COVID-19 and people with disabilities

Assessing the impact of the crisis and informing disability-inclusive next steps

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1 Executive summary

People with disabilities feel they have not been heard or included in the planning of measures to fight the pandemic. In the many plans and guides produced by the government, the disability perspective has not been included, at least explicitly. Nor have measures been taken to facilitate access to information on the coronavirus or on the measures planned or adopted. Representative organizations of groups with disabilities have assumed this role as facilitators of information and providers of support.

During the pandemic, cases of gender-based violence have continued. The government has maintained this service, considered essential, which has favoured continuity of care. It has also provided for the use of alternative means to meet the needs of women with other limitations such as deafness. Organizations of people with disabilities have signed a manifesto against gender violence, of which they are also victims. In socio-sanitary residences, there is a need to guarantee the quality of the services and care provided, as well as to rethink these services to avoid such alarming and negative consequences as the excessive mortality detected in these institutions. The Independent Living Movement calls for a new law that does not focus on dependency but on self-management of independent living, as it is considered more in line with a rights perspective.

The pandemic has limited or prevented the implementation of many social, educational, and labour services that has especially affected the group with disabilities. The closure of day centres, associations, occupational centres, and the reduction of production in many special employment centres, as well as the limitations in presence in formal and informal education, and the closures of sports, recreational and leisure centres, physiotherapy, etc., have substantially limited the possibilities of habilitation and rehabilitation of this group. Our reports and documents attest to the increase in behavioural and psychological problems, setbacks in the acquisition of skills, and other similar problems, in people with disabilities.

Access to justice has also been limited, so that the group with disabilities has seen their possibilities of access to it reduced. In addition, complaints have been received related to the lack of understanding by society of the therapeutic outings to which this population was entitled during confinement. Aspects such as mobility restrictions, the need for information and consent to treatment and vaccination, are also highlighted by the organizations. The unequal situation experienced by especially vulnerable groups such as the institutionalized elderly is reiterated in reports and publications.

Access to education has been limited in many cases, since the group with disabilities needs more support that has not been received. On the other hand, educational, economic and social circumstances mean that these people have less access to technology and can benefit to a lesser extent from these products, especially if teaching is neither cognitively accessible nor universally accessible.

Employment has been one of the areas that has experienced the greatest and fastest decline as a result of the pandemic. The government has launched an important package of measures aimed at companies and the self-employed. The maintenance of these measures seems key, together with the search for means for their financing.

Throughout this process, some important lessons have been learned that can become good examples and recommendations for the future. On the one hand, representative organizations of people with disabilities, and in particular Plena Inclusión, have made a very intense and productive effort to prepare materials or to finance studies focused on COVID-19 and its impact on people with disabilities. Its task of information, dissemination, positioning and financing of studies and publications has filled the administration's gap in terms of offering accessible information for people with disabilities and their families. The current situation has also allowed us to see that initiatives that allow us to rethink companies and services (remote diagnostics, teleservices, tele-training) can be key to face similar crises more adequately. On the other hand, this crisis has been an opportunity to claim the commitment to standardized, inclusive, person-centred services, instead of segregated services.

Disability inclusivity of disaster and recovery planning

There are no inclusive plans that address the rights of people with disabilities.

Impact of the virus on mortality among people with disabilities

Although we lack specific data on the death rates of people with disabilities during the pandemic, since the disability variable has not been included in the studies nor have detailed statistics been published, several data allow us to infer the disadvantage they have experienced in this regard. First, the opinion of major NGOs on intellectual and developmental disabilities is that those who are institutionalized experienced higher mortality rates in contrast to those living in family homes. Second, numerous data support the reality of a much higher mortality rate in residential institutions. Although the elderly, and particularly those in a situation of dependency, have been the main affected, there are also increases in mortality in institutionalized people with intellectual and developmental disabilities. For many people with disabilities with previous medical conditions (hypertension, diabetes), the coronavirus poses a higher risk, which could lead to higher rates of medical complications and death.

Outline of key concerns about a disproportionately negative impact of the COVID-19 crisis on people with disabilities

The pandemic has increased the negative consequences of the ongoing economic crisis. Poverty levels have clearly increased. People in economically and socially vulnerable situations have found it more difficult to survive. In the group with disabilities where unemployment is high and employment is precarious, the crisis has led to more job losses or a reduction in job quality. In turn, this has led to problems in making daily payments for housing, food or consumption of services. The numerous measures implemented by the government, such as the Minimum Living Income, the prohibition of evictions or rent increases, as well as aid for the payment of electricity, gas, etc., are essential to face this situation.

Access to transportation during the pandemic has been very limited, both for the general population and, consequently, for the population with disabilities. The regulation focused on the reduction of transport services of all kinds, has added more limitations to an economically vulnerable group that is mainly a user of public transport.

The restrictive measures for mobility, leaving the home or having gatherings, put in place to prevent the spread of COVID-19, have led to additional restrictions for groups with disabilities. These, in some cases, have not been adequately informed about these measures. In other cases, because they are institutionalized, they have had to face more restrictive measures than those that exist for those who live in more standardized alternatives. Nor have they had equal access, especially in the case of institutionalization, to health services. The data also seem to indicate that there have been violations of equal rights and non-discrimination based on disability or other personal conditions (e.g. medical). Representative organizations of groups with disabilities call attention to respect human rights and those established in the Convention on the Rights of Persons with Disabilities.

More generally speaking, it is possible to summarize the main inequities that the pandemic is presenting to disabled groups as follows:

- health inequities, above all for those with the most significant limitations living in institutions;
- education inequities due to the lack of services and supports, and
- employment disadvantages which in turn impact on access to essential items and services.

Examples of good practice

1. The government's consideration of families with members with disabilities as a particularly vulnerable group (see Section 5.1), allows access to aid to somewhat reduce the especially negative economic situation of this population.
2. The publication of adapted and accessible materials for people with intellectual and developmental disabilities and their families, by Plena Inclusion, has been a very useful way to train, inform and take into account the needs of the group.
3. The development of activities of NGOs based on the use of technology (seminars, tutorship, contact, communication, etc.) in the field of social services has made it possible to particularly replace the usual supports, but in the educational system this has not been the answer.

Recommendations and opportunities for change

Please identify up to 3 key recommendations for using recovery planning as a chance to enhance disability rights and inclusion in light of the disruption and social change brought about by the crisis.

1. The commitment to person-centred-services and community-based services, with self-management of aids for independent living, can prevent many of the disadvantage situations identified in this pandemic to people with disabilities.
2. The transformation of companies and services, taking advantage of technologies, is a way to be followed by organizations in the sector and by social, educational and employment services. Efforts must be made to ensure universal accessibility, in the physical, cognitive and economic domains.

2 Disability-inclusive disaster and recovery planning

Article 11 – Situations of risk and humanitarian emergencies & Article 4(3) – involvement of persons with disabilities

2.1 Commitments to disability in disaster management and recovery strategies

The Government has launched several plans focused on recovery. None of the various plans for recovery explicitly mention disability.

They have also published a series of good practice guides for managing the pandemic and controlling the spread of the virus. In the majority of these guides, people with disabilities are not mentioned, nor is this term included.

People with disabilities are expressly mentioned in a few guides or documents. For example, the document 'Measures for the reduction of contagion by the SARS-CoV-2 coronavirus in homes for tourist use'[1] stresses the importance of taking into account the needs of workers and customers with disabilities, as well as giving them priority when developing preventive measures; for example, if there are queues, as well as that workers are aware of the needs of this group. Another example is the Action Guide for women who are experiencing gender violence at home during the state of alarm,[2] the cover of which indicates that adapted services are offered for people with disabilities.

In the guide on measures taken in matters of migration and foreigners in the face of COVID-19,[3] reference is made to instruction 2020/03/20 of the Secretary of State,[4] which provides specific measures to guarantee the protection of vulnerable groups, such as those associated with gender violence, people with disabilities or serious illnesses.

Since social services in Spain (like education and health) are transferred to the autonomous communities state-wide, regulations have been developed to try to ensure equality between territories. We mention below the regulation published in accordance with the pandemic in which people with disabilities are mentioned. Here, Royal Decree-Law 37/2020,[5] of 22 December 2020, of urgent measures to deal with situations of social and economic vulnerability in the field of housing and transportation, establishes that the autonomous communities must report monthly to the Ministry responsible for these issues, in order to guarantee the coordination and monitoring of actions in the field of social services.

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[1] See: https://www.lamoncloa.gob.es/serviciosdeprensa/notasprensa/industria/Documents/2020/060820-Viviendas-Uso-Turistico.pdf.

[2] See: https://violenciagenero.igualdad.gob.es/informacionUtil/covid19/GuiaVictimasVGCovid19.pdf.

[3] See: https://www.inclusion.gob.es/cartaespana/documentos/Guia_preguntas_medidas_tomadas_SEM.pdf.

[4] See: https://blogextranjeriaprogestion.org/wp-content/uploads/2020/03/Instrucci%C3%B3n-Medidas-Coronavirus-Sistema-Acogida-Asilo.pdf.

[5] See: https://www.boe.es/boe/dias/2020/12/23/pdfs/BOE-A-2020-16824.pdf.

Royal Decree-Law 25/2020,[6] of 3 July 2020, on urgent measures to support economic reactivation and employment, establishes subsidies for tourism research, development and innovation projects. One of its lines of financing is related to the improvement of tourism accessibility through very diverse actions.

Royal Decree-Law 17/2020,[7] of 5 May 2020, establishes measures to support the cultural and tax sector to face the economic and social impact of COVID-19. This law stipulates that Spanish productions of feature films and short films and audiovisual series will have special subsidies if they are directed exclusively by people with disabilities.

Order TMA / 378/2020,[8] of 30 April 2020, establishes the criteria for the tenants of a habitual residence to be able to access temporary financing aid. This is another of the urgent complementary measures in the social and economic sphere to deal with COVID-19 that have been established in Spain. The aforementioned Order establishes that a person with a disability can benefit from these aids even if they are the owner or usufructuary of a home in Spain if they prove that said home is inaccessible to the owner or to some of the people who make up the living unit.

Royal Decree-Law 15/2020,[9] of 21 April 2020, on complementary urgent measures to support the economy and employment, establishes broader economic limits, in terms of family unit earnings, in the event that any of the members of the family unit have declared disability, situation of dependency or illness that disables them to carry out a work activity. This implies that even if the income is higher in these cases, they may continue to be entitled to the established financial aid.

Order TMA / 336/2020,[10] of 9 April 2020, modifies the aid provided for in the State Housing Plan 2018-2021, as another of the urgent complementary measures in the social and economic sphere to face COVID-19. This Order establishes that public housing may be transferred or rented to low-income family living units. It establishes, like the previously mentioned rule, broader limits.

Royal Decree-Law 11/2020,[11] of 31 March 2020, establishes urgent complementary measures in the social and economic sphere to deal with COVID-19. This rule defines the “situation of economic vulnerability” to be able to obtain moratoriums or aid for the rent of the habitual residence. People with disabilities have higher income limits per living unit in order to benefit from these measures.

A regulation tries to guarantee the continuity of services for people with disabilities. Here, Royal Decree-Law 10/2020,[12] of 29 March 2020, which regulates a recoverable paid work permit to reduce the mobility of the population in the fight against COVID-19, establishes that those who care for the elderly, minors, dependents will not be able to receive these aid or people with disabilities.

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[6] See: https://www.boe.es/buscar/pdf/2020/BOE-A-2020-7311-consolidado.pdf.
[7] See: https://www.boe.es/boe/dias/2020/05/06/pdfs/BOE-A-2020-4832.pdf.
[8] See: https://www.boe.es/boe/dias/2020/05/01/pdfs/BOE-A-2020-4759.pdf.
[9] See: https://www.boe.es/buscar/pdf/2020/BOE-A-2020-4554-consolidado.pdf.
[10] See: https://www.boe.es/boe/dias/2020/04/11/pdfs/BOE-A-2020-4412.pdf.
[11] See: https://www.boe.es/buscar/pdf/2020/BOE-A-2020-4208-consolidado.pdf.
[12] See: https://www.boe.es/boe/dias/2020/03/29/pdfs/BOE-A-2020-4166.pdf.

Royal Decree-Law 8/2020,[13] of 17 March 2020, of extraordinary urgent measures to face the economic and social impact of COVID-19, establishes several relevant measures. One of them is of an economic nature and establishes the transfer to the different regions of an additional economic item. According to the regulations, this Fund may be used to finance projects and employment contracts. This is to strengthen home care services to guarantee care, support, bonding with the environment, safety and nutrition for the elderly, disabled or dependent. In this way, an attempt is made to compensate for the closure of dining rooms, day centres, occupational centres and other similar services. It is also intended to increase and reinforce the operation of home telecare devices to increase the monitoring and surveillance of the beneficiary population of said service. This regulation also regulates the Right to adapt the schedule and reduce the working day for those who are in charge of people with an illness, disability or dependency. This rule also defines what a "situation of economic vulnerability" is and, as previously indicated, increases the established income margins when a disability occurs in a living unit.

2.2 Involvement of people with disabilities in disaster management and recovery strategies

Usually, organisations representing disability feel they have not been heard or taken particular account of in these circumstances. For example, in one study, organizations that work with people with intellectual and developmental disabilities,[14] found that 60 % of those surveyed consider that the central and regional governments have not taken sufficient measures to protect people with DID during the health emergency. This negative assessment is due, in most cases, to the lack of economic resources and personal protective equipment and the absence of protocols and policies focused on the disability sector, a sector that has felt forgotten during this crisis. The focus of the national and autonomous authorities has been on the elderly. Although the concern is fully justified, this has limited the attention given to other groups that are also institutionalized, such as people with intellectual disabilities or mental illness.

2.3 Disability impact assessments and research to inform disaster management and recovery planning

Although it is not possible to speak of systematic evaluations of the impact of the coronavirus on people with disabilities, there are studies carried out by academics and representative organizations of people with disabilities that demonstrate the negative impact of the pandemic on vulnerable populations. The political measures

[13] See: https://www.boe.es/boe/dias/2020/03/18/pdfs/BOE-A-2020-3824.pdf.

[14] Navas, P., Verdugo, M. A., Amor, A. M., Crespo, M. y Martínez, S. (2020). COVID-19 y discapacidades intelectuales y del desarrollo: impacto del confinamiento desde la perspectiva de las personas, sus familiares y los profesionales y organizaciones que prestan apoyo. Plena inclusión España e Instituto Universitario de Integración en la Comunidad (INICO), Universidad de Salamanca. Downloadable from the Internet at: https://sid-inico.usal.es/wp-content/uploads/2020/12/Informe-COVID-19-y-discapacidades-intelectuales-y-del-desarrollo.pdf.

implemented in this period are also more evidence of the need to provide responses to vulnerable groups.[15] [16]

2.4 Use of disaster management and recovery planning funds

The existing evidence supports that representative organizations of people with disabilities have experienced the consequences of the pandemic in a particularly intense way. For example, one study of organizations working with people with intellectual and developmental disabilities shows that they have had to make significant financial efforts to ensure the health of their employees and the people who provide support.[17] During the period between March 15 and 15 June 2020, organisations, on average, made a weekly expenditure of EUR 483 in protection material and other investments necessary to respond to sanitary restrictions. In global terms, they have invested a total of EUR 359 261 in the mentioned period. In addition, 59 % have had to reinforce their workforce, with expenses that, together, amount to almost one million euros (EUR 958 591). This economic over-effort translates into 83.6 % (n = 61) of the organizations surveyed having seen their annual income reduced due to the situation caused by COVID-19. The losses of these organizations would amount to more than three million euros (EUR 3 124 306).

For this reason, the central government has implemented economic support measures for these organizations. Here, Royal Decree-Law 33/2020, of 3 November 2020, which adopts urgent measures to support Third Sector of Social Action entities at the state level,[18] demonstrates the need to use funds for the recovery of this group. This legislation recognizes that "one of the consequences of the current extraordinary situation (health, economic and social crisis) has been the exponential increase of social demands to the entities of the Third Sector of Social Action. It also indicates that the network of associations linked to the Third Sector of Social Action has been suffering a series of unprecedented tensions that endanger the very survival of many entities, whose work is essential to promote the welfare of a large part of Spanish society. The legislation also points out that the Third Sector of Social Action as a whole has been forced to make this extraordinary effort through structures that had not yet recovered from the global financial crisis of 2008” (p. 2). This legislation makes it possible to provide liquidity through subsidies granted to a large number of entities, including those representing groups with disabilities.

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[15] Navas, P., Verdugo, M. A., Amor, A. M., Crespo, M. y Martínez, S. (2020). COVID-19 y discapacidades intelectuales y del desarrollo: impacto del confinamiento desde la perspectiva de las personas, sus familiares y los profesionales y organizaciones que prestan apoyo. Plena inclusión España e Instituto Universitario de Integración en la Comunidad (INICO), Universidad de Salamanca. Downloadable from the Internet at: https://sid-inico.usal.es/wp-content/uploads/2020/12/Informe-COVID-19-y-discapacidades-intelectuales-y-del-desarrollo.pdf.

[16] Amor, A. M., Navas, P., Verdugo, M. Á. y Crespo, M. (in press) Perceptions of people with intellectual and developmental disabilities about COVID-19 in Spain: A cross-sectional study. *Journal of Intellectual Disability Research.*

[17] Navas, P., Verdugo, M. A., Amor, A. M., Crespo, M. y Martínez, S. (2020). COVID-19 y discapacidades intelectuales y del desarrollo: impacto del confinamiento desde la perspectiva de las personas, sus familiares y los profesionales y organizaciones que prestan apoyo. Plena inclusión España e Instituto Universitario de Integración en la Comunidad (INICO), Universidad de Salamanca. Downloadable from the Internet at: https://sid-inico.usal.es/wp-content/uploads/2020/12/Informe-COVID-19-y-discapacidades-intelectuales-y-del-desarrollo.pdf

[18] See: https://www.boe.es/buscar/pdf/2020/BOE-A-2020-13491-consolidado.pdf.

3 Mortality connected to COVID-19 among people with disabilities

Article 10 – The right to life

3.1 Are official statistics available concerning the overall mortality rate of people with disabilities?

Yes, partial data is available.

It is difficult to find mortality statistics for specific groups. However, through state data on the Leading Causes of Death in Spain[19] coinciding with the first wave of the coronavirus (January-May 2019 and 2020), it is possible to see the number of people with "other mental and behavioural disorders" who died in the period January-May 2019 was 216. In In the same period from January to May 2020, the number rose to 288 (a variation of 33.3 %). However, the number of people with Alzheimer's disease who died from January-May 2019 was 6 331. In the period January-May 2020, the number of deaths was 7,201 (an increase of 13.7 %). The number of senile people who died in the aforementioned period in 2019 was 849 people, compared to the 952 who died in that period in 2020 (an increase of 12.1 %). Deaths due to hypertensive diseases are one of the most common causes of death and at the same time have experienced a greater increase (17.6 % compared to the period of 2019). It should be noted that the vast majority of causes of death have experienced increases. In the same line, in the period of January-May 2019[20] to the same period in 2020 there has been an increase in the group of people over 65 years of age.

On the other hand, continuing with state data,[21] if we exclude the increase in causes of death due to COVID, the March-May variation from 2019 to 2020, the third cause of death that has increased the most has been Alzheimer's (27.3 % increase), after diabetes mellitus (39.5 % increase) and hypertensive disease (37.1 % increase).

If we look at the data on deaths in hospitals, nursing homes and homes,[22] homes, we can see that on average from 2016 to 2019, 58 % of people died in hospitals, followed by 28 % who died at home and 15 % who died in nursing homes. In 2020, 55 % of those who died did so in hospitals, followed by 26 % who died at home, and 19 % who died in social and health care homes. These data are explained in the light of the numerous deaths that occurred this year in residences for the elderly in situations of dependency in many cases.

According to estimates of Plena Inclusion,[23] an NGO representing the collective of people with intellectual disabilities, around a hundred people with intellectual or developmental disabilities who use residences or sheltered centres have died in Spain

[19] See: https://www.epdata.es/datos/mortalidad-estimada-registrada-cualquier-causa-coincidiendo-epidemia-coronavirus/521/espana/106.

[20] See: https://www.epdata.es/muertes-cualquier-causa-espana-edad/8018234e-6eca-4e67-a92c-f4a51cbf372a.

[21] See: https://www.epdata.es/causas-muertes-aumentaron-primera-ola-epidemia-coronavirus-espana/28f89296-10dc-4e3a-908b-cd0b4bab2e1b.

[22] See: https://www.epdata.es/muertes-hospitales-residencias-domicilio-particular-espana/16cb86cc-0685-4b88-95d1-0049f6fabd96.

[23] See: https://www.europapress.es/epsocial/igualdad/noticia-plena-inclusion-estima-100-fallecidos-centros-personas-discapacidad-intelectual-pandemia-20200413191326.html.

in the context of the crisis caused by the coronavirus pandemic. Most have died in hospitals and others in the residence itself.

Other evidence is derived from the data provided by the political manager of residential centres for the elderly, disabled or mentally ill.[24] In his appearance in April in the regional government, he indicated that, of the 6 444 people who died in these centres, almost 82 % could be attributable to COVID-19, although it is not possible to know for sure because in many cases there is no evidence confirming death from COVID-19.

On the other hand, in the results of a study[25] conducted in Spain in which the authors analysed the frequency of cognitive impairment (CI) in deceased COVID-19 patients at a tertiary hospital in Spain, among the 477 adult cases who died after admission from 1 to 31 March 2020, 281 had confirmed COVID-19. CI (21.1 % dementia and 8.9 % mild cognitive impairment) was a common comorbidity. Subjects with CI were older, tended to live in nursing homes, had shorter time from symptom onset to death, and were rarely admitted to the ICU, receiving palliative care more often. CI is a frequent comorbidity in deceased COVID-19 subjects and is associated with differences in care.

The data allow us to estimate that the highest mortality rates correspond to older people in residential care, probably dependent and with Alzheimer's dementia. In this population group, there are many circumstances that make them a particularly vulnerable group, which is why quantitatively they represent the highest number of deaths. It should be noted that, as previously indicated, in absolute numbers the percentage of deceased persons with mental and behavioural disorders, a category that includes persons with disabilities, experienced an increase from January-May 2019 to January-May 2020 of 33.3 %.

Another element that allows us to estimate a higher prevalence of deaths is related to the study data with a representative sample of people with disabilities,[26] 5 % of the group claim to have been affected by the virus. In addition, 8 % indicated that they did not know if the disease had passed, although they had symptoms associated with COVID-19. Also, it was asked if the affected persons with symptoms had been diagnosed in any health centre by COVID-19, 9 % of them said they had, thus detecting a higher prevalence rate than the one presented in the Seroprevalence study conducted by the Ministry of Health at the national level. Individuals with physical disabilities report a higher rate of affected persons. In sum, more infections have occurred in people with disabilities. Therefore, it is to be expected that a higher percentage of this group has experienced negative consequences, especially if we take into account the existence of a higher prevalence of associated risk factors, since in this study 18 % suffer from respiratory diseases, 17 % reported hypertension and 15 % immunosuppression. Given that the official statistics on deaths do not specify or include the disability variable but rather the disease variable causing the death, these data must be taken with the necessary prudence. As we pointed out before, a large

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[24] See: https://www.servimedia.es/noticias/1245755.

[25] Martín-Jiménez, P., Muñoz-García, M. I., Seoane, D., Roca-Rodríguez, L., García-Reyne, A., Lalueza, A., Pérez-Martínez, D. A. (2020). Cognitive Impairment Is a Common Comorbidity in Deceased COVID-19 Patients: A Hospital-Based Retrospective Cohort Study. In (Vol. 78, pp. 1367-1372): IOS Press.

[26] Fundación Once, Odismet (2020). Efectos y consecuencias de la crisis de la COVID-19 entre las personas con discapacidad. Downloadable at: https://www.odismet.es/sites/default/files/2020-07/Informe_EstudioCOVID_19_v3_0.pdf.

number of deaths are related to hypertensive diseases, which also coincides with one of the risk factors mentioned in this study.

3.2 Are official statistics available concerning the mortality rate of people with disabilities who have died from complications connected to COVID-19?

No data is available concerning how many people with disabilities have died from complications connected to COVID-19 during the period of the pandemic.

No data is available of all people who died from complications connected to COVID-19 during the period of the pandemic, what proportion were people with disabilities.

No data is available concerning the place of death of people with disabilities with a confirmed diagnosis of COVID-19.

No data is available concerning the place of residence of people with disabilities that have died with a confirmed diagnosis of COVID-19.

4 Access to health

Article 25 – Health

4.1 Emergency measures

Numerous documents and regulations have been published in Spain stressing the need for non-discrimination on any grounds, including disability. Special measures are also proposed to attend to the characteristics and needs of this group. We list the most relevant documents below.

In the Report of the Ministry of Health on ethical aspects in pandemic situations: SARS-CoV-2[27] published in April 2020, it is established that "The measures adopted will be governed by the principles of equity, non-discrimination, solidarity, justice, proportionality and transparency" (p. 2). It also suggests that if the scarcity of resources requires the establishment of criteria for prioritizing access to them, it must be based on objective, generalizable, transparent, public and consensual criteria, "without prejudice to also assessing the unique and individual aspects that each sick person presents due the virus" (p. 2). They also argue that it is a moral imperative to provide medical professionals with guiding criteria and point out, among others, the following:

- No discrimination for any reason other than the clinical situation of the patient and objective survival expectations, based on evidence.
- The principle of maximum benefit in the recovery of human lives, which must be compatible with the continuation of the care initiated individually for each patient.
- Severity of the patient's disease state showing the need for intensive care (assistance in intensive care units and access to mechanical ventilation).
- Objective expectations of recovery of the patient in the short term to their previous state of health, taking into account the concurrence or not of accompanying serious pathologies that show a fatal prognosis (terminally ill patients with a prognosis of irreversibility, irreversible coma, etc.), although it may involve additional clinical care.

They also point out that it will only be legitimate to resort to the prioritization criteria when all the existing possibilities have been exhausted to have the necessary healthcare resources and to optimize the use of those available. They indicate that the medical team responsible for the patient will be the one who must assume the implications of their decision, so that a third party is not suitable to impose their criteria, unless they are also involved in the care of that patient. It is advisable to request or receive guidance from the healthcare ethics committee of the same hospital, whenever possible for the time available, or from other physicians with greater experience and maturity, including an ad hoc committee.

The authors also indicate that "The absolute prohibition of the use of criteria based on discrimination for any reason in order to prioritize patients in these contexts should be underlined. In this sense, excluding patients from access to certain healthcare resources or to certain treatments, for example, solely for reasons of advanced age, is contrary, as discriminatory, to the very foundations of our rule of law (article 14 of the

[27] See: https://www.mscbs.gob.es/profesionales/saludPublica/ccayes/alertasActual/nCov/documentos/200403-INFORME_PANDEMIA-FINAL-MAQUETADO.pdf.

Constitution Spanish). In this sense, older patients, in case of extreme shortage of healthcare resources, should be treated under the same conditions as the rest of the population, that is, taking into account the clinical criteria of each case in particular. Accepting such discrimination would entail a devaluation of certain human lives because of the life stage in which these persons find themselves, which contradicts the foundations of our Rule of Law, in particular the recognition of the equal intrinsic dignity of every human being by virtue of the fact of being human. Similar arguments are applicable in order to proscribe any discrimination for reasons such as disability in any of its manifestations, or that which certain groups of minors may suffer" (p. 5).

In the document of Coordinated response actions for the control of the transmission of COVID-19,[28] the alert levels and the measures or actions proposed for each level are defined. In social-health centres (for the elderly, disabled, dependency), there are limitations on visits, leaving the centres and suspension of activities, except in cases of justified services. This document also establishes the need in hospital contexts for Ensuring the appropriate isolation of cases and quarantine of contacts including the necessary social resources and the availability of areas fitted out to that effect (p. 10).[29]

For its part, the document "Equity in Health and COVID-19 Analysis and proposals to address epidemiological vulnerability linked to social inequalities",[30] indicates that there are communication barriers related to the lack of adaptation of the messages to people with disabilities, language barriers or those associated with the means of diffusion of the messages for some groups. In response to this and other inequalities, it is proposed to identify and analyse situations of social and epidemiological vulnerability, with a focus on equity and social determinants of health, among other general measures. In addition, they propose specific measures such as: 1) Guarantee access to adequate masks in all situations of social vulnerability, 2) Establish mechanisms for the specific and safe care of vulnerable patients during confinement or situations of mobility restrictions, both face-to-face and telematics. 3) Establish the appropriate measures for the dispensing of drugs in a remote mode. 4) Mitigate the effect that confinement can have in the cases of persons deprived of liberty.

The early response plan in a COVID-19 pandemic control scenario,[31] prepared by the Ministry of Health, proposes a series of non-pharmacological or protection and prevention measures at the community level that emphasize the need to "Have prevention strategies that include aspects related to the organization of spaces and schedules, coordination with the healthcare system, procedures on case management, creation of stable coexistence groups, collaboration with public health and

[28] See: https://www.mscbs.gob.es/profesionales/saludPublica/ccayes/alertasActual/nCov/documentos/Actuaciones_respuesta_COVID_22.10.2020.pdf. An English version of the document is also available at: https://www.mscbs.gob.es/profesionales/saludPublica/ccayes/alertasActual/nCov/documentos/Actuaciones_respuesta_COVID-19_ENG.pdf.

[29] See: https://www.mscbs.gob.es/profesionales/saludPublica/ccayes/alertasActual/nCov/documentos/Actuaciones_respuesta_COVID-19_ENG.pdf.

[30] See: https://www.mscbs.gob.es/profesionales/saludPublica/ccayes/alertasActual/nCov/documentos/COVID19_Equidad_en_salud_y_COVID-19.pdf.

[31] See: https://www.mscbs.gob.es/profesionales/saludPublica/ccayes/alertasActual/nCov/documentos/COVID19_Plan_de_respuesta_temprana_escenario_control.pdf.

reorganization of activities depending on the setting" (p. 20). It also indicated that "these strategies should be taken into account to minimize the risk of epidemic outbreaks in especially vulnerable environments such as residences for the elderly, people with disabilities or mental health centres and reception centres or shelters" (p. 20).

Royal Decree-Law 21/2020, of 9 June 2020, on urgent prevention, containment and coordination measures to face the health crisis caused by COVID-19[32] established that "The competent administrations must ensure compliance by the owners of residential social service centres and day centres with the disinfection, prevention and conditioning regulations of the facilities that they establish. In particular, they will ensure that their normal activity is carried out in conditions that allow the risk of contagion to be prevented at all times". It also stated that "The heads of the centres must have contingency plans for COVID-19 aimed at the early identification of possible cases between residents and workers and their contacts, activating, where appropriate, the coordination procedures with the service structure of health that corresponds".

The document on Management in primary and home care of COVID-19 (18 June 2020)[33] indicates that if the person is dependent and therefore needs a companion, he or she can go with the patient to the health centre, and accompany him, if necessary, in the ambulance. In the document on Clinical Management of COVID-19: hospital care (18 June 2020)[34] the need for a family member or legal representative to be with the patient in paediatric cases is specified in the document management in the emergency COVID-19 (26 June 2020).[35] It also establishes that if the person is a dependent or minor, a relative can accompany him / her on ambulance transfers.

Regarding the recommendations on communication strategies against pandemic fatigue, approved by the Inter-territorial Council of the National Health System on 16 December 2020,[36] it is stipulated that "In addition to adapting content, formats and channels to different needs, messages and materials must be available in the relevant languages and guarantee their accessibility to people with visual, hearing and / or cognitive disabilities" (p. 18).

The technical document of recommendations for action for the home care social services in the face of the COVID-19 crisis (18 March 2020),[37] sponsored by the Ministry of Social Rights and Agenda 2030, states that "In Spain, a total of 45 000

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32 See: https://www.boe.es/buscar/pdf/2020/BOE-A-2020-5895-consolidado.pdf.

33 See: https://www.mscbs.gob.es/profesionales/saludPublica/ccayes/alertasActual/nCov/documentos/Manejo_primaria.pdf.

34 See: https://www.mscbs.gob.es/profesionales/saludPublica/ccayes/alertasActual/nCov/documentos/Protocolo_manejo_clinico_ah_COVID-19.pdf.

35 See: https://www.mscbs.gob.es/profesionales/saludPublica/ccayes/alertasActual/nCov/documentos/Manejo_urgencias_pacientes_con_COVID-19.pdf.

36 See: https://www.mscbs.gob.es/profesionales/saludPublica/ccayes/alertasActual/nCov/documentos/Recomendaciones_estrategias_comunicacion_fatiga_pandemica.pdf.

37 See: https://www.mscbs.gob.es/ssi/familiasInfancia/ServiciosSociales/docs/Covid19/Rec_atencion_domiciliaria.pdf.

people have a home help service (most of them older people) to whom we must add another 10 000 people in need of support for daily life who have stopped receiving various types of care in day centres and similar resources, as they have been subject to precautionary closure and cessation of activity in recent days.. These people are now confined to their homes and both they and their families, if any, need at this time more than ever, the timely support of home social services." For this reason, it is stated that "The continuity of care should govern all ongoing home help services regardless of the person's conditions (disability, assessed degree of dependency, etc. ...) or the provision system (Autonomy System Personnel and care for the Dependency, standardized home help as a basic benefit of the Concerted Plan, etc. …)".

The Recommendations Document on the Use of Masks in the Community in the Context of COVID-19 (10 June 2020),[38] suggests that the use of a mask will not be recommended in the following cases: "children under 3 years of age, respiratory distress that may be aggravated by the use of a mask, people with disabilities or a dependent situation that prevents them from being autonomous in removing the mask, people who present behavioural alterations that make their use unviable, when activities are carried out that hinder or prevent the use of masks and when people are in their place of residence or when they are alone."(p. 4).

To facilitate access to protection material against COVID-19, Royal Decree-Law 28/2020,[39] of 22 September 2020, remote work, a tax rate of 0 % applicable to the Value Added Tax is regulated on intra-community deliveries, imports and acquisitions of goods necessary to combat the effects of COVID-19 (masks, gloves, etc.). This measure is intended for public and private medical centres. As for the consumer, the Council of Ministers approved in November 2020 the reduction of the Value Added Tax (VAT) of masks from the maximum rate of 21 % to the super-reduced rate of 4 %. The objective is to facilitate vulnerable groups to access these products without their income situation harming them.

Despite the aforementioned, the document of the Ombudsman on actions during the pandemic indicates that the Ombudsman has received complaints in which he denounces the harassment suffered by some people with intellectual disabilities when they went out for therapeutic walks, despite the fact that such walks were allowed by the Decree that regulated the state of alarm. The Ombudsman proposed to the Administration to carry out a campaign to promote and spread information on the existence of these exceptions, so that people with disabilities would not be victims of harassment or aggression. In addition, it was requested that those who violate the right of these people to exercise their freedom of movement and their therapeutic outings be punished with their antisocial behaviour while the confinement decreed in the state of alarm lasted.

The Ombudsman also highlights the need to promote a solid public portfolio of social and health care, which offers a mixed assistance adequate to the needs of patients, especially the elderly or disabled, who are more dependent and require prolonged health and social care. The social and demographic evolution and the greater life expectancy make this need urgent. The supply of beds in medium-stay public hospitals

[38] See: https://www.mscbs.gob.es/profesionales/saludPublica/ccayes/alertasActual/nCov/documentos/Recomendaciones_mascarillas_ambito_comunitario.pdf.

[39] See: https://www.boe.es/boe/dias/2020/09/23/pdfs/BOE-A-2020-11043.pdf.

is very scarce, almost minimal for the existing demand. The ombudsman recalls that this is the profile of patients that has suffered the most during this crisis when the capacity of acute care hospitals did not give more than itself.

On the other hand, the Ombudsman also expressed to the Minister of Health his concern about reports referring to the use of patient prioritization procedures in intensive care units and recalled the importance for professionals to have general criteria to assist their work in making medical decisions in the most extreme situations. What is ethical and required is to clinically single out decisions of this nature, applied to each patient. Refusing groups of people, due to age or disability, is not admissible. Each person has characteristics, a state of health, clinical conditions that doctors have to assess, and all the attention that that specific person needs must be devoted to them, with the resources and material means that are available.

In the study to which we have alluded several times in these pages, carried out with a representative sample of people with disabilities[40] 12 % indicate that they have not been able to access the required medical care. In 58 % of cases, people with disabilities have had their medical appointments and check-ups cancelled or postponed. Quite the reverse, access to drugs has not been affected by the anomalous situation caused by COVID-19. In 80 % of the cases, the people with disabilities surveyed have been able to access the necessary medications. Telephone inquiries and electronic prescriptions have helped such access.

Along these lines, the president of the Spanish Confederation of People with Physical and Organic Disabilities (COCEMFE), claims in an interview[41] that people with disabilities should not pay for the COVID-19 crisis with a decline in their rights. In addition, he criticized that "the collapse of the health system made us live moments in which people with disabilities with severe symptoms of COVID-19 were not admitted to hospitals" and recalled "the difficulties in accessing medicines and health products by many people considered risk by health authorities, such as transplant recipients, children and adolescents with cancer, and other people with chronic diseases, multi-pathological or immunosuppressed states”.

AEDEM (The Spanish Multiple Sclerosis Association) emphasized that "the COVID-19 crisis cannot serve to put aside other pathologies that already existed before this virus appeared.[42] That is why the associative movement considers it urgent to have access to complete information on data related to multiple sclerosis and on the impact of the situation generated by COVID-19 on affected people, nationally and internationally.
Also, the ASEM Federation (Spanish Federation of Neuromuscular Diseases) shows its concern about the so-called “new normal”, as it indicates that “they cannot allow people with neuromuscular diseases to be immersed in a situation of neglect or defencelessness”, being also a group at risk.[43]

[40] Fundación Once, Odismet (2020). Efectos y consecuencias de la crisis de la COVID-19 entre las personas con discapacidad. Downloadable at: https://www.odismet.es/sites/default/files/2020-07/Informe_EstudioCOVID_19_v3_0.pdf.

[41] See: http://semanal.cermi.es/noticia/entrevista-presidente-cocemfe-anxo-queiruga-companeros-no-deben-pagar-crisis-sanitaria-social-economica-retroceo-derechos.aspx.

[42] See: https://www.cocemfe.es/informate/noticias/las-personas-con-esclerosis-multiple-reclaman-medidas-urgentes-por-la-crisis-del-covid-19/.

[43] See: https://www.cocemfe.es/informate/noticias/federacion-asem-explica-al-gobierno-la-situacion-de-las-personas-con-enfermedades-neuromusculares-por-la-covid-19/.

The Spanish Confederation of People with Physical and Organic Disabilities (COCEMFE) calls for the distribution of the millions of rapid antibody detection tests to be expedited urgently[44] to the Government and that will serve to increase the ability to diagnose COVID-19 early. As stated, “The situation that is being experienced in our centres is increasingly serious since these measures that we now want to start taking come with a real delay, given that we have been in confinement for almost a month. The establishment of action protocols in case of the existence of workers diagnosed with coronavirus is essential to avoid its spread in the workplace. COCEMFE reminds that residential centres are not medical centres, so they are not medicalized, nor do they have the means or personnel to attend to critical situations that require specialized health care (doctors or nurses) or intensive care units, having only the staffing ratios established by the regulations in relation to the number of residents. For this reason, health authorities are asked to ensure that people living in these facilities follow the same criteria as the rest of the population for access to health services.

The Confederation Autism Spain also claims the "right to health of people with disorders of the spectrum of autism in health crisis situation COVID-19”.[45] In this document they claim that the consideration of this group as especially vulnerable is guaranteed and that therefore, the early identification of the infection is guaranteed, through the priority performance of tests and medical tests when there are indicators of disease. They also request that reasonable accommodations be applied in situations in which people with ASD affected by COVID-19 must be hospitalized or receive health care.

A representative study of the population with intellectual and developmental disabilities (IDD) in Spain[46] concluded that the prevalence of COVID was around 5 %. These figures may be underestimating reality, since few people with DID who live with their families have been able to take the test.

4.2 Access to hospital treatment for COVID-19

Data is not available concerning the number of people with disabilities who, because of COVID-19 symptoms, have been hospitalised and admitted to intensive care units.

4.3 Treatment for COVID-19 in congregate settings

Although there are no specific data, the following news can be used as an indicator of the situation. Thus, in a news item published on 25 November 2020 on the organization's website, Plena Inclusion España[47] appreciates and is grateful that the

[44] See: https://www.cocemfe.es/informate/noticias/cocemfe-pide-que-se-agilice-el-reparto-de-test-de-deteccion-del-covid-19-en-los-centros-de-atencion-a-personas-con-discapacidad/.

[45] See: https://estadoalarmatea.org/wp-content/uploads/2020/04/documento_de_posicionamiento_autismo_espana_derecho_a_la_salud.pdf.

[46] Navas, P., Verdugo, M. A., Amor, A. M., Crespo, M. y Martínez, S. (2020). COVID-19 y discapacidades intelectuales y del desarrollo: impacto del confinamiento desde la perspectiva de las personas, sus familiares y los profesionales y organizaciones que prestan apoyo. Plena inclusión España e Instituto Universitario de Integración en la Comunidad (INICO), Universidad de Salamanca. Downloadable from the Internet at: https://sid-inico.usal.es/wp-content/uploads/2020/12/Informe-COVID-19-y-discapacidades-intelectuales-y-del-desarrollo.pdf.

[47] See: https://www.plenainclusion.org/informate/actualidad/noticias/2020/plena-inclusion-agradece-la-decision-del-gobierno-de-iniciar-la.

Government of Spain has decided that one of the groups that will first receive the COVID-19 vaccine will be people with disabilities in residences, as well as the professionals who work in them. The confederation, which brings together 935 associations and manages 1 016 residences in which more than 1 700 people with disabilities are cared for, values that the health of thousands of people who have suffered the scourge of the pandemic with special virulence is prioritized. In fact, since the health crisis began nearly 300 people in the Plena Inclusion residences have died because of the virus.

Plena Inclusión has also published a guide on residential care for people with disabilities during the pandemic,[48] as well as a Guide with Relief Measures and Reduction of Restrictions Strategies to offset the impact of COVID-19 on residential and housing resources.[49] This document highlights the need to introduce improvements in the services they provide and that, as suggested in a recent study, are related to:[50] (a) improve the professional-user ratios and promote work in natural contexts; (b) reduce large structures that concentrate a large number of people; (c) introduce measures that guarantee adequate access to resources; and (d) advance in the technological transformation of organizations and the training of people with IDD and their families in ICTs. This view is shared by managers of such resources. Professionals also point out that the situation caused by the COVID-19 were generated conflicts with their professional ethics, especially in regard to the ban on visits in residential contexts.[51]

On the other hand, the characteristics of residential services, where many resources (rooms, toilets, dining rooms) are shared rooms, creates difficulty in the strict application of social distance measures, etc. This explains, according to the aforementioned document,[52] that outbreaks in residential centres present an average of 17 cases per outbreak in nursing homes, and 11 cases per outbreak in centres for people with disabilities. It is also indicated that the average size of residential centres, both for the elderly and for people with disabilities, in Spain is close to 70 beds, although half of the residences in Spain exceed 100 beds. The larger the size, the more personnel, the greater the risk of entry of the virus and the more difficult it is to contain the infections.

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[48] See: https://www.plenainclusion.org/sites/default/files/plena_inclusion._guia_para_residencias_durante_el_covid19.pdf.

[49] See: https://www.plenainclusion.org/sites/default/files/plena_inclusion._medidas_de_alivio_en_los_recursos_residenciales.docx.pdf.

[50] Navas, P., Verdugo, M. A., Amor, A. M., Crespo, M. y Martínez, S. (2020). COVID-19 y discapacidades intelectuales y del desarrollo: impacto del confinamiento desde la perspectiva de las personas, sus familiares y los profesionales y organizaciones que prestan apoyo. Plena inclusión España e Instituto Universitario de Integración en la Comunidad (INICO), Universidad de Salamanca. Downloadable from the Internet at: https://sid-inico.usal.es/wp-content/uploads/2020/12/Informe-COVID-19-y-discapacidades-intelectuales-y-del-desarrollo.pdf.

[51] See: https://www.plenainclusion.org/sites/default/files/plena_inclusion._medidas_de_alivio_en_los_recursos_residenciales.docx.pdf.

[52] See: https://www.plenainclusion.org/sites/default/files/plena_inclusion._medidas_de_alivio_en_los_recursos_residenciales.docx.pdf.

A Spanish study[53] where people with intellectual disabilities are asked about their appraisal of the COVID-19, concluded that the supports received by people with IDD during lockdown were conditioned by the person's living context. Those living in specific settings had fewer natural supports, and those living with their family relied heavily on the family to address their needs because of service closure. The authors state that to find a balance between ensuring safe health conditions for people with IDD and continuing to work with them on their life project, it must be ensured that there is further development of the natural supports for those living in specific settings, and that the provision of supports should not depend entirely on the existence of specific services, so that supports can reach people with IDD residing in their home.

4.4 Public health promotion and testing during the pandemic

As the Ministry of Health itself recognizes in the report: "Equity in Health and COVID-19 Analysis and proposals to address the epidemiological vulnerability linked to social inequalities[54] "From the communication point of view, barriers have been detected related to the lack of adaptation of messages about prevention measures or those related to illness to people with disabilities. On the other hand, when alternatives to the proposed measures have been considered for those who cannot follow them due to a situation of dependency, they have not always been adequately communicated.

Difficulties have been detected in access to medical care for people with disabilities and/or dependence. In addition, the digital divide has affected the possibility of teleworking and appropriate distance education, the management of various procedures, the supply of basic necessities, access to and use of health and social services, access to information, social support, resulting in greater vulnerability to infection. Among the people most affected by the digital divide are people with disabilities. The document proposes measures to improve these and other deficiencies detected.

Specific measures for the protection of people with disabilities at home against the coronavirus have been proposed by organizations such as Plena Inclusión. Here, in the document "Guide to home support during the coronavirus",[55] a series of guidelines and recommendations for a safe home coexistence are offered. For example, it indicates that families and the person with disabilities must be informed in a clear, concrete and simple way to minimize their alarm and anxiety. A new evaluation of the impact of isolation on the family structure will be carried out, taking into account both the care for the sick person or those with suspected contagion, and the support for the family member with disabilities. Easy-to-read instructions and/or images will be provided to ensure, as far as possible, the understanding of the family member with a disability. If a person with a disability lives alone, the necessary indications and support for their isolation will be articulated. If the individual presents any symptoms, an

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[53] Navas, P., Amor, A. M., Crespo, M., Wolowiec, Z., & Verdugo, M. Á. (2021). Supports for people with intellectual and developmental disabilities during the COVID-19 pandemic from their own perspective. *Research in Developmental Disabilities, 108,* 103813. https://doi.org/10.1016/j.ridd.2020.103813.

[54] See: https://www.mscbs.gob.es/profesionales/saludPublica/ccayes/alertasActual/nCov/documentos/COVID19_Equidad_en_salud_y_COVID-19.pdf.

[55] See: https://www.plenainclusion.org/sites/default/files/guia_apoyos_en_casa_durante_el_coronavirus.pdf.

adequate telephone follow-up will be ensured and they will make sure that the individual has the telephone number of the reference health personnel who gave indications on how to proceed according to the evolution of the symptoms. For any medical decision, the primary care services should be contacted, as established in each autonomous community.

4.5 Impact of the COVID-19 crisis on access to health services for general or pre-existing physical and mental health conditions

During the first wave of the pandemic, there was a significant collapse of the healthcare system. All this, together with the lack of experience in this regard, led to decisions in hospitals and residential centres that did not guarantee equal opportunities in relation to the health of residents in institutions. Several internal documents from regional and national governments, hospitals, and residences, which were leaked to the media, insisted on not taking to hospitals or not treating residents with COVID-19 symptoms who arrive at hospitals.

As an example, In the document prepared in March 2020:[56] ethical recommendations for decision-making in the exceptional situation of the COVID-19 pandemic crisis in intensive care units, written by the Bioethics Group of the Spanish Society of Intensive, Critical Care Medicine and Coronary Units (SEMICYUC), the following recommendations were made:

- Do not admit people in whom minimal benefit is expected, such as, for example, (...) [people with] very limited functional situations, fragile conditions, etc. (p. 11)
- Priority admission should be given to those who will benefit the most or have the greatest life expectancy at the time of admission. (p. 11)
- When faced with two similar patients, priority should be given to the person with the highest Quality-Adjusted Life Years (QALY). (p. 11)
- In older people, disability-free survival should be taken into account over survival itself. (p. 11)
- Carefully assess the benefit of admitting patients with a life expectancy of less than 2 years, established by NECPAL or a similar tool. (p. 11)
- Take into account the social value of the sick person. (p. 12)

In addition, a series of specific recommendations were made:

- Any patient over 80 years of age and with comorbidities will preferably receive (…) non-invasive mechanical ventilation. (p. 12)
- Any patient with cognitive impairment, due to dementia or other degenerative diseases, would not be eligible for invasive mechanical ventilation. (p. 12)
- Therapeutic appropriateness decisions should ideally be agreed with the patient and/or family members, but if consensus decisions are not possible, the guarantor of decision making is the patient's healthcare team. (p. 13)
- Specialised life support should be restricted to those patients who can benefit most from it. (p. 13)

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

In response to this document, the Spanish Bioethics Committee,[57] states that the spread of a utilitarian mentality or, even worse, of contrary prejudices towards the elderly or people with disabilities should be prevented. The term "social value" is extremely ambiguous and ethically debatable because every human being, by the mere fact of being human, is socially useful, in view of the ontological value of human dignity. (p. 7). In this sense, it would be radically unjust if the people whose health is most threatened by a possible contagion of the coronavirus were, in turn, the most harmed by this crisis (p. 7). Furthermore, the committee echoes the WHO recommendations on the management of ethical issues in the face of epidemics and states that: In some cases, an equitable distribution of benefits and burdens may be considered fair, but in others, it may be fairer to give preference to groups that are worse off, such as (…) the sick, or the vulnerable (pp. 9-10).

They also point out that the SEMICYUC recommendation that "any patient with cognitive impairment, due to dementia or other degenerative diseases, would not be eligible for invasive mechanical ventilation", is not compatible with the International Convention on the Rights of Persons with Disabilities. It is also recalled that the Convention prohibits any type of discrimination on the grounds of disability (article 5), the right to life of persons with disabilities under equal conditions (article 10), the protection of this groups in humanitarian emergencies (article 11), or the avoidance of discriminatory denial of health services on the grounds of disability (article 25). They therefore conclude that it is clear that the disability of the illness can never be in itself a reason to prioritize care for those without disabilities (p. 10).

Another example, in the Technical document: Recommendations to nursing homes and social health centres for COVID-19 (Version of 5 March 2020)[58] prepared by the Ministry of Health, it was indicated that (p. 5): "As a standard, all residents with acute respiratory symptoms should restrict their movements as much as possible and stay in a room with good ventilation (..). The protocols established by the social health centres for the prevention of diseases transmitted by air, such as the flu, must be strictly followed. As a precautionary measure, it is recommended that all residents with respiratory symptoms who are going to be treated (…) wear a surgical mask".

This accumulation of circumstances helps to explain why in the "Report of the COVID-19 and Residences Working Group" (24 November 2020)[59] it is stated that between 47 % and 50 % of deaths of the residents were due to COVID-19 disease in the first wave. Continuing with this report, it is noted that these death rates are comparable to those in the United Kingdom (45 %), France (46 %), Sweden (46 %), Scotland (47 %) or Northern Ireland (49 %); significantly below Belgium (61 %), Australia (75 %), Canada (80 %) or Slovenia (81 %) and above Denmark (35 %), Austria (36 %), Israel (39 %) or Germany (39 %). It is also noted that in Spain around 6 % of the people who were living in residences have died from COVID-19 in the first wave of the pandemic in Spain. This percentage is higher than those in countries such as Scotland (5.5 %), United Kingdom (5.2 %), Belgium (5.0 %), United States (4.2 %), or France (2.5 %).

[57] http://assets.comitedebioetica.es/files/documentacion/Informe%20CBE-%20Priorizacion%20de%20recursos%20sanitarios-coronavirus%20CBE.pdf.

[58] https://www.mscbs.gob.es/profesionales/saludPublica/ccayes/alertasActual/nCov/documentos/Centros_sociosanitarios.pdf.

[59] https://www.mscbs.gob.es/ssi/imserso/docs/GTCOVID_19_RESIDENCIAS.pdf.

Similarly, the report continues indicating that 72.6 % of residents in residences are dependent persons.

In short, throughout the pandemic but especially during the first wave, the overflow of the system and the lack of planning, together with the characteristics of the residences and residents, notably increased the mortality of dependent elderly people, as well as probably that of people with disabilities in residential centres.

The impact can also be noted indirectly through the claims made by representative organizations of people with disabilities. The document on the right to health of people with intellectual or developmental disabilities in the health crisis of COVID-19,[60] prepared by Plena Inclusion states that the presence of an intellectual or developmental disability does not limit the survival of people after contracting COVID-19. It does not imply a life-threatening situation and in no case can it be used to justify a limitation of the therapeutic effort. It also states that all residential services must have adequate medical assistance in the event that people who live in them get sick with COVID-19. They also indicate that any approach that establishes as a general criterion that social care teams should not transfer patients with disabilities with COVID-19 to hospitals, except in very justified cases with a high probability of recovery, is discriminatory (and contrary to the law). They also point out that any provision that requires this transfer to the hospital to be previously authorised by the hospital emergency services is also discriminatory, since this type of authorization is not required for the rest of the population. In no case should the weight of the decision on whether or not a person has a high probability of recovery be left to the staff of the social care home teams that do not have the necessary training to carry out this type of clinical judgment since, in many of these cases, they do not even have contracted health personnel. On the other hand, they claim that any prioritization criteria in the care of the population must be disability neutral. It also claims other aspects such as: The use of a criterion linked to the result of "disability-free survival" as a criterion, even when it refers to older people, is unnecessary and implies "per se" a negative value judgment on disability as something undesirable that evokes eugenic approaches. In any case, the use of the criterion of the patient's “social value”, apart from being impossible to evaluate, is contrary, as has already been established, to the inherent dignity and intrinsic value of people.

4.6 Vaccination programmes

A COVID-19 vaccination schedule has been established in Spain,[61] and an ethical framework has been established in which the principles of equality and dignity of rights, necessity, equity, protection of the disabled and minors, in this order, prevail. Additional principles are social benefit and reciprocity. In addition, the following more procedural principles have been taken into account: participation, transparency and accountability. The following group prioritisation has been established for the first stage:

1. Residents and health and social health personnel in residences for the elderly and with disabilities.
2. Front-line health personnel.

[60] See: https://www.plenainclusion.org/sites/default/files/el_derecho_a_la_salud_de_las_personas_con_discapacidad_intelectual_o_del_desarrollo_en_la_crisis_sanitaria_del_covid19.pdf.

[61] See: https://www.sindromedown.net/wp-content/uploads/2020/11/vacunacion.pdf.

3. Other health and social health personnel.
4. People with disabilities who require intense support measures to lead their lives (major non-institutionalised dependents).

At the moment no other groups have been established, as they are waiting to know the availability of vaccines.

As of 21 January 2021, the document of Vaccination Strategy against COVID-19 in Spain is based on the ethical principles of necessity, equity and reciprocity. In this way, priority is given to the vaccination of those people who are most exposed to the risk of illness and those who are most at risk of hospitalisation and death (p. 11).

However, some organisations disagree with this protocol. For example, the Down España Federation sent a letter to the Ministry of Health and the Health Councils of the different Autonomous Communities indicating the risk of people with Down syndrome over 40 years of age or with comorbidities before COVID-19.[62] Taking into account the State Vaccination Plan against COVID-19,[63] Down España has justified the importance of including people with Down syndrome within the priority groups for vaccination. Among other reasons, they argue that the Spanish Vaccination Calendar recognizes a specific vaccination calendar for people with Down syndrome, due to their particular predisposition to suffer from respiratory tract infections, together with a lower immune response to certain vaccines. Therefore, they are already part of the priority group for vaccines such as Hepatitis B, the pneumococcal vaccine or the flu vaccine.

To facilitate access to vaccination information, Plena inclusion has designed an easy-to-read guide[64] to explain to people with intellectual and/or developmental disabilities what the COVID-19 vaccine is all about.

The Spanish Government has also published an infographic on the vaccination process.[65] It has also published a link to track vaccination in Spain.[66] Yet, there is a feeling in the country that the vaccination program has not been sufficiently planned. There are logistical problems and certain priority professional groups cannot be vaccinated in some Autonomous Communities. There is also concern about the different types of vaccines (Pfizer / BioNtech, Moderna and AstraZeneca / Oxford vaccines are being used in Spain) and their target groups.

As of 19 January 2021, the Spanish Committee of Representatives of People with Disabilities (CERMI) has urged to accelerate the process of vaccination against COVID-19 among all people with disabilities, pointing out as a very negative element the great "inequality" between territories. Although it is recognised that vaccination is

[62] See: https://www.sindromedown.net/noticia/down-espana-solicita-que-se-incluya-a-las-personas-con-sindrome-de-down-en-los-grupos-prioritarios-de-vacunacion-contra-la-covid-19/.
[63] See: https://www.sindromedown.net/wp-content/uploads/2020/11/vacunacion.pdf.
[64] See: https://www.plenainclusion.org/sites/default/files/plena_inclusion._estrategia_de_vacunacion_contra_el_covid-19._lectura_facil.pdf.
[65] https://www.mscbs.gob.es/profesionales/saludPublica/prevPromocion/vacunaciones/covid19/docs/INFOGRAFIA_VACUNACION_COVID19_02.pdf.
[66] https://www.mscbs.gob.es/profesionales/saludPublica/ccayes/alertasActual/nCov/vacunaCovid19.htm.

advancing in residences for people with disabilities, care centres for dependent persons and day care centres, it warns that there are still areas where the process has not yet reached, such as people with disabilities with high support needs who are not institutionalized, which should be a priority. On the other hand, it has been warned that, once again, there is a lack of accessibility in the information provided to the public on the pandemic and in particular on vaccination, which "leaves a sector of the population without access to the basic data from which a conscious and informed decision must arise”.[67]

[67] https://www.cermi.es/es/actualidad/noticias/el-cermi-exige-que-las-personas-con-discapacidad-no-%E2%80%9Cqueden-fuera%E2%80%9D-de-los.

5 Income and access to food and essential items

Article 28 – Adequate standard of living and social protection

5.1 Emergency measures

In the social sphere, a series of urgent measures have been put in place to deal with COVID-19.[68] These are classifiable as: (1) Financial aid for low-income families; (b) Measures aimed at consumers and families in vulnerable situations.

With respect to financial assistance for low-income families, the Minimum Living Income has been implemented[69] [70] and families with members with disabilities can benefit from it. Regarding the measures aimed at consumers and families in vulnerable situations, they are divided into: (a) guarantee of the supply of electricity, oil derivatives, gas and water, (b) Termination of contracts without penalty for consumers and users, which allows sales or services that could not be carried out to be terminated without penalty for the seller. These measures also protect the most vulnerable, including families with members with disabilities.

The government has also provided additional financial aid to the Autonomous Communities to deal with situations of vulnerability. This makes it possible to reinforce home care for elderly, dependent or disabled people affected by the closure of day centres or social centres. It also makes it possible to reinforce and expand home telecare devices in such a way as to increase surveillance of the beneficiary population of this service. Along the same lines, these funds make it possible to reinforce the staff of social service centres and nursing homes. These sites are considered[71] to be considerably more vulnerable and it is therefore urgent to medicalize these centres. This requires reinforcing the staff with personnel and sanitary equipment, with more resources and with Personal Protective Equipment for the professionals of these centres. The Ministry of Health has issued a mandatory order to improve care and health security in all homes for the elderly, dependent people and people with disabilities. In addition, these grants also make it possible to assist homeless people, and to put in place more than 19 500 beds in more than 1 000 buildings.

5.2 Impact of the COVID-19 crisis

No more information is available concerning the impact of the COVID-19 crisis on income and poverty and on access to food for people with disabilities.

[68] See: https://www.mscbs.gob.es/ssi/covid19/guia.htm#.
[69] See: https://www.mscbs.gob.es/ssi/covid19/ingresoMinVital/home.htm.
[70] See: https://www.boe.es/buscar/pdf/2020/BOE-A-2020-5493-consolidado.pdf.
[71] See: https://www.mscbs.gob.es/ssi/covid19/ccaa/home.htm.

6 Access to transportation and the public spaces

Article 9 – Accessibility

6.1 Emergency measures

According to Order TMA / 424/2020,[72] on the distribution of occupation of public transport, special attention will be given to enabling spaces for people with disabilities.

Similarly, in Order TMA / 400/2020,[73] of 9 May 2020, which establishes the conditions to be applied in Phase I of de-escalation in terms of mobility and sets other requirements to ensure safe mobility, it also states that in the distribution of the use of public transport, special attention will be paid to the provision of spaces for people with disabilities.

6.2 Impact of the COVID-19 crisis

In Spain, orders have been issued to reduce the frequency and services of public transport by land, sea and air.[74] [75] Given that the vulnerable population is mainly users of this transport, it is foreseeable that the reduction of these services has negatively affected people with disabilities.

[72] See: https://www.boe.es/buscar/pdf/2020/BOE-A-2020-5192-consolidado.pdf.
[73] See: https://www.boe.es/boe/dias/2020/05/10/pdfs/BOE-A-2020-4912.pdf.
[74] See: https://www.boe.es/boe/dias/2020/03/30/pdfs/BOE-A-2020-4195.pdf.
[75] See: https://www.boe.es/buscar/pdf/2020/BOE-A-2020-4008-consolidado.pdf.

7 Involuntary detention or treatment

Article 14 – Liberty and security of person
Article 15 – Freedom of torture or cruel, inhuman or degrading treatment or punishment
Article 16 – Freedom from exploitation, violence and abuse
Article 17 – Protecting the integrity of the person

7.1 Emergency measures

In a report prepared by Plena Inclusión,[76] it is indicated that some of the measures during the pandemic did not sufficiently take into account the will and situation of people in residential centres. The walking hours reserved for the elderly were accompanied by the prohibition of entry and exit of the same elderly if their home was a residence. In situations of isolation of people with cognitive impairment, containment measures that were not ethically plausible could have been adopted. These situations have sometimes resulted in legal proceedings in defence of the rights of individuals, and also in the legal uncertainty of the managers towards the application of some measures. The same can be said of the right to information of people in residential centres (not always properly informed of what was happening) and, of course, of their right of access to the services provided by all social protection systems, and especially those of the National Health System. The report goes on to indicate that the regulations of the Autonomous Communities establish measures in relation to the visits that aim to guarantee the safety of the visits with protocols for their execution, such as, for example, the manner and place, staggering, disinfection and ventilation of the rooms, etc. However, other measures are restrictive in relation to the frequency (1 per week), duration of 1 hour or the number of contact persons permitted. In accordance with the foregoing, the timeliness of these measures must be examined in light of the principle of proportionality (suitability, necessity and proportionality). Another aspect that has suffered intense restrictions in the lives of people living in residential centres, continues the Plena Inclusión report, are the outings. Outing is related to the fundamental right to freedom of movement and any restriction to it must be carried out respecting the right to non-discrimination, that is, restrictions on the freedom of movement of people residing in centres must be the same as for the rest of the public and any more restrictive measure must be adequately motivated and the mere existence of a disability will never be sufficient justification. The different regional regulations include the limited possibility for residents to go on outings for therapeutic purposes, for reasons of health, health care or extreme necessity. Some go so far as to prohibit outings in general.

Another issue addressed in the aforementioned report is the vaccination against COVID-19. Regarding the vaccination of the general population and of people with intellectual disabilities, from a legal point of view, it is indicated that vaccination[77] is voluntary and there are no legal grounds for its imposition. Therefore, it requires the informed consent of the person. In addition, Spanish regulations establish that the

[76] See: https://www.plenainclusion.org/sites/default/files/plena_inclusion._medidas_de_alivio_en_los_recursos_residenciales.docx.pdf.

[77] See: https://www.plenainclusion.org/sites/default/files/plena_inclusion._medidas_de_alivio_en_los_recursos_residenciales.docx.pdf.

patient will be informed, even in case of disability, in a way that is appropriate to their understanding, complying with the duty to also inform their legal representative.[78] Furthermore, if […] they are not capable of making decisions, at the discretion of the responsible physician, or his/her physical or psychological condition does not allow them to take charge of their situation, the consent will be given by the persons related to them for family or de facto reasons or by their legal representatives when the patients' capacity are judicially modified. This does not prevent their participation from being guaranteed […] as far as possible in decision -making throughout the entire process.

Finally, it should be noted that the prohibition of going outside in the confinement phases has been a significant problem for people with dementia and their caregivers. Here, the results of a Spanish study showed the worsening of neuropsychiatric symptoms in patients with Alzheimer's disease (AD) and amnesic mild cognitive impairment (MCI) during the 5 weeks of lockdown in Spain, with agitation, apathy and aberrant motor activity being the most affected symptoms.[79]

7.2 Impact of the COVID-19 crisis

As noted, the coronavirus crisis has affected the psychological adjustment of people with disabilities or dependency. Institutionalized people have seen their mobility limited and, in some cases, ethically questionable measures have had to be resorted to. The limitations of family contact in these circumstances have also been another of the factors highlighted in the previously mentioned documents. To this must be added that the restrictions have, in some cases, led to the maintenance of COVID-19 patients in social-health residences, reducing their access to hospitals.

[78] See: Ley 41/2002, de 14 de noviembre, básica reguladora de la autonomía del paciente y de derechos y obligaciones en materia de información y documentación clínica, downloadable at: https://www.boe.es/buscar/pdf/2002/BOE-A-2002-22188-consolidado.pdf.

[79] Lara, B., Carnes, A., Dakterzada, F., Benitez, I., & Piñol-Ripoll, G. (2020). Neuropsychiatric symptoms and quality of life in Spanish patients with Alzheimer's disease during the COVID-19 lockdown. European Journal of Neurology, 27(9), 1744-1747. doi:10.1111/ene.14339.

8 Violence, exploitation or abuse

Article 16 – Freedom from violence, exploitation and abuse

8.1 Emergency measures

The government has also planned a series of measures for female victims of gender violence as well as their children. Specifically, women who are suffering from gender-based violence in the situation of home confinement under the state of alarm by COVID-19, can benefit from the services for women victims of gender-based violence, as they have been declared essential services. These services continue to operate at full capacity as they cannot benefit from the measures established in Royal Decree-Law 10/2020,[80] of March 29, which regulates a recoverable paid leave for employed persons who do not provide essential services, in order to reduce the mobility of the population in the context of the fight against COVID-19.

Several associations of women with disabilities have signed a manifesto on "Violence against women and girls with disabilities during Confinement".[81] Among other aspects, they demand: the need to integrate the perspective of disability and gender in the definition and implementation of measures to protect citizens on a permanent basis. They also demand the incorporation of the "women" and "disability" indicators in official research, records and statistics.

8.2 Impact of the COVID-19 crisis

We do not have additional or more detailed information in this regard.

[80] See: https://www.boe.es/buscar/pdf/2020/BOE-A-2020-4208-consolidado.pdf.

[81] See: https://www.cocemfe.es/wp-content/uploads/2020/07/20200721-Webinario-Violencia-Confinamiento-Manifiesto.pdf.

9 Independent living

Article 19 – Living independently and being included in the community

9.1 Emergency measures

In the report: "COVID-19 and the Institutional and Organizational Management of Nursing Homes in Spain: Difficulties and Lessons",[82] the authors stated that if nursing homes would have put into place measures to prevent the entry of the virus and its transmission within the nursing homes, the number of deaths had been sensibly lesser. They argue that beyond the current crisis, it is necessary to rethink the future of the long-term care sector. Fourteen years after the definition of the Spanish dependency system, and after the budget cuts introduced by Royal decree-law 20/2012, it appears crucial:

- To secure quality long-term care services for the older-age adults and for those who care for them, mostly women. The entire society will benefit from the return on investment made to achieve this objective.
- To avoid 'medicalization' of the nursing homes, exploring alternatives such as developing coordination structures between the health and social services sectors.
- To be attentive to proposals related to the future of the Social Services and Long-Term Care System and its de-professionalization.

The fact that during the pandemic, the insufficient response of residential services, which are available for social and health care, has once again led the Independent Living Movement to demand a law that promotes self-management and independent living, instead of support consisting of residential alternatives, especially for people with greater impairments. Thus, Live Independent Movement (MVI) in Spain,[83] made up of the Federation for Independent Living (FEVI), the Forum for Independent Living and Fun (FVID) and the SOLCOM association (for community solidarity of people with functional diversity and social inclusion), have been demanding the need to promote personal assistance as a right for years and as the best option for people with functional diversity to lead a life with equal opportunities and be included in society. To achieve this, they propose a specific law on Independent Living and Personal Assistance, detached from the current dependency law, which develops and reinforces the right for all those who request it. They argue that the Law for the Promotion of Personal Autonomy and Dependency Care (LEPA), in force in Spain since 2007, limits the encouragement and promotion of the Personal Assistance system. According to the MVI, the dramatic effect with which the pandemic has had an impact on the residential model shows that the best option is to live in the community and achieve equal opportunities. The MVI has drafted and submitted to the government a Proposed Organic Law[84] regulating personal assistance to realize the fundamental human right

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[82] Eloísa del Pino, Francisco Javier Moreno-Fuentes, Gibrán Cruz- Martínez, Jorge Hernánez-Moreno, Luis Moreno, Manuel Pereira-Puga, Roberta Perna (2020) Informe Gestión Institucional y Organizativa de las Residencias de Personas Mayores y COVID-19: dificultades y aprendizajes. Instituto de Políticas y Bienes Públicos (IPP-CSIC) Madrid. http://dx.doi.org/10.20350/digitalCSIC/12636.

[83] See: https://asociacionsolcom.org/propuesta-del-movimiento-de-vida-independiente-remitida-a-la-comision-de-reconstruccion-social-y-economica-del-congreso-de-los-diputados/.

[84] See: http://forovidaindependiente.org/wp-content/uploads/2020/10/Proposicion-de-ley-de-vida-independiente.pdf.

of people with functional diversity to live independently in Spain and to be included in the community (Law on Independent Living for people with functional diversity). This proposal advocates self-management of the benefit for independent living.

As an illustration of the impact of the pandemic on different groups of people with disabilities, in a study on the situation of the population with intellectual and developmental disabilities (IDD) in Spain during the pandemic,[85] it is concluded that 19.9 % of people with DID surveyed claims not to have received the support they needed. Furthermore, 31.3 % of the families saw the support they received significantly reduced or even stopped receiving it altogether. Failure to receive the necessary support has generated important consequences : (a) around 60 % of the people with DID surveyed expressed greater nervousness and anxiety during the health emergency , an aspect that was also verified by the families ; (b) behavioural problems increased in 37.0 % of those who already had them; (c) 43.9 % of the people who experienced changes in their usual supports manifested, according to their relatives, a setback in previously acquired skills; and (c) 66.3 % of the family members who spent confinement with the person with DID experienced more stress or anxiety due to care overload and difficulties in reconciling family and work life (p. iv).

9.2 Impact of the COVID-19 crisis

As noted, several reasons explain the more negative impact of the pandemic on people with disabilities. On the one hand, the services and supports to which the law gave them the right have been greatly reduced. On the other hand, the law provides for services more oriented to the institutionalisation of people with severe impairments than to the promotion of independent living. As a result, organizations representing different disabilities are calling for changes in regulations and preferential attention to the needs of vulnerable groups.

[85] Navas, P., Verdugo, M. A., Amor, A. M., Crespo, M. y Martínez, S. (2020). COVID-19 y discapacidades intelectuales y del desarrollo: impacto del confinamiento desde la perspectiva de las personas, sus familiares y los profesionales y organizaciones que prestan apoyo. Plena inclusión España e Instituto Universitario de Integración en la Comunidad (INICO), Universidad de Salamanca. Downloadable from the Internet at: https://sid-inico.usal.es/wp-content/uploads/2020/12/Informe-COVID-19-y-discapacidades-intelectuales-y-del-desarrollo.pdf.

10 Access to habilitation and rehabilitation

Article 26 – Habilitation and rehabilitation

10.1 Emergency measures

The Royal Decree-Law 10/2020 of 29 March 2020, regulating a recoverable paid leave for employees not providing essential services, in order to reduce the mobility of the population in the context of the fight against COVID-19, establishes the services considered essential and which must therefore continue to operate at full capacity during the pandemic.

In this regulation, activities related to social services, such as those carried out in day centres or occupational centres, are not considered essential. Regarding work activities, many activities in non-essential sectors have been reduced and so the activities of many special employment centres that carried out work for these companies. On the other hand, the education sector has initially seen the elimination and subsequent reduction of face-to-face attendance. This situation has posed significant problems for many vulnerable families with little access to tele-training modalities or with difficulties in assuming educational tasks for their children with disabilities. In addition, activities related to physiotherapy, gyms and spaces for sports activities have also been reduced. In short, all these limitations in the provision of social, educational, employment and health care services have had a clearly negative impact on the group of people with disabilities.

10.2 Impact of COVID-19 and/or emergency measures adopted

We do not have specific data in this regard.

11 Access to justice

Article 13 - Access to justice

11.1 Emergency measures

Like all services, access to justice services has been limited by the pandemic. As indicated on the website of the Ministry of Justice,[86] all face-to-face procedures are carried out by prior appointment and with limited capacity, being mandatory to wear a mask and have it properly placed at all times to be able to access and stay in the offices of the Ministry.

As mentioned in the report, Coronavirus pandemic in the EU –Fundamental Rights Implications (Spain, November 2020),[87] the elderly people are one of the groups whose social rights were particularly negatively impacted by the pandemic.

11.2 Impact of COVID-19 crisis

There is not more specific information available.

[86] https://www.mjusticia.gob.es/es/ciudadanos/atencion-ciudadano-covid19.

[87] See: https://fra.europa.eu/sites/default/files/fra_uploads/es_report_on_coronavirus_pandemic_november_2020.pdf.

12 Access to education

Article 24 – Education

12.1 Emergency measures

In a study in Spain and other European countries,[88] the objective was to examine parental experiences of home schooling during the COVID-19 pandemic in families with or without a child with a mental health condition across Europe. The study concludes that the adverse effects of home schooling will likely have a long-term impact and contribute to increased inequalities. Given that school closures may be less effective than other interventions, policymakers need to carefully consider the negative consequences of home schooling during additional waves of the COVID-19 pandemic and future pandemics.

Plena Inclusión has also proposed several measures to ensure that the return to the classroom is, safe:[89] “The reopening of the classrooms means the return of more than 8 million students in Spain, of which 722 000 students have special educational needs, and of them 220 208 are students with intellectual disabilities or pervasive developmental disorder. An 83 % of these students with intellectual or developmental disabilities, more than 183 200, are enrolled in regular schools and 17 % are enrolled in one of the 473 Specific Educational Centres in Spain (more than 37 000 students with intellectual or developmental disabilities)”. Specifically, the document proposes that the government develop a Plan to tackle the problems detected (financial, educational, etc.), and also propose measures to be implemented at the educational centre level.

A measure with a potential positive impact is related to the development and distribution of transparent masks to meet the needs of deaf and lip-reading student. Here, last December,[90] FIAPAS (Confederation of families of people with deafness) has been expressly consulted by the General Directorate of Consumption in the process of drawing up the new Order which will establish the information and marketing requirements for hygienic masks. This new order, whose requirements must be met by hygienic masks to safeguard the protection of consumers, includes a provision relating to transparent hygienic masks that, in addition to being applicable to all that is established throughout the articles of the Order, establishes some specific provisions to ensure their safety and functionality.

FIAPAS (confederation of associations of families of deaf people) details some of the violations of rights experienced in these times of pandemic, and that focusing on educational material,[91] are related to: (a) Distance education without support resources

[88] Thorell, L. B., Skoglund, C., de la Peña, A. G., Baeyens, D., Fuermaier, A. B. M., Groom, M. J., Christiansen, H. (2021). Parental experiences of home-schooling during the covid-19 pandemic: Differences between seven European countries and between children with and without mental health conditions. European Child & Adolescent Psychiatry. doi:10.1007/s00787-020-01706-1

[89] See: https://www.plenainclusion.org/sites/default/files/guia_rapida_vuelta_segura_a_las_aulas_de_plena_inclusion_0.pdf.

[90] See: http://www.fiapas.es/actualidad-y-agenda/nota-informativa/fiapas-participa-en-el-proceso-de-elaboracion-de-la-nueva-orden.

[91] See: http://www.fiapas.es/actualidad-y-agenda/noticia/fiapas-reinvindica-respuestas-efectivas-para-proteger-los-derechos-de.

for hearing and oral communication, such as subtitling and hearing aid products for connection with the device (computer, Tablet); (b) Reduction or cessation of specialized educational supports and speech therapy; (c) Difficulties or limitations in accessing supplies, spare parts and repairs for hearing aids.

12.2 Impact of the COVID-19 crisis

In the document prepared by Plena Inclusión on the right to education during COVID-19, the main problems that people with disabilities have in this area are highlighted. These are related to: (1) Difficulties in accessing technological resources to be connected with the educational centre, (2) Internet access limitations; (3) lack of cognitive accessibility of digital environments, (4) lack of knowledge or specialization to provide specific support to carry out tasks (learning-oriented activities) and therapeutic sessions (physiotherapy, psychology, speech therapy), (5) inability to reconcile the time dedicated to this support with the development of work activities, (6) problems when conducting therapeutic outings with their children, which has caused more problems for the management of behaviours and emotions. Specifically, 38 % of the families claim to make fewer therapeutic outings than their child would need due to the treatment received from the neighbourhood environment or the police services. Other limitations are related, according to the aforementioned report, with: (7) Students who finish their educational (they have reached 21 or are close to it) and are excluded from the school system, without being able to complete the last full school year, (8) Low digital skills in the face of internet security risks lead to greater vulnerability (for example, cyberbullying). In order to respond to all these needs, measures are proposed that consist of increasing support of all kinds (economic, human, training). The paper also insists on the need to include organizations representing disability when managing pandemics like this one.

In sum, students with disabilities have faced greater disadvantages than students without disabilities. Social and economic factors contribute to this, as well as those inherent to the greater needs of support and attention they require. Hence the need for global plans to undertake and finance the multiple needs detected and the disadvantageous situations that impede the progress of these students.

13 Working and employment

Article 27 – Work and employment

13.1 Emergency measures

A series of urgent measures have been put in place in the social and economic sphere to deal with COVID-19.[92] These are classifiable as: (1) Help for renting a home or work premises; (2) measures for workers; (3) help for small and medium-sized enterprises.

These aspects are regulated in different laws. With respect to employment measures, a package of measures was implemented to avoid massive layoffs during and due to the COVID-19 crisis. In general, most benefits provide higher income limits in cases of disability.

13.2 Impact of the COVID-19 crisis

Regarding employment, in a study carried out with a representative sample of people with disabilities,[93] at the time of application of the survey, 53 % were unemployed, only 27 % are working for others and 2 % are self-employed. To this, it must be added that among those who work, 37 % do so part-time. Following the pandemic, 12 % reporting losing their jobs, 37 % have been placed on temporary furlough or reduced hours, and 14 % have gone to teleworking. In this sense, and with the available data, the report affirmed that people with disabilities are being affected to a greater extent by these exceptional formulas. As the report continues to suggest, the explanation can be found in the majority employment typology among the group linked to services, customer service, restaurants, commerce ... activities that have been curtailed in order to avoid social contact. Although the report insists on the need to be prudent, the results suggest that clearly people with disabilities are significantly affected by the current economic situation and this impact is significantly higher than that faced by the general population. As indicated in the report, further evidence of the particularly negative impact on this group is the fact that April accumulated the lowest number of specific contracts for people with disabilities in 14 years, with a 74 % drop in employment compared to April of last year. In short, it is "a discouraging scenario" (p. 35). On the other hand, in the face of the economic crisis triggered by COVID-19, of the self-employed with active disabilities, 28 % have applied for temporary unemployment relief, (ERTE)[94] and 14 % have opted for the telework formula.

The aforementioned report concludes[95] that 37 % of respondents do not have any benefit. If we take into account that 53 % are unemployed, we are facing an important segment that is not receiving any type of income. Specifically, 51.6 % of the

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92 See: https://www.mscbs.gob.es/ssi/covid19/guia.htm#.

93 Fundación Once, Odismet (2020). Efectos y consecuencias de la crisis de la COVID-19 entre las personas con discapacidad. Downloadable at: https://www.odismet.es/sites/default/files/2020-07/Informe_EstudioCOVID_19_v3_0.pdf.

94 Note: Under the ERTE, workers are still technically employed by the company which still pays their social security contributions but does not have to pay their salary.
The ERTE enables those who are entitled to it, to claim unemployment benefit – which will be up to 70 % of their original salary.

95 Fundación Once, Odismet (2020). Efectos y consecuencias de la crisis de la COVID-19 entre las personas con discapacidad. Downloadable at: https://www.odismet.es/sites/default/files/2020-07/Informe_EstudioCOVID_19_v3_0.pdf.

unemployed say they do not receive any benefits. The situation is most acute for women, as among those who do not receive any benefit, 56.2 % are women, and 47.6 % have physical disabilities followed by 16 % with psychosocial disabilities. Furthermore, 27 % receive a permanent disability pension and 13 % receive unemployment benefits.

The aforementioned report continues by stating that[96] the lack of income as a consequence of the pandemic has increased the disadvantageous situation faced by this group. This lack of income means that: 23 % of respondents indicated that they would have to forego certain services and leisure activities, 22 % said they would not be able to pay loans and mortgages, and another 10 % said they would not be able to pay for basic goods. The people themselves advocate for greater control over compliance with the job reservation quota for workers with disabilities.

In sum, despite the government's efforts to implement measures to alleviate the urgent needs of companies and employees and self-employed workers, the numerous examples presented in this section show that the group of workers with disabilities has experienced more negative consequences in terms of employment than the general population. This is due to factors such as the type of employment they usually perform, which is more unstable and less qualified, and therefore suffers more from the consequences of a crisis. It is also related to the fact that in many cases they carry out work commissioned by companies in compliance with alternative measures to hiring a quota or quota of workers with disabilities. Given that companies in general have experienced substantial reductions in their income and activity, so have Special Employment Centres, for example. On the other hand, the reduction in human resources in companies of the third sector and the problems in the survival of these companies have led many workers with disabilities to receive less support. Additional problems related to the reduction in available transportation, social distance measures, mobility restrictions, etc., have significantly affected these workers. To this must be added the problems inherent (anxiety, worry, grief) when facing a situation as complex as the one we face and that negatively affects these workers and their motivation, performance, etc. The extra financial aid granted by the government to these entities is not enough to alleviate this situation.

[96] Fundación Once, Odismet (2020). Efectos y consecuencias de la crisis de la COVID-19 entre las personas con discapacidad. Downloadable at: https://www.odismet.es/sites/default/files/2020-07/Informe_EstudioCOVID_19_v3_0.pdf.

14 Good practices and recommendations

14.1 Examples of good practice

A good example is the government's consideration of families with members with disabilities as a particularly vulnerable group (see Section 5.1), allows access to aid to somewhat reduce the especially negative economic situation of this population.

The following is a selection of materials published, sponsored or disseminated by Plena Inclusión,[97] a representative organization of people with intellectual and developmental disabilities, focusing on: (1) facilitate access to information on COVID-19 issues through the publication of easy-to-read documents and infographics (2) to provide information to families and services on related issues, (3) to provide the entity's positions on policy decisions such as outing restrictions, confinements, educational measures, health measures, etc. (4) to disseminate research on intellectual disabilities and COVID-19. All these documents are good practices to make information accessible.

14.2 Recommendations

The transformation of companies and services, taking advantage of technologies, is a way to be followed by organizations in the sector and by social, educational and employment services. Efforts must be made to ensure universal accessibility. An example is the transformation of memory rehabilitation services for people with cognitive impairment, as a result of the restrictions imposed for the pandemic. As the authors indicate.[98] Measures adopted to address the negative experiences of confinement included keeping informed about the situation, accessing health and social services, having a support network that prevents risk of exposure to COVID-19 and guarantees food and medical supplies, a daily routine with maintained sleeping habits and leisure activities, staying physically and mentally active with cognitive stimulation exercises, and ensuring social connectedness using technology. Television sets were the preferred technological devices to access COVID-19 information, watching television as a recreational activity, and perform memory exercises as an intellectual activity. Television-based telehealth support using TV-Assist Dem demonstrated potential for cognitive stimulation.

The commitment to person-centred-services is especially advisable in socio-sanitary residences. One set of recommendations refers to the situation of users of nursing homes. In the study: “The impact of COVID-19 on users of Long-Term Care services in Spain”[99] the authors analysed the high mortality rates among users in nursing homes. They summarise several lessons learned and sources of action at short, medium, and long term. These are very productive and useful suggestions that we are summarising next. Concerning short and medium-term calls for action, the authors propose that:

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[97] Publications are available at: https://www.plenainclusion.org/informate/publicaciones.

[98] Benaque, A., Gurruchaga, M. J., Abdelnour, C., Hernández, I., Cañabate, P., Alegret, M., González-Pérez, A. (2020). Dementia Care in Times of COVID-19: Experience at Fundació ACE in Barcelona, Spain. Journal of Alzheimer's Disease, 76(1), 33-40. doi:10.3233/JAD-200547.

[99] Zalakain, J. Davey, V. & Suárez-González, A. The impact of COVID-19 on users of Long-Term Care services in Spain. LTCcovid, International Long-Term Care Policy Network, CPEC-LSE, 28 May 2020.

- Infection prevention and control: from international experience we have learned that the best way to prevent COVID-19 infection in care homes appears to be 1) blanket testing of staff and residents and 2) isolation of any positive cases.
- Care homes also need to be provided with resources to isolate individuals affected and, if this is not feasible, local governments and institutions should provide the means for isolation (e.g., transferring infected individuals to quarantine centre.
- A Priority should be to release all available information on the current situation in nursing homes.
- Adequate provision of personal protective equipment and efforts to hire and train new staff in their use are essential.
- Staff in care homes have taken on unprecedented levels of responsibility and had to work in physically and psychologically draining scenarios. The provision of psychological support must be prioritised. Also, financial compensation for the extra demands placed on staff would help to boost morale.
- It is essential to carry out a nationwide assessment in order to evaluate the measures that have been taken and clearly establish which factors have had the largest impact in the spread of the virus in nursing homes.
- In the short term, clarifying the type of healthcare that care home residents should receive is urgent: when should they be admitted to hospital and when and how they should be cared for in the care home. People who become ill in a residential centre have a right to public healthcare, both general and specialised, as a result of their status as citizens. That they should have this right violated because of their age or disability status is inadmissible. The rights of people with long-term care needs to access intensive care (ICU) must be clarified and even regulated and guaranteeing so that no discrimination takes place on the basis of age, long-term care needs, dementia diagnosis or other issues. Providing better health services in care homes is one of the major needs of the Spanish residential long-term care model, without necessarily converting care homes into medical centres.
- Ensuring continuity of support for people living with dementia is crucial to provide compassionate care in COVID-19 times. Partners in care can be enabled to accompany their relatives or friends with dementia in hospitals and care homes by implementing appropriate infection control protocols and use of PPE. The use of technology to support video calls with friends and family when a person with dementia is isolated should be encouraged.

Regarding longer term policy implications, the authors state:

- The Spanish long-term care system lacks an adequate information management system and, more broadly, a shared innovation, evaluation and knowledge management model.
- In this context, there is also a pressing need for the development of a shared quality indicator system, not only based on structure and process indicators, but, mainly, on outcome indicators related to the quality of life.
- The COVID-19 crisis has highlighted the Spanish long-term care system's shortcomings and the need to develop a more community-based, more individualised and more person-centred model to achieving the best possible quality of life for people with long-term care needs and their families.
- The debate on the quality of residential care cannot be separated from the debate on the funding of the long-term care system.

- The COVID-19 crisis has also brought to the surface systemic problems in relation to human resource management. Professional profiles are poorly developed in terms of competences and training, and working conditions are less than ideal. In contrast with the health care system's response to COVID-19, there has been a clear lack of leadership in the response to the crisis.
- The care home sector is increasingly dominated by private for-profit providers, and there are longstanding concerns about decreasing quality standards as a result of efforts to contain costs in order to generate expected profit margins. The private management model of public services undoubtedly requires strengthening the inspection and evaluation capacities of public administrations, as well as changes in contracting-out policies.
- The governance of the Spanish long-term care system involves all three levels of government (central, regional and local), which makes the system very unwieldy. This complicated governance makes it very difficult to adopt and implement ambitious measures and it has created legal difficulties in relation to, for example, purchasing equipment and re-organizing the workforce in response to the pandemic. The COVID-19 crisis should prompt the revision of the institutional and territorial framework of the social services system in Spain.
- Provision of post-diagnosis support for people living with dementia is almost non-existent in the public health and care system in Spain. Post-diagnostic support teams, if they had been in place, might have played a major advisory role supporting people living with dementia and their families to adjust to the challenges imposed by the confinement and the disruption of other support services.

14.3 Other relevant evidence

No more information is available.

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