

# Moving towards a better understanding of well-being for children with complex disabilities from using the Innowalk

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## Introduction

Children with more severe physical disabilities are limited in their ability to participate in physical activities and exercise. It is known that increasing physical activity levels improves well-being across the general population, including children without disabilities. Whether this is so for those children who have mobility limitations and cannot communicate their feelings, is currently unknown. Well-being has different definitions and is especially problematic to measure, for those whose ability to speak is reduced<sup>1</sup>. This research is observing non-ambulant children using the Innowalk<sup>2,3</sup> (Figure 1), a robotic device, as one context for them to indicate their well-being, to support the development of a new well-being scale (WEBS).

## Patient and methods

Ten children aged four to eighteen, with a range of physical and learning disabilities, supported by their parents in a special school context. A consultation group includes two young adults with cerebral palsy. Exploratory case study series made up of observations (field notes), scoring PRIME-O<sup>4</sup> and Be well checklist<sup>5</sup> and the new well-being scale, plus parental reported diaries and child/ parent interviews. Preliminary constructs being tested in the new proposed well-being scale, based on PhD data and the research advisory group (shown in Figure 2) include calmness, comfort, creativity, energy levels, engagement with other people or activities, expressing joy<sup>6</sup>.



Figure 1: © Innowalk, Made for Movement

## Proposed new well-being scale: Figure 2

Well-being scale (WEBS)						Well-being scale (WEBS)																
Name	Age	Level of GMFCS	Observation Session number	Timing length of session (minutes)	Date	Comments: has the energy to participate																
		I II III IV V	1 2 3			Descriptor	Poor	Low	Usual	Good	Excellent											
<b>Calmness</b> Comments- e.g. calmness in mood- excitability / withdrawn						<b>Engagement with other people/activities</b> 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Descriptor	Withdrawn	Quiet	Calm	Excited	Very excited	Descriptor	Poor	Low	Usual	Good	Excellent											
<b>Comfort</b> Comments- e.g. soiled in equipment, internal spasms, fits observed, self-reported behaviours reduced to g. reflux, hand in mouth to reduce pain, eye pressing, head banging						<b>Bringing joy to others</b> Comments- e.g. could be smiling or laughter, expressive sounds indicating pleasure																
Descriptor	Unsettled	Fidgety	Usual	Satisfied	Relaxed	Descriptor	Poor	Low	Usual	Good	Excellent											
<b>Creativity</b> Comments- expressing self in different ways e.g. music/ drawing/ calligraphy						<b>Person completing the observational well-being scale</b> Role or Relationship to Child/ Young person _____ Supported by _____ Activity participated in _____																
Descriptor	Poor	Low	Usual	Good	Excellent	<table border="1"> <thead> <tr> <th>Descriptor</th> <th>Poor</th> <th>Low</th> <th>Usual</th> <th>Good</th> <th>Excellent</th> </tr> </thead> <tbody> <tr> <td>1</td> <td>2</td> <td>3</td> <td>4</td> <td>5</td> </tr> </tbody> </table>						Descriptor	Poor	Low	Usual	Good	Excellent	1	2	3	4	5
Descriptor	Poor	Low	Usual	Good	Excellent																	
1	2	3	4	5																		
<b>Energy levels</b>																						

## Results

Data is still being analysed using Braun and Clark's six stages of analysis<sup>7</sup>. Figure 3 highlights some quotes. In addition to academic papers, funding is being sought for an accessible booklet to be produced for the participants: *'My well-being stories about the Innowalk'*.



Figure 3: Qualitative comments so far

## Conclusion

The observational well-being scale being developed will potentially enable the content validity to be evaluated in a future larger study, to test out the psychometric properties of this proposed well-being scale (WEBS) in wider contexts.

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