

Measures to Successfully Overcome Barriers and Disparities in Dementia: Achieving Cultural Inclusivity



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DR | KARAN
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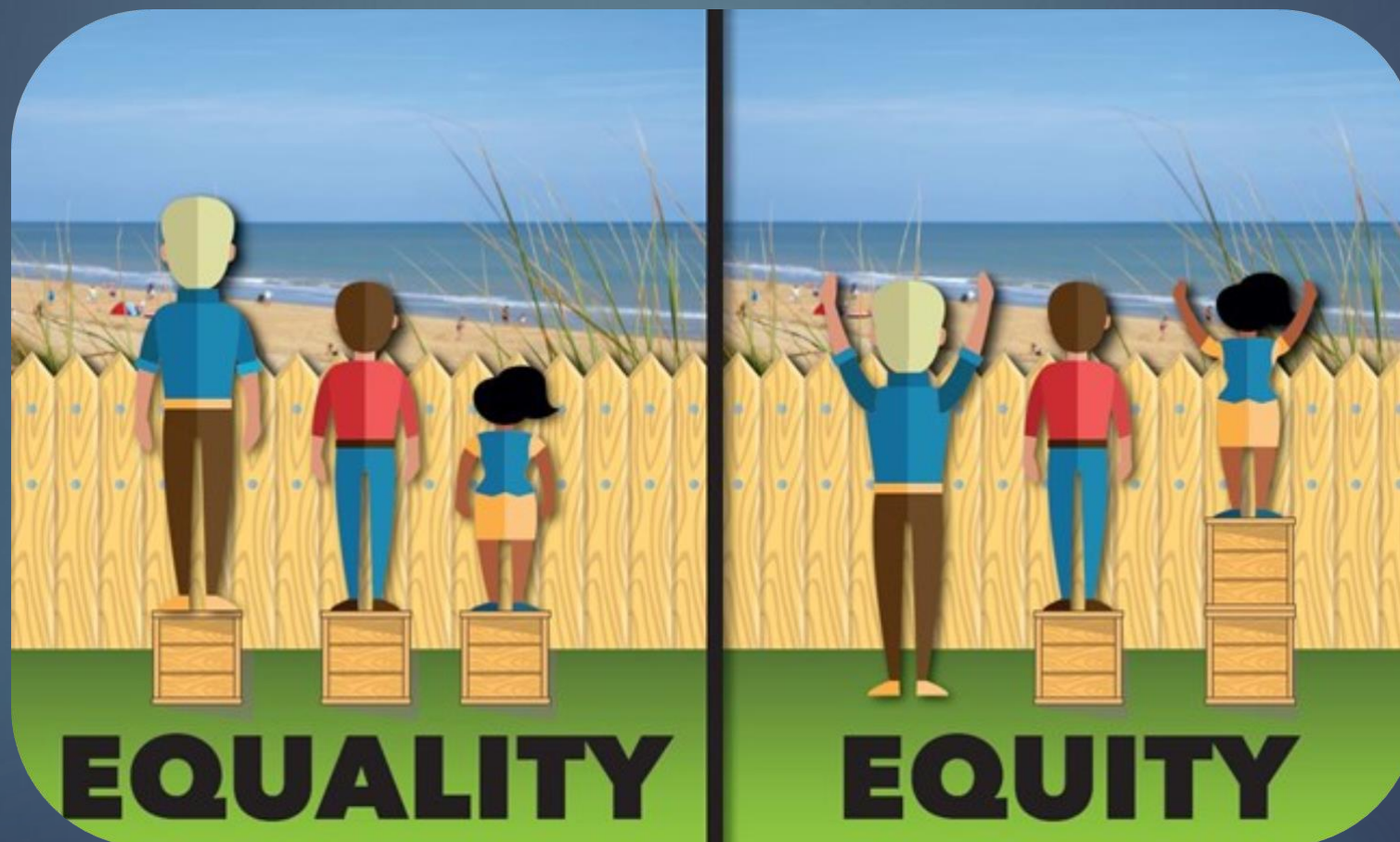
Session Outcomes

- Understand Equality, Diversity and Inclusion: health inequalities in dementia care.
- Recognise ways to improve linguistic and cultural inclusion in dementia care.
- Consider how culturally inclusive dementia care can be achieved via a person-centred approach.

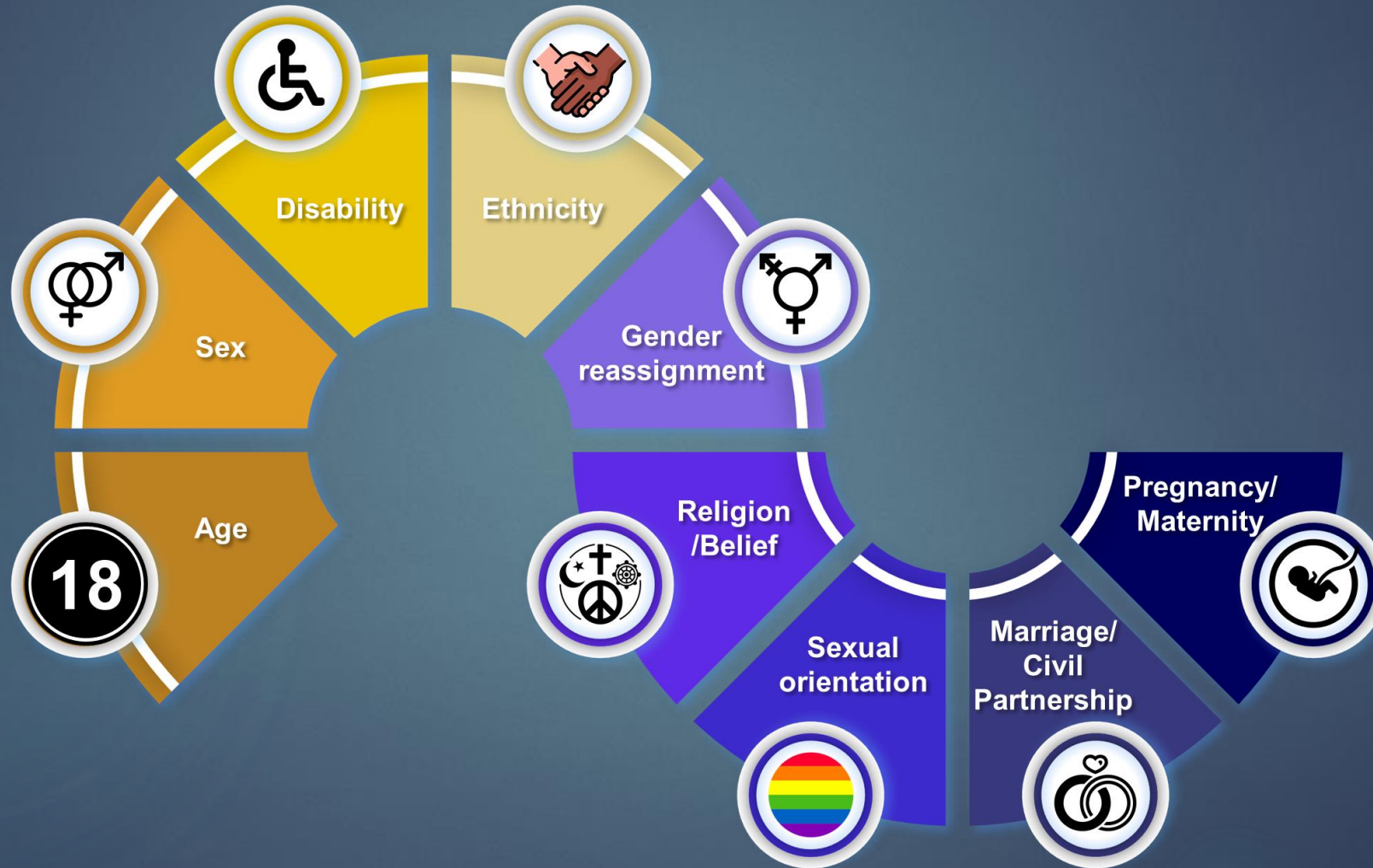
Equality, Diversity and Inclusion (EDI)



EDI refers to ensuring fair treatment and opportunity for all



The Equality Act 2010



Health inequalities in dementia care: the evidence base



Low representation in dementia services for people from: ethnic minority groups, LGBTQ+ communities, rural locations

Higher proportion of women in caring roles than men

Lack of support for: younger people (diagnosed <65years), rare forms of dementia, learning disability

Covid-19: lack of digital literacy skills

Ethnic minorities: Inappropriate or inadequate support coupled with problems caused by language barriers^{1,2}

Late or missed diagnosis

People who experience health inequalities are much less likely to be represented in health and social care research studies including clinical trials^{3,4}

Socioeconomic disadvantages – poorer health outcomes

Experiences of subconscious bias and indirect, and sometimes direct, racial discrimination in services⁴



Dementia does not discriminate

- Current estimate of nearly 25,000 people with dementia from ethnic minority backgrounds in England and Wales.
- This number is expected to grow to nearly 50,000 by 2026 and over 172,000 people by 2051.
- This is nearly a seven-fold increase in 40 years. It compares to just over a two-fold increase in the numbers of people with dementia across the whole UK population in the same time period.
- People from ethnic minority backgrounds are not just getting older but they are also growing in numbers

Dementia in ethnic minority communities: Evidence-base



- Risk factors: higher incidences of hypertension, diabetes and stroke
- Lower levels of knowledge and awareness about dementia
- No word for 'dementia' in certain languages
- Stigma of mental health
- Hidden problem
- Low dementia diagnosis
- Present themselves in crisis situations: need for early intervention
- Lack of culturally appropriate assessment tools
- Lack of culturally inclusive dementia services: “Caucasian-centric”
- Lack of culturally appropriate psycho-social interventions
- Carers as resources



Service Perspective

- Fear of the 'unknown'
- Being 'politically correct:' *'I'm sometimes frightened to ask in case I say the wrong thing'* (Care worker)
- Assumptions about community support: *'They look after their own don't they?'*
- Reliance on family for information
- Language is seen as the biggest barrier

Cultural Assumptions...



- ▶ *“I still can’t believe that services still think that all Asian people are the same. They sent me a Gujarati speaking care worker, when my mum speaks Punjabi. They are two completely different languages but in their eyes, we are south Asian and they sent me a south Asian care worker” (Balwinder Kaur, aged 32 years, cares for mother).*
- ▶ Harbans Kaur (aged 70 years, cares for husband) removed her husband from day care because *“when he used to go to day care, they just assumed that he wanted Asian food and that he wouldn’t be interested in the fish and chips they served every Friday... but we’ve always eaten fish and chips on a Friday. The children used to love it. Little things like this kept happening, and I felt bad for him.”*



- ▶ *“I don’t know why but I feel that healthcare professionals just think that Asians look after their own, and so they are okay. They don’t need any help or support. But we are not okay. In fact, it’s the opposite. People in the family and the community don’t really understand what dementia is and so we have no support. The only support we have is whatever services are available and it’s so so sad that very few of them, if any, are culturally inclusive” (Jazz, aged 50 years, cares for mother).*

Rani, aged 44 years, cares for father-in-law



'He went into respite care, became unwell and ended up in hospital for a while. I didn't realise he wasn't eating until I went into visit him and saw a sign by his bed saying nil by mouth. I questioned them about this and they told me that the speech therapist had been in and confirmed that he could no longer swallow. They said that he should go to Compton Hospice... They were basically telling me that he was ready to die and there was no way back for him. So, naturally, I demanded to speak to the speech therapist...'



...she was assessing him with a banana yoghurt. I couldn't believe it. He doesn't like bananas and he doesn't eat yoghurt. I took some home cooked Indian food in and he ate it.. He ate it all in front of her. That day I brought him back home and decided that he would never go to respite again, or to any other place for that matter. If I didn't go in, he would be in a hospice dying right now. What made them think they could make such a massive decision like that without talking to us first Karan? What kind of a system is this?'

**Rani
cont...**

In the case of Rani...

- *Was this because staff weren't being culturally inclusive?*
- *Or... because staff weren't being person-centred (whereby care is tailored to individual needs)?*



Cultural Inclusivity...

- ▶ Cultural Inclusion is an organisational effort and practices in which different groups or individuals having different backgrounds are culturally and socially accepted and welcomed

"You can't be person-centred without being culturally inclusive, and you can't be culturally inclusive without being person-centred. The two go hand in hand."

DR KARAN JUTLLA

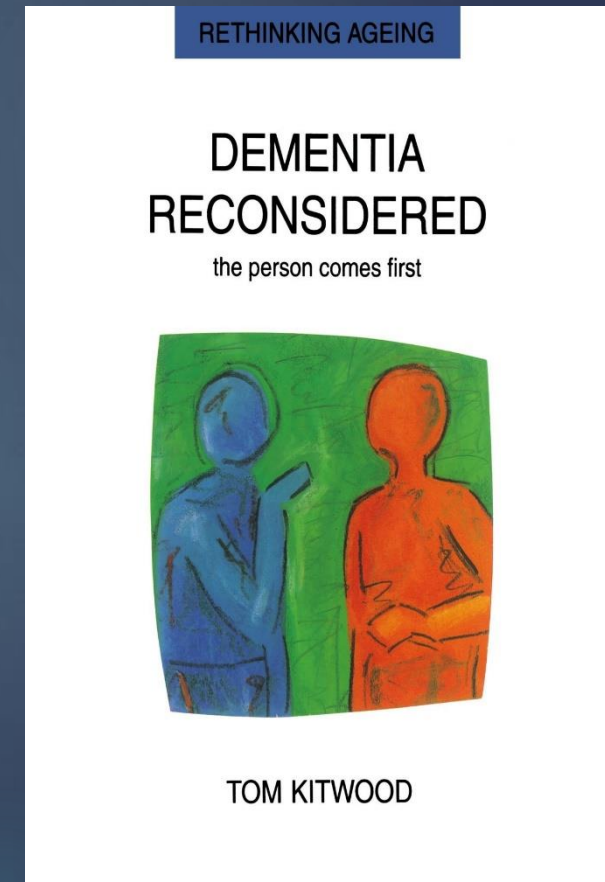
CULTURAL INCLUSIVITY IN
dementia care

Person centred care & Personhood....



Person Centred Care are the processes by which service providers maintain the Personhood of those who receive their services.....

“Personhood is a standing or status that is bestowed on one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust.....”



Cultural competence



- For Gallegos et al. (2008:54) cultural competence refers to *'the process by which individuals and systems respond respectfully and effectively to people of all cultures, languages, classes, races, ethnic backgrounds, religions, and other diversity factors in a manner that recognises, affirms, and values the worth of individuals, families, and communities and protects and preserves the dignity of each.'*

Cultural competence cont...



- Involves more than having an awareness of cultural norms. It is an approach that values diversity and promotes inclusivity
- It represents a value-based perspective that recognises individuality (Gallegos *et al.* 2008)
- **Requires 'cultural humility'**: a lifelong commitment to self-evaluation and the awareness that one's own culture is not the only or best one (Schuessler *et al.* 2012)
- Reflects upon individual cultural bias's and stereotypes

Person Centred Guiding Principles



- ▶ Do my actions **V**alue and honour the people that I work with?
- ▶ Do I recognise the **I**ndividual uniqueness of the people I work with?
- ▶ Do I make a serious attempt to see my actions from their **P**erspective or stand point?
- ▶ Do my actions provide the **S**upport for people to feel socially confident and that they are not alone?



**Professor Dawn
Brooker**
Care fit for VIPS

How inclusive is your practice?



- ▶ Is it a true reflection of the local communities you serve?
- ▶ Does the environment bring a sense of belonging and inclusion?
- ▶ Are you practicing advanced communication skills? – language is not always verbal
- ▶ Are you supporting personhood through meaningful, inclusive activity?
- ▶ Are you going the 'extra distance' to find out what people want and need?
- ▶ Are working *with* them to give them the support they need?
- ▶ Are you practicing self-reflection?



- Funding
- Resources
- A diverse, skilled workforce
 - Diverse leaders
 - Co-production
- Grass roots approach
 - Creativity

In addition to
person centred
dementia care



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