

# Champions for well-being: The role of professionals who advocate to support disabled children's participation in recreational activities.

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# Aims of my talk

- To provide the context of my PhD study
- To report some case study findings related to well-being/ voice
- To propose an adaptation of positioning theory
- To open up discussion about advocacy and how you think health and social care professionals perceive this role

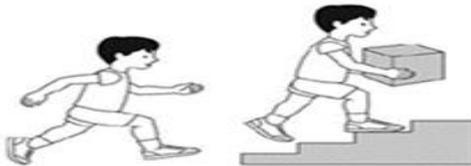
# ‘VOCAL’

- Title is: “Beyond Physiotherapy: Voices Of Children and Young People with Cerebral Palsy and their Carers about ‘Participation’ in Recreationalal Activities (VOCAL)
- A PhD qualitative, comparative, case study design using visual methods to capture the ‘voices’ of children who have mobility, communication and learning disabilities.
- Participants were aged nine to sixteen years.
- Levels III-V of the Gross Motor Function Classification System.

# Gross Motor Function Measure

*Palisano et al, 1997; Reid et al, 2011*

## 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.

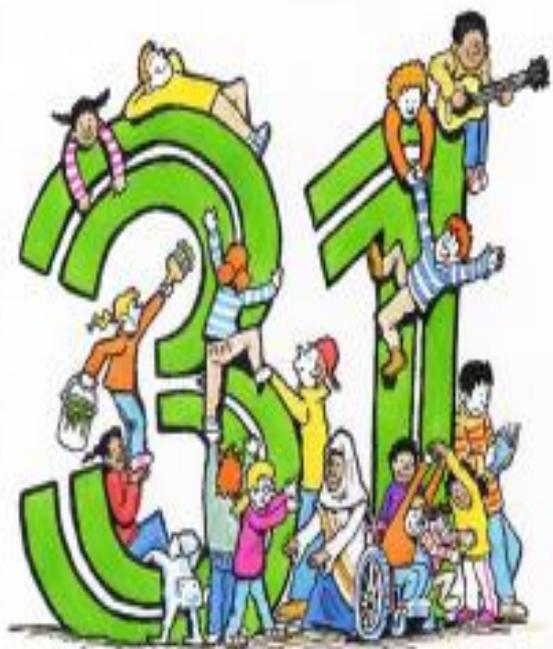


### GMFCS Level V

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.

# Participation

- Imms et al (2016) have proposed a family of participation related constructs (fPRC) of which 'attendance' and 'involvement' are the main attributes.



'Have the right to rest, leisure, play and recreation and to take part in cultural and artistic activities'

<http://www.playwales.org.uk/eng/>

# Positioning theory (Harré and Langenhove 1999)

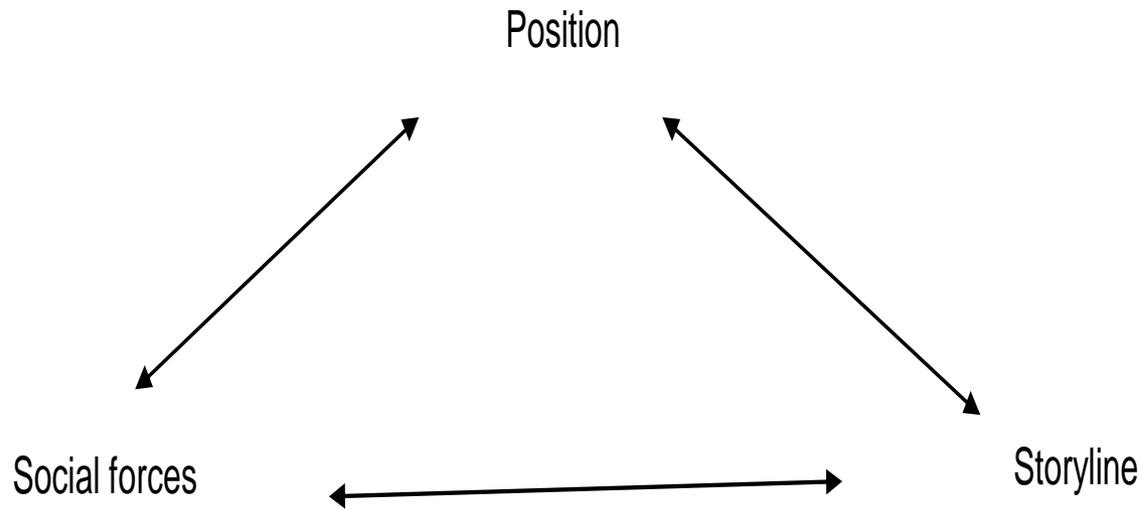


Figure 1: Mutually determining triad from Harré and Langenhove (1999 pg.18)

# Research question and aims

- How do children and young people with cerebral palsy and their carers view, experience and choose their level of participation in recreational activities?
- The aims were to explore their perceptions of the well-being impact from their level of participation, including the facilitators and barriers.

# Comparative Case study design

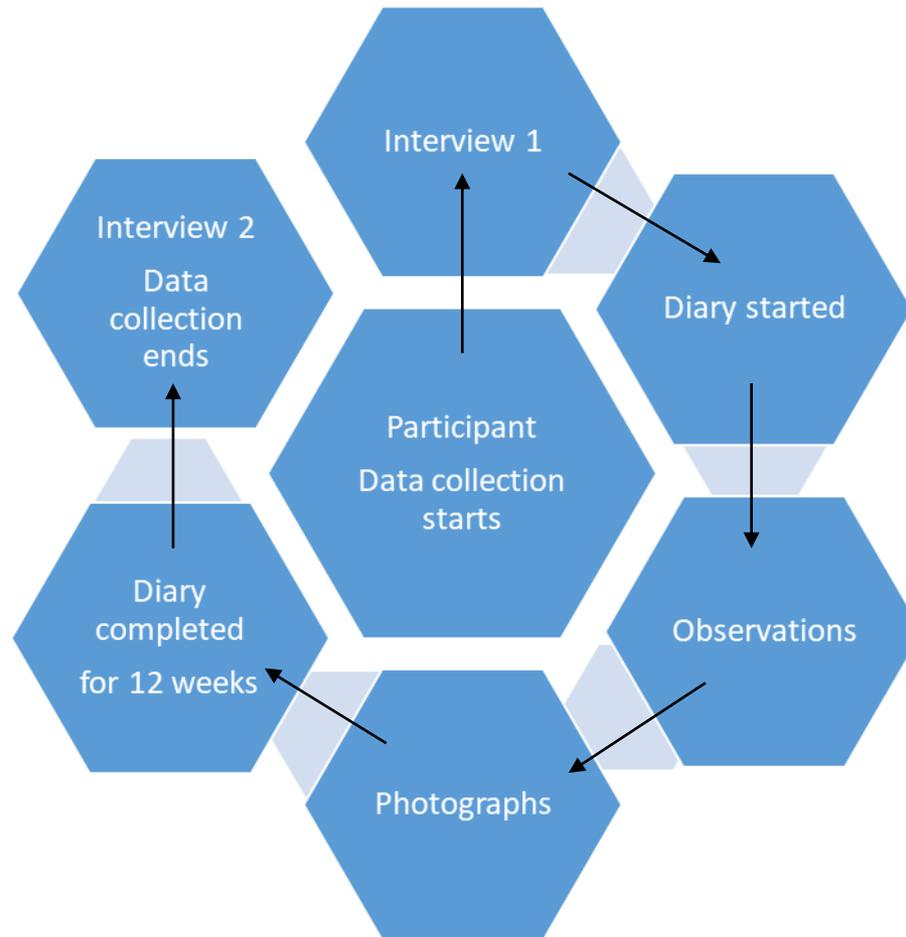
(Yin 2016)

Two groups:

1. Participatory group
2. Limited Participatory group

Participants (children via communication aids and parents) took part in two interviews, kept a diary for twelve weeks to which the parents added some photographs and an observation at one of their usual activities was carried out by the researcher where photographs were taken.

# Mosaic of data collection



# Nick's diary (PG) - pattern of participation/ different voices

Saturday 25/03/17 - Day 6

Got up late and lounged about after breakfast. Played on my iPad and squirmed about on the floor before lunch.

Then **Carer** came to take me out...

I went to **Outdoor museum with carer** - I ENJOYED DRIVING MY CHAIR AROUND. WE WENT TO THE FARM SECTION AND SAW A GUINER FOWL, SOME SHEEP AND SOME PIGS. WE THEN STROLLED AROUND THROUGH A WOODED AREA WHERE WE SAW SOME SQUIRRELS, AND LOOKED AT THE OLD BUILDINGS THAT WERE THERE.

# Findings

- Seven case studies were completed.
- Data were analysed using Braun and Clark's six stages of thematic analysis.
- First the participatory group(PG) then the limited participatory group(LPG) were analysed, then the across case comparisons were made.
- Positioning theory has been developed further.
- Pseudonyms:  
(PG): Lily-May, Clare, Nick and Matthew,  
(LPG): Poppy, Bree and James
- The across case analysis led to the identification of three across case themes.



# Across Case Themes

1. Participation enhancers.
2. Champions for disabled children's emotional well-being.
3. Hindrances to participation.

# Overall themes

| Theme  | Subthemes                                    |  |
|--|--|--|
| <b>1. Participation enhancers</b>                                | i. Parental advocacy                         | ii. Innovative designs                 |
|  | iii. Reasonable adjustments                  | iv. Equipped volunteers                |
| <b>2. Champions for disabled children's emotional well-being</b> | i. Expressing choices to indicate well-being | ii. Parental and professional advocacy |
| <b>3. Hindrances to participation</b>                            | i. Undermining attitudes                     | ii. Being treated differently          |
|  | iii. Limited training of volunteers          |  |

# Advocacy

| Theme  | Subthemes                                    |  |
|--|--|--|
| <b>1. Participation enhancers</b>                                | i. Parental advocacy                         | ii. Innovative designs                 |
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# Advocacy

- 1. Participation enhancers

## Subtheme

- (i) Parental Advocacy

- 2. Champions for disabled children's emotional well-being

## Sub-themes

- (i) Expressing choices to indicate well-being
- (ii) Parental and professional advocacy

# Matthew's Mum(PG)

*“Yeah I’m a good advocate for the Surfability and the Ice Cool Kids Skiing Group. 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...I think also living round here, this area is classed as a deprived area, so I think alorra parents of children with disabilities are not very well educated and some of them have got special needs themselves, so they wouldn’t think to do it (surfing)...”*

# James (LPG)



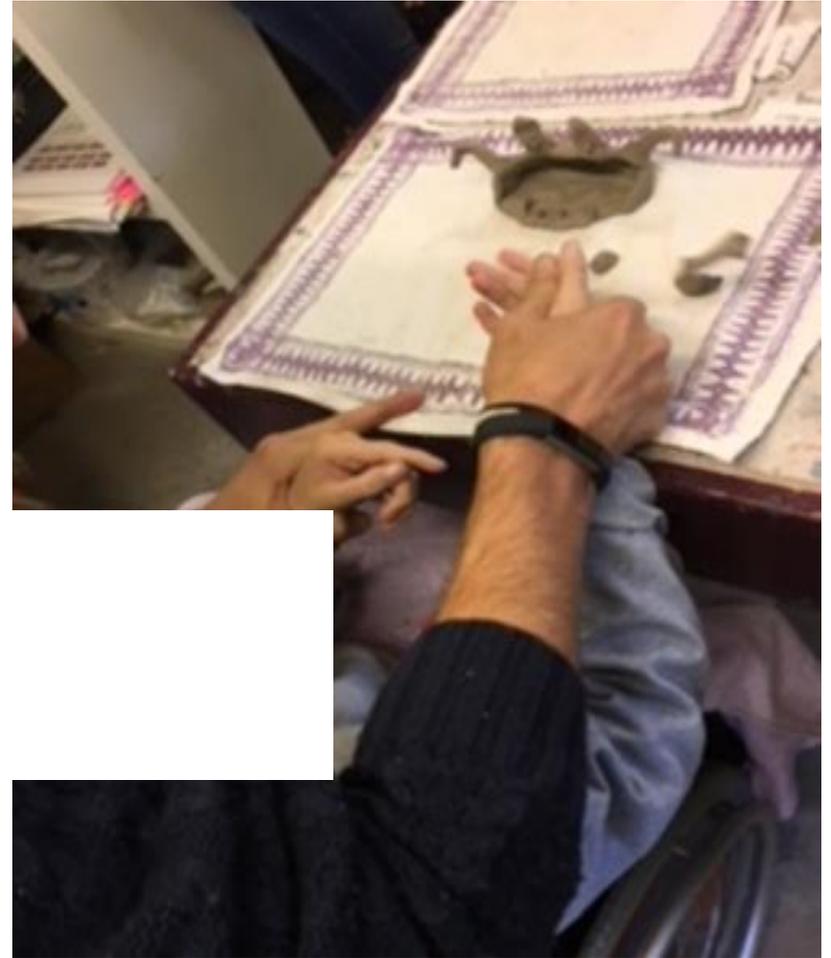
*“Went to museum to see dinosaur exhibition with friends. Lift not working so needed to ring and be admitted through staff entrance as the lift was broken and using this staff lift was not easy as it was not really designed for a large powered wheelchair (Diary)*

*...I don't think people realise that you are that reliant on it. They think, oh yes, there's an alternative, but the alternative isn't as easy as the other one, because it's a very small lift, so it's really hard to actually get in there with a wheelchair....(Interview)”*

## Diary entry

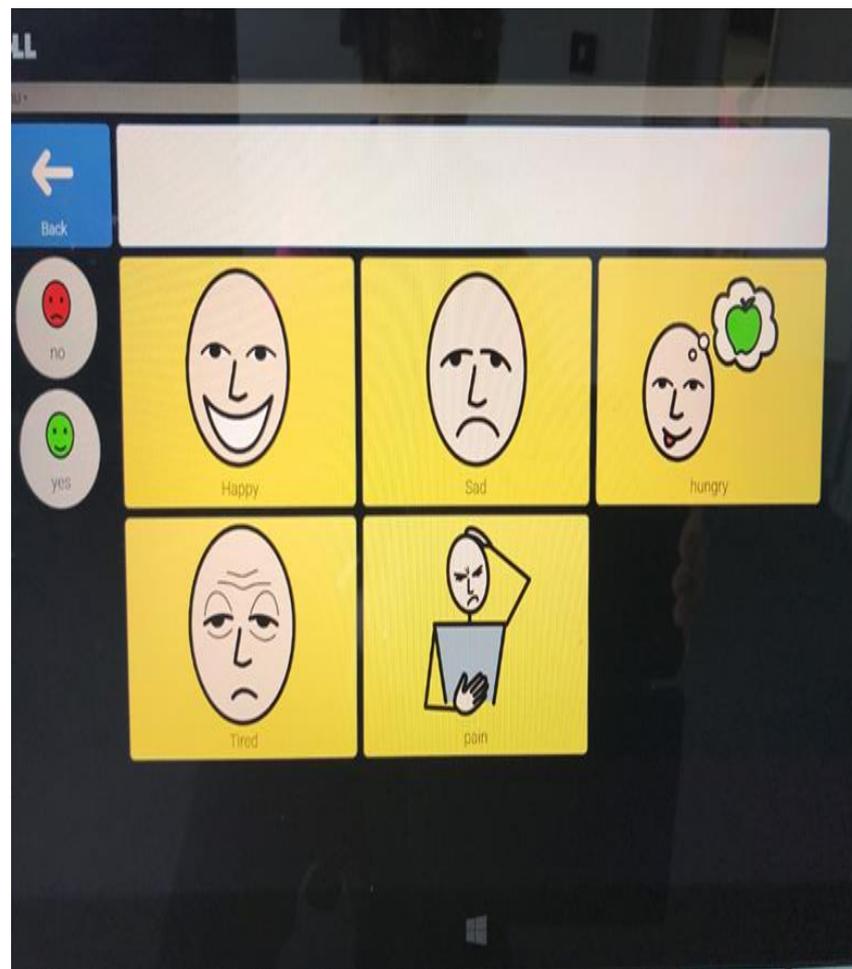
*“Pottery at X Farm. We were a bit disappointed with this activity, we were sat just inside the doorway which wasn’t very wide and had a big lip to get his chair over. We weren’t offered an apron as the other children were. We felt very rushed and Poppy wasn’t given very much time to do the activity in his own time. We were rushed out of the room before the activity had actually ended whilst everyone else carried on with their pottery.... Poppy did however enjoy the very brief pottery class.....but it was really disappointing...”*

## Poppy (LPG)



# Children's own advocacy

The children determined their own level of participation, sometimes it was hard to determine if they enjoyed it, so the well-being effects were uncertain for example Poppy's (LPG) Eye gaze technology responses were not consistent



# Professional Advocacy

Lily-May (PG) Poor sleep pattern/  
Fatigue

Mum had sought help from her  
Occupational Therapist and was  
able to borrow a large cot bed  
which had *'been life changing, it's  
just been amazing...we're so much  
more calm...'*

Discrepancy with costings for it to  
be a permanent solution



## Social worker- Matthew (PG)

Social worker established that Matthew was bored at the respite centre as he was not receiving appropriate stimulation, once this was addressed his behaviour improved:

*“It’s (respite) gone well, if he slept well.... the indicators for the respite centre would be that he wouldn’t eat his food and Matthew loves his food.....so that was a sign that he wasn’t happy. Crying, screaming, attacking me, trying to get back out and while he was there,....he was very upset and took a lot of calming...and they’d talk him down and he’d be fine but that’s all gone now.... thanks to my social worker ...”*

# Relaxed orchestral performance

Bree's (LPG) mother's 2<sup>nd</sup> interview:

*“It was brilliant, that was really good ...really, really good and 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 it was really....they had pupils come on from one of the valleys 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...”*

# Unhelpful professionals

Clare's Mother's Interview (PG)“...one of things I've been looking at, is when they build the extension.... the OT brought a Rep to look at an outdoor hoist but he said there isn't an outdoor hoist, but the company would adapt an indoor one. It's going to cost how many grand, I don't know. I said I can't believe there is no outdoor hoist, why? The OT said 'because people in wheelchairs don't go outside that much'...What!! How can you say that! That's all we do, get used to it...they don't do outdoor things...much...Really!! Well we do now, the next generation coming up, we are doing outdoor stuff....”.

# Unhelpful volunteers

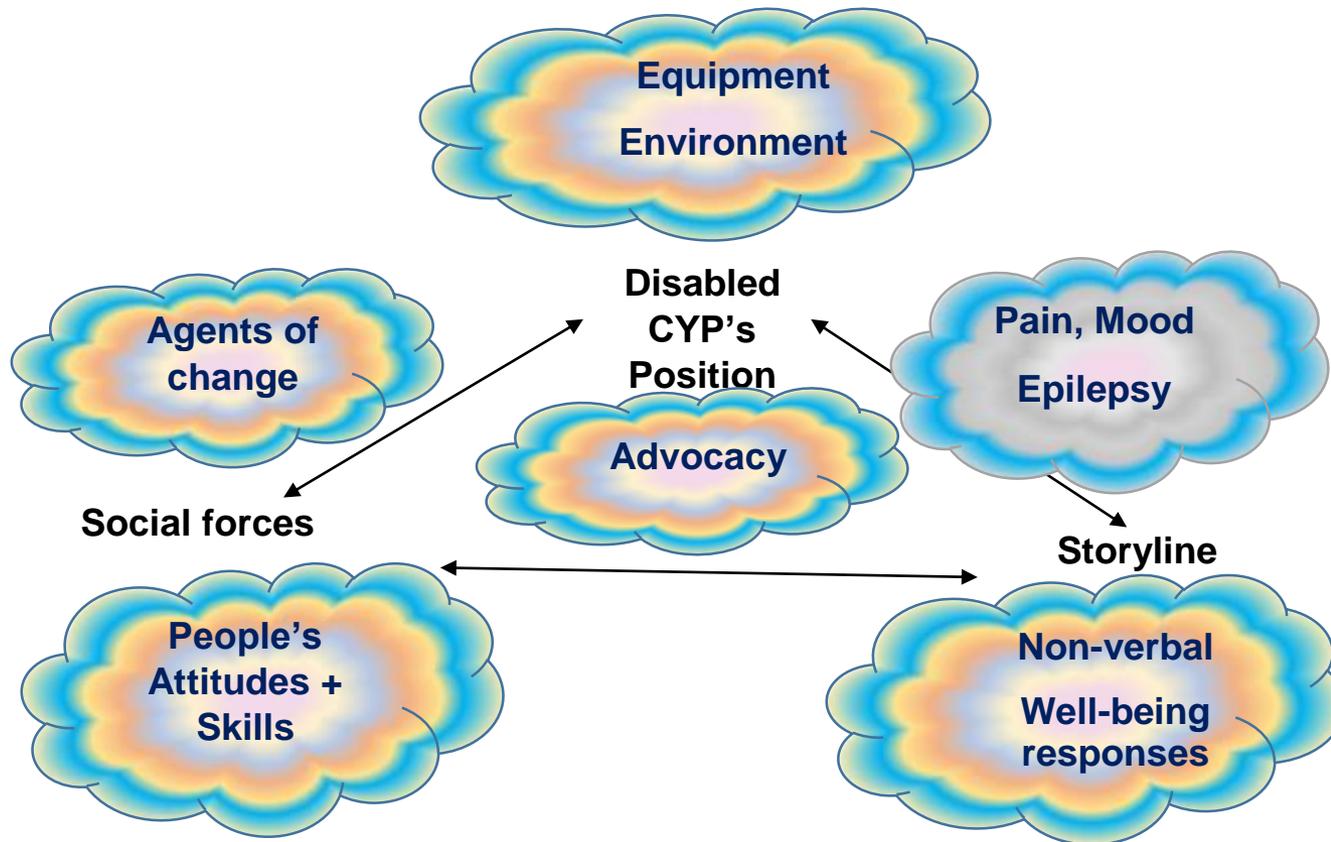
Nick's father interview *"....I had a couple of episodes there that I regret ....I spoke badly to the staff there but you know you get frustrated sometimes. Because I thought that the bike hadn't been properly adjusted ....I was worried for Nick's safety and they've got a hoist there in the back of a broom cupboard that no one knows how to use ....and so if I wanted to use the hoist ...it's such a difficult process then to get it...that it just puts you off completely even bothering ...There was a local art workshop, Nick was making Christmas lanterns and enjoying making a mess with glue everywhere... one girl up there certainly came over a couple of times and said 'how's he getting on'. Whereas we were left to our own devices and there were 2 or 3 kids there who were 'wow' these wonderful creations they got quite a lot of attention, whereas Nick's was very modest.."*

# Well-being effects

- The participation opportunities enabled the children and young people to choose how much they were involved which impacted upon their emotional well-being however, this was a fluctuating state. Pain and epilepsy were confirmed barriers to participation.
- When professional staff or volunteers were perceived to be unhelpful this created barriers for them. There was reported to be a lack of social confidence in relating to non-verbal children.

# Positioning Theory adapted

'Kaleidoscope of well-being': adapting the mutually determining triad (Harrè and Langenhove 1999)



# Advocacy ?

- Not all people considered the needs of disabled children to facilitate their participation.
- How can we as Healthcare professionals influence this?
- What do you think about advocacy?

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# Questions/Comments ?

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