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# Exploring self-advocacy for children and young people with complex disabilities: How can we hear their voice?

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- To provide the context for my PhD research that explored participation and well-being with children and young people with cerebral palsy using creative methods.
- To focus on how their voices were illustrated and who were/are the champions of their well-being
- To explore how to move the agenda of well-being forwards in physiotherapy.



- Clinical background as a physiotherapist in the NHS, academic since 2002
- Concern for non-ambulant and non-verbal children- are we doing enough?
- Previous research about Adapted cycling in partnership with Pedal Power, Cardiff
- Opportunity to carry out a staff PhD part time in 2015-2021- sponsored by the CSP Charitable trust award



Gap in literature about participation for non-verbal children and young people with cerebral palsy with limited mobility (Imms et al 2016).

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

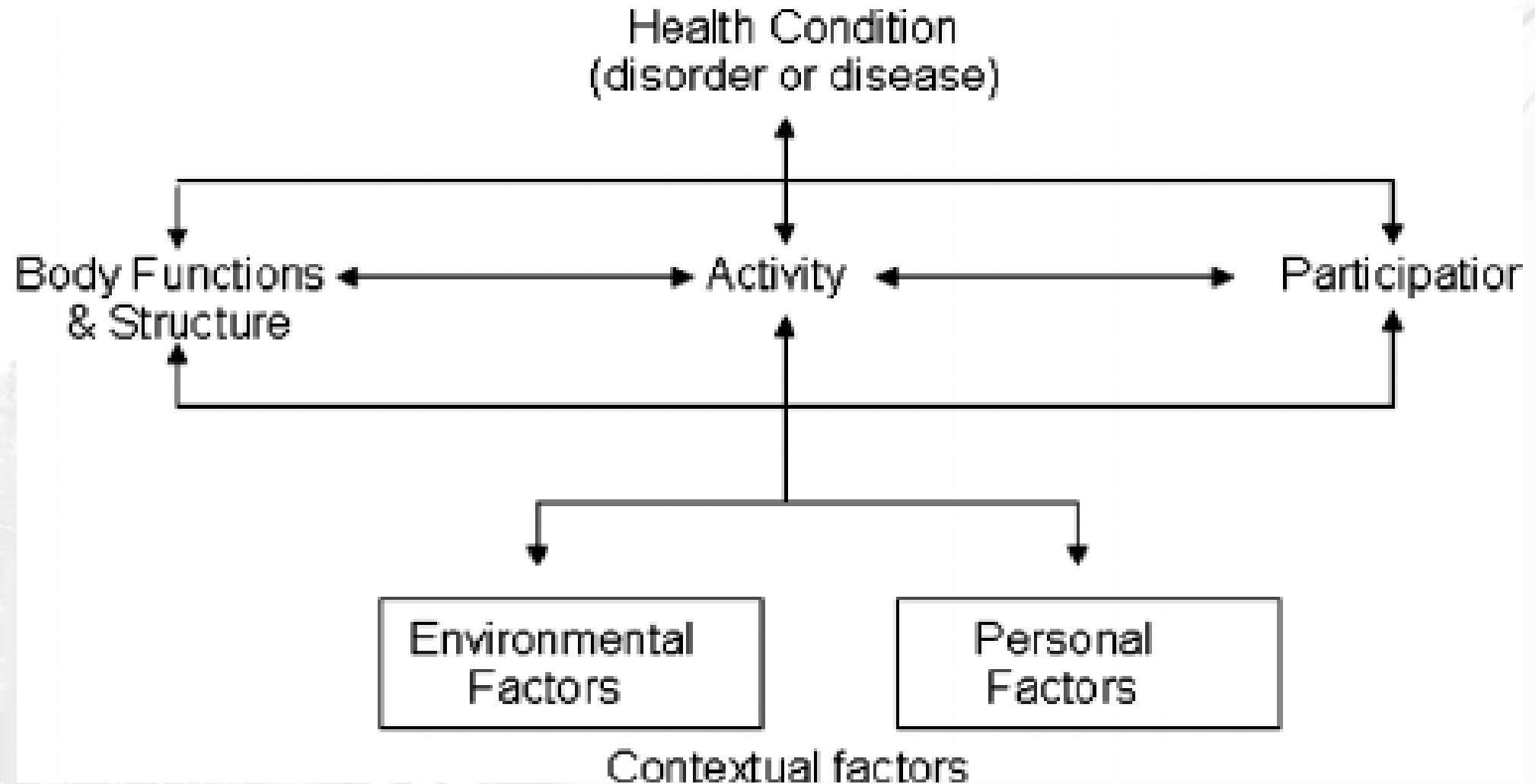
Very little is known about their perceptions of their own well-being- no current valid and reliable measure for cerebral palsy (Mpundu-Kaambwa et al 2018)

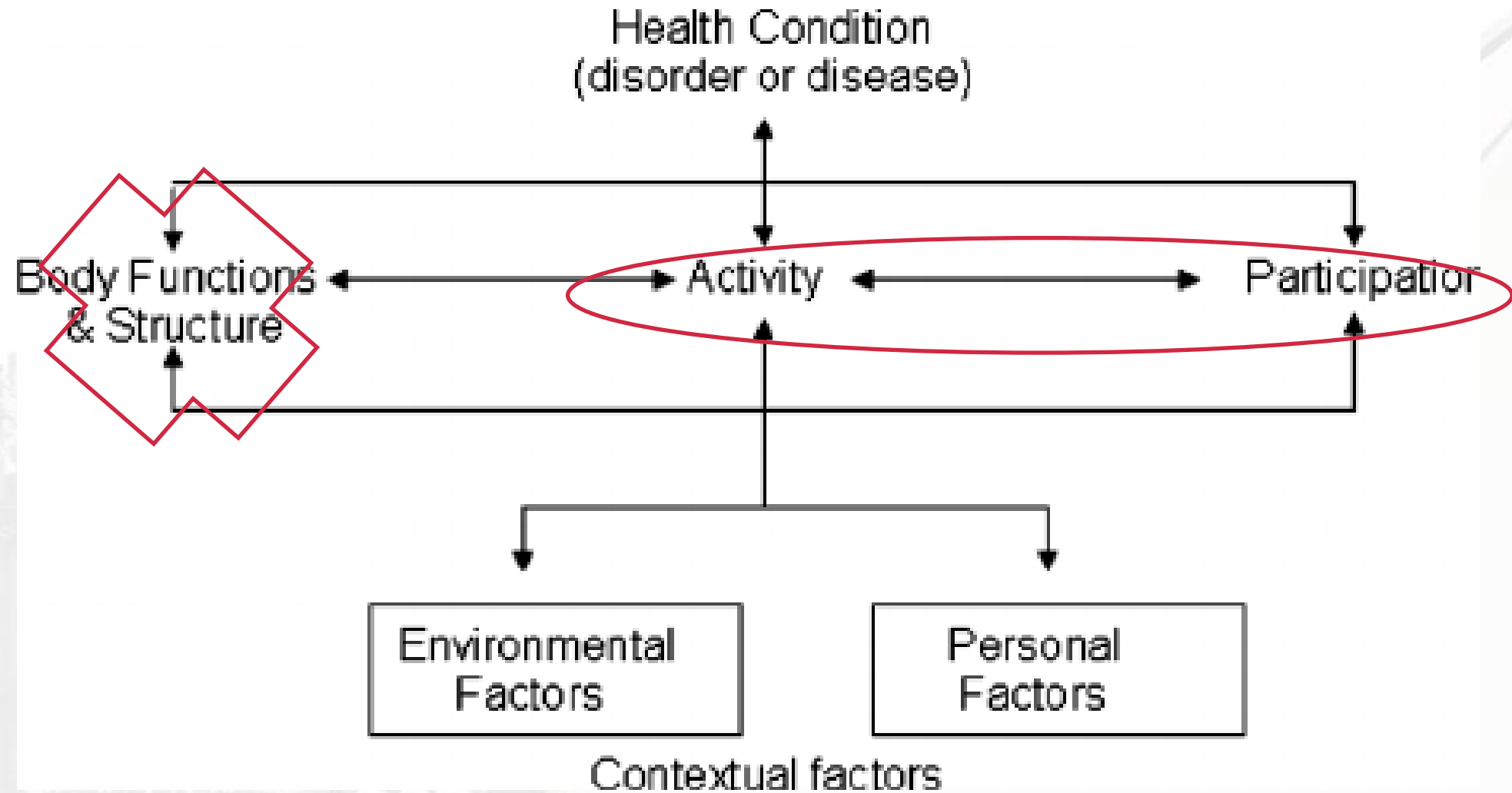


***“Cerebral Palsy describes a group of permanent disorders of the development of movement and posture, causing physical activity limitation, that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain. The motor disorders of cerebral palsy are often accompanied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

Rosenbaum et al, 2007





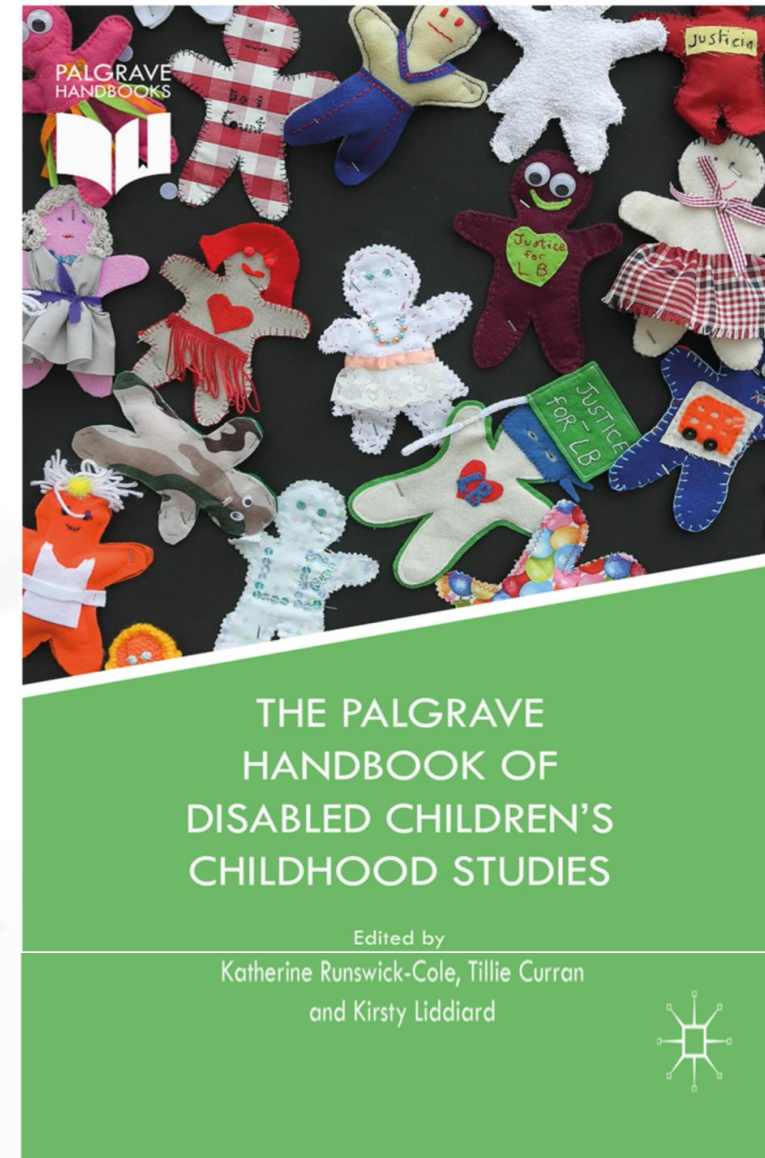




# Ethical position: Inclusive research ( Runswick-Cole et al, 2017)

- Researching *'with'* not *'on'* disabled children and young people.
- Those with most severe disabilities usually excluded from research
- Pilot data: Chapter 9

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“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:

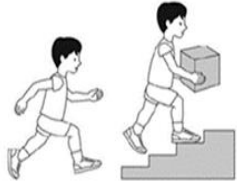
*“A positive sense of Well-Being, which enables an individual to be able to function in society and meet demands of everyday life; people in good mental health have the ability to recover effectively from illness, change or misfortune” (Lite 2012 p.4).*

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 which directly impacts upon their perceived quality of life (whatworkswellbeing,2022).

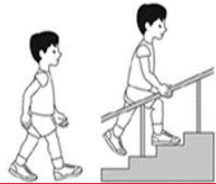


## GMFCS E & R Descriptors and Illustrations for Children between their 6<sup>th</sup> and 12<sup>th</sup> birthday



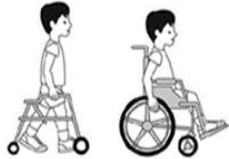
### GMFCS Level I

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.



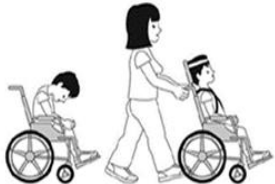
### GMFCS Level III

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 traveling long distances and may self-propel for shorter distances.



### GMFCS Level IV

Children use methods of mobility that require physical assistance or powered mobility in most settings. They may walk for short distances at home with physical assistance or use powered mobility or a body support walker when positioned. At school, outdoors and in the community children are transported in a manual wheelchair or use powered mobility.



### GMFCS Level V

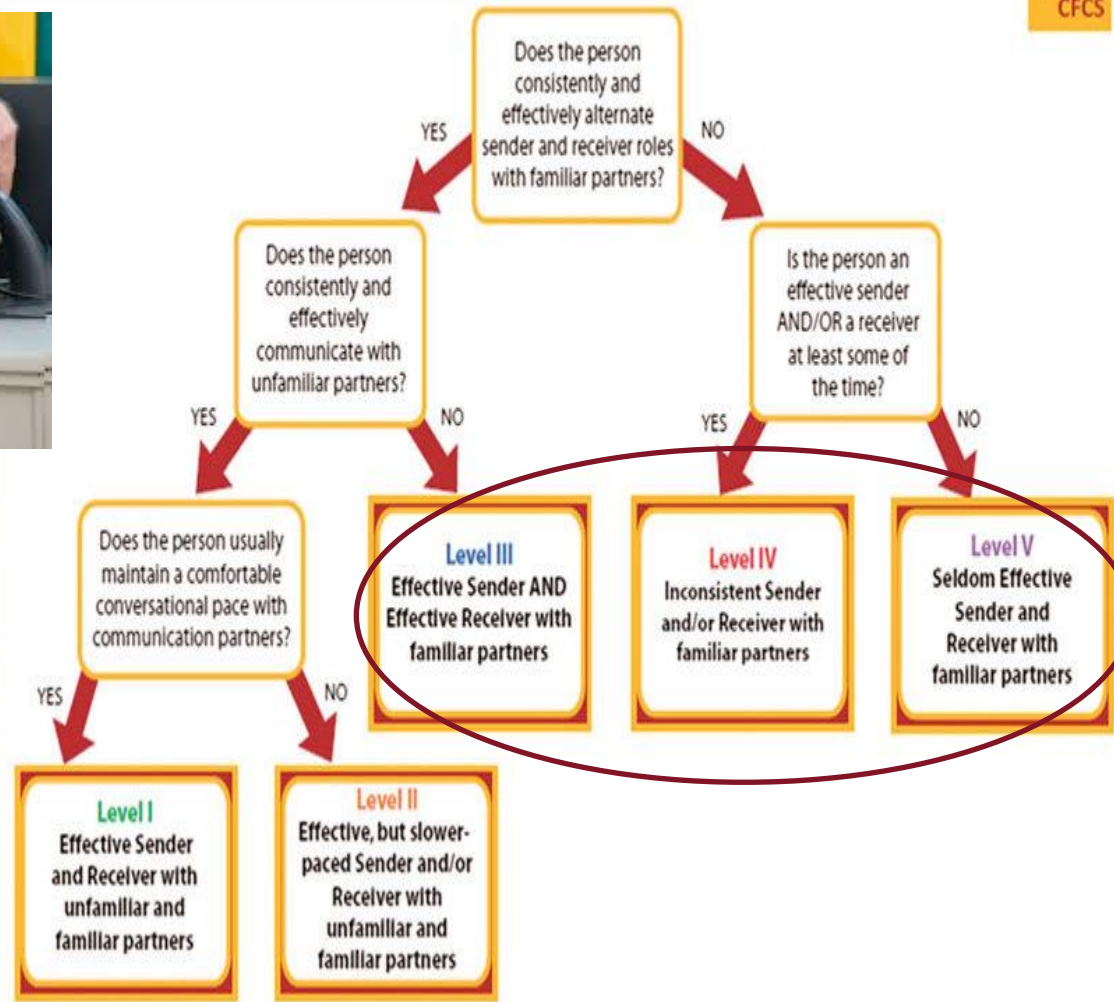
Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements.

GMFCS descriptors copyright © Palisano et al. (1997) Dev Med Child Neurol 39:214-23  
CanChild: www.canchild.ca

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The Royal Children's Hospital, Melbourne



## 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 creative and visual methods, with two groups, a participatory group (PG n=4) and limited participatory group (LPG n=3).



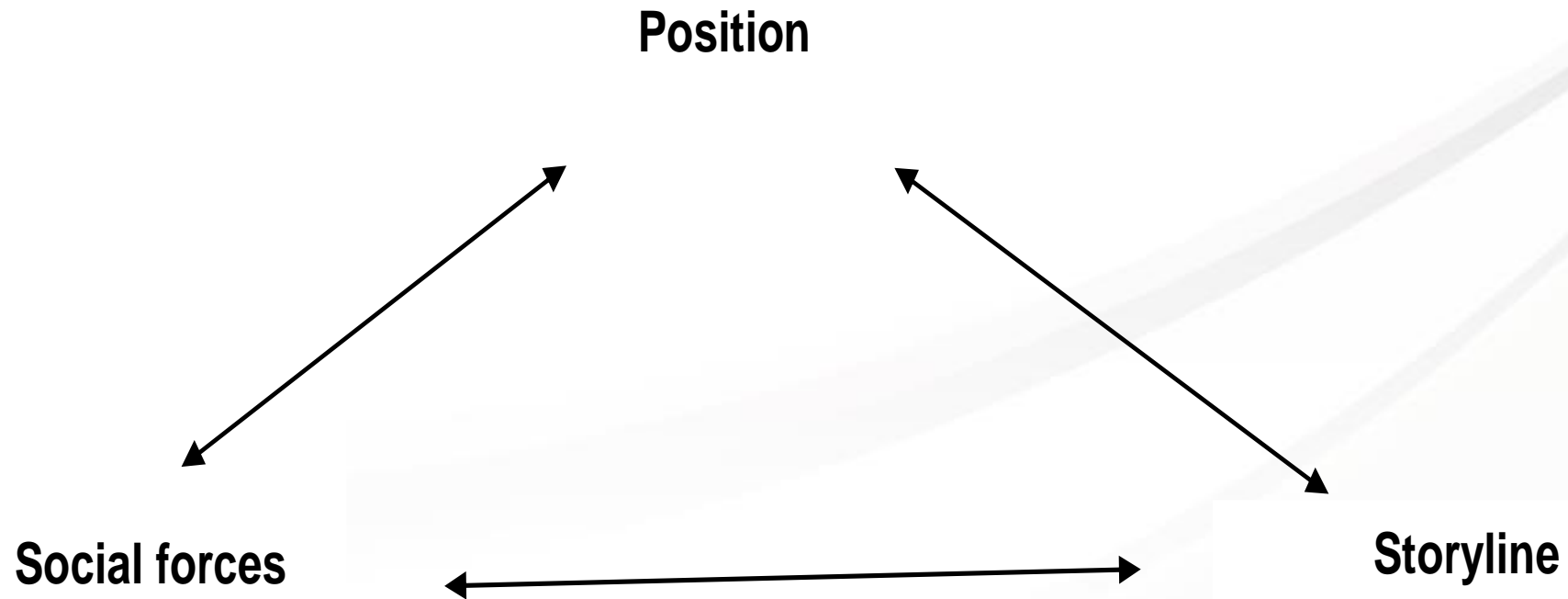


Figure 1: Mutually determining triad from Harré and Langenhove (1999 pg.18)



# 'Mosaic' of individual data sources to make up each single case study (Pickering et al 2023a)

Consent / assent process

2 interviews: 12 weeks apart

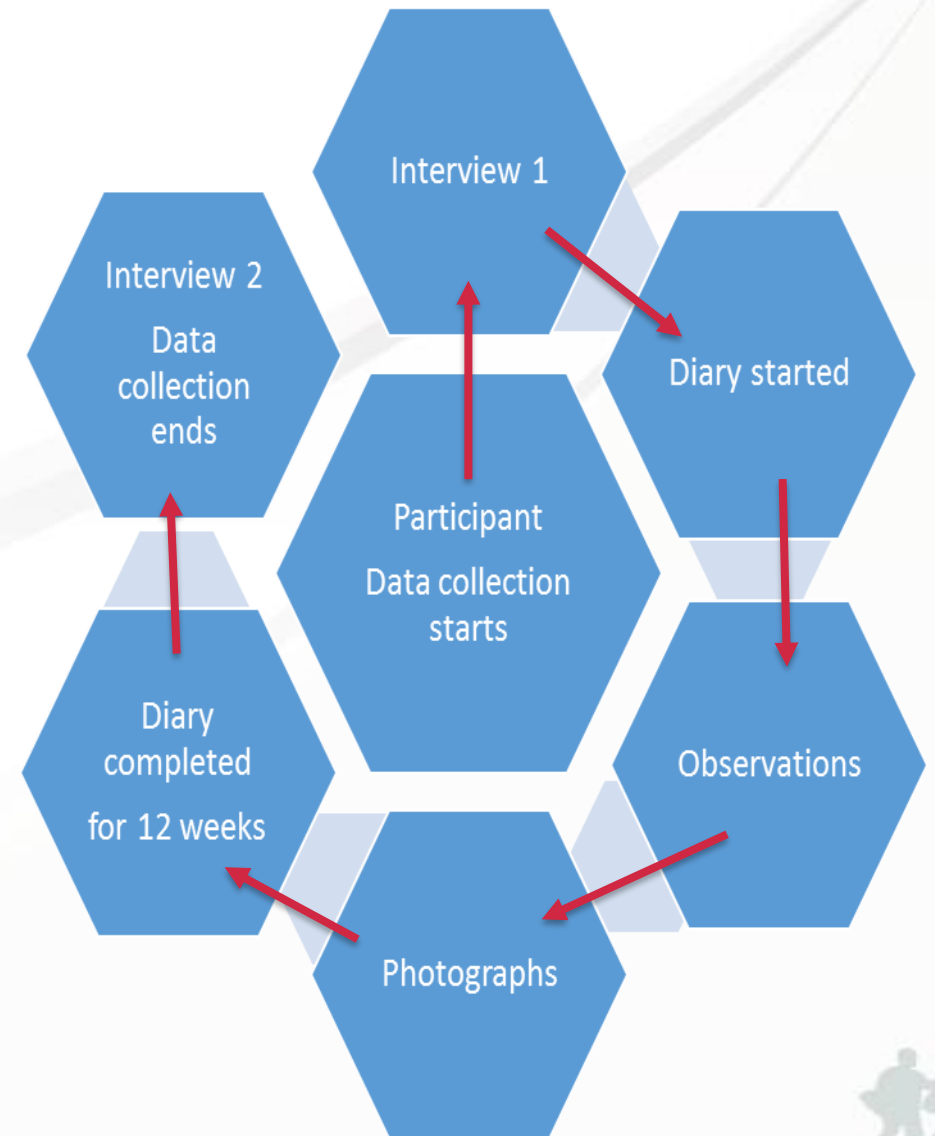
Diary kept in between by parents

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><b>Barriers:</b> 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><b>Positive:</b> Shows happiness by smiling and clapping (18), Spinning spinner (7).</p> <p><b>Negative:</b> 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	Mother, <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.



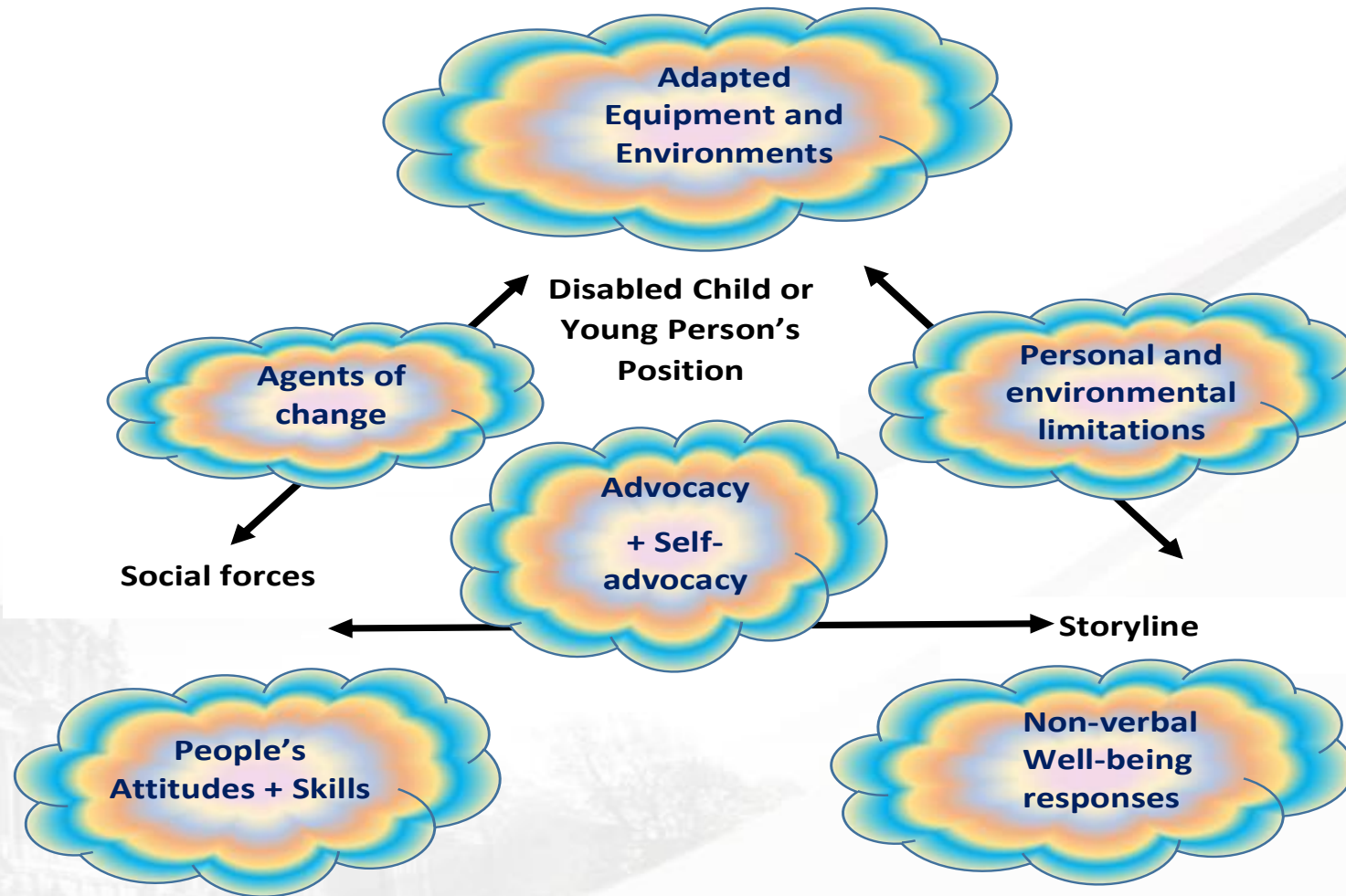


Figure 1: 'Kaleidoscope of Well-being' for disabled Children and Young People's participation in Recreational Activities - adapted from mutually determining triad from Harré and Langenhove (1999 pg. 18).



# 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'*

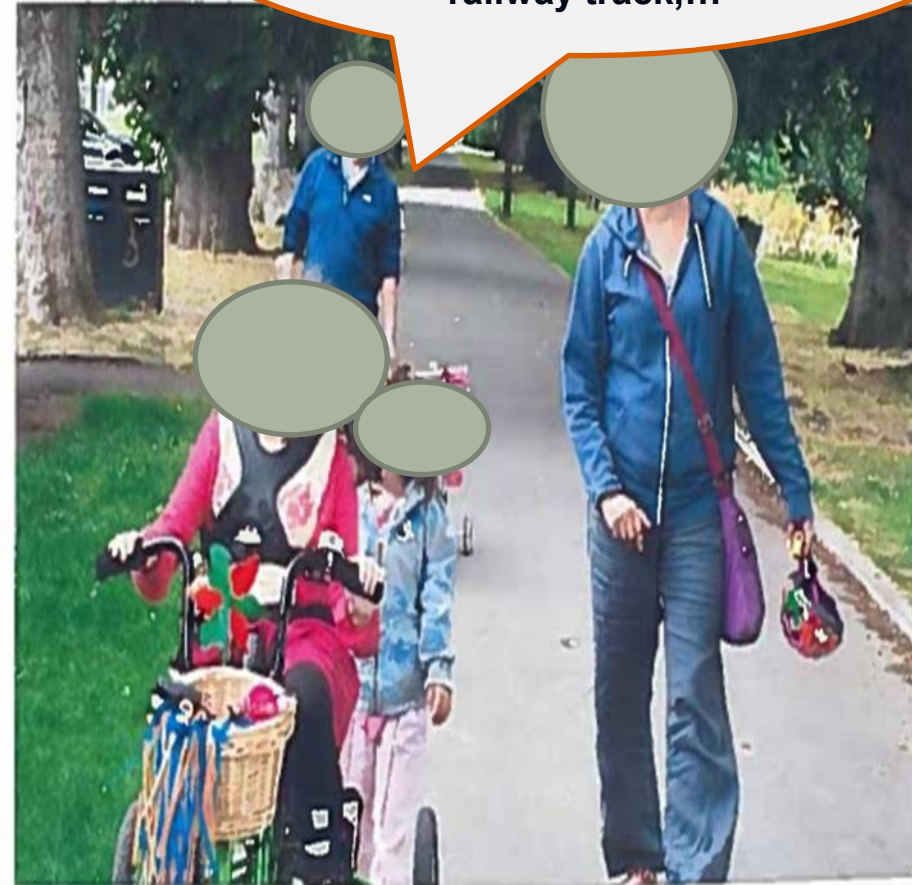


## Participation observation field notes

*'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.



Carnevale et al (2017) propose that children with complex health needs are relationally embedded agents, whilst still dependent upon their parents to support their interests.

‘Empathic attunement’-Carnevale argues that emotion is not an objective truth and can vary. Thus, well-being can fluctuate. Carnevale also proposes that children’s voices provide a morally meaningful expression of agency, including those who communicate differently.

Challenge is to listen- are we always tuning in to listen?

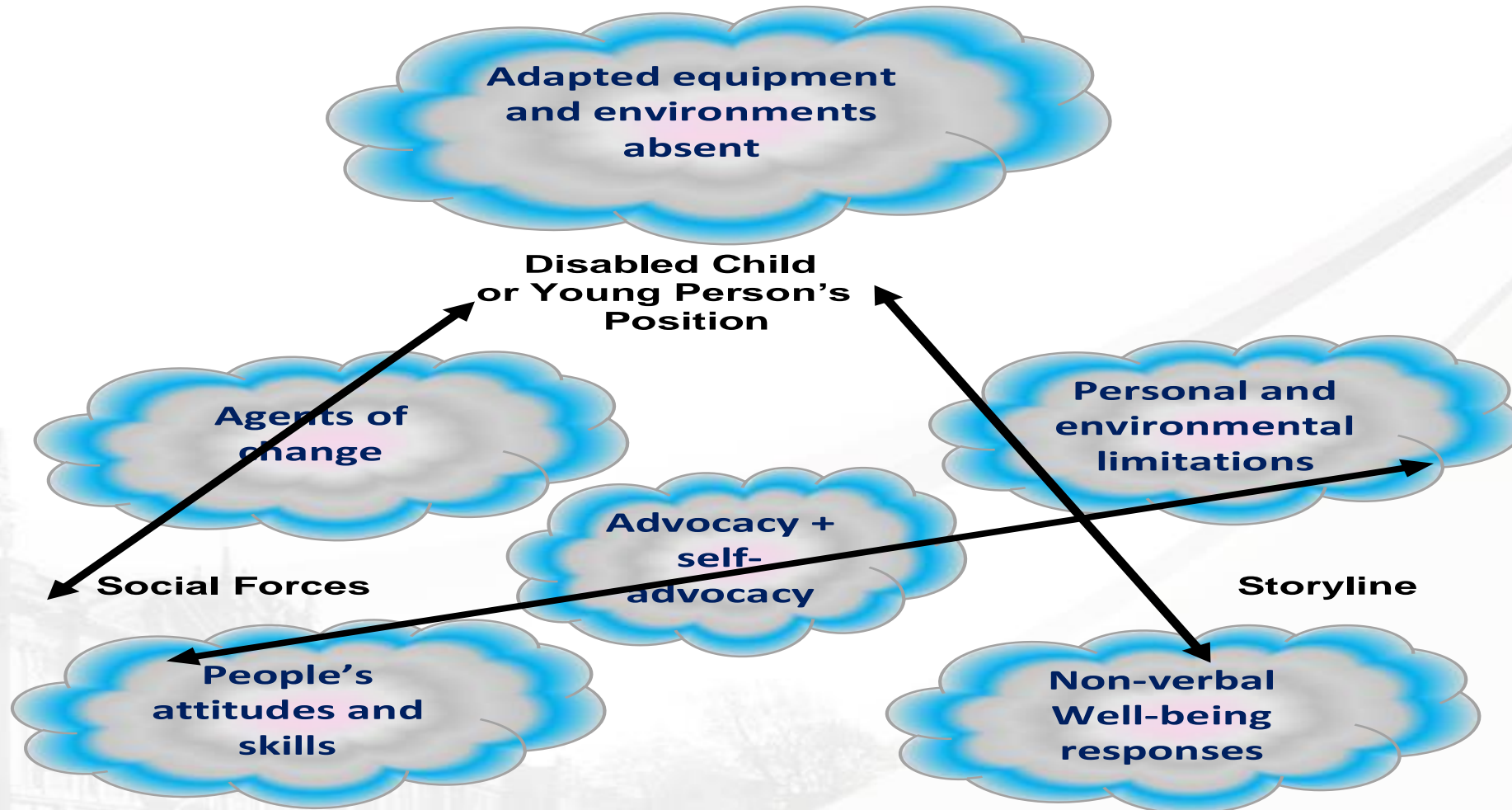




At the first observation, Nick propelled himself about 4 laps around the track in the hall using 2 feet together, sometimes alternate feet. After he had finished on the RaceRunner, I observed Nick absorbing the social atmosphere by driving his chair around, he gave me good eye contact and a smile. However, at the second and third observations Nick only managed 1 lap outdoors. Dad thought this was possibly attributed to a recent spinal brace to manage his scoliosis, which was uncomfortable for him to wear and restricted his movements. Thus, Nick was offered the opportunity for RaceRunning, but he chose to engage with this in a fluctuating way, determining his own well-being from his level of participation, creating his own storylines.

Although Nick loved swimming, there were times he did not want to do this, even when it was available at home.





**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".*



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 in promoting well-being for children and young people.

Further post-doc development has developed and piloted a scale for well-being with disabled children who use the Innowalk (WEBS study – sponsored by an APCP bursary 2022-2023).



- What do you think about the role of physiotherapists as advocates?
- Are we always tuning in to listen?
- Do you think that children and young people's well-being should be measured?
- If so, how?
- Do you already have any measures that you use?-please get in touch

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