



From the IIMHL and IIDL Update List

COVID-19: Country Resources for Disability

Issue 15 - 13 August 2020

Jennifer Johnson, Ruby Moore, Valerie Bradley (United States) and
Kenneth Fleming, Charlie McMillan (Scotland)

Introduction

This special edition of Update features a second in depth look at how some IIDL member countries are responding to COVID-19, including national strategies and coordinating mechanisms, surveys and data, interfaces with health/mental health, practical resources and systemic reflections on progress and lessons learned so far.

The Sponsoring Countries Leadership Group of IIDL is planning a series of zoom events focussing on the theme – “Lifting the veil on COVID-19” and additional resources will become available for IIDL and IIMHL members in coming months.

Eddie Bartnik
Chair- Sponsoring Countries Leadership Group
International Initiative for Disability Leadership

United States

Centers for Disease Control and Prevention (CDC) Guidance

- [Guidance for people who are at higher risk for severe illness](#). Based on currently available information and clinical expertise, older adults and people of any age who have serious underlying medical conditions might be at higher risk for severe illness from COVID-19.
- [Guidance for older adults](#) about their potential risks during the pandemic, symptoms, developing a care plan, and more.
- [Guidance for people with disabilities](#) - addresses potential risks during the pandemic, how people with disabilities can protect themselves, and how to prepare.
 - [Guidance for people with developmental and behavioral disorders](#)
- [Caring for people with developmental and behavioural disorders](#)
- [Guidance for caregivers of people living with dementia](#)
- [Guidance for direct service providers](#)

- [Guidance for group homes for people with disabilities](#)

Department of Health and Human Services (HHS) Office of Civil Rights

- On March 28, the HHS Office for Civil Rights published [OCR Bulletin: Civil Rights, HIPAA, and the Coronavirus Disease 2019 \(COVID-19\)](#) to ensure that entities covered by civil rights authorities keep in mind their obligations under laws and regulations that prohibit discrimination on the basis of race, color, national origin, disability, age, sex, and exercise of conscience and religion in HHS-funded programs.
- The bulletin states that, "...persons with disabilities should not be denied medical care on the basis of stereotypes, assessments of quality of life, or judgments about a person's relative "worth" based on the presence or absence of disabilities or age. Decisions by covered entities concerning whether an individual is a candidate for treatment should be based on an individualized assessment of the patient and his or her circumstances, based on the best available objective medical evidence."
- A fact sheet for health care professionals titled [Safeguard Against Disability Discrimination During COVID-19](#) is available from the [Center for Dignity in Healthcare for People with Disabilities](#). A second [Fact Sheet](#) describes the rights of people with disabilities and self-advocacy tips when receiving medical care.

National Disability Rights Network (NDRN)

The National Disability Rights Network has created a [new video series](#) on the rights of people with disabilities during the COVID-19 pandemic and what to do if they are violated. The series includes:

- [Transportation Rights](#)
- [Housing Rights](#)
- [Healthcare Rights: The Effects of COVID-19 on the African American Community](#)
- [Stop The Spread in Jails & Prisons](#)
- [Indian Health Services & Medical Rationing](#)
- [Domestic Violence: The Right to Be Safe at Home](#)

As part of the Disability Awareness and Sensitivity in Healthcare (DASH) initiative, the University of Miami's Mailman Center for Child Development has [created a rapid response team training for triage team members](#) who are faced with making resource allocation decisions during shortages (e.g. ventilators, etc.). This brief training details how to prevent discrimination against people with disabilities during a public health emergency. It covers actions that triage team members and institutions can take to protect patients with disabilities, and it reviews tips for effective communication and the provision of accommodations. While this training is intended for members of triage teams who will be involved in making resource allocation decisions, others may also benefit from reviewing this content.

Intellectual Disability/Developmental Disability Resources

- [Fact sheet](#) from the Center for Dignity in Healthcare for People with Disabilities that describes the rights of people with disabilities and self-advocacy tips when receiving medical care, particularly during COVID-19
- The ACL-funded Self-Advocacy Resource and Technical Assistance Center (SARTAC) and [Green Mountain Self-Advocates](#) have created a series of plain language resources for people with developmental disabilities:
 - Information on COVID-19: Available in [English](#) and [Spanish](#)
 - [Tips for working with direct service providers/support staff during COVID-19](#)
 - [Words to Know About the Coronavirus](#)
- The Washington State Developmental Disabilities Council worked with self-advocate Ivanova Smith to create “What in the World is Going On? Plain talk for Pandemic Times”
 - [Booklet \(PDF\)](#)
 - [YouTube Video](#)
 - [Written Transcript](#)
- The Michigan Developmental Disabilities Institute at Wayne State University has compiled [self-care resources](#) addressing physical, mental, emotional, and spiritual well-being
- University of North Carolina: [Supporting Individuals with Autism Through Uncertain Time](#)
- People First Wisconsin has videos with [fun things to do online](#) and [tips to stay healthy](#) during the coronavirus pandemic
- The [California State Council on Developmental Disabilities](#) has fact sheets for people with disabilities, including:
 - [Top Questions from Self-Advocates \(Spanish\)](#)
 - [Top Questions from Family Advocates \(Spanish\)](#)
 - [CDD Phone Tree Tips \(Spanish\)](#)
 - [How to Stay Healthy from COVID-19 \(Spanish\)](#)
 - [Ideas for Activities While Sheltering in Place \(Spanish\)](#)
 - [10 Tips to Support Someone During Times of Change \(Spanish\)](#)

Person Centred Planning

ACL's National Center on Advancing Person-Centered Practices and Systems has developed a [Health Care Person-Centered Profile](#) to assist people with disabilities, older adults, and others to communicate their needs and preferences with hospital and other health care staff. During the COVID-19 pandemic, people with communication, comprehension, and behavioral challenges may face the possibility of a hospital visit without significant others or usual supporters present. To address the heightened challenges this poses, a group of experts in person-centered planning developed a tool that people, and their families and caregivers can fill out and share with medical staff upon hospital intake or care site transfer.

The tool has two pages: a Health Care Information Sheet for capturing brief and vital information about the person's health status and a Health Care Person-Centered Profile for describing who the person is, what is most important to the person, and

how best to provide support—vital information that can help medical staff provide more tailored and person-centered care.

The Health Care Information Sheet also has a section for detailed contact information to help medical staff reach a person's emergency contact or legal representative. It contains a section for indicating whether advance directives are in place and where those documents can be found.

The tool and accompanying instructions and examples were jointly developed by experts from Support Development Associates and the University of Missouri Kansas City Institute for Human Development Charting the LifeCourse Nexus, and by Janis Tondora from the Yale University Program for Recovery and Community Health.

Communication Needs

This [web page](#) includes resources to help people with complex communication needs prepare in case emergency assistance is needed, as well as information and tools for caregivers and healthcare providers. It was created by the Rehabilitation Engineering Research Center on Augmentative and Alternative Communication at Penn State University, which is funded by ACL's National Institute on Disability, Independent Living and Rehabilitation Research.

[Tools to use when verbal communication is not possible due to an individual's disability, injury, or shock.](#)

- These printable communication boards from Temple University Institute on Disabilities feature pictures, words and a "keyboard". They also include a planning page to record key information that may be needed during an emergency.
 - [English Emergency Communication Tool \(PDF\)](#)
 - [Spanish Emergency Communication Tool \(PDF\)](#)
- The UConn Center for Excellence in Developmental Disabilities developed [a flipbook](#) that provides strategies and tools to help emergency/medical personnel communicate with people who do not use speech. Aids include an emergency QWERTY board that can be used to spell words by pointing, pain charts, sign language basics, and icon-based tools. It can be printed out and hung inside emergency vehicles for easy reference on the job.
- The Patient-Provider Communication Forum, with the support of the United States Society of Augmentative and Alternative Communication (USSAAC), is providing [free communication supports](#) for people with disabilities and their health care workers.

For people who are deaf, hard of hearing or DeafBlind

This [web page](#) provides tips to help people who are deaf, hard of hearing or DeafBlind communicate at the hospital while COVID-19 precautions are in place. It includes a list of smartphone applications and a printable medical placard that may be helpful. It was created by the Deaf/Hard of Hearing Technology Rehabilitation Engineering Research Center, funded by ACL's NIDILRR.

People living with Paralysis

The Paralysis Resource Center, an ACL grantee, has created [this resource](#) for people living with paralysis. See also:

- [SCI, flu, and coronavirus](#) by Nurse Linda
- [El coronavirus \(COVID-19\) y la parálisis](#)
- Coronavirus fact sheet (PDF):
 - [English](#)
 - [Spanish](#)

3 National Core Indicator COVID-19 Bulletins that were written using our National Core Indicators data from 2018-2019.

National Core Indicators Data COVID-19 Bulletin on Isolation and Loneliness: #1

https://protect2.fireeye.com/url?k=be6aeaf7-e23ec3dc-be6adbc8-0cc47a6d17cc-f233b92bdf0031f9&u=https://protect2.fireeye.com/url?k=ca538223-96079b5f-ca53b31c-0cc47adc5fa2-ef1c019eea3cca65&u=https://www.nationalcoreindicators.org/upload/core-indicators/Examining_NCI_COVID_FINAL.pdf

National Core Indicators Data on Life Activities: COVID 19 Bulletin #2

https://protect2.fireeye.com/url?k=c6185d2b-9a4c7400-c6186c14-0cc47a6d17cc-b5b9ba555a5419ac&u=https://protect2.fireeye.com/url?k=5925818b-057198f7-5925b0b4-0cc47adc5fa2-ca02fc825a9e6288&u=https://www.nationalcoreindicators.org/upload/core-indicators/Social_Isolation_during_COVID_19.pdf

National Core Indicators COVID-19 Bulletin #3: Data on Family Experiences

https://protect2.fireeye.com/url?k=1de06509-41b44c22-1de05436-0cc47a6d17cc-3827f46be7d05377&u=https://protect2.fireeye.com/url?k=adc37a40-f197633c-adc34b7f-0cc47adc5fa2-00a8c92e393c337f&u=https://www.nationalcoreindicators.org/upload/core-indicators/Respite_and_crisis_in_time_of_COVID.pdf

Scotland – COVID 19 and people with disability

Across Scotland a range of organisations sought to ensure that equalities and human rights have been at the forefront of their response to the Covid-19 Pandemic. This has included gathering information and data about the practical impact of the pandemic on people with disabilities.

A Disabled Persons Organisation (DPO), Inclusion Scotland carried out a survey of 822 people with disabilities. The [findings](#) indicated that the Covid-19 crisis is having a significant impact on the mental health of disabled people and their carers. Around

15% of all respondents stated that their mental health has been negatively affected by the current crisis. Particular concerns were about a lack of social care support, increased caring responsibilities and challenges in accessing food and medicine. Similar concerns were identified in a [survey](#) carried out by the Scottish Commission for People with Learning Disabilities (SCLD.) SCLD created two surveys, one for people with learning/intellectual disabilities and one for their parents, carers and supporters. There were 350 responses; 127 from people with learning disabilities and 223 from parents, carers and supporters. In addition to the issues identified above, digital exclusion was considered to be a key issue for people with learning disabilities, particularly for their mental health and wellbeing.

Addressing this challenge sat behind an [initiative](#) led by the Universities of Warwick, Oxford and Glasgow, supported by SCLD, which published a series of guided self-help booklets developed to support people with mild to moderate learning/intellectual disabilities during the COVID-19 outbreak. The booklets can be used with the support of family members, friends, volunteers and carers and are also suitable for social work and health professionals. The booklets are intended to give people with learning/intellectual disabilities an opportunity to talk through their feelings with people providing support to them. There is a guide accompanying each booklet, explaining how the content can be delivered. SCLD led the engagement strand for this work, and addressing the digital deficit, nearly 12,000 hard copies of the booklets were printed and posted to people with learning/intellectual disabilities and their supporters.

The wider need to capture, collate and curate accessible resources led SCLD to establish a Coronavirus resources [hub](#). This has collected a range of resources from across Scotland, the UK and internationally. Clinical professionals have also focused on developing resources to support practitioners and people with learning/intellectual disabilities, with NHS Grampian providing a comprehensive [collection](#) of easy read guides.

On a wider policy and strategic level, Scotland's move out of lockdown has been guided by the Scottish Government's Route [Map](#). This document has been updated frequently as Scotland moves through its phases and is formed by a partnership approach which seeks to listen to the views of key partners and stakeholders, to businesses, organisations and people across Scotland. It is also underpinned by a focus to protect the most at risk and safeguard human rights.