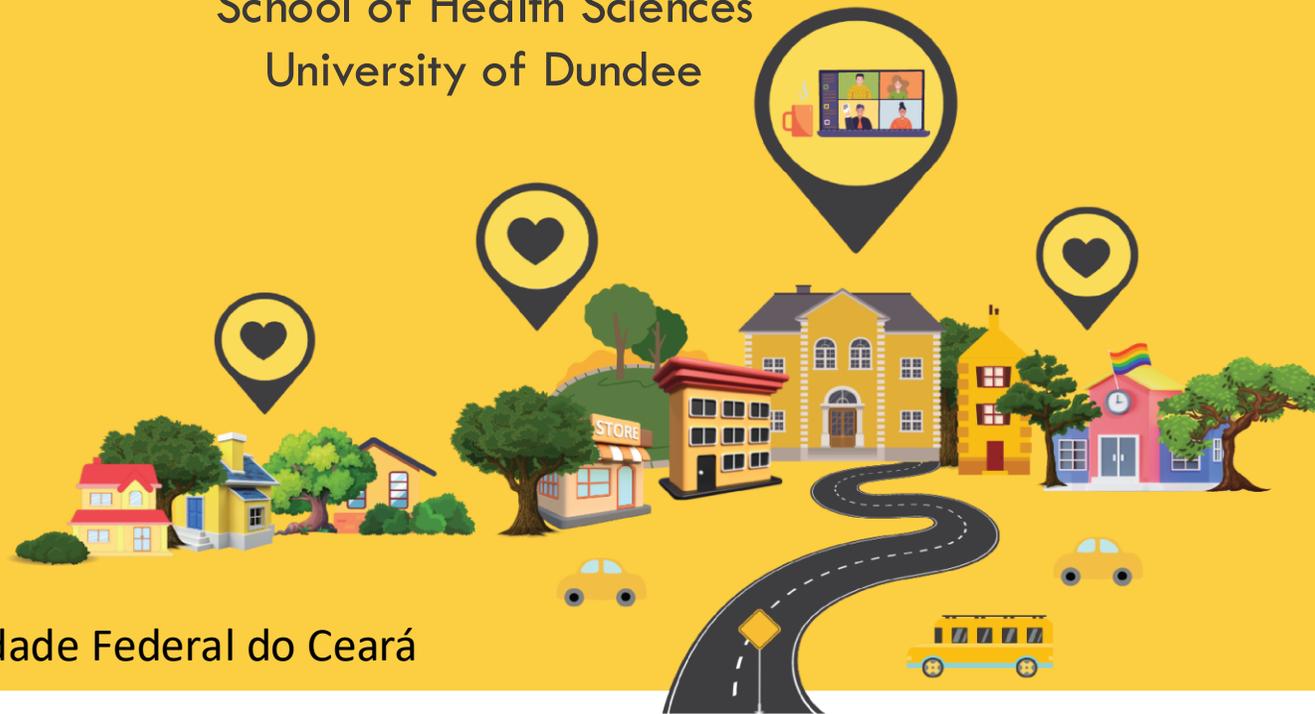# IncludeAge

Inclusion of **diverse older people** in community and public places and virtual spaces

Inclusive Place-Making with Seldom Heard People: The IncludeAge Project

Professor Judith Sixsmith

School of Health Sciences

University of Dundee

29th November, Universidade Federal do Ceará

University of Dundee

The IncludeAge Story

The Call

The Funding

£12 million

Reals: 74,295542

IncludeAge

£1.7 million

Reals: 10,525202

6 Commissioned projects

LD/LGBT+: Intersectional Perspectives for Community Inclusion: IncludeAge

Disability: Intersectional Stigma of Place-based Ageing (ISPA)

Loneliness: Socially inclusive ageing: a lifecourse study of new ageing populations

Frailty/Ethnicity: Understanding the varied experiences of frailty in older age with respect to ethnicity

Ethnicity: Storying Life Courses for Intersectional Inclusion: Ethnicity and Wellbeing Across Time and Place

Ethnicity: Promoting inclusivity in pension protection and saving among men and women from UK BME communities

The IncludeAge Team

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Community Inclusion in an Ageing World

- Ageing populations increasing globally

- Diverse older people

- Under served and under researched

  - 1.1 million UK older LGBT+.

  - 1.3 adult UK Learning Disabilities.

- Community inclusion

  - Improves mental and physical health

  - Decreased depression and anxiety

  - Community enrichment

  - Avoids age silos

World not ready for aging population
The number of people in the world aged 60 and older is expected to grow past 2 billion by the year 2050.

Total population of people aged 60 and older

- Developing countries
- Developed countries
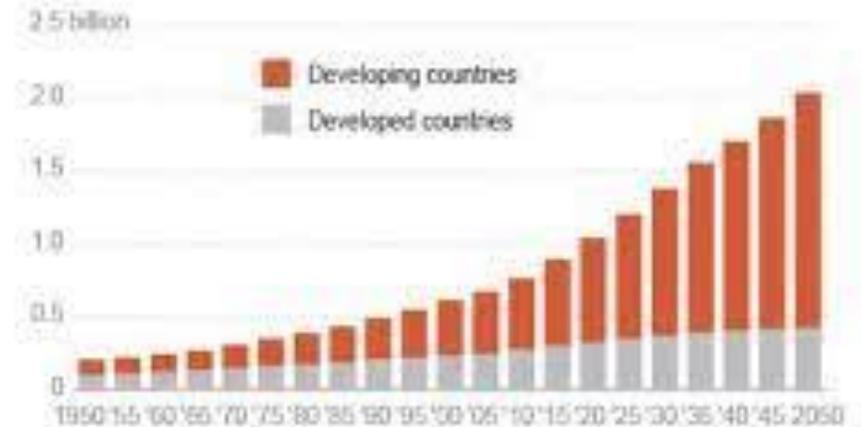
SOURCE: United Nations Population Fund

AP

Digital Inclusion

UK government defines digital inclusion as:

"[…] making sure that people have the capability to use the internet to do things that benefit them day to day."
(Government Digital Service, *Government Digital Inclusion Strategy* (2014)

Digital Inclusion in an Ageing World

- Age and digital divide

    - 87% of adults ages 50 to 64 are online

    - 82% of those ages 65 to 69

    - 75% of those ages 70–74,

    - 80+ at 44%.

- BUT many struggle to access services, supports, everyday activity & enjoyment

- Older LGBT+ people with LD more excluded, esp if PMLD

- LGBT+ people may experience abuse, trolling, discrimination

- Under researched groups: What are their online experiences of digital inclusion/exclusion

Barriers to and facilitators of inclusion: people with LD

Inclusion of people with LD	
Barriers	**Facilitators**
• Lack of interest by developers/researchers • Risk of bullying • Gatekeeping • Insufficient knowledge of victimisation • 'Eternal children'	• Peer approval and support • Convenient access to digital tools and platforms • Adaptations to individual needs • Available social network

Barriers to and facilitators of inclusion: LGBT+ people

| Inclusion of people who are LGBT+	
Barriers	Facilitators
• Pressure towards heteronormativity • Self-censorship • Fears of exposure • Abuse, trolling, discrimination	• Targeted platforms • Peer support & reciprocal interactions • Safety, privacy, confidentiality • Fluidity of choice

The IncludeAge Project

Aims

I. Develop understandings of how to co-create inclusive physical, social, cultural, and virtual community spaces and places, services, and resources with and for mid-older aged people with IDD of different levels of abilities and LGBT+ people to enhance community participation

II. Translate findings into inclusive policy and practice

Objectives

i) Build collaborative, transdisciplinary partnerships to generate and analyse qualitative and quantitative data via survey, interviews, place study, social networks to understand LGBT+ and LD experiences of local and online inclusion and exclusion

ii) Conduct workshops with professional and practitioner stakeholders to understand how local and online spaces and places can be made accessible to provide supportive, inclusive communities for mid-older people with LD and those who are LGBT+ (WP 2).

iii) Generate potential solutions for the development of local / online community spaces and places which facilitate inclusion, minimise exclusion and encourage social and community participation in mid-older IDD and LGBT+, reducing layers of inequality

iv) Translate and mobilise knowledge from research findings to provide strategies and recommendations to influence policy and practice
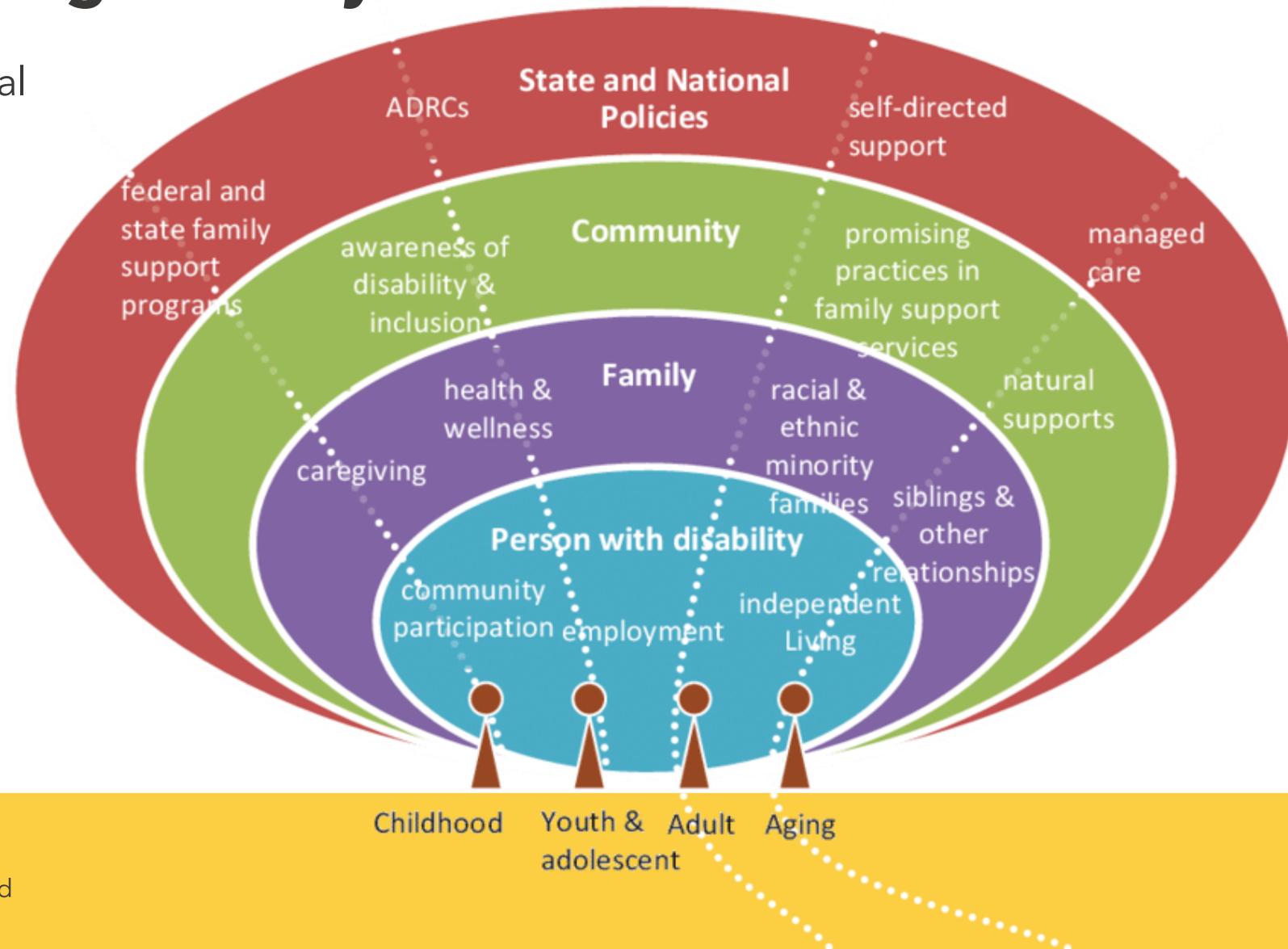
The IncludeAge Project

- Exploring the challenges of community inclusion of mid-older people (40+):

  - Who are LGBT+

  - With Learning Disabilities (LD)

  - Both

- What does community inclusion/exclusion mean?

- Experience of physical and online spaces and places

- Transversal

- 40 months

Ageing

LGBT+   LD
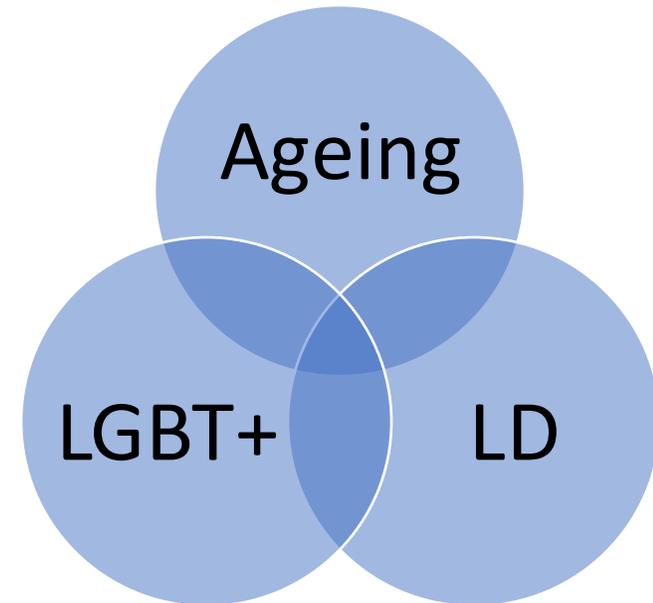
The IncludeAge Theory

- Social ecological
- Life course
- Intersectional

Community-Based Participatory Research

- Promote voices of diverse stakeholders

- Priorities experts by experience

- Full and equal partners in long term commitment

  - Expert-by-experience stakeholders

  - Sectoral stakeholders

  - International Reference Groups

- Brings experiential knowledge and resources

- Empowerment

- Opportunity for positive, relevant social change

IncludeAge Experts by Experience

- **Community Advisory Groups** 3 meetings/year)
  - The Gold Group: 8 LGBT+
  - The Discovery Group: 5 LD, 3 service providers
  - Input
  - Communications: frequency, appropriate
  - Team training
  - Challenges of inclusion
  - **TIME**
  - **RESOURCES**

Inclusionary practice

- Proposal, tools/ instruments development with, by, and for mid-older people who are LGBT +/with LD

- Ensure that

  - Marginalised voices are heard and experiences valued

  - Seat at/space in steering group meetings

  - Shared learning emphasised

  - Attention to communications: e.g. Easy Read

  - Constant consultations and feedback loop

- BUT ethical, cultural and scientific challenges

CAG member testing device
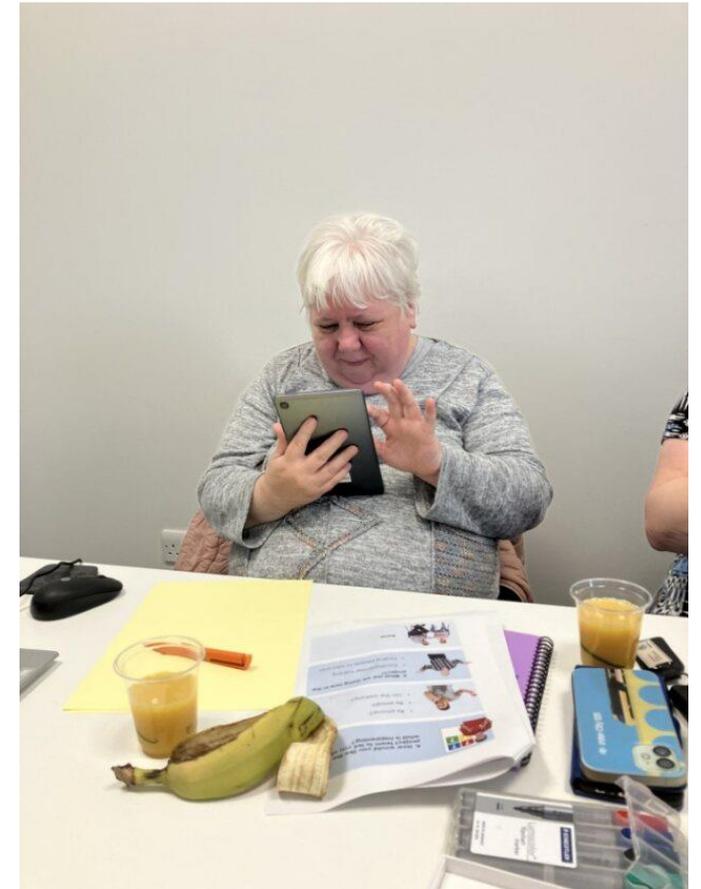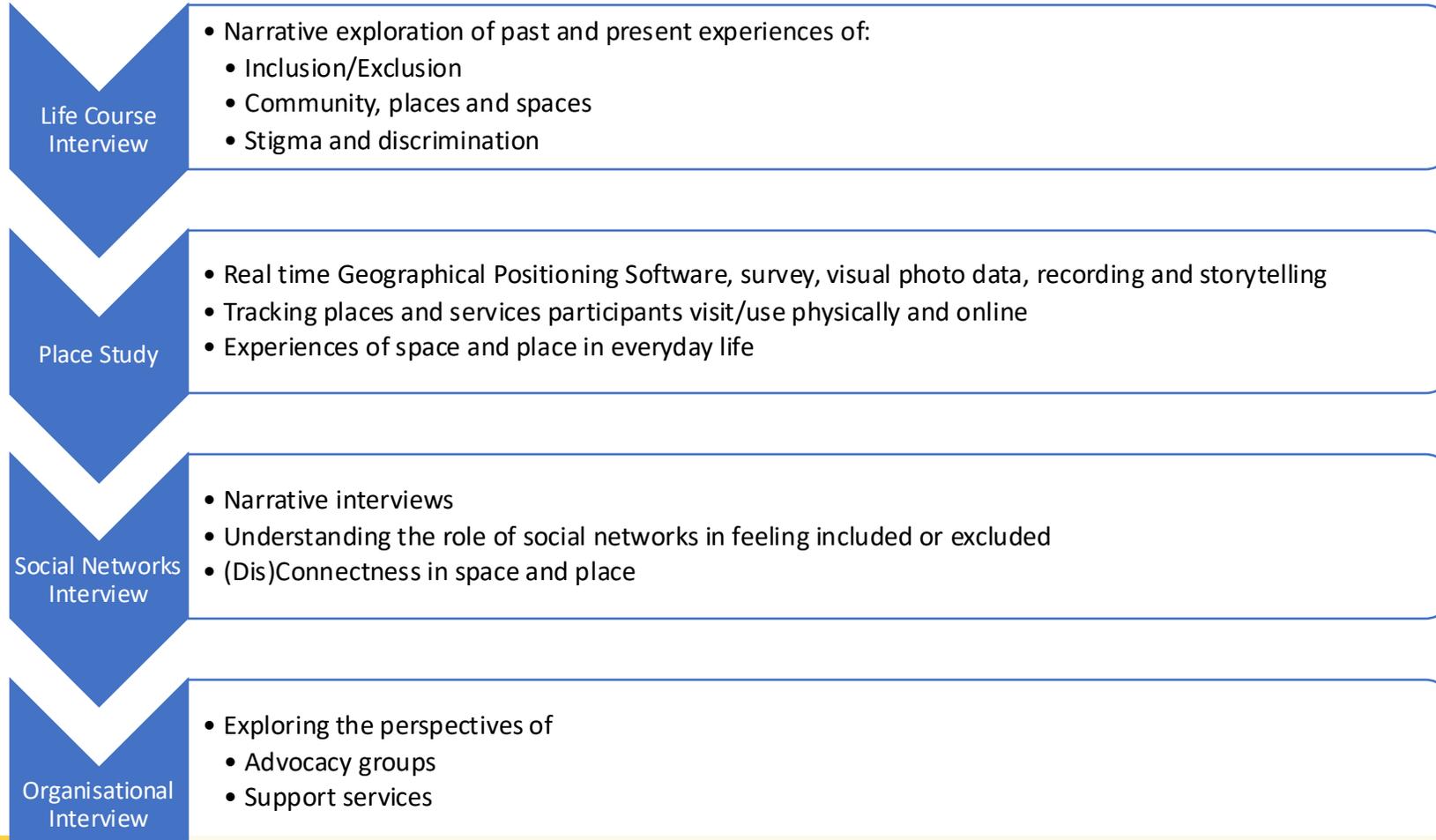
Co-researchers

- 5 mid-older LGBT+

- 5 mid-older LD

- Issue of Diversity

- Employed not volunteers = commitment

- Training

- Individual tailored support and handbooks

- Concept discussions/drop-ins

- Protecting Vulnerable Groups Certificate (PVG)

- Phones

- Agreeing and organising work

- Team training

LGBT+ co-researcher training session

The Integrated Research Design
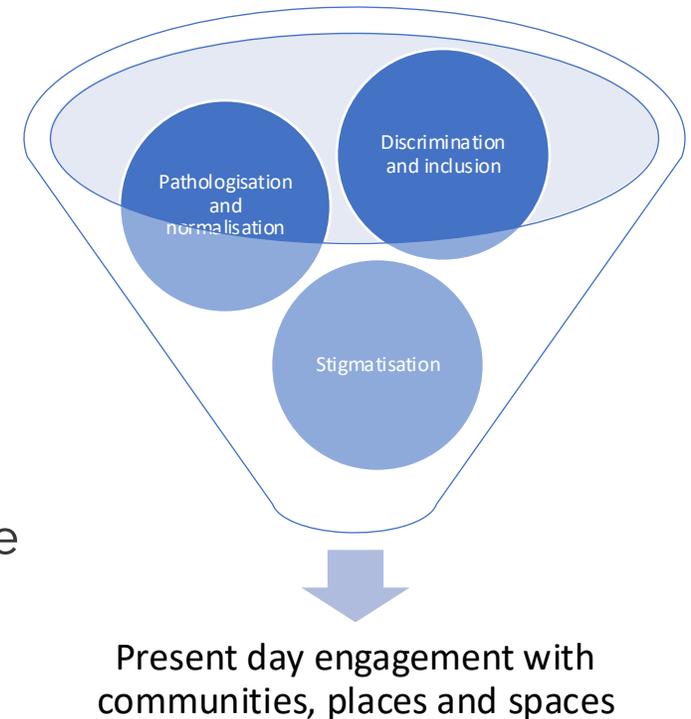
Community Based Participatory Research

Knowledge Translation

Life Course Interview
- Narrative exploration of past and present experiences of:
  - Inclusion/Exclusion
  - Community, places and spaces
  - Stigma and discrimination

Place Study
- Real time Geographical Positioning Software, survey, visual photo data, recording and storytelling
- Tracking places and services participants visit/use physically and online
- Experiences of space and place in everyday life

Social Networks Interview
- Narrative interviews
- Understanding the role of social networks in feeling included or excluded
- (Dis)Connectness in space and place

Organisational Interview
- Exploring the perspectives of
  - Advocacy groups
  - Support services

Potential Solution Workshops

The Life Course Interview

- 80 LGBT+/80 LD narrative interviews

- Understanding diverse histories
  - Interlacing personal & societal past and present
  - Situated belonging
  - Object symbols
  - Paper timelines

- Tracing inequalities to understand cumulative disavantage

- Experience and identity
  - Past traumas and fears
  - Positive experiences
  - Intersubjective and shared learning

Discrimination and inclusion

Pathologisation and normalisation

Stigmatisation

Present day engagement with communities, places and spaces

The Place Study

- ArcGIS Online (AGOL) – 2 platforms

  - Geographic Information System

  - **Real time**, locational, survey, qualitative and visual data

- The AGOL Place Study (with 30 LGBT+/LD)

  - Digital/Paper based -4 months, seasonal

  - Experiential 5-15 physical and online communities

  - Survey: Belonging, accessibility, safety, social context

  - Participants record thoughts, feelings, emotions

  - Photographic data capture

- Follow up interview

Social Networks Interview

- 20 participants (LGBT+/LD)

- What role do social networks play in participant understandings of:

  - What community means

  - Connections across time, people and place

  - Inclusion/exclusion in places and spaces

- Create a network map populated by people important to participant

- Explore:

  - Role of relationships in place and space, past and present

  - How they help shape inclusion and exclusion

Organisational Interviews

- Capturing organisational perspectives on inclusionary/exclusionary practices

- 80 interviews

- Public agencies, services, voluntary and community representatives

- Inclusionary challenges

- Risk taking/avoidance

Workshops

- Co-analysis

- Deliberative dialogue

- Visioning

- Knowledge cafes

- Emphasis on diversity: people, knowledges

- Multiple perspectives

- No single instrument delivers all we need to know

- Co-creation at heart of project

- Gain a holistic appreciation of people, place, community

- Empowering based on local knowledge

- Grows skills, expertise and innovation

- Reflexive analysis

IncludeAge – a co-productio

Organisational interview

Life-course interview

Social Networks interview

Place Study

Place Study follow-up interview

Workshops and KT

Thank you for listening

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Include Age

Social Networks Interview

Understanding people in place relationships

Important person in participant's life

Relationship

Age

Frequency of contact

Mode of contact

Meaning and experience