



# Reflections from the ISPA researchers at the Summit for Persons with Disabilities

November 2023

In Partnership with



# CELEBRATING PEOPLE WITH DISABILITIES IN EDINBURGH WITH THE ISPA PROJECT

## ***DR DIANNE THEAKSTONE AND THE ISPA TEAM***

### **Introducing our reflections on the Summit**

The 'Twelve Pillars of Independent Living' were developed from the 1980s by the Disabled People's Movement. Around 40 years later, on the 25th of November 2023, I found myself attending the first ever Summit at the Scottish Parliament held to celebrate 'people living with disabilities'. As well as being registered blind and having a keen interest in disabled people's activism, I was there to represent a co-production project called Intersectional Stigma of Place-Based Ageing (ISPA).

Here I present reflections from those who attended online and in-person, with four ISPA members invited to attend the summit in person (including myself), and another nine ISPA members watching online together and submitting questions remotely. The main themes I reflect on are disabled people's agency, housing and stigma. I close with some key take-away points.

### **Agency**

The Independent Living Movement has highlighted the importance of language as a key way to address power relationships between disabled and non-disabled people, as well as supporting positive affirming disabled identities. Even before attending the summit, I was struck by the language surrounding the event. For example, the summit favoured the international, person-first approach 'people with disabilities', rather than the UK Disabled People's Movement's preference for 'disabled people'.



DIANNE THEAKSTONE, VIKKI MCCALL AND JULIA LAWRENCE  
IN THE DEBATING CHAMBER IN THE SCOTTISH PARLIAMENT

I understand the arguments for both phrases. However, I feel that 'disabled person' accurately describes my lived experience as a blind person where I'm often hindered by external barriers, such as shared space environments, unstaffed train stations, wheely-bins blocking pavements...I could go on, and on! 'People with disabilities' gives me the sense of these challenges being attached to me, when they are actually forms of discrimination imposed upon my everyday life.

## Being in the room where it happens

I was interested in the summit's emphasis on the agency of disabled people and the importance of 'being in the room where it happens'. Pam Duncan-Glancy's (MSP) observation that, "sometimes you feel like a project manager as a disabled person as there is so much to wade through" chimed with my lived experience of disablement, as outlined above. Does society expect disabled people to have super-human levels of energy so that they can work/volunteer, plan and navigate travel, and so on and then, participate in endless consultations, as well as advocating for their rights and oh yes, having a social/family life?



VIKKI MCCALL AND DIANNE THEAKSTONE AT THE PODIUMS IN THE SCOTTISH PARLIAMENT – IN THE ROOM WHERE IT HAPPENS

This sense of continual and often overwhelming societal expectations of disabled people's agency was touched upon by some of the ISPA members.

Most have experienced similar everyday challenges to me concerning their access to independent living:

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*“Train travel is a ‘hit or miss’. I’ve come across difficulties when there are non-staffed stations and I need assistance to get on and off trains.” (ISPA CPR)*

*“I was left on a train, went past my destination and I was unable to get off because the train doors would not open plus, no train personnel were around to assist.” (ISPA CPR)*

*“Motorbility services can be a challenge - poor customer interface and you feel ‘fobbed off’.” (ISPA CPR)*

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ISPA members went on to note that they felt that they were the “awkward” voice in the room. Self-advocacy or that of others, remains a necessity and there were worries within the group that not all disabled people have such opportunities. The group touched upon “survivor guilt” - that disabled people who are able to advocate for their own needs are “better off” as they’ve successfully navigated systems.

As a user of screen-reader assistive technologies, I’ve first-hand experience of accessibility challenges as services shift online. This presents a particular challenge around agency as sometimes it is not possible/easy to discuss the issues with the person providing the service. Another ISPA member recounted that:

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*“My swimming club bank account was closed without my knowledge. I was advised: apply online to get a new account.” (ISPA CPR)*

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## **Where was housing?**

Going back to the 'Twelve Pillars of Independent Living', I was intrigued to find out whether the Scottish Parliament prioritised specific areas of disabled people’s lives, and wanted to hear more about plans surrounding cross-area policy and practice. The summit discussed many key themes, but the other ISPA members and I noticed that housing was only mentioned on the periphery, with summit speaker Baroness Grey Thomson noting the continued challenges of obtaining even small items, such as ramped entrances, for wheelchair users.

I was disappointed by this outcome since, as Maslow highlighted in 1967, shelter is a basic need. Unsurprisingly, other ISPA members also outlined that housing-related issues were important to them. For those looking to social housing for an accessible place to live, navigating the allocation process was very challenging. The impact of a lack of funding for the aesthetic elements, or “shabbiness” of common areas (such as lift lobbies), as well as for home adaptations in social housing, was disheartening for ISPA members who take pride in their homes and neighbourhoods.

## Housing and stigma

A theme not discussed within the summit, but which came up for ISPA members, involved common misconceptions surrounding housing tenures. As somebody who has stayed with family, in private rent, in mid-market rent and been a homeowner, I could relate to the illusion that living in your own home gave some control; or, that in social housing you are always better supported. For instance, while a homeowner, I discovered that there were no garden services provided by the local council for disabled people, and struggled to find and finance self-employed gardeners.

Repairs, I found, were quicker and smoother to arrange as a mid-market rent tenant. ISPA members also highlighted that the design of housing and services tends to stick to quite a fixed idea of what 'disability' looks like. In practice, disabled people have their own needs, wants and tastes. For example, a wheelchair user requiring features such as level access and fall and rise kitchen units may also need colour contrasts or automated/voice-automated doors.

## Summit take-away points

- There is still much to do, with reports of weekly and often daily discrimination against disabled people.
- There was a note that people have to pick their fights, and this can be pretty exhausting.
- There was a call for innovative solutions to work towards an accessible and equitable world.
- Disabled people have hidden costs – cost of living, effort, emotion and stress.
- Services and interventions need to embrace flexibility and move away from a universal model of disability.
- Challenges and specific stigmatisation resulted in “unstable” and “unpredictable” conditions. Stigma can undermine services and leads to a view of disability as something that is fixed, almost like there is a universal model of disability which shapes services and interventions.

## Intersectional Stigma of Place-Based Ageing (ISPA) Project

The ISPA project is an ambitious, 5-year participatory mixed and method study that will explore and understand how the stigma attached to where people live can intersect with experiences of disability and ageing. This will provide nuanced insights into the structures and systems that drive exclusion and allow us to tackle the inequalities experienced by older disabled adults. Do visit <https://www.youtube.com/@ispaproject> for an audio and visual overview.

We aim to develop interventions related to home and environmental modifications that encourage interventions for inclusive approaches within housing, health and social care delivery. This in turn supports people to age well within homes and communities across England, Scotland, and Wales. The project is funded by the Economic and Social Research Council (Ref: ES/W012677/1) and runs from September 2022 to September 2027.

The Intersectional Stigma of Place-Based Ageing (ISPA) Project is a collaboration between the University of Stirling and the University of St Andrews, Newcastle University and University of Bristol. We are also partnered with the Housing Learning and Improvement Network (Housing LIN) and Scottish Federation of Housing Associations (SFHA).

### Contact Details



Dr Dianne Theakstone is a full time Research Fellow supporting all of the work on the ISPA Project, with special focus on the co-production and building a UK-wide group of Community Peer-Researchers. This includes a diverse range of disabled adults to ensure lived experience is at the heart of the ISPA project.

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The support of the Inclusive Ageing call grant number: ES/W012677/1 from the Economic and Social Research Council (ESRC) is gratefully acknowledged.