

# The experiences of people with intellectual disabilities in England and Scotland during COVID-19

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University  
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VIA VERITAS VITA



ICED  
International Centre  
for Evidence in Disability



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- Project funder
  - **UK Research and Innovation (UKRI)**
- Project outline
  - **70 people with disabilities and 28 disability organisations interviewed**
  - **Two rounds: April-June 2020 and February-April 2021**

# Background

- 1.5 million people with intellectual disabilities in the UK
- Scotland: 3x more likely to have severe symptoms; 2x more likely to die
- England: Number of deaths twice the rate of general population

- 24 participants with an intellectual disability
  - 13 adults
  - 6 caregivers of adults
  - 5 caregivers of children
- 12 key informants from organisations of and for people with disabilities
- Interviews conducted via Zoom or, where requested, email
- Key areas explored: work, education, leisure, social care, health and government response

# Results: COVID measures/information

- Information on the virus and measures was often inaccessible

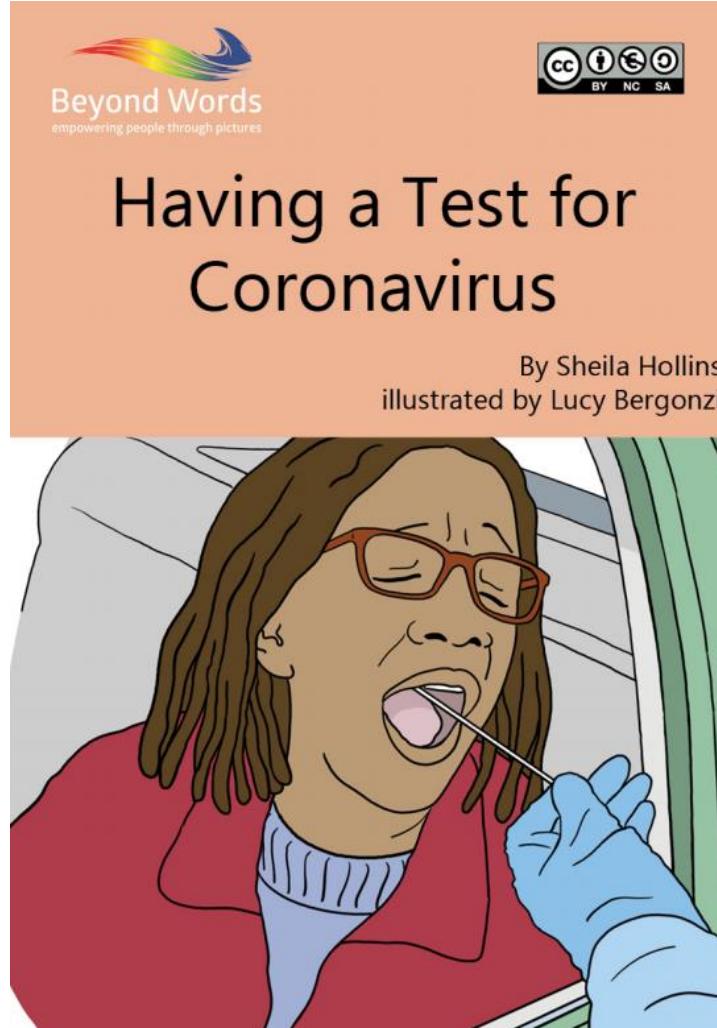
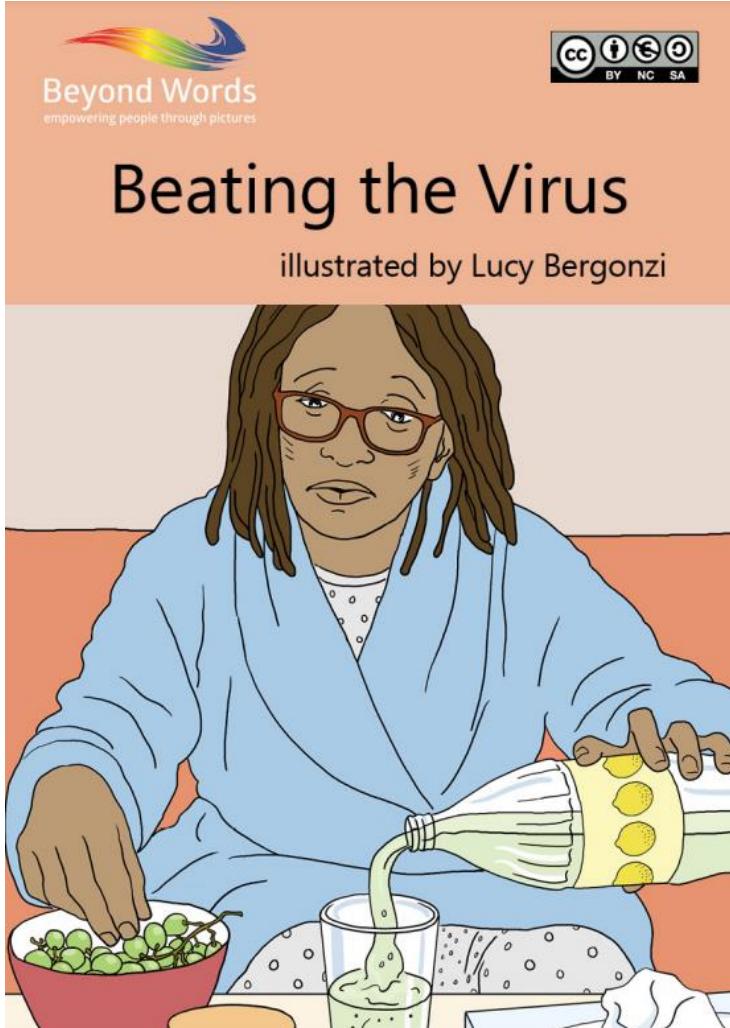
"R: They sent out forms. They're not in large print, and quite often they use giant words. Shouldn't they have made Easy Read versions for people?"

I: Have they provided any information for people with learning disabilities on COVID?

R: They sent forms to everybody. But I got the same form Angie [her friend] got... It would have been better if they did, like, Easy Read versions and stuff."

(Susan, Scotland)

# Results: COVID measures/information



# Results: Disrupted routines and lost activities

- Participants missing their routines and activities
  - At a loss without routine
  - Lost independence and confidence
  - Isolated
  - Feeling useless
- Third sector have stepped in online
  - BUT digital exclusion is an issue

# Results: Social care and reversion to family

- Social care packages removed
  - Virtually overnight for many
  - No consultation

"[name of provider], who provide most of Maurice's care, phoned me up and said:

'Obviously this virus is getting more serious, so we've had to prioritise the support we provide, and in two days, Maurice's care will be ceasing altogether, and it's over to you. You need to now cover all of it.'

So as you can imagine, that was a surprise."

(Abby caregiver of Maurice, Scotland)

# Results: Cuts to funding

- Funding is being re-assessed
  - Many worried that funding will be cut in the future
  - Substantiated by key informants

# Results: COVID policy/government response

- Ultimately, people with intellectual disabilities feel forgotten about
  - Not seen in society and easy for government to forget about them

"When I watched them (news briefings) with mum - religiously as well, because we needed to know what was happening - every time we watched them, I never once heard the word learning disability. We were completely forgotten about.

\*voice breaking\* Do they ever think about people like us? .... We're missing out on our social care, and our healthcare. Because of the coronavirus, because of shielding. But could they care less? No. Do they care? No."

(Kelly, England)

# Summary

- Initial government response inadequate
- People with intellectual disabilities were forgotten
- Need to build back better