Moving towards a better understanding of well-being for children with complex disabilities who use a robotic device, the Innowalk ©Made for Movement

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COMET 2023

In Cork, Ireland, 22nd June 2023

CARDIFF UNIVERSITY
PRIFYSGOL CAERDYDD

Well-being Web

Well-being Web

Date of completion:

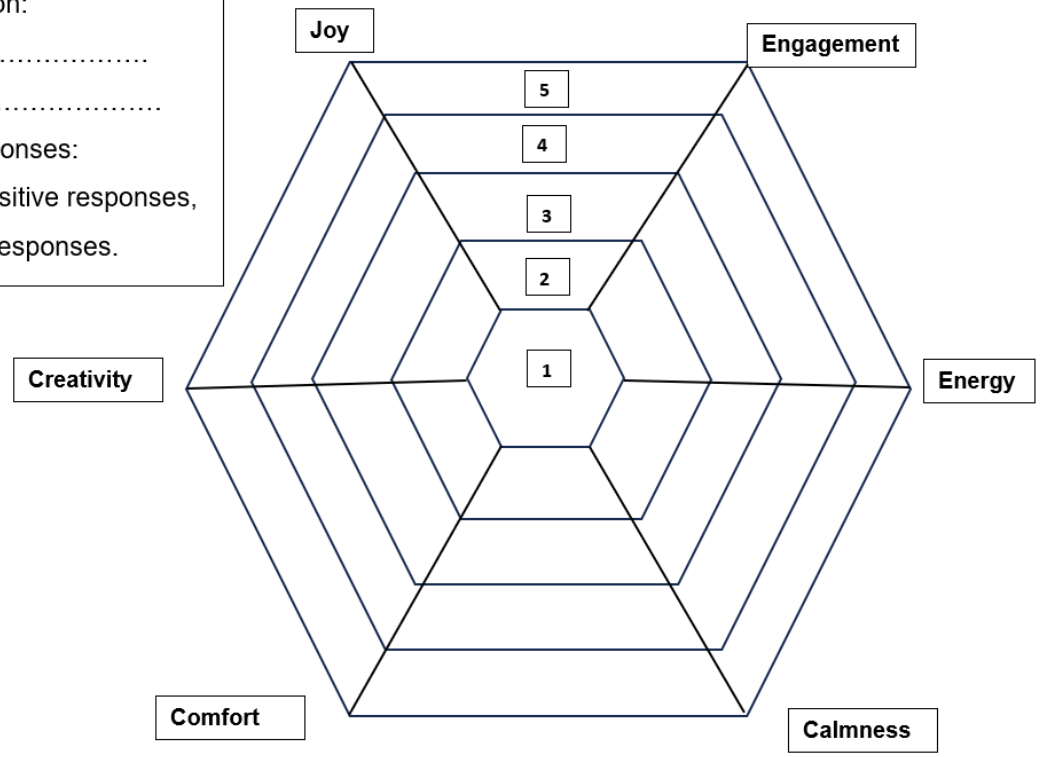
Baseline……

Activity type……

Scale 1-5 of responses:

5 shows most positive responses,

1 shows limited responses.



Aims of this work in progress paper

- 1. To provide background of the context of this research
- 2. To explain about well-being of children with complex disabilities
- 3. To provide impressions from the data
- 4. To discuss the need for a well-being measure but explore some of the complexities

Background

- PhD completed in 2021
- Context with children who cannot walk or talk
- ‘Well-being’ was a construct that I highlighted as needing further research, utilising positive attributes observed in the data that enabled participation – calmness, comfort, creativity, being energised, engagement with others/ activities, expressing joy.
- This is now published proposing a kaleidoscope of well-being. Pickering et al (2023)
- Post –doc Research Development Programme – 1 year in School of Healthcare Sciences
- Applied for funding – 4 grants not awarded but small bursary from UK clinical interest group:

Association of Paediatric Chartered Physiotherapists

(Bursary awarded 1st August 2022-31 July 2023)

PICo

- Problem: The lack of a valid and reliable measurement scale for the well-being of children and young people with complex disabilities (Mpundu-Kaambwa et al (2018).
- Interest: Developing and testing a new scale by observing the well-being of non-ambulant and non-verbal children and young people when using the Innowalk.
- Context: Special School setting for children and young people with complex disabilities
- Outcome: The domains established could enable the content validity to be evaluated in larger funded study, to test the psychometric properties of the WEBS.

Innowalk research

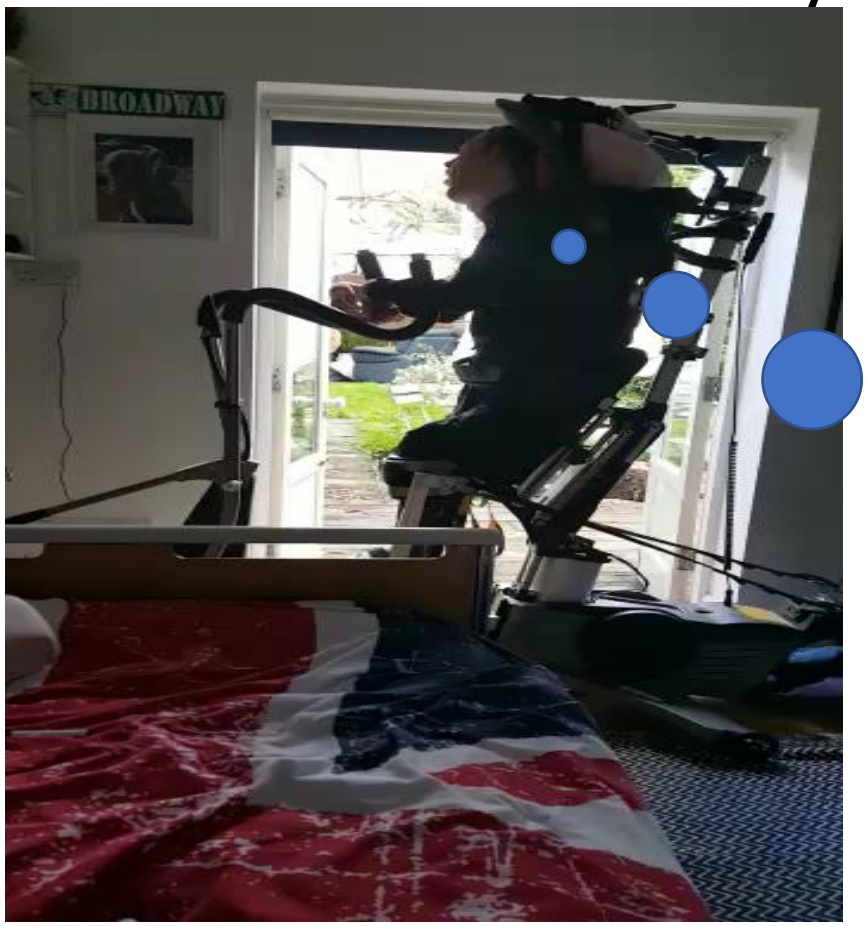
Novak et al (2019) recommended robotic devices as having a strong evidence base for effectiveness in cerebral palsy and other childhood onset disabilities.

The Innowalk, a robotic device, is a dynamic standing frame has recently been reported to demonstrate an improvement in quality of life (Lauruschkus et al 2022). Health economic review- cost effective for parents, but not health services in Sweden(although prescribed here and Norway for non-ambulant children).

Previously reported to have benefits for respiratory, circulation, skin integrity, light physical activity, gastrointestinal function, stretching of muscles and joints, mental function (linked to well-being) and bone mineral density (Verschuren et al 2016).

Consultation-Innowalk-Joe young adult

Email: I've been doing an hour each time and am going faster now. Yes, fine to use my video



I was away for a week and my Personal Assistant noticed that without the Innowalk, I had more spasms. So, it really helps my body to feel more relaxed.

Joe uses a chin switch to type his work

Well-being

- Watson et al (2012) describe emotional well-being as both a contextual and relational dynamic as well as an embodied, subjectively experienced phenomena.

- Pickering et al (online 2023) I have proposed a kaleidoscope of well-being- which fluctuates in different contexts

- Researchers did not find a valid and reliable measure of well-being for those with complex disabilities- Mpundu-Kaambwa et al (2018)

Research question and aims

Research question: How can the well-being of children and young people with complex disabilities be better understood, from using the Innowalk?

Aims/ objectives

1. To carry out a review of current well-being measures/checklists/scales for adults and children with complex disabilities.

2. To pilot, by observations, develop and test an observational scale that enables well-being indicators to be recorded with non-verbal children and young people with complex disabilities.

3. To obtain child and parental opinions by written diary records and an interview related to well-being following them using the Innowalk.

Context- special school

Innowalk-Made for movement

Consultation

Leo aged 10 years spoke with me on a Microsoft Teams video call with his physio, about using the Innowalk and how he perceives this benefits his well-being. When asked if he would recommend this for other children who cannot walk, he said:

> "*it's good for your legs, it's good for your arms, it's good for your belly, it's really good*"

He gave it 100/10 as he said it was the first time he was able to feel walking and he likes being taller than other people. It makes him feel good.

Leo's mum stated:

> "*the Innowalk has improved Leo's well-being by making his legs more comfortable by* ***increasing his range of movement and it being easier for him to lift his legs afterwards***. ***He has slept better and now has regular bowel movements***".

Research design

Case study- 10 participants (children and young people aged 4-18 years), plus their parents

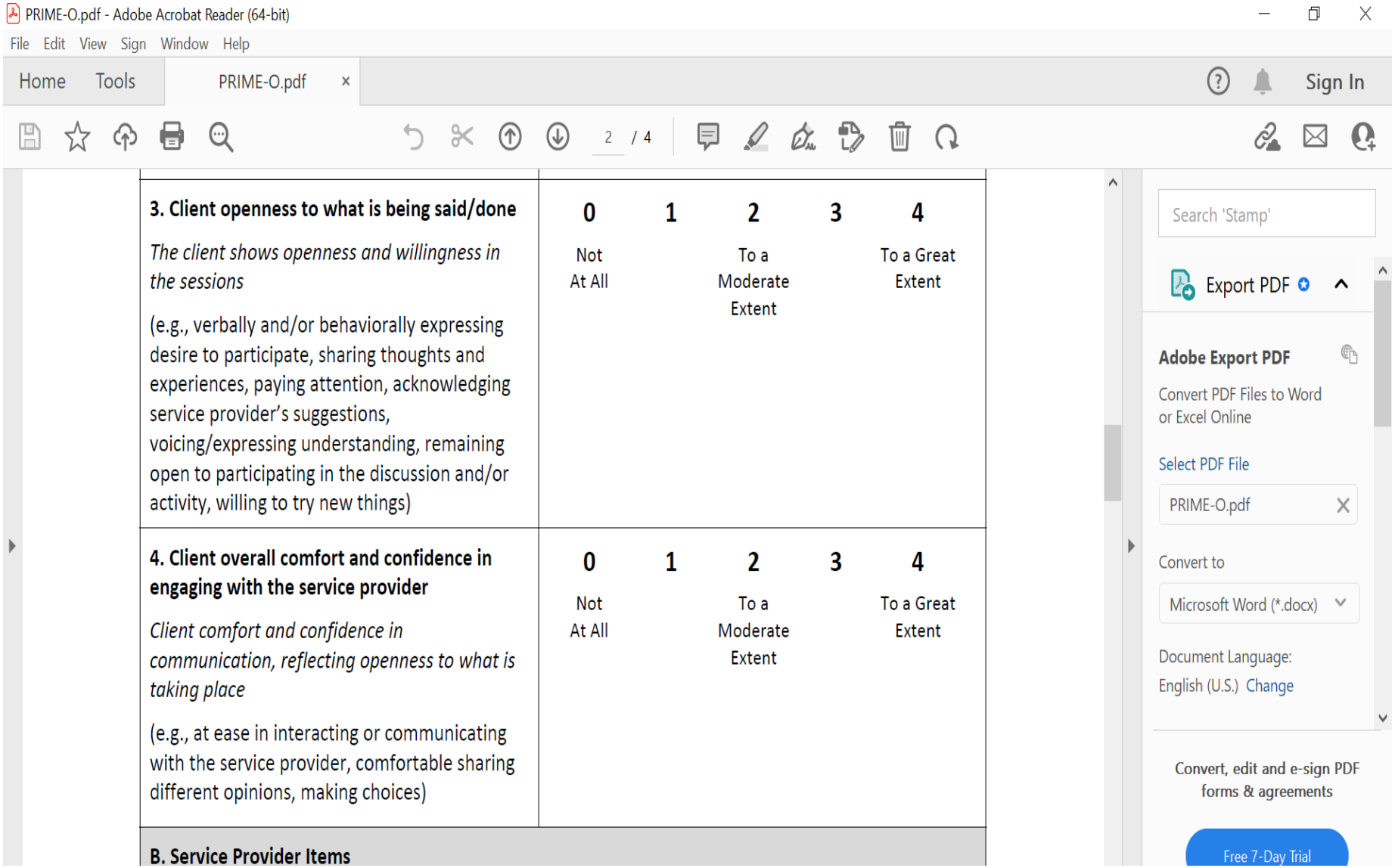
Each case made up from 3 sessions of observational field notes, diaries and interviews with children and their parents.

Analysis is being carried out using Braun and Clarke's(2018) thematic analysis for the qualitative aspects and descriptive statistics used from the proposed devised well-being measurement scale.

Well-being measures- literature

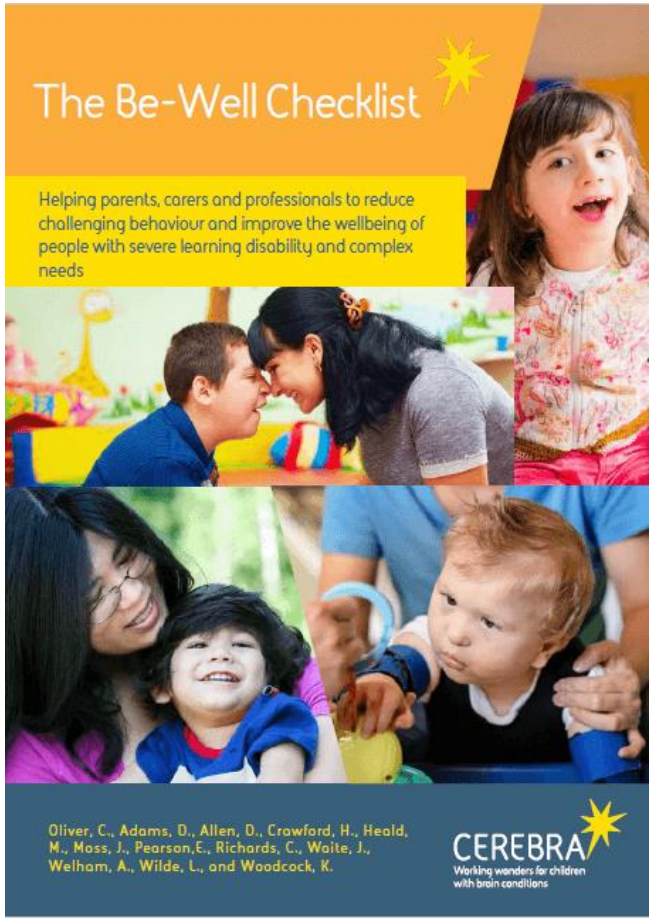
- Be-Well checklist
- PRIME- O
- Leuven Scale (special school already use)
- Own ideas from PhD data to develop a well-being observational scale

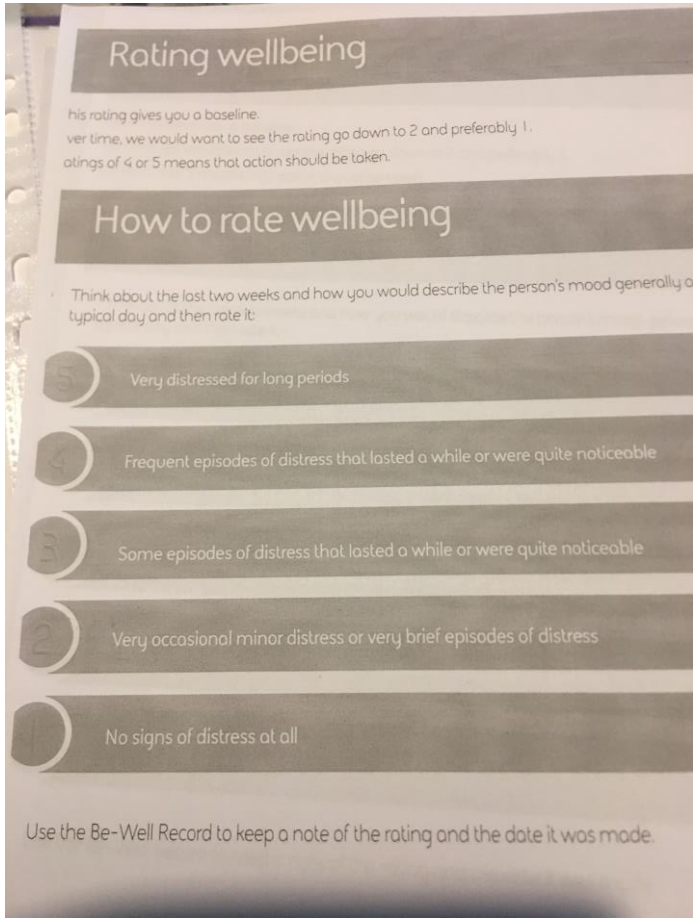
PRIME-O



3. Client openness to what is being said/done *The client shows openness and willingness in the sessions* (e.g., verbally and/or behaviorally expressing desire to participate, sharing thoughts and experiences, paying attention, acknowledging service provider's suggestions, voicing/expressing understanding, remaining open to participating in the discussion and/or activity, willing to try new things)	**0** Not At All **1** **2** To a Moderate Extent **3** **4** To a Great Extent
4. Client overall comfort and confidence in engaging with the service provider *Client comfort and confidence in communication, reflecting openness to what is taking place* (e.g., at ease in interacting or communicating with the service provider, comfortable sharing different opinions, making choices)	**0** Not At All **1** **2** To a Moderate Extent **3** **4** To a Great Extent
B. Service Provider Items	

Be-Well checklist





Domains being tested from observations

Well-being scale (WEBS)-draft version1

Name	Age	Level of GMFCS I II III IV V	Observation Session number 1 2 3	Timing length of session (minutes)	Date

Calmness

Comments- e.g. calmness in mood- excitability or withdrawn.

Descriptor	Withdrawn	Quiet	Calm	Excited	Very excited
Likert scale	1	2	3	4	5

Comfort

Comments-e.g. settled in equipment, minimal spasms, fits observed, self-injurious behaviours reduced e.g. reflux, hand in mouth to reduce pain; eye pressing; head banging.

Descriptor	Unsettled	Fidgety	Usual	Settled	Relaxed
Likert scale	1	2	3	4	5

Creativity

Comments- expressing self in different ways e.g. music/ drawing/craft/games.

Descriptor	Poor	Low	Usual	Good	Excellent
Likert scale	1	2	3	4	5

1

Well-being scale (WEBS)-draft version1

Energy levels

Comments-has the energy to participate.

Descriptor	Poor	Low	Usual	Good	Excellent
Likert scale	1	2	3	4	5

Engagement with other people/activities

Comments- wanting to engage with people in the surroundings by eye contact, gesture or spoken words. Showing intent to be involved in the activity or disengaging.

Descriptor	Poor	Low	Usual	Good	Excellent
Likert scale	1	2	3	4	5

Expressing joy

Comments- e.g. could be smiling or laughter; expressive sounds indicating pleasure.

Descriptor	Poor	Low	Usual	Good	Excellent
Likert scale	1	2	3	4	5

Person completing the observational well-being scale_____

Role or Relationship to Child/ Young person_____

Supported by_____

Activity participated in_____

2

Diary instructions

Research diary: Name_____

An exploration of well-being with children and young people with complex disabilities, and their families, from using the Innowalk (WEBS study)

Diary instructions for WEBS study

This record is where you can write down anything that you think relates to your child or young person's well-being in relation to using the Innowalk at Ysgol Y Deri. You can write the date and anything you have observed such as their level of stiffness, comfort, enjoyment that you think has changed since using the Innowalk. I will collect the diary at school, and it will help to inform the questions we can chat about in your interview, after I have observed your child or young person using the Innowalk three times in school. Any questions please get in touch. Contact: pickeringdm@cf.ac.uk

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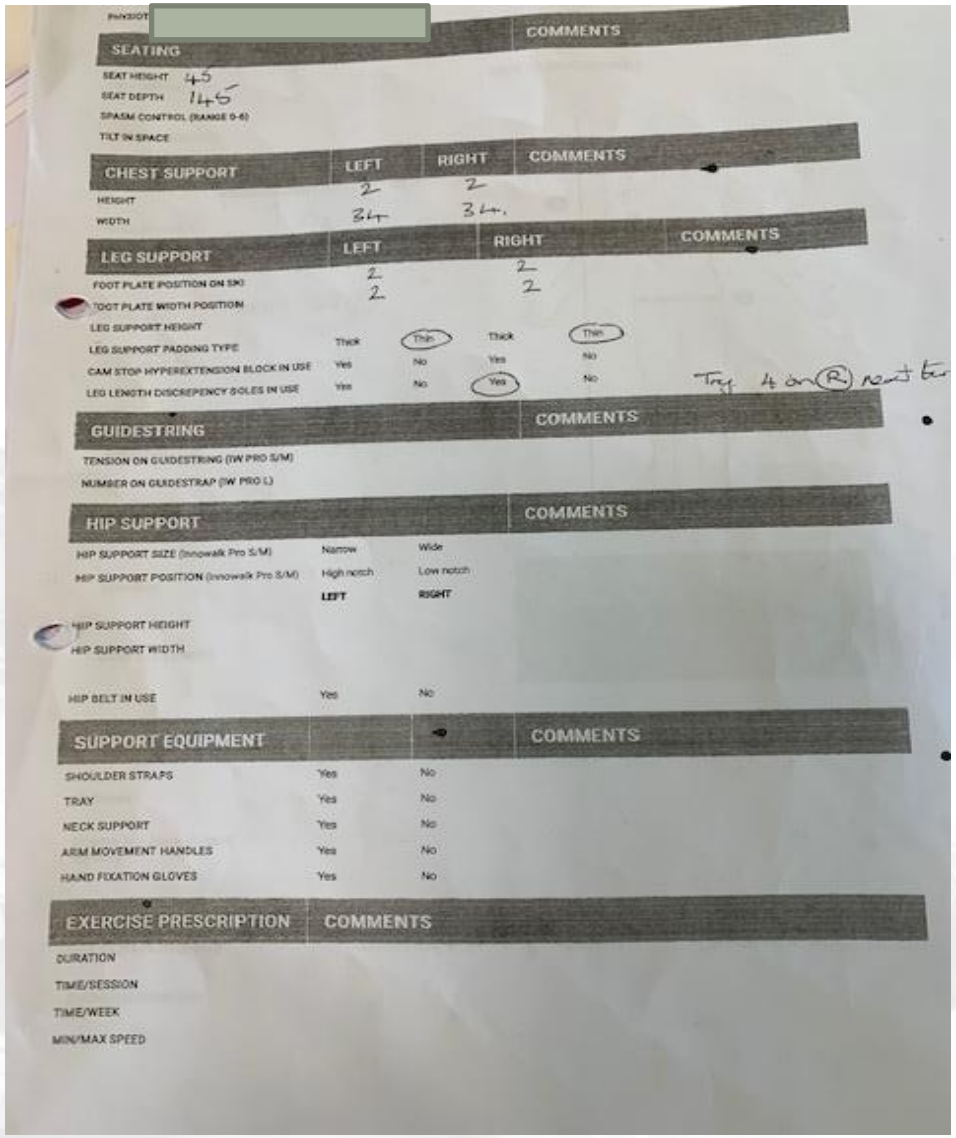
Technical set up complex, need a hoist or step



SEATING			COMMENTS
SEAT HEIGHT	45		
SEAT DEPTH	145		
SPASM CONTROL (RANGE 0-6)			
TILT IN SPACE			

CHEST SUPPORT	LEFT	RIGHT	COMMENTS
HEIGHT	2	2	
WIDTH	34	34.	

LEG SUPPORT	LEFT	RIGHT	COMMENTS
FOOT PLATE POSITION ON SKI	2	2	
FOOT PLATE WIDTH POSITION	2	2	
LEG SUPPORT HEIGHT			
LEG SUPPORT PADDING TYPE	Thick / (Thin)	Thick / (Thin)	
CAM STOP HYPEREXTENSION BLOCK IN USE	Yes / No	Yes / No	
LEG LENGTH DISCREPENCY SOLES IN USE	Yes / No	(Yes) / No	Try 4 on (R) next to

GUIDESTRING	COMMENTS
TENSION ON GUIDESTRING (IW PRO S/M)	
NUMBER ON GUIDESTRAP (IW PRO L)	

HIP SUPPORT			COMMENTS
HIP SUPPORT SIZE (Innowalk Pro S/M)	Narrow	Wide	
HIP SUPPORT POSITION (Innowalk Pro S/M)	High notch	Low notch	
	LEFT	RIGHT	
HIP SUPPORT HEIGHT			
HIP SUPPORT WIDTH			
HIP BELT IN USE	Yes	No	

SUPPORT EQUIPMENT			COMMENTS
SHOULDER STRAPS	Yes	No	
TRAY	Yes	No	
NECK SUPPORT	Yes	No	
ARM MOVEMENT HANDLES	Yes	No	
HAND FIXATION GLOVES	Yes	No	

EXERCISE PRESCRIPTION	COMMENTS
DURATION	
TIME/SESSION	
TIME/WEEK	
MIN/MAX SPEED	

Work in Progress

Participants/ chosen name	Age	Gender	Condition
1 Charlie	18	Male	Cerebral Palsy
2 Star	14	Female	Spina Bifida
3 Every	8	Female	Spina Bifida
4 Joey	8	Male	Cerebral Palsy
5 Zelia	17	Female	Cerebral Palsy
6 Judy	4	Female	Rett's Syndrome
7 Barney	18	Male	Cerebral Palsy
8 Black Panther	11	Male	Cerebral Palsy
9 Zac	8	Female	Cerebral Palsy
10 Melanie	13	Female	Cerebral Palsy
	Mean 11.9	4 male; 6 female	7 CP; 2 SB; 1 Rett's

Mean data for 10 cases

	Child 1	Child 2	Child 3	Child 4	Child 5	Child 6	Child 7	Child 8	Child 9	Child 10		Total mean	Standard deviation	Median	min	max
Mean Time (min)	29.3	31.6	23.3	24.9	15.6	15	30	29	30	32.3		26.1	6.3	29.2	15	32.3
Mean Distance (KM)	1.4	1.6	4.4	1.4	0.72	0.6	5.4	1.3	1.5	1.4		1.9	1.6	1.4	0.6	5.4
Mean Revolutions per minute	39.3	42.6	43.6	39.6	34.3	35.6	41.6	39	43.6	40		39.9	3.1	39.8	34.3	43.6

Field notes: Child 5 – Zelia (Observation 3)

4.45pm Hoisted into Large Innowalk

Tolerated slow speed quite well (36 rpm) for a while (0.4km) as sped up to 44 rpm, then complained of pain in right hip so slowed down to 39 rpm, to adjust for this.

Talked about an aquarium visit in Bristol last week.

Strong spasm in legs which stopped the Innowalk- Left leg spasms stopping the Innowalk at 4.58pm and 5.02pm

Sometimes gets cramp in right foot when working hard with personal trainer.

5.05 pm Decided would like to stay longer in Innowalk and do less walking today. Stated she feels relaxed when gets off the Innowalk.

Observed to be more wobbly on walker after Innowalk today and leaning to the left side.

Qualitative comments so far

Star(14): *"Feels like I'm flying"*

Zelia (17): *"My legs feel different, more relaxed"*

Joey's Mum: *"...so the first time he went on the Innowalk he slept all night, and his sleep was really bad"*

Melanie (13): *"The Innowalk helps me stand straighter than I can by myself "*

Joey (8): *"Feels like I'm walking… I like being taller than you"*

Diary entry Barney (19 years)

*“ My son is 19 years old, he stopped using a standing frame at 10 years old due to hip surgery. When school had the Innowalk, physio suggested we try it…for over a year my son has been using the Innowalk once a week for 30-45 minutes…..I feel the Innowalk has made a massive difference for my son…**he is happier, has better bowel movements , longer muscle release on his hamstrings, his whole posture is more relaxed**…..I would highly recommend this equipment for anyone with disabilities to try”*

Impressions of the data so far

Benefits

- Restorative sleep improved-relaxation benefits/ reduced leg spasms.
- Easier handling afterwards for 2-4 days.
- Regular bowel movements.
- Children like that they can control the speed themselves –empowering.
- Parents perception that even this ‘passive’ motion is exercise – has circulatory benefits?
- Children look forward to this weekly session- prefer to usual physiotherapy.

Drawbacks

- Complicated to set up – difficult to delegate
- Expensive
- Large
- Passive motion- therefore no muscle strengthening effect- Limited motor learning carry over as not an active process
- **Equity of provision** limits intensity as all suitable children get offered 1 session per week not the recommended dose of 3 times per week for strengthening benefits

Discussion

Unsure about trying to contain these well-being constructs into a Likert scale as these fluctuate and it is not easy to quantify on a scale:

Comfort,

Calmness,

Energy,

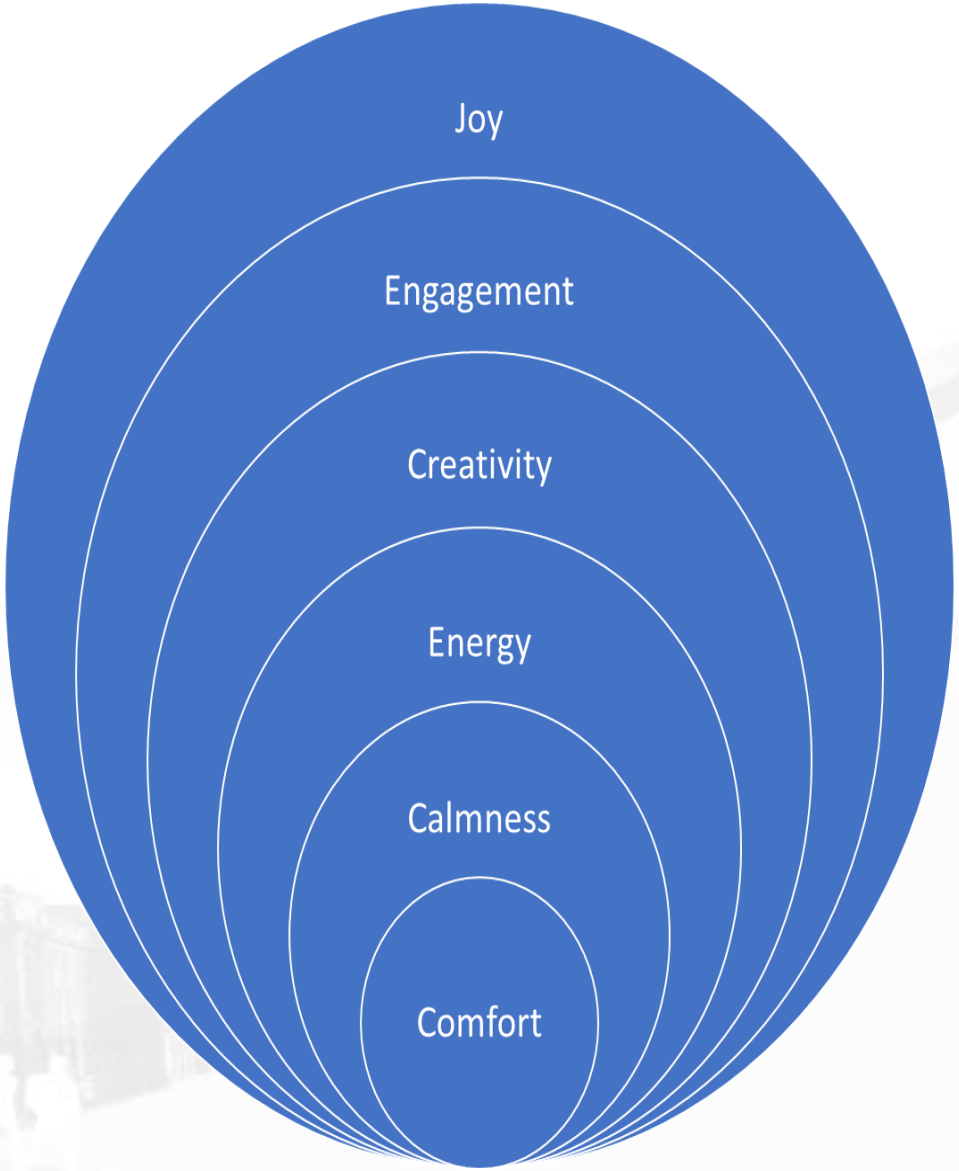
Creativity,

Engagement,

Joy.

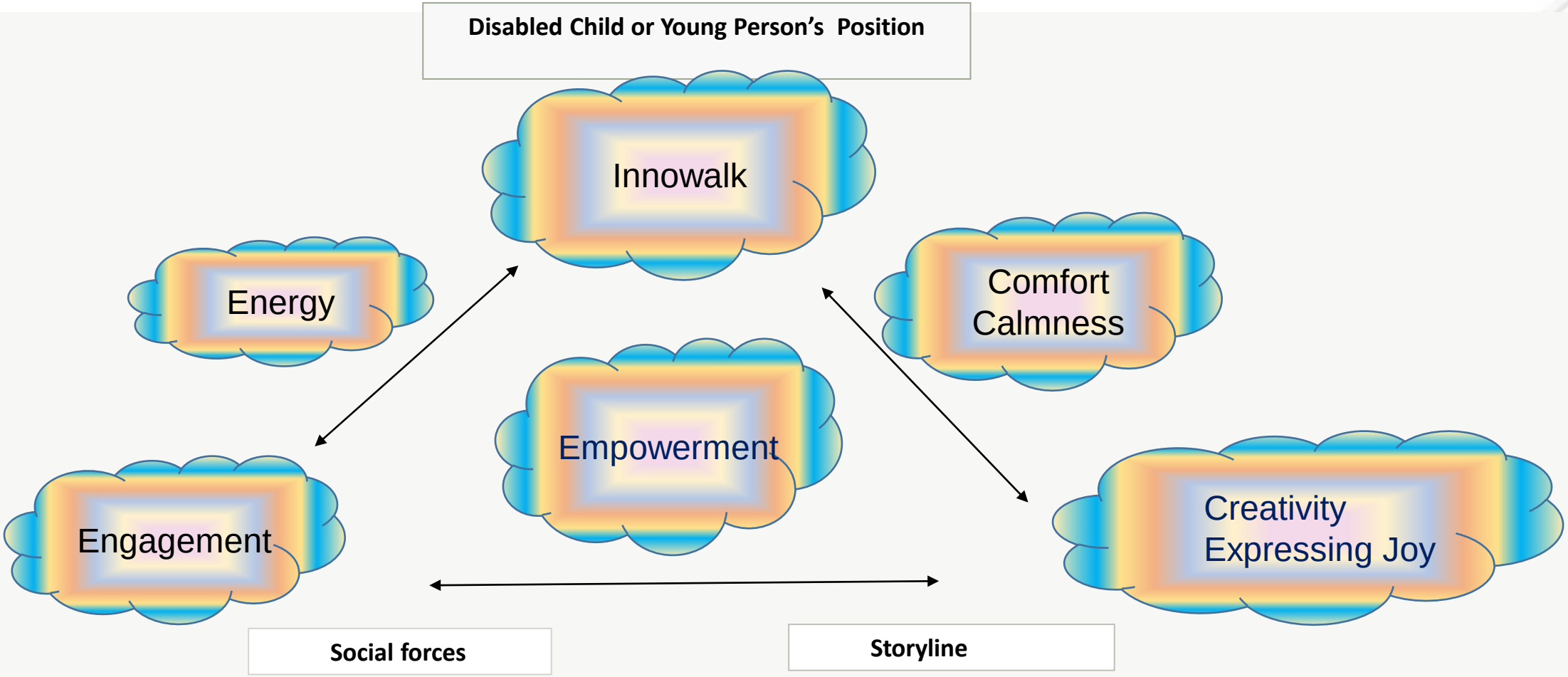
Venn Diagram ? Hierarchy

Observed:
Some leg spasms
Listening to music
Playing games on the tray
Excitement
Some fatigue afterwards
Varying moods
‘Banter’ between staff and participants



Benefits described:
Sleep
Bowel movements
Relaxation
Less leg spasms
Better imaginative play
Enjoy better than typical physiotherapy

Kaleidoscope of well-being- in equilibrium (Pickering et al 2023)



Kaleidoscope of well-being- skewed