

## The impact of COVID-19 on the rights of persons with disabilities

### Social exclusion and access to health and other services

18 November 2021

Ines Bulic Cojocariu  
Deputy Director  
European Network on Independent Living – ENIL



1

## Who is and what does ENIL?

- **The European Network on Independent Living (ENIL)** is a non-governmental organization working in the disability field promoting independent living through human and civil rights since 1989.
- A cross-disability network of grassroots organizations.
- ENIL advocates and lobbies for Independent Living by promoting the values, principles (self-determination, self-representation, choice and control, de-institutionalisation) and practices to enable full citizenship of disabled people.
- Dr Adolf Ratzka's definition: Independent Living is having the same range of options and same degree of self-determination taken for granted by non-disabled.
- This includes the opportunity to make choices and decisions regarding where to live, with whom to live and how to live.
  - **The right to just be ordinary!**

2

## The COVID-19 DRM Survey

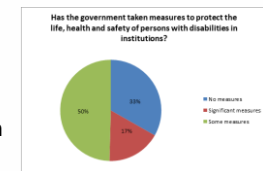
- Launched on 20 April 2020, by the Coordinating Group of the COVID-19 Disability Rights Monitor ('COVID-19 DRM'): Validity Foundation, ENIL, International Disability Alliance, Disability Rights International, Centre for Human Rights at the University of Pretoria, International Disability and Development Consortium and Disability Rights Fund
- Endorsed by:
  - the UN Special Rapporteur on the Right to Health, Mr. Dainius Pūras,
  - the UN Special Rapporteur on the Rights of Persons with Disabilities, Ms. Catalina Devandas-Aguilar, and
  - the UN Independent Expert on the enjoyment of human rights by persons with albinism, Ms. Ikponwosa Ero
- Stakeholders: Governments, national human rights monitoring mechanisms, persons with disabilities and their representative organisations
- What states were doing to protect core rights of persons with disabilities, including the right to life, access to health and essential services; those identified as "most vulnerable" violations: people in institutions, children, older persons, homeless persons and rural settings
- 25 languages, 2,152 responses collected from 134 countries around the world (over 2/3 of UN member states), 3,000 written testimonies

3

## Inadequate measures to protect persons with disabilities in institutions

**Governments failed to protect the right to life of persons with disabilities in institutions.** Emergency measures that were taken have exacerbated existing human rights abuses and failed to prevent further human rights abuses:

- the denial of access to healthcare, bans on visitors
- isolating residents when there was an outbreak
- systemic violations of fundamental freedoms and human rights of PwD detained institutions of any size
- became the epicentre of COVID-19 infections and deaths (include group homes, psychiatric hospitals, retirement homes for older PwD, residential schools for children, and other residential settings where PwD are detained against their will)
- failed to provide personal protective equipment (PPE) and adequate sanitation in institutions

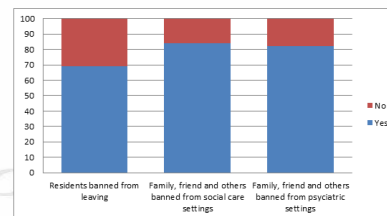


4

## Inadequate measures to protect persons with disabilities in institutions

### Further deprivation of liberty

- Institutions around the world were cut off from the rest of society, without any monitoring mechanisms in place
- Safety and wellbeing within institutions. fears that additional human rights abuses (closed doors)
- Staff and medics who had been inside institutions during the pandemic reported that residents were overmedicated, sedated, or locked up. This situation is having a devastating effect on the mental health of the residents.
- The mental health of children with disabilities in institutions



**Collective complaint Validity v. Finland:**  
<https://enil.eu/news/finland-ngos-seek-legal-recognition-that-locking-people-in-institutions-is-not-a-lawful-response-to-covid-19-epidemic/>

5

## Inadequate measures to protect persons with disabilities in institutions

### Measures to inform people in institutions about the state of emergency:

- 26% of respondents stated that no measures were taken to inform people, including about bans and restrictions on visitors
- that persons living in institutions were not provided with adequate information to protect themselves from COVID-19

### Older persons with disabilities in institutions:

- One third said that no measures were taken to protect the life, health and safety of older persons with disabilities in institutions
- Measures that were taken were problematic
- Concerns about the effects of isolation on the mental health of older persons
- Governments took general measures, that did not ensure the protection and inclusion of older people with disabilities

6

## Measures to protect PwD in the community

- They were abandoned by the government and trapped at home, with no means to access food, medicine, or other basic supplies.
- Strict curfews - PwD were at increased risk of police harassment, intimidation, and violence
- Access to information – information about the pandemic was received on television, radio, or social media
- The lack of specific types of information, including preventive measures to prevent infection, where to obtain testing and treatment, the nature of emergency regulations, lockdown rules, accessing emergency food, and social assistance schemes.

Services and supports that persons with disabilities cannot access during the COVID-19 pandemic	Percentage	Number of respondents
No access to personal assistance	38%	809
No access to informal care	33%	708
No access to home support	29%	604
No access to assistive technology	23%	490

- Information available in Accessible Format:  
Sign Language 44%, Easy-to-read 38%, Audio 33%,  
Multiple languages 23%, Screen readers 22%, Not been provided 21%

7

## Measures to protect PwD in the community

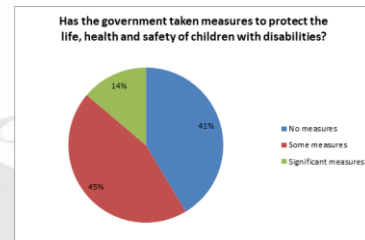
- A third had no access to food, essentials, adequate nutrition during the COVID-19 pandemic as a result of the rising cost of living, including a rise in the cost of medication and rent - persons with disabilities were living in poverty before the COVID-19 pandemic!
- Police brutality, harassment, and abuse:
  - PwD and their family members have had no choice but to break curfew rules to access food and essential medical supplies, because no exceptions were made for them
  - Public information campaigns were largely inaccessible throughout the pandemic - (77%) did not have information about penalties resulting from breaking state of emergency rules (fines, sanctions, arrest) imposed on PwD
  - 33% did not have access to food or medical supplies. This resulted in a dangerous situation in which police and security forces tasked with enforcing lockdowns encounter PwD leaving their homes to meet their basic needs

8

## Disproportionate impact on underrepresented groups of persons with disabilities

### Children with disabilities :

- disproportionately affected by the measures taken by governments
- experienced multiple forms of discrimination on the basis of disability and age
- their government took no measures to protect the health and safety of children with disabilities in institutions or in the community
- many essential supplies and services were unavailable to children: (access to food and medicine, to essential healthcare, respite care, rehabilitation, or education)
- (55%) no measures to support families of children with disabilities during the pandemic
- families who were instructed to stay at home with their child with a disability did not receive any guidance or financial support from the government



9

## Disproportionate impact on underrepresented groups of persons with disabilities

### Women and girls with disabilities:

- specific rights violations due to the interaction of discrimination on the basis of disability and gender identity, as well as age
- 25 testimonies of grave human rights abuses which included multiple forms of assault and violence - reports of sexual assault, domestic violence, and police brutality against women and girls with disabilities
- women were isolated at home with abusive partners or relatives and with no access to school or workplaces
- fears that the actions taken by governments, which made women and girls with disabilities more isolated than ever before, would increase the risk of sexual violence.
- the pandemic has made the situations even worse because women and girls could not access police, women's shelters, social workers, or trauma

10

## Disproportionate impact on underrepresented groups of persons with disabilities

### Homeless persons with disabilities

- 51% respondents (667) said that their government took no measures to protect the life, health, and safety of persons with disabilities living on the streets or in homeless shelters
- many respondents were extremely concerned about their health and safety, especially children with disabilities living on the streets.
- persons with disabilities were at an increased risk of homelessness as a result of the pandemic

### Persons with disabilities in remote and rural areas:

- few measures were taken by their government to protect persons with disabilities in remote and rural areas.
- they faced additional barriers to accessing food, medication, and health care
- they did not have adequate access to information in areas without access to the internet, phones, and other technologies

11

## Denial of access to healthcare

### 1. Denial of treatment for COVID-19 and triage discrimination

- 52% said that they were denied or deprived of healthcare for COVID-19

### 2. No access to medication and essential healthcare

- half of the respondents said that people could not access therapies
- 43% said that people in their country did not have access to rehabilitation
- 30% did not have access to medication during the pandemic. This included essential, life-saving medications, and medication used in the treatment of psychosocial disabilities.

### 3. Multiple barriers to accessing medication:

- unaffordable medications, no transportation, inability to leave home due to curfews, lack of accessible transport, living in remote, rural areas, and loss of personal assistance services.
- lack of access was linked to inflation or the rising cost of living during the pandemic

12

## Impact of the COVID on the situation of PwD

- The public image and perception of PwD was damaged:  
Need to be taken care of  
Vulnerable citizens
- Return to the medical model  
Investments in making institutions safer, building new ones – Recovery and Resilience Facility
- Many pwd felt useless, dependent and a burden to society due to loss of support
- Isolation during the pandemic made some persons with disabilities consider living in group to feel better/have company
- Some pwd and some parents, families and friends are angry about what happened to them and join forces to lobby now
- With online communication, those with internet could take part in meetings and events from around the world
- Some people were able to work from home, leave sheltered workshops, and will be able to do so in the future
- Proof of how dangerous institutions are - the debate of urgent DI IS ON THE TABLE AGAIN

13

## Recommendations should guide immediate action:

1. Ensure that **all recovery efforts protect the rights to life, health, liberty, freedom from torture, ill-treatment, exploitation, violence and abuse, the rights to independent living and inclusion in the community, and to inclusive education**, among others, for persons with disabilities without any discrimination on the basis of disability.
2. Ensure that **all persons with disabilities have immediate access to food, medicine, and other essential supplies**.
3. Ensure that persons with disabilities have **equal access to basic, general, specialist, and emergency health care** and that triage policies never discriminate on the basis of disability or impairment.
4. Enact **emergency deinstitutionalisation** plans, as informed by persons with disabilities and their representative organisations, including adopting an immediate ban on institutional admissions during and beyond the pandemic, and the **transfer of funding from institutions into community supports and services**.
5. Allocate **adequate financial and human resources** to ensure that persons with disabilities are not left behind in the COVID-19 response and in the recovery process.

14



## Recommendations should guide immediate action:

6. Provide economic, financial, and social support to ensure that persons with disabilities can enjoy their right to fully participate in the community on an equal basis with others, including having **access to personal assistance at all times**.
7. Guarantee full participation, meaningful involvement, and leadership of persons with disabilities and their representative organisations at **every stage of planning and decision-making processes in COVID-19 responses**. Take steps to **meaningfully involve children and young people with disabilities and their families and caregivers** in the design and implementation of all policies in response to the pandemic.
8. Ensure that **emergency responses are disability-inclusive** and take into account the **diverse and individual needs of persons with disabilities, in particular those experiencing intersectional forms of discrimination and marginalisation** such as women and girls with disabilities, persons living in rural or remote areas, deaf and hard of hearing persons, persons with deafblindness, persons with intellectual or psychosocial disabilities, and persons with autism.

15

## Recommendations should guide immediate action:

9. Prioritise **inclusive education for children and young people with disabilities**, especially children and young people living in congregate care. Ensure alternative education provision is accessible and provides reasonable accommodations based on the individual needs of children and young people with disabilities to guarantee their right to education.
10. Prioritise the **dissemination of comprehensive and accessible information** in a variety of formats for persons with disabilities concerning the pandemic, response efforts, and public health information and guidance.
11. Provide **disability-awareness training for police and law enforcement authorities**, and accountability for disproportionate enforcement of public health-related restrictions. Ensure **access to justice** for persons with disabilities who have experienced or are at risk of experiencing abuse, violence, or exploitation as a result of emergency measures.

16



EUROPEAN NETWORK  
ON INDEPENDENT LIVING (ENIL)  
Secretariat

**Interactive dashboard:**  
[www.covid-drm.org](http://www.covid-drm.org)

**Thank you for your attention  
& Let's build back inclusively!**  
[www.enil.eu](http://www.enil.eu)

LIKE US ON  
 **facebook**

ENIL Brussels Office at Mundo J,  
Rue de l'Industrie 10, 1000 Brussels, Belgium  
Tel: 0032 (0)2 893 25 83