Inequalities exposed by the COVID-19 pandemic in the UK: the experiences of people with intellectual disabilities

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Overview

- Reminder about who we include in the term intellectual disabilities.
- Pre-COVID-19 pandemic experiences of deprivation, including income-deprivation.
- Central argument of this presentation, with supporting evidence relating to 3 key areas of deprivation experienced during the COVID-19 pandemic.
- Potential policy responses.

Who we include in the term ‘intellectual disabilities’

Intellectual disability includes the presence of:

- A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;
- A reduced ability to cope independently (impaired social functioning);
- which started before adulthood, with a lasting effect on development.

The term ‘learning disabilities’ is often used in the UK.

Pre-COVID-19 pandemic experiences of deprivation, including income-deprivation

Employment – involuntarily excluded from the labour market

Education – low level of attainment and skills achieved

Health – significant risk of premature death

Crime – risk of personal and material victimisation

Housing and local services – challenges with physical and financial accessibility of housing and other services/resources

Living environment – variable quality of 'indoor' and 'outdoor' environment

Income – deprivation relating to low income/no control of income

Central argument of this presentation

The COVID-19 pandemic has exacerbated these pre-existing experiences of deprivation for individuals with intellectual disabilities.

On those domains of deprivation about which we have information, people with intellectual disabilities appear to have fared less well than others during the pandemic.

This has led to an increase in impoverished lives, premature deaths and contraventions of human rights.

Example 1: Healthcare

1. Inclusion in Frailty Scale during COVID-19

The *COVID-19 rapid guideline: critical care in adults* published by NICE in March 2020 initially recommended the use of the Clinical Frailty Scale on admission to hospital.

This disadvantaged people with intellectual disabilities from accessing critical/intensive care, as it considered how much support people need to live day-to-day.

After some outcry, the guideline was changed in April 2020 to clarify that the scale ought not be used with people with intellectual disabilities.

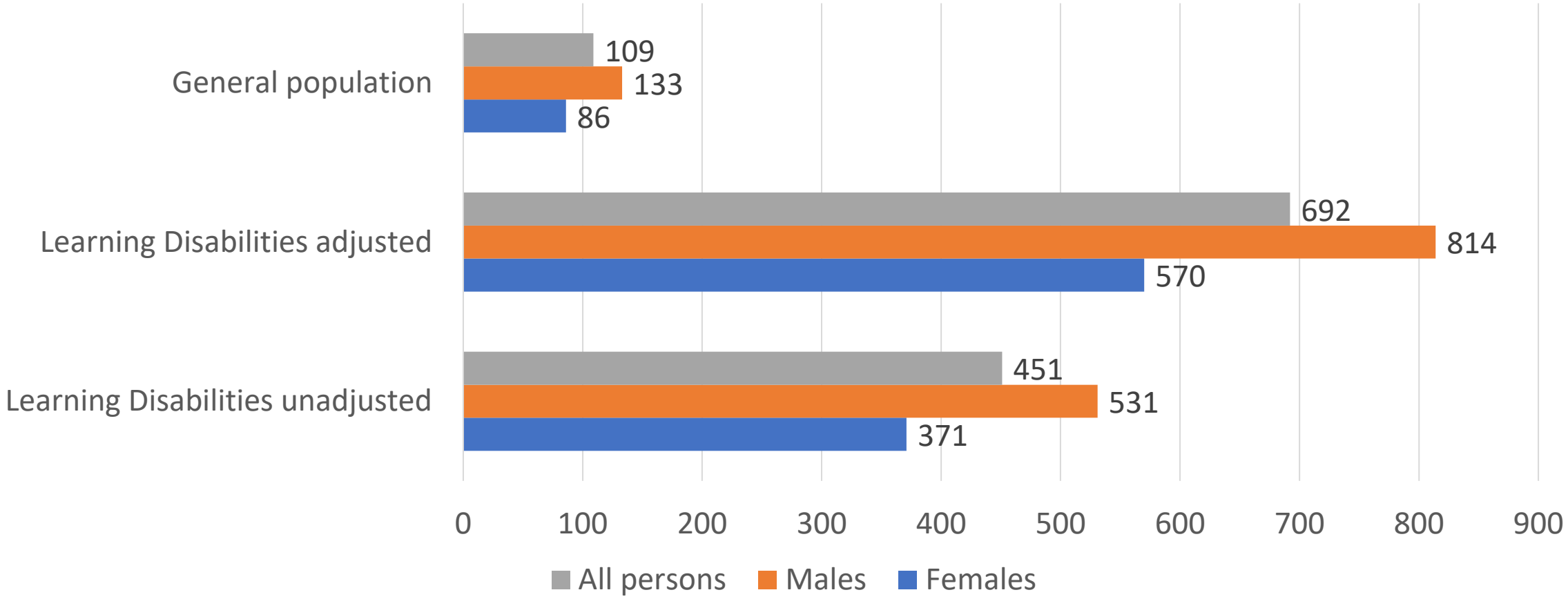
2. Protection from COVID-19

- Age thresholds for shielding people disproportionately disadvantaged people with intellectual disabilities.
- Almost a quarter of people with intellectual disabilities who died from COVID-19 before the end of 2020 were thought to have contracted the virus during a previous hospital visit for an unrelated condition.
- Social distancing was impossible for some who relied on close contact with paid carers for everyday care.
- Initially people with intellectual disabilities were not prioritised for the COVID vaccine - despite data showing they were more likely to die from COVID than the general population - until a government U-turn in February 2021 meant they could get priority access. There were also concerns that people with intellectual disabilities had been struggling to get access to booster jabs.

3. Access to health services

- NHS 111 was unable to tailor services for people with intellectual disabilities, and the protocols they used failed to take account of the level of concern raised by carers.
- Tools and equipment used to detect deterioration in primary and community settings was often not used for people with intellectual disabilities.
- Specialist nurses for people with intellectual disabilities were often deployed to other clinical areas or had to work from home.
- The legal requirement for 'reasonable adjustments' to be made for disabled people was not upheld in COVID-19 national policies e.g. the restriction of visitors in hospitals.

4. Age standardised COVID-19 death rates (to 5 June 2020) per 100,000



From Public Health England (2020)
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/933612/COVID-19__learning_disabilities_mortality_report.pdf

Example 2: Access to local services

Access to support

- A reduction in overall support, or no access to support, for many people with intellectual disabilities compared to before the pandemic (42% of people with mild/moderate intellectual disabilities; 55% people with profound and multiple intellectual disabilities).
- Provision of more online support compared to before the pandemic (45% of people with mild/moderate intellectual disabilities; 23% carers of people with profound and multiple intellectual disabilities).

Impact of changes to support

"As a family we have worked round the clock to minimise a negative impact on our son. But we are absolutely exhausted now…"

"She is frustrated at lack of meaningful activity and is not allowed to go to a day service that she used to enjoy, even though it has been open since April."

"Support staff have to prioritise clients needing 24/7 care; with many staff sick or self isolating, shift cover has been stretched very thin, & shifts cancelled."

"The impact of not being out of the care home in nearly 18 months has resulted in mobility being reduced, deteriorating mental health, reduced quality of life."

"Bored. Frustrated. Exhibited some violent behaviour. Forced to spend too much time with housemates he didn't choose. After some months became lethargic. Resigned to reduced life."

Example 3: Income

Provision of funding in lieu of direct provision of services (personal budgets)

- For most people with intellectual disabilities the amount of funding in a personal budget had stayed the same since the start of the pandemic (61% people with mild/moderate intellectual disabilities; 71% of people with profound/multiple intellectual disabilities).
- A third were paying for services they no longer received (31% people with mild/moderate intellectual disabilities; 39% of people with profound/multiple intellectual disabilities).
- A quarter felt that services and supports had become more expensive during the pandemic (25% people with mild/moderate intellectual disabilities; 29% of people with profound/multiple intellectual disabilities).

Family expenditure on support services

- A sizeable proportion of people with intellectual disabilities or their family members were paying for services from their own money (36% people with mild/moderate intellectual disabilities; 42% of carers of people with profound/multiple intellectual disabilities).
- This can have a significant impact on caregivers, including substantial financial strain.
- 13% had cut back on services and supports during the pandemic because they couldn't afford them.

Personal income

- Although the issue is touched on by some studies, the economic status of people with intellectual disabilities, including income mobility, poverty, and income patterns have not yet been thoroughly examined.
- Examining employment rates is not sufficient to deepen our understanding of the full extent of poverty among individuals with intellectual disabilities – because the amount earned is too insignificant to have an effect on their overall economic status…but…
- The part time, low paid jobs that people with intellectual disabilities are likely to work in were the hardest hit during the pandemic as these types of positions were less likely to accommodate people working from home. While the crisis did not appear to affect wages, there would be large impacts on the hours worked by these employees significantly affecting their overall income.

Concluding comments

- The UK is not alone in seeing an increase in the inequalities experienced by people with intellectual disabilities during the COVID-19 pandemic.
- Policy and practice needs to consider and act upon the disproportionate effects of the pandemic on people with intellectual disabilities.
- We must ensure that inequalities are lessened, not further increased.

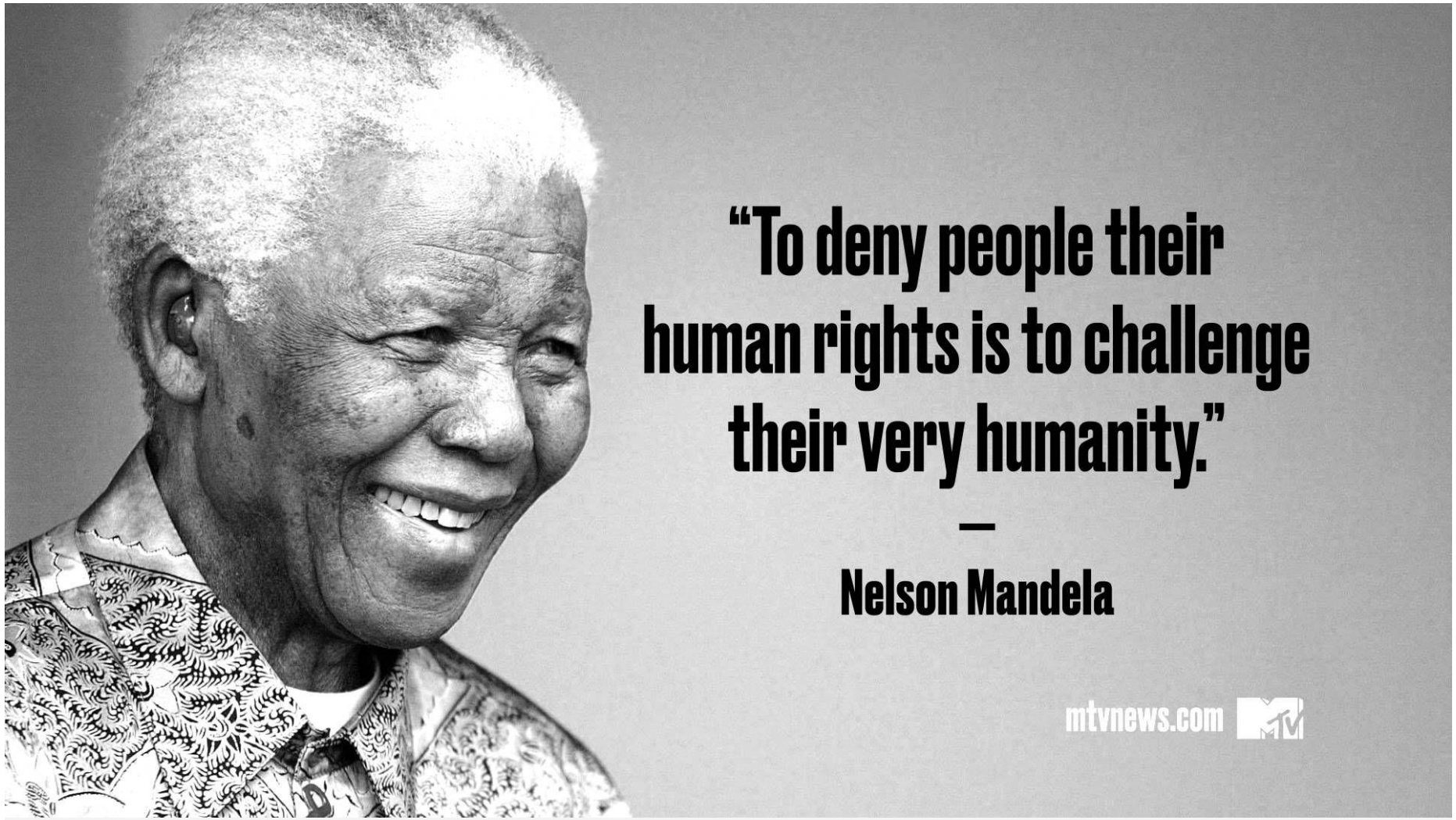
Concluding comments

What could 'levelling out' policies look like?

1. Recognise the role of prejudice, social oppression and discrimination
2. Reduce disability employment gap
    - Provide support and advice for employers
    - Share 'risk', with the government paying sick pay/covering absences/incentivising employment
    - Uphold regulations in the Equalities Act 2010
    - Ensure the benefits system works in line with employment practices
    - Uphold employee rights

Concluding comments

3. Prioritise waiting lists in the NHS according to the impact of the condition, or the impact of waiting for treatment, on an individual and their quality of life.
4. Reassess support needs to take into account the impact of the pandemic.
5. Address social and structural exclusions in the 7 domains of deprivation:
    - Employment
    - Education
    - Health
    - Crime
    - Housing and local services
    - Living environment
    - Income


“To deny people their human rights is to challenge their very humanity.”
—
Nelson Mandela
mtvnews.com
QuotesIdeas.com

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