

People with learning disabilities, health inequalities and COVID-19: An overview

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Health inequalities
before COVID-19

COVID-19
infections and
deaths

Living through a
pandemic



Before COVID-19: Health inequalities

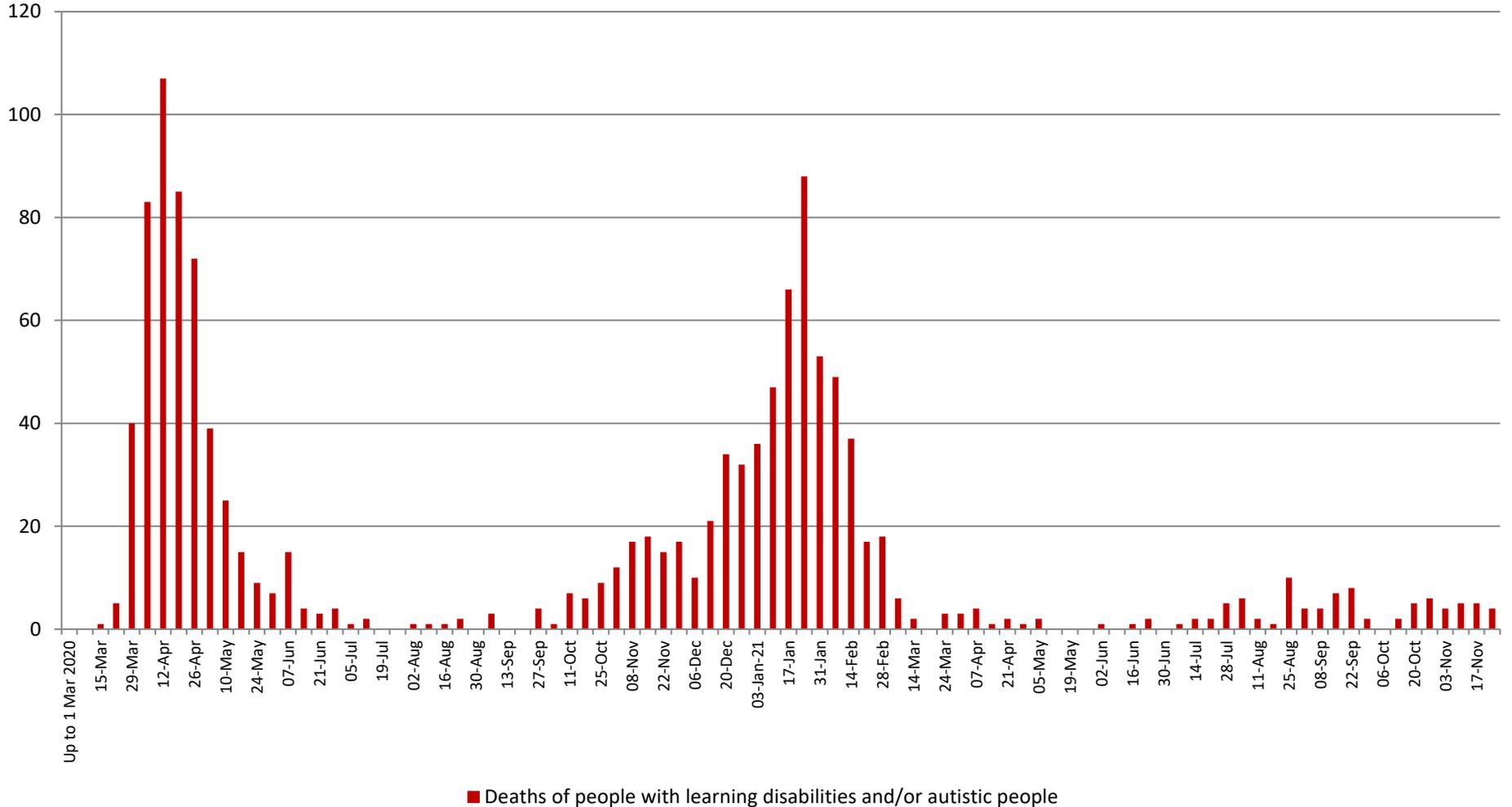
- People with learning disabilities 15-20 years earlier than other people, and the gap isn't closing
- Bad things (all of which make people ill) are more likely happen to people with learning disabilities
 - Being poor as a child
 - Bullied and abused
 - Excluded and isolated
 - Being poor and unemployed as an adult
 - Poor health care



COVID-19 infections and deaths

- People with learning disabilities are:
 - Twice as likely to get COVID-19 (Henderson et al, 2021)
 - Between three and four times more likely to die of COVID-19 (Henderson et al, 2021; PHE, 2020; ONS, 2021)
- Peak age of death 55-64 years for people with learning disabilities (PHE, 2020)
- Living in a place with a lot of other people puts people at higher risk from COVID-19 (PHE, 2020; ONS, 2021)
- Likely that over 2,600 people with learning disabilities in England have died of COVID-19, and people are still dying

Confirmed COVID-19 deaths in hospitals of people with learning disabilities and/or autistic people - NHSEI



COVID-19 health service responses

- People with learning disabilities admitted to hospital for COVID-19 in first pandemic peak (Baksh et al., 2021) - compared to others matched on age, sex, ethnicity
 - More likely to have severe COVID-19 symptoms, and more likely to have other health conditions placing people at risk
 - 37% less likely to receive non-invasive respiratory support, 40% less likely to receive intubation, 50% less likely to be admitted to ICU
 - 56% increased risk of dying from COVID-19 after being hospitalised, and died faster

COVID-19 health service responses

- 73% of people with learning disabilities who died in 2020 had a DNACPR (LEDER programme, 2021)
- COVID-19 vaccination rates now high (90% plus) for most groups of adults with learning disabilities
 - Still lower for younger age groups and for people from minority ethnic communities (OpenSafely, 2021)
 - Very little increase in coverage in recent weeks

Living through a pandemic – what are people's experiences?

- UKRI COVID-19 project with multiple partners across the UK
- Interviewing (remotely) adults with learning disabilities
- Online survey for family carers/support workers of adults with learning disabilities who could not take part in an interview
- Three waves of data collection Dec 2020 through to August 2021
- Wave 3 report and briefings out now
<https://warwick.ac.uk/fac/soc/cedar/covid19-learningdisability/results/wave3results/>
 - Approx 500 interviews with adults with learning disabilities (Cohort 1)
 - Approx 300 surveys from family carers/support workers (Cohort 2)



Headline 1: People are doing their bit to keep themselves and others safe – vaccines and testing

- More than 9 out of 10 people have had both doses of the COVID-19 vaccine
- Nearly 9 out of 10 people would have a COVID-19 booster vaccine
- Nearly 4 out of 10 people had had at least one COVID-19 test in the last month



Headline 1: People are doing their bit to keep themselves and others safe – following the rules

- People have been following the rules with lockdowns and restrictions
- Nearly 9 out of 10 people in Cohort 1 and over half of people in Cohort 2 are wearing facemasks
- For at least half of people, family carers/support workers are using some form of PPE when in close contact



Headline 2: People are paying a price for this

- Half of people are worried about leaving the house
- Over 2 out of 10 people are often/always worried or anxious
- At least 2 out of 10 people had a new or worsening health problem in the last month
- Over half of family carers/support workers report general feelings of stress, tiredness, disturbed sleep



Headline 3: Support has not gone back to normal – social care

- 2 out of 10 people in Cohort 1 and half of people in Cohort 2 are getting less service support now than before the pandemic
- For at least 4 out of 10 people, service support involves going out less
- For nearly half of people in Cohort 1 and a quarter of people in Cohort 2, more of their service support is online



Headline 3: Support has not gone back to normal – social care

- Paying for services
- The personal budgets of more than 3 in 10 people are being used for services they are not currently getting
- For around 4 out of 10 people, the person or their family are paying for some services out of their own pockets



Headline 4: Lifting of restrictions generally means a more restricted life for some people

- Massive issue for people with greater support needs, particularly people with Profound and Multiple Learning Disabilities (PMLD)
 - 2 out of 10 people in Cohort 2 are still 'shielding'
 - For over half of people in Cohort 2, continuing restrictions were having a negative impact on the person
- For at least a quarter of people in both cohorts it was not felt to be safe enough for them to go to all the places they used to



Headline 5: The impact of COVID-19 is continuing

- Less than 1 in 10 people said their life had gone back to normal
- At least three quarters of people said their life would not get back to normal until 2022 or later, if ever
- People said that everyone going back to face masks and social distancing, and low numbers of people getting COVID-19 locally, would help them feel safe to go out
- More than 8 out of 10 people with support staff wanted all their support staff to be COVID-19 vaccinated



Headline 6: For some people, there have been some good things

- Getting online and connecting with people
- Having a more relaxed pace of life – not having to get up early and rush off somewhere, especially when the activity is not enjoyable or meaningful
- Spending more time with people who are close
- For many people, things were better in the summer of 2021 than they were last winter



What matters now

- Many people and families feel they have been forgotten and abandoned through COVID-19
- Managing to survive on no/little support doesn't mean people don't need support
- What about people and families who are still shielding or stuck inside – what is the path to a better future for them?
- Could be a chance for people to reset how they want to be supported, but this isn't an excuse for cuts or saying online activities are the same
- How are services going to rebuild trust?



What next?

- Existing pervasive health inequalities, starting in childhood
- COVID-19 likely to have widened these inequalities further
- Eligibility and visibility within health and social care systems becoming a life and death issue
 - There were 1,500 fewer adults with learning disabilities receiving long-term social care at the end of March 2021 compared to the end of March 2020
- What does building back better mean for this large and diverse group?



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