



Neglect and discrimination. Multiplied

How Covid-19 affected the rights of people with intellectual disabilities and their families



@InclusionEurope

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Foreword

Dear friends, colleagues.

It has been nearly 8 months since the pandemic started... and the world we used to know has changed significantly. However, for people with intellectual disabilities, most of the problems already existed, and have simply been exacerbated and sometimes made visible to the general public.

I believe Inclusion Europe is a perfect platform to share our stories. With this report, we want once again to share the stories of our lives throughout our network and give Europe tools to understand people with intellectual disabilities and their families.

During the difficult times of the Covid-19 pandemic Inclusion Europe and its members organised webinars to share good practices and information. This provided us with first-hand experiences on how Covid-19, and the measures taken by governments, have affected the lives of people with intellectual disabilities and their families.

We would like to thank our members for the tremendous amount of work they have been carrying out, which was intensified during this period. We recognise their crucial role in upholding the rights and voices of persons with intellectual disabilities and their families across Europe, through

relentless awareness campaigns and advocacy towards decision makers.

Moreover, we also recognise the role of support and caring they had during those times, filling many gaps, and assuring the support they could. We would like to express our gratitude to the people who continued working (in workshops, day care centres, residential services) and who provided crucial support and kept close contact with people and their families in these challenging times.

With their feedbacks, and the available resources, we were able to see similarities and divergences between countries. Yet, all the information clearly shows that the pandemic highlighted social issues already present, and that people with intellectual disabilities have been disproportionately affected by the crisis and measures taken.

Finally, Inclusion Europe would like to share a thought for all families who have lost a loved one and express our condolences and support.

We would also like to express our support to those who are still stuck in institutions or confined home without any support.



Jyrki Pinomaa
Inclusion Europe president

Easy to read summary

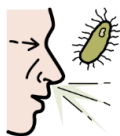


Inclusion Europe wants people to know what happened to people with intellectual disabilities and their families during the Covid-19 crisis.



The report shows people with intellectual disabilities were segregated and discriminated against once more.

Numbers



Numbers are important to see how Covid-19 changed the lives of persons with intellectual disabilities. For example, to know how many people died in institutions or hospitals.

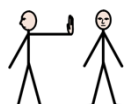


The European Union and countries need to investigate.

Health



The Covid-19 pandemic showed that accessibility of health and emergency services is bad. Accessing treatment in hospitals was not sure for persons with intellectual disabilities sick.



For example, there were triage protocols, to determine if a person could have access to treatment if the hospital was full of people sick.

Sometimes, the medical personnel did not know how to behave with people with intellectual disabilities.

People working in institutions did not have enough protections (masks, gloves).

Institutions



Persons with intellectual disabilities were isolated from their families and friends for months. They were at high risk of infection. It is proof that institutionalisation is harmful and is a violation of European values and human rights.

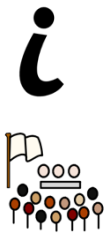
Support services and the role of families

Because of lockdown, day care centre and support services closed. Many persons with intellectual disabilities got no support. This had a big impact on families having to take care. This led to panic and worry for everyone. Some countries supported to families. Several countries are letting parents take paid leave so that they can stay home and look after their children.

Education



Schools had to close and be online. People with intellectual disabilities were left behind, because they did not have support, or the material was not accessible. When schools reopened, some did not allow children with intellectual disabilities. Many families were afraid.



Access to information and consultations

Information was not in easy-to-read.

Some people did not understand the situation.

Disability organisations talked to governments
to tell them to consult people with intellectual disabilities.

Employment

Due to the Covid-19, many people lost their jobs.

The situation was very uncertain.

People with disabilities are afraid to lose their jobs.

Why this report?

Death rate of people with intellectual disabilities due to Covid-19 is estimated 3,6 times that of the general in England.¹

What about other countries in Europe?

Why were death rates so much higher than the general population?

What happened to people with intellectual disabilities during the pandemic?

To what extent were people with intellectual disabilities and their families abandoned or supported during the pandemic?

How do we yet again find ourselves in this situation, witnessing large-scale human rights violations, abandonment, and isolation?

This is what we wanted to describe and bring to light.

This report is far from a complete picture.

This report also does not cover the many support measures governments took, mostly by extending

social benefits and other tools to support people in the situation.²

Our aim is simple: To document the many instances of neglect and direct human rights violations that occurred.

Because they are symptomatic of the segregation and discrimination people with intellectual disabilities and their families have been facing for decades.

Inclusion Europe is the European movement of people with intellectual disabilities and their families.

With members in 40 European countries, we represent over 20 million citizens.

Following the Covid-19 crisis we monitored both the work of our members and what was made available, to ensure that what people with intellectual disabilities and their families

¹ Death rates of people with learning disabilities, November 2020 https://www.gov.uk/government/publications/covid-19-deaths-of-people-with-learning-disabilities?fbclid=IwAR0evXNcf8LEigmgu-P0zgXkggI2CCwtQ5-P_Qlvjtf_03d4b3QPUQiABDs

² See for example Proposal for joint employment report 2021 (<https://ec.europa.eu/social/BlobServlet?docId=23156&langId=en>) or Living, working and Covid-19 (<https://www.eurofound.europa.eu/publications/report/2020/living-working-and-covid-19>)

experienced during this very hard time is not forgotten.

We want to draw these lessons so that in another eventual health or sanitary crisis, people with disabilities and families are not left behind again. Do

not have to suffer the same discrimination again.

We also want to ensure people with intellectual disabilities' interests are reflected in the recovery processes.

Our members, other disability organisations and NGOs undertook a tremendous amount of work to provide support during the pandemic. They advocated to uphold the rights of persons with intellectual disabilities and their families across Europe. They provided support and care. They stepped in to fill so many gaps in how the governments informed the public about the situation. Governments turned to them in the time of crisis – they must turn to them also when distributing money in the recovery process.
Milan Šveřepa, director of Inclusion Europe

Conclusions and recommendations

“The Covid-19 pandemic is intensifying inequalities experienced by the world’s one billion people with disabilities”

António Guterres, UN Secretary-General³

The Covid-19 sanitary crisis did not in fact bring new issues concerning the situation of people with intellectual disabilities: **it intensified, magnified the segregation and discrimination of people with intellectual disabilities**. Many human rights of people with intellectual disabilities were violated during this period.

People with intellectual disabilities were not properly taken into account before the crisis; e.g. the consultation of people with intellectual disabilities was not a priority and, in some countries, people

with intellectual disabilities still do not have legal capacity,⁴ which means they are denied their right to participate in civil and political life.

The Coronavirus crisis sheds light on their exclusion; **it should spur governments and institutions to finally design and deliver a world that includes people with intellectual disabilities and their families**.

The European Union must build a stronger social union to protect European citizens and people living in the EU.

Investigation and data collection

Having data to measure the consequences and impact of Covid-19 is a necessity. Data should be collected in a coordinated, comprehensive manner,

disaggregated by age, gender and type of disability. This is a crucial aspect, as it is the starting point to understand how the Coronavirus crisis has

³ Coronavirus and human rights: New UN report calls for disability-inclusive recovery, October 2020, <https://www.un.org/fr/desa/coronavirus-and-human-rights-new-un-report-calls-disability-inclusive-recovery>

⁴ <https://www.inclusion-europe.eu/legal-capacity/>

affected people with disabilities and to draft an appropriate response.

The need to harmonise the process of collecting the data (whether people died in institutions, hospitals or at home) is essential. For instance, knowing the death rates of people in residential institutions compared to the ones living in the community is crucial for

understanding the role large, congregated settings played in the spread of the virus.⁵

The European Union and the Member States should investigate and assess the extent and consequences of the Coronavirus on the lives of people with intellectual disabilities.

Residential care institutions

Institutionalisation of people is harmful and constitutes degrading treatment, in violation of EU values of respect for human dignity, freedom, equality, the rule of law and respect for human rights.⁶ As Member States are proving to be unwilling or unable to realise the transition to community-based care, the EU should explore new ways of ensuring that the segregation of people with intellectual disabilities ends.

To end institutionalisation and segregation of people with intellectual disabilities in residential institutions, the EU has to urge Member States to fulfil their obligations under article 19 of the CRPD.

To prevent further harm, funding during recovery should be allocated to disability services and organisations.

Recovery funding must be specifically allocated to community-based disability support and services.⁷

⁵ Residential institutions are becoming hotbeds of infection and abuse – government's need to act now, European Disability Forum, 31 March 2020, <http://edf-feph.org/newsroom/news/residential-institutions-are-becoming-hotbeds-infection-and-abuse-governments-need-act>

⁶ "The Union is founded on the values of respect for human dignity, freedom, democracy, equality, the rule of law and respect for human rights, including the rights of persons belonging to minorities. These values are common to the Member States in a society in which pluralism, non-discrimination, tolerance, justice, solidarity and equality

between women and men prevail." Article 2 of the Treaty on the European Union,

<https://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:12008M002:EN:HTML>

⁷ Covid-19 crisis: people living in institutions must not be written off, 24 April 2020,

<https://deinstitutionalisation.com/2020/04/24/covid-19-crisis-people-living-in-institutions-must-not-be-written-off/>

Healthcare

People with intellectual disabilities were not, once again, considered from the beginning. Coronavirus proved **the necessity of improving the accessibility of health care services and emergency responsiveness.**

Education is needed of health and social care professionals working in hospitals or emergency centres, to be aware of

the situation of people with intellectual disabilities. A human rights-based approach to healthcare services must be taught to avoid discrimination. Support and better communication with patients with intellectual disabilities is needed.

The EU must develop guidelines on providing health care to people with intellectual disabilities

Information and consultation

The lack of accessible information is a direct consequence of the lack of consideration and consultation with people with intellectual disabilities in policy-making.

There is a general lack of consultation of people with intellectual disabilities; the pandemic showed that people with intellectual disabilities were rarely consulted in efforts to contain the pandemic.⁸

Providing public information services in an accessible manner, such as phone helplines (112) is a necessity. Specific measures such as helplines that are accessible for people with intellectual disabilities are also required.

Information that is easy to understand, such as easy-to-read,⁹ benefits everyone in a crisis.

People with disabilities are often portrayed only as “vulnerable”; in fact they played significant role in ensuring the public received information that was easy to understand and relevant to the many situations people find themselves in.

The EU has to monitor and ensure that Member States provide the information in an accessible manner as is mandatory.

People with intellectual disabilities and their representative organisations have to be consulted.

⁸ COVID-19: Who is protecting the people with disabilities? – UN rights expert, UN OHCHR, 17 March 2020,

<https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=25725>

⁹ <https://www.inclusion-europe.eu/easy-to-read/>

“We must be included in discussions about the way services will be provided. We need to make sure that our rights are respected and that we are not left behind. Self-advocates have a voice. We must to be heard.”

László Bercse, chair of EPSA¹⁰

Employment

Many people with intellectual disabilities have lost their jobs during the pandemic. And many more are at risk, working in highly affected industries such as hospitality.

Given the already alarming low employment rates of people with disabilities, protecting jobs of people with intellectual disabilities is crucial.

As is investing in community-based support to ensure good conditions for their staff.

The EU must ensure that persons with intellectual disabilities are included in employment support and recovery plans to address the disproportionate unemployment rate of people with disabilities.

Women and girls with intellectual disabilities

Women with intellectual disabilities are more likely to experience violence.¹¹ And the rate of violence against women has increased during the pandemic.

It is a necessity to ensure women with intellectual disabilities are **included in**

the mainstream protection mechanisms and that a specific focus, support and means are provided to ensure they are in a safe environment, away from any aggressor and with the necessary support.

¹⁰ <https://www.inclusion-europe.eu/wp-content/uploads/2020/03/2020-05-22-Self-advocacy-activities.pdf>

¹¹ <https://www.inclusion-europe.eu/violence-against-women-with-intellectual-disabilities/>

We have seen how people with intellectual disabilities were left down during the pandemic, suffering higher death rates, being isolated in institutions, discriminated in access to healthcare, losing their education, employment, or support.

Governments must consult people with intellectual disabilities in all decisions that affect them.

The least they can do is to ensure the lost lives and the suffering were not for nothing, that future generations benefit from changes stemming from these hard-bought lessons.

What we saw happen in Europe

This part collects information on what happened in Europe to people with intellectual disabilities throughout the Covid-19 crisis.

There is a brief overview of the situation and then specific information from various countries, collected via Inclusion Europe members' testimonies or public news.

The purpose is to highlight key developments impacting on the rights of people with intellectual disabilities and families. The picture is far from complete.

Healthcare

Discrimination in access to health care

For **people with intellectual disabilities who contracted Covid-19**, access to healthcare and treatment in hospitals was not guaranteed in many EU countries.

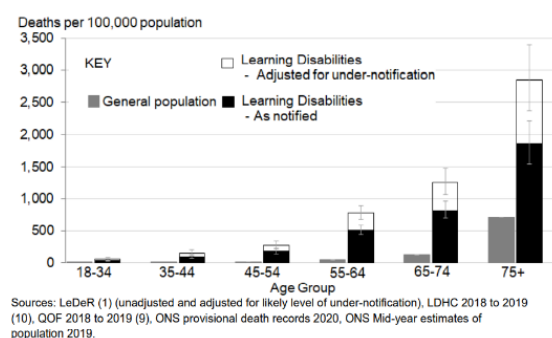
In some Member States, the government or hospitals put *triage protocols* in place to determine which person was a priority to treat, taking into account age and other comorbidity factors. Sometimes, this was done following nonofficial directions, but in some cases these directions were written down and do-not-resuscitate orders issued, which clearly constitutes a discriminatory practice.

Regular care stopped for some patients with intellectual disabilities during the Covid-19 crisis, as there were either no resources available, no transportation, other priorities and restrictions or no possibilities for care staff to come to people's facilities.

People with intellectual disabilities dying at a rate 3 times that of general population.¹²

What about other countries?

Especially those with high numbers of people in large residential institutions?



Belgium: the equality body UNIA received several testimonies of people with disabilities who did not receive the same treatment, for instance people being told they were not a priority¹³ or even a person with an intellectual disability who was kicked out of a hospital because she was crying and shouting too much.¹⁴ UNIA did a survey aimed at people with disabilities and their family members, which indicated that people with disabilities in Belgium faced many problems in their everyday lives, including difficulties accessing healthcare.¹⁵ Based on the results and on individual complaints, UNIA called for the government to disseminate a clear message on the right to access

healthcare on equality and non-discriminatory basis of people with disabilities.

Belarus: the government did not acknowledge the existence of the pandemic and did not take any measures to limit the spread of the Covid-19.¹⁶

Croatia: the Ombudsman for Persons with Disabilities asked the Civil Protection Headquarters to ensure the admission and treatment of persons with disabilities, and called parents of children with disabilities and adults with disabilities to adhere to the staff's recommendations.¹⁷

¹² Deaths of people identified as having learning disabilities with COVID-19 in England in the spring of 2020. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/933612/COVID-19_learning_disabilities_mortality_report.pdf

¹³ Testimony from a mother of an autistic child, 10 April 2020, <https://www.sudinfo.be/id178878/article/2020-04-10/selon-un-medecin-severine-serait-moins-prioritaire-quun-patient-normal-pour-une>

¹⁴ Les personnes handicapées et les personnes âgées ont le droit d'être soignées, by UNIA 10 April 2020, <https://www.unia.be/fr/articles/les-personnes-handicapees-et-les-personnes-agees-ont-le-droit-detre-soignee>

¹⁵ Rights of Persons with Disabilities during COVID-19 and beyond. ENNHRI CRPD working group newsletter. February-June 2020, issue I.

¹⁶ Information obtained from the Belarus disability organisation BelAPDiIMI, October 2020

¹⁷ Pita li i sada tko za osobe s invaliditetom? <https://trecadobhrvatska.com/pita-li-i-sada-tko-za-osobe-s-invaliditetom/>

England: there is evidence that people were not given fair access to healthcare. If it is not what happened the most in the country, it still caused big worries.¹⁸

National Health Services (NHS) issued a guidance which heightened fears, because it suggested that many people with disabilities would be refused life-saving treatment, if they were admitted to hospital.¹⁹ Self-advocacy organisations campaigned to change the government's rules on going out, hospital visiting, treatment decisions and checking services. They are still campaigning to make sure people with disabilities are in the top priorities to be tested.²⁰

According to the Office for National Statistics, 59% of all deaths involving Covid-19 from March to July 14 were among people with disabilities.²¹

Finland: the Finnish Association of People with Physical Disabilities reported several cases of hate speech directed against persons with disabilities in the context of the outbreak, for instance people accusing people with

disabilities of taking the health care resources needed to combat the virus.²²

France: in the capital region, an administrative decision established discriminatory criteria to accept patients, measuring the capacity of an individual to receive reanimation based on "clinical fragility" and "neurocognitive state".²³ Disability organisations fought discriminatory treatment and caught the attention of the media and the government, who reiterated the prohibition of discrimination in access to healthcare and presented a series of measures to guarantee equal access to healthcare during the Coronavirus emergency beginning of April.²⁴

Germany: the government decided not to issue a statement explicitly prohibiting discrimination against people with disabilities when admitting them to hospitals, even though political parties and the federal government's Disability Commissioner expressed their concern and will for the government to

¹⁸ Samantha Clark, Chief Executive of Learning Disability England on self-advocates in England during the Coronavirus emergency in a webinar held by Inclusion Europe, 22nd of May 2020, <https://www.inclusion-europe.eu/wp-content/uploads/2020/03/2020-05-22-Self-advocacy-activities.pdf>

¹⁹ Coronavirus: Anger over 'terrifying and discriminating' intensive care guidance, 26 March 2020, <https://www.disabilitynewsservice.com/coronavirus-anger-over-terrifying-and-discriminating-intensive-care-guidance/>

²⁰ Gary Bourlet, Co-Founder of Learning Disability England, and Samantha Clark, Chief Executive of Learning Disability England on self-advocates in England during the Coronavirus emergency in a webinar held by Inclusion Europe, 22 May 2020, <https://www.inclusion-europe.eu/wp-content/uploads/2020/03/2020-05-22-Self-advocacy-activities.pdf>

²¹ Coronavirus (COVID-19) related deaths by disability status, England and Wales: 2 March to 14 July 2020, September 2020 <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/coronaviruscovid19relateddeathsbydisabilitystatusenglandandwales/2marchto14july2020>

²² Information obtained from the Finnish Association of People with Physical Disabilities (Invalidiliitto), March 2020

²³ Information obtained from the French disability organisation Unapei, October 2020

²⁴ Isabelle Chandler, Director of Advocacy and Influence at Unapei on the Impact of Coronavirus emergency on people with intellectual disabilities, families in France in a webinar held by Inclusion Europe, 13th of May 2020, <https://www.inclusion-europe.eu/wp-content/uploads/2020/03/2020-05-13-France-impact-of-coronavirus.pdf>

take actions in accordance to German constitutional laws.²⁵

Italy: discriminatory medical guidelines and recommendations were issued, such as the one developed by the Italian Society of Anaesthesia Analgesia Resuscitation and Intensive Care in case of “*exceptional conditions of imbalance between needs and available resources*”.²⁶

Due to the lack of beds in intensive care units, priority was given to young people with no underlying conditions. They aimed to save scarce resources for patients with a “*greatest chance of survival*”, prioritising younger and healthier patients over the elderly and those with under-lying conditions.²⁷

People with intellectual disabilities were often considered as “second-class” patients, who did not deserve to be treated equally compared to other people considered with more chances of survival. In some cases, ambulances were called but never came. When allowed into hospitals, people with intellectual disabilities and their families had difficulties to find adequate assistance and trained persons for that assistance, resulting in inappropriate or

inadequate care. Plus, medical personal most frequently did not consider the difficulties of this category of patients to relate to new and unknown contexts. Families also had difficulties to reach to their hospitalised relatives because of the restrictions, which resulted in people with disabilities being left alone.²⁸

Disability organisations published a joint statement to denounce this.²⁹ Anffas, the organisation representing people with disabilities and their families, launched several appeals and public statements asking for specific directives to protect people with intellectual and neurodevelopmental disabilities precisely in relation to hospitalisation and its management.

Malta: therapies such as physiotherapy, occupational therapy or speech therapy ceased due to the pandemic. Despite many demands, no mental health support has yet been offered to those persons with disability and their family members who need it due to the pandemic situation.³⁰

Netherlands: the Dutch Association for Intensive Care has drawn up a

²⁵ Coronavirus: Germany weighs controversial triage issues, 27 April 2020, <https://www.dw.com/en/coronavirus-germany-weighs-controversial-triage-issue/a-53240936>

²⁶ Raccomandazioni di etica clinica per l'ammissione a trattamenti intensivi e per la loro sospensione, in condizioni eccezionali di squilibrio tra necessità e risorse disponibili, SIAARTI, March 2020,

<http://www.siaarti.it/SiteAssets/News/COVID19%20-%20documenti%20SIAARTI/SIAARTI%20-%20Covid19%20-%20Raccomandazioni%20di%20etica%20clinica.pdf>

²⁷ Italian doctors on coronavirus frontline face tough calls on whom to save, 9 March 2020,

<https://www.politico.eu/article/coronavirus-italy-doctors-tough-calls-survival/>

²⁸ Daniela Cannistraci and Gianfranco de Robertis from Anffas Onlus Nazionale on the Impact of Coronavirus emergency on people with intellectual disabilities and their families in Italy in a Webinar held by Inclusion Europe, April 2020, <https://www.inclusion-europe.eu/wp-content/uploads/2020/03/2020-04-09-Italy-impact-of-coronavirus.pdf>

²⁹ Statement by Italian organisations - The Massacre of the Innocents, March 2020, translated version by the European Disability Forum of the statement “*la strage degli innocenti*” signed by several Italian organisations <http://edf-feph.org/newsroom/news/statement-italian-organisations-massacre-innocents>

³⁰ Information provided by the disability organisation MFOD, October 2020

'pandemic scenario' in May 2020, classifying triage admission criteria for intensive care in case 'intensive care unit beds' become scarce (phase 3). These criteria are based on "*a person's chances of survival*" and are articulated in the "clinical frailty scale", in which an admission can be denied on the grounds of complex support needs or a disability.³¹

Portugal: there is no report nor data to show if people with disabilities, especially with intellectual disabilities, were treated unfairly or denied their right to access healthcare. Access to healthcare seems to have been maintained. People with disabilities were even considered as a group that would need extra attention and should be provided with all the health care they need if they were infected and ill with Covid-19. Government norms prohibited doctors to discriminate against persons with disabilities when accessing treatment and the Health Authority (DGS) issued a norm specially stating that intensive care medicine should avoid the "no-value" or "low-value" when doing triage of incoming patients.³²

However, they faced the same problems as everyone else, due to the shutdown

of most health services not considered as essential during the first couple of months. The guidelines issued by the Health Authority in July recognised the need for additional protective measures and that people with disabilities should have the possibility to pursue their therapies and other health interventions.³³ However, it ultimately depended on service providers, and many remained actually shut down.

Slovenia: access to adequate and inclusive healthcare was already a concern for many before the pandemic, and Covid-19 only revealed once more the unpreparedness of the healthcare sector to provide care for persons with disabilities.³⁴

Spain: the representative committee of people with disabilities (CERMI), the Democratic Union of Pensioners and Retirees of Spain (DUP), and the Spanish Confederation of Senior Organizations (CECOMA) requested scientific societies to revise their protocols and ensure they were in accordance with international human rights law standards,³⁵ following medical guidelines edited to help doctors choose which patient to prioritise.³⁶

³¹ Draaiboek Pandemie Deel 1, May 2020, <https://www.demedischspecialist.nl/sites/default/files/Draaiboek%20pandemie%20deel%201.pdf>

³² Covid-19: fase de mitigação, March 2020 <https://www.dgs.pt/directrizes-da-dgs/normas-e-circulares-normativas/norma-n-0052020-de-26032020-pdf.aspx>

³³ Covid19, July 2020, <https://covid19.min-saude.pt/wp-content/uploads/2020/07/i026463.pdf>

³⁴ National Consultation of Sožitje Slovenia on the Impact of the Covid-19, Guardians, 2020

³⁵ Pensionistas, mayores y personas con discapacidad piden que no se les discrimine en la atención sanitaria, March 2020, <https://www.cermi.es/es/actualidad/noticias/pensionistas-mayores-y-personas-con-discapacidad-piden-que-no-se-les-discrimine>

³⁶ https://semicyuc.org/wp-content/uploads/2020/03/%C3%89tica_SEMICYUC-COVID-19.pdf

Lack of protective equipment

Protective equipment took time to arrive and was not given to care workers and workers coming into residential institutions. Even as supply of protective equipment started to improve, services for people with disabilities and families supporting them were overlooked.

France: there was a lack of protective equipment during the lockdown, especially for medical and care workers.³⁷ Initially, the non-recognition of the medical-social sector as high-priority in the distribution of protective equipment caused infections among people supporting people with disabilities, which made them feel abandoned by the government.³⁸ In July, the government announced that those considered vulnerable would receive subsidised masks.³⁹

Germany: residential institutions faced a lack of personal protective equipment and funding to support their preventive measures.⁴⁰ The disability organisation, Fachverbände für Menschen mit Behinderung, highlighted that assistance facilities and mobile services needed to be given priority when distributing stocks of protective equipment. Additionally, they

underlined that tests had to be made available for persons with disabilities, employees of support services and carers relatives so that the necessary treatment and quarantine measures could be initiated as quickly as possible.⁴¹

When a person living or working in an institution or group home contracted the virus, there were no additional tests available for other residents. This has made the tracking and controlling of the spread of the virus a challenge.⁴²

Italy: carers, relatives or social workers lacked the necessary masks and protective equipment to avoid infection and contamination, even when country stocks were refilled. Authorities privileged health care facilities over support services and facilities when

³⁷ Coronavirus : la pénurie de masques, grande colère des soignants, March 19 2020,

https://www.lemonde.fr/planete/article/2020/03/19/coronavirus-la-penurie-de-masques-grande-colere-des-soignants_6033655_3244.html

³⁸ Information obtained from the French disability organisation Unapei, October 2020

³⁹ Masques gratuits : quels Français y auront droit ?, July 23 2020,

https://www.francetvinfo.fr/sante/maladie/coronavirus/deconfinement/masques-gratuits-quels-francais-y-aurent-droit_4054007.html

⁴⁰ 13 Million Menschen, einfach übersehen, 30 March 2020,

<https://www.sueddeutsche.de/politik/gesundheitspolitik-coronavirus-menschen-mit-behinderung-1.4860711>.

⁴¹ Menschen mit Behinderung müssen besser vor COVID-19 geschützt werden, April 2020,

<https://www.lebenshilfe.de/presse/pressemeldung/menschen-mit-behinderung-muessen-besser-vor-covid-19-geschuetzt-werden/>

⁴² Information obtained from the German disability organisation Lebenshilfe, October 2020

distributing personal protective equipment.⁴³

To fill this serious gap and support families, people with disabilities all the workers who interacted with people with disabilities, the disability organisation Anffas started from the beginning to look for and provide them with protective equipment. Together with several other associations, they repeatedly called for affordable and adequate protection, not only in hospitals but also in the residential institutions for people with disabilities.

Luxembourg: every country resident received free protective equipment, but sadly only in May. When the lockdown finished, exemptions for people with disabilities and with other health conditions not to wear a mask, with a medical certificate, were granted.⁴⁴

Portugal: protective equipment was and still is insufficient. At first, the organisations and service providers had to find ways to get them, either by donations, or by using their own financial resources. However, at a

certain point, protective equipment was provided by the Civil Protection and Social Security.

Although not all the services were allowed, Fenacerci, the organisation representing people with intellectual disabilities, continued to cover for the needs of their beneficiaries and received subsidies from the government to the Covid-19. Some of it was used to buy protective equipment, people with disabilities being a priority.

People with intellectual disabilities and autism (with more than 60% of disability rate) were not obliged to wear masks or other protective equipment in public places.⁴⁵

Spain: support services in dire need of masks, gloves and gowns, had to come up with homemade solutions, including microwaving equipment in the hope of sterilising them.⁴⁶ A court declared a regional government as responsible of violating the right to life, physical integrity and health, for putting its workers at risk by failing to provide appropriate equipment.⁴⁷

⁴³ Statement by Italian organisations - The Massacre of the Innocents , 30 March 2020, translated version by the European Disability Forum of the statement "[la strage degli innocent](http://edf-feph.org/newsroom/news/statement-italian-organisations-massacre-innocents)" signed by several Italian organisations <http://edf-feph.org/newsroom/news/statement-italian-organisations-massacre-innocents>

⁴⁴ Quelles mesures prévoit le nouveau plan, Septembre 2020, <https://paperjam.lu/article/quelles-mesures-prevoit-nouvel>

⁴⁵ Covid-19: pessoas com elevado grau de deficiência não têm de usar máscara ou viseira, June 2020, <https://tvi24.iol.pt/sociedade/coronavirus/covid-19-pessoas-com-elevado-grau-de-deficiencia-nao-tem-que-usar-mascara-ou-viseira>

⁴⁶ 43 muertos en 15 días en una residencia de mayores de Leganés Norte, 29 March 2020,

<http://www.telemadrid.es/programas/telenoticias-fin-de-semana/muertos-residencia-mayores-Leganes-Norte-2-2217698210--20200329022634.html>

⁴⁷ Juzgado de lo Social de Teruel, Sección 1ª, June 2020, rec. nº 114/2020

El Supremo falla que Sanidad lesionó los derechos de los médicos por la falta de EPI, 11 October 2020, https://www.elconfidencial.com/espana/2020-10-11/tribunal-supremo-sanidad-derechos-medicos-epi_2784703/

Residential care institutions

Living conditions

Life quality of people living in residential institutions during the Covid-19 was overall bad.

At the beginning of lockdown, social isolation and prohibition to see family members was the norm. People were isolated in their rooms, there were restrictions to the mobility and prohibitions to go see family members and friends.

Living in institutions also led to higher risk of exposure to the virus, especially in bigger and congregated institutions. In some, devoted care personnel stayed during the whole confinement fearing to expose their patients to the virus, whereas in other it was mandatory for them to stay and/or be isolated in separate facilities. But in most cases, staff was reduced, people living there had no possibility to see each other and were exposed to the virus as care personnel would go from room to room as well as outdoors with a risk of spreading the virus.



The UN Special Rapporteur on the rights of persons with disabilities highlighted the high risk of contamination in institutions and called for restrictions on contact with loved ones to be narrowly tailored.⁴⁸ Yet, some countries made the decisions to discharge hospital patients into care homes without testing them for the virus, creating high risks of contamination.⁴⁹ The UK government even mentioned it *"very unlikely that people receiving care in a care home will become infected."*⁵⁰

While several Member States gradually lifted bans on visits to institutional settings for children and adults with disabilities, after criticism from the care sector, disability organisations and organisations representing older people, some countries kept very long and strict restrictions.

⁴⁸ COVID-19: Who is protecting the people with disabilities? – UN rights expert, UN OHCHR, 17 March 2020,

<https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=25725>

⁴⁹ Coronavirus: how the government breached disabled people's rights 17 times during the pandemic, 23 July 2020,

<https://www.disabilitynewsservice.com/coronavirus-how-the-government-breached-disabled-peoples-rights-17-times-during-the-pandemic/>

⁵⁰ Guidance for social or community care and residential settings on Covid-19,

<https://www.gov.uk/government/publications/guidance-for-social-or-community-care-and-residential-settings-on-covid-19/guidance-for-social-or-community-care-and-residential-settings-on-covid-19#guidance-on-facemasks>

***"What changed with the pandemic?
I am locked up in the centre.
I cannot go to therapies,
to the store.
I feel bad from all this.
It has been like this for half a year" ⁵¹***



Austria: from May, the Ministry of Health published recommendations to allow the gradual opening of residential institutions, with prerequisites, such as the systematic testing of employees and residents, social distancing and delimited visiting areas.⁵²

Belgium: UNIA, the equality body, noted that parents of children with disabilities living in institutions had to make a choice between bringing their child home or going for long periods without seeing them.⁵³

When lockdown measures started to diminish, strict restrictions remained, e.g. one visitor at the time, only in outdoor areas and always the same person.⁵⁴ The Covid-19 Care Task Force determined strict conditions from the 4th of May to allow visits for care providers, with the possibility for more than one person to visit as long as these persons belong to the same "contact bubble". Plus, sufficient staff, protective equipment and a risk assessment plan had to be made.⁵⁵ Disability organisations asked for *"priority access to tests for persons with disabilities"*

⁵¹ Interview of residential care institution in Poland, by the Polish Disability Forum.

<https://www.youtube.com/watch?v=hCD6JnGyWOw&feature=youtu.be&fbclid=IwAR3bm6qSHX12rQCz21-kCQfG9C6thLMYm2NPQTCDYfe7xHLkPI-OLF6FD1Q>

⁵² Besuche wieder erlaubt: Begegnungszonen im Altersheim, 28 April 2020, <https://kurier.at/chronik/oesterreich/besuche-wieder-erlaubt-begegnungszonen-im-altersheim/400825352>

⁵³ COVID-19 : des mesures de protection dans le respect des droits fondamentaux, Unia 20 March 2020, <https://www.unia.be/fr/articles/covid-19-des-mesures-de-protection-dans-le-respect-des-droits-fondamentaux>

⁵⁴ Maatregelen van de Nationale Veiligheidsraad van 15 april, 15 April 2020, https://www.belgium.be/nl/nieuws/2020/maatregelen_van_de_nationale_veiligheidsraad_van_15_april_2020

Consignes aux centres de jour et d'hébergement accueillant des personnes handicapées, 21 April 2020, <https://www.vaph.be/sites/default/files/documents/15288/mededeling-vaph-10-bezoekregeling-14-mei-2020.pdf>

⁵⁵ Richtlijnen bezoekregeling voor personen met een handicap die verblijven bij vergunde zorgaanbieders of in multifunctionele centra, 14 May 2020, <https://www.vaph.be/documenten/mededeling-aan-personen-met-een-handicap-die-verblijven-bij-vergunde-zorgaanbieders>

*residing in institutions and their relatives in order to enable them to resume essential family contacts."*⁵⁶

Denmark: on the 25th of April, and following numerous criticisms, people living in so called care homes were allowed 1 or 2 regular visitors, in theory in outdoors areas.⁵⁷

England: self-advocacy organisations campaigned on social media with the hashtag #right2home to raise awareness on the right to live where people with intellectual disabilities want to, near their home and families, as during the lockdown some people in secure units were not allowed to see other people and family carers.⁵⁸

Estonia: out of the 178 care homes, 13 were infected by Covid-19. Following this, strict restrictions were put in place by the government with no visits allowed. Some institutions were closed to the public with health care staff also isolated with the people living in institutions.⁵⁹ In certain regions, following the number of infections,

cities decided to test all healthcare professionals, such as in Pärnu.⁶⁰

Finland: on the 15th of May, updated instructions on the prevention of coronavirus infections in units providing 24-hour care and treatment were issued by the Ministry of Social Affairs and Health, which mentioned that visits were still prohibited, but secure units could be set up to enable visits.⁶¹ In some other institutions, residents from a housing service provider for people with intellectual disabilities have not been allowed to meet their families since lockdown started and until it ended. People with disabilities in institutions were prohibited of going back to their families, even those who were not infected by the coronavirus.⁶² Restrictions to the mobility of people with disabilities are claimed to be unlawful. A complaint was lodged with the Ombudsman for Equality concerning housing services for people with intellectual disabilities and criticising the general prohibition on visits.⁶³

⁵⁶ Quand pourrions-nous ressortir des institutions (ou y revenir) ?,

<https://www.inclusion-asbl.be/actualites/quand-pourrions-nous-ressortir-des-institutions-ou-y-revenir/>

⁵⁷ Borgere på sociale botilbud kan nu modtage besøg på udeareale, 13 May 2020,

<https://sim.dk/nyheder/nyhedsarkiv/2020/maj/borgere-paa-sociale-botilbud-kan-nu-modtage-besog-paa-udearealer/>

⁵⁸ Gary Bourlet, co-founder of Learning Disability England, and Samantha Clark, chief executive of Learning Disability England on self-advocates in England during the Coronavirus emergency in a webinar held by Inclusion Europe, 22nd of May 2020, <https://www.inclusion-europe.eu/wp-content/uploads/2020/03/2020-05-22-Self-advocacy-activities.pdf>

⁵⁹ Uude koroonaviirusesse nakatunuid on tuvastatud 13 hooldekodus, 20 April 2020, <https://vorumaateataja.ee/koik->

[uudised/eesti-elu/24941-uude-koroonaviirusesse-nakatunuid-on-tuvastatud-13-hooldekodus](https://www.err.ee/1083581/parnu-tammiste-hooldekodus-tuvastati-nakkus-20-inimesel)

⁶⁰ Pärnu Tammiste hooldekodus tuvastati nakkus 20 inimesel, 29 April 2020, <https://www.err.ee/1083581/parnu-tammiste-hooldekodus-tuvastati-nakkus-20-inimesel>

⁶¹ Ministry of Social Affairs and Health has updated instructions on prevention of coronavirus infections in units providing 24-hour care and treatment, 15 May 2020, <https://stm.fi/en/-/stm-paivitti-ohjetta-koronavirustartunnan-ehkaisysta-ymparivuorokautisen-hoidon-toimintayksikoissa-toimintakykya-ja-yhteydenpitoa-laheisiin-tuetaan-my>

⁶² Rörligheten för personer med funktionsnedsättning begränsas lagstridigt, 8 May 2020,

<https://fdv.fi/sv/kontakt/media/pressmeddelanden/article-143777-73472-rorligheten-for-personer-med-funktionsnedsattning-begransas-lagstridigt>

⁶³ For more information, see: <https://www.hs.fi/kaupunki/art-2000006504901.html>.

France: the visit ban was lifted end of April, with the possibility for two members of the family to come visit, under the responsibility of service providers.⁶⁴

Germany: the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth created a “Frequently Asked Question” format webpage to answer questions on how to visit and keep in touch with “old people”, also providing information for people living in institutions.⁶⁵

The organisation representing the interests of patients and persons in care institutions issued an urgent call not to keep infected persons in the institution.⁶⁶

Greece: psychiatric units locked people in their rooms and deprived them of access to mobile phones and the internet. They were often not allowed to contact their family and friends, or only had the possibility to use one single phone, which increased the chance of transmitting Covid-19.⁶⁷

Hungary: following massive numbers of contamination in care homes, the National Chief Medical Officer ordered

the Municipality of Budapest to implement immediate measures such as guaranteeing the continuity of care provision. Indeed, in some institution there were serious problems of doctors who did not come, which contributed to the late detection of infections.⁶⁸

Italy: disability organisations intervened in a letter: “These are people who die in silence, often they are not even included in the count of ‘deaths from Covid-19’ because they have been denied the right to be tested, as some mayors are already denouncing. People about whom it is said ‘they would have died anyway’. However, we know - and the statistics confirm - that if properly treated they could have lived for one, two, ten, twenty years”.⁶⁹

In another letter to the government, they highlight the numerous problems that residential structures have been experiencing, whether it is people with disabilities or workers who have been abandoned and the numerous deaths. The document underlines the management and organisational problems. Adding to this the profound economic crisis due to the Covid-19, there will be serious repercussions on

⁶⁴ Coronavirus : dans les Ehpad ou à domicile, le confinement des personnes âgées « allégé », 20 April 2020,

⁶⁵ Angebote für ältere Menschen, April 2020,

<https://www.bmfsfj.de/bmfsfj/themen/corona-pandemie/angebote-fuer-aeltere-menschen>

⁶⁶ Maßnahmen für Pfleger in der Corona-Krise reichen nicht, March 2020,

<https://ga.de/news/panorama/massnahmen-fuer-pfleger-in-der-corona-krise-reichen-nicht-aid-49680739>

⁶⁷ Τα δικαιώματα των ψυχικά ασθενών στην εποχή της πανδημίας COVID-19, May 2020,

https://mentalhealth-law.blogspot.com/2020/03/covid-19.html?fbclid=IwAR0Q-RNXOdIGBH0SIUPpNgaqY5xCzY633_Q13QZ4WVKfC0bHbgsJmw57d4

⁶⁸ Pesti úti idősotthon – Azonnali intézkedések végrehajtására kötelezte az országos tisztifőorvos a Fővárosi Önkormányzatot, 10 April 2020, <https://koronavirus.gov.hu/cikkek/pesti-uti-idosotthon-azonnali-intezkedesek-vegrehajtasara-kotelezte-az-orszagoss-tisztifoovos>

⁶⁹ Statement by Italian organisations - 30 March 2020, translated version by the European Disability Forum of the statement “la strage degli innocenti” signed by several Italian organisations <http://edf-feph.org/newsroom/news/statement-italian-organisations-massacre-innocents>

the quality and the continuity of services for people with severe disabilities and non-self-sufficient elderly people, as well as the related maintenance of current employment levels.⁷⁰

Disability organisations⁷¹ called on the government to intervene in institutions, both in those where Covid-19 cases had already occurred and those spared, to establish an “Active Surveillance Model” to prevent the spread of the infection and ensure full respect for the rights of citizens with disabilities and workers.⁷²

Luxembourg: important number of infections were also declared in care homes,⁷³ and restrictions were also applied to visitors when the reopening started.⁷⁴

Malta: *Agenzija Support*, the agency providing services and support to persons with disabilities restricted visits to residential centres and day centres were closed. Later on, professionals from the agency conducted webinars to

help affected persons and their parents cope with the challenges and adapt to the change in daily routines.⁷⁵ Family members said, they would have wished to be offered some physical and/or mental support through that specific time.⁷⁶

Netherlands: from the 11th of May, the government allowed visits in a first group of nursing homes, but with strict requirements.⁷⁷

In September, the Association for the Disabled Care expressed its concern about the shortage of tests for care workers, as it impacts the quality of care for persons with disabilities.⁷⁸

The disability organisation *Ieder(in)* received numerous reports of people experiencing interruptions in care or support and placed in isolation when another resident or a carer was possibly infected. Some day care facilities suddenly closed, without alternatives for users. Additionally, residents and their families were not consulted on

⁷⁰ Anffas, Agespi, Anaste, ANSDIPP, ARIS and Uneba, sent a joint letter to the attention of the Italian Parliament, the Presidency of the Council of Ministers, the Ministry of Health, the Ministry of Labor and Social Policies, the Regions, the Unified Conference (Conferenza Unificata - an Italian legal institution) and the National Association of Italian Municipalities (ANCI) <http://www.anffas.net/dld/files/INQUADRAMENTO%20SU%20REMUNERAZIONE%20PERIODO%20DI%20SOSPENSIONE%20DEI%20SERVIZI%20E%20RICHIESTA%20DI%20INTERVENTO%20A%20LIVELLO%20CENTRALE.pdf>

⁷¹ Anffas, United for Autism (Uniti per l'Autismo), Angsa, the Italian Society of Environmental Medicine (Società Italiana di Medicina Ambientale – SIMA), and the National Research Council (CNR – Consiglio Nazionale delle Ricerche)

⁷² COVID-19 e RSD: necessario ed urgente attivare un modello di sorveglianza attiva per tutelare le fasce più a rischio, 20 April 2020,

<http://www.anffas.net/it/news/14111/covid-19-e-rsd-necessario-ed-urgente-attivare-un-modello-di-sorveglianza-attiva-per-tutelare-le-fasce-piu-a-rischio/>

⁷³ Fiche ARS, stratégie de prise en charge des personnes âgées en établissements et à domicile dans le cadre de la gestion de l'épidémie de Covid-19, 30 March 2020, <https://solidarites-sante.gouv.fr/IMG/pdf/strategie-prise-en-charge-personnes-agees-covid-19.pdf>

⁷⁴ Reprise des visites dans les structures pour personnes âgées dans le cadre du dé-confinement progressif, 27 April 2020

⁷⁵ Social security responses to Covid-19: the case of Malta, 19 June 2020, <https://www1.issa.int/news/social-security-responses-covid-19-case-malta>

⁷⁶ Information provided by the disability organisation MFOD, October 2020

⁷⁷ Minister de Jonge wil vanaf 11 mei test met bezoek in verpleeghuizen, *nederlands Dagblad*, 27 April 2020, <https://www.nd.nl/nieuws/politiek/968522/de-jonge-wil-vanaf-11-mei-weer-bezoek-toelaten-in-aantal-verpleeg>

⁷⁸ Gehandicaptenzorg in gevaar door tekort aan testcapaciteit, September 2020,

<https://nos.nl/artikel/2347042-gehandicaptenzorg-in-gevaar-door-tekort-aan-testcapaciteit.html>

measures affecting them and that visits were denied.⁷⁹

Poland: the largest residential institution for people with intellectual disabilities had 405 residents and 12 members of the staff tested positive.⁸⁰ In another residential institution, 52 residents (out of 67) and 8 staff member (out of 14) got infected.⁸¹ Following this, medical students, nurses and doctors volunteered to help and a company offered to disinfect some buildings for free in Warsaw.⁸² Statistics show that people living in residential institutions were almost 17 times more at risk of contracting Covid-19.⁸³ While the general population had an infection rate of 0.053% and a mortality rate of less than 0.01%, those living in institutions had an infection rate of 0.9% and a mortality rate of 0.29%.⁸⁴

Portugal: in March, and revised in July,⁸⁵ the Directorate-General for Health issued a set of guidelines for the visits to residential institutions for the elderly

(ERPI) and to social support establishments for children, youth, elderly and people with disabilities.⁸⁶ People with disabilities living in residential units were not able to receive visits from family members or friends, during the lockdown. They also had their access to rehabilitation services or to other activities stopped. In some cases, when the occupational activity centre was in the same structure, they were able to continue to attend the day centre, but with limitations on the activities provided.

Romania: over 300 residents and staff were infected in a Neuro-psychic Recovery and Rehabilitation Centre in Suceava.⁸⁷

242 residents (out of 369) in a psychiatric institution were locked up in a separate building because they were infected with Covid-19. The residents and the staff should have been admitted to the hospital, however, only the staff was admitted.⁸⁸ In the

⁷⁹ Brief Kamer: voorkom de fouten van de eerste corona-golf, October 2020, <https://iederin.nl/brief-kamer-voorkom-de-fouten-van-de-eerste-corona-golf/>

⁸⁰ Przebadali ponad 650 osób w największym domu pomocy w Polsce. Było nerwowe oczekiwanie, są wyniki, 18 May 2020, <https://tvn24.pl/wroclaw/koronawirus-w-polsce-dps-legnickie-pole-badanie-650-osob-w-najwiekszym-osrodku-pomocy-w-kraju-4583774>

⁸¹ Ognisko koronawirusa pod Radomiem. Zakażonych 60 osób w domu pomocy społecznej w Niedabyli, 28 March 2020, <https://wiadomosci.gazeta.pl/wiadomosci/7,173952,25827056,ognisko-koronawirusa-pod-radomiem-zakazonych-60-osob-w-domu.html>

⁸² Studenci, pielęgniarki i lekarze. Ochotnicy chcą ratować dom opieki przy Bobrowieckiej, 14 April 2020, <https://tvn24.pl/tvnwarszawa/mokotow/koronawirus-w-warszawie-w-domu-opieki-przy-bobrowieckiej-pomoga-studenci-medycyny-4554829>

⁸³ Information provided by the disability organisation PSONI, October 2020

⁸⁴ <https://www.youtube.com/watch?v=hCD6JnGYOW&feature=youtu.be&fbclid=IwAR3bm6qSHX12rQCz21-kCQfG9C6thLMYm2NPQTCDYfe7xHLkPI-OLF6FD1Q>, October 2020

⁸⁵ <https://www.dgs.pt/directrizes-da-dgs/orientacoes-e-circulares-informativas/orientacao-n-0092020-de-11032020-pdf.aspx>

⁸⁶ Coronavirus pandemic in the EU – Fundamental Rights Implications in Portugal. European Union Agency for Fundamental Rights, June 2020, https://fra.europa.eu/sites/default/files/fra_uploads/pt_report_on_coronavirus_pandemic_june_2020.pdf

⁸⁷ Coronavirus pandemic in the EU – Fundamental Rights Implications, European Union Agency for Fundamental Rights, 4 May 2020, https://fra.europa.eu/sites/default/files/fra_uploads/ro_report_on_coronavirus_pandemic_may_2020.pdf

⁸⁸ Read the full letter at: <http://edf-feph.org/urgent-appeal-requesting-access-covid-19-medical-treatment-romania>

beginning of April, the government issued an ordinance for social care workers to be isolated at work for periods of 14 days, alternated by two weeks in preventive isolation at home.⁸⁹ After being hospitalised, residents with disabilities were infected with Covid-19 in the Deva Country Hospital and the Hunedoara Hospital, and were sent to residential centres from Păclișa, Brănișca and Orăștie, without being tested.⁹⁰

Slovenia: many families were asked to take their relative with disabilities home, which heavily increased pressure on families, as there were no community-based support services available and the financial support stayed with institutions and did not follow the persons with disabilities. On the other hand, families of those who stayed in institutions were worried for their family members in isolation.⁹¹

242 residents (of 369) in a psychiatric institution were locked up in a separate building because they were infected. The residents and staff should have been admitted to a hospital – only staff were.⁹²

Death rates in institutions

Collecting accurate information on death rates in institutions is still difficult, as countries throughout the European Union collect and publish data in a different manner and the death rates of people with intellectual disabilities in institutions are nearly never reported.

Some countries put people in nursing homes for elderly people to create space in hospitals. Many people with intellectual disabilities are being placed in nursing homes, even if they are of much younger age. This makes it highly possible for people with intellectual disabilities to be among the victims of Covid-19 reported deaths in the nursing homes for elderly people.

⁸⁹ COVID-19 : protecting residents with disabilities and the elderly by isolating employees in nursing and social care homes, Centre for Legal resources, 16 April 2020, <https://www.crl.ro/en/romania-covid-19-protecting-residents-with-disabilities-and-the-elderly-by-isolating-employees-in-nursing-and-social-care-homes/>

⁹⁰ Covid-19: Romania is paying in human lives the price of a failed deinstitutionalisation process,

<http://covid19.crl.ro/en/covid-19-romania-is-paying-in-human-lives-the-price-of-a-failed-deinstitutionalisation-process/>

⁹¹ National Consultation of Sožitje Slovenia on the Impact of the Covid-19 Pandemic on Children, Adolescents, Adults and the Elderly with Intellectual Disabilities and their Families / Guardians, 2020

⁹² See Romania, above

“The share of Covid-19 related deaths in care homes - where older people with disabilities are overrepresented - ranges from 19% to an astonishing 72%.”⁹³

Finland: the media reported in April that national data did not include deaths in care homes in the Helsinki and Uusimaa districts, as municipalities, who monitor the situation in care homes, had not submitted the data to the hospital district.⁹⁴

Germany: figures referring to institutional care included residential

care facilities for older people, facilities for persons with disabilities, homeless shelters, prisons and communal settings for refugees and asylum seekers.⁹⁵

Poland: an NGO raised concerns that data provided only covered nursing homes, omitting data from other care and treatment facilities.⁹⁶

Despite the lack of harmonisation throughout Europe and non-disaggregated data, there are some numbers on the number of people dying.

Belgium: 6,467 people, half of the the total, died in residential care settings.⁹⁷

France: during the Coronavirus crisis, 300 people with disabilities have died in hospitals (May 2020). The government does not have yet the figures regarding

people with disabilities who died at home.⁹⁸

Ireland: there have been 100 outbreaks of Covid-19 cases confirmed in disability services, 36 in mental health facilities

⁹³Coronavirus and human rights: New UN report calls for disability-inclusive recovery, October 2020, <https://www.un.org/fr/desa/coronavirus-and-human-rights-new-un-report-calls-disability-inclusive-recovery>

⁹⁴ Finland's coronavirus fatalities likely under-reported by dozens, April 2020, https://yle.fi/uutiset/osasto/news/finlands_coronavirus_fatalities_likely_under-reported_by_dozens/11312030

⁹⁵ Daily Situation Report of the Robert Koch Institute, May 2020, https://www.rki.de/DE/Content/InfAZ/N/Neuartiges_Coronavirus/Situationsberichte/2020-05-31-en.pdf?__blob=publicationFile

⁹⁶ COVID-eutanazji nie było, ale prokuratura przygląda się DPS-om, May 2020, <https://serwisy.gazetaprawna.pl/zdrowie/artykuly/1477517,dps-zol-koronawirus-prokuratura-sprzet-ochronny-personel-medyczny.html>

⁹⁷ Amnesty International. https://www.amnesty.be/IMG/pdf/20201116_rapport_belgique_mr_mrs.pdf

⁹⁸ Unapei on the Impact of Coronavirus emergency in France, Webinar held by Inclusion Europe, May 2020, <https://www.inclusion-europe.eu/wp-content/uploads/2020/03/2020-05-13-France-impact-of-coronavirus.pdf>

(May),⁹⁹ with 16 confirmed deaths in residential settings.¹⁰⁰

Italy: according to the report of the Superior Health Institute, (Istituto Superiore di Sanità) "Covid-19 Epidemic - National Update" of 16 June 2020¹⁰¹ the majority of cases (39.2%) contracted the disease in a nursing home or in a residence for people with disabilities, (23.2%). Anffas recorded outbreaks in 17 of its health residences for people with disabilities (out of 156), with 57 persons with disabilities and 52 staff members who were infected, and 5 deaths among persons with disabilities.

Netherlands: the mortality rate doubled among residents of institutional settings in week 14 (30 March - 5 April) compared with the average rate for the first weeks of 2020.¹⁰²

Portugal: nursing homes for older people are associated with 40 % of all Covid-19 related deaths in Portugal (April).¹⁰³ In mid-August, the percentage dropped a bit (38,7%). From the total of

1 761 deaths, 681 were of people in nursing homes, most of them in the north of the country (309) and Lisbon region (206).

Beginning of September, there were still 23 nursing homes with active cases of Covid-19, 19 of them in the region of Lisbon and 4 in the north of Portugal.¹⁰⁴

There is no data regarding the number of deaths or infections in residential units among people with disabilities, nor of the number of people with disabilities who died due to the Covid-19.

Romania: the Romanian National Authority for the Rights of Persons with Disabilities, Children and Adoptions reported that 10% of the country's total Covid-19 related deaths were of people with disabilities living in institutions.¹⁰⁵

Spain: it is estimated that 19 983 people over 65 years old have died of Covid-19 in retirement homes during the pandemic¹⁰⁶, which represent around 65% of all Covid-19 related deaths in the country. The organisation representing people with intellectual disabilities,

⁹⁹ <https://www.thejournal.ie/disability-settings-covid-19-outbreaks-5090731-May2020/>

¹⁰⁰ Mortality Census of Long Term Residential Care Facilities: 1 January - 19 April 2020, May 2020,

<https://www.gov.ie/en/publication/868ad8-mortality-census-of-long-term-residential-care-facilities-1-january-/>

Deep concerns' about lack of reporting of Covid-19 deaths among people with intellectual disabilities, April 2020, <https://www.thejournal.ie/inclusion-ireland-simon-harris-covid19-5084581-Apr2020/>

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https://www.epicentro.iss.it/coronavirus/bollettino/Bollettino-sorveglianza-integrata-COVID-19_16-giugno-2020.pdf

¹⁰² Sterfte onder bewoners van institutionele huishoudens bijna verdubbeld, News release, 16 April 2020,

<https://www.cbs.nl/nl-nl/nieuws/2020/16/sterfte-onder-bewoners-van-institutionele-huishoudens-bijna-verdubbeld>

¹⁰³ Portugal, Directorate-General for Health press conference, 24 April 2020,

¹⁰⁴ <https://covid19.min-saude.pt/ha-23-lares-de-idosos-com-surtos-ativos-em-portugal/>

¹⁰⁵ Situația răspândirii epidemiei COVID-19 în sistemul de asistență și protecție a copilului la finalul stării de urgență

<http://andpdca.gov.ro/w/situatia-raspandirii-epidemiei-covid-19-in-sistemul-de-asistenta-si-protectie-a-copilului-la-finalul-starii-de-urgenta/>

¹⁰⁶ Radiografía del coronavirus en residencias de ancianos: más de 19.900 muertos con COVID-19 o síntomas compatibles, RTVE, September 2020,

<https://www.rtve.es/noticias/20200909/radiografia-del-coronavirus-residencias-ancianos-espana/2011609.shtml>

Plena Inclusión, estimated in April that 140 people with disabilities died in institutional settings,¹⁰⁷ but this number is likely to be much higher. There is a lack of disaggregated data regarding Covid-19 related deaths in institutions.

Sweden: data from about 1 700 death certificates in Sweden show that 90 % of those dying of Covid-19 were 70 or older, and almost 50 % of deaths related to Covid-19 are of persons over 70 living in nursing homes (April).¹⁰⁸ More than two-thirds of the 5 776 deaths were older people in care settings, the

majority in residential homes (August).¹⁰⁹

United Kingdom: over 22 000 care home residents died because of Covid-19 (May).¹¹⁰

The Care Quality Commission in England conducted a research on the number of deaths of persons with intellectual disabilities between April and May and found that there was a 134% increase in the number of death notifications this year in comparison to the same period last year.¹¹¹

¹⁰⁷ Plena Inclusión estima unas 140 muertes en centros de personas con discapacidad intelectual por COVID-19, EuropaPress, April 21 2020, <https://www.europapress.es/epsocial/igualdad/noticia-coronavirus-plena-inclusion-estima-140-muertes-centros-personas-discapacidad-intelectual-covid-19-20200421133457.html>

¹⁰⁸ Pressträff om covid-19 14 April 2020, <https://www.youtube.com/watch?v=FgcDLWD0PFY>

¹⁰⁹ How Covid exposed the world's lack of care, 14 August 2020, <https://unherd.com/2020/08/how-covid-exposed-the-worlds-lack-of-care/>

¹¹⁰ Research estimates put 'real' care home COVID-19 death toll at over 22,000, 14 May 2020 <https://www.carehomeprofessional.com/research-estimates-put-real-care-home-covid-19-death-toll-at-over-22000/>

¹¹¹ CQC publishes data on deaths of people with a learning disability, 2 June 2020 <https://www.cqc.org.uk/news/stories/cqc-publishes-data-deaths-people-learning-disability>

Education

Home schooling

The consequences of Covid-19, such as the shutdown of schools and other social distancing measures, constituted a major problem for learners with intellectual disabilities, their families and teachers. Across Europe, schools, governments and organisations found new ways to enable students to pursue their education and development. Several EU member states introduced distance learning to ensure the continuity of education.

Home-schooling can be difficult for learners with or without disabilities, but because of the prevailing discrimination, some aspects are more problematic for learners with intellectual disabilities, i.e. inaccessible technology, lack of support for learners, especially those with complex support needs, and a drastic change in the routine.

Therefore, most of the people with intellectual disabilities were unable to continue their learning and development during the coronavirus lockdown, which could have dramatic consequences on the development of children with intellectual disabilities. Professionals warned against potential regressions for children who stopped learning.



Estonia, Italy and Latvia provided guidelines to guarantee access to education to learners with disabilities, but this was not the case for most EU countries.¹¹²

Belgium: civil society organisations drew attention to the difficulties to access distance learning of children with

¹¹² Estonia : Soovitud õpetajale, koolijuhile, lapsevanemale, noortevaldkonnale, March 2020,

<https://www.hm.ee/et/soovitud-opetajale-koolijuhile-lapsevanemale>

Italy: Emergenza sanitaria da nuovo Coronavirus. Prime indicazioni operative per le attività didattiche a distanza, March 2020,

<https://www.usr.sicilia.it/index.php/tutte-le-news/3807-emergenza-sanitaria-da-nuovo-coronavirus-prime-indicazioni-operative-per-le-attivita-didattiche-a-distanza>

Latvia: Mācības attālināti, vadlīnijas. Izglītības un zinātnes ministrija

disabilities, and the financial burden it represented for parents.¹¹³

Bulgaria: the Ombudsman together with the CRPD Monitoring Council issued state recommendations to make school education accessible for children with disabilities.¹¹⁴

Croatia: it was significantly challenging to offer support to children with disabilities during the pandemic, as they needed their individual classroom assistants. Due to the lack of instructions, teachers used social platforms to connect and exchange ideas on the challenges.

France: online learning was put in place, but many children with intellectual disabilities could not attend these online classes as they did not have the digital tools required. Partial support from teachers was insufficient, and families were not able to provide extra support due to structural barriers, causing an impact on the quality of the education received.¹¹⁵ That is why organisations, such as UNAPEI, provided digital support to students with intellectual

disabilities, and shared a number of educational teaching resources with carers (i.e. educational games, nursery rhymes, speech therapy activities, examples of planning to organise the day).¹¹⁶

Germany: Inklusion Bayern highlighted that many children who had personal support during class lost their support while home-schooling. While the right to support in times of home-schooling is a legal entitlement, neither the municipalities or the district as cost bearers, nor the welfare associations, have complied with the obligation to inform the families.¹¹⁷

Ireland: a survey with 733 parents of children with disabilities showed that home education was not working for many children with disabilities.¹¹⁸

Italy: parents of students with complex support needs drew government's attention by demanding that trained teachers and assistants would be allowed to provide support for their children at home.¹¹⁹ Distance learning has brought out once again the

¹¹³ GRIP network education is concerned about the restart of the schools, 12 May 2020,

<https://www.gripvzw.be/nl/artikel/397/netwerk-onderwijs-van-grip-maakt-zich-zorgen-over-de-heropstart-van-de-scholen>

¹¹⁴ Rights of Persons with Disabilities during COVID-19 and beyond. ENNHRI CRPD working group newsletter. February-June 2020, issue I.

¹¹⁵ Information obtained from the French disability organisation Unapei, October 2020

¹¹⁶ Clara Alibert, UNAPEI on the Impact of Coronavirus emergency on people with intellectual disabilities, families in France in a webinar held by Inclusion Europe on the 13th of May 2020,

<https://www.inclusion-europe.eu/wp-content/uploads/2020/03/2020-05-13-France-impact-of-coronavirus.pdf>

¹¹⁷ Wie behinderte Kinder beim Home-Schooling benachteiligt werden, 21 May 2020,

<https://www.mainpost.de/regional/wuerzburg/wie-behinderte-kinder-beim-brhome-schooling-benachteiligt-werden;art735,10448975>

¹¹⁸ Home education not working for many children with disabilities, May 2020,

<http://www.inclusionireland.ie/content/news-items/1859/home-education-not-working-many-children-disabilities>.

¹¹⁹ Antonella Perini started this [petition](#) to Presidente del Consiglio dei Ministri Giuseppe Conte, Luca Zaia, Elena Bonetti and Lucia Azzolina : Emergenza coronavirus: Gianluca, bimbo disabile a casa senza aiuti.

discrimination against students with disabilities, in particular with intellectual and neurodevelopmental disabilities. Students with disabilities have in fact been practically abandoned to themselves: they were unable to attend distance education because they did not have the appropriate support, possibly losing all the important progress made in the months preceding the lockdown. To support the students and their teachers, Anffas created a dedicated section on its website with documents in easy-to-read format and with augmentative communication versions¹²⁰.

Malta: at the end of August, more than 87% of the 1 300 educators questioned in a survey said they did not wish to physically go back to schools. Learners might not return to school unless numbers go down.¹²¹ It is clear that students with an intellectual disability did not perform well, or not at all, during distance learning.¹²²

Notwithstanding the various communications passed between the Malta Federation of Organisations Persons with Disability (MFOPD) and the

Ministry for Education requesting MFOPD's participation in the post Covid-19 Education Think Tank, the national umbrella organisation for the disability sector was left out.¹²³

Portugal: students with complex support needs were not fully taken into consideration when designing and providing online or home-schooling solutions. In fact, the activities were not accessible, the timetable was not adapted, and the teachers were not prepared.¹²⁴ This resulted in having students with disabilities totally left out of the school community and of the learning process.

Slovenia: with the closure of schools, students with intellectual disabilities suddenly did not have access to therapies provided in school. Families fear this will impact their child's development.¹²⁵

Spain: every morning during the confinement, public television would broadcast educational material; however, it was not accessible for children with disabilities.¹²⁶

¹²⁰ The documents are still available here

<http://www.anffas.net/it/linguaggio-facile-da-leggere/didattica-a-distanza-risorse-e-materiali-per-alunni-e-studenti-con-disabilita/> 23wq

¹²¹ Students should not return to school until COVID-19 numbers down – union, 21 August 2020,

<https://timesofmalta.com/articles/view/students-should-not-return-to-school-until-covid-19-numbers-down-union.813303>

¹²² Information provided by the disability organisation MFOPD, October 2020

¹²³ Information provided by MFOPD

¹²⁴ Estudo ODDH "Deficiência e COVID-19" - Divulgação de resultados preliminares

http://oddh.icsp.ulisboa.pt/index.php/pt/mediateca/eventos/item/455-covid_estudo

¹²⁵ Information obtained from Slovenian disability organization, Sožitje Slovenia, 2020

¹²⁶ CERMI, El Cermin denuncia ante el defensor del pueblo la ausencia de accesibilidad de los materiales lectivos del Ministerio de Educación que se emiten por televisión durante el cierre de colegios, March 2020,

<https://www.cermin.es/es/actualidad/noticias/el-cermin-denuncia-ante-el-defensor-del-pueblo-la-ausencia-de-accesibilidad-de>

Reopening of schools

In some EU countries, schools for children with intellectual disabilities would not reopen at the same time as mainstream schools. As for the mainstream schools, some of them would not welcome children with intellectual disabilities, or support person and some parents were scared to let children get back to school.

Czechia: mainstream schools started reopening but education settings for children with disabilities remained closed.¹²⁷ The Ombudsman had to intervene.¹²⁸

Croatia: the situation did not improve with the beginning of the new academic year. Students with disabilities and complex support needs are usually schooled through the model of partial integration in mainstream schools, where they attend general educational subjects in dedicated classrooms (language, mathematics, nature, and politics) with a dedicated teacher, and other subjects such as arts, music, psychical education and theology are taught alongside other peers without disabilities. However, with the new guidelines of the Croatian Institute for Public Health and the Ministry of Science and Education¹²⁹, students with disabilities are now only allowed to

receive instruction in their dedicated classrooms. This decision was made to lower the risk of infection, but it constitutes a step back in the process of inclusion as children with disabilities are now completely excluded from their regular classrooms and have no social contact with their peers.

Cyprus: the Education Ministry set a committee to examine the possibility for children with disabilities to get back to school and have their support person on a case-by-case basis. This led to protesting, so in consequence the Commissioner for Administration and academics intervened to prevent the risk of discriminatory and unlawful treatment.¹³⁰

France: the State's Secretary in charge of People with Disabilities said that getting children with disabilities back to school was a priority. However, roughly half of the parents of children with

¹²⁷ The open letter is available at: <https://www.detiuplnku.cz/cs/otevreny-dopis-ministru-skolstvi-a-zdravotnictvi/>.

¹²⁸ <https://www.ochrance.cz/aktualne/tiskove-zpravy-2020/deti-s-postizenim-maji-pravo-chodit-do-skoly/>

¹²⁹ Hrvatski zavod za javno zdravstvo i Ministarstvo znanosti i obrazovanja (2020). Upute za sprječavanje i suzbijanje epidemije covid-19 vezano za rad predškolskih ustanova, osnovnih i srednjih škola u školskoj godini 2020. /2021. https://www.zagreb.hr/UserDocsImages/fotogalerija/gradske%20vijesti/Upute_vrtici_i_skole_24_08_2020_HZJZ-

1.pdf?fbclid=IwAR26X3MV6nAXn_lrkQ3r45nf-418Iz0C-fejQ4xMEqpwDtcisvclbhKJ_Pl

¹³⁰ Επιτροπος Διοικήσεως: Παραβίαση των δικαιωμάτων των παιδιών ΑμεΑ, 21 May 2020,

<https://www.kathimerini.com.cy/gr/kypros/paideia/epitropos-dioikiseos-parabiasi-ton-dikaion-ton-paidiwn-me-eidikes-anagkes> ;

Για άλλη μια φορά τα παιδιά με αναπηρία εκτός σχολείου..., 21 May 2020, <https://paideia-news.com/panepistimio-kyproy/2020/05/21/gia-alli-mia-fora-ta-paidia-me-anapiria-ektos-sxoleiou%E2%80%A6/>

disabilities did not want that their children to go back to school as they are scared.¹³¹ Many were also refused to return to school, due to organisational issues or to lack of staff, but also due to prejudices from the administration.¹³² Shortly after schools were reopened, 28 establishments and 262 classes were closed due to confirmed cases.¹³³

Ireland: the Department of Education was strongly criticised for its lack of support to prepare the return to school. One school even set up an isolation class for children with Covid symptoms in a garden shed.¹³⁴ Out of the 1,2 thousand Irish parents surveyed by AsIAM, 77% of families with a child in the autism spectrum felt that their return to school would need more support, but less than half believe they would receive it.¹³⁵

Italy: on the first day back to school, there was still very little information for families of students and pupils with disabilities – who already have trouble every year to get support. To help students with disabilities to start the year with their peers, the Italian federation to overcome disability, FISH,

worked upstream to present appropriate propositions and operational solutions to the competent institutions, recalling also the need to improve distance learning in anticipation of a new lockdown. Anffas also developed several useful documents for students, families and schools: a *vademecum* and a handbook aiming to support the safe return to school activities and to guarantee the safeguard of the right to education and to an inclusive school.¹³⁶

Malta: schools re-opened in the first week of October. Parents had the possibility to choose whether to send their children to school or online learning. Physical attendance to school was/is not obligatory. The disability organisation MFOPD was never included in the post Covid discussions and decisions regarding the education of pupils with disabilities. A number of teachers who provide specific services such as teachers for the visually and hearing impaired, early intervention services as well as other important services being provided by the National School Support Services stopped. These

¹³¹ Isabelle Chandler, director of Advocacy and Influence at Unapei on the Impact of Coronavirus emergency on people with intellectual disabilities, families in France in a webinar held by Inclusion Europe on the 13th of May 2020,

<https://www.inclusion-europe.eu/wp-content/uploads/2020/03/2020-05-13-France-impact-of-coronavirus.pdf>

¹³² Information obtained from the French disability organisation Unapei, October 2020

¹³³ Coronavirus en France : combien d'écoles et de classes fermées depuis la rentrée ?, 8 September 2020,

<https://www.lanouvelrepublique.fr/a-la-une/coronavirus-en-france-combien-d-ecoles-et-de-classes-fermees-depuis-la-rentree>

¹³⁴ Anger as shed to be used as school Covid-19 isolation room, 25 August 2020,

<https://www.rte.ie/news/education/2020/0826/1161376-isolation-school/>

¹³⁵ Autistic families concerned about the return to school, survey finds, 17 August 2020, <https://asiam.ie/autistic-families-concerned-about-the-return-to-school-survey-finds/>

¹³⁶ Prontuario per il corretto avvio dell'anno scolastico 2020/2021 per bambini/e, alunni/e, studenti/sse con disabilità, loro famiglie, insegnanti e operatori

[http://www.anffas.net/dld/files/Prontuario%20Anffas%20per%20il%20corretto%20avvio%20dell'a%20s%202020%2021%20\(2\).pdf](http://www.anffas.net/dld/files/Prontuario%20Anffas%20per%20il%20corretto%20avvio%20dell'a%20s%202020%2021%20(2).pdf)

teachers were instead used to assist mainstream education, because classes had to be split and more teachers were required.

Spain: during the second phase of the deconfinement, education centres for children with disabilities could welcome their students again, but many regional

governments decided not to reopen them for health-related reasons.¹³⁷

Portugal: return to school only started on the 14th September, and there is still very little information on what will happen for students and pupils with disabilities.

¹³⁷ Las autonomías rechazan reabrir las escuelas para los niños de 0 a 6 años, 15 May 2020,

<https://www.lavanguardia.com/vida/20200515/481148949264/desescalada-escuelas-colegios-apertura-ninos-fases.html>

Access to support and the role of families

Access to support

As there were some strict lockdown measures, a lot of community-based care and support had to stop during the coronavirus emergency. This led people living independently to very problematic situations.

Some people with intellectual disabilities had to go live with their families during the lockdown, and families had to care for them as there was no access to support of any kind.

Support for children also stopped, and many day care centres closed.

More day-to-day aspects changed, such as food delivery: it used to work well for people with disabilities, but being used by everyone during the pandemic it made it unavailable for people with disabilities.



Austria: the Independent Monitoring Committee, the Council of People with Disabilities, and the Self-Advocacy NGO, raised awareness through a press release about the lack of psychosocial services for women with disabilities who often face additional challenges, including caring responsibilities, precarious work and isolation.¹³⁸

Albania: to mitigate the challenges faced by persons with disabilities due to Covid-19, the People's Advocate recommended the government to

ensure financial assistance and support to persons with disabilities, especially to those residing in rural areas, as well as to identify and accommodate homeless people with disabilities.¹³⁹

Belgium: people with disabilities who returned home at the beginning of the Covid-19 outbreak were not allowed to return to day-care centres, leaving behind many families struggling to adequately support them.¹⁴⁰

¹³⁸ Corona crisis: consider situations of women with disabilities, May 2020,

https://www.ots.at/presseaussendung/OTS_20200528_OTS0016/corona-krise-situationen-von-frauen-mit-behinderungen-beachten

¹³⁹ Information on the Activities in protection of the rights of persons with disabilities (April – June 2020),

https://drive.google.com/file/d/1ewDZfASt0DqwZp11AFMGBS_AoOXx2ITPT/view

¹⁴⁰ Le confinement impacte aussi les personnes handicapées: "les familles ne tiendront pas longtemps", La Libre, 21 March 2020, <https://www.lalibre.be/regions/bruxelles/le-confinement-impacte-aussi-les-personnes-handicapees-les-familles-ne-tiendront-pas-longtemps-5e760478f20d5a29c678fcdc>

As for transports, the Belgian rail operator announced at beginning of March it would no longer support people with disabilities. The National Superior Council of Persons with

Disabilities called for those measures to be properly publicised and for a possibility to provide support in urgent situations.¹⁴¹

“Most self-advocacy organisations and support networks are closed and not available as before.

For the ones that were living independently it is difficult as we find ourselves more dependent and left alone.”¹⁴²

Estonia: the Estonian Association of Persons with Reduced Mobility noted that many people were deprived of rehabilitation services during the emergency.¹⁴³

Finland: the Finnish Disability Forum raised awareness on the challenges and difficulties for persons with disabilities to access essential services such as personal support and home care.¹⁴⁴

France: the lockdown was hard to manage for people with intellectual disabilities as well as for people under guardianship, and it has even led to

over-disability situations. The restriction measures applied during the lockdown reinforced obstacles to their daily needs and put in danger their fundamental rights (including access to food, healthcare, and education). For example, the closure of post offices and banks, particularly in rural areas, made it difficult to withdraw cash for people who are not authorised to use a credit card. Many shops no longer accepted cash, people under guardianship could

¹⁴¹ COVID-19: La SNCB n’assiste plus les personnes handicapées, March 2020, <http://ph.belgium.be/fr/nouvelles-amp-presse/20-03-2020-covid-19-la-sncb-n-assiste-plus-les-personnes-handicap%C3%A9es.html>

¹⁴² László Bercse, Chair of the European Platform of Self-Advocates, explains how the COVID-19 pandemic affected the lives of self-advocates and the work of self-advocacy organisations in Europe in a webinar on Self-advocacy activities during the Coronavirus emergency, 22 May 2020, [https://www.inclusion-europe.eu/wp-](https://www.inclusion-europe.eu/wp-content/uploads/2020/03/2020-05-22-Self-advocacy-activities.pdf)

[content/uploads/2020/03/2020-05-22-Self-advocacy-activities.pdf](https://www.inclusion-europe.eu/wp-content/uploads/2020/03/2020-05-22-Self-advocacy-activities.pdf)

¹⁴³ <https://epl.delfi.ee/uudised/ehk-inimesed-nuud-moistavad-eriolukord-andis-oppetunni-puuetega-inimeste-vajadustest-ja-uhiskonna-voimalustest?id=90041897>

¹⁴⁴ Vammaisten ihmisten oikeudet ja niiden toteutuminen koronaviruksen aiheuttamassa poikkeustilanteessa, March 2020, https://vammaisfoorumi.fi/wp-content/uploads/2020/04/vammaisten_oikeudet_STM_310320.pdf

not even buy food.¹⁴⁵ As for food deliveries, the online demand was too high, and no priority was given to people with disabilities. The Ombudsman intervened to remind authorities and shops that payment in cash could not be refused.¹⁴⁶

Ireland: the Oireachtas Special Committee on Covid-19 raised some concerns following the announcement that some day care services for people with intellectual disabilities may not reopen until December or January.¹⁴⁹

Italy: Anffas denounced the state of

***Many shops no longer
accepted cash, people
under guardianship
could not even buy food.¹***

Georgia: the social protection mechanisms under the government's anti-crisis and economic plan did not sufficiently address the needs of persons with disabilities during the crisis. The Ombudsman called upon the government to review the plan and consider specific support measures for persons with disabilities.¹⁴⁷

Hungary: stores did not allow deliveries and no support was provided by the government nor by institutions.¹⁴⁸

total abandonment in which families and their relatives with disabilities were left. During the lockdown, numerous demands were made by families asking for support because services were suspended. They had to take care of a situation that was becoming unsustainable due to the prohibition of leaving their homes, especially for people with intellectual disabilities and neurodevelopmental disabilities, suddenly deprived of their routines and habits.¹⁵⁰

¹⁴⁵ Isabelle Chandler, Unapei on the Impact of Coronavirus in France in a Webinar held by Inclusion Europe, May 2020, <https://www.inclusion-europe.eu/wp-content/uploads/2020/03/2020-05-13-France-impact-of-coronavirus.pdf>

¹⁴⁶ Information obtained from the French disability organisation Unapei, October 2020

¹⁴⁷ Public Defender (Ombudsman) of Georgia, COVID-19, https://drive.google.com/file/d/1z7vze-hjBNVjz0y_Cj1LsBKshUgDoqan/view

¹⁴⁸ COVID-19 Disability Rights Monitor Dashboard, June 2020, <https://www.driadvocacy.org/covid19-drm-dashboard-launch/> ; Hungary <https://www.covid-drm.org/data?country=HU>

¹⁴⁹ Some disability day services may not reopen until December, committee told, July 2020, <https://www.rte.ie/news/coronavirus/2020/0717/1153959-covid-committee-day-services/>

¹⁵⁰ The Anffas magazine La Rosa Blu dedicated to the pandemic situation, July 2020, <https://www.flipbookpdf.net/web/site/952f7cb709b9c7bfa7adbfbab87e780bea7be5e7FBP19955166.pdf.html>

Beginning of October, an amendment led by Anffas, aiming to introduce greater and specific benefits in the workplace for parents with children with disabilities of any age who tested positive for Covid-19 was deposited.¹⁵¹ To date, the Law was not modified but an agenda was voted committing the Government *"to provide for adequate support measures, in the form of paid leave or other similar instruments, [...] also removing any age limit in the application of the benefits, with reference to children with disabilities."*¹⁵²

Luxembourg: Apemh expressed disappointment in September that after the lockdown they had hoped life would gradually get back to normal, but this hope was quickly dashed away and lives stayed punctuated with restrictions and constraint. This led to great frustration as many activities from their services have stopped.¹⁵³

Malta: the Commissioner for the Rights of Persons with Disability raised concerns about the provision of physical, occupational, speech and language therapy services for children with disabilities, which had stopped in March.¹⁵⁴ MFOPD highlighted the fact that all therapies needed by persons with disability should be declared essential therapies so as not to be discontinued. They also highlighted the

fact that safe measures should be taken for those people with disabilities who find difficulties with social distancing to be able to get out of their homes. The state of the mental well-being of people with disabilities and their close family members, and the lack of support received, were continuously brought up by MFOPD.¹⁵⁵

Netherlands: one third of the people relying on home care or support from a district nurse received less or no care due to the Covid-19. Another survey showed that 60 % of people with disabilities have seen the care they need stopped or diminished, with almost half saying their physical wellbeing had deteriorated.¹⁵⁶

Portugal: Day care centres opened gradually since the shutdown ended, but it is believed that most of them are not working at full capacity, since some families prefer their relative with disabilities to remain home with them.

During the shutdown, service providers in charge of the meals had to continue to do so, even if people were not attending the service. They could pick up the meals themselves or get them delivered. This was done to ensure that families did not have too much extra burden and that people still had access to food. The residential support service

¹⁵¹ the amendment XII on art. 21-bis to the Draft Law no. 104/2020 (A.C. 2700)

¹⁵² Information provided by the disability organisation Anffas, October 2020

¹⁵³ Newsletter, September 2020, http://apemh.lu/images/APEMH_Newsletter_N36_final.pdf

¹⁵⁴ Bulletin 3, European Fundamental Rights Agency, June 2020,

https://fra.europa.eu/sites/default/files/fra_uploads/fra-2020-coronavirus-pandemic-eu-bulletin-june_en.pdf

¹⁵⁵ Information provided by MFOPD

¹⁵⁶ Uitstel geplande zorg door de coronacrisis, April 2020, <https://www.patientenfederatie.nl/downloads/peiling/326-onderzoek-uitstel-geplande-zorg-door-de-coronacrisis/file>

(SAS), where people living at home would get the support they needed, was maintained in most cases.

Romania: the Ombuds body expressed his concern on the fact that only few mental health specialists were able to offer online support to persons with psychosocial disabilities, who were deeply affected by the emergency measures.¹⁵⁷

Scotland: the Scottish Human Rights Commission highlighted that social care was one of the most affected during the Covid-19 pandemic. As a result, care packages have been reduced or terminated, which severely impacted the lives of persons with disabilities and their carers.¹⁵⁸

Serbia: the prohibition of movement, which was one of the state measures to combat Covid-19, seriously impacted the support services and assistance for persons with disabilities. The Protector of Citizens called upon Ministries to ensure adequate support for persons with disabilities and issue curfew passes to carers.¹⁵⁹

Slovakia: the Ombuds body reported the cancellation of personal support and

social and health services usually provided to people with disabilities.¹⁶⁰

Slovenia: activities and care centres closed down, interrupting the daily routine and social contacts of persons with intellectual disabilities, which led to irritability, rapid mood swings, apathy, as well as aggression and self-harm.

Moreover, many parents feared contracting Covid-19, as they were worried of who would take care of their child with an intellectual disability, given the large deficits in 'emergency accommodation'.¹⁶¹

Spain: after the lockdown, the regional government of Galicia took the decision to keep day care centres closed and give low-income families a 500€ monthly check to cover the cost of a personal carer. After pressure from local organisations, defending that this was not a solution for most families, day care centres were reopened under strict conditions.¹⁶²

Ukraine: the monitoring of the Commissioner for Human Rights on the CRPD showed that the closure of rehabilitation centres during the Covid-19 pandemic diminished the independence of persons with

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https://www.avpoporului.ro/index.php?option=com_content&view=article&id=526&lang=ro-ro&Itemid=160

¹⁵⁸ The Scottish Human Rights Commission's submission to ENNHRI CRPD Working Group's Newsletter, <https://drive.google.com/file/d/1OTS8p-kGdRr7sBwD3DGtWnDf57Hmwr43/view>

¹⁵⁹ Contribution of Protector of Citizens of the Republic of Serbia, https://drive.google.com/file/d/1RrT7zg9O-5pgYv_IH67u6xKa2mkkIhmH/view

¹⁶⁰ Bulletin 3, European Fundamental Rights Agency, May 2020, https://fra.europa.eu/sites/default/files/fra_uploads/fra-2020-coronavirus-pandemic-eu-bulletin-june_en.pdf

¹⁶¹ National Consultation of Sožitje Slovenia on the Impact of the Covid-19 Pandemic on Children, Adolescents, Adults and the Elderly with Intellectual Disabilities and their Families / Guardians, 2020

¹⁶² Los centros de día podrán abrir en Galicia: atención individual y cita previa, June 10 2020, <https://www.laregion.es/articulo/galicia/centros-dia-podran-abrir-galicia-forma-individual-citaprevia/20200610195042951884.html>

disabilities and increased social tension in families and home settings. It also proved that girls and women

with disabilities were at greater risk of domestic violence when self-isolating.¹⁶³

Family carers

The coronavirus crisis is having immediate impact on the lives of persons with disabilities, and families also feel the burden of this crisis.

To mitigate the impact of school closures, some countries adopted special leave measures and most of them encouraged employers to allow working from home. But for families of persons with disabilities, the coronavirus crisis added an excessive burden to caring and supporting responsibilities as schools and rehabilitation services ceased. Some were even unable to work, facing financial consequences.

The end of the confinement period did not arrange everything for parents. Schooling solutions for children with intellectual disabilities are already challenging under 'normal' circumstances. Adding to it the uncertainty of Covid-19 makes the situation mentally exhausting for parents, some of them on the edge of a burnout.¹⁶⁴

Austria: financial support was also extended to people with care obligations for persons with disabilities because of the closure of care facilities.¹⁶⁵

Belgium: the Belgian family organisations asked for a specific leave for parents with young children or with children with disabilities. In May, the government adopted a Covid-19 leave. Single parents or parents with children

with disabilities could take this leave on a full-time basis.¹⁶⁶

Bulgaria: amendments to the labour code were made to grant annual paid leave, upon request, to certain employees such as mothers or single fathers of a child with disabilities, and employees with a certain degree of disability.¹⁶⁷

Czechia: the closure of many community social services also left

¹⁶³ Input from the Ukrainian Parliament Commissioner for Human Rights to CRPD WG Quarterly Newsletter, <https://drive.google.com/file/d/1pXyEhOtR6eAWy4ebCydrBdCcdkZeibym/view>

¹⁶⁴ La vie des parents n'est toujours pas revenue à la normale depuis la fin du Covid, September 2020,

<http://www.slate.fr/story/195176/rentree-scolaire-covid-19-epuisement-burn-out-crise-charge-sante-mentale-parents-meres-enfants>

¹⁶⁵ 44 neue Gesetze zur Bekämpfung der Corona-Krise abgesegnet, March 2020,

<https://www.diepresse.com/5787945/44-neue-gesetze-zur-bekämpfung-der-corona-krise-abgesegnet>

¹⁶⁶ COFACE Families Europe, The changing face of work and family life under COVID-19, October 2020

¹⁶⁷ Закон за мерките и действията по време на извънредното положение, обявено с решение на Народното събрание от 13 март 2020, March 2020 <https://dv.parliament.bg/DVWeb/showMaterialDV.jsp?idMat=147150>

families to care for relatives with disabilities, financial support was extended to them.¹⁶⁸ One of the parents with children below 13 years old could take a "leave of absence", initially receiving 60% of their salary, which was later raised to 80%.¹⁶⁹

Finland: in October, a temporary provision for the "Transmittable Diseases Act" worried disability organisations because it would allow social and health care activities to be changed, without necessarily respecting fundamental rights of people with intellectual disabilities such as the fact that social care professionals would have to perform medical acts or no visits would be allowed.¹⁷⁰

France: after two months of lockdown, sometimes without any respite

solutions, the families are now exhausted, causing burnouts.¹⁷¹

Germany: changes were introduced in parental leave payments, taking the normal salary of the parents as a reference instead of their salary during the Covid-19 crisis.¹⁷²

Italy: people with disabilities' families waited a long time for the Italian Parliament to approve new legislation regarding caregivers. During the pandemic, the families of people with intellectual disabilities were left alone to cope with a burden often far beyond their own strength, due to the total lack of an adequate network of services and supports. Per consequence, Anffas, submitted its own detailed amendment

"As a single mother, I am now caring for my severely disabled son alone, 24/7, without any assistance, without rest, with more demand for shopping, cooking, feeding and intensive care".

¹⁶⁸ Aktuální informace k ošetřovnému
<https://www.cssz.cz/web/cz/aktualni-informace-k-osetrovnemu>

¹⁶⁹ COFACE Families Europe, The changing face of work and family life under COVID-19, October 2020

¹⁷⁰ Kehitysvammaiset ja vastaavaa tukea tarvitsevat ihmiset on huomiotava tartuntatautilain muutoksissa
<https://www.tukiliitto.fi/ajankohtaista/kehitysvammaiset-ja-vastaavaa-tukea-tarvitsevat-ihmiset-on-huomioitava-tartuntatautilain-muutoksissa/>

¹⁷¹ Isabelle Chandler, Director of Advocacy and Influence at Unapei on the Impact of Coronavirus emergency on people with intellectual disabilities, families in France in a Webinar held by Inclusion Europe on the 13th of May 2020,
<https://www.inclusion-europe.eu/wp-content/uploads/2020/03/2020-05-13-France-impact-of-coronavirus.pdf>

¹⁷² COFACE Families Europe, The changing face of work and family life under COVID-19, October 2020

text.¹⁷³ Regarding parental leave, the government adopted an extraordinary parental leave of 15 days with 50% of the salary, or if they could not take this leave, a bonus of 600€ to hire a babysitter. While the general age limit was 12 years old, there was no age limit for families with children with disabilities.¹⁷⁴

Lithuania: the Parliament voted for a financial package introducing sickness benefits for persons supporting people with disabilities in need of care following the closing of day care centres.¹⁷⁵

Luxembourg: a parental leave was granted for families with children below 13 years old, and parents of children with disabilities aged 13 to 18 (or up to 25) were granted leave for family reasons, on condition they receive the special supplementary allowance for children with disabilities.¹⁷⁶

Portugal: two types of financial support were in place for carers when the person they care for could not attend the services they used to attend:

- the right to justification of absences from work without loss

of rights, except in respect of retribution, with the creation of a monthly support corresponding to 2/3 of their salary, never lower than the minimum wage (635 euros).

- self-employed persons became entitled to exceptional monthly support corresponding to 1/3 of their contribution base for the first quarter of 2020. This support could never be lower or 2,5 higher than the indexed social support (IAS). These financial solutions did not cover school break periods.

However, carers did not get any support (e.g. mental health issues, burnout, etc) to help them cope with this new situation.¹⁷⁷

Slovenia: once Covid-19 measures gradually eased, employers called on their employees to return to work, which presented a challenge for parents taking care of children with intellectual disabilities, as schools and social services were still closed. This has impacted parents' competitiveness in the labour market.

¹⁷³ To download Anffas and Fish memoirs, click here <http://www.anffas.net/it/news/14362/lappello-delle-famiglie-anffas-i-caregiver-non-possono-piu-aspettare/>

¹⁷⁴ COFACE Families Europe, The changing face of work and family life under COVID-19, October 2020

¹⁷⁵ Kokių valstybės paramą gaus darbuotojai, darbdaviai ir prižiūrintys artimuosius?, 19 March 2020,

<https://socmin.lrv.lt/lt/naujienos/kokia-valstybes-parama-gaus-darbuotojai-darbdaviai-ir-priziurintys-artimuosius>

¹⁷⁶ COFACE Families Europe, The changing face of work and family life under COVID-19, October 2020

¹⁷⁷ FAQs COVID-19 Medidas Relativas a Pessoas com deficiência, Suas Famílias e Entidades que lhes Prestam Apoio, April 2020, <http://www.seg-social.pt/documents/10152/16722120/FAQs+defici%C3%A7%C3%A3o+a+%28004%29.pdf/d921bb2e-4e02-4312-a0af-04dc3facf230>

Access to information and consultation

At the beginning of the Coronavirus emergency, people with intellectual disabilities were not given accessible information. Information was not provided in easy-to-read and understand language, which is problematic for people with intellectual disabilities because some cannot access the internet without support to find the information, some have difficulties reading, and some need support to understand the guidelines. The importance of accessible information was however crucial to understand the situation, the risks and the prevention advice such as social distancing.



Moreover, people with disabilities were often portrayed as more “vulnerable” and at risk of getting sick. It is thus a paradox that the information was not made clearly accessible, and actually quite stressful creating an anxiogenic climate.

There were exemptions in some countries to go outside or not wear a mask for people with intellectual disabilities, but some people were insulted and even fined.

Croatia: people with disabilities face many obstacles that prevent them from fully and effectively participating in society, especially now that the country has been placed in the ‘twilight zone’ where the whole country is under great pressure.¹⁷⁸

Concerning accessible information, the Ombudswoman for Persons with Disabilities issued several

recommendations stressing out the importance of accessible information.

Cyprus: people with intellectual disabilities who could not understand the information were fined for not respecting the rules.¹⁷⁹

England: more than 85 persons with disabilities and allies have signed a letter warning National Health Services that its system ignored the needs of

¹⁷⁸ Rights of Persons with Disabilities during COVID-19 and beyond. ENNHRI CRPD working group newsletter. February-June 2020, issue I.

¹⁷⁹ Επέβαλαν πρόστιμο 300 ευρώ σε άτομο με νοητική αναπηρία!, Dialogos, 31 March 2020,

<https://dialogos.com.cy/epevalan-prostimio-300-eyro-se-atomo-me-noitiki-anapiria/>

people with disabilities, as “test and trace” programmes were not accessible. They say the system was designed without thought for access.¹⁸⁰

France: disability organisations quickly collaborated with the government to ensure accessible communication, and translate the authorisation needed to go out in easy-to-read. However, there were still cases of people with intellectual disabilities who accumulated fines because they did not understand they could not leave their house without

Italy: some self-advocates groups from the disability organisation Anffas contributed to support their peers and their families by creating accessible videos and information in easy-to-read language in order to explain the emergency situation and the importance of following sanitary and social distancing rules.¹⁸³

Anffas, through its Crisis Unit, also developed several documents and guidelines written in easy-to-read and augmented communication language concerning multiple themes such as on the situation and how they could better

an official authorisation.¹⁸¹ As police authorities did not receive appropriate training when it comes to intellectual disability, the easy-to-read, many officers did not recognise the easy-to-read version of the authorisation as valid, which proves the importance of universal accessibility of government measures.¹⁸²

Ireland: the people Inclusion Ireland interviewed all agreed that the information on to Covid-19 needed to be made available in easy-to-read.

manage stress, quarantine or how to put health prevention measures into practice (hands-washing, etc.), emergency management in residential institutions,¹⁸⁴ recommendations to frontline staff for the handling of patients with intellectual disabilities,¹⁸⁵ fact sheets and medical history for families.¹⁸⁶ All these documents were created with the contribution and the

¹⁸⁰ Coronavirus: NHS England faces legal action over ‘test and trace access flaws’, 11 June 2020,

<https://www.disabilitynewsservice.com/coronavirus-nhs-england-faces-legal-action-over-test-and-trace-access-flaws/>

¹⁸¹ Isabelle Chandler, Director of Advocacy and Influence at Unapei and Clara Alibert on the Impact of Coronavirus emergency on people with intellectual disabilities, families in France in a Webinar held by Inclusion Europe on the 13th of May 2020, <https://www.inclusion-europe.eu/wp-content/uploads/2020/03/2020-05-13-France-impact-of-coronavirus.pdf>

¹⁸² Information obtained from the French disability organisation Unapei, October 2020

¹⁸³ Watch all the videos about stress management on Anffas YouTube channel here:

<https://www.youtube.com/channel/UCS9782L9UJj5YQxLqviVRtW>

¹⁸⁴ Documento sulla gestione delle emergenze nei centri residenziali, April 2020,

[http://www.anffas.net/dld/files/Gestione%20delle%20emergenze%20nei%20centri%20residenziali%202020_0\(1\).pdf](http://www.anffas.net/dld/files/Gestione%20delle%20emergenze%20nei%20centri%20residenziali%202020_0(1).pdf)

¹⁸⁵ Raccomandazioni per il personale in prima linea per la gestione di pazienti con disabilità intellettive e disturbi del neurosviluppo durante l'epidemia di covid-19, <http://www.anffas.net/dld/files/raccomandazioni.pdf>

¹⁸⁶ All the documents developed by the Crisis Unit of Anffas Nazionale are available here:

<http://www.anffas.net/it/news/13964/creazione-unita-di-crisi-covid-19-anffas-nazionale/>

collaboration of the same people with intellectual disabilities¹⁸⁷.

Luxembourg: information was delivered quickly and in easy to understand.

Netherlands: in October, the disability organisation Ieder(in) wrote a letter to the Dutch Parliament urging them to consult persons with disabilities and their representative organisations in measures affecting them, as well as to include them in Crisis and Support Teams, to avoid making the same mistakes as at the beginning of the pandemic. They also addressed the shortage in suitable care facilities for persons with complex support needs and called upon ministers to ensure their appropriate solution and continuity of support for young persons with disabilities.¹⁸⁸

Portugal: according to disability organisation Fenacerci, government conferences did not reach to people with intellectual disabilities.¹⁸⁹ They did most of the information in easy-to-read, without support from the state.¹⁹⁰ Some

international organisations or the National Institute for Rehabilitation also did. Authorities collaborated with civil society to produce guidelines on institutional care, which was a successful joint effort.¹⁹¹ Disability organisations were in regular contact with the government.

Slovenia: the information provided by the Government at press conferences was not accessible for persons with intellectual disabilities, which increased fear and distress.¹⁹²

Spain: CERMI reported that the official measures taken were not made accessible for people with intellectual disabilities, such as easy-to-read versions.¹⁹³ People with disabilities also faced aggression because they were exempted of the prohibition to go out, and some suggested they should wear a blue bracelet to be recognised, which was criticised.¹⁹⁴

United Kingdom: during the Covid-19 emergency, people with intellectual disabilities did not always understand what happened as there was not

¹⁸⁷ All the documents in accessible language are available here: <http://www.anffas.net/it/news/14028/emergenza-codiv-19-informazioni-utili-in-linguaggio-facile-da-leggere-e-comunicazione-aumentativa-alternativa>

¹⁸⁸ Brief Kamer: voorkom de fouten van de eerste corona-golf, October 2020, <https://iederin.nl/brief-kamer-voorkom-de-fouten-van-de-eerste-corona-golf/>

¹⁸⁹ European Agency for Fundamental Rights, Coronavirus pandemic in the EU – Fundamental Rights Implications in Portugal, 3 June 2020, https://fra.europa.eu/sites/default/files/fra_uploads/pt_report_on_coronavirus_pandemic_june_2020.pdf

¹⁹⁰ Information in easy-to-read available here: <https://www.fenacerci.pt/servicos/covid-19-centro-de-recursos-organizacional/#05>

¹⁹¹ Information obtained from Joaquim Pequicho, from the Portuguese organisation FENACERCI, October 2020

¹⁹² National Consultation of Sožitje Slovenia on the Impact of the Covid-19 Pandemic on Children, Adolescents, Adults and the Elderly with Intellectual Disabilities and their Families / Guardians, 2020

¹⁹³ CERMI, Excluidos en la exclusión: La vulneración de los derechos de las personas con discapacidad durante la pandemia, July 2020, <https://www.cermi.es/es/actualidad/noticias/excluidos-en-la-exclusi%C3%B3n-la-vulneraci%C3%B3n-de-los-derechos-de-las-personas-con>

¹⁹⁴ Autismo España, Las personas con autismo pueden salir a la calle por derecho y sin identificativos, 28 March 2020, <http://www.autismo.org.es/actualidad/articulo/las-personas-con-autismo-pueden-salir-la-calle-por-derecho-y-sin-identificativos>

enough information in easy-to-read, and digital tools are not always easy to use.¹⁹⁵

Wales: a self-advocacy group explained how people with learning disabilities were struggling with the situation,

reporting feelings of loneliness, boredom, frustration and even extreme behaviour including suicidal thoughts and assaults on support staff due to confusion, lack of an end date, a defined timescale, variety of sources.¹⁹⁶

¹⁹⁵ Gary Bourlet, Co-Founder of Learning Disability England, and Samantha Clark, Chief Executive of Learning Disability England on self-advocates in England during the Coronavirus emergency, May 2020, <https://www.inclusion-europe.eu/wp-content/uploads/2020/03/2020-05-22-Self-advocacy-activities.pdf>

¹⁹⁶ The Effect of the Coronavirus Pandemic on People with Learning Disabilities Across Wales, Phase 1, prepared by Philippa Davies from All Wales People First, 13 May 2020, <https://allwalespeople1st.co.uk/wp-content/uploads/2020/05/The-Effect-of-the-Coronavirus-Pandemic-on-People-with-Learning-Disabilities-Across-WalesPhaseOneFinalDraft.pdf>

Employment

For some people with intellectual disabilities working in the open labour market, they were not able to go to work anymore. Some countries provided special leave provisions.

For people working in sheltered workshops, as many day care services and enterprises closed, people with disabilities were left behind. This is extremely problematic, as people working in sheltered workshop are not covered by labour law provisions.

Finally, many people with intellectual disabilities are concerned and afraid to lose their job. Getting a job is complicated for someone with an intellectual disability, but adding to that potential recession and stereotype of “fragility” makes it even more worrisome.

“We are worried about the effect of the COVID-19 on employment of persons with intellectual disabilities. We know that we are the first ones to be pushed outside the labour market when a financial and social crisis happens.”

Bulgaria: some special provisions were done to enable people with disabilities paid leave.

Czechia: the organisation Rytmus, supporting employment of people with intellectual disabilities in the open labour market, estimated that around 20% of their clients lost their job during the COVID-19 crisis as many were employed in the hotel and restaurant sector that closed down.¹⁹⁷

Denmark: according to Klapjob, an initiative on supported employment for people with intellectual disabilities in the open labour market, people with intellectual disabilities who were employed in the open labour market had contracts falling under employment law and could then equally benefit from the support given to companies by the government to cover part of their salaries during the lockdown period.¹⁹⁸

England: a research by Leonard Cheshire revealed that 71% of persons

¹⁹⁷ My Talents. For Diversity, <https://www.inclusion-europe.eu/my-talents-for-diversity/#online-catalogue>

¹⁹⁸ Webinar organised by Inclusion Europe, September 2020
<https://www.youtube.com/watch?v=OBregCS2UL8&t=75s>

with disabilities, who were employed in March 2020, have either lost their job, lost income, or have been furloughed. Moreover, two out of five employers expressed their doubts on employing persons with disabilities due to concerns of adequate support, and one in five employers stated their unlikelihood to employ persons with disabilities due to the pandemic.¹⁹⁹

France: the umbrella organisation of people with disabilities, Collectif Handicap, anticipates an increase in dismissals of people with disabilities, declaring them unfit, as the context and policies are not prone to encourage companies to employ people with disabilities, even when there is a mandatory quota.²⁰⁰

Italy: from March 17th to July 31st, the so-called “vulnerable” public and private workers benefitted from a particular protection. It concerned workers with a recognition of severe disability, people undergoing life-saving therapies or a certification attesting their immunodepression or oncological diseases. They were able to take time off from work by equating the absence from the workplace to hospitalisation.²⁰¹ However, starting from July 31st, because there was no extension of these benefits provided, a serious

protection gap was created. In the end, benefits were extended until 14th of October, but mechanisms to benefit from those are very cumbersome.²⁰²

Starting from the 16th of October, the category of “vulnerable” workers changed, and disability organisations are worried it will not fully substitute the previous one.

Ireland: Inclusion Ireland interviewed 11 persons with intellectual disabilities, and they all lost their jobs due to Covid-19. Most of them had worked in centres and services for people with disabilities. People missed the social interaction with people they knew at work, in their day services and with their friends and families.²⁰³

Malta: a grant for people with disabilities who could not pursue their job was given.²⁰⁴

Portugal: the closing of small and medium enterprises due to the pandemic that provided work for people with intellectual disabilities had a huge impact. The organisations who are finding job placements for people with intellectual disabilities are having great difficulties to find places where people can work or do their vocational training, creating additional challenges.

¹⁹⁹ Charity calls on government as discriminatory employment practices against disabled people rise, October 2020, <https://thiis.co.uk/charity-urges-government-as-discriminatory-employment-practices-against-disabled-people-rise/>

²⁰⁰ Coronavirus : entre discrimination et amalgame, l'emploi des personnes handicapées sous la menace, September 2020, <https://www.sudouest.fr/2020/09/02/coronavirus-entre-discrimination-et-amalgame-l-emploi-des-personnes-handicapees-sous-la-menace-7798435-4688.php>

²⁰¹ art. 26 of the “Cura Italia” Decree-Law no. 18/2020

²⁰² Legislative Decree no. 104/2020

²⁰³ The Experiences of Adults with Intellectual Disabilities in Ireland During the Covid-19 Crisis, September 2020, inclusion Ireland and Technological University Dublin

²⁰⁴ Social security responses, June 2020, <https://ww1.issa.int/news/social-security-responses-covid-19-case-malta>

Slovakia: the association for persons with intellectual disabilities suspended all group sessions for self-advocates and closed their sheltered workshop.²⁰⁵

Spain: it is estimated that around 60% of the people with disabilities who are

currently employed could lose their job due to the pandemic, and 42% became partially unemployed during the confinement. 12% of the people with disabilities who are unemployed at the moment were laid off due to the sanitary crisis.²⁰⁶

²⁰⁵ BIVIO je ohrozené - prosím, pomôžte!, 26 March 2020, <http://www.zpmpvrs.sk/>

²⁰⁶ Fundación ONCE, Efectos y consecuencias de la crisis de la COVID-19 entre las personas con discapacidad, July 2020,

https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=&ved=2ahUKEwid05Hg697rAhUCwKQKHTX3BfYQFiABegQIAhAB&url=https%3A%2F%2Fwww.odismet.es%2Fsites%2Fdefault%2Ffiles%2F2020-07%2Finforme_EstudioCOVID_19_v3_0.pdf&usg=AOvVaw2XleHmnuSsMcQybkw2UGx

Other resources

European Parliament resolution

The European Parliament approved in July 2020 a resolution on the rights of persons with intellectual disabilities during the Covid-19 crisis.²⁰⁷

The Parliament says:

- the COVID-19 crisis and the lockdown measures reveal the persisting and ongoing social segregation and discrimination against persons with intellectual disabilities;
- the availability of disaggregated data to determine the impact of the effects of the pandemic on persons with intellectual disabilities is limited;
- it has been reported that persons with intellectual disabilities have been denied medical treatment, have been locked down in institutions and face social isolation with no possibility to receive visits from family members or to return to their relatives, and that discriminatory triage guidelines have been introduced;
- the COVID-19 crisis has shown that the concept of inclusive education is not yet a reality; in many Member States learners with intellectual disabilities have not been able to continue their learning during the lockdown; families lack support for the education of learners with intellectual disabilities, in particular with regard to accessible digital and innovative technologies and distance-learning;
- a considerable lack of protective equipment has been reported for persons with disabilities, especially for those living in institutions, their carers and staff;

²⁰⁷ <https://www.inclusion-europe.eu/european-parliament-in-defence-of-people-with-intellectual-disabilities-covid19/>

The Parliament:

- Strongly condemns any medical discrimination against persons with intellectual disabilities;
- Recalls that medical guidelines must be non-discriminatory and must respect international law and existing ethical guidelines on care in the event of emergencies, health crises and natural disasters;
- Recalls that support services, personal assistance, physical accessibility and communication for persons with intellectual disabilities must be provided during lockdown by adopting innovative methods of health care delivery;
- Requests that data be collected in each Member State concerning the treatment of persons with intellectual disabilities in hospitals, institutions and community-based services and on mortality rates of persons with disabilities in order to assess whether or not persons with disabilities are receiving adequate protection, health care and support during the COVID-19 crisis;
- Underlines that everyone has the right to independent living and to be informed immediately and correctly, in an accessible format, about the pandemic and the measures affecting them and their family; demands that all public health communications be accessible to persons with disabilities and be provided in plain language, in a variety of traditional and digital formats, and in their national sign languages;
- Stresses that the COVID-19 pandemic has exposed major flaws in support systems for a number of at-risk groups in society; underlines that investing in the gradual transition from institutional care to community-based services for persons with intellectual disabilities should be a priority; underlines that investment funds should support the provision of personalised support services, as many of the providers of these services have suffered greatly during and after the pandemic and are at risk of being closed down indefinitely;

[The resolution in full and in all EU languages.](#)

Inclusion Europe reports

5 steps to prevent harm

to people with intellectual disabilities and their families in an emergency

1. Inform clearly
2. Deliver the information
3. Help to deal with emergency
4. Help to overcome isolation
5. Protect disability rights



1. **Inform clearly** about what people should do to protect themselves and others.

2. **Deliver the information** to people with intellectual disabilities and their families.



3. **Help to deal with emergency**, limited services and crisis plans.

4. **Help to overcome isolation** while social distancing measures are in place.



5. **Protect disability rights** and related funding.

Petition to defend the rights of people with intellectual disabilities and their families in times of COVID-19 emergency

"We have to ensure people with disabilities have equal participation in society. So, we need support funding for the families and Europe needs to ensure people with disabilities aren't left behind."

Ulrike Muller, MEP (Germany, Renew Europe Group)

Lack of education for children with intellectual disabilities made worse in the Coronavirus emergency

How are the disability rights affected by the coronavirus pandemic?

Other resources

[European Disability Forum](#)

[Autism Europe](#)

[ENIL: Disability rights monitor](#)

[Mental Health Europe](#)

[Inclusion International](#)