

**A 'Kaleidoscope of well-being' to represent
the experiences of non-verbal,
physically disabled
children and young people's participation
in recreational activities.**

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- Gap in knowledge for participation for non-verbal children and young people with cerebral palsy with limited mobility (Rosenbaum and Gorter 2012; Imms et al 2016).
- Very little is known about their perceptions of their own well-being (Mpundu-Kaambwa et al. 2018)

Social justice was promoted by ethically positioning their ‘different’ voices at the centre of my enquiry (Curran and Runswick–Cole 2013)

“Positioning theory”-previously based upon spoken language, now adapted and illustrated by a kaleidoscope of well-being (Harre and Langenhove, 1999).

‘Positioning’ is meant as both the physical and metaphorical social ‘positions’ of the participants at a recreational activity.





Play Wales, 2013

“Right to rest, leisure, play and recreation and to take part in cultural and artistic activities”

(United Nations Children’s Fund, 1989 p.10)



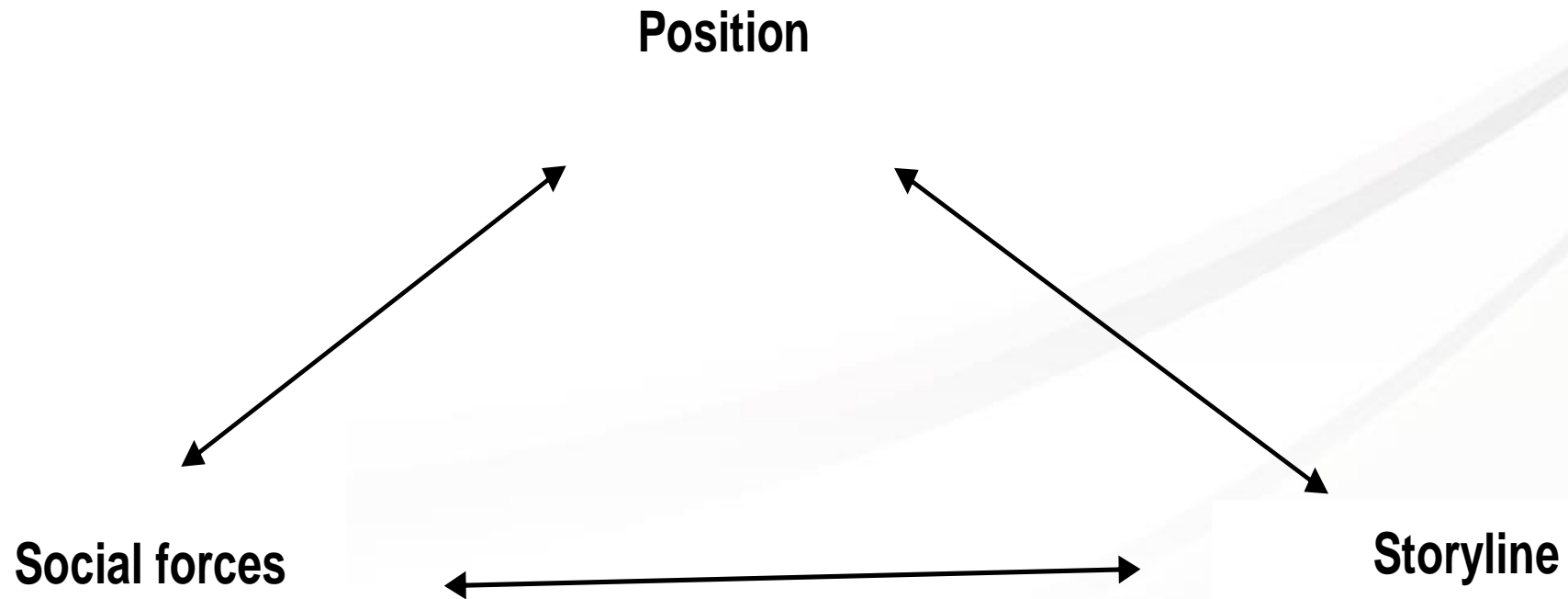


Figure 1: Mutually determining triad from Harré and Langenhove (1999 pg.18)



The 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
- Levels III-V on the GMFCS/CFCS, supported by their parents.
- A comparative case-study design^(Yin 2018) was developed with visual methods, with two groups, a participatory group (4) and limited participatory group (3).



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

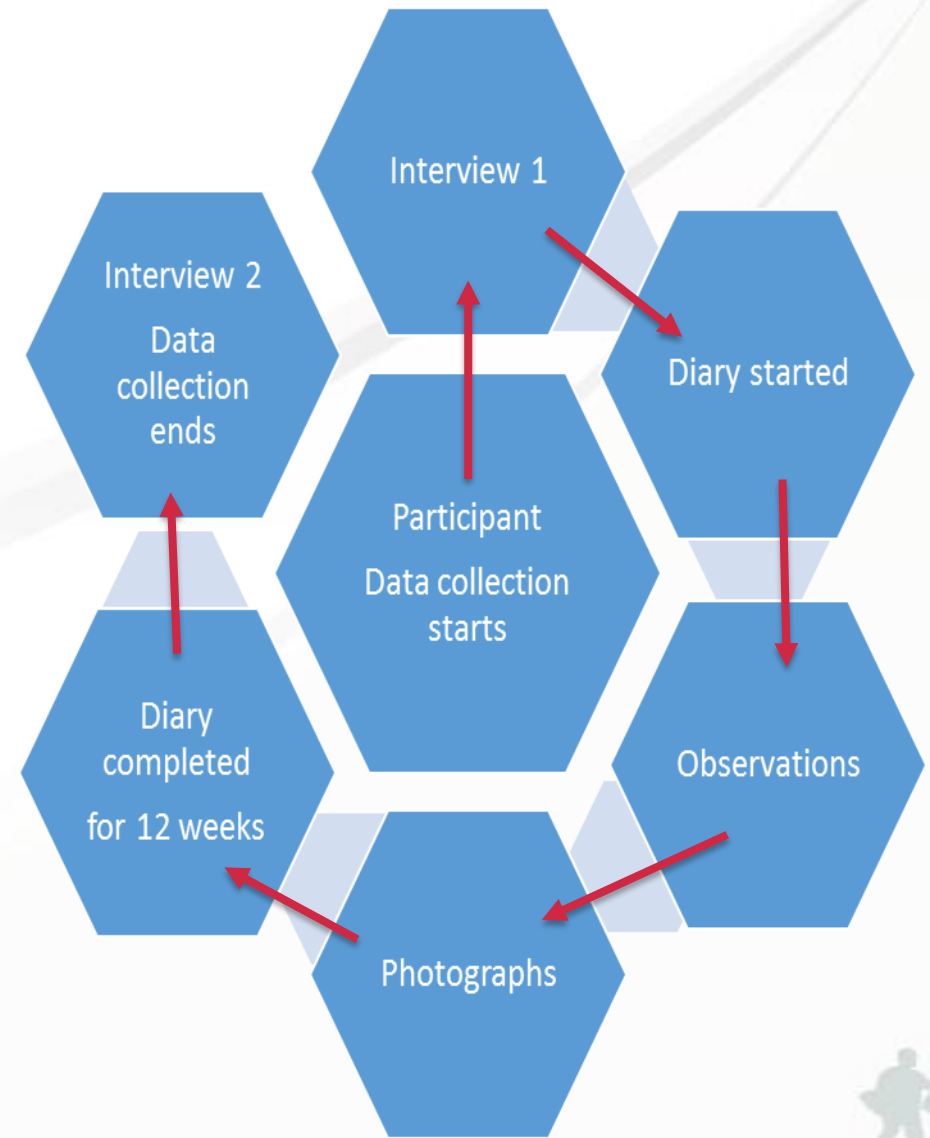
2 interviews: 12 weeks apart

Diary kept in between

Observation of one of their usual recreational activities during this time

Photographs sent by parents or taken by researcher (anonymised)

7 case studies



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

- 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.



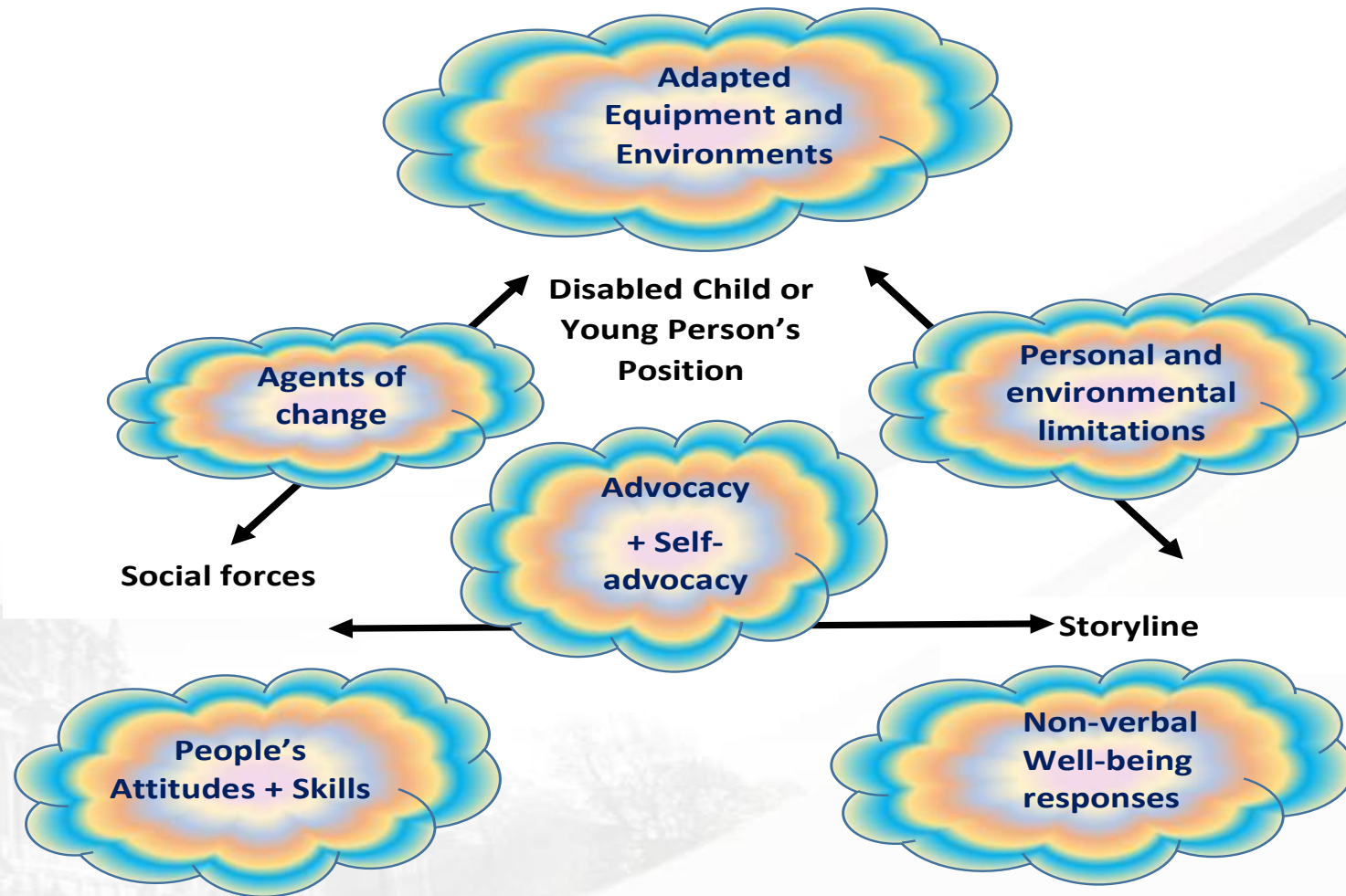


Figure 1: 'Kaleidoscope of Well-being' for disabled Children and Young People's participation in Recreational Activities - adapted from mutually determining triad from Harré and Langenhove (1999 pg. 18).



Matthew surfing and Clare's bike riding

Participation observation field notes

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



'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'

Interview 1

"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



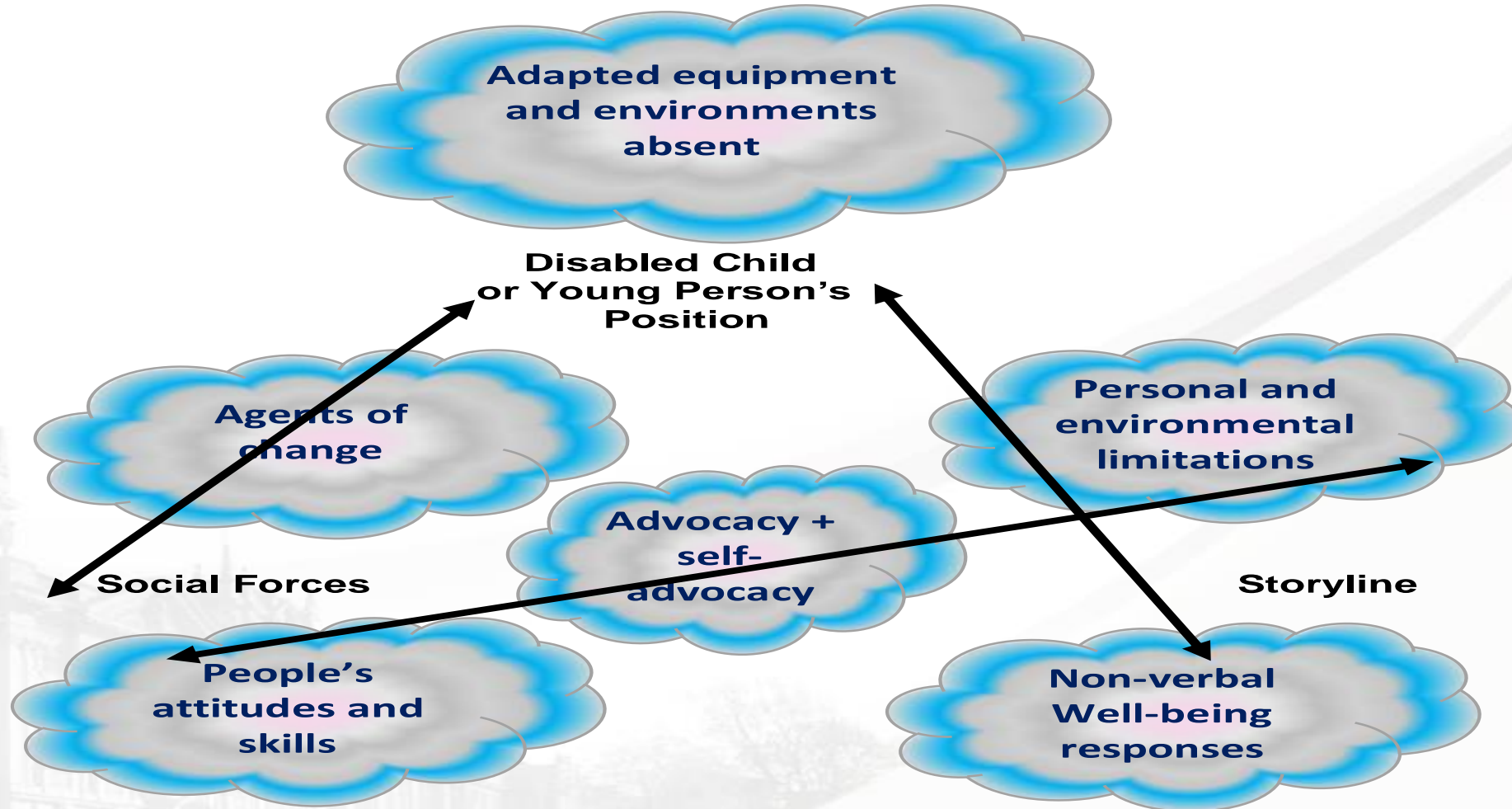


Figure 2: 'Kaleidoscope of well-being' illustrating skewed mutually determining triad with grey clouds when factors adversely affected well-being.



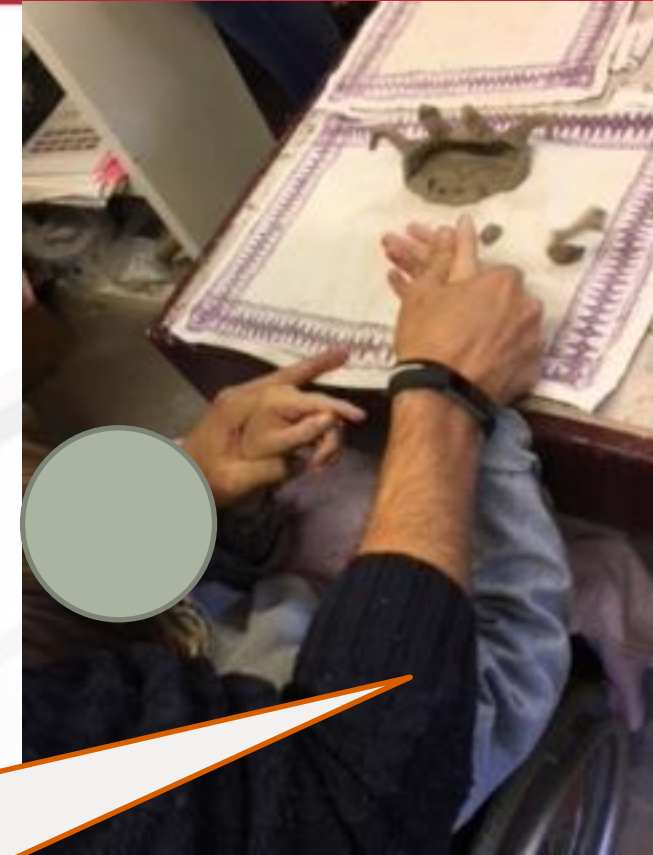
Interview 2

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



Diary entry

The activity lasted about 15 minutes, no introduction, no names, no welcome and as we walked through the door to enter the lady taking the class looked at Poppy and said "Oh look at that"!! I'm not sure what she was referring to but it wasn't a great welcome. Poppy did however enjoy the very brief pottery class.



Pottery event



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!”



More people should take the time to listen to the voices of disabled children and young people as they were shown to self-advocate their well-being by their intentional behaviours.

There is a need to explore how professionals perceive their role of advocacy with disabled children and young people.

Policy makers and designers of equipment and environments should consider how to increase the choices of recreational activities for non-verbal children with limited mobility.



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