

International group with an interest in mortality of people with intellectual and developmental disabilities (v4 – updated 8.4.2020)

Below is a collation of information and resources about COVID19, submitted by members of an international group of professionals, policy makers and academics with an interest in mortality of people with intellectual and developmental disabilities.

Activism

National collaborations in the Netherlands to jointly answer Corona-related questions from care organizations for people with ID in a CoOVID19 Rapid Response (Dutch Association of Academic Collaborative Centers Intellectual Disabilities). The aim is to assist health care organizations in rapidly answering their questions related to corona and its consequences for the care and support for people with an intellectual disability. Scientists affiliated to all Dutch Academic Collaborative Centers jointly collect relevant scientific knowledge from the (inter)national literature. All questions and answers, including source evidence that will be drawn upon, will be posted in both Dutch and English on the website of the Dutch Association of the Academic Collaborative Centers Intellectual Disabilities. They are more than willing to add information from abroad.

Contact Petri Embregts

<https://www.academischewerkplaatsen-vb.nl/knowledge-questions-covid-19/>

Data analysis

(Maarten Cuypers, and Esther Bakker van Gijssel with colleagues, Netherlands) Has started a national prospective registry for Covid19 suspected and confirmed cases among people with ID in The Netherlands. It is financed by the Ministry of Health as an initiative of the academic collaborative 'Stronger on your own feet'. Medical specialists for people with intellectual disabilities are asked to register all corona related care and disease progression. We started to recruit care providers to enter data in our system on 24.3.2020.

For more information see:

<https://www.sterkeropeigenbenen.nl/corona>

(Pauline Heslop, England) Learning Disabilities Mortality Review (LeDeR) programme. The programme receives notification of all deaths associated with COVID19 of people with ID. At notification core details are collected. Each death is then fully reviewed and further information is available subsequent to that. www.bristol.ac.uk/sps/leder

(Helen Leonard, Australia) Institute is encouraging of doing COVID-19 research but not sure whether they could get access to the data soon enough.

(Mary McCarron) As part of IDS TILDA they are including questions regarding COVID 19 in the end of life sections.

(Yona Lunskey, Canada) The government might be tracking information within each province for people who receive funded services from the developmental disabilities sectors.

Questions for future data analysis

It might be helpful to consider common questions across the countries to enable us compare deaths of people from COVID19.

Concerns in Spain about people with IDD living in residential facilities. Can we find out more about deaths in residential facilities?

Ethics/equality

Alabama State - Criteria for mechanical ventilator triage following proclamation of mass-casualty respiratory emergency (see p.8).

<http://www.adph.org/CEP/assets/VENTTRIAGE.pdf?referringSource=articleShare>

Nursing Times: Avoid frailty score in Covid-19 guidance when assessing LD patients

<https://www.nursingtimes.net/news/policies-and-guidance/avoid-frailty-score-in-covid-19-guidance-when-assessing-ld-patients-24-03-2020/>

Information/news

Article in Irish Health.com about **people with ID being a vulnerable group re COVID19**

<http://www.irishhealth.com/article.html?id=27072>

New York Times opinion piece by Ari Ne'eman '**I Will Not Apologize for My Needs**'

<https://www.nytimes.com/2020/03/23/opinion/coronavirus-ventilators-triage-disability.html>

Information about the first death in Louisiana – a man with ID with ‘a lot more living to do’.

https://www.nola.com/news/coronavirus/article_43453e10-6708-11ea-bb84-d7e8951022df.html?fbclid=IwAR018qQyP3qJ0NbhFz-vuTzReBjYlv5ZnxnPh0QnonY7B8OZtlEdeOZFw

Saba Salman. **My sister has a learning disability and I can’t visit her because of coronavirus.**

<https://www.theguardian.com/society/2020/mar/24/my-sister-learning-disability-cant-visit-coronavirus>

Policy

Guidance for people who are preparing to enter health care and deal with triage protocols

This is specifically addressing weight discrimination, but provides good structure content, and examples which may be useful.

#NoBodyIsDisposable Know Your Rights Guide to Surviving COVID-19 Triage Protocols

<https://tinyurl.com/covidknowyourrights>

NHS England. Responding to COVID-19: Mental Health, Learning Disabilities and Autism

<https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/covid-19-mh-lh-autism-cell-update-number-1-15-march-2020.pdf>

NHS England – Guidance for NHS staff on supporting people with learning disabilities

https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/C0031_Specialty-guide_LD-and-coronavirus-v1_-24-March.pdf

Center of Research Excellence in Health and Disability, Australia

A message about people with disability and the covid-19 response

<https://credh.org.au/news-events/covid-19-and-people-with-disabilities/>

All the following available from (and already shared by) Julian Trollor

3DN, in association with CID, Inclusion Australia and AADDM, is calling for concerted action to ensure the right to access to COVID-19 screening, prevention and health care for people with intellectual and developmental disabilities. You can help by viewing and endorsing the Statement here: <https://3dn.unsw.edu.au/news/endorse-our-position-statement-covid-19>

UNSW, Sydney Australia. Access to covid-19 prevention, screening and treatment for people with intellectual or developmental disability.

UNSW, Sydney Australia. Position statement on access to covid-19 prevention, screening and treatment of people with intellectual or developmental disability
https://unsw.au1.qualtrics.com/jfe/form/SV_a3LKIXK0A19N045

UNSW, Sydney Australia. Letter expressing concern about Version 1 of the COVID-19 Guidelines released on 17/03/2020 by the Australian and New Zealand Intensive Care Society

UNSW, Sydney Australia. Letter 2 about Version 1 of the COVID-19 Guidelines released on 17/03/2020 by the Australian and New Zealand Intensive Care Society

COVID-19 and Disability: Recommendations to the Canadian Government from Disability Related Organizations in Canada – March 24, 2020

Endorsed by several national and provincial organizations.

<https://archdisabilitylaw.ca/> (scroll to bottom of page for the document)

Ireland - a very positive announcement on 25.3.2020 that people with ID will come under the **priority groups for testing**.

Practice

Project ECHO AIHPC Webinars for Intellectual Disability Services

All Ireland Institute of Hospice and Palliative Care is collaborating with the Trinity Centre for Ageing and Intellectual Disability and The Daughters of Charity Disability Support Service, St Francis Hospice, Dublin, and Tallaght University Hospital to deliver a Project ECHO AIHPC Webinars for Intellectual Disability Services to provide information and guidance to Intellectual Disability Services during the COVID-19 outbreak.

The presentations and resources from previous Project ECHO AIHPC Webinars for Intellectual Disability Services can be viewed at:

<http://www.professionalpalliativehub.com/covid-19/project-echo-aiihpc-webinars-intellectual-disability-services>

<https://www.tcd.ie/tcaid/about/webinars.php>

Previous webinars:

Tuesday 7 April at 11am - Dr Regina McQuillan, Palliative Medicine Consultant and Medical Director, St. Francis Hospice - Advance Care Planning & Anticipatory Prescribing during a Crisis.

Research evidence

Evidence Aid. Summaries of relevant research about COVID19 which are available as soon as each is ready.

<https://www.evidenceaid.org/coronavirus-covid-19-evidence-collection/>

Resources

Books Beyond Words – Beating the virus

A short wordless story, that will help people to understand what to do if you have Coronavirus and how to keep yourself and those who you care about safe. The story also shows how to safely help others who may be self-isolating.

Supplementary text at the end of the story gives information on where people can seek help if they are unwell and signposts to other useful resources.

Currently in black and white and free to those who need the resource.

<https://booksbeyondwords.co.uk/downloads-shop/beating-the-virus>

NHS. Supporting Neurodiverse Children In Challenging Times Such As During Self-Isolation – video

<https://www.youtube.com/watch?v=dXPtqmHKNoE&feature=youtu.be>

Learning Disability England

A collection of resources, many of which are in easy read

<https://www.learningdisabilityengland.org.uk/what-we-do/keeping-informed-and-in-touch-during-coronavirus/>

Inclusion Europe. Information about COVID19 and social distancing (easy read and multiple languages)

<https://www.inclusion-europe.eu/coronavirus-pandemic/#1584977061628-16fcec00-a699>

Learning Disability Senate, England

A collection of resources for families, and resources for people with intellectual disabilities

<https://www.bild.org.uk/ldsenate/>

COVID-19 toolkit. (Wisconsin, Canada)

<https://wi-bpdd.org/wp-content/uploads/2020/03/Wisconsin-COVID-19-Resource-Toolkit-numbered-1.pdf>

This is an organized and clear information directed specifically at people to help them focus on their own needs to stay healthy and safe, as well as how to make contact with people if they need support. It provides information specific to Wisconsin but could easily be adapted.

Learning Disability Wales – collection of resources (including easy read information and videos) about Coronavirus

https://www.ldw.org.uk/project/coronavirus/?utm_source=Keep+up+to+date&utm_campaign=bc8b7061f2-EMAIL+CAMPAIGN+2018+06+25+01+01+COPY+01&utm_medium=email&utm_term=0_fb73837fdc-bc8b7061f2-114528261

Inclusion North. Information about Coronavirus (COVID-19) (easy read)

<https://inclusionnorth.org/wp-content/uploads/2020/02/coronavirus-update-24.3.2020.pdf>

Mencap. Information about coronavirus (easy read)

<https://www.mencap.org.uk/sites/default/files/2020-03/Information%20about%20Coronavirus%20SrS1.pdf>

Health Care Access Research and Developmental Disabilities. How to stay safe, well and connected

<https://www.hcarddcovid.com/info> (updated web link)

National Alliance for Direct Support Professionals guidance. The role of Direct Support Professionals (DSPs) and Coronavirus.

Information about COVID-19 for direct support workers, particularly those for people with IDD. This video provides clear information about the virus and measures that DSPs should be taking to prevent spread. https://www.youtube.com/watch?v=ud4Q4e_hcuw&feature=youtu.be&fbclid=IwAR0nAIWDmDF3ac8SBuQQ_V8az4GbNNOqcf3iZgYLAvlkXuKyELgZ7bz7Bw

The Center for START Services at the University of New Hampshire Institute on Disability/UCED.

This webpage includes some useful links to resources that are specific to supporting people with mental health support needs and IDD.

<https://www.centerforstartservices.org/covid-19-resources>

The Eden Alternative. Combating feelings of social isolation and helplessness

Resource page on strategies to combat feelings of social isolation and helplessness. This is focused on supports for elders but provides some resources that could be relevant for many people who are seeking help to craft new ways of living for people with IDD.

<https://www.pioneernetwork.net/wp-content/uploads/2020/03/Resources-from-The-Eden-Alternative.pdf>

Green Mountain self-advocates

Plain Language Booklets on COVID-19 (English and Spanish)

<http://www.gmsavt.org/>

WHO. Parenting in the time of COVID-19

To help parents interact constructively with their children during this time of confinement, these six one-page tips for parents cover planning one-on-one time, staying positive, creating a daily routine, avoiding bad behaviour, managing stress, and talking about COVID-19. Not specifically aimed at parents of children with ID, but may be relevant.

<https://www.who.int/emergencies/diseases/novel-coronavirus-2019/advice-for-public/healthy-parenting>

British Medical Association, Care Quality Commission and Royal College of General Practitioners.

Joint statement on advance care planning

<https://content.govdelivery.com/accounts/UKCQC/bulletins/283e565>

RADiANT Guidance documents

1. People with intellectual disability and mental health/behavioural problems: guidance on COVID-19 for in-patient psychiatric settings
2. People with intellectual disability and mental health/behavioural problems: guidance on COVID-19 for community settings

Both are available at: <http://radiant.nhs.uk/>