



Intersectional Stigma of Place-Based Ageing (ISPA) Project

Celebrating Year Two

September 2024

In Partnership with

















OF PLACE-BASED AGEING (ISPA)

TWO YEAR UPDATE

Intersectional Stigma of Place-Based Ageing (ISPA) Project

The ISPA project is an ambitious, 5-year participatory and mixed method study, exploring how the stigma attached to where people live can intersect with experiences of disability and ageing.

In September 2022, we began the journey to provide insights into the structures and systems that drive exclusion, in order to tackle the inequalities experienced by older disabled adults.

This report gives you a roundup of activities we have seen in Year 2 of the project, from its successes and data collection to publications and ongoing networking.

Delivering on Inclusion

The Intersectional Stigma of Place-Based Ageing (ISPA) Project is funded by the Economic and Social Research Council to understand and help tackle the negative consequences of stigma. An inclusive approach is vital, which means we co-produce our research and ensure that lived experience is central in all we do.

This update on the Project comes fresh from hosting and celebrating 'Homes for Life' on Scottish Housing Day on the 18th September 2024, with the Scottish Housing Minister (frontpage and figure 1).

The ISPA Project is building momentum and enthusiasm around how we centralize housing solutions to tackle stigma linked to age, disability and place.



Figure 1: PI Vikki McCall opening Scottish Housing Day 2024 sharing community peer-researcher lived experiences and why we need to tackle stigma.

DISABILITY

PLACE

AGE

Celebrating Success in the Intersectional Stigma of Place-Based Ageing (ISPA) Project Team

The ISPA Project has been celebrating a lot of success, firstly with the wonderful news of our Co-Investigator Kim McKee's promotion to Professor.

Kim was also nominated alongside
Lisa Davison and our other ISPA
colleagues for Research Culture
Awards this year, specifically for
outstanding activity dedicated to
enhancing Research culture. Other
team nominations for Outstanding
Early Career Researcher (ECR) for
Anna Pearce, and Outstanding
Mentor for Vikki McCall. Vikki was
also a finalist in the Herald Higher
Education Awards, for outstanding
staff contribution to the University of
Stirling.



Figure 2: Lisa, Julia and Kim at the Research Culture Awards.



Figure 3: Lisa winning their award at the Celebrating Scottish Research Conference!

However, a big congratulations to:

Our fabulous Project Co-ordinator Julia Lawrence for her Research Culture award win (above)!

&

Our incredible data guru Lisa Davison (left), who won an award for Supporting Early Career Researchers!

We also welcomed Anna Pearce and Carol Gallagher McCulloch to the ISPA team this year.



A big thank you to our amazing ISPA partners Housing LIN, who invited us to the House

of Lords, an amazing experience that reinforced the importance of everyone's work in housing, health and social care. We were also able to present at the successful Housing LIN Summit 2024, on 'Inclusive Spaces: Retrofitting to Adapt our Homes for 21st Century Standards'.

Principal Investigator (PI) Vikki McCall also attended the Buckingham Palace Garden Party this year, nominated by the Social Care Institute for Excellence (SCIE), who are key members of the ISPA Inclusive

Living Alliance. SCIE also included us in an incredible Showcase webinar.

Figure 5: Buckingham Palace garden party, Vikki with Alliance member Rebekah Luff. SCIE.



Figure 4: Attending House of Lords, Vikki with Alliance member Alison Benzimra, United St Saviors Charity.

The team and many of our



Figure 6: Dianne, Vikki and Julia at the Scottish Parliament.

community peer-

researchers attended the first ever Summit at the Scottish Parliament and in Edinburgh, which was held to celebrate 'people living with disabilities'.

We represented ISPA at the Healthy Ageing Showcase, facilitating discussions amongst professionals from a variety of backgrounds, to come up with inclusive solutions that encourage healthy ageing across the UK.



Figure 7: Alasdair and Vikki at the Ageing Showcase

ISPA was showcased alongside some of the leading work and innovation in the area of healthy ageing with the Healthy Ageing Challenge, Economic and Social Research Council, and Susan Kay and Sarah Allport from the Dunhill Medical Trust.



We have also been flying the flag for ISPA all across the UK, from the Highlands to Eastbourne, from the Scottish Borders to Barry!

There are almost too many events to report, with us presenting around 40 plus events since September 2023!

Some highlights include:



Figure 9: Vikki with the Chair of the Scottish Borders older persons forum, Diana Findley, at the Borders Ageing Showcase.

Inclusive living alliance boards, with Eildon Housing Association (HA), Forth HA, and Horizon HA's AGM.

We were also at the Borders Ageing Showcase (above). We had a full house at Tenants' Participatory Advice Service (TPAS) Scotland's annual conference, and we also just snuck in an amazing roundtable hosted by Housing LIN at Housing 2024 in Manchester!



Figure 8: Alliance member Northstar tenants celebration event. ISPA Team Members Vikki (Left), Rose (Right).

Presentations to the Centre for Inclusive Living, Perth, Keynote at the Scottish Federation of Housing Associations (SFHA) Scottish Rural & Islands Housing Conference and the Chartered Insitute for Housing (CIH) conference. We Presented at the British Society of Gerontology, Housing Studies Conference as well as for the Cross-Party Group on Disability. Some of the most fun events have been presenting to our



Figure 10: Vikki and Jeremy at Housing 2024

Our Early Career Network

On 4th-5th of December 2023 we had the first in-person event of our Early Career Network (ECN) in Stirling (see photograph of the participants). The ECN aims to develop a new network of people with less than 10 years' experience in their field, bringing these people together with the ISPA team to share experiences, learn new skills, and support future careers, whether that is in research or in professional areas (e.g., housing managers, those working in policy). Since the December event, there have been two further online 'reading group' activities where members of the ECN identify publications to read and discuss. This month's topic was ethical research with participants.



Figure 11: Louise, Rose, Vikki and our early career members

In September 2024, some of our ECN members participated in an international networking and study event organized by Dr Lisa Davison. The event brought 14 early career researchers (PhD students and postdoctoral researchers) from Sweden together with 14 early career researchers from across the UK and Ireland, for an exciting week of networking. Activities included opportunities to present on their research, engage in methods and writing workshops and even a Stirling Ghost Walk!



Figure 12: Early Career Researchers International Networking Event, University of Stirling.



Figure 13: Vikki and Rose presenting on the ISPA project at the international networking event.

Exploring the representation of disability in homes and neighbourhoods (work package 1)

ISPA is combining diverse quantitative datasets to understand and make new connections between disability, place, stigma and multiple inequalities (including income, health, class, age). Rather than focus on a single dataset, we intend to approach the questions in a more exploratory manner and run analyses on multiple datasets. Applications to access are being made to Children of the 90s (ALSPAC); Millennium Cohort; BCS50, 70; HAGIS; ELSA and UKHLS. It is novel to look so widely across different datasets, and we hope it may give more sophisticated insights about the intersections of stigma than a single data set alone.

The analysis so far has focused on the English Longitudinal Study of Ageing (ELSA), Understanding Society and exploring Scottish Household Data (SHS) focusing on the dimensions of discrimination and intersections between age and disability.

Some really interesting patterns are emerging, especially in the overlap between age, disability and place. To summarise, those living in more multi-deprived areas are more likely to experience discrimination. Also, 50% of those aged 85+ who reported any type of discrimination, reported age and/or disability discrimination.



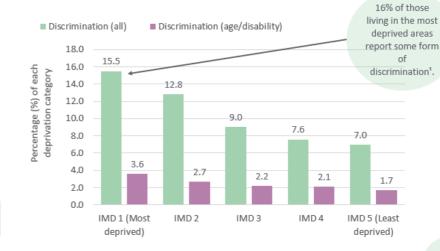
Furthermore, looking at the Scottish data we see place-based patterns. For example, nearly 1 in 2 people living in multi-deprived areas of Scotland report living with disabilities. We will be sharing this more widely soon, but it is good to have a sneak peek!

DISCRIMINATION AND DEPRIVATION IN THE UK

In England, 27% of females and 25% of males living in the most deprived areas are disabled compared to 14% and 12% in the least deprived areas².

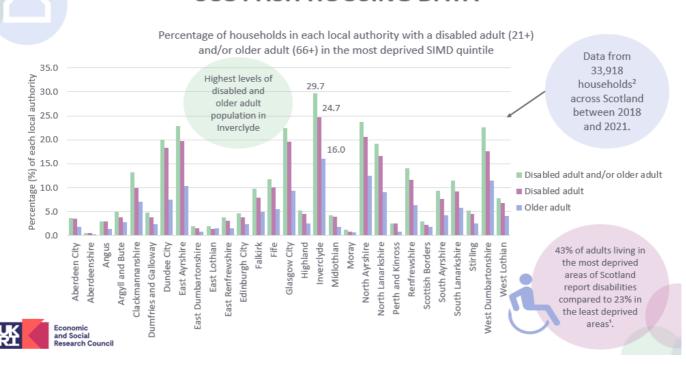
Using data from UKHLS (Understanding Society) waves 11 and 12 (2019/22), we found **2,160** individuals aged between 30 and 101 experiencing some form of discrimination; **45% of whom** reported more than one type, e.g. age AND disability².

21% of those experiencing age discrimination also experience discrimination based on a disability¹.





SCOTTISH HOUSING DATA



In the second year of the ISPA
Project, the quantitative analysis
within Work Package 1 (WP1) has
focused on analysis of UK-based
survey data including the UK
Household Longitudinal Study
(UKHLS or Understanding Society)
and the Scottish Household Survey
(SHS). Our summary report Mapping
Age and Disability Discrimination
(found here) offers descriptive
findings across Scotland and some of
our results from the regression
analysis using UK Data.



Insights into the Quantitative analysis in Year 2 of the Intersectional Stigma of Place-Based Ageing (ISPA)

Project

September 2024



Connecting 'ageing-in-place' to lived experiences of stigma (work package 2)

Work Package 2 is collecting the everyday experiences of over 100 people with disability and/or ageing-related challenges. Most of the people taking part are 45 years or older because evidence tells us that ageing is an experience unique to each individual, particularly those with disabilities, because of a range of structural, social, risk and health system issues (i.e. not the individual themselves) (WHO, 2023; Kings Fund, 2022).

Those taking part are being invited to complete 3 diaries per year over two years (six in total), covering themes such as 'growing older', 'your home and neighbourhood', and 'your plans for the future'.

What's been happening this year?

We are just finishing the first diary wave, 'growing older' which started in May. We have sent out around 112 diaries so far!

The questions in Diary 1 were developed with ISPA Community Peer Researchers during 3 workshops, and they were informed by our Neighbourhood Mapping activities we've been doing since ISPA started. In the end, we developed 11 questions, and people were able to complete these diaries in a range of ways: for instance, over the phone, in a meeting with an ISPA researcher, by email, by voice note, and by pen and paper.



Figure 14: An ISPA diary and a fish-shaped jar opener, which a CPR identified as an essential item in their home

What have we learnt?

From Diary 1 we learnt a lot about what formats work best for people, which questions have worked well, and we now have a better sense of what works best for our CPRs.

We've also been starting to analyze our results, although this is still in progress. But to give you a flavour of this, one of the questions we asked was: "What 5 words come to mind when you think of growing older?". Carol Gallagher McCulloch, one of the ISPA Research Assistants, has created the following 'word cloud' image from the words we received from CPRs. In the word cloud, the largest words are those which were mentioned most frequently, so the image helps give a sense of common issues for our CPRs. For instance, 'health' and 'pain' were clearly important. This is just one example of how we are beginning to explore the information, and we will develop this further over the next few months.





Figure 15: Word Cloud of most frequently selected words when asked about ageing.

What's next?

As well as continuing our analysis of Diary 1, we have developed Diary 2 on the topic of 'Your Surroundings' (home and local environment), and will be distributing this to our CPRs in September 2024. Similarly to Diary 1, we developed 8 questions with input from some of our amazing CPRs.

We've also learnt that we need a little more background information from our CPRs to help us interpret our diary findings (for instance, about types of homes and living arrangements, and more detail about specific adaptations). We are therefore developing a short questionnaire to gather this information, and plan to send this out in December 2024.

Co-production and building a cohort of disabled Community Peer-Researchers (work package 3)

Our main focus and success has very much been on building our amazing group of Community Peer Researchers.

We are delighted to say we have more than DOUBLED our target of 50 CPRS, with us having signed up over 100 people!

We have been joined by some incredibly motivated people with a range of experiences, doing neighborhood mapping across Scotland, England and Wales.

Co-production at the heart of ISPA Building our group of Community Peer Researcher groups

As the WP2 package update indicates, we are all in the middle of the diary process, collecting amazing information and insights.



Figure 16:ISPA team at the Summit for Persons with Disabilities



Our Community Peer Researchers are at the heart of our project, and have been busy sharing their lived experiences, as well as working towards policy change. ISPA Research Fellow, Dr Dianne Theakstone, made sure to capture the reflections of this work in our reflective report on the first ever Summit at the Scottish Parliament held to celebrate people living with disabilities (<u>found here</u>).

We also are working on bringing out lived experiences of inclusive interventions, through case studies in the project. Here is a report on one of the first interventions called 'Nurturing Inclusion' (found here).



Figure 17: Front page of the Nurturing Inclusion report

This reflective piece focuses upon insights from lived experiences of disablement, provided by the ISPA group. We examine: why is it so important to ensure inclusion for disabled people within outdoor as well as indoor spaces?

We will be continuing to share Community Peer Researcher activity and reflections throughout the course of the ISPA Project, with blogs written by our CPRs upcoming in Year 3.



Tackling inequalities via organizational change, policy and practice (work package 4)

The ISPA Project is impact-focused. It will establish how accessibility in homes and neighbourhoods can be increased, alongside how to effectively engage with policy makers and influencers to support organizational change and future planning.

To begin this work, we conducted an evidence review in Year 1 and produced a journal

article, which gives insight to the fragmented, interconnected landscape that overlaps strategies around housing, technology, sustainability, ageing, health and social care.

Our practice-base insights were published February 2024 'Thinking about Stigma in Housing, Health and Social Care Delivery'.



1. Stigma is often intensified for excluded groups.



Thinking about Stigma in Housing,
Health and Social Care Delivery
Implications from the Intersectional Stigma of Place-Based Ageing (ISPA)
Project Evidence Review
February 2024

- 2. Stigma is particularly important to the lived experiences of older people and disabled people.
- 3. Inclusive design is a key part of helping older people and disabled people to feel included.

The publication of our first journal article is now under 2nd stage review in a world-leading housing journal. We also presented these ideas at the *Housing Studies Association* annual conference in Sheffield in April.

Making Change via an <u>Inclusive Living Alliance</u>

We have been building an Inclusive Living Alliance to support implementation of home and neighborhood modifications.

The number of Alliance members is now 36, with an increasing number in England and Wales, helping us to fulfil our ambitions to have nationwide reach and impact.



We very much welcome our new members, with our amazing Alliance now including:



We also hosted an event on 'Thriving Communities' at the University of Stirling, bringing in key experts to share expertise with the ISPA Inclusive Living Alliance.

The key takeaway from the event was that the way we design homes needs to change.

We design with good health and mobility of the occupants as the overriding assumption, but the moment something changes, a 'standard' home no longer fits our needs. The effect of this is that choices become depleted, discrimination kicks in and stigmatisation happens due to capabilities being impacted.



Figure 18: Our Thriving Communities event

We are grateful to landlords and housing developers for supporting the recruitment of Community Peer Researchers. Diary 1, focusing on the experiences of growing older, has been completed, and the Diary 2, about place and surroundings, is being collected in October.

Our goal to make a difference to those ageing with disabilities, has driven our recruitment of Community Peer Researchers. Among these 120 people, 65% count themselves as disabled, though many with limiting long term illnesses or age-related change and difficulties refuse the label 'disabled'.

While a significant percentage have physical disabilities, almost 20% have mental health issues, and more than 12 percent reveal that they have learning disabilities or are living with autism. This poses new challenges to us as an Alliance - how do we ethically and effectively support these participants to share their stories? What insights might we all as researchers and practitioners learn from their lived experiences? These concerns will be taken forward in the next part of the project.

If these issues are already exercising you, then remember there are Alliance partners who can provide advice. Talking Mats use a visual communication tool to help people who have communication difficulties express their views. Friend Autism run adult autism support groups, while The Scottish Commission for People with Learning Disabilities is working to create system change and empowering people with learning disabilities opportunities to make choices. Contact details for these projects can be found on the ISPA web pages on the <u>Housing LIN website</u>.

<u>The Inclusive Living Alliance - ISPA - Inclusive Design - Design - Topics - Resources - Housing LIN.</u>

In the Autumn, we will also be publishing a 'Do you Discriminate by Design?'
Thinkpiece from our ISPA Alliance
Roundtable in London (report here).

Although this stage of the project is more focused on our community peer-researchers and data collection, we will be coming to the Inclusive Living Alliance soon to start seeing how we can be breaking down barriers, created by stigma and linked to ageing, disability, and place.



Figure 19: ISPA were partners in the Roundtable in London



Just to finish, Vikki was also invited to sit in an expert panel for the Social Policy Association (SPA), discussing housing challenges and what they may mean for the next general election - in Year 3 we hope to engage the new UK Government with our findings to help inform evidence-based decision making.



Contact Details



Professor Vikki McCall, Faculty of Social Sciences, University of Stirling and Principal Investigator on the Intersectional Stigma of Place-based Ageing (ISPA) project

E-mail: vikki.mccall@stir.ac.uk

Tel: +44 (0) 1786 467698.

X: @vikki_mccall and @HousingStirUni



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

