# Loneliness, COVID 19, disabled people (and others)

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# Rough guide to loneliness

1. Loneliness (before coronavirus)

2. Additional issues (after coronavirus)

3. Safeguarding considerations

4. Local examples

5. What can we do

This report is based on feedback from local disabled people who connect with Real, our staff, comments from TH COVID-19 Community Champions, and national research

# Loneliness (before coronavirus)

- Loneliness for many disabled people is not a new issue

- Several reports already exist (eg from Sense on behalf of Jo Cox foundation, July 2017) with excellent commentary on the issues, prevalence and potential solutions

- But COVID 19, lockdown, social distancing and other virus protection measures are making things much worse, directly and indirectly

# From the Jo Cox Commission on Loneliness

- Everyone experiences loneliness at certain times, especially transitions in life, e.g. school to adulthood, moving home, retiring

- Disabled people experience the same, but have additional issues

- Many barriers are practical, e.g. lack of access to transport, buildings, living in poverty/additional costs, appropriate social care

- But many others are attitudinal
  - 49% of non-disabled people they believe they don't have anything in common with disabled people
  - 26% admit they have avoided engaging in conversation with a disabled person

# From the Jo Cox Commission on Loneliness

There are 12.9 million disabled people living in the UK

- 23% say they feel lonely on a typical day

- 53% report feeling lonely

- this rises to 77% for young disabled people

Both the causes, and the potential solutions, vary significantly across impairment types

(e.g. sensory impairments, learning disability, autism, physical mobility impairment, mental health conditions, dementia, neurological conditions, cancer, HIV)

# Some impairment specific "highlights" from the report

- 14% of adults with a visual impairment say they never or rarely have as much social contact as they would like

- For people with learning disabilities
  - 49% would like to spend more time outside their home
  - 45% do not think they spend enough time with friends
  - 18% feel alone and cut off from other people

- For people with autism
  - 79% of autistic people, and 70% of their families, feel socially isolated
  - 81% feel lonely at least some of the time
  - 81% of young disabled people with autism spend less time socialising that their peers

# Some impairment specific "highlights" from the report

- One in four people will experience a mental health problem in any given year.

- The relationship between mental health and loneliness is often two-way (each one can course/contribute to the other)

- People who are socially isolated are more likely to experience stress, have low self-esteem, and have sleep problems

- 90% of people with mental health problems experienced social stigma and discrimination, limiting their social connectedness

# Some impairment specific "highlights" from the report

- On dementia:
  - More than a third of people with dementia admit to feeling lonely
  - This rises to 62% for people who live alone
  - 33% say they have lost friends following diagnosis
- 74% of people with a brain injury say their social life has been negatively affected
- People with conditions like multiple sclerosis, motor neurone disease and Parkinson's report very sharp increases in social isolation as their condition progresses
- One in four people diagnosed with cancer say they lack the support of family or friends
- A third of people living with HIV aged 50 or over are socially isolated, and 80% of them experience moderate to high levels of loneliness

# Link to the report

- [https://www.sense.org.uk/umbraco/surface/download/download?filepath=/media/1460/campaign-loneliness-someone-cares-if-im-not-there.pdf](https://www.sense.org.uk/umbraco/surface/download/download?filepath=/media/1460/campaign-loneliness-someone-cares-if-im-not-there.pdf)
- Contains really good case studies, analysis of the issues, and suggestions for addressing them

# Campaign to End Loneliness

- Psychology of Loneliness - report from Campaign to End Loneliness (July 2020)

- Foreword by Baroness Diana Barran MBE, Minister for Civil Society and Minister for loneliness

- Suggests expanding on an historic focus on social and practical elements of anti-loneliness projects, towards addressing projects that develop people's self-confidence

- The report was started before and finalised during the first lockdown

- https://www.campaigntoendloneliness.org/wp-content/uploads/Psychology_of_Loneliness_FINAL_REPORT.pdf

# Additional issues after coronavirus

- Disabled people experience additional difficulty accessing public space safely
  - Fear of people not following appropriate social distancing/use of facemasks
  - Difficulty using public transport safely (difficulty using masks, touching surfaces, abuse if can't use a mask)
  - Less able to use alternatives, e.g. walking or cycling
- Left feeling unsupported after withdrawal of shielding support (coronavirus didn't get any less serious, but the support disappeared)
- Reports of increased tension within families no longer accessing day services for family members, especially younger people now reliant on family members more
- It is amplified the impact of existing digital exclusion faced by disabled people
- On mental health
  - existing conditions being made worse
  - new conditions arising as a result of loneliness/isolation

# Safeguarding

- Increased risk of social and financial exploitation of those left isolated

- Increased risk of self-neglect (following depression or just not able to access services)

- Already there have been reported increases in domestic abuse in Tower Hamlets (June 2020)

- Greater risk of scamming, e.g. door-to-door

# Local example #1

A grandmother had been living in a residential care home in Tower Hamlets for some years. She used to go out by herself for a walk to the shops, and to spend time in the communal lounge watching TV or chatting to other residents. Staff closed the lounge, requiring residents to stay in their own rooms.  This lady was reduced to sitting immobile for long periods, and consequently developed a serious pressure sore, which became infected.  The family decided to take her from the residential home to stay with themselves.  Sadly, despite their best care, the infection spread, and the woman died in May.

# Local example #2

A young woman who grew up outside London, with a history of eating disorders and self-harm. After about 10 years in NHS mental health institutions, she was discharged to live with her parents in July 2019. The pressure of isolation during the lockdown got to her and she began self-harming again, after which she was hospitalised again in May. Things have spiralled downhill since.

# Local example #3

Social Isolation during pandemic of an elderly disabled woman who uses an electric wheelchair. Lives on 5th floor TH Homes flat and relies on the lift that sometimes breaks down. When it breaks down she can't get her food shopping. She has no mobile or computer because she was hacked once and she is nervous about it happening again. She relies on her landline. During Covid19 she has found it difficult to get through to council and TH Homes when needed. Hangs on phone sometimes for up to 7-10 minutes then gives up. She has found Darrel Ummah Centre in Bigland Street during Covid 19 helpful with food parcels and also they gave a gift.

# Local example #4

Young man with mental health living in a hostel near Hackney Road. Was on the housing list and offered a flat in Commercial Street during Covid19 and given a date by the hostel when he should leave. He couldn't make contact with his support worker who was self isolating and wasn't capable of moving by himself. He was lucky to have a friend who organised everything but the flat wasn't in a ready state to be moved into (no heating) so he was camping whilst electricity was fixed etc. People with mental health (and other) issues need back up support if their support worker isn't contactable.

# Potential solutions (from Jo Cox report)

- Increasing awareness
  - Improving social attitudes
  - Increasing professional awareness and support
- Improving access to services
  - Enabling independence through access to social care
  - Providing access to services that respond to loneliness
- Tackling poor accessibility
  - Ensuring physical access to communities
  - Providing accessible transport
  - Addressing the digital divide
- Addressing financial barriers
  - Providing fair and adequate financial support
  - Increasing access to employment and work experience

# Other thoughts on solutions

- It's hard! (and especially when people are not online, living in poverty, don't have English as a first language, et cetera)
- Telephone contact schemes (could be developed between THC and volunteers)
- There needs to be a big focus on addressing digital exclusion
- Need to take into account wider access factors
- It could be a long time before vaccination reaches all of the people who are currently stuck at home
- Review Tower Hamlets Council anti-loneliness strategy to make sure it addresses the different aspects of disability appropriately, and is responsive to the current situation
- Promote national and local initiatives on keeping in touch and befriending

# Have a Chat video



https://youtu.be/wTCtXa2zYQU