Coronavirus and people with intellectual disabilities
COVID-19 and people with intellectual disabilities in the UK – Infections and deaths

• People with intellectual 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 intellectual 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 intellectual 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

Deaths of people with learning disabilities and/or autistic people
COVID-19 and people with intellectual disabilities in the UK – Social care

• Social care policy and guidance has been focused on older people in residential care homes (in England, 95% of adults with intellectual disabilities getting long-term social care are not older people in care homes)

• ‘Easement’ of social care responsibilities

• Guidance for people with intellectual disabilities living alone / with family / in supported living and those supporting them, has been slow and not always seen as helpful
COVID-19 and people with intellectual disabilities in the UK – Health care

• Health care responses (documented for the first COVID-19 peak) have been discriminatory for people with intellectual disabilities
  • Do Not Resuscitate Orders
  • Once in hospital with COVID-19, less likely to get intensive COVID-19 care
  • Withdrawal of specialist therapy and primary care for people with intellectual disabilities (e.g. annual health checks) when NHS is under COVID-19 pressure
  • Struggle to prioritise people with intellectual disabilities for the COVID-19 vaccine

• COVID-19 vaccination rates now 90%+ for most groups of adults with intellectual disabilities, but lower in younger age groups and among people from some minority ethnic communities
The Coronavirus and people with learning disabilities project

• Tracking people’s experiences and support throughout the pandemic
  • Wave 1 - December 2020 - February 2021
  • Wave 2 - April – May 2021
  • Wave 3 - July – August 2021

• Cohort 1 - Zoom/phone interviews with 500 adults with intellectual disabilities

• Cohort 2 - Online surveys for 300 family members/support workers about adults with intellectual disabilities who could not take part in an interview

• Project website https://warwick.ac.uk/fac/soc/cedar/covid19-learningdisability
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Headline 1: People are doing their bit to keep themselves and others safe – vaccines and testing

• 10% of people in Cohort and 13% of people in Cohort 2 are reported to have had COVID-19
• Over 90% of people in both cohorts have had both doses of the COVID-19 vaccine
• Over 85% of people in both cohorts would be willing to have a COVID-19 booster vaccine
• 37% of people in both cohorts had had at least one COVID-19 test in the last four weeks
  • Mainly before going out, or because everyone where they live gets tested
  • Cohort 1 mainly do the test themselves, Cohort 2 mainly need someone to do it for them
Headline 1: People are doing their bit to keep themselves and others safe – social restrictions

- People have been complying with lockdowns and restrictions
- 88% of people in Cohort 1 and 56% of people in Cohort 2 are wearing facemasks
- For 61% of people in Cohort 1 and 46% of people in Cohort 2, family carers/support workers are using some form of PPE when in close contact
- Television news still the most common way to find out about changes to COVID-19 rules (69% of people in Cohort 1; 56% of family carers/support workers in Cohort 2)
Headline 2: People are paying a price for this

- Half of people are worried about leaving the house
- Over 20% of people are often/always anxious
- 19% of people in Cohort 1 and 28% of people in Cohort 2 had a new or worsening health condition in the last four weeks
- Over half of family carers/support workers report general feelings of stress, tiredness, disturbed sleep
- 14% of family carers/support workers have contacted GP in the last four weeks about their own health
Support has not returned to pre-pandemic levels – health services

- Around a third of people in both cohorts had been in contact with a GP surgery in the last four weeks, mainly by phone (similar to Wave 2)
- Of those waiting for a planned medical procedure, 39%-56% of people had been waiting more than 6 months
- Of those people who usually have a learning disability annual health check, 38% of people in Cohort 1 and 32% of people in Cohort 2 had had a check in 2021
Headline 3: Support has not returned to pre-pandemic levels – social care services

• Social care support now vs before the pandemic:
  • 20% in Cohort 1 and 48% in Cohort 2 are getting less service support (11% and 6% are getting more)
  • Support now means going at less and being online more

• The personal budgets of more than 30% of people are being used for services they are not currently getting

• For 36% in Cohort 1 and 42% in Cohort 2, the person or their family are paying for some services out of their own pockets
Headline 3: Support has not returned to pre-pandemic levels – social care services

• Biggest gaps between pre-pandemic and summer 2021:
  • Day services, community activities, contact with social workers, short breaks/respite, further education

• Consistent support all through the pandemic:
  • Personal assistants/support workers helping at home; going out of the house with personal assistants/support workers

• Social care services for people in Cohort 2 (people with greater support needs) are less likely to have returned to pre-pandemic levels
Headline 4: Lifting of restrictions generally means a more restricted life for some people

- A big and continuing issue for people with greater support needs, particularly people with Profound and Multiple Intellectual Disabilities (PMID)
  - 19% of people in Cohort 2 were still ‘shielding’ in summer 2021
  - For 55% of people in Cohort 2, continuing restrictions were reported to be having a negative impact on the person

- For 24% of people in Cohort 1 and 30% of people in Cohort 2 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

• 5% or fewer people reported that their life had gone back to normal
• At least three quarters of people reported that their life would not get back to normal until 2022 or later, if ever
• Over 80% of people in Cohort 1 and family members/support workers in Cohort 2 think that support workers should have to have the COVID-19 vaccination to work with the person
• People most commonly reported that reinstating public health measures (face masks, social distancing) and low local COVID-19 case rates would help them feel safe to go out
“I don’t even want to hope”

Building back better?

• 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?