



### **Dementia And Diversity**

Tuesday 24 September 15.30-17.15

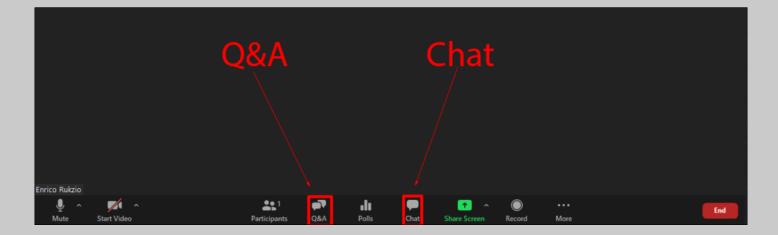






### Housekeeping

- Please type questions in the Q&A box upvote or comment on other delegates' questions
- Use the chat box to talk to each other, make comments or share resources
- If you have any technical problems, use the chat box to send us a direct message
- Please complete the short survey at the end of this session
- This webinar is being recorded and will be made available to those who have signed up
- Presenters Please say "next slide" when you are ready to move on





### Agenda



- 15.30 Professor Vic Rayner Chair's opening remarks
- 15.35 Dathi Clayton Member of the DHWG and living with dementia
- 15.45 Andrew Gilliver LGBT Foundation
- 15.55 **David Truswell** Dementia and ethnicity
- 16.05 Ronald Amanze Being Creative
- 16.15 Adam Preston / Amy Davies Manchester LGBT scheme
- 16.25 Cecilia Toole Sight and Mind
- 16.35 Mohammed Akhlak Rauf Meri Yaadain, CIC
- 16.45 Wendy Wells & John Simmons Dementia resources
- 16.50 Q&A panel
- 17.15 End



### A Safe Space - Kent Surrey Sussex Academic Health Science Network

- We respect people's pronouns
- We do not allow any homo-phobic, bi-phobic, or trans-phobic comments
- We believe people are who they say they are and do not question their (gender/sexual) identity.
- We treat each other with kindness, respect, and consideration
- We encourage curiosity and a willingness to learn. Please ask questions. It's ok to make mistakes, as long as you are well-intentioned.



### Vic Rayner OBE

## Chief Executive, National Care Forum Chair's opening remarks





More than 944,000 people in the UK have dementia.

1 in 11 people over the age of 65 have dementia.

Most people affected by dementia live in their own homes and a third live on their own

### Five key messages from the Dementia Friends initiative

- 1 Dementia is not a natural part of ageing
- 2 It is caused by diseases of the brain
- 3 It is not just about memory loss
- 4 It is possible to live well with dementia
- 5 There is more to the person than the dementia



### **Dathi Clayton**

LGBTQI+ Inclusive Housing for People with Dementia





# LGBTQI+ Inclusive Housing for People with Dementia

- Creating Safe and Supportive Environments
- Dathi Clayton
- Aalter, Belgium

### Introduction

- Topic Overview: The importance of inclusive housing for LGBTQI+ people with dementia.
- Statistics: LGBTQI+ older adults are at a higher risk of dementia and face unique challenges.

### Challenges Faced by LGBTQI+ People with Dementia

- Discrimination and Stigma: Historical and ongoing discrimination affects care.
- Isolation: Social isolation worsens mental health and accelerates dementia progression.
- Healthcare Barriers: LGBTQI+ individuals often face barriers in accessing dementia care.

### Importance of Inclusive Housing

- Safety and Comfort: Safe spaces are essential for the well-being of LGBTQI+ residents.
- Cultural Competence: Trained staff can better support LGBTQI+ residents.
- Community and Belonging: Inclusive housing fosters a sense of community.

### Best Practices for Inclusive Housing

- Inclusive Policies: Non-discrimination policies ensure inclusivity.
- Staff Training: Ongoing training on LGBTQI+ issues and dementia care.
- Design Considerations: Physical spaces should support inclusivity (e.g., private rooms).

### Case Studies

- Rainbow House, Stockholm: A pioneering initiative in LGBTQI+ inclusive housing for older adults, offering tailored services and a community-focused environment.
- Fundacion 26 de Deciembre, Madrid: A community organization providing housing and support for LGBTQI+ seniors, emphasizing dignity and respect.

### Recommendations

- Policy Changes: Advocate for policies supporting LGBTQI+ inclusive housing.
- Community Engagement: Encourage community involvement in creating inclusive environments.
- Collaboration: Partner with LGBTQI+ organizations and dementia care providers.

### Conclusion

- Summary: LGBTQI+ inclusive housing is crucial for the well-being of people with dementia.
- Call to Action: Advocate and support the development of inclusive housing.
- Q&A: Open for questions.

### References

SAGE (USA) – SAGE is a leading organization in the U.S. dedicated to improving the lives of older LGBTQ+ people. Their programs include affordable housing projects in New York and South Florida, and they provide resources through the National Resource Center on LGBTQ+ Aging. Their Long-Term Care Equality Index (LEI) also lists over 200 long-term care communities committed to LGBTQ+ inclusivity across the U.S.(SAGE USA)(HRC).

**Stonewall Housing (UK)** – This UK-based organization focuses on providing safe and supportive housing for LGBTQ+ people, including older individuals. They work to address housing needs and challenges specific to LGBTQ+ communities, particularly those experiencing discrimination or isolation.

LGBTQ+ Senior Housing Inc. (USA) – Based in Philadelphia, this initiative creates affordable, supportive, and inclusive housing for LGBTQ+ seniors. They are working on a community project called **John C. Anderson Apartments**, specifically designed for LGBTQ+ older adults.

Village Montréal (Canada) – In Quebec, Village Montréal offers an LGBTQ+ inclusive living environment for seniors. They provide a unique residential model with tailored services and a community spirit aimed at older LGBTQ+ residents.

**Humanitas (Netherlands)** – In Rotterdam, Humanitas offers intergenerational housing options, welcoming LGBTQ+ seniors into a supportive and inclusive living environment. This community model also includes programming for residents to combat social isolation and promote well-being.

### Thank You!

- Contact Information: litchidc@gmail.com
- For further inquiries, feel free to reach out.



### **Andrew Gilliver**LGBT Foundation





# Learning from Greater Manchester Dementia LGBTQ+ Support & Training

Andrew Gilliver (he/him) - Pride in Practice Coordinator, LGBT Foundation

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A series of 10 training sessions were commissioned from LGBT Foundation by Dementia United following feedback from the Greater Manchester Online Dementia Support Group Evaluation Report.

Report can be found here: <u>GREATER MANCHESTER LGBTQ+ ONLINE DEMENTIA</u> <u>SUPPORT GROUP - Dementia United (dementia-united.org.uk)</u>

### **Feedback**

Services supporting people affected by dementia would benefit from specific Dementia LGBTQ+ awareness training including shared experiences from members of the group.

### **Objectives**

To raise awareness across health and social care staff in Greater Manchester focusing on;

- Why LGBTQ+ people living with dementia may need additional support
- Improving services and care, being more confident to support LGBTQ+ people living with dementia



















### Online LGBTQ+ Dementia Support Group -Evaluation



The evaluation asked people who use the service -facilitators, the LGBTQ+ Dementia Co-Ordinator and all stakeholders their views on the group:

'It is a very valuable lifeline, especially for older LGBTQI+ people dealing with ageing brain issues'.

"The support has been good. I got a background from the Teams meetings and what issues LGBTQ+ people face."

"I do feel more confident supporting someone from the LGBTQ+ community"

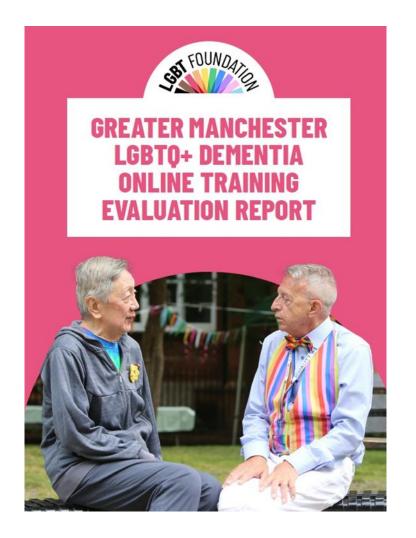
'I am able to connect every month with people I can relate to and with organisations that support us"

#### Themes from Evaluation - Successes

Facilitation of the online monthly meeting required support from a care coordination role.

- Continued Support and commitment from all 10 localities across Greater Manchester.
- Wider connections being made with GM Dementia programme/events/national groups.-Excellent peer support from the group Improved knowledge of LGBT+ issues
- Ongoing connections with wider organisations.
- Main goal –improved access to services for LGBTQ+ people affected by dementia.





The training was co-produced from those involved in the Greater Manchester LGBTQ+ Online Dementia Support Group

### Subjects covered in the training;

- An introduction to LGBTQ+ Health Inequalities
- Information on why LGBTQ+ people affected by dementia may need additional support
- Input from those involved in the Greater Manchester LGBTQ+ Online Dementia Support Group
- Suggestions on improving services and care, being more confident to support LGBTQ+ people living with dementia.

The training was designed so that all attendees could ask questions or raise any points throughout the session as well as at the end of the training.

The training was delivered over 1.5 hours via MS Teams

### **Qualitative Feedback Themes**



- That there is a gap in knowledge of LGBTQ+ people's experiences particularly around dementia and other long-term conditions.
- The importance of LGBTQ+ visibility in care services.
- Support for organisations to be more LGBTQ+ inclusive in general.
- How monitoring of sexual orientation, gender identity and trans status can make a difference to the LGBTQ+ community if done appropriately with full staff understanding and support.
- The need for ongoing support including Dementia LGBTQ+ training for staff in care homes.

Link to Training Evaluation Report: <a href="https://dementia-united.org.uk/wp-content/uploads/sites/4/2024/04/Greater-Manchester-LGBTQ-dementia-online-training-evaluation-report.pdf">https://dementia-united.org.uk/wp-content/uploads/sites/4/2024/04/Greater-Manchester-LGBTQ-dementia-online-training-evaluation-report.pdf</a>



### Learning

- Working together with those providing the training, attendees were able to look at how they begin to make their organisations
  more LGBTQ+ inclusive along with furthering their own learning in support of their colleagues and service users.
- There has been an increased demand for information from health and social care staff across GM and new members joining the online support group, following the successful delivery of the training by LGBT Foundation.

#### Recommendation

- Further Dementia LGBTQ+ awareness and inclusion training, particularly among those working in the care sector.
- Targeting Dementia LGBTQ+ training for care homes is needed

Training is available via LGBT Foundation's Training Academy which is available for anyone wanting to gain knowledge and confidence in LGBTQ+ inclusion within a safe space <a href="https://lgbt.foundation/help/our-training-academy/">https://lgbt.foundation/help/our-training-academy/</a>

OR

Pride in Practice training and support which can be tailored towards health and care professionals.

https://lgbt.foundation/pride-in-practice-for-healthcare-professionals/

### **Useful Contacts / Resources**



- LGBT Foundation A full list of services can be found at <a href="https://www.lgbt.foundation">www.lgbt.foundation</a>
- **Dementia United** Working to make Greater Manchester the best place to live if you have dementia or are caring for someone who does. <a href="https://dementia-united.org.uk/">https://dementia-united.org.uk/</a>
- Dementia UK Newly created Consultant Admiral Nurse service for the LGBTQ+ community.
   <a href="https://www.dementiauk.org/news/specialist-dementia-support-lgbtq-community/">https://www.dementiauk.org/news/specialist-dementia-support-lgbtq-community/</a>
- LGBTQ+ Advisory Group a group of individuals who are passionate about improving the lives of all LGBTQ+ people affected by dementia. <a href="https://lgbtqdementia.org/">https://lgbtqdementia.org/</a>
- Skills for Care LGBTQ+ learning framework knowledge, skills and values for working affirmatively with LGBTQ+ people in later life.
   https://www.skillsforcare.org.uk/Developing-your-workforce/Care-topics/Equality-diversity-and-inclusivity/LGBTQ-learning-framework.aspx



# David Truswell Dementia and Ethnicity



# Dementia and Cultural Diversity

**David Truswell** 

September 2024



# Common cultural issues in accessing services for Black, Asian and minority ethnic communities

- An anxiety about stigma in their own community group regarding dementia that leads people living with dementia to withdraw from their community
- A feeling of community isolation by carers
- A fear of experiencing discrimination or lack of understanding from mainstream dementia services that makes people reluctant to seek help
- A lack of information on dementia that feels relevant for people's own personal circumstances
- A belief that dementia is a natural part of ageing and nothing can be done
- Language and cultural practices that impact on day to day care and support
- Anxieties about loss of independence after a lifetime of self-reliance and resilience

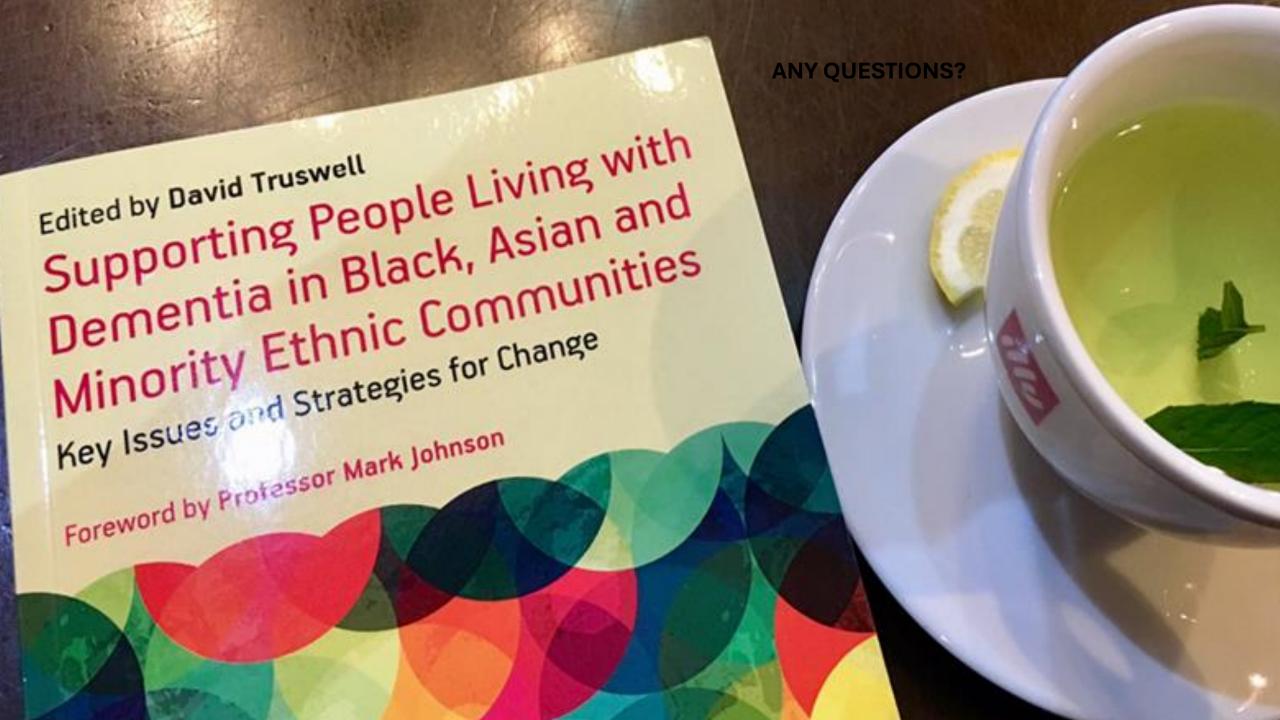
### Common services barriers

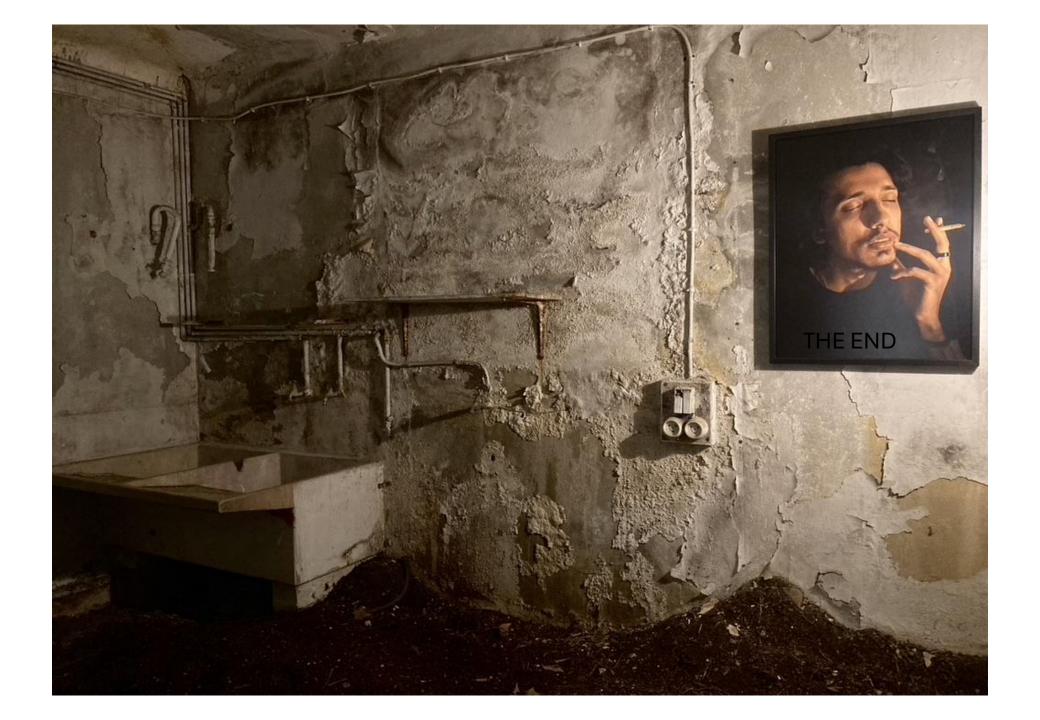
- Staff assume families will 'look after their own'
- Diagnostic materials not appropriate
- Lack of appropriate reminiscence materials and materials for social interventions
- Staff unfamiliar with working with family group rather than just an individual
- Staff unfamiliar with working with an interpreter
- Lack of information on local and national community resources
- Pharmacology and ethnicity interactions unknown
- Pharmacology and traditional medicine interactions unknown
- Dying matters



### Recommendations

- 1. A national repository of information and resources should created.
- 2. Resource and funding investment must targeted at information about dementia for the demographically higher risk BAME groups.
- 3. Better support for BAME carers
- 4. It should be a requirement that for funding UK research organisations must show how they will actively work to include BAME and other underserved communities in their research.
- 5. Co-production & social prescribing—Generating Solutions by involving communities, people living with dementia and their carers has far more potential to encourage engagement of BAME







# Ronald Amanze Being Creative







### Championing diversity through, music, creativity and the arts



- I use creative and music compositions as a means to share my thought and express my self,
- Creativity /music in my life as enabled me to build relationships and have conversation
  where there was no or little cultural inclusion or understand of the beauty and value of
  diversity, or alternative conversations.
- Through creativity and the arts it as not only provided me an outlet and voice were I was not being heard.
- But also served as a bridge for others to perhaps understand me and the value of the arts as a langrage we can **ALL** embrace under the umbrella of the beautiful of diversity.
- Listening between the lines of my poem which was written as a dementia diary
- Its is about not being seen nor being heard in a space that so often advocates diversity and inclusion.
- Diversity through the arts have enabled me to build so many wonderful relationships even with health related social services (SMILE)



# Adam Preston / Amy Davies Manchester LGBT Extra Care scheme





## Russell Road:

Manchester's LGBTQ+ Majority

Extra Care Scheme

Adam Preston (he/him)

### What is Russell Road?



- Extra Care: social rent,80 one- and two-bed apartments
- Partnership between LGBT Foundation,
   Great Places Housing Group and
   Manchester City Council
- LGBTQ+ majority (at least 51%)



Co-produced alongside a Community Steering Group

### Vision

- Reduce social isolation
- Improve the health and wellbeing of residents
- Provide affirming and inclusive care in a safe environment
- Become a Centre of Excellence / wider influence
- Enable LGBTQ+ older people to age happily, securely and with Pride!





# Why do we need LGBTQ+ affirming care?



**Historical** context

Conversion / aversion "therapy"

Lived experience of prejudice and discrimination

Social isolation and loneliness

**Chosen / Logical** families

**Lack of training** and awareness of LGBTQ+ identities

Going back in the closet

**Mistreatment** and physical abuse



The LGBT people forced 'back in the closet' when they enter

residential care



B B C NEWS

### Gay man abused by staff in Croydon care home

① 15 August 2023



2 Aug 2023

LGBTQ+ abuse in care homes revealed

LGBTQ elders struggle with health care, **№** NBC NEWS housing and isolation

'I find myself once again living a lie' older LGBT people need safe housing

## Housing, Ageing and



Care

74%

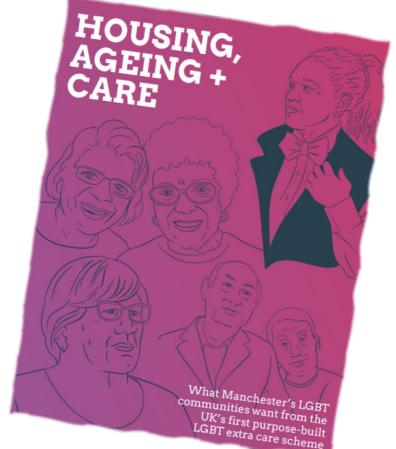
interested in moving into an LGBTQ+ scheme in the future

89%

Agreed there should be more supported housing options for older LGBTQ+ people

67%

Of over 75s would be uncomfortable in a non-LGBTQ+ care setting



Housing, Ageing and Care report (2020)

## Co-production



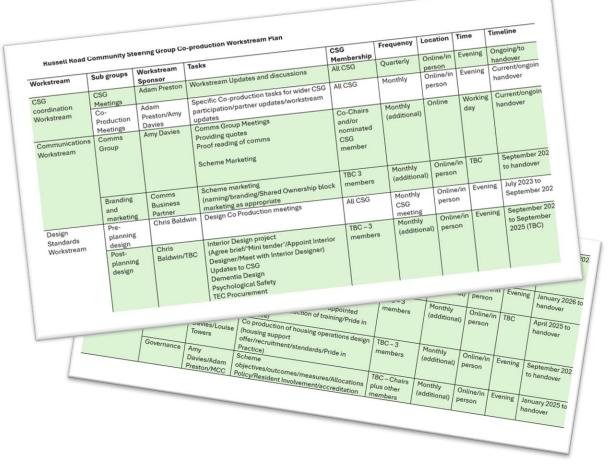
- Community Steering Group
- The value of lived experience
- Over 20 CSG events since March
   2023
- Visits to other schemes;
   walkabouts; design meetings;
   local Prides; public consultations



# Steering Group influence



- Internal apartment layouts
- Interior design spec
- Co-production of care tender questions
- Services and facilities
- Community engagement



### Facilities



• Communal spaces — Residents lounge

- Treatment Rooms

- Roof terrace / garden

• Public spaces - Meeting rooms

- Café / pop-up Village venues

- Multi-purpose spaces

• Activities - Pride in Ageing events

- LGBT Foundation services

- Film Nights / socials etc



### Next Steps



- Planning decision expected this week
- Work on site commences Autumn
- Co-production continues
- Training and Education

Approx 2.5 year construction
 period ...Opening 2027!





### Cecilia Toole Sight and Mind





### Mohammed Akhlak Rauf MBE Meri Yaadain, CIC



# Dementia, Housing and minoritised ethnic communities

#### **Mohammed Akhlak Rauf MBE PhD**





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#### How do the other half live?



Close-knit communities





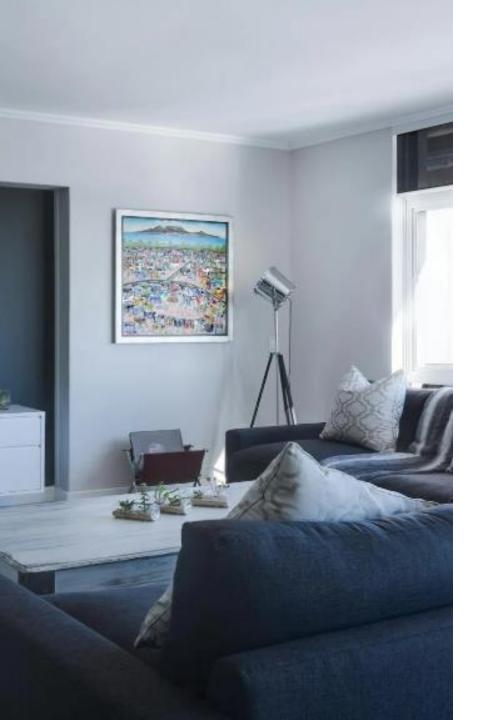
Everything on your door step

Owner occupied housing





Homes for life



#### How do the other half NOT live?



**Extended families** 

Close-knit communities





Everything on your door step

Owner occupied housing





Homes for life



**Experts** 

Nothing without us:

As dementia increases what are our coping strategies



Research

Tackle your bias and prejudice:

Is there a need for different types of housing as well as differing amenities and services



**Cultural humility** 

Your worldview may not be the only worldview:

Faith, language, social norms, cultural expectations



#### Location

- Easy access to cultural and social needs food, place of worship, access to people from ones own community.
- Partnership with community organisations.

#### Building

 Similarities and differences - environment, privacy, shower, prayer facilities, etc.

#### Consultations

- Speak with minoritised ethnic communities especially older people and whilst reminding them of issues such as dementia and its impact.
- Training for staff.



# Wendy Wells & John Simmonds Dementia Resources



#### Housing & Dementia | Go to information resource





Created a hub for all of the best information, advice & support for people with dementia, their families & carers as well as policy makers, practitioners & academics

- √ Adaptations
- ✓ Charities
- √ House design
- ✓ Research
- ✓ Housing options
- √ Financial support
- ✓ Care

- ✓ Communication tools
- ✓ Post diagnostic support
- ✓ Support groups
- ✓ Feedback
- ✓ Commercial providers
- ✓ Technology
- ✓ Board dementia champions
- ✓ Integrated care systems / partnerships



<u>dementia information</u> <u>hub (padlet.com)</u>

#### Housing & Dementia | Go to information resource



#### Why we created it?

So much information but all dispersed and hard to find

Hosted on Housing LIN website

What do we need?

Populate with links, files, reports

Spread the word

Use it...full of good practice



#### News and resources

HOUSING NETWORKS

Dementia and Housing Working

Welcome to the Dementia Housing Working Group news and resources section, which includes

# Dementia and Diversity

What guidance is out there?



**BMA** 

How to manage discrimination from patients and their guardians/relatives



### Panel discussion







10 Dec 24

Dementia friendly technology

Mar 25

Faith and dementia

We hope to see you again