

My Adventures in the Innowalk ©Made for Movement



Author Dr Dawn Pickering; Illustrator Alison Howard



Dedication

This book is dedicated in memory of the late Professor Robert van Deursen, whose vision and support enabled this research approach to be developed, promoting social justice.

Acknowledgements

The production of this storybook was supported by the Bailey Thomas Charitable Trust Research award 2023-2024.

The data created for this storybook was supported by the Association of Paediatric Chartered Physiotherapists Research award 2022-2023.

The collaborators in this study have not been named to protect the anonymity of the participants.

Rikke Damkjær Moen, Medical manager, Made for Movement Group AS

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Background

This storybook “My adventures in the Innowalk” is aimed as an accessible research output for the participants and their families. It aims to give ‘voice’ to those whose voices are often overlooked. The ten children and young people’s own words are placed in “*italics*”. They chose a different name to protect their identity, their ages stated were at the point of data collection. Whilst a small number of books are printed for the participant’s benefit, this illustrated storybook has also been created in a shorter version as an audio storybook. In this way, the research data has been co-produced in a format for the children and young people to understand.

This storybook came about from data that was collected during a research study funded by the Association of Paediatric Chartered Physiotherapists in 2022. This study observed ten children and young people using the Innowalk Pro at a special school in Wales, for evidence of their well-being. The Innowalk is a robotic device, that supports standing and cycling for non-ambulant people.

The three observations of each participant were mapped onto a new well-being scale. The domains of this well-being scale include calmness, comfort, creativity, energy, engagement and joy. This was also supported by interviews and a diary, written by the children or their parents. The children’s specific age at the time of the study is stated. Their stories are presented from the youngest to the eldest, to describe and promote their well-being experiences of the Innowalk.

The funding for this story book came from the Baily Thomas Charitable Trust in 2023. This enabled a graphic illustrator to be employed and Alison Howard was recruited for this task. Alison and I have worked in tandem to develop each illustration, based on the raw data, and some additional photographs, which the parents provided, to authenticate the illustrations. It has been a joy to work on this book, as an accessible research output. This contribution to knowledge about disabled children’s well-being is unique and forms part of disabled children’s social justice, as their voices deserve to be heard.

Dr Dawn Pickering, Reader in Childhood Disability, © Cardiff University, July 2024.

Foreword

I have known Dawn Pickering for over 20 years as a valued colleague in the field of childhood onset disability. Dawn is a champion of participation for all and has a passion for enabling everyone's voice to be heard. For individuals with complex disability, being heard can present huge challenges, particularly for those who are non-verbal. Hearing from this group despite the barriers and challenges has been a consistent aim in Dawn's academic research. It is important these individuals' voices are heard so we can support them to live the lives they want and develop the services that meet their needs.

My Adventures in the Innwalk, is an exciting way of sharing the results from one of Dawn's studies with the individual participants and their families, and in turn a wider audience, including other people with lived experience and professionals. This challenging but important area of work has required creativity and innovation in data gathering, research methodology and results sharing. This book is an example of such creativity. Each page shares a different child or young person's experience of the Innwalk, it shares their interests and explores what is important for them in terms of quality of life.

We can learn much from this book about what is important to these particular children and young people, but also how we need to think creatively to communicate with everyone and not exclude some groups because the communication challenge is too great. Dawn has succeeded with this book in developing a simple, appropriate and accessible tool.

I hope you enjoy your read as I did, and that this book becomes part of a new genre of books, with stories meaningful and relevant to the lives of those with complex disabilities.

Jenny Carroll MA MCSP PGC(HE)

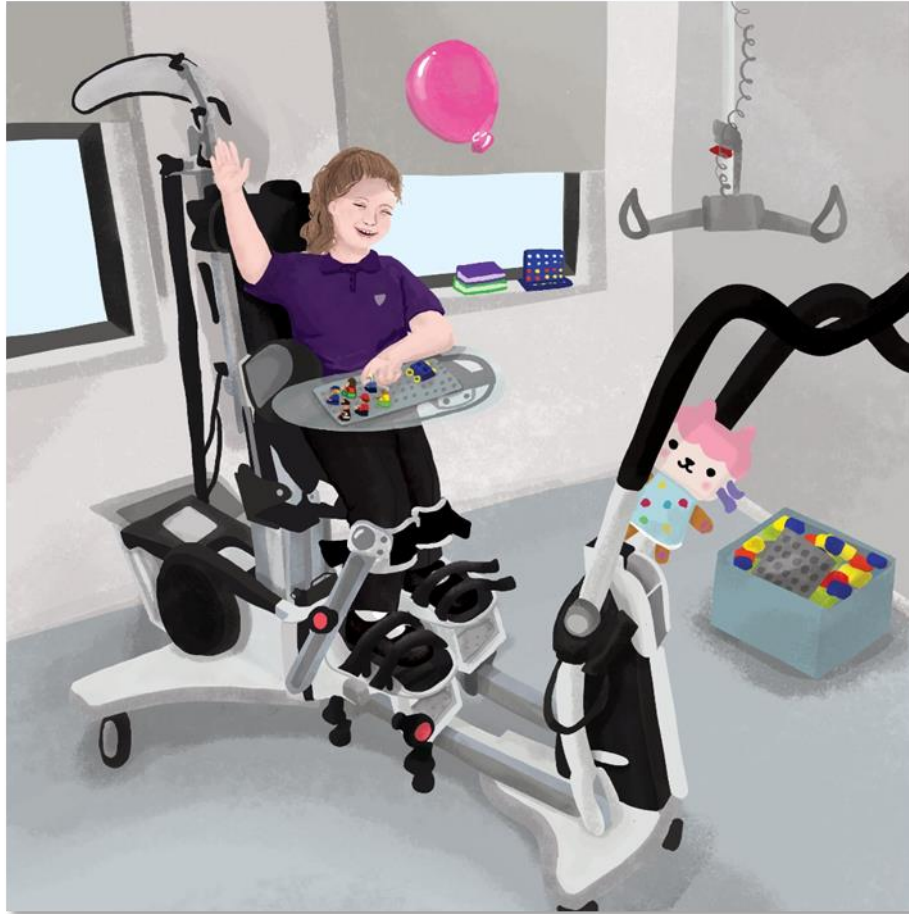
Centre Director and Consultant Physiotherapist Cerebral Palsy Cymru

My name is Katie, when I used the Innowalk, I was 4 years old. I was observed enjoying playing with the mirror balls, when I was in the Innowalk. I liked being sung nursery rhymes and listening to music. I clapped my hands and vocalised in response to playing peek a boo. I laughed and smiled a lot when I was seen in the Innowalk, and my Mum said that I enjoy being in a crowd of people. My physio says that my arms and legs are easier to stretch straight afterwards.



My mum says that: "it's amazing Katie gets to go in Innowalk, this the most she can do physically. It's helping her to use her body - like if we did exercise-the endorphin release. I hope that Katie might get that sense of achievement or joy when using the Innowalk."

My name is Everly, when I used the Innowalk, I was 8 years old. *“I like my dolly ‘Jade Ellie’ to watch me in the Innowalk. I love to play made up games, with the Duplo people on the tray. Sometimes, I like to play a balloon volleyball game called ‘Oosh’, to make the physios run around, and I love being the champion. Sometimes, I can use my left hand better when my body is supported in the Innowalk. I clap and laugh a lot when I am in the Innowalk”.*



My Mum says: “The Innowalk has lengthened Everly’s attention span and that she plays more imaginative games and likes to video her finger play. It has helped her to stay calm and lifts her mood, it helps her to sleep better. Everly is also less stiff and can go to the toilet more regularly. I can see she enjoys the Innowalk and misses it when we can’t come”.

My name is Zac, when I used the Innowalk, I was 8 years old. *“The Innowalk makes my legs more relaxed and keeps a good range of movement. I like to operate it myself with the remote, to control my speed and the gradient of how much of a stretch it gives me. I find it fun, and it doesn’t get boring. I would give it 8/10 for enjoyment and I feel proud of how upright I can be. My Tamagotchi buzzes a lot during a session. I like to play Uno flip and connect 4 with my sister and the physios. I like to choose blue when it’s my turn. I feel safe and secure, it’s not as scary as you might think. My legs feel fine after the Innowalk”.*



My Mum said that: “I think the moving of the Innowalk is really good for Zac’s comfort in her legs compared with her standing frame, which is static. Zac is way more enthusiastic for the Innowalk. I’ve noticed that she’s more independent, as she can control the speed herself. So, she’s more empowered”.

My name is Joey, when I used the Innowalk, I was 8 years old. *“I like to play on my iPad when I am in the Innowalk. I play different games Knightswood, Fireworks and a pandemic game. I like unlocking mystery items. I am able to push my body more upright when I am supported in the Innowalk. I love to go fast. I feel good in the Innowalk, and my legs are more relaxed for a whole day afterwards. I like the feeling of being in it-it definitely does help me”.*



My Mum said that: “his legs feel more mobile and looser, it is easier to change him. He sleeps better and stands a lot straighter”.

My name is Black Panther, when I used the Innowalk, I was 9 years old. *“I feel good in the Innowalk, I think it is fabulous. I shout and laugh a lot when I am in Innowalk, I am proud to be in it, as I am taller, and I can go fast. I love to tell jokes and socialise with people. My best activity is shooting the nerf gun at the gnome. I also love to use the Virtual Reality headset and watch the wrestling. I think I can feel my legs better, but sometimes my legs feel painful afterwards”.*



My Mum says that: *“my sleep and circulation have improved, and I can go to the toilet more regularly. I am happier since going in the Innowalk and it is easier to lift my legs as I have a better range of movement. My circulation is better and that this has helped my water retention. As I have a baclofen pump to help with my muscle tone, this did not change for me”.*

My name is Melanie, when I used the Innowalk, I was 13 years old. *“I was anxious when I first used the Innowalk, but now it helps me to relax and sleep better. It enables me to sleep in different positions, on my stomach or side, as I am more relaxed at night afterwards. I like it because it simulates walking and benefits my circulation.*



The Innowalk makes me feel calm and I love to play Uno flip when I am in there. It's hard for me to stay upright in sitting, so this helps me to be straighter. It feels like a standing frame and stands me more upright than I can stand by myself. It feels comfortable, my legs feel good after the Innowalk. It's never been uncomfortable and makes me feel less tense in my muscles”.

My name is Star, when I used the Innowalk. I was 14 years old. *“I think the Innowalk is kind of nice and fun. I always enjoy my sessions. Sometimes I go on it with my friends, we chat and play games together. My legs feel cool, it’s like I’m walking when in the Innowalk, as I can’t walk, it gives me exercise and makes me feel tall. I especially enjoy playing with my finger skateboards, Uno, Balloon volleyball, O and X’s and Connect 4 with the staff. Here I have created a ramp out of foam, for my finger skateboard”*



My Mum says: “Star loves being in the Innowalk, and she continues to find new and fun ways to enjoy her time in it. She is always really happy, excited and enjoys going in the Innowalk. One day she came home very excited as she had finally stood up for the first time in the Innowalk. I can visibly see her thigh muscles are getting bigger, since she’s been consistently going on the Innowalk”.

My name is Zelia, when I used the Innowalk, I was aged 17 years old. *“The Innowalk is a big machine that makes my body feel smooth and calming and I find it enjoyable, but my muscles can feel tender afterwards. It makes my mind feel that it’s not fizzing about, and it helps me when I’m not in my head, to be more in my mind. My muscles just feel relaxed and floppy. Sometimes I have strong spasms in my legs which stops the Innowalk, but it can be quickly reset. I feel safe in the Innowalk and that I’m not going to fall. I look forward to my weekly sessions where I can chat to the people there.”*



My Dad said that “I was surprised that her legs felt different for 48 hours afterwards - as her muscles are always tight, but they felt looser, and it was easier for her to walk. She likes the speed and how far she can travel in the Innowalk.” My Mum said that “We see it as a potential future form of exercise”.

My name is Barney, when I used the Innowalk, I was 19 years old. *“I like to listen to talk sport radio or George Ezra’s music, when I am in the Innowalk. I love to dance and like rap music too. Sometimes I use the Virtual Reality headset, where I imagine I am walking over a bridge. The Innowalk makes my legs ache, but then they feel good for a while afterwards. I love to chat to people and find out if they used the Satnav to get here.”*



My Mum said: “It makes a huge difference. Barney really enjoys it, which to find something that he looks forward to is great, it puts him in a better mood. He sleeps better through the night, and it has been brilliant for his toileting. I have had dreams about him walking, this is the closest I will get to that dream coming true”.

My name is Charlie, when I used the Innowalk, I was 18 years old. Charlie was observed to like listening to all kinds of music and looking at animal or bird pictures on the phone, when he was in the Innowalk. He prefers to wear sunglasses as he is sensitive to bright lights. He is reported to tolerate being more upright in this, despite his stiff legs, after not standing for ten years. The Innowalk also helps him to clear his chest. Sometimes he smiled and laughed, sometimes he slept in the Innowalk.



My mum said: “A few strides in and his legs become loose, stretched out, a few coughs bringing up any secretions. His whole posture is more relaxed. Charlie gets release in his hamstring muscles for three days and his bowels have become more regular, he also sleeps better after he has been in the Innowalk”.

About the creators of this story book

‘My adventures in the Innowalk’

Dr Dawn Pickering

Dawn is a Reader in Childhood Disability at Cardiff University’s School of Healthcare Sciences. As well as providing training for healthcare professionals, Dawn has been a volunteer at various accessible recreational activities. These include Frame Running and Sailing. Throughout her doctoral and post-doctoral research Dawn’s aim has been to bring the voices of disabled children and young people to the forefront, to advocate for their well-being. This was achieved through visual and creative methods. This story book has been co-produced using the children’s own words, supported by their parents. This represents their social justice, as part of Cardiff University’s Civic mission under the umbrella of citizenship science.

Alison Howard

Alison Howard (Alison Howard Illustration) is an LGBTQ+, autistic illustrator based in Cardiff who creates work to spread awareness and advocate for important causes such as mental health, disability, charities, and LGBTQ+ rights. Alison produces her illustrations using digital, traditional, and mixed media methods.

“As an autistic illustrator, I was excited to be a part of this project as I understand the importance of advocating for the empowerment of those whose voices and representation are often overlooked in media and society, and how illustration can be a powerful tool to do this. I’ve enjoyed working with Dawn to produce the illustrations for this book and I am very grateful for the opportunity to collaborate on this project.”

"It is an outstanding societal contribution concept of the book, to focus on the aspirational and quality outcomes of the Innowalk Pro, from the view of the child or young person".

Stephen Kilpatrick, Head of UK, Made for Movement

"This is a great little book. Not only is it highly readable but it's incredibly patient-centred. By focussing on the true feelings of the patients involved you get to know, first-hand, just how the Innowalk can benefit and enhance the lives of disabled children."

Ted Shiress, Consultation group patient expert

"It is wonderful to hear and see the experiences of children and young people who often have limited opportunities for physical activity participation and expression within society and the media. Dawn is a very competent advocate. I welcome the insight she provides into families lives via this novel and engaging contribution".

Karen Visser, Senior Lecturer: Physiotherapy, Cardiff University

"This fantastic collection of stories enables disabled children's voices to be heard and really showcases the potential of the Innowalk".

Dr Carly Reagon, Senior Lecturer, Occupational Therapy, Cardiff University and author of 'The Toll House'.

"It's an innovative way of looking at agency and access and demonstrates how someone in an eye level static location can benefit from active movement, experience acceleration and speed, as well as feeling safely supported in an upright posture, when not able to move by themselves"

Gabriela Todd, Frame Running

"This is an excellent resource for children, young people and parents to introduce them to Innowalk. As the book directly foregrounds the accounts of Innowalk users, and includes engaging illustrations, it is able to offer its readers accessible, supportive, and essential insights".

Dawn Mannay, Professor of Creative Research Methodologies, Cardiff University