Race, ethnicity and culture: Addressing inequality in access to healthcare for people with Intellectual Disability (C12)

1. Impact of culture on health in people with ID

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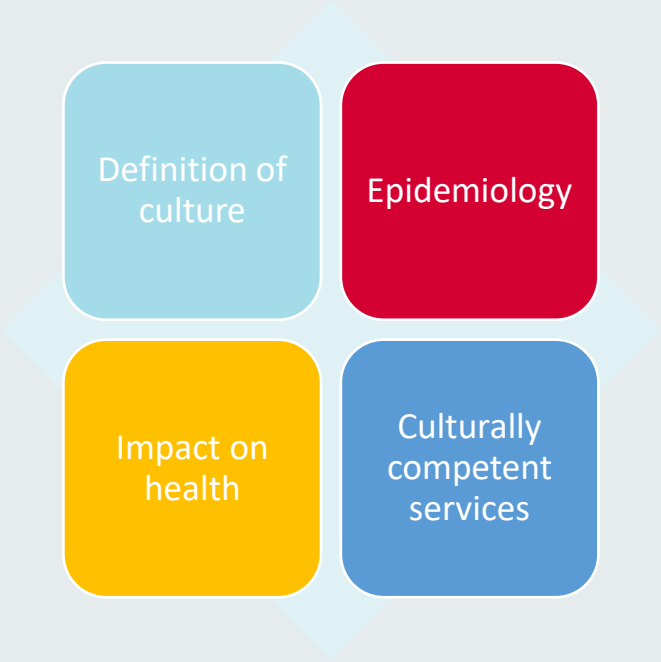
UCL Division of Psychiatry

Will discuss



What is culture and why it matters for health

- The ideas, customs, and social behaviour of a particular people or society (OED)
- Political, legal, ethical, values and practices
- Public Health approaches to equitable care
- Integrated multidisciplinary approach to health research including Humanities
- WHO on sociocultural determinants of health

How does culture influence health?

- Intersection of culture with structural and societal factors may lead to poor outcomes
- Compounds financial and personal costs within and across cultures
- Need to understand how culture may impact health seeking behaviour in populations

Padlet Questions

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Culture and intellectual disabilities

- People with intellectual disabilities experience higher rates of mental and physical ill-health, as well as excess mortality, often from avoidable causes
- Disparities in care for people with intellectual disability may be based on ethnicity (covid-19)
- Understand disease risk factors and presentation in minoratised groups, and to identify interventions which facilitate help-seeking in patients and their carers.

Disability models and health seeking behaviour

- Biomedical model: deficit is located within the individual causing the disability
- Screening, rehabilitation and social care are 3 strategies that draw on this model
- Espoused by families/individuals of higher SES

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- Social model: belief that disability is a social construct, and the result of inequitable practices as well as lack of understanding of people with intellectual disability
- Distinction between impairment and disability

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- Biopsychosocial model: encompasses aspects of both
- Recognises the role of the environment as barrier/facilitator in social participation and better functioning

Morbidity and mortality from non-communicable diseases in people with intellectual disabilities

- NCDs are (chronic) conditions cancers, chronic lung diseases, diabetes, epilepsy, kidney disease, osteoarthritis, dementias, Parkinson's disease
- Highlighted conditions account for 80% of premature mortality
- Associated with multimorbidity and polypharmacy
- Limited access to health promotion, disease self-management strategies, and access to screening programmes

Epidemiology

- NCD: physical disabilities (30%), mental health problems (30%), communication difficulties (30%), visual impairments (20%), and hearing impairments (10%)
- 54 studies included in review by Tyrer et al
- Mortality globally occurs earlier in people with intellectual disabilities
- No improvements in rates over a 10 year period

Impact of culture on help seeking

- Southeast Asia/Northern European ethnic groups may shun help from “outsiders”
- Beliefs about intellectual disabilities (will improve with age/marriage) may impede help seeking
- Traditional healing/shamanism (Ghana, Somalia, Laos) vs/with Western treatments

Mortality and ethnicity

- Children with Down syndrome from a Black African/Caribbean background have significantly increased risk of mortality compared to White counterparts
- Data from England (2020) suggest that compared with a white British person with intellectual disabilities, people of Asian/Asian British ethnicity are 9.2x more likely to die, mixed/multiple ethnicities are 3.9x likely and Black/African/Caribbean/ Black British ethnicity 3.6x

Morbidity and ethnicity

- South Asians are at higher risk of acute glaucoma, chronic kidney disease, coronary heart disease, and diabetes.
- People from ethnic minority backgrounds are more likely to have profound and multiple intellectual disabilities
- Latinos and Black people with intellectual disability are significantly more likely to describe their physical and mental health as fair/poor
- Latinos and Black people are more likely to be obese

Prevention

- reducing risk factors, adapting lifestyles, increasing awareness of screening programmes, increase activity

- Negative health perceptions
- Lack of reasonable adjustments

Access to healthcare

- Physical location, affordability, and cultural acceptability
- Candidacy: provides a holistic perspective on access to health care by analysing how people identify themselves as 'candidates' for health care.
- People with intellectual disabilities are underrepresented in services
- Knowledge, literacy about health needs, cultural suitability
- Services may act as safe space when in distress or stigmatised

Barriers to access-carers

- Family carers found the health service complex and often suffered from stress and poor emotional well-being
- Consequences include health needs of the person with intellectual disability remaining unmet, and carers not having the confidence to complain
- Preference for staff to be of similar ethnic backgrounds

What can be done to improve access?

- Reasonable adjustments including signposting and availability of interpreters
- Resources around communication and health documents ("passports") to be encouraged
- Training in cultural sensitivity and increase awareness via community groups or trusted individuals
- Train in *Cultural Formulation Interviewing* (the cultural identity of the individual, the cultural explanations of the individual's illness, the cultural factors related to psychosocial environment and levels of functioning, cultural elements of the relationship between the individual and the clinicians, and the overall cultural assessment for diagnosis and care)

The Access Model

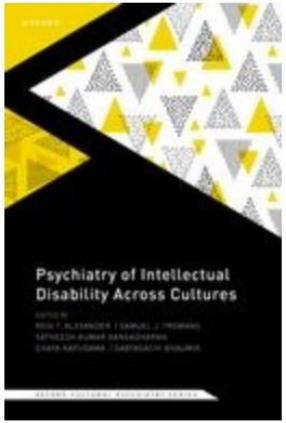
- Assessment
- Communication
- Cultural negotiation and compromise
- Establishing respect and rapport
- Sensitivity
- Safety

UK based national initiatives

- **Stopping the Overmedication of People with Intellectual Disabilities (STOMP/STAMP)**
- **National Audit of Deaths**
- **Incentivised Annual Health Checks**

Future research directions

- International multicentre studies to capture potential differences in health inequalities and mortality across various cultural and ethnic backgrounds.
- Investigating the impact of COVID-19 on exacerbating the mortality disparities for preventative strategies
- Use of artificial intelligence and digital technologies in producing risk models for NCDs in neurodevelopmental conditions.



Psychiatry of Intellectual Disability Across Cultures

Thank you

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Padlet Questions

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Race Ethnicity and Culture

- How are Minority Groups Identified in your experience?

- Is there a common understanding of the terms…
  - South Asian
  - Indigenous
  - First Nation

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Race, ethnicity and culture: Addressing inequality in access to healthcare for people with Intellectual Disability (C12): The UK experience

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School of Medicine and Dentistry

Where opportunity creates success


ETHNIC
MINORITY
BAME
GROUPS
UK
WHITE
BLACK
ASIAN
MINORITISED
ETHNICITIES
EXPERIENCES
IDENTITY
STATISTICAL
POPULATION
PEOPLE
TERM
RACE
USING
INDIVIDUAL
DISTINCT
INCLUDING
SIGNIFICANT
ETHNICITY
WHEREVER
NEGATIVE
RACISM
PHYSICAL
CHARACTERISTIC
COMMON
FACT
IRISH
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COMMONLY
FIRST
INCLUDE
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USE
USUALLY
DIVERSITY
RACIAL
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SOCIAL
SOLICITOR
RACIALLY
EQUALITY
RECENTLY
DIVERSE
ASSIGNING
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ONS
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GROUPING
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BRITISH
CATEGORIES
SPEAKING
APPEARANCES
IDENTITIES
INDIVIDUALS
SPECIFIC
CATEGORISATION
DIFFERENT
WITHIN
COMPARISONS
MINORITIES
SKIN
ATTRIBUTES
PROBLEMATIC
OTHERS
SIMPLY
ALTHOUGH
BECOME
CHANNEL
BASED
INDIAN

Overview

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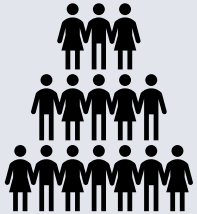
1. What do we know about the current cause of health inequalities in England in relation to access, experience and outcomes?
2. What are the current approaches through policies to addressing health inequalities?
3. Can differences in outcomes be quantified through data available?
4. Do the findings from answering the above questions fit with lived experience?

Background & Methodology

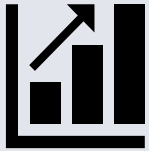
- We used an experience-based co-design approach. This means the research was guided by a Working Group of ‘experts by experience’ who are people with a learning disability from ethnic minority backgrounds and/or their carers.
- The Working Group were involved at every stage of the research process, from helping with ethics applications, to informing the foci of the work, to disseminating findings.

Background



Over 1.3 million people in England have an Intellectual disability (Mencap, 2019). However, there is a paucity of data around the proportion of this population who are also from an ethnic minority.

People with intellectual disabilities from ethnic minorities are at risk of ‘double discrimination’ as members of two minoritised groups.



Evidence from Learning from lives and deaths – people with a learning disability and autistic people (LeDeR) suggests people from ethnic minorities have some of the poorest outcomes.

Background

- Capturing accurate ethnicity data is important to uncover potential patterns of disadvantage for different ethnic groups, bias and racism.

- Ethnicity is a self-identified construct which may be challenging for people with a learning disability who may rely on others for definition and explanation.

- There is no mandated procedure for collecting ethnicity in the NHS.

Policy Review

- 36 national policy documents reviewed for England from 2001 onwards, including:
    - NHS England and other national policies relevant to people with an intellectual disability
    - Department of Health and Social Care responses to reports
    - Relevant White Papers
- Policies rarely mention inequalities in the lives of people with an intellectual disability from ethnic minorities.
- Recently, government responses to the LeDeR reports have recognized these inequalities.
- Specific policy directions relating to people with an intellectual disability from ethnic minorities are rare.

Administrative Dataset Review

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- Twenty seven routine administrative datasets reviewed for England to determine the feasibility of analysing data relating to people with an intellectual disability from ethnic minorities.
- Different datasets have different purposes relying on different information systems, criteria for intellectual disability and ethnicity vary.
- Five of the 27 datasets contained publicly available information that compared some aspect of the experience of people with an intellectual disability across ethnic groups.
- The potential for administrative datasets to provide ongoing monitoring of the health, experiences and service responses to people with an intellectual disability across ethnic groups is under-utilized at the moment.

Scoping Review

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- **Literature search:**
  - and 94 papers were included in the final review.
  - Thirty-six were mixed-methods and qualitative papers, the remaining papers were quantitative.

- **Themes:**
  - Preliminary findings from the final sample of papers were discussed with the Working Group.
  - The themes to explore in the review were developed through an iterative process between the academic team and working group.

What did we find?

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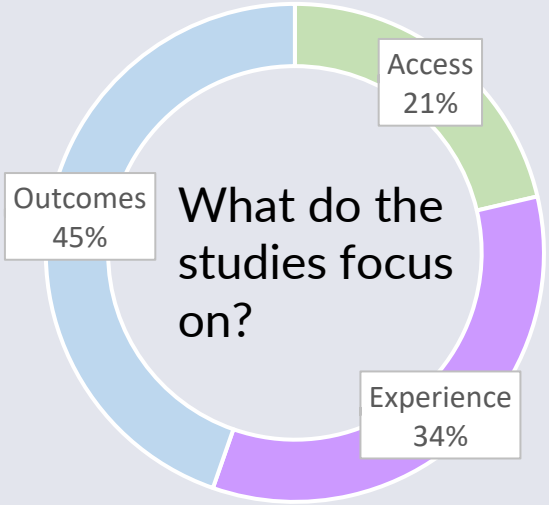

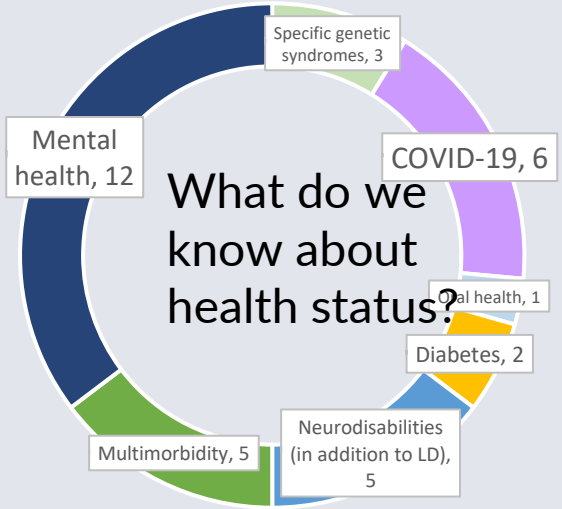

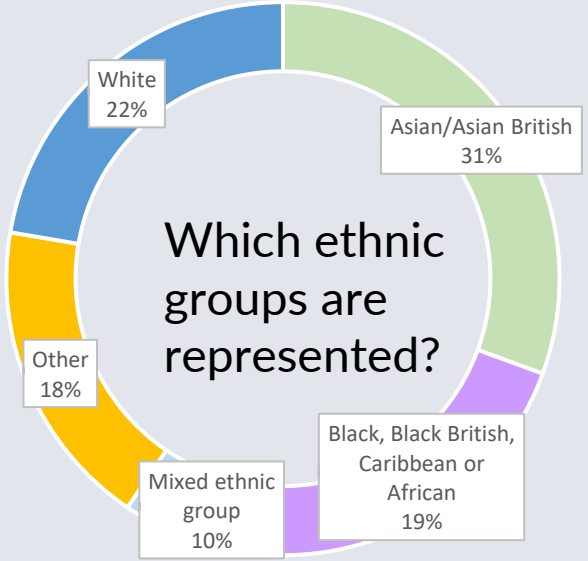

Findings – Themes

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Discrimination

- Only **two studies explicitly focused on discrimination** (Ali et al., 2013; Azmi, Hatton, Emerson & Caine, 1997).
- Several studies discussed lack of culturally appropriate services and language barriers.
- Discussion of barriers through the lens of discrimination or racism was rare.

Community and family networks

- 'South Asian' groups had **more family members in their social network** who acted as support (Bhardwaj, 2018; O'Hara, 2003)
- **High levels of stress and psychological symptoms in carers** (e.g. Akbar et al., 2020; Masefield et al., 2022)

LeDeR

- LeDeR reports suggest that people from ethnic minority groups **may die at a younger age**.
- Males from an 'Asian/Asian British' background with profound and multiple learning disability had a median age at death at around **30**.
- This is the **lowest** median age at death of all ethnic groups (Heslop et al., 2020).

Findings – Themes

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COVID-19

- Being from an ethnic minority and having a learning disability were both factors associated with an **increased risk of adverse COVID-19 health outcomes** (e.g. LeDeR 2020).
- **Ethnicity and having a learning disability were identified as independent risk factors** (e.g. Carey et al., 2021; Cummins et al., 2021).

Transitional care

- Greater levels of unmet needs in relation to culturally appropriate services in those from 'South Asian' backgrounds compared to those of 'Caucasian' ethnicity (Bhaumik et al., 2011).

The learning disability register

- One paper (Chaplin et al., 1996) found **'Asian' adults are underrepresented on the register.**
- Nine papers used the learning disability register as part of their recruitment or analysis.

Health Inequalities-LeDeR data findings

- People from ethnic minority backgrounds had a lower median age at death, regardless of the severity of their intellectual disability
- Black, Black British, Caribbean or African ethnicity has been associated with the highest risk of death at a younger age compared to the white population
- People from ethnic minority backgrounds with a intellectual disability were disproportionately affected by COVID-19

A Case Study of Ethnicity Recording

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Completeness:

- 92.6% of records contained an ethnicity code.

Validity:

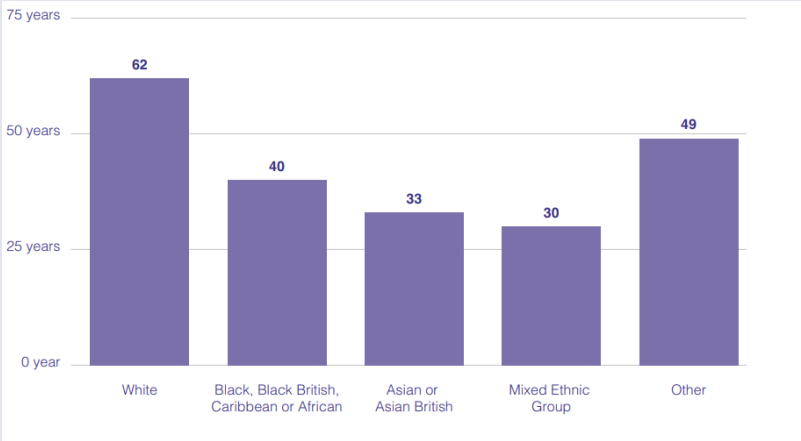
- 73.4% of these codes were valid according to the NHS Data Dictionary
- 72.7% were valid according to census categories

Prevalence of learning disability:

- Overall, 0.57% of patients in the Lancashire and South Cumbria ICB were on the intellectual disability register

LeDeR Data -Median Age at Death

- The median age at death for people from ethnic minority groups was **34 years** (min=4; max=96), compared to **62 years** (min=4; max=104) for people denoted as ‘white’.
- However, the number of people in the ethnic minority group is **considerably smaller** than those in the ‘white’ group so this must be interpreted with caution.



Workshop Findings

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Discrimination

- Some participants experienced discrimination but found it hard to tell whether this was ableism or racism.
- People reported instances of reasonable adjustments not being adhered to.
- Some participants provided personal experiences where they acknowledged that they may have been treated differently due to their ethnic background.
- Examples included being spoken to in a distasteful or derogatory way, being denied access to treatment that was deemed to be beneficial or being prompted to pay for services which were expected to be free.

Workshop Findings

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Community and family networks

- Support from these networks were important for the general health and wellbeing of self-advocates.
- Support from self-advocacy groups was particularly important for people who lacked frequent family support, however sometimes culturally appropriate services were unavailable.
- Carers also expressed that they lacked support from their wider family and within their communities, possibility due to the stigma of intellectual disability, which resulted in feelings of isolation.
- Their experiences did not align with the findings from the scoping review and felt like healthcare professionals also held the stereotype that ‘South Asian’ families have big support networks.

Implications

- The intersection of disability and ethnicity results in **compounded discrimination**.
- This discrimination exacerbates inequalities in access and experiences of healthcare for people with an intellectual disability from ethnic minority backgrounds.
- However, recognising and understanding the source of discrimination can be difficult for people.
- These disparities can be reduced by clinicians having effective communication and an enhanced understanding of intellectual disability.
- Understanding an individual's needs from the first point of contact is important for the allocation of resources.

Discussion

- What Types of Data are available for you to explore health inequalities?

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Questions for Group Discussion

- How is institutional racism highlighted and addressed in accessing healthcare by this population group?

- What are the policy initiatives that have worked from your experience in addressing health inequality for people with intellectual disability

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Thank you!

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