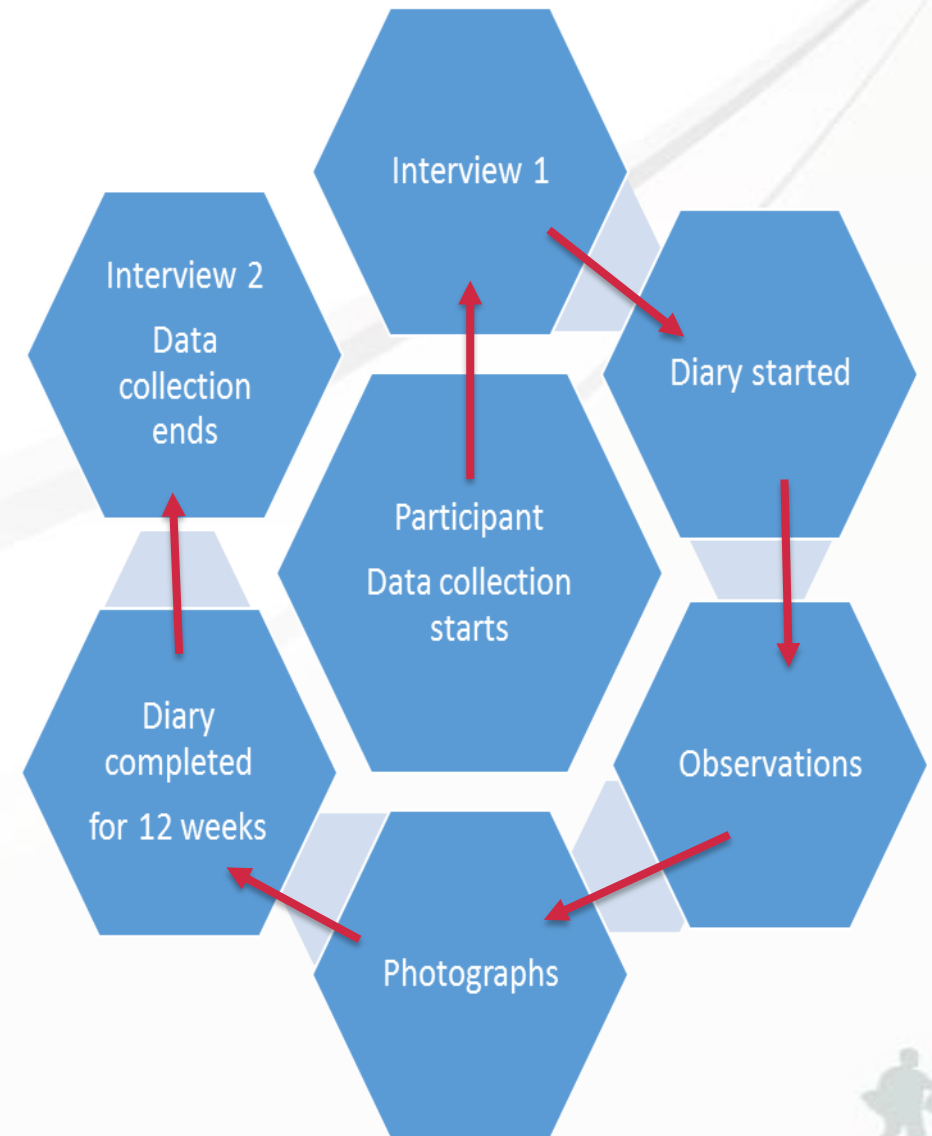
Diary kept in between by parents

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 of codes- mapped to research question and aims

'Nick' Data sets (PG)	Views (by proxy Dad/ Mum/ carers) [number of entries]	Experiences:	Choices	Emotional well-being indicators
<p>Interview 1 1 hour, 5 mins, 22 seconds Dad and Mum briefly towards end.</p>	<p>Caring demands high- can't walk or talk (7), Deaf (1), He's not demanding (4), Love him to bits (1), Placid (3), Severely disabled child (20), Stigma of using term autistic tendencies? (1)</p> <p>Barriers: Access to hoist (10) Disappointment when not included in community activities (2), 'How disabled is he?'- uniformed organisation for secondary age (1), Still on own- in bubble (1), Volunteers (4) - these are both a facilitator and barrier.</p>	<p>Bike riding (20), Carers/ Respite at home mainly (18), Charity trips (5), Drive in car/van (9), Drive Powered wheelchair (7), Front of car (2), Museums (3), Park (3), Race Running (5), Sailing (8), School (44), Skiing (3), Swimming (1), Watching people (1).</p>	<p>Control of eating (2), Drive own powered wheelchair to shop for food (2), Out in car/ van for drive (9), Repetitive behaviours (1), Spinning spinner (7), Swimming (2).</p>	<p>Hard to read as benign and tolerant.</p> <p>Positive: Shows happiness by smiling and clapping (18), Spinning spinner (7).</p> <p>Negative: Goes very quiet when unhappy (2), Maybe tearful or gestures (uses Makaton sign language) when unhappy (1).</p>

Theme	Sub-themes
Enablers for participation	Volunteers, Respite choices
Well-Being indicators	Nick's behaviours, Parent's emotional responses



Results- participants demographics

PG/ LPG	Name (Pseudonym)	Age	Gender	Gross Motor Function Classification System	Communication Function Classification System	Family	Welsh Index of Multiple Deprivation
LPG	Bree	9	Female	III	Non-verbal/ IV	<u>Mother</u> , Father, older step brother and younger sister	99%
PG	<u>Clare</u>	9	Female	IV	Communication aid III-IV	Single <u>Mother</u>	29%
LPG	James	14	Male	V	Non-verbal/ V	Looked after child, single foster <u>mother</u>	52%
PG	<u>Lily-May</u>	16	Female	III	Communication aid IV	Single <u>Mother</u> , younger sister	96%
PG	Matthew	14	Male	IV	Non-verbal/ IV	<u>Mother</u> , Father, younger brother and sister	4%
PG	Nick	14	Male	IV	Non verbal III	<u>Mother</u> , <u>Father</u> , younger brother, older sister	99%
LPG	Poppy	9	Male	IV	Non-verbal- Eye Gaze Technology/ IV	<u>Mother and Father</u>	96%

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.



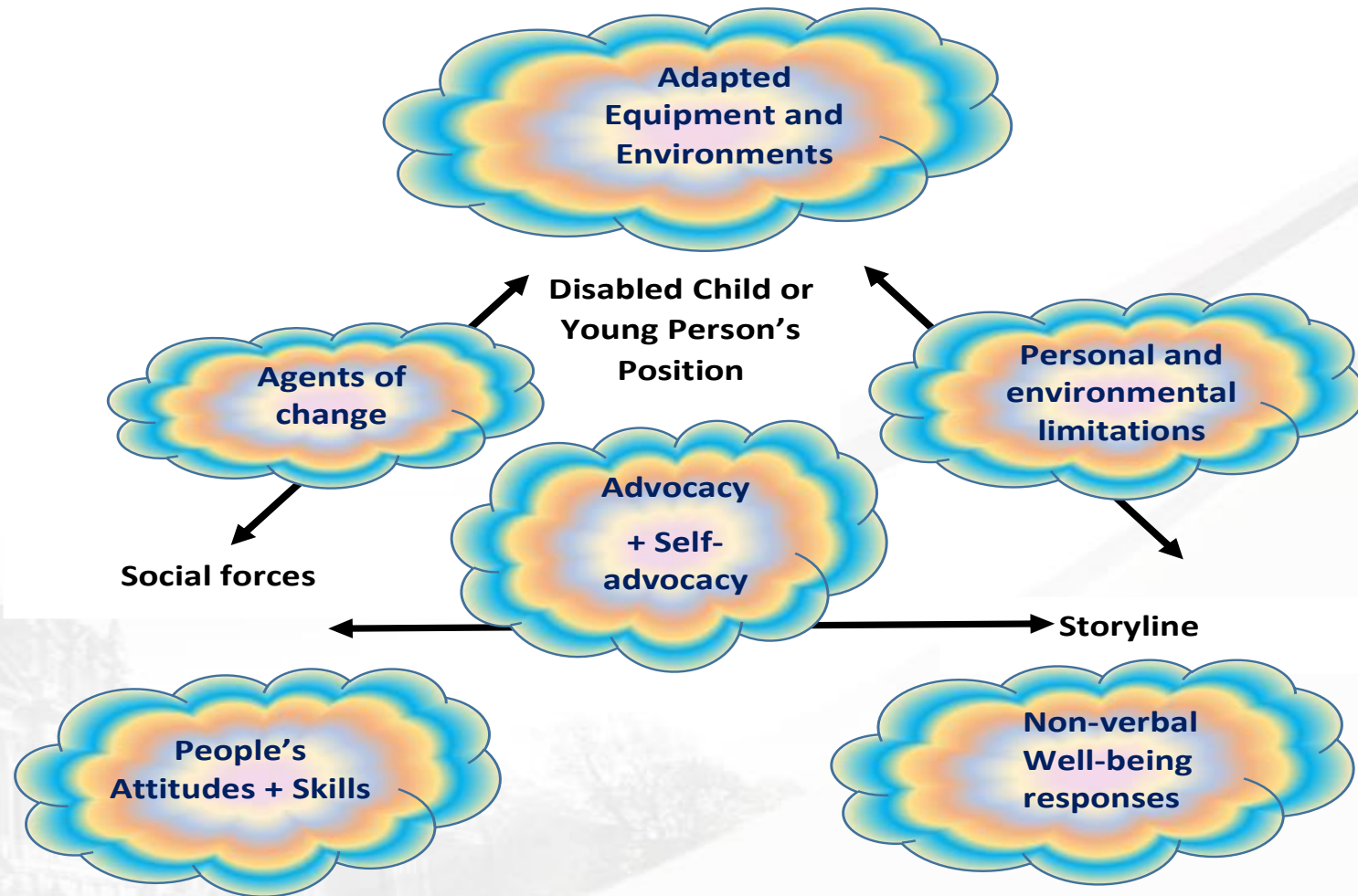


Figure 1: 'Kaleidoscope of Well-being' for disabled Children and Young People's participation in Recreational Activities - adapted from mutually determining triad from Harré and Langenhove (1999 pg. 18).



1. Participation enhancers:

Interview 1

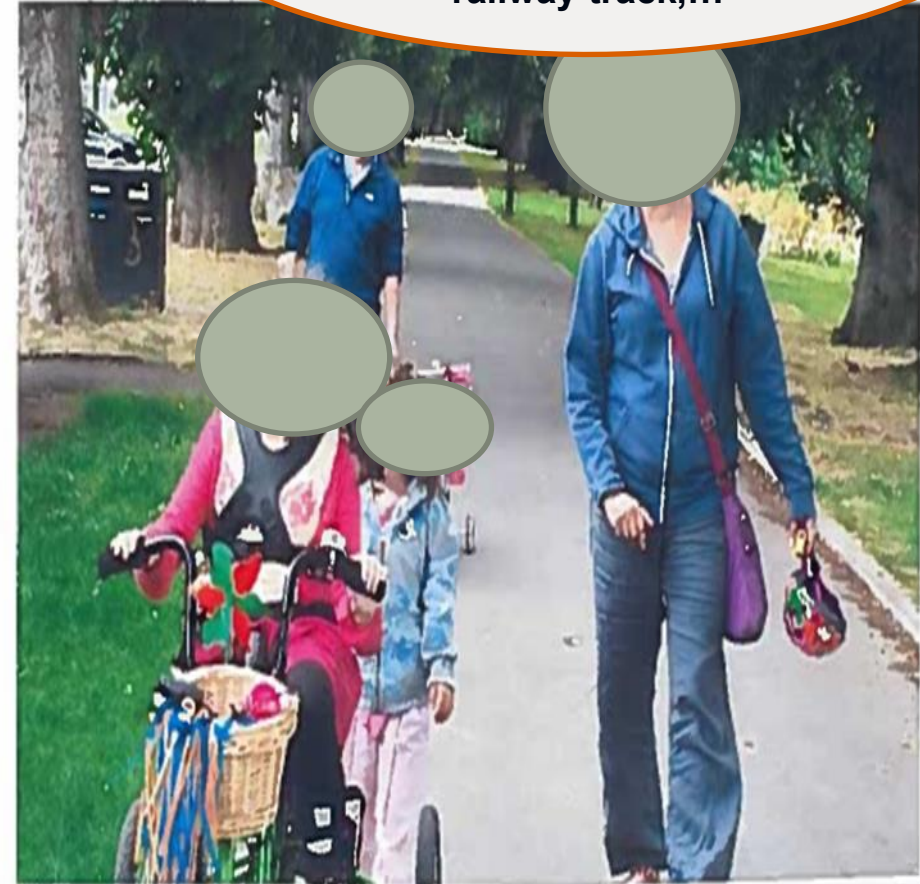
'This is the best feeling ever, to see your child so happy, you can forget about all the worries or hospital appointments and just for that moment see him on the waves, it's amazing'



Participation observation field notes

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

"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,..."



Interview 2



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.



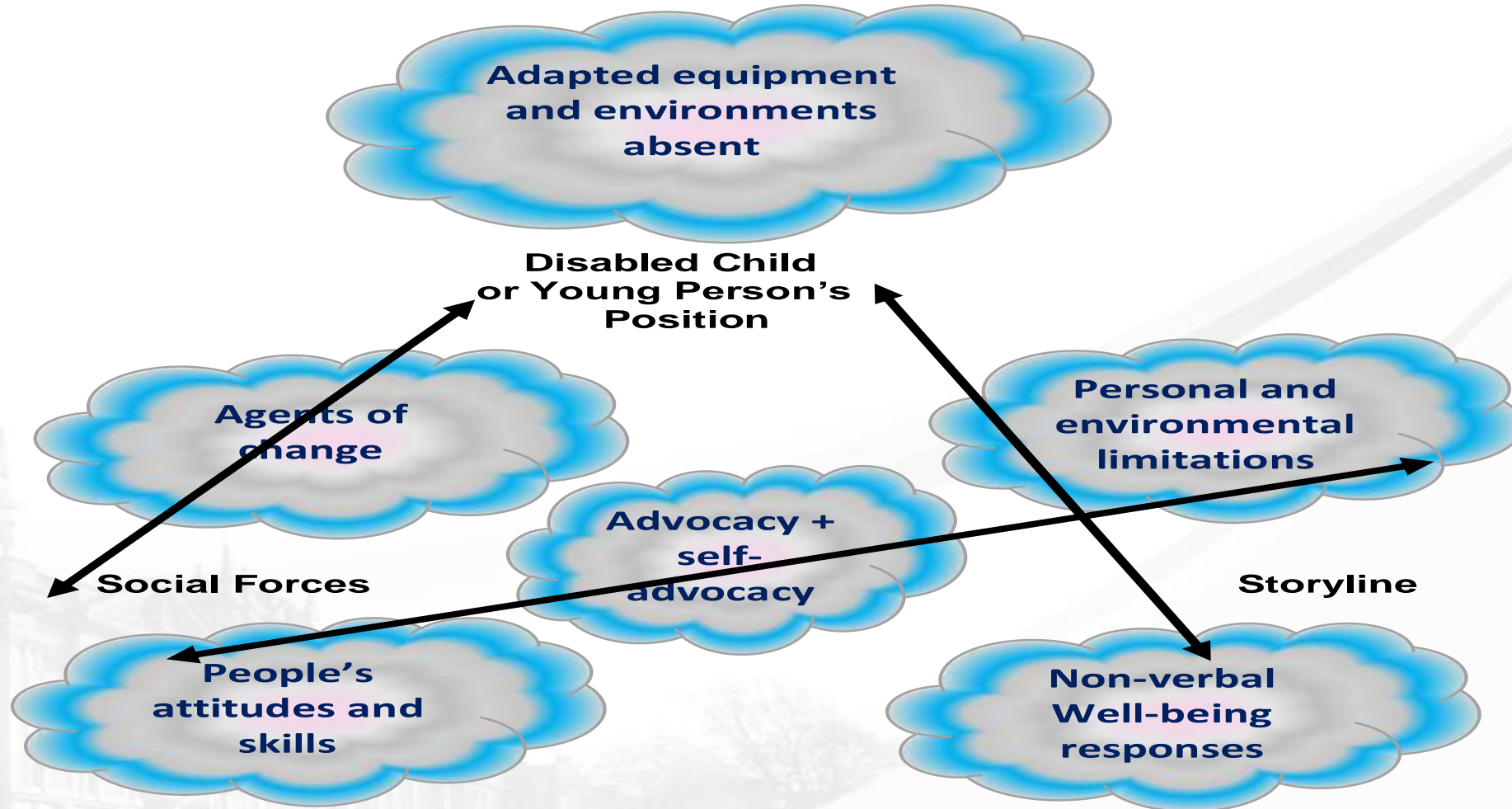


Figure 2: 'Kaleidoscope of well-being' illustrating skewed mutually determining triad with grey clouds when factors adversely affected well-being.



3. Hindrances to participatory experiences

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:

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".



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)

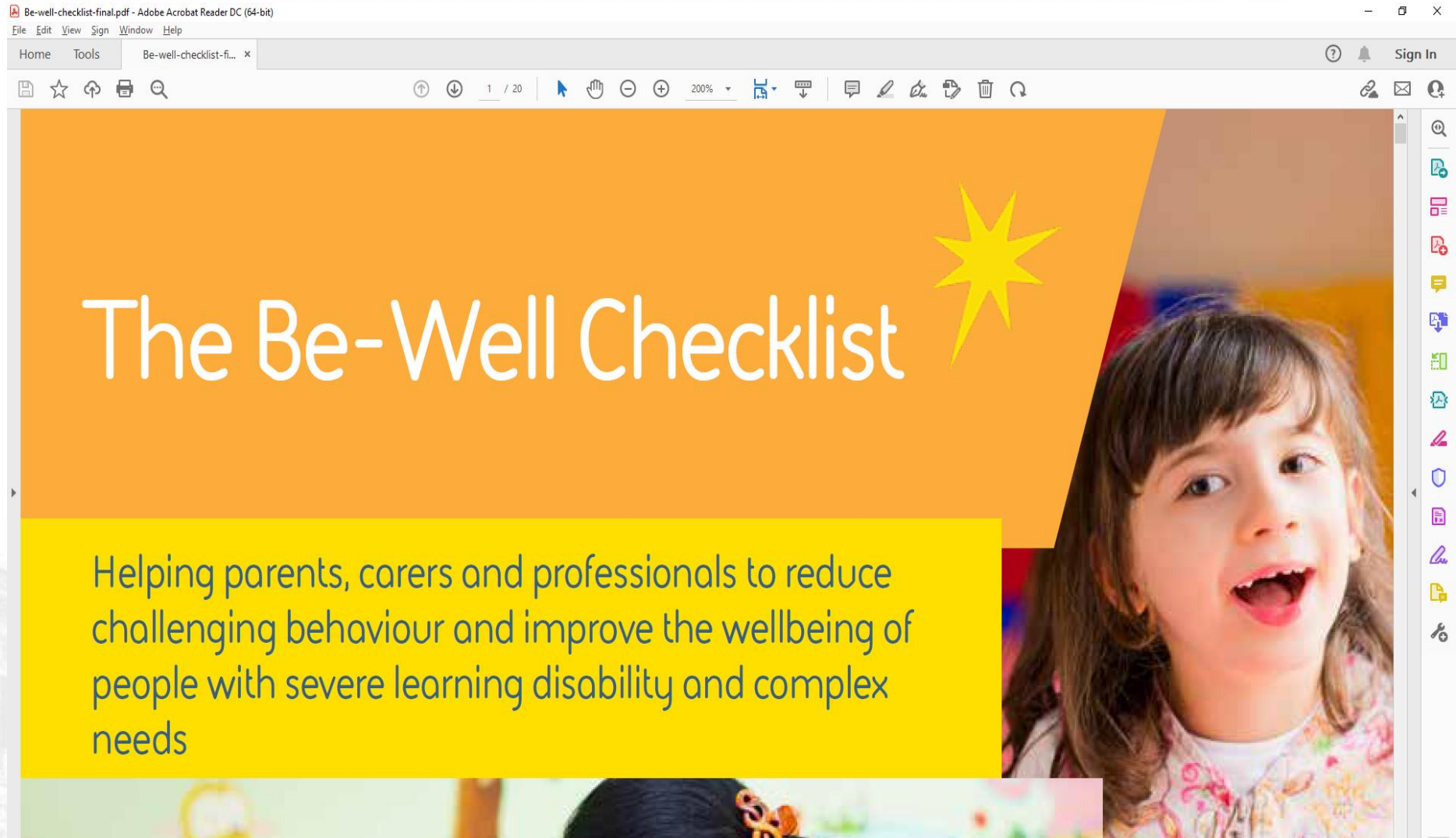
The Leuven Scale for Well-being

Level	Well-being	Signals
1	Extremely low	The child clearly shows signs of discomfort such as crying or screaming. They may look dejected, sad, frightened or angry. The child does not respond to the environment, avoids contact and is withdrawn. The child may behave aggressively, hurting him/herself or others.
2	Low	The posture, facial expression and actions indicate that the child does not feel at ease. However, the signals are less explicit than under level 1 or the sense of discomfort is not expressed the whole time.
3	Moderate	The child has a neutral posture. Facial expression and posture show little or no emotion. There are no signs indicating sadness or pleasure, comfort or discomfort.
4	High	The child shows obvious signs of satisfaction (as listed under level 5). However, these signals are not constantly present with the same intensity.
5	Extremely high	The child looks happy and cheerful, smiles, cries out with pleasure. They may be lively and full of energy. Actions can be spontaneous and expressive. The child may talk to him/herself, play with sounds, hum, sing. The child appears relaxed and does not show any signs of stress or tension. He/she is open and accessible to the environment. The child expressed self-confidence and self-assurance.

The Leuven Scale for Involvement

Level	Well-being	Signals
1	Extremely low	Activity is simple, repetitive and passive. The child seems absent and displays no energy. They may stare into space or look around to see what others are doing.
2	Low	Frequently interrupted activity. The child will be engaged in the activity for some of the time they are observed, but there will be moments of non-activity when they will stare into space, or be distracted by what is going on around.
3	Moderate	Mainly continuous activity. The child is busy with the activity but at a fairly routine level and there are few signs of real involvement. They make some progress with what they are doing but don't show much energy and concentration and can be easily distracted.
4	High	Continuous activity with intense moments. They child's activity has intense moments and at all times they seem involved. They are not easily distracted.
5	Extremely high	The child shows continuous and intense activity revealing the greatest involvement. They are concentrated, creative, energetic and persistent throughout nearly all the observed period.





- Questions?



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