

The impact of the COVID-19 pandemic on people with learning disabilities

KCL Learning Disability Services Series
14th June 2022

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- 1) People with learning disabilities and the COVID-19 pandemic – peaks and consequences
- 2) Trying to track the impact of the pandemic
- 3) What next?



1) People with learning disabilities and the COVID-19 pandemic – peaks and consequences



Coming into the pandemic...

- People with learning disabilities dying 15-20 years earlier than other people, with the gap not closing
- Pervasive socio-economic inequalities, throughout people 's lives, made worse by austerity
- Continuing evidence of institutional discrimination in specialist and mainstream health services



As the pandemic hit...

- Complete lack of pre-pandemic planning or even awareness of people with learning disabilities
 - No PPE
 - No testing
 - No guidance
 - No support for families
 - Withdrawal of social care services
 - 'Easement' of legal duties

VODG
@VODGmembership

From today's @BBCBreakfast - thanks to @chrishattoncedr for supporting @VODGmembership in collating data that highlights how #COVID19 is impacting disabled people and their services. Full story here: vodg.org.uk/news/new-data-...

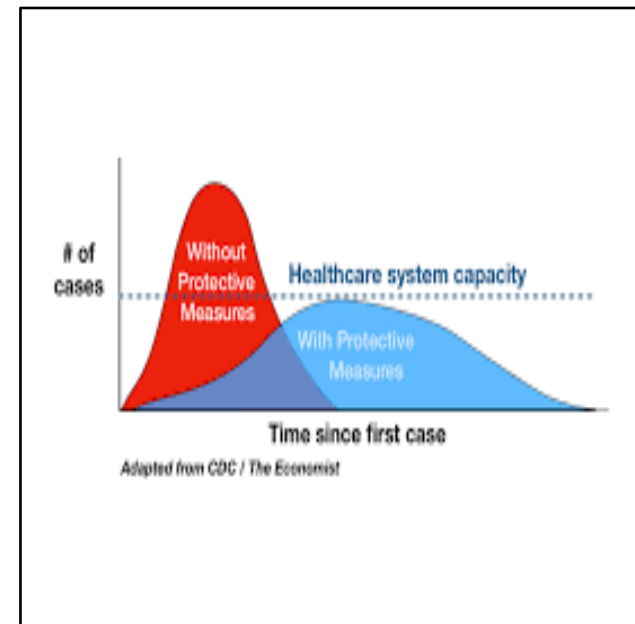


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7 Retweets 3 Quote Tweets 16 Likes

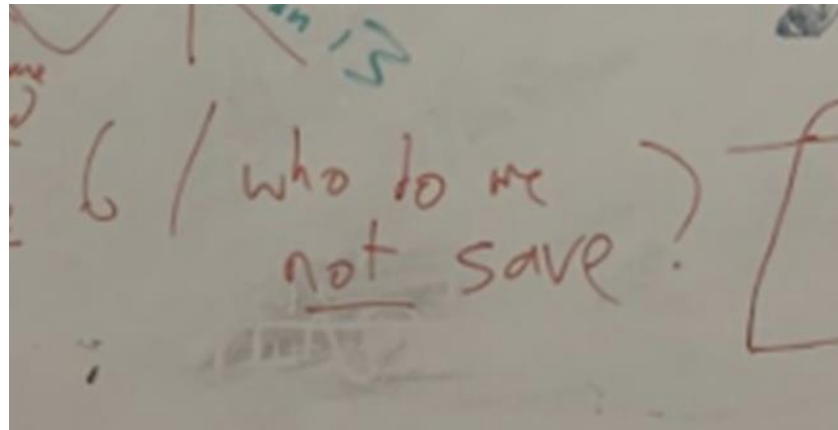
As the pandemic hit...

- COVID-19 risk viewed in terms of specific lists of medical ‘conditions’
 - ‘Underlying health conditions’
 - ‘The vulnerable’
 - Little consideration of multiple health conditions or social and economic conditions putting people at risk
- ‘Flattening the curve’
 - Implicit herd immunity strategy
 - Late introduction of public health protection measures, including lockdown



As the pandemic hit...

- 'Protect the NHS'
 - Health service priority was hospital capacity for treating and managing COVID-19
 - Diversion of health professionals and resources from other health services – ongoing therapies stopped
 - Institutional discrimination in health service responses to people with learning disabilities: DNARs and NICE guidelines



Who stepped into the void? Disabled people's organisations



Get help when you need it during the coronavirus outbreak

Contact



News: NEWS | Thirteen Venture Arts artists on show in the



Home About What We Do Support Us Events Lottery News Gallery Contact Us Fundraising Appeal

February 2022

HOME's big open, show across Greece

We are incredibly excited for our exhibition. Congrats to Bilal Khan, Daniele Horace Lindezey, Matthew Bell, and Rami Imtiaz who has also been our Gallery Exhibitor (pictured below).

Other resources that can help



14 FEB

Everybody Dance – Zoom (Monday night)

- 🕒 7:00 pm – 8:00 pm
- 📍 Online via Zoom

Join Dance Leader David and Dance Artist Millie for our new Everybody Dance sessions on Monday nights and dance your way to feeling better! If the booking form doesn't load, please click on this link: <http://bit.ly/Everybody-Dance-Mondays>



15 FEB

Everybody Dance – Zoom (Tuesday)

- 🕒 2:00 pm – 3:00 pm
- 📍 Online via Zoom

Join DanceSyndrome for our "Everybody Dance" classes on Zoom and dance your way to feeling better! If the booking form doesn't load, please click on this link: <http://bit.ly/Everybody-Dance-Tues1>



18 FEB

Friday Night Dance Party – Zoom

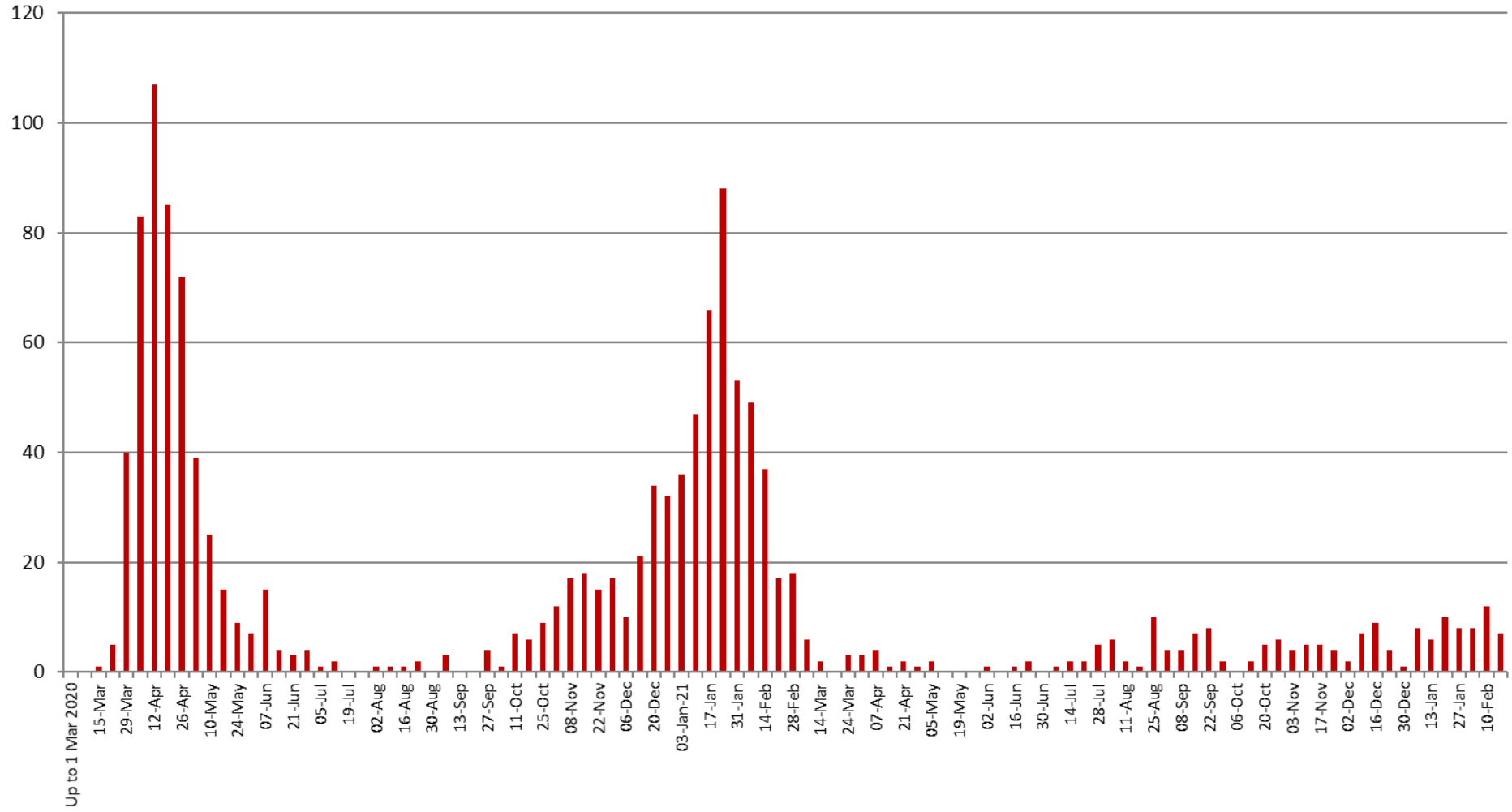
- 🕒 6:00 pm – 7:00 pm
- 📍 Online via Zoom

Kick start your weekend with a DanceSyndrome Friday Night Dance Party!... a fun filled inclusive dance workshop in which each week we'll explore a different decade of music to inspire us. If the booking form (below) doesn't load, please click on this link: <https://bit.ly/Fri-Night-Dance> If the booking form doesn't load properly below, please click on this link: <https://bit.ly/Fri-Night-Dance>

The consequences – infections and deaths

- In the first two peaks of the pandemic, people with learning disabilities were:
 - Twice as likely to get COVID-19 (Henderson et al, 2021, in press)
 - Between three and six times more likely to die of COVID-19 (Henderson et al, 2021; PHE, 2020; ONS, 2021)
 - More likely to die from COVID-19 at younger ages than other people
- This increased risk might be reducing over time and with vaccinations
- Living in a place with a lot of other people puts people with learning disabilities at higher risk from COVID-19 (PHE, 2020; ONS, 2021)
- Likely that over 2,700 people with learning disabilities in England have died of COVID-19 so far

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

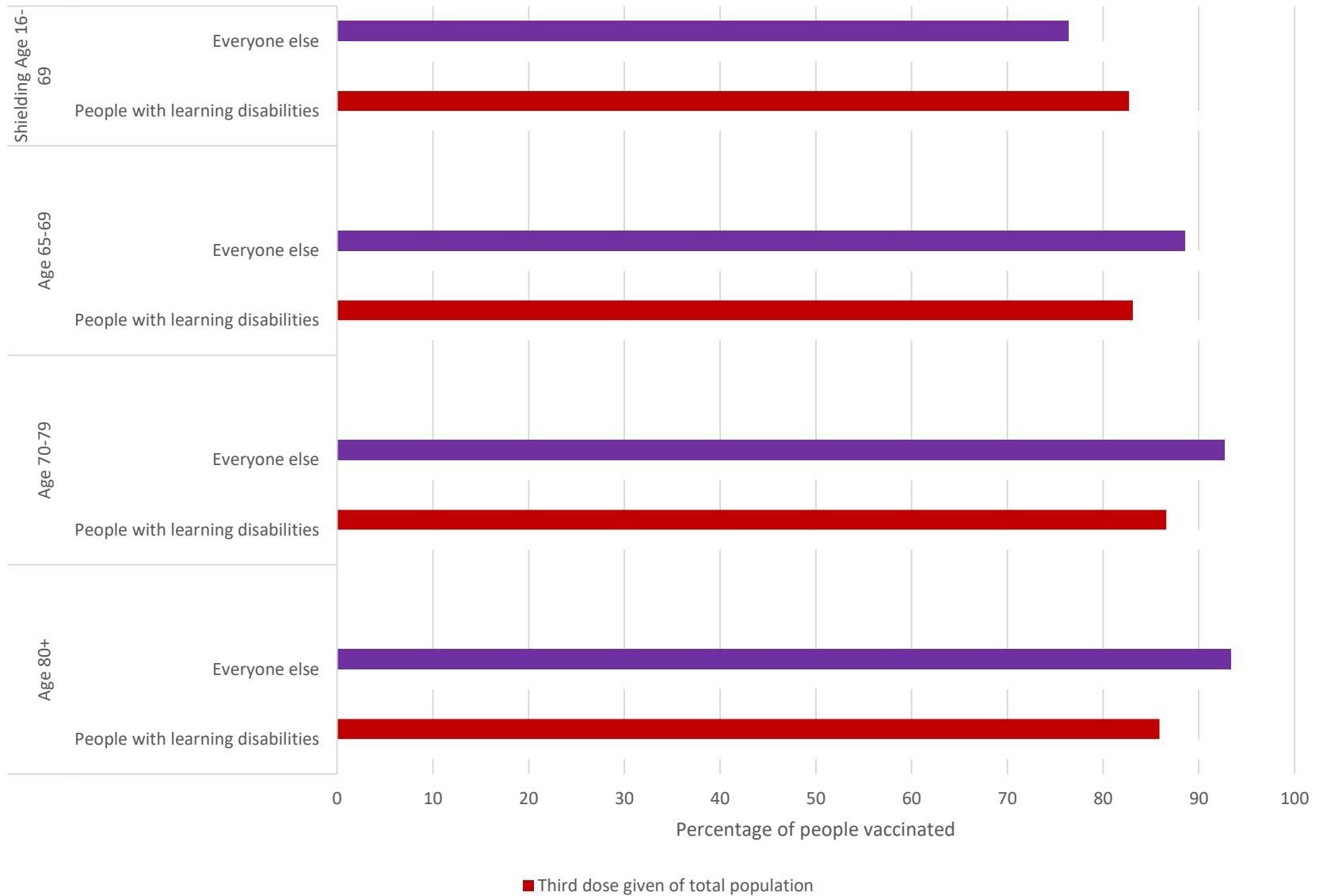


■ Deaths of people with learning disabilities and/or autistic people

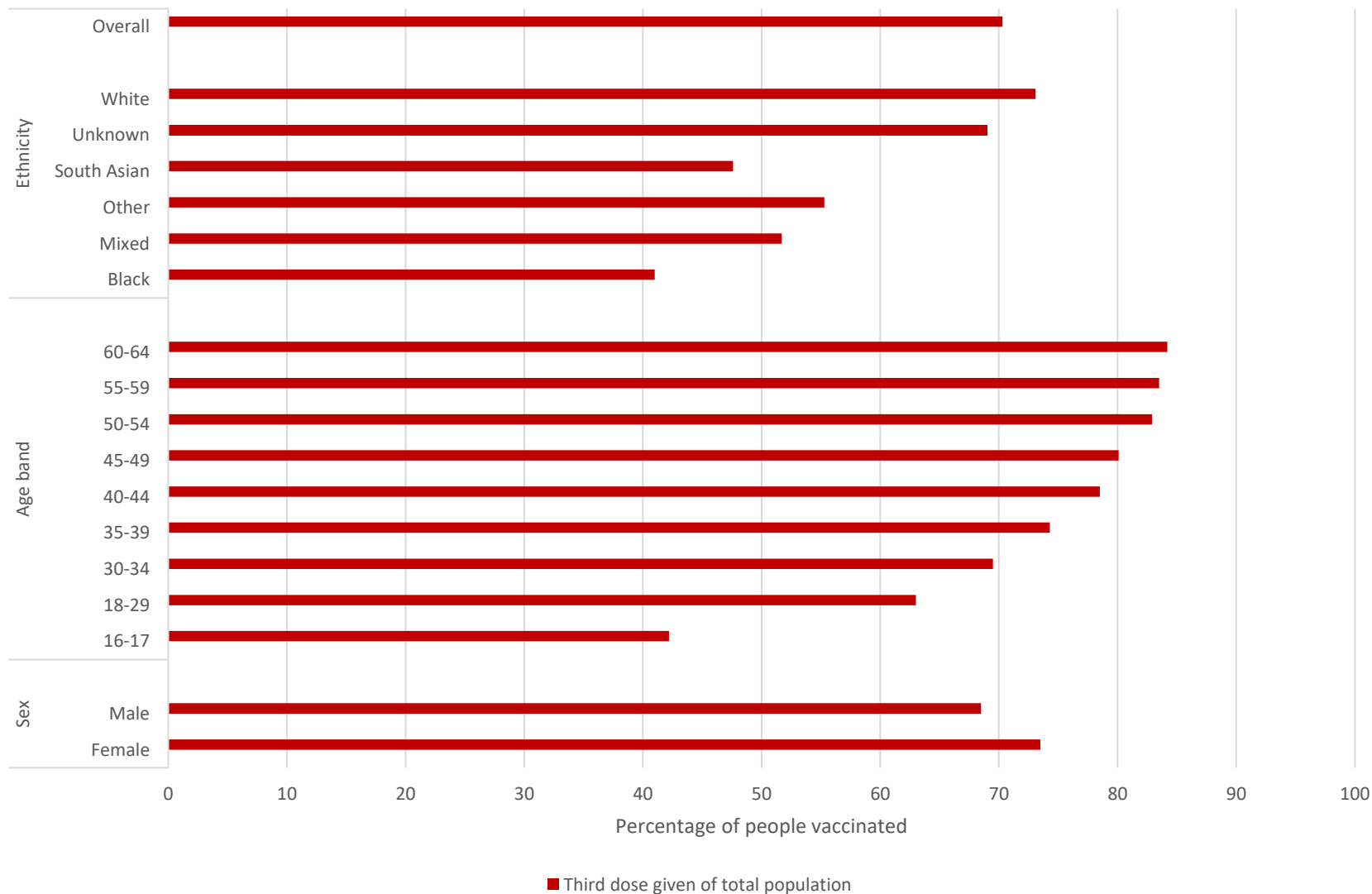
Vaccination: a relative success?

- COVID-19 vaccination rates with at least one dose now high (90% plus) for most groups of adults with learning disabilities
- COVID-19 booster vaccination rates around 80% for older and shielding adults with learning disabilities
 - Still lower for younger age groups and for people from minority ethnic communities (OpenSafely, 2022)
 - Vaccination for children and young people?
 - Fourth dose boosters?

Vaccination coverage (third dose) up to 20 April 2022 - England (OpenSafely weekly report)



Vaccination coverage (third dose) up to 20 April 2022 among adults with learning disabilities aged 16-64 - England (OpenSafely weekly report)

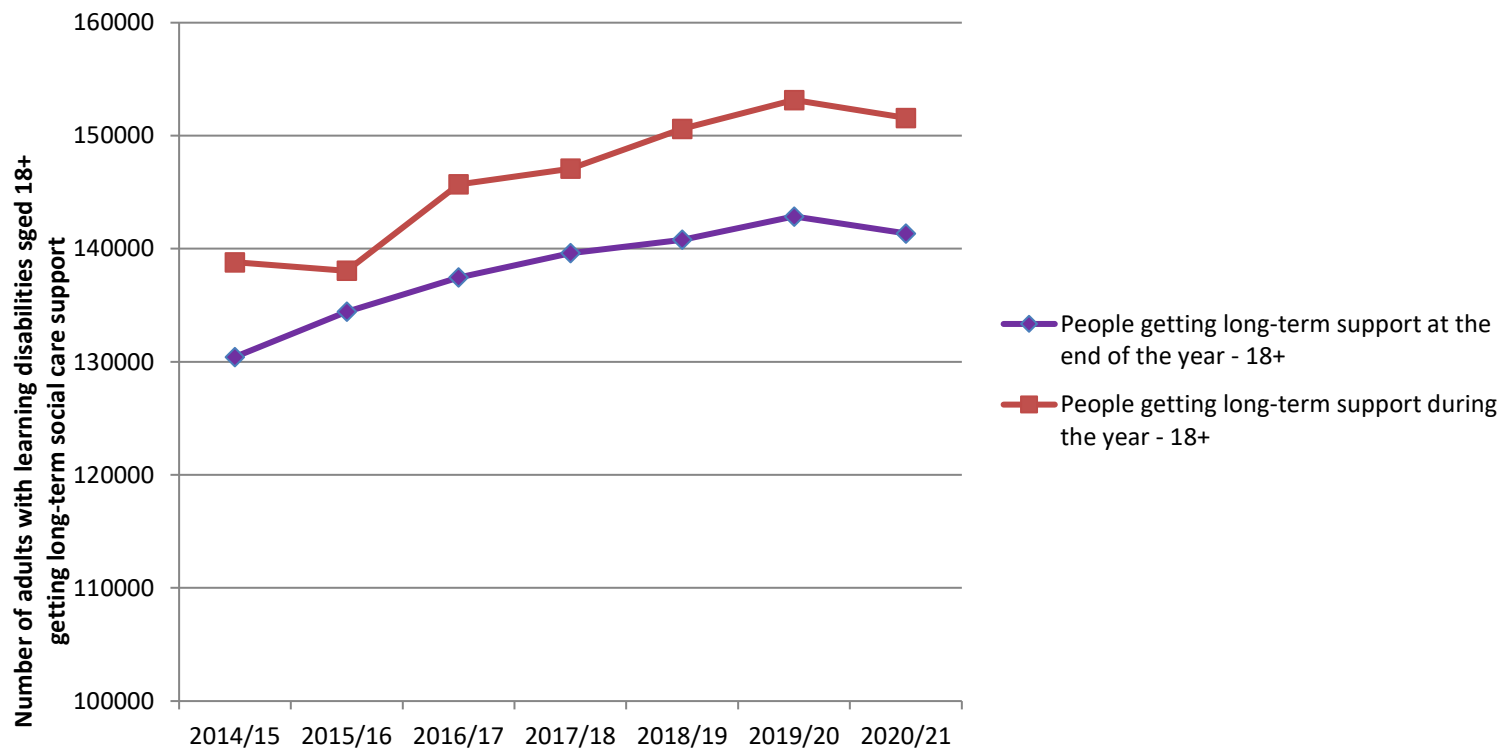


2) Trying to track the impact of the pandemic



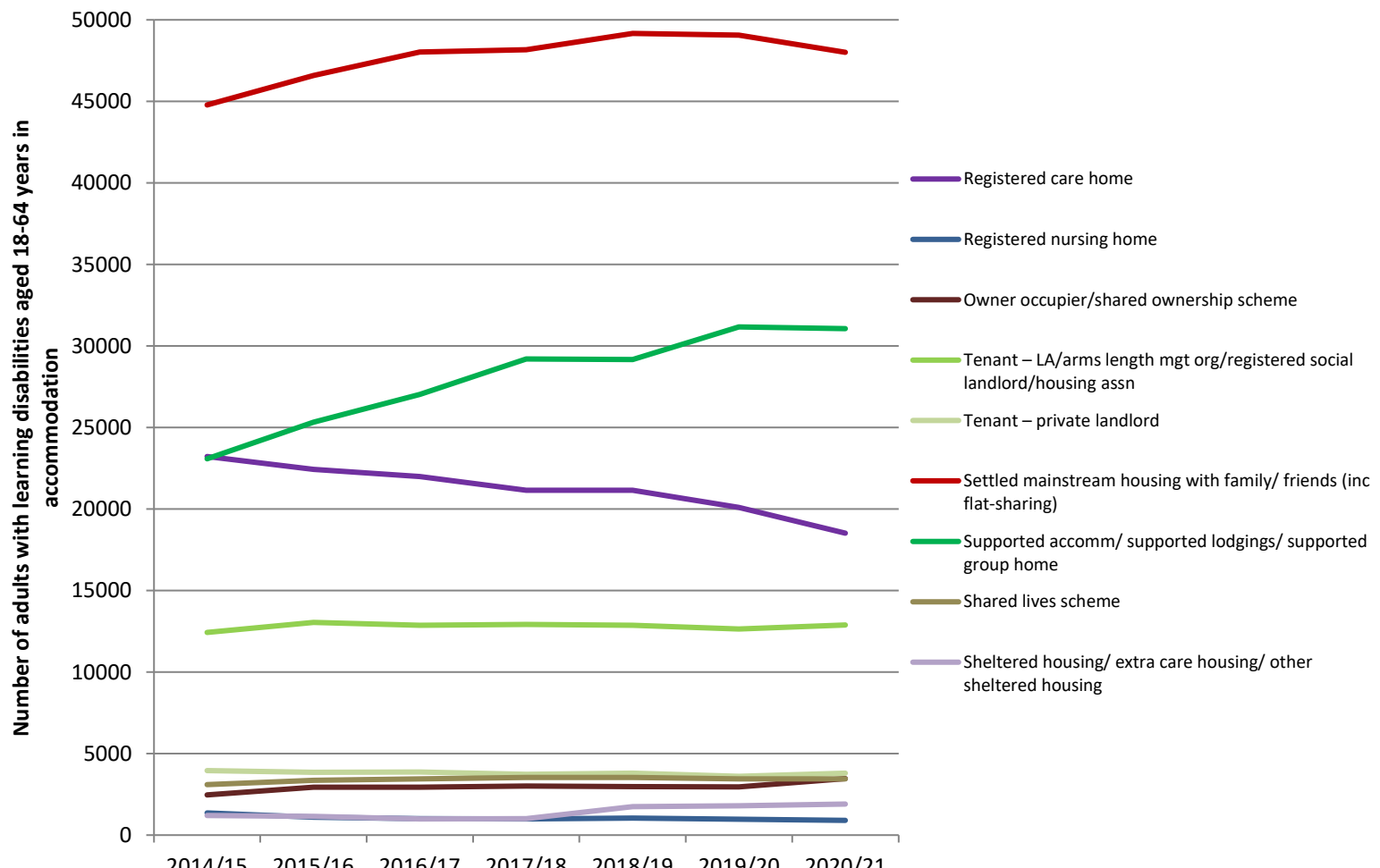
Tracking the impact of the pandemic – social care statistics

- 1,500 fewer adults with learning disabilities getting long-term social care in England at the end of March 2021 compared to the end of March 2020 (NHS Digital, 2021)



Tracking the impact of the pandemic – social care statistics

- 1,055 fewer adults with learning disabilities aged 18-64 in settled housing with family/friends in England in 2020/21 vs 2019/20 (NHS Digital, 2021)



Tracking the impact of the pandemic: The Coronavirus and people with learning disabilities project



<https://warwick.ac.uk/fac/soc/cedar/covid19-learningdisability>

The project



- Trying to track people's experiences, circumstances, and support throughout the pandemic
- Trying to make sure questions are relevant to policy-makers, groups of people with learning disabilities, family members, across the UK
- Trying to get information public quickly for multiple groups of people to use
- Project website <https://warwick.ac.uk/fac/soc/cedar/covid19-learningdisability>

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Co-Investigators: Prof David Abbott (University of Bristol), Dr Stephen Beyer (Cardiff University), Dr Jill Bradshaw (University of Kent), Dr Nick Gore (University of Kent), Prof Pauline Heslop (University of Bristol), Prof Andrew Jahoda (University of Glasgow), Anna Marriott (National Development Team for Inclusion), Prof Katrina Scior (UCL), Dr Laurence Taggart (Ulster University), Prof Stuart Todd (University of South Wales)

Partner organisations: All Wales People First, Learning Disability Wales, All Wales Forum of Parents and Carers of People with Learning Disabilities, Scottish Commission for Learning Disability, Promoting a More Inclusive Society (PAMIS), Positive Futures, Mencap Northern Ireland, Learning Disability England, PMLD Link, Positive Futures, CAN Northern Ireland, Families Involved in Northern Ireland (FINI).

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Disclaimer



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The Coronavirus and people with learning disabilities project



- Cohort 1 - Zoom/phone interviews with adults with learning disabilities (approx. 500 people at Wave 3)
- Cohort 2 - Online surveys for family members/support workers about adults with learning disabilities with greater needs who could not take part in an interview (approx. 300 people at Wave 3)
- People and families interviewed/surveyed 3 times:
 - Wave 1 - December 2020 - February 2021 (largely lockdown)
 - Wave 2 - April – May 2021 (restrictions easing)
 - Wave 3 - July – August 2021 (most restrictions removed)

People are doing their bit to keep themselves and others safe

- By July/August 2021
 - More than 9 out of 10 people had both doses of the COVID-19 vaccine, and would have a booster
 - People had been following the rules with lockdowns and public health protection measures (not going out; wearing facemasks; testing etc)
 - For at least half of people, family carers/support workers were using some form of PPE when in close contact



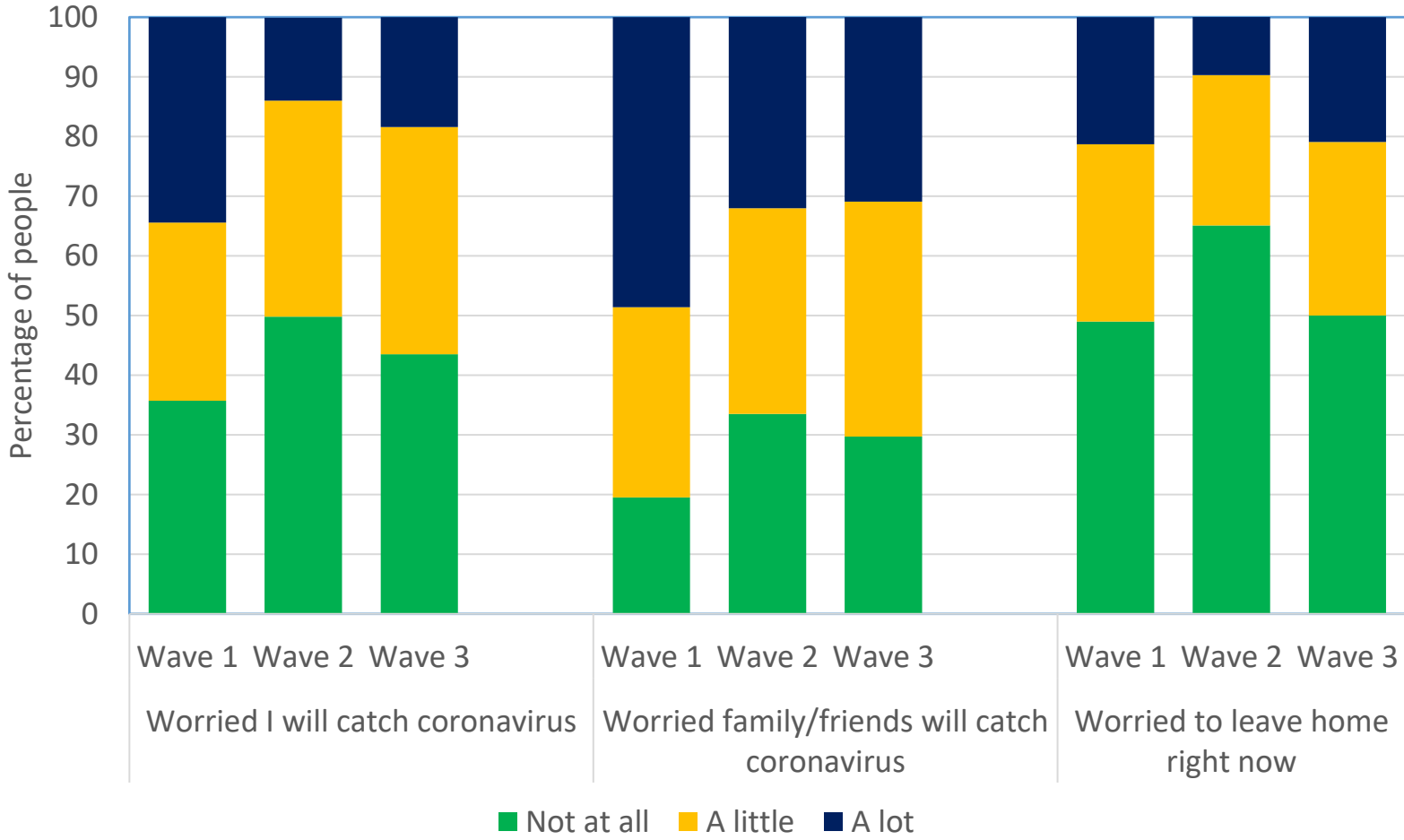
I asked a chemist how to do it [*A lateral flow test*]. I made a video of how to do it for people with learning disabilities to go on our website. It tickled the nose and you have a timer. It's easy.

People are paying a price for this

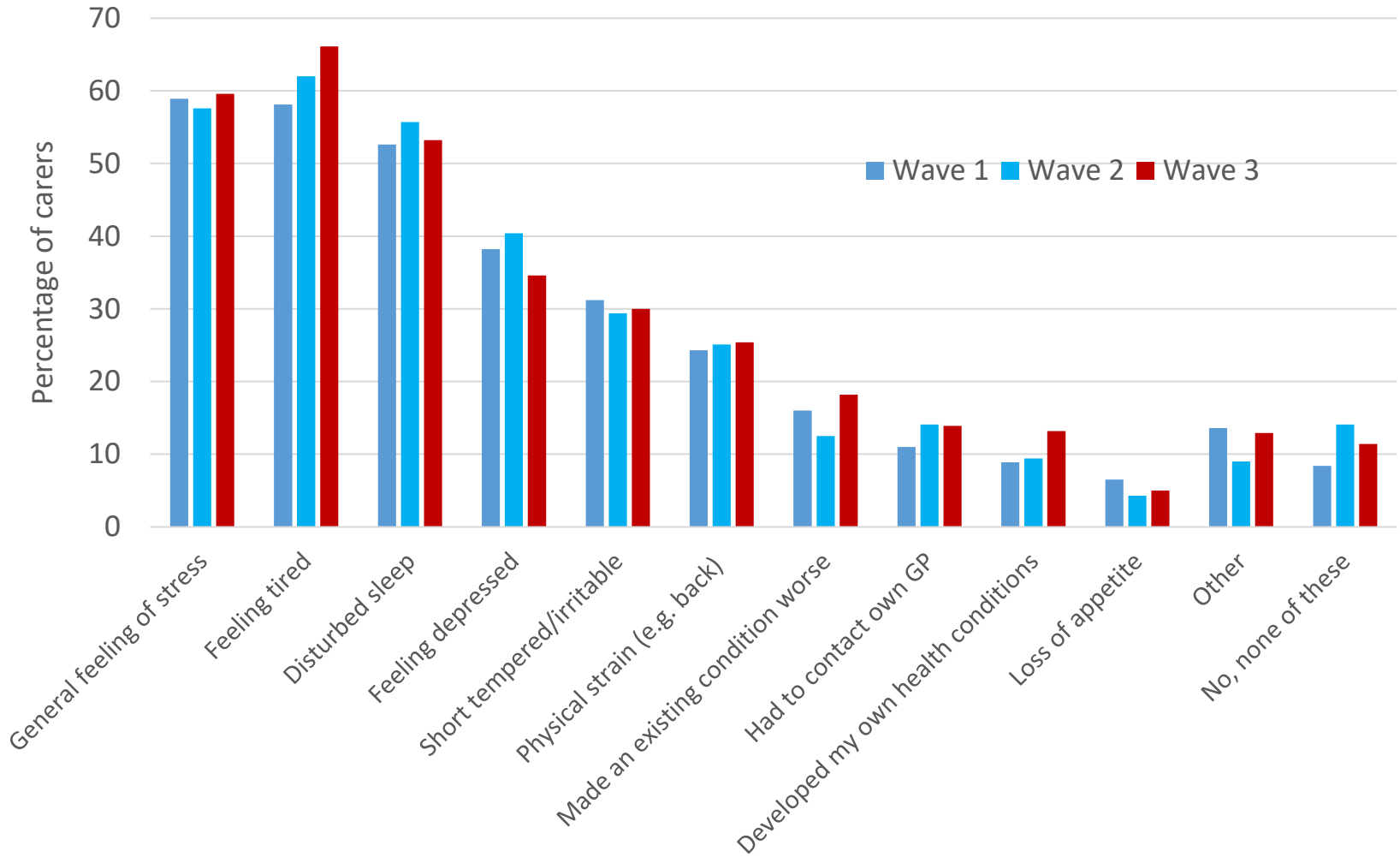
- By July/August 2021
 - Half of people were worried about leaving the house
 - Over 2 out of 10 people were often/always worried or anxious
 - At least 2 out of 10 people had had a new or worsening health problem in the last month
 - 2 out of 10 people with a paid job before the pandemic had lost their job
 - Over half of family carers/support workers reported general feelings of stress, tiredness, disturbed sleep



Worries about the pandemic – Cohort 1 (UK)



Effect of caring role on family/paid carers in last 4 weeks – Cohort 2 (UK)



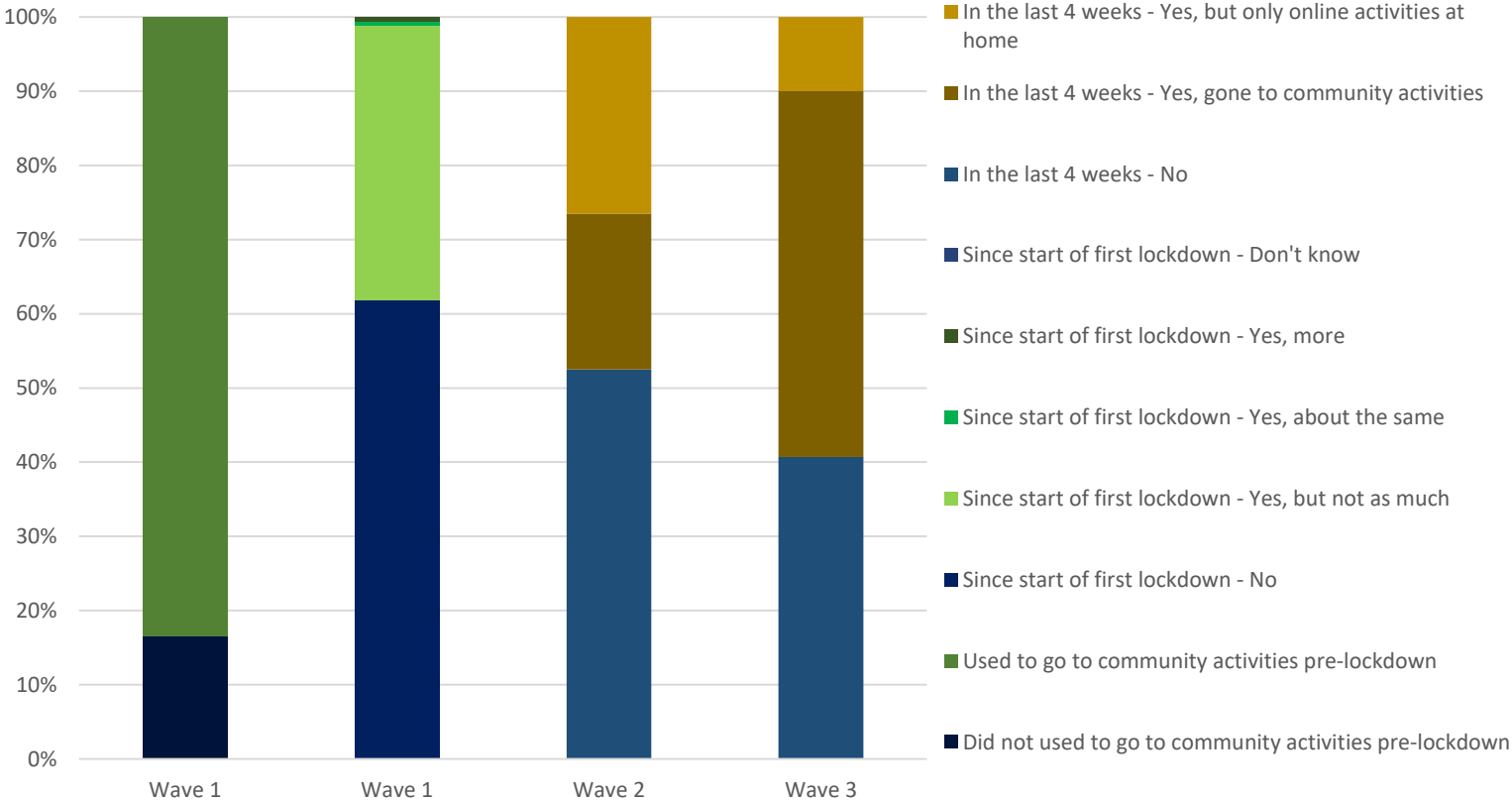
Service support has not gone back to normal

- By July/August 2021
 - Contact with health professionals (GP, annual health checks, therapists) and social care services was not back to the levels they were before the pandemic
 - Some service support had shifted towards online and away from face-to-face support
 - Support was returning more slowly for people with greater needs
 - Waiting list times for planned medical tests, hospital appointment or operations were increasing
 - For around 4 out of 10 people, the person or their family were paying for some services out of their own pockets



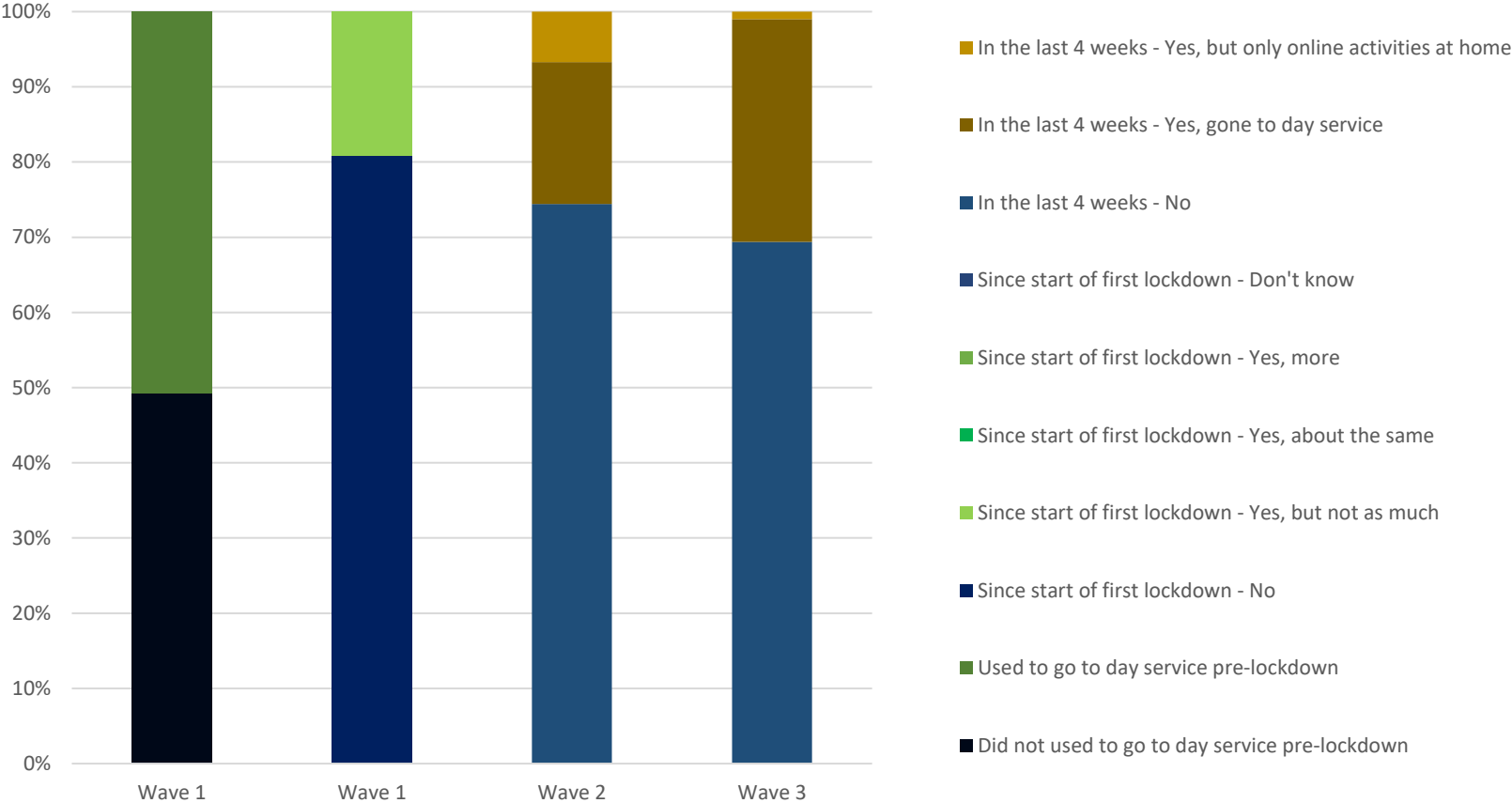
Have you been going to community activities? Cohort 1 (England)

Cohort 1 England - Have you been going to community activities?



Has the person you support/care for been going to a day service? Cohort 2 (England)

Cohort 2 England - Has the person you support/care for been going to a day service?



For some people, there have been some good things

- Getting online and connecting with people
- A more relaxed pace of life – not having to get up early and rush off somewhere
- Spending more time with people who are close
- Better contact with neighbours



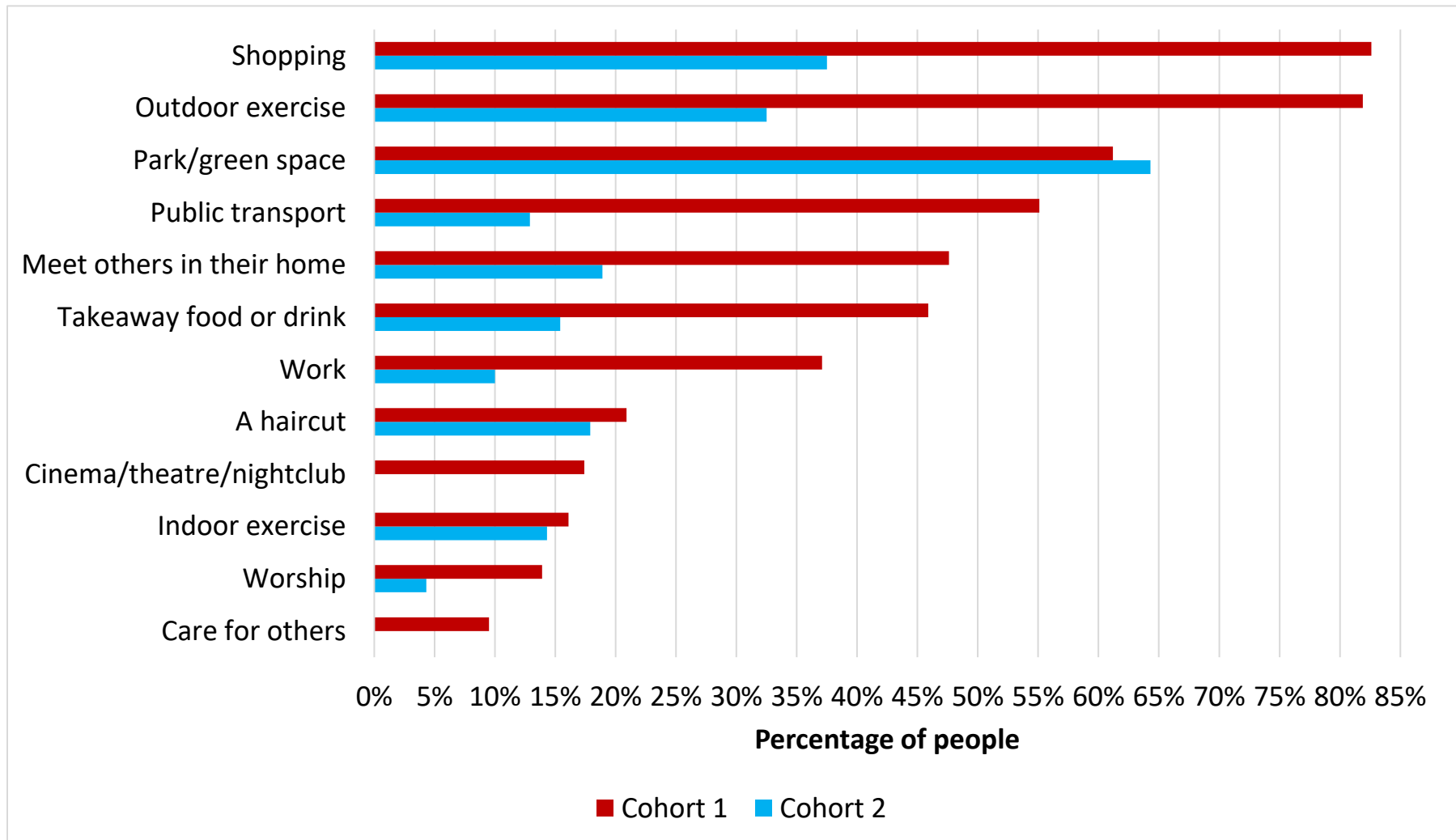
Because we all had to go through the same thing. So, we did things to support each other. You have to help people, you just can't help yourself, you have to help others.

Lifting of public health protections generally means a much 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 with greater needs were still 'shielding' in July/August 2021
 - For over half of people with greater needs, a continuing restricted life was having a negative impact on the person
 - No 'roadmap' to how things will get better
- Comparison – 13% of people considered to be clinically extremely vulnerable in England were still shielding in April 2022 (ONS, 2022)



Leaving the house in the last 7 days at Wave 3 - Cohort 1 vs Cohort 2 (UK)



The impact of COVID-19 is continuing

- By July/August 2021
 - 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 facemasks 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



What are you looking forward to when we can do more?

Kissing my girlfriend and being close, being back to work and going on transport and to the cinema and things like that

I don't even want to hope

Don't know - just stay in

Having a hug and being able to see us with no full PPE on. Being able to take him out to open spaces for walks and fresh air



3) What next?



Is the England/UK experience unusual?

- International scoping review (Taggart et al., 2021)
 - “Limited availability and access to basic public health prevention and protection measures
 - Imposing lockdowns on people with intellectual and developmental disabilities and their carers has significantly impacted upon the person’s behavioural presentation and/or mental health as well as the well-being of family carers
 - Closures of schools, education, day-care, respite, community activities, and employment
 - Compulsory covert DNR orders placed upon this population
 - Restrictions of access to acute hospitals and lifesaving equipment
 - Violations of the rights to life of people with intellectual and developmental disabilities”

Implications for policy - England

- Pathways Associates in NW England ran an online conference to discuss what should happen next
- Learning Disability England and PMLD Link identified policy priorities, using findings from the project
- Policy briefings for England produced
- Short films commissioned by self advocacy groups, family members and support staff

Implications for policy - England

- Links to policy briefings and short films collected here

<https://www.learningdisabilityengland.org.uk/welcome/work-with-members-and-partners/uk-covid-research/>

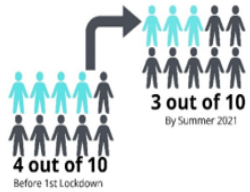
- Similar activities in each part of the UK

<https://warwick.ac.uk/fac/soc/cedar/covid19-learningdisability/results/policybriefing/>



1) Jobs and money

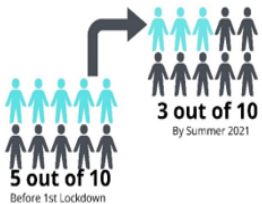
Group 1 - People with a paid job



Fewer people with learning disabilities have paid jobs now than they did before the pandemic.

Only very few people in Group 2 had a job before the pandemic but this also went down.

Group 1 - People with a volunteer role



People in Group 1 who did volunteering jobs went down from 5 out of 10 people before the first lockdown to 3 out of 10 people in summer 2021.



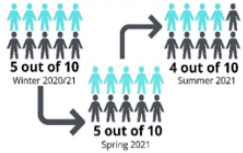
Ideas for Change

- There should be more jobs for people with learning disabilities.
- There should be more volunteering jobs available.
- It should be easier to work for just some of the time and not to have to worry about benefits.



2) Mental health and wellbeing

Group 1 - People lonely at least some of the time



Around half of the people in Group 1 were lonely at least some of the time each time we did the interviews.

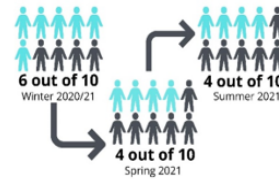


Some people with learning disabilities said that they had felt worried or anxious often or always during the pandemic.



Some people with learning disabilities in Group 1 said that they had felt sad or down often or always.

Amount of Carers feeling stressed



During the study, family members said that caring meant they felt tired and stressed.



Ideas for Change

- People with learning disabilities need more opportunities to meet other people.
- People need better advice about mental health.
- Families need more support.



3) Services



Day Centre

Before the pandemic 4 out of 10 people in Group 1 went to a day service. By summer 2021, it was only 3 out of 10.

Before the pandemic, 5 out of 10 people in Group 2 went to a day service. By summer 2021, it was only 3 out of 10.



Community Life

Before the pandemic, 8 out of 10 people in both groups went to community activities. By summer 2021, it was only 5 out of 10 for Group 1 and 3 out of 10 in Group 2.



The amount of people who had help from PAs or support workers went down during the pandemic.



Ideas for Change

- Not everyone was getting enough support before the pandemic. People should get more support now.
 - Services should change now as people might want different things than they did before the pandemic.
 - People should be asked if they want online or face to face services or both.
-

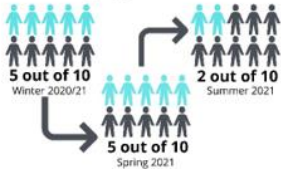


4) Health



During the study, only just over half of people in Group 1 rated their health as good.

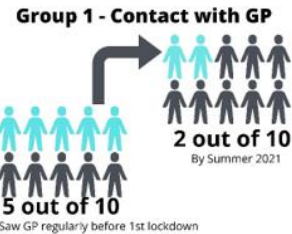
Group 2 - Good health rating of people they support/care for



In winter 2020/21 and spring 2021, five out of ten people in Group 2 said their health was good. In summer 2021, only 2 out of 10 people said their health was good.

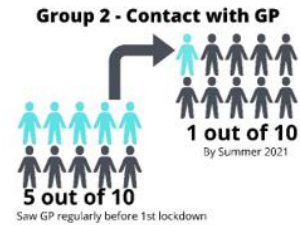


By summer 2021, 4 out of 10 of people with learning disabilities who said they usually had an annual health check had had one in 2021 (in person or by phone or video call).



Just over half of people in Group 1 and just under half of people in Group 2 said they used to see their GP regularly before the pandemic.

By summer 2021, less than two out of ten people in Group 1 and one out of ten people in Group 2 had seen their GP in person.



Ideas for Change



- Annual health checks should always be done and they should be done well.
- It needs to be easier to get an appointment at the doctors.
- People might not have gone to the doctor because of the pandemic so there needs to be more support now to make sure people can see who they need to see.



5) Using the Internet



Most people with learning disabilities in Group 1 had access to the internet. Fewer people in Group 2 had access to the internet where they live and access to a device to use the internet with.



People mostly used the internet for being with friends and family online.

By summer 2021, most people in Group 1 still enjoyed taking part in online activities.



Ideas for Change

- People need more support to keep learning digital skills
 - Support staff need digital skills training so they can help people
 - Everyone needs access to digital devices.
-

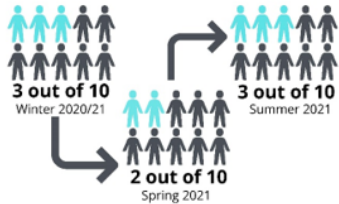


6) Information



Most people got information about changes to Coronavirus rules from the television.

Group 1 - People who did not find it easy to find good information about coronavirus



People with learning disabilities in Group 1 did not always find it easy to find good information about Coronavirus.

Carers finding accurate information about how COVID-19 affects them



Family members and paid carers said that it was difficult to find accurate information about how Coronavirus affects them.

Ideas for Change



- Television should carry on being a good way for people to find out information about Coronavirus.
- Important Government information should always be accessible.
- Families of people with the greatest support needs must not be forgotten when important information is shared.

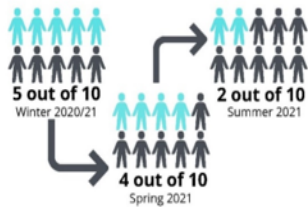


7) The experiences of people with greater support needs



People with profound and multiple learning disabilities were more likely than other people in Group 2 to get less support now than before the pandemic.

Group 2 - People who were shielding



Some people with learning disabilities were shielding throughout the study.

2 out of 10 people in Group 2 were still shielding in summer 2021.



Ideas for Change

- Support for families of people with PMLD should be urgently improved.
 - Services need to connect with people who are shielding to find out what they need.
-

Four questions from Pathways Associates

- What should services do for the many people and families who feel they have been forgotten and left behind through COVID-19?
- What should services do for people and families who are still shielding or stuck inside – what is the path to a better future for them?
- How can we build hope for ourselves?
- How can services rebuild trust?



Martin Stevens

