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Executive Summary

Researchers have not yet developed a valid and reliable measure of well-being for children with complex disabilities. Complex disabilities refer to those children with learning disabilities and complex needs such as those with cerebral palsy. This disability can make participation in physical activities harder, but the impact upon well-being is unknown. Well-being in this study refers to how children can indicate from their behaviours whether they are enjoying participation in the Innowalk, a robotic device.

Consultation took place with disabled adults, children and young people and their parents, to discuss the domains of a proposed well-being scale. Based upon their contributions and previous doctoral research, well-being indicators included calmness, comfort, creativity, energy levels, engaging with others and expressing joy. Participants were observed in a special school context when using the Innowalk. The Innowalk is reported to have health and well-being benefits for non-ambulant people but is expensive to purchase and maintain.

A case study series observed ten children, on three occasions when they participated in the Innowalk, for evidence indicating their well-being. Observational field notes were made, and these were mapped onto two existing scales the Be-Well checklist and PRIME-O, as well as the proposed new observational well-being scale (WEBS). The data were supported by their parents keeping a diary during this time, followed by interviews.

The observational scales were analysed descriptively. Interview and diary data were analysed thematically, and three themes were identified: Well-being: Mood and achievements; Participation: Anticipation and tolerance; Physical effects: Improved self-regulation and self-care. The new WEBS scale is discussed and how well-being can fluctuate during a session, making this hard to contain or measure. The participants indicated that they enjoyed their experiences in the Innowalk, which supports existing research. What this study adds are the descriptors of aspects of well-being including comfort, calmness, creativity and engagement. Further work will be developed to explore staff perceptions of measuring well-being and to refine the WEBS scale on a larger population of disabled children, young people and young adults.

Background

This study aimed to explore the perceived well-being effects of using the Innowalk Pro with children and young people at Ysgol Y Deri, Penarth. The construct of well-being for disabled children is not yet well understood and this study also sought to explore potential domains to develop a new scale. To begin the process of developing a new scale, a narrative literature review was carried out.

Literature Review

An initial literature search was carried out in June 2022. The literature found was managed in EndNote 21 reference manager. The following databases were searched from 2002-2022: Web of Science, PubMed, Medline, CINAHL, Google scholar, Embase, PsychInfo, Ovid MCare, ASSIA, Joanna Briggs Institute and Cochrane. The key words used with Boolean terms AND/OR were well-being; wellbeing; measures; complex cerebral palsy; children and young people; non-ambulatory; non-verbal populations; Innowalk. Topics excluded were Drugs; Surgery; Botox, Transition and parent's views. This search was repeated in July 2023 which added two studies.

In total 14 relevant studies were found which were grouped into Innowalk (Schmidt-Lucke et al 2019; Lauruschkus et al 2022; Pekanovic et al 2022), Well-being (McCarthy et al 2002, Cheshire et al 2010, Dodds 2016; Mpundu-Kaambwa et al 2018; What works wellbeing 2022; Pickering et al 2023); Quality of Life (Böling et al 2016; Coleman et al 2022); Physical activity, bone density, sleep and nutrition (Verschuren et al 2016; Dodds 2016; Paul et al 2022). Additionally, three observational measures were found that included aspects of well-being, which generated five studies. These were the Leuven Scale (Vos et al 2010 and 2013), PRIME-O (King et al 2019) and the Be-Well checklist (Oliver et al 2020 and 2022). The next section gives a critical commentary of the evidence found that led to the research question and two aims stated at the end of this section.

Innowalk

The Innowalk is a robotic device, powered by electricity, that generates a circular movement in the legs by passive assistance and is relatively new to the UK (Made for Movement 2023; Lauruschkus et al 2022). The Innowalk enables non-ambulant people to be placed in sitting and gradually raised vertically into standing by a hand control. The Innowalk Pro is an expensive device and is large to store, it lends itself to be included within a school, gym or department for shared usage. The cost in 2023 is £45,000 (+VAT), with maintenance costs of £1,298 Per Annum (+VAT). It has been established in Sweden and Norway as essential to early management for children who do not have limitations in weight bearing. It has reported benefits for circulation, maintaining bone density, reducing muscle tone, enabling bowel function, enhancing sleep patterns and well-being (Schmidt-Lucke et al 2019).

Pekanovic et al (2022) described the Innowalk as safe although dosage was unclear, the positive effects included body stability, joint mobility, and enhancement of digestive function. Lauruschkus et al (2022) found that perceived quality of life was enhanced and although it was not deemed cost effective in the health economic analysis for healthcare organizations, parents perceived it was cost effective for their

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child's long term care needs into adulthood, as a maintenance and preventative device. Llamas-Ramos et al's (2022) systematic review evaluated that more studies are needed, as the Innowalk is only one of several robotic devices that offer supported motion.

Well-being

Well-being in this context refers to how children and youth with complex disabilities indicate that they are thriving in their environments, which directly reflects their perceived quality of life (What works well-being, 2022). Complex disabilities refer to those children with severe learning disabilities, who are usually excluded from research. This includes those who are non-verbal and non-ambulant. As early as 2002, well-being was considered important by McCarthy et al (2002), when evaluating the properties of the Gross Motor Function Measure (GMFM), the Pediatric Evaluation and Disability Inventory (PEDI), the Pediatric Outcomes Data Collection Instrument (PODCI), and the Child Health Questionnaire (CHQ) measurement tools. However, well-being was not their main focus. Cheshire et al (2010) called for a more positive approach to well-being looking for prosocial behaviours, but this was by proxy parental reporting. Currently available questionnaires related to well-being (Muris et al 2003), used with typically developing children, are problematic for those who cannot communicate verbally or have a learning disability and experience epilepsy, fatigue or pain (Verschuren et al 2016). Previously, researchers have not found a valid and reliable measure of well-being for those with complex disabilities (Mpundu-Kaambwa et al 2018).

The Leuven Scale showed promise as an observational well-being tool, with clear descriptors that relate to well-being, but researchers are still establishing its validity (Vos et al 2010;2013). Ysgol Y Deri staff already use this tool to monitor well-being with non-verbal children. The PRIME-O was developed and has descriptors looking at the child's engagement with staff and activities during therapy (King et al 2019). It is an observational measure that captures indicators of affective, behavioural, and cognitive components of engagement for both clients and therapists. It is divided into three sections the client, the provider and the overall engagement with a Likert scale ranging from 0 (not at all) to 4 (to a great extent). It is not specific to well-being and is language based which has limitations for the non-verbal children (Appendix A). The 'Be-Well checklist' was developed for children with profound disabilities (Oliver et al 2020; 2022) (Appendix B). This is based upon observations over a 2-week period and is particularly designed to monitor behaviours that challenge. It has five levels with 1 being 'no signs of distress' to five being 'very distressed for long periods'. These reflect anxiety and low mood, cognitive difference, emotional dysregulation, expressive communication, learned or functional behaviours, pain and discomfort, sensory sensitivity and sleep. Many of these focus on the negative aspects of well-being which cause distress to the children and their carers. Pain, discomfort and sleep disturbance are key factors that limit physical activity participation with this group of children, which diminishes their well-being (Dodds et al 2016).

Previous doctoral research has shown some positive indicators of well-being-these were calmness, comfort, creativity, engagement with others and joy (Pickering et al 2023). These indicators are illustrated by a 'Kaleidoscope of well-being', showing

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that well-being can fluctuate for children with complex disabilities in different environments, with different people, and having or not having suitable equipment to support their needs. As the Innowalk is suggested to influence well-being it was therefore considered a suitable activity to explore the characteristics of well-being in order to develop a new well-being measure. Thus, for this study it was decided that an observational scale could be developed by observing the children for indications of their well-being, during a three sessions with the Innowalk.

Quality of Life

Quality of life (QoL) for these children has often been measured by proxy from the parents or carers. Boling et al (2016) tested the CP-QOL questionnaire in Finland, which was originally developed in Australia by Waters et al (2013). The children who were able to complete this themselves perceived they had the same QoL as their typically developing peers. Coleman et al (2022) describes QoL and well-being as interchangeable. These include a sense of community and social integration with self-perceived physical, cognitive, emotional, and social functioning being aspects that impact engagement. Coleman et al (2022) suggest more needs to be done to enable families with disabled children to flourish within their functional capabilities.

Physical activity and bone density

Physical activity is known to maintain bone density, which can be compromised in non-ambulant children with cerebral palsy (Novak et al 2013). The Association of Paediatric Chartered Physiotherapists (UK) have produced a guide to bone health management, based upon a consensus of opinions (2023). Whilst medication can be given to maintain the child's bone density, preventing the stiffness and contractures associated with being non-ambulant, is more challenging (Dodds 2016). A device such as the Innowalk, which creates a passive assisted motion, can support upright weight bearing to maintain bone density, when walking is not achievable (Goodwin et al 2018; Lauruschkus et al 2022).

All of these aspects were considered in developing the research question and aims: the proposed Innowalk well-being benefits, current knowledge of well-being and quality of life in this population, and the benefits to their physical health and well-being.

Research question:

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

Aims of the study:

1. To pilot, by observations, develop and test an observational scale that enables well-being indicators to be recorded with children and young people with complex disabilities.
2. To obtain child and parental opinions by written diary records and an interview related to well-being, following them using the Innowalk.

Research Method

A case study design was used (Yin, 2017). Each case comprised measures, observational field notes, diaries and interviews with children, young people and their parents. Three visits were made to observe each child where observational field notes were written. Three separate occasions were decided so that it would not be skewed by a one off good or bad day. These field notes were used to score the PRIME-O (King et al 2109) and Be-Well (Oliver et al 2020) checklists and the new observational well-being scale developed (WEBS). The PRIME-O scale has five Likert points on the scale ranging from 0 Not at all, 1, 2 To a moderate extent 3, 4 To a great extent. The Be-Well checklist has five points ranging from 1 no signs of distress to 5 very distressed for long periods. The new WEBS scale has five scores with 1 reflecting poor, 2 low, 3 usual, 4 good and 5 excellent. The time, distance, and speed data were collected each time the participants went in the Innwalk, and the means calculated over the three sessions. The diaries were kept over the period between session one and three and were used to guide the interview which followed the observational data collection period.

Advisory group

A small number of people were recruited to an advisory group in the Autumn of 2021-Spring 2022, which included a parent and a teenager who used an Augmentative and Alternative Communication device, a young adult using the Innwalk at home, a young adult living who was ambulant with cerebral palsy, and a child attending the school and his mother. Early ideas about well-being, based upon doctoral research, were shared with this group, to consider the domains that might be useful in the new observational well-being scale (Pickering et al, 2023). These were Comfort, Calmness, Creativity, Engagement with others/ activities and Joy. Energy was an additional concept added by discussion with the advisory group, thus making six domains for the new observational scale (WEBS) which were scored across five points, ranging in their descriptors (Appendix C).

Recruitment

Ysgol Y Deri is a large special school in South Wales, providing education and therapy services catering for a wide and diverse range of differently abled pupils. The school had purchased a small and large version of the Innwalk devices in 2021, which were being used every day in physiotherapy, for their pupils and some outpatients. Parents were approached by the physiotherapy staff and given a participant information sheet (Appendix D). This information was also created for different age groups, seeking to make this accessible for them (Appendix E). The age range for inclusion was four to eighteen years and participants needed to be using the Innwalk. Some participants had been using the Innwalk for a year, others were new to the device.

Consent

Consent was achieved with the parents who gave their written consent, additionally some children could give their own written consent. Where the participants had communication or learning difficulties they were included if they gave their ongoing assent and did not show any distress by the researcher's presence at the

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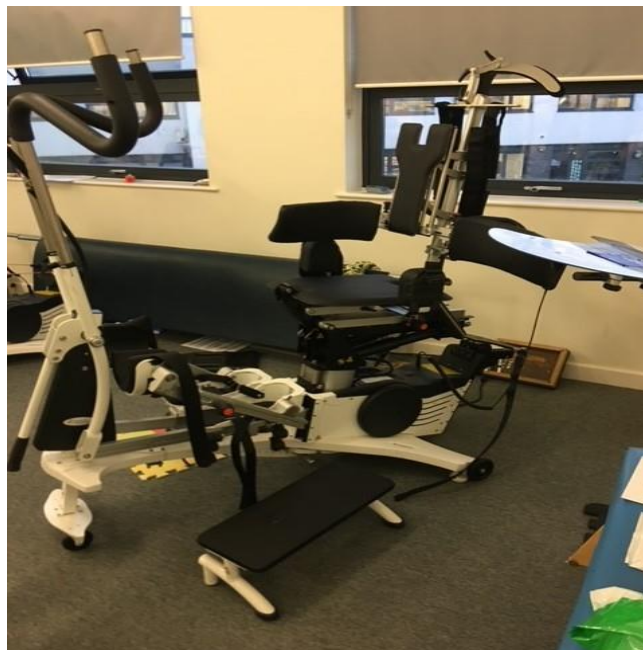
observations. Each participant chose their own pseudonym to protect their anonymity and confidentiality, with parental support if necessary.

Data collection

Data were collected from September 2022 until May 2023 at the school. An image of the large Innowalk at the school can be seen in Figure 1 with a step, however most participants were hoisted into the device. Initially two children were observed, to pilot the research protocol. The research protocol was implemented following consent where an initial observation was made, a paper diary given and arrangements for follow up for the next two subsequent visits. Some of these visits were weekly, others had gaps, due to the participant's illnesses. At the final third observation, the diary was collected, and arrangements were made to carry out an interview at a future date.

Fourteen site visits were made to the school to observe the children three times, where field notes were made. These were later transcribed. Parents and some of the children kept a written diary in the small book provided. Nine out of ten diaries were returned to the researcher after the final observation. The diaries were also transcribed by the researcher. The diary entries helped to direct the interview questions, as an elicitation technique (Bartlett and Milligan 2020). The interview questions can be seen in Appendix F. Some of these were online via zoom/teams, others were held at the school, where a Dictaphone was used. Two children took part in a BBC documentary related to using Virtual Reality, whilst in the Innowalk, permission to include this video in the analysis was given. Interview data was transcribed externally by TP Transcription Limited, funded by the APCP bursary. Each child was given a £30 gift voucher, for participating in the study, a choice of Love to shop or Amazon were given.

Figure 1 Innowalk in situ at the school with a step for those who could step up.



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Data storage

Data was stored on Cardiff University's one drive which is password protected. Personal data related to age and type of disability, email addresses or telephone numbers were used during the duration of the study, but not retained after this. This identifiable data was stored separately to the study's data in a locked cabinet.

Data analysis

The PRIME-O, the Be-Well and the new WEBS tool developed scores were inputted into excel and analysed with descriptive statistics, guided by Dr Nichola Gale. Qualitative data from observational data field notes, diary and interview data were transcribed and coded, utilising Braun and Clarke's six stages of analysis to identify themes (Braun and Clarke 2018). Coding took place within each case and individual reports were sent to the families (Example given in Appendix D), then across case comparisons were made. Codes were clustered into central organising concepts and three overall themes identified.

Results

Ten children were recruited and gave consent or assent to take part in the study. The mean age was 11.9, the median 12 years. Four male and six females took part and their disabilities included 7 with cerebral palsy, 2 with spina bifida and 1 with Rett's syndrome. This data can be seen in Table 1. The observations highlighted the need for individual technical set up, where the Innowalk had to be adjusted after every participant. The 2 Innowalks were positioned in the physiotherapy room and only these staff adjusted it each time.

Table 1 Participants details

Name (pseudonym)	Age	Gender	Disability	Non-verbal
Charlie	18	Male	Cerebral Palsy	Yes
Star	14	Female	Spina Bifida	No
Everly	8	Female	Spina Bifida	No
Joey	8	Male	Cerebral Palsy	No
Zelia	17	Female	Cerebral Palsy	No
Katie	4	Female	Rett's Syndrome	Yes
Barney	18	Male	Cerebral Palsy	No
Black Panther	11	Male	Cerebral Palsy	No
Zac	8	Female	Cerebral Palsy	No

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Melanie	13	Female	Cerebral Palsy	No
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Once the cases were compared the total mean, standard deviation, median and minimal and maximal values were calculated in excel as shown in Table 2.

Table 2: Overall Mean, Standard Deviation, Median and minimal and maximal values of time, distance, and speed in the Innwalk

	Total mean	Standard deviation	Median	Min	Max
Mean Time (minutes)	26.1	6.3	29.2	15	32.3
Mean Distance (Km)	1.9	1.6	1.4	0.6	5.4
Mean Revolutions per minute	39.9	3.1	39.8	34.3	43.6

Table 2 highlights the variations in time, speed and distance covered which varied by age and level of disability of the participants.

Measures

The PRIME-O checklists were scored from the field notes observations, but these were limited in the information they provided, particularly for the non-verbal children such as Charlie and Katie (King et al 2019). There was a lack of consistency between the three observation sessions making it difficult to interpret after averaging the results. Those young people who preferred to chat rather than play games scored 4 across every section. Whilst this was an observational scale it was possibly not designed to be used for this type of passive therapy intervention. Table 3 illustrates these results.

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Table 3 PRIME-O results

Mean scores of PRIME-O Likert Scale 0 not at all, 1, 2 To a moderate extent 3, 4 To a great extent;
Green shading Child, Orange shading provider, blue shading overall

	PRIME-O Qu 1-child interest and enthusiasm	PRIME-O Qu 2-child strengths-based language	PRIME-O Qu 3-Child openness to what being said and done	PRIME-O Qu 4-child overall comfort and confidence in engaging	PRIME-O Qu 5-Provider interest and enthusiasm	PRIME-O Qu 6-Provider use of strengths-based language	PRIME-O Qu 7-Provider overall comfort and confidence in engaging the child	PRIME-O Qu 8-Provider listening/ communication behaviours	PRIME-O Qu 9-Overall warmth of the interaction	PRIME-O Qu 10-Collaborative nature of the interaction
Charlie	2	0	0	1.5	3.6	3.3	3.3	2	4	0
Star	4	3.6	3.6	4	4	4	4	3.6	4	4
Everly	4	1.6	2.6	2.6	3.3	3.3	4	4	4	2.6
Joey	3.3	3	2.6	2	3	2	3.3	2	3.3	2.3
Zelia	4	4	4	4	4	4	4	4	4	4
Katie	3	2	2	2	3.6	2.6	4	2.6	2.6	0.5
Barney	1.6	0	1.6	1.3	2.6	2.6	4	2.5	2.3	3
Black Panther	3.3	3	3.6	3.3	4	3	4	4	4	3.6
Zac	4	3.6	3.6	4	4	4	4	4	4	4
Melanie	4	4	4	4	4	4	4	4	4	4

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The Be-Well checklist was designed to be used over a 2-week period (Oliver et al 2020) and none of the children were seen to be highly distressed during the Innowalk sessions. If they showed minor distress (2) their needs were attended to by staff, in a timely manner. It is possible if they were more significantly distressed, they would not have participated in the Innowalk. These results are shown in Table 4.

Table 4 The Be-Well checklist mean scores:

1 no signs of distress- 5 very distressed for long periods.

Charlie	1.3
Star	1
Everly	1.3
Joey	1.3
Zelia	1.6
Katie	1.3
Barney	2
Black Panther	1.3
Zac	1
Melanie	1

The Observational Well-being scale developed (WEBS)

The WEBS average results are shown in Table 5. Scores ranged from 2.3 to 5. Comfort and energy were seen lowest with Barney, but staff attuned to his needs when discomfort was shown.

Table 5 Mean scores of WEBS domains

WEBS domain scored 1-5	Charlie	Star	Everly	Joey	Zelia	Katie	Barney	Black Panther	Zac	Melanie
Comfort	3	4	4	4	3.6	4	2.3	3.3	3	3
Calmness	5	3.6	4.3	4.3	4	2.6	4	4	4.3	5
Creativity	3	4.6	5	5	3.6	3.3	3	4	5	4.6
Energy	4	4.3	4.3	4	3.3	4	2.3	3.3	4.6	5
Engagement	3	5	5	3.6	5	4.3	2.6	4.3	5	5
Joy	3	4.6	5	4.3	3.6	3.3	2.6	4.6	4.6	5

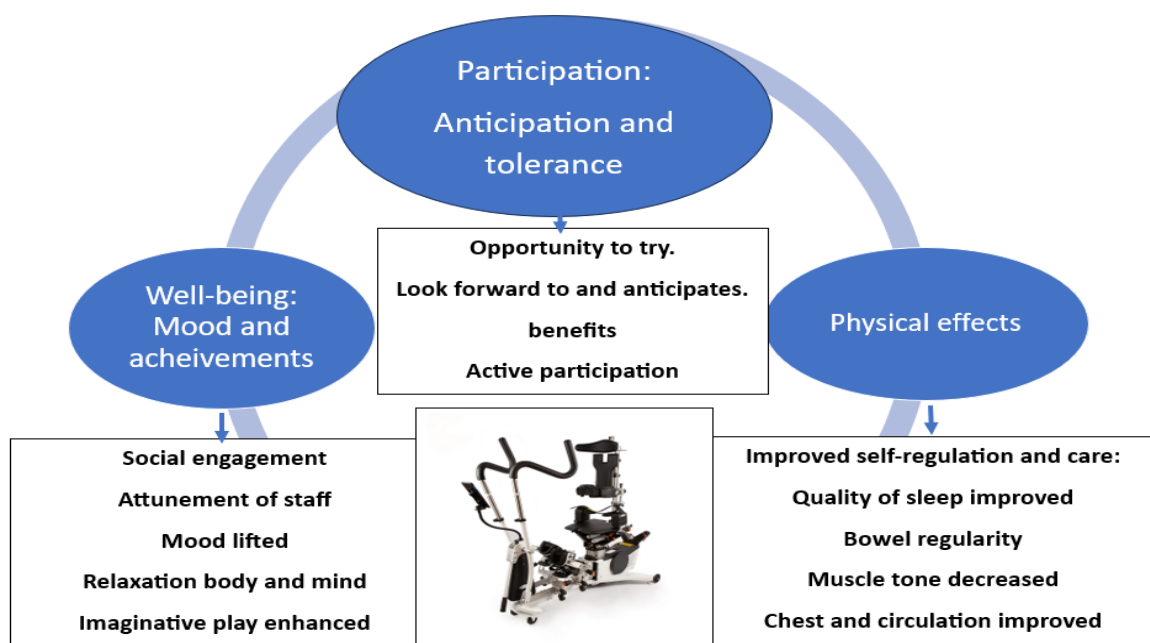
The results of the qualitative data analysis of the field notes, interviews and diaries will now be described.

Themes

The diary and interview data are represented by the three overall themes that were identified and are shown in Figure 3 in blue circles. The subthemes are shown in the text boxes.

1. Well-being: Mood and achievements
2. Participation: Anticipation and tolerance
3. Physical effects: Improved self-regulation and self-care

Figure 3: Overall themes and subthemes



These themes and subthemes will be illustrated using quotes and illustrations from the data.

1. Well-being: Mood and achievements.

Social engagement

All participants related to the staff and other people present, whilst they were in the Innwalk. There were sometimes group games which encouraged this engagement. Even those without spoken language, Charlie and Katie, were observed to respond by their non-verbal behaviours of eye gaze, vocalizing or smiling. This was closely aligned to the way staff behaved towards them by attuning into their needs.

Attunement of staff

Staff were observed to respond quickly to each participant's needs. This included the complex setting up for each participant and find suitable activities to occupy them. Many of these were interactive such as the balloon volleyball, shooting the nerf gun, using the Virtual Reality head set and playing Uno Flip card games. Others were content with music and playing with their own devices such as iPad or Tamagotchi. Some participants preferred to just chat as they enjoyed the environment.

Mood lifted.

All participants except Katie's mum, reported going in the Innwalk lifted their child's mood. Katie's mum reported it did not change her mood noticeably, but her mood varied according to how tired she was. Everly's Mum felt that going in the Innwalk calmed and lifted her mood. Joey's mother also felt it calmed him, Melanie stated it had a calming effect on her. Barney's mother was pleased they had found something he looked forward to each week which put him in a better mood and stopped him 'witching (kicking off)'. The bonus of using a virtual reality headset, meant Barney was more motivated as his mother stated:

"Virtual reality in the Innwalk helps with Barney's motivation-he feels he is walking...he really enjoys it."

This was observed during one of the field visits as shown in Figure 4.

Figure 4 Barney using Virtual Reality in the Innwalk



Relaxation of body and mind

Zelia stated that she felt comfortable and safe in the Innwalk, that she was not going to fall over, as when she was walking. Zac also felt safe and secure. Melanie additionally described the Innwalk as comfortable and helping her legs to relax which helped her to sleep better. Zelia felt the Innwalk was smooth and calming, helping her mind feel more relaxed as she stated:

"It makes my mind feel more... so my mind's not fizzing about, and it helps me when I'm not in my head to be more in my mind"

Imaginative play enhanced.

Everly was reported to have become more creative with her play since using the Innowalk and that this has “*lengthened her attention span*”. It is possible as she primarily crawled to get around, that being supported in an upright position, gave her the opportunity to use two hands together for play, which enabled this to develop. This is illustrated by Figure 5, where she had lined up the Duplo people as if in a classroom.

Figure 5: Everly’s play activity with Duplo figures.



2. Participation: Anticipation and tolerance.

Opportunity to try.

Katie’s mother felt it was amazing that she had the opportunity to go in the Innowalk and hoped that she got a sense of joy and achievement from this experience. Zac’s mother agreed with this sense of achievement. Although Melanie had been anxious at first, she was now very comfortable in the Innowalk.

Look forward to and anticipate.

Zelia, Barney and Zac were reported to look forward to their weekly Innowalk sessions. Zac was “*always enthusiastic about the Innowalk*” whereas previous physiotherapy sessions had not always been enjoyable for her. Black Panther said that the Innowalk was “*fabulous and it feels good*” and he was observed not wanting to leave the session.

Benefits

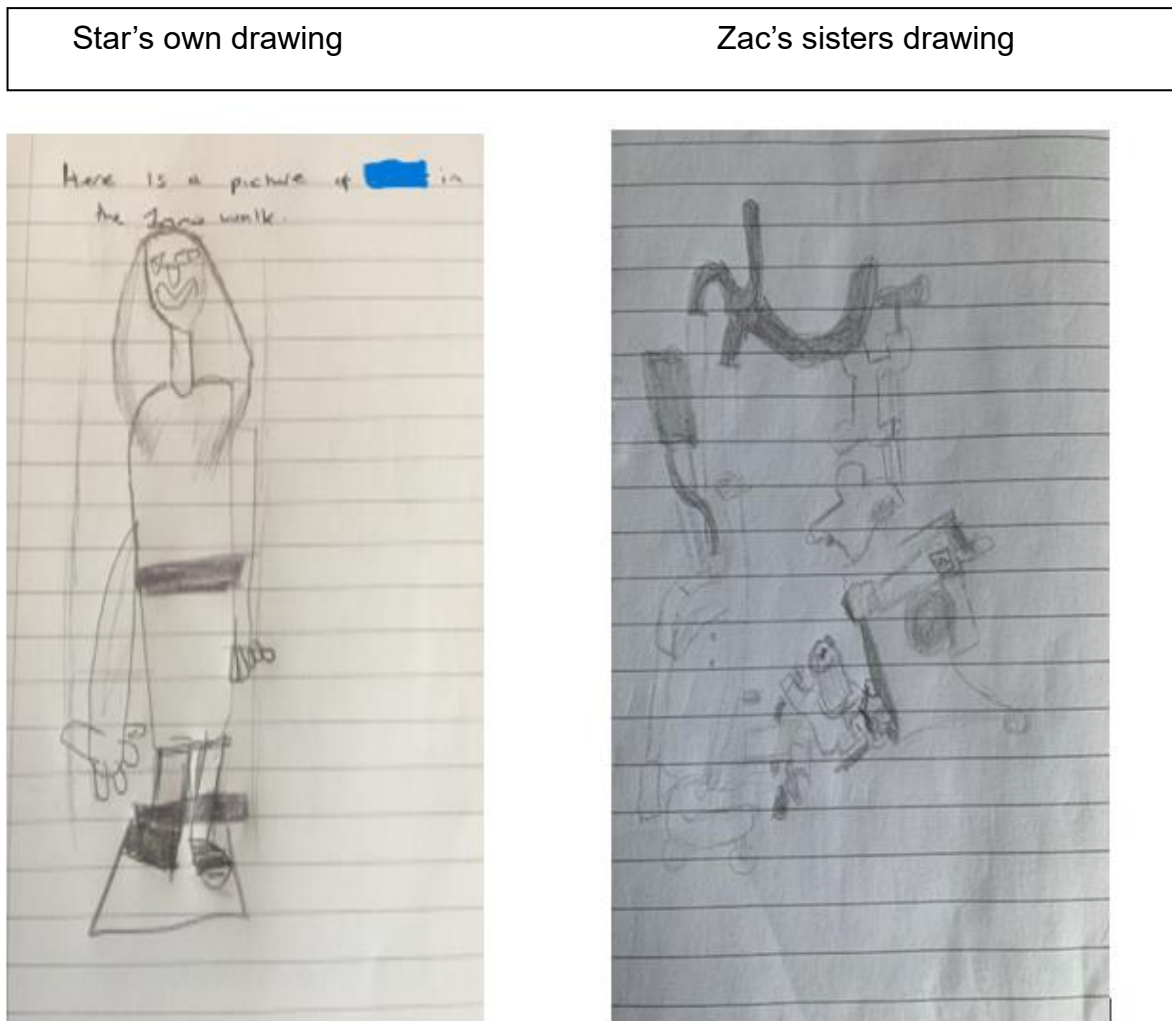
Star enjoyed the social participation and enjoyed dancing to music and singing. Star stated:

“My legs feel cool, it’s like I’m walking when in the Innowalk, as I can’t walk-gives me exercise and makes me feel tall.... (diary entry) I was very eexercised (Star’s spelling)”

Black Panther, Katie and Joey’s mother felt that despite it being a passive motion it was having some exercise benefits.

Two participants, Star and Zac’s sister drew pictures of the Innowalk as shown in Figure 6.

Figure 6 Drawings of the Innowalk



Active Participation

Two participants, Joey and Black Panther were observed to participate actively in the motion, when the Innowalk was moving. Zelia stated that she sometimes actively participated. The majority of participants seemed to enjoy the passive motion with their legs. None were observed to use the arm poles, they preferred to use the table for activities or to rest their arms on.

3. Physical effects: Improved self-regulation and self-care.

For many participants, the physical benefits of using the Innowalk related to improvements in sleep, bowel function and reduced muscle tone. Charlie and Black Panther were reported to have chest clearance and circulatory benefits respectively.

Quality of sleep improved.

For some participants, no difference was noted in sleep patterns. However, for Charlie, Katie, Barney, Black Panther and Melanie there was a change. Katie appeared to be more alert and awake by the Innowalk but was reported to be a poor

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sleeper anyway. Melanie felt the relaxation enabled her to move into different positions as she stated:

“The Innowalk helps if I want to sleep in different positions, on my stomach or side. I am more relaxed at night afterwards.”

Bowel Regularity

Only two participants, Charlie and Barney, were reported to now have regular bowel movements, perceived to be as direct result from using the Innowalk. Their constipation was also supported with medication. Zelia was not sure if it was coincidence that she went after her weekly session.

Muscle tone decreased.

Charlie and Zelia’s parents reported the effects on reducing muscle tone lasting for more than two days afterwards. Charlies’ mum stated:

“His hamstrings are very tight... 5 strides and instant release trying to move position to a more standing position each time... good cough today, helps bring up secretions and wind”.

Zelia described for up to two days afterwards it was easier to wash herself in the shower as her quote illustrates:

“It’s very easy to wash myself. It feels very stable in my stomach, when I wash my feet”.

Two participants, Star and Everly did not report any change in muscle tone.

Chest and circulation improved.

Charlie was the only participant who demonstrated chestiness and during his Innowalk sessions this was observed to help him clear his secretions which his mother suctioned. Black Panther’s mum and Melanie reported improved circulation and postural alignment after being in the Innowalk as her quote highlights:

“I like it cos’ it simulates walking and benefits my circulation...It’s hard for me to stay upright in sitting, so this helps me be straighter”.

The next section will discuss these findings in relation to existing literature.

Discussion

A case study design is not intended to be generalizable, but the depth generated can provide rich insights (Yin, 2017). This case study series provides both quantitative and qualitative data, that has created a better understanding of well-being in children and young people with complex disabilities, who used the Innowalk. This combination of data provides a unique perspective of bringing together aspects of physical health and well-being when using the Innowalk.

The PRIME-O (King et al 2019) measure gave some insight into well-being particularly for those with language-based communication. It was useful for the participants who had spoken language, where they scored the maximum, but it was

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limited for those whose language was minimally verbal or non-verbal. The Be-well checklist (Oliver et al 2020; 2022) was not specific enough for one off intervention and both had ceiling effects. The field notes, interview and diary data have highlighted aspects of well-being not previously considered with this group of participants with complex disabilities. The three themes illustrate a positive aspect of achievement and participation from a group of children and young people who have limited physical opportunities (Dodds 2016). The physical effects from using the Innowalk are well documented, and these findings concur with these in terms of enhanced sleep, bowel function and reduced muscle tone and to a lesser extent circulatory and respiratory effects, within this small sample (Schmidt-Lucke et al 2019; Lauruschkus et al 2022; Pekanovic et al 2022).

This observational well-being scale (WEBS) developed for this study has shown some strengths and limitations. Whilst a Likert scale allows a range of responses to be scored, the starting place for each one as a baseline might be different. It was challenging working with the Likert scale and the descriptors as participants fluctuated within a session, but an overall impression was made of their responses during the time. Using the word 'usual' requires a person who knows that participant well to know if they are displaying their typical behaviours. In this study, all the participants were familiar to the staff and some of the time parents were present. Therefore, it is proposed that the new WEBS scale should be completed by people familiar with the participant.

As previously suggested, well-being can fluctuate in different environments and with different people and equipment (Pickering et al 2023). Even within each Innowalk session, the well-being domains of comfort, calmness, creativity, engagement, energy levels and joy varied. However, overall, this study has shown that the Innowalk does have well-being effects in that it is comfortable to use, creates an observable calmness, enables creativity to develop, and facilitates engagement with people or activities. This is provided the children have enough energy to participate. The participants themselves did not describe the Innowalk experience as joyful, but it created joy for parents and staff.

The Innowalk was the context for this study to explore how a better understanding of well-being could be developed. The Innowalk was observed to be a positive experience for all participants with the majority preferring to use the tray for activities, as many were not able to use the arm poles. It might be useful to have the choice to purchase the Innowalk without the arm poles, if they are not intended to be used. In this study the setting up and monitoring of the Innowalk was not delegated to other school staff. If this were to change training and risk assessments would need to be carried out.

The current narrative from each participant will be written up into an accessible illustrated format for the children and young people. Additionally, to establish the content validity, this WEBS scale would need to be tested in a larger population in different contexts. Whilst parents and some young people spoke about the importance of their well-being, this study did not explore staff views about the need

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for or the usefulness of a well-being scale. Further research is planned to explore this with qualified staff.

Conclusion

This study has added to knowledge by exploring the research question ‘How can the well-being of children and young people with complex disabilities be better understood, from using the Innowalk?’ The insights the participants gave, reinforced the positive well-being effects, beyond the established physical benefits. The six domains of comfort, calmness, creativity, engagement, energy and joy offer some insights into these aspect of well-being with children and young people with complex disabilities. Thus, this context of using the Innowalk has enabled moving forwards towards a better understanding of well-being for children with complex disabilities.

Dissemination outputs

Opportunities to present this work have included a mixture of online and in person conferences. These are listed below in bullet point format:

1. Patient Reported Outcome Measures 2022 (Online) Pickering DM, Pickles T and Shiress T. A study protocol to develop the domains of an observational well-being scale (WEBS) for non-verbal children and young people with cerebral palsy from using the Innowalk.
2. An exploration of well-being with children and young people with complex disabilities, and their families, from using the Innowalk (WEBS study). Pickering DM College of Biomedical and Life sciences Population away day, Cardiff 2023
3. Moving towards a better understanding of well-being for children with complex disabilities from using the Innowalk Poster Pickering European Academy of Childhood Disability, Slovenia, May 2023
4. Communication Medicine and Ethics conference, Cork, Free paper presentation. Moving towards a better understanding of well-being for children with complex disabilities who use a robotic device, the Innowalk ©Made for Movement. Pickering DM Ireland June 2023. Publication to be submitted to Communication and Medicine journal 2023.
5. An exploration of well-being with children and young people with complex disabilities and their families, from using the Innowalk. (Virtual poster) Pickering DM, Gale N, Mahenthiralingham A, Cusack E Chartered Society of Physiotherapy Conference, Cardiff 2023
6. Moving towards a better understanding of well-being for children with complex disabilities who use a robotic device the Innowalk ©Made for Movement (Poster) Pickering DM Association of Paediatric Chartered Physiotherapists, Manchester, 2023 (Appendix H)-not presented due to adverse weather affecting travel to Manchester

Dissemination will also include a booklet ‘*My adventures in the Innowalk*’ funded by the Bailey Thomas Charitable Trust Fund November 2023- April 2024

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Appendix A

PRIME-O

© King, Chiarello, Thompson, McLarnon, Smart, Ziviani & Pinto (2015)

Research Version 2

Session Rating Scale—Observation Version

Participant ID: _____ Date: _____ Observer: _____

Purpose of the Scale

This scale is intended to capture **observable indicators** of client and service provider engagement in therapy sessions.

Depending on the session, the client can be the child, young person, or parent/ caregiver. Client engagement refers to investment and active involvement in the client role. It is shown by behaviors indicative of client **receptiveness** to what is happening, **willingness** to take part in the session, and **self-efficacy** in carrying out intervention tasks (in the session or later on).

Like clients, service providers can display a range of verbal and nonverbal indicators of their level of engagement in the session. Their use of strengths-based language and listening/ communication behaviors reflects their own level of engagement—and also serves to engage the client.

Instructions

You are asked to **make ratings and take field notes** regarding 3 sets of items:

- A. Client Items
- B. Service Provider Items
- C. Client-Provider Interaction Items

Focus on **indicators of level of engagement**, considering the client alone, the service provider alone, and then their interaction. Keep in mind **cultural variations** in (a) the words that people use to describe feelings and behaviors (which may vary from person to person), and (b) the range of behaviors that might indicate involvement in the client or service provider role.

Items/Behaviors	Rating and Notes (about context for rating; describe the setting)
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A. Client Items					
1. Client interest and enthusiasm <i>The client shows positive body language and enthusiasm, indicating receptiveness to the therapist and therapy</i> (e.g., eye contact, open posture, sustained interest rather than boredom or disinterest, displaying energy, showing enthusiasm as appropriate, various facial expressions as appropriate, positioning/setup)	0	1	2	3	4
	Not At All		To a Moderate Extent		To a Great Extent

1

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Research Version 2

2. Client use of strengths-based language <i>The client shows a positive orientation to themselves or their child in the context of therapy</i> (e.g., focus on their own functioning and abilities rather than deficits, expresses pride in effort or accomplishment, positive self-statements regarding abilities or achievements, focus on solutions rather than problems, positive affirmation regarding the self, expresses belief in self or abilities)	0	1	2	3	4
	Not At All		To a Moderate Extent		To a Great Extent

focus on solutions rather than problems, positive affirmation regarding the self, expresses belief in self or abilities)					
3. Client openness to what is being said/done <i>The client shows openness and willingness in the sessions</i> (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	1	2	3	4
	Not At All		To a Moderate Extent		To a Great Extent
4. Client overall comfort and confidence in engaging with the service provider <i>Client comfort and confidence in communication, reflecting openness to what is taking place</i> (e.g., at ease in interacting or communicating with the service provider, comfortable sharing different opinions, making choices)	0	1	2	3	4
	Not At All		To a Moderate Extent		To a Great Extent
B. Service Provider Items					
5. Provider interest and enthusiasm <i>The provider shows interest and attention</i> (e.g., eye contact, open posture, sustained attention rather than boredom or disinterest, participating behaviorally or physically, displaying energy, various facial expressions as appropriate, positioning/setup)	0	1	2	3	4
	Not At All		To a Moderate Extent		To a Great Extent

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(e.g., eye contact, open posture, sustained attention rather than boredom or disinterest, participating behaviorally or physically, displaying energy, various facial expressions as appropriate, positioning/setup)	Extent
--	--------

2

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Research Version 2

<p>6. Provider use of strengths-based language</p> <p><i>Use of positive language acknowledging client strengths</i></p> <p>(e.g., person-first language, positive wording, focus on function and abilities rather than deficits, focus on solutions rather than problems, empowerment and empathy rather than pity or sympathy, emphasizing resilience, providing compliments appropriately, positive confirmation)</p>	0	1	2	3	4
	Not At All		To a Moderate Extent		To a Great Extent
<p>7. Provider overall comfort and confidence in engaging the client</p> <p><i>Provider comfort and confidence in interacting with the client</i></p> <p>(e.g., appears relaxed in interacting with the client—in relating to the client, supports or encourages the client to take the lead)</p>	0	1	2	3	4
	Not At All		To a Moderate Extent		To a Great Extent

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<p>7. Provider overall comfort and confidence in engaging the client <i>Provider comfort and confidence in interacting with the client</i> (e.g., appears relaxed in interacting with the client—in relating to the client, supports or encourages the client to take the lead)</p>	<p>0 1 2 3 4 Not At All To a Moderate Extent To a Great Extent</p>
<p>8. Provider listening/communication behaviors <i>Use of active listening and good communication skills</i> (e.g., sustained attention, attentive body language, re-stating, paraphrasing, checking for understanding, clarifying, probing, providing validation, recognizing underlying messages, effective use of silence)</p>	<p>0 1 2 3 4 Not At All To a Moderate Extent To a Great Extent</p>
<p>C. Client-Provider Interaction Items (dealing with reciprocity; mutual engagement)</p>	
<p>9. Overall warmth of the interaction (rapport) <i>Demonstrations of positive rapport and mutual relationship</i> (e.g., demonstrations of being in tune with one another, mutual responsiveness, empathy, trust, openness, caring)</p>	<p>0 1 2 3 4 Not At All To a Moderate Extent To a Great Extent</p>

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Research Version 2

<p>10. Collaborative nature of the interaction <i>Overall sense of mutual contribution to the interaction</i> (e.g., power sharing, all parties contributing to the discussion and interactions in a balanced manner as appropriate (asking questions, answering questions, making suggestions, participating physically or behaviorally), joint goal setting, seeking and providing feedback openly, reciprocal interaction)</p>	<p>0 1 2 3 4 Not At All To a Moderate Extent To a Great Extent</p>
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Appendix B

Be-Well checklist (Oliver et al 2020)

How to rate wellbeing

- Think about the last two weeks and how you would describe the person's mood generally on a typical day and then rate it:

5

Very distressed for long periods

4

Frequent episodes of distress that lasted a while or were quite noticeable

3

Some episodes of distress that lasted a while or were quite noticeable

2

Very occasional minor distress or very brief episodes of distress

1

No signs of distress at all

Appendix C

Observational Well-being scale developed (WEBS)

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
	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
	1	2	3	4	5
Creativity					
Comments- expressing self in different ways e.g. music/ drawing/craft/games.					
Descriptor	Poor	Low	Usual	Good	Excellent
	1	2	3	4	5
Energy levels					
Comments-has the energy to participate.					
Descriptor	Poor	Low	Usual	Good	Excellent
	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

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	1	2	3	4	5
Bringing joy to self or others					
Comments- e.g. could be smiling or laughter; expressive sounds indicating pleasure.					
Descriptor	Poor	Low	Usual	Good	Excellent
	1	2	3	4	5

Appendix D Participant information sheet



Dr Dawn Pickering

PARTICIPANT INFORMATION SHEET

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

You and your child or young person are being invited to take part in a research project. Before you decide whether or not to take part, it is important for you to understand why the research is being undertaken and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. You can explain it to your child or young person using the separate age-appropriate information sheet.

Thank you for reading this.

1. What is the purpose of this research project?

The Innowalk is new to Wales, so not many people who find standing and walking difficult, have been able to try this yet. Research in Sweden has suggested the families find this cost effective for their child's health and well-being. In this research project I am especially interested to understand more about well-being for your child or young person who use the Innowalk. This research has been approved by the School of Healthcare sciences ethics committee in June 2022 Rec 895.

2. Why have I been invited to take part?

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You have been invited because your child or young person is aged between 5 and 18 years and using the Innowalk at Ysgol Y Deri.

3. Do I have to take part?

No, your participation in this research project is entirely voluntary and it is up to you to decide whether or not to take part. If you decide to take part, I will discuss the research project with you and ask you to sign a consent form for you and your child or young person. If the child or young person is able to, they can also sign their own separate consent form. If you decide not to take part, you do not have to explain your reasons and it will not affect your legal rights. Your decision not to take part will not affect the physiotherapy care your child receives. You are free to withdraw your consent to participate in the research project at any time, without giving a reason, even after signing the consent form.

4. What will taking part involve?

I plan to come into the school and observe your child or young person on three occasions when they are using the Innowalk in physiotherapy. I will also ask you to keep a written record, in a paper diary provided, of any observations you see that you think relate to well-being – such as level of comfort or a change in sleep or bowel movements. Once you give your written consent for you and your child or young person to take part, the data will be collected over a three-week period. At end of this, I will arrange a chat either in school or via telephone or online platform such as Microsoft Teams/ Zoom to discuss your views about your child's well-being in relation to using the Innowalk. This interview will be audio recorded either with a Dictaphone or via the online platform. If I am also able to chat to your child or young person, that will be done in school, supported by relevant technology such as Eye Gaze or Augmentative and Alternative Communication aids which will be audio recorded.

5. Will I be paid for taking part?

No but your child can receive a gift voucher. You should understand that any data you give will be as a gift and you will not benefit financially in the future, should this research project lead to the development of a new well-being assessment.

6. What are the possible benefits of taking part?

There are not any direct benefits to the you or your child from taking part, but your contribution will help me to understand more about well-being from using the Innowalk. This will help to support the development an observational well-being tool, to use with other children with disabilities in other contexts.

7. What are the possible risks of taking part?

There is minimal risk of any additional physical harm as your child will continue to receive their usual physiotherapy care. There is the potential for emotional harm by highlighting your child's well-being indicators. Any new concerns will be addressed with support from the school staff and your GP, to ensure you are receiving appropriate services to support you and your child or young person.

8. Will my taking part in this research project be kept confidential?

All information collected from (or about) you and your child or young person during the research project will be kept confidential and any personal information you provide will be managed in accordance with data protection legislation. Please see 'What will happen to my Personal Data?' (below) for further information.

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This data will be stored at Cardiff University on password protected computers and yours and your child or young person's confidentiality and anonymity will be protected by using pseudonyms (false name), which you can choose. The data is stored for up to five years after this study has ended.

If I become aware of any information that suggests that you or your child might be at risk of harm, the local authority safeguarding children and vulnerable adult's procedures will be followed. This is also in keeping with Cardiff University's policies and may require your identity to be given, in these exceptional circumstances.

9.What will happen to my Personal Data?

Cardiff University is the Data Controller and is committed to respecting and protecting your personal data in accordance with your expectations and Data Protection legislation. Further information about Data Protection, including:

- your rights
- the legal basis under which Cardiff University processes your personal data for research
- Cardiff University's Data Protection Policy
- how to contact the Cardiff University Data Protection Officer
- how to contact the Information Commissioner's Office

may be found at <https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection>

As Ysgol Y Deri will be the place where data collection takes place, they will be the gatekeepers to pass on any information about this study to you. The data collected will be in the form of field notes from observations, a diary which you write and anonymised interview data which will be transcribed by the lead researcher. Cardiff University will not need to share any identifiable data with any third party for the purposes of this research project. This project is estimated to be carried out over one year when this data will be managed and processed.

Dr Dawn Pickering will anonymise all the personal data it has collected from, or about, you or your child in connection with this research project, with the exception of your consent form. Your consent form data will be retained in accordance with the University's Records Retention Schedules and may be accessed by members of the research team and, where necessary, by members of the University's governance and audit teams or by regulatory authorities. Anonymised data will be stored on the University's one drive system which is password protected. Your personal contact details with the signed consent forms will be kept in a secure locked cabinet, separate from the research data, so no-one can identify you from this. Anonymised information will be kept for a minimum of five years but may be published in support of the research project and/or retained indefinitely, where it is likely to have continuing value for research purposes.

Personal data collected up until the point of participant withdrawal from the research project will be stored in accordance with the University's Records Retention Schedules. Note that it will not be possible to withdraw any anonymised data that has already been published or in some cases, where identifiers are irreversibly removed during the course of a research project,

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from the point at which it has been anonymised. Non-identifiable data will be shared with Mr Tim Pickles, statistician, for analysis purposes.

10. What happens to the data at the end of the research project?

The data collected during the research project will be used after the end of the research project for publications and conference dissemination. The data will not be made publicly available and/or shared within the University and/or shared outside of the University. Any future research using the data will be limited to a deeper understanding of well-being for non-verbal children and young people with complex disabilities. The data will not be shared via a data repository which would be openly available to others. Any personal data will be removed before any form of sharing takes place.

11. What will happen to the results of the research project?

It is my intention to publish the results of this research project in academic journals and present findings at conferences. Additionally, an illustrated booklet for the children and young people will be produced. Participants will not be identified in any report, publication or presentation and your chosen pseudonym will be used. There will be an intention to use verbatim quotes from participants.

12. What if there is a problem?

If you wish to raise a complaint about any aspect of this WEBS research, firstly, notify myself, Dr Dawn Pickering. If you feel your complaint has not been handled to your satisfaction, you may contact the Chair of the School Research Ethics Committee: Dr Kate Button/ buttonk@cf.ac.uk.

You are free to withdraw your consent to participate in the research project at any time, without giving a reason, even after signing the consent form.

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, you may have grounds for legal action, but you may have to pay for it.

13. Who is organising and funding this research project?

The research is organised by Dr Dawn Pickering in the School of Healthcare sciences at Cardiff University. The Association of Paediatric Chartered Physiotherapists has awarded a bursary which enables you to receive a £30 gift voucher of your child's choice.

14. Who has reviewed this research project?

This research project has been reviewed and given a favourable opinion by the appropriate School Research Ethics Committee, Cardiff University in June 2022.

15. Further information and contact details

Should you have any questions relating to this research project, you may contact me during normal working hours:

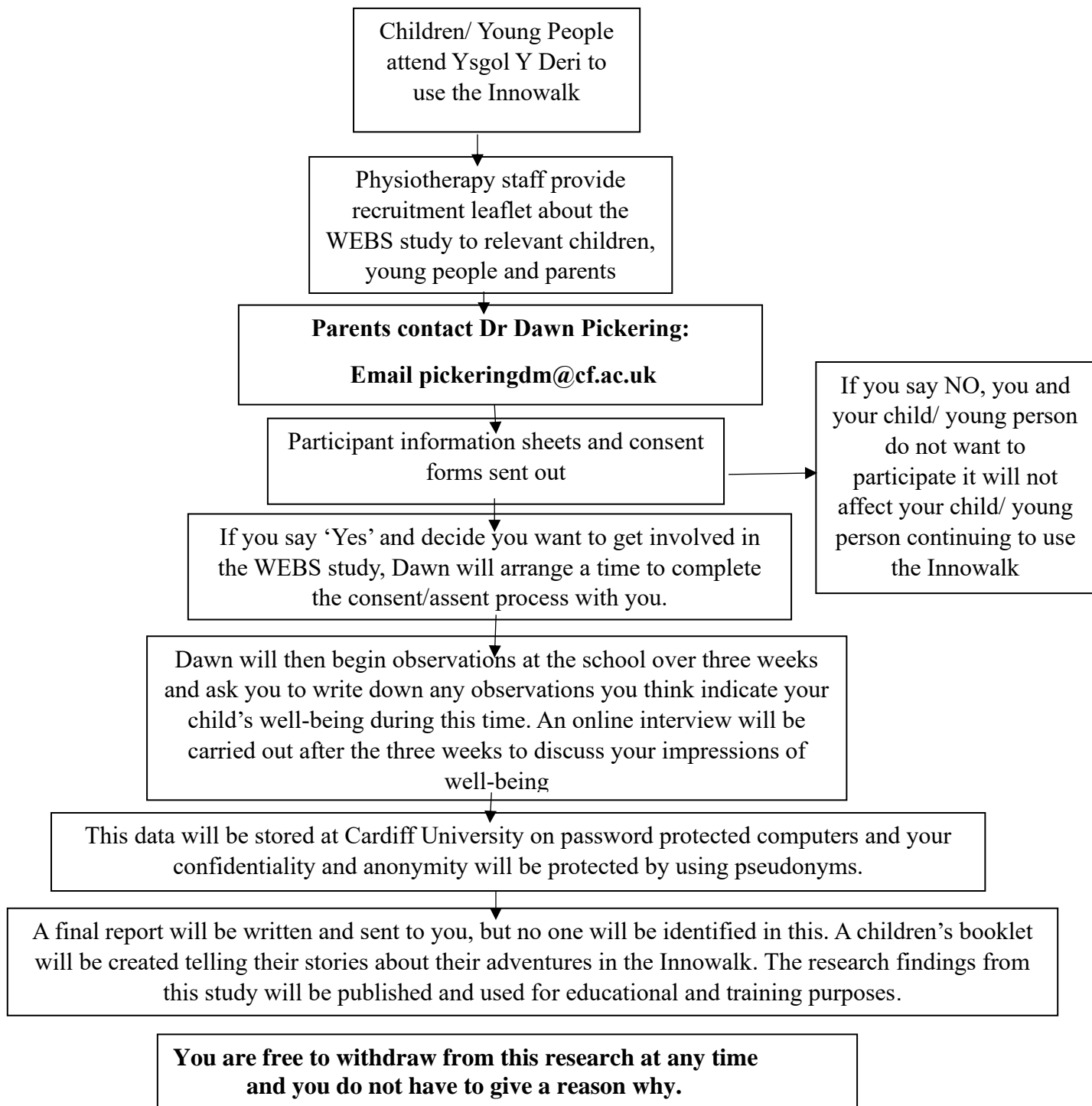
Dr Dawn Pickering, Senior Lecturer at Cardiff University; School of Healthcare Sciences, Ty Dewi Sant, Heath Park, CF 14 4XN

Email: pickeringdm@cf.ac.uk ; Telephone: 02920 687741 (24-hour answer phone).

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Thank you for considering taking part in this WEBS research project. If you decide to participate, you will be given a copy of this Participant Information Sheet and a signed consent form to keep for your records.

How can I or my child/ young person get involved in this WEBS research study?



**Contact details: Dr Dawn Pickering, Senior Lecturer at Cardiff University; School of Healthcare Sciences, Ty Dewi Sant, Heath Park, CF 14 4XN
Email: pickeringdm@cf.ac.uk ; Telephone: 02920 687741 (24 hour answer phone).**

Appendix E Child participation leaflet

Well-being Research (WEBS) Study



How can I help
people to understand
how using the
Innowalk helps me?



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Who is doing this research?

My name is Dr Dawn Pickering. I teach Physiotherapy at Cardiff University and I am carrying out some research about how you think using the Innowalk helps you.



What is the WEBS study about?

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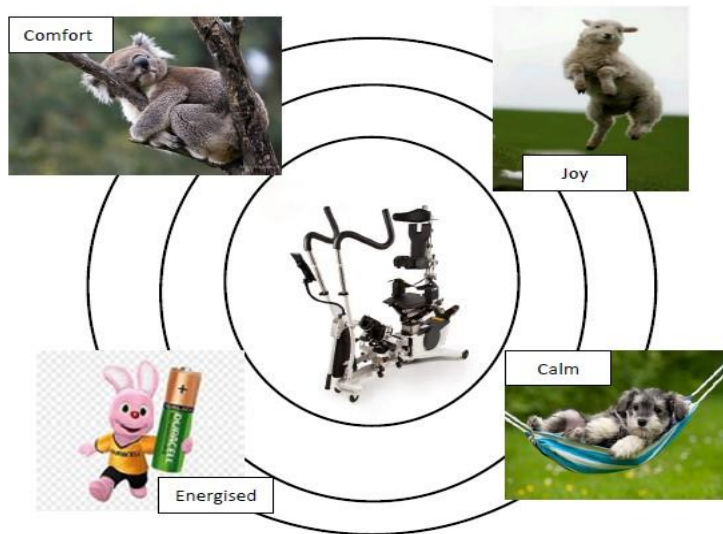
I would like to know what children and young people with different walking and talking abilities think are the benefits from using the Innowalk. I would like to come and observe you three times using the Innowalk, at your school, Ysgol Y Deri. I will ask your parents to keep some notes over these three weeks of things which they notice, such as sleeping better and going to the toilet more easily.

Why am I doing this?

The Innowalk costs a lot of money, not many children have the choice yet to use this yet in Wales. If you choose to be part of this WEBS research, we can learn more about the effects from using the Innowalk. I know it is sometimes hard for you to speak about activities, so by letting me watch how you move and behave, can help us understand better the effects of the Innowalk.

What is involved?

I would like you to give me permission to come and see you in school when you use the Innowalk and to make some notes. I will be looking for things you do that show me joy; what activities you enjoy whilst being in the Innowalk; the people you like to be with; if you feel you have enough energy to join in with what other people are doing; if you feel comfortable; if it makes you feel calm and what creative things you like to do in there. I have used some animal pictures on a web, to help you think about these ideas which show me your feelings:



If you able to chat to me about what using the Innowalk means to you I can record this for my records.

What will this research be used for?

The information you and your parents give me will be used to create a story book called "My Well-being-adventures in the Innowalk". You will receive a copy either in print or on a screen. This will help other people to learn about the benefits of the Innowalk. What you have shown me about the effects of the Innowalk will be

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developed into a scale, in the future, to test with other boys and girls who have different walking and talking abilities.

Will I be paid? You will be offered a £30 gift voucher of your choice.

Do I have to take part?

No, you can volunteer and change your mind at any time.

Safety and Well-being

Your safety is very important, if you tell me about something dangerous or tell me someone is in danger this will have to be reported to another adult which could be your teacher or, in some cases, a police officer.

Your Consent/ Assent

(Only sign if the sentences below are true)

I have read the information leaflet (or had read to me) and I understand this WEBS research study.

I have had the opportunity to think about the information on this leaflet and have asked any questions I may have - you can email me anytime: pickeringdm@cf.ac.uk

I know that this WEBS project aims to help people learn more about my well-being.

I understand that I can choose a different name to protect me from being recognised.

I know I can decide to stop the project at any time, and I do not have to give a reason.

Your Name: _____

Your Signature: _____

Today's date: _____

Parent/Guardian's Signature: _____

Appendix F

Interview questions

Thank you for coming into my research study about the Innowalk and your well-being, diary used as a prompt.

1. Thank you for writing in the diary- use as a prompt to start conversation

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2. Can you tell me how the Innowalk makes a difference to you or your child?
3. I have used some words to describe what I think well-being means are you happy we discuss these to see if you think they are a good fit? Prompts -comfort, calm, creative, engaging, energy, joyful.
4. Can you suggest any other words to describe well-being?
5. If you know another child/ young person who might like to try the Innowalk how would you describe it to them?
6. Gift voucher order and thanks

Appendix G-Example of Zac's individual report

Zac case study preliminary report August 2023

Zac (false name chosen) was eight years old at the time of the study and attended the school as an outpatient to use the Innowalk, weekly. Zac attended with her mother and twin sister and was observed three times in the Innowalk between November 2022 and February 2023. Her mother kept a written diary during this intervening time which Zac and her sister contributed to. An interview took place with Zac and her mother on 20th February 2023.

The two aims of this part of the research were to:

1. To pilot, by observations, develop and test an observational scale that enables well-being indicators to be recorded children and young people with complex disabilities.
2. To obtain child and parental opinions by written diary records and an interview related to well-being following them using the Innowalk.

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

In the literature there were already two observational scales. These were the PRIME-O and Be-Well checklists and although they were used, they were found not be sensitive enough to pick up on the subtle well-being changes observed with the participants in this study.

An adult with living with cerebral palsy, Mr Ted Shires, supported the development of the new observational well-being scale, called 'WEBS', to enable inclusion of children who could not speak themselves, to tell me about their experiences in the Innowalk. The scale shown in Figure 1a was piloted in this study. Please note that not all the descriptors are relevant for Zac, as she can talk. The constructs that were considered important to indicate well-being were calmness, comfort, creativity, engagement with others or activities, energy and bringing joy to self or others.

The diary, interview and field notes from the observational data have been analysed using stages of coding the words which were then clustered into theme identification. Each participant's data will be managed in the same way and then across case

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comparisons made to develop overarching themes from all the data. Zac's results are being shared with you now, at an interim stage, in order that you can give any feedback, if you wish to, in order to influence a greater understanding of well-being.

Zac's average speed, distance travelled and time in the Innowalk were 43.6 revolutions per minute, 1.5 KM and 30 minutes.

Figure 1a: WEBS proposed observational well-being scale.

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
	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
	1	2	3	4	5
Creativity					
Comments- expressing self in different ways e.g. music/ drawing/craft/games.					
Descriptor	Poor	Low	Usual	Good	Excellent
	1	2	3	4	5
Energy levels					
Comments-has the energy to participate.					
Descriptor	Poor	Low	Usual	Good	Excellent
	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.					

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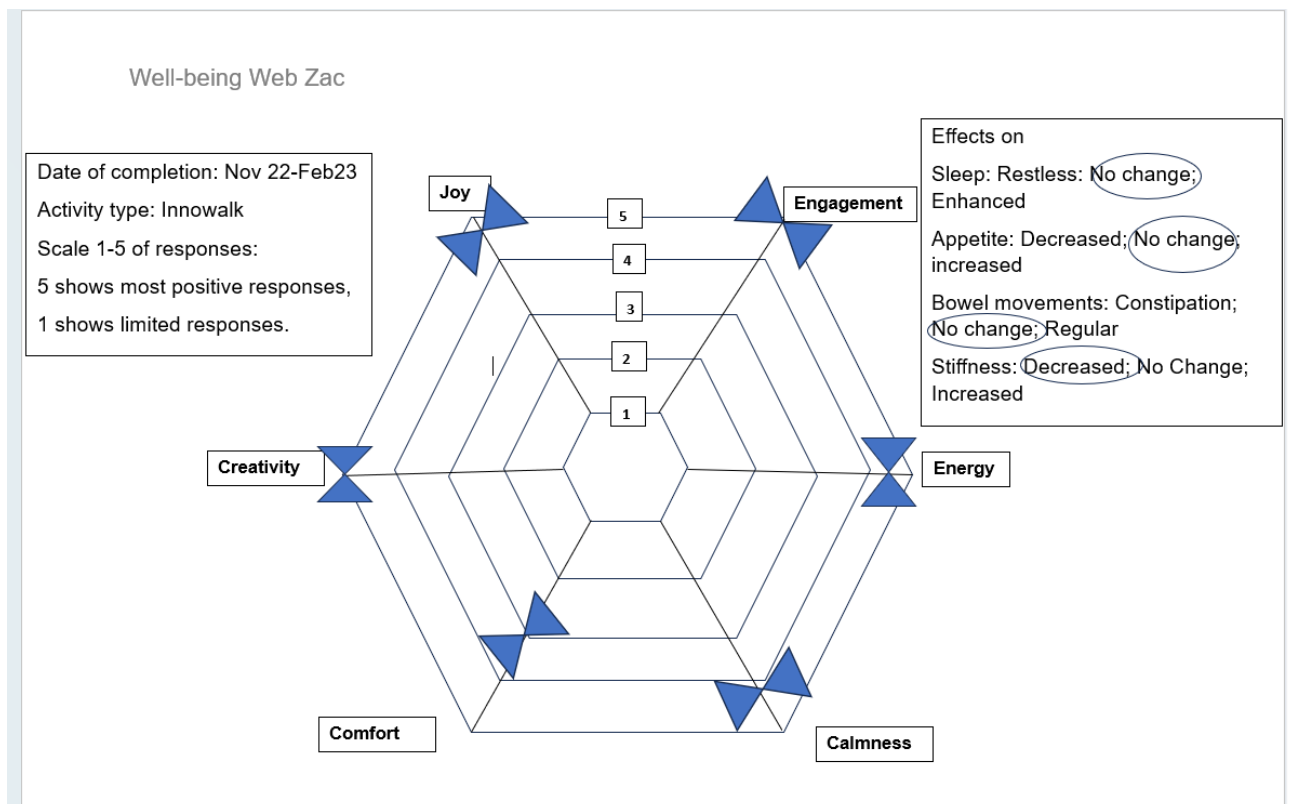
Descriptor	Poor	Low	Usual	Good	Excellent
	1	2	3	4	5
Bringing joy to self or others					
Comments- e.g. could be smiling or laughter; expressive sounds indicating pleasure.					
Descriptor	Poor	Low	Usual	Good	Excellent
	1	2	3	4	5

Zac's average scores (mean taken from 3 separate observations) on this WEBS scale were:

Comfort Calmness Creativity Energy Engagement Joy
 3 4.3 5 4.6 5 4.6

These scores are mapped onto a Web as shown in Figure 2a.

Figure 2a Well-being WEB for Zac




The analysis of the interview, diary and observational data has led to two overarching themes, with subthemes. These are supported by some quotes in italics


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to illustrate their meaning in Table 1a. Zac was observed playing with different activities during her Innowalk sessions, these included Tamagotchi, Connect 4 and Uno Flip. Sometimes she played with her sister or the staff. Zac's engagement with other people was always excellent. The Innowalk was occasionally uncomfortable, but staff were attuned to her needs and taught her to adjust the settings. Particularly the speed and level of uprightness. Zac then enjoyed controlling these aspects herself. The level of stiffness reduced in her legs was reported to last for 2 days.

Table 1a Summary of themes and subthemes

Well-being benefits	Innowalk drawing	Physical effects
<i>"Friend told her it was fun before tried it- it is fun"</i>		Legs less stiff
<i>"Feels fine"</i>		Calming
Comfortable- <i>"no pain"</i>		Tiredness- <i>"always consider if she is up to this each week";</i> <i>"I am sometimes more tired afterwards"</i>
Joyful for mum		<i>"Movement is really good"</i>
Empowered to control herself		<i>"Although it's a passive motion, she does get weight bearing"</i>


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<p><i>“It’s not scary – I feel safe and secure”</i></p>		<p><i>“My legs are moving in a smooth circular motion”</i></p>
<p><i>“Like atmosphere”</i></p>		<p><i>“Sometimes gets pins and needles with standing frame, but not with Innowalk”</i></p>
<p><i>“Zac’s always enthusiastic and the Innowalk and it gives her a sense of achievement”</i></p>		<p><i>“Zac can’t hold herself that upright, so achieves better posture”</i></p>
<p>Smiling and happy</p>		<p><i>“Tray is fab as allows me to play games (Uno Flip, connect 4)- doesn’t get boring”</i></p>


Please do not hesitate to contact me if you wish to discuss further:

Dawn Pickering: pickeringdm@cf.ac.uk

Appendix H APCP Poster



Moving towards a better understanding of well-being for children with complex disabilities who use a robotic device the Innowalk¹ ©Made for Movement



This research study was awarded an APCP bursary 2022-2023 Dr Dawn Pickering (@pickeringdm@cf.ac.uk; @DawnMPickering) Senior Lecturer in Physiotherapy, Cardiff University.

Background

The Innowalk¹ is a dynamic standing frame that generates passive motion for non-ambulant children. Reported benefits of the Innowalk are respiratory, circulation, skin integrity, light physical activity, gastrointestinal function, stretching of muscles and joints, mental function (linked to well-being) and bone mineral density and quality of life². The Innowalk is expensive and requires technical set up.

Researchers have not yet developed a valid and reliable measure for well-being for children with profound disabilities³. Well-being in this context is referring to how these children are able to indicate they are enjoying activities in their environments.

Consultation took place with some disabled adults, children and young people and their parents, to discuss and develop the domains of the proposed well-being scale (WEBS). Based upon this and previous doctoral research⁴, well-being indicators included calmness, comfort, creativity, energy levels, engaging with others and expressing joy. This is represented by a kaleidoscope of well-being as this fluctuates in different environments, with different people and equipment.

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

Aims of project :

1. To pilot, observe, develop and test a new observational well-being scale (WEBS) that records well-being indicators in non-verbal and non-ambulant children and young people with complex disabilities.
2. To obtain child and parental perceptions on well-being, by written diary records and interviews from using the Innowalk.

Methodology

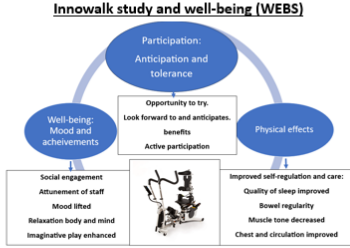
Ethical approval was granted by the School of Healthcare sciences at Cardiff University August 2022 REC895.

A case study series observed ten children, three times using the Innowalk in a special school. Field notes were made, and these were mapped onto the proposed new well-being scale (WEBS) shown in Figure 1. Data was supported by their parents keeping a diary during this time, followed by interviews with the child and or parent. The observational scale was analysed descriptively. Interview, field notes and diary data were analysed thematically, and three themes were identified.

Figure 1 The Observational well-being scale (WEBS)

Well-being scale (WEBS)						Well-being scale (WEBS)					
Name	Age	Level of Disability	Observation	Theming	Date	Observation	Age	Level of Disability	Observation	Theming	Date

Figure 2 Themes and subthemes identified (WEBS)



Conclusions / Implications for practice

The WEBS scale showed some consistency; however, it needs to be tested in a larger population to establish the feasibility and content validity.

Further research output is being created in an accessible booklet for the participants. A future survey will be carried out to explore practitioners views about the need for a well-being scale.

References

- 1 Innowalk Made for Movement, 2021 <https://www.madeformovement.com/innowalk> [Accessed 31.7.23]
- 2 Lauruschkus, K et al 2022 s. *Disabilities* 2022, 2,73-85 <https://doi.org/10.3390/disabilities2010000>
- 3 Mpundu-Kamukama et al (2018). A review of preference-based measures for the assessment of quality of life in children and adolescents with cerebral palsy. *Quality of Life Research*, 27, 1781-1799.
- 4 Pickering et al (2023) Disability and Rehabilitation Online <https://www.tandfonline.com/epint/CWZNSAAXMCAQNKSEMDJ/full?target=10.1080/09638288.2023.2194850>