

COVID-19 and people with disabilities

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

Netherlands



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Table of contents

1	Executive summary5			
2	Disa	bility-inclusive disaster and recovery planning	8	
	2.1		ies	
		, , , ,		
	2.2	Involvement of people with disabilities in disaster management and		
		recovery strategies	11	
	2.3	Disability impact assessments and research to inform disaster		
	•	management and recovery planning	11	
	2.4	Use of disaster management and recovery planning funds		
3		tality connected to COVID-19 among people with disabilities		
	3.1 Are official statistics available concerning the overall mortality rate of			
	0.1	people with disabilities?	13	
	3.2	Are official statistics available concerning the mortality rate of people with		
	0.2	disabilities who have died from complications connected to COVID-19?		
4	Δος	ess to health		
4	4.1	Emergency measures		
	4.2	Access to hospital treatment for COVID-19		
	4.3	Treatment for COVID-19 in congregate settings		
	4.3 4.4			
		Public health promotion and testing during the pandemic		
	4.5	Impact of the COVID-19 crisis on access to health services for general of		
	4.6	pre-existing physical or mental health conditions		
E	4.6 Vaccination programmes			
5		me and access to food and essential items		
	5.1		22	
_	5.2	Impact of the COVID-19 crisis		
6		ess to transportation and the public spaces		
	6.1			
_	6.2	Impact of the COVID-19 crisis		
7		luntary detention or treatment		
		Emergency measures		
_		Impact of the COVID-19 crisis		
8		ence, exploitation or abuse		
	8.1	Emergency measures	28	
		Impact of the COVID-19 crisis		
9		pendent living		
	9.1			
	9.2			
10		ess to habilitation and rehabilitation		
		Emergency measures		
		Impact of COVID-19 and/or emergency measures adopted		
11	Acce	ess to justice	33	
	11.1	Emergency measures	33	
	11.2	Impact of COVID-19 crisis	33	
12	Acce	ess to education	34	
	12.1 Emergency measures			
		Impact of the COVID-19 crisis		
13	Working and employment			
		Emergency measures		
		Impact of the COVID-19 crisis		
		•		

14	Good practices and recommendations	36
	14.1 Examples of good practice	
	14.2 Recommendations	
	14.3 Other relevant evidence	37

1 Executive summary

Disability inclusivity of disaster and recovery planning

The main disaster and recovery planning plans and policies pay almost no attention to people with disabilities. A broad category of people deemed 'less able to take care of themselves' are referred to in all disaster planning as a group to take into account but without specifying who belongs to this group and exactly how disaster planners should plan for eventualities for this group. Emergency information was not made fully accessible for people with disabilities before the start of the COVID-19 pandemic.

The COVID-19 pandemic led to active policies by the National Government to make emergency information more fully accessible. A few months into the pandemic disabled people's organisations pressured the National Government to formulate a specific COVID-19 strategy plan especially for people with disabilities.

Impact of the virus on mortality among people with disabilities

There are no overall statistics available concerning the overall mortality of people with disabilities, as disability is not registered in the standard statistics on mortality causes.

The mortality rate among people eligible for long term care (elderly people and people with disabilities deemed in need of residential care) is registered. These statistics show a considerably higher all-cause mortality rate among receivers of long-term care than among the general population.

The mortality rate by COVID-19 is 3 to 4 times higher among people with intellectual disabilities living in residential care compared to the general population and mortality rates are increased from a younger age.¹

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

The most significant negative impact of the COVID-19 crisis on people with disabilities and their family and friends was the decision in March 2020 to forbid all access by family and friends to people living in care homes and institutions. It has been fiercely contested as a violation of human rights. It meant that families who would visit every weekend or who would come to help on a daily basis before the pandemic, could not even have direct contact with their loved ones when they were severely ill and dying. At the end of April 2020, the strict ban on all visits was somewhat lifted. The main rule remained (until May): no visitors unless the care institution would decide that one or two specific family members should be allowed access to someone's private room within the institution. In the second lockdown period care institutions allow for one visitor. See section 7.

Registratie COVID-19 in database. (Registration COVID-19 database) by Academic Collaborative 'Sterker op eigen benen' of Radboud university medical centre. https://oda93f8e-6ee7-45d9-be21-eecb55ca3e69.filesusr.com/ugd/d45b6c 31e956195d884b74b08f0362e4cc2893.pdf.

Letter to Parliament. https://www.rijksoverheid.nl/binaries/rijksoverheid/documenten/kamerstukken/2020/03/19/kamerbrief-over-aanscherping-bezoek-verpleeghuizen-in-verband-met-COVID-19/Kamerbrief+over+aanscherping+bezoek+verpleeghuizen+in+verband+met+COVID-19.pdf.

The closing down of day care activity centres for adults with disabilities mirrored the advice for the Dutch workforce to work as much as possible at home. It proved very difficult to offer enough and adequate digital alternative day care for people with intellectual disabilities and mental health problems. Staying at home meant being left alone without the means to get together and have meaningful activities.

The closing down of day care centres for children with disabilities and special schools was aligned with the closing down of all schools and regular day care centres for small children. The impact on children with disabilities was disproportionately negative for the children and their parents as alternative care and support and alternative digital lessons were usually less available for these groups. See section 9.

Examples of good practice

Three examples of good practice in terms of government or other initiatives to avoid or mitigate a disproportionately negative impact of the crisis on people with disabilities are as follows:

- The regular consultation by the Minister of Health with the organisation of people with disabilities is good practice which resulted in a specific strategy especially for people with disabilities in which the rights as described in the CRPD were taken into account with all new COVID-19 measures.
- The pandemic had led to the regular participation of a sign language interpreter during life broadcasted announcements, something that had not been done before April 2020. The National Government also invested more than usual in making information more visually available and in easy read formats.
- The vaccine roll-out strategy has taken the more vulnerable health condition of people with Down syndrome into account. This group has been prioritised compared to the general population in vaccination as part of the larger groups of people considered to be more vulnerable such as people with respiratory disease, kidney failures etcetera.

Recommendations and opportunities for change

Three 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 are as follows:

- Recommendation 1: Plan for specific strategies for people with disabilities in all general disaster and recovery planning at the level of the Safety Regions and do so in close consultation with organisations of people with disabilities.
- Recommendation 2: The Health Inspectorate could use regular inspections and could actively seek information (or commission research) about mortality rates and the impact of COVID-19 measures such as restricting visits to care homes and institutions, closing down of day care activities, and providing care for people with disabilities living independently in the community. The Health Inspectorate published short reports on notifications they received by care providers and individuals but did not actively pursue the gathering of information on impact.
- Recommendation 3: Closing down all schools is considered to have had huge impact on pupils of primary and secondary schools. The impact on regular students will be made visible by monitoring study results per schools and possible declines in exam results. Such monitoring is not possible for students with disabilities as they visit in majority segregated special schools where only a minority of students do exams. It is recommended to commission research on the impact of the COVID-19 pandemic on children with disabilities and their families not only on closing downs schools but also on closing down day care centres, where no alternative care was offered.

2 Disability-inclusive disaster and recovery planning

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

2.1 Commitments to disability in disaster management and recovery strategies

National policies pertaining to general management of disaster or recovery planning mention people with disabilities as a specific group within the category 'people who are less able to take care of themselves'. The national strategy lays out that Government is responsible for those who are less able to take care of themselves during a crisis. Exactly how Government will take care for this group is not described in any way at national level. 4

The national strategy for disaster and recovery planning is a mixture of national, regional and local responsibilities. The formal national strategy plan in disaster management is a mainly procedural one as the management of disaster or recovery planning is by law⁵ a responsibility of each mayor of each municipality. The mayor is the official who is to design and organise disaster planning. All mayors of all municipalities are by law required to cooperate with other mayors within fifteen designated safety regions. The mayor of the largest city within such region will act as chair. Actual strategy plans are made at the level of these 15 safety regions. These safety regions are also primarily responsible for the handling of infectious diseases. Specific issues, such as the national alert system are organized at a national level. If infectious diseases are manifesting themselves at national level, the Minister of Health, Welfare and Sports takes over the responsibility for the strategy on handling that specific disease based on the Public Health Act⁶ albeit without taking away responsibility at regional level.

A report by the Institute of Physical Safety describes how national Government does not address the issues of who are less able to take care of themselves, what different kinds of disabilities (or different levels of abilities to take care of themselves) would mean for disaster planning, and the lack of specific instructions how the safety plans in each region should plan for eventualities for people with disabilities.⁷ The report notes the lack of structural attention being paid in disaster legislation and disaster planning for people with disabilities and other groups who are less able to take care of themselves.

The main national plan for disaster management: *Bevolkingszorg op orde de vrijblijvendheid voorbij*. (taking care of population, beyond noncommitment). Report commissioned by Veiligheidsberaad. July 2012 https://bfgv.nl/wp-content/uploads/2015/06/Rapport-Bevolkingszorg-op-orde-2.0.pdf.

Noted in a report by the Institute Physical Safety. Verminderd zelfredzamen ten tijde van rampen en crises: de overheid een zorg? (less able to take car during disaster and crisis, does government care?'). Instituut Fysieke Veiligheid (2018) https://www.ifv.nl/kennisplein/Documents/20181203-IFV-Verminderd-zelfredzamen-ten-tijde-van-rampen-en-crises.pdf.

Wet veiligheidsregio's (Act on Safety Regions) https://wetten.overheid.nl/BWBR0027466/2021-01-01.

Wet publieke gezondheid (Wpg) 2008 https://wetten.overheid.nl/BWBR0024705/2021-01-09.

Institute Physical Safety. Verminderd zelfredzamen ten tijde van rampen en crises: de overheid een zorg? (less able to take car during disaster and crisis, does government care?'). Instituut Fysieke Veiligheid (2018) https://www.ifv.nl/kennisplein/Documents/20181203-IFV-Verminderd-zelfredzamen-ten-tijde-van-rampen-en-crises.pdf.

There are examples of the regional disaster management plans of safety regions that reference people with disabilities in a limited way. For example, in two regional plans a brief reference is made to the danger of fires and the vulnerability of persons with disabilities dependent on long term care and living in institutions. In both regions efforts are being made to cooperate with care providers in taking preventive measures, like installing alarm systems; to involve people with disabilities (instead of actors) in practising evacuating buildings; and to set up a system to alert large numbers of off-duty staff of care providers in case of emergencies during the night at residential locations with no or only a single person on night watch for large groups of people with disabilities.

Specific issues concerning disaster or recovery planning are regulated at the national level such as the organisation of the national emergency telephone number and the national alert system. A policy commitment has been made to make the emergency telephone number accessible for people with sensory disabilities via different methods (sign language interpreter and text service). The national alert system makes use of sirens that cannot be heard by people who are deaf. Since 2008 a system was introduced to alert people who are deaf via their mobile phone. This alert system via mobile phone will in the near future replace the sirens system. After a specific emergency situation (a terrorist attack on passengers of a tram in Utrecht in 2019), people who are deaf and their advocacy organisations complained publicly about the lack of sign language interpretation when the public was formally being warned to stay indoors during the attack. In reaction to these complaints a policy commitment has been made to make an action plan to provide accessible crisis communication such as sign language interpretation at nationally broadcasted public announcements on emergency matters.

If infectious diseases are manifesting themselves at a national level, the Minister of Health, Welfare and Sports takes over the responsibility for the strategy on handling that specific disease based on the Act Public Health. A national strategy has been laid out by RIVM, the National Institute on Health and Environmental Matters on how the national Government will seek advice. This strategy lays out the procedures the national Government should follow such as the instalment of an national outbreak management team; what kind of experts should be asked to take a seat in that outbreak management team and how and according to what time lines Government will base its policy decisions on their advice.

These two strategy plans are of are the Safety region Twente: *Beleidsplan VRT*, 2016-2019. Veiligheidsregio Twente 2015 https://vrtwente.nl/media/1175/beleidsplan-vrt-2016-2019-definitief-ab-29062015.pdf and the Safety region Gelderland Zuid: *Jaarthema 2017* https://www.vrgz.nl/organisatie/jaarthemas/.

According to the national federation of disabled people's organisation lederin, full accessibility has indeed been realised in February 2021 https://iederin.nl/alarmnummer-112-nu-ook-te-bereiken-via-e-sms/.

See for instance national broadcaster NOS: https://nos.nl/artikel/2277528-geen-gebarentolk-na-aanslag-utrecht-ik-voelde-me-tweederangsburger.html.

Wet publieke gezondheid (Wpg) 2008 https://wetten.overheid.nl/BWBR0024705/2021-01-09.

Rijksinstituut voor Volksgezondheid en Milieu, May 2020. Landelijke advisering bij infectieziektedreigingen en –crises https://www.rivm.nl/sites/default/files/2020-05/Folder%20landelijke%20advisering%20bij%20infectieziektedreigingen%20en%20-crises_0.pdf.

This strategy has been effectuated for the COVID-19 pandemic since February 2020.¹³ The Minister of Health Welfare and Sports is responsible for the COVID-19 strategy. The Prime Minister coordinates within national Government as more ministers are involved in the strategy. The National Government is advised by both the National Institute on Health and Environmental Matters and an outbreak management team. The Minister of Health is to coordinate his decisions with mayors and the 15 safety regions. These regions are still responsible for the handling of infectious diseases. Mayors are also heading the municipal health agencies¹⁴ who are to perform all necessary measures to control infectious diseases, such as performing the testing of people and administering vaccines.

People with disabilities are referenced in multiple specific COVID-19 measures such as measures to close down day-care centres for people with disabilities (closed during the periods in which schools were closed), the use of face masks in public transport and adapted transport (people with disabilities who cannot wear face masks are exempted from the duty to wear them).

In June 2020 a specific and more comprehensive COVID-19 strategy aimed at people with disabilities, their families and their care workers was published. The strategy aims at preventing or reducing the risk of isolation, preventing poorer health, and reducing health risks and the risk of becoming infected. The strategy not only covers health issues but also takes into account effects of the pandemic and lockdown measures on domains such as work, education, transport, living and leisure activities. The strategy commits to test all COVID-19 measures affecting people with disabilities to the Convention on the Rights of Persons with disabilities CRPD. It states that:

- people with a disability (or their organisations) should be consulted on the effect of COVID-19 measures;
- that people with a disability should be made able to participate safely in all domains in society on an equal footing with people without disabilities;
- that all crisis communications should be accessible, for instance by providing easy read material:
- continuity of care, support and treatment is a priority. Guidelines on how to continue care and support during lockdown periods and on what conditions for instance visitors are allowed within care institutions or in private homes, are being negotiated with care providers and DPO's;¹⁶
- that a balance will be sought between reducing risk of contagion and social and psychological welfare when considering measures during lockdown;

More information on actual measures on handling the pandemic can be found at the website of the RIVM: https://www.rivm.nl/coronavirus-COVID-19 and at the general website of National Government: https://www.rijksoverheid.nl/onderwerpen/coronavirus-COVID-19.

In Dutch: Gemeentelijke Gezondheids Dienst. They can be found at this website: https://www.qqd.nl/.

¹⁵ COVID-19-strategie voor mensen met een beperking of chronische ziekte: 'een veilige terugkeer naar het gewone leven. (COVID-19 strategy for people with a disability or chronic illness: a safe return to normal life)

https://www.rijksoverheid.pl/documenten/kamerstukken/2020/06/04/kamerstrief-over-stand-van-

https://www.rijksoverheid.nl/documenten/kamerstukken/2020/06/04/kamerbrief-over-stand-vanzaken-COVID-19.

An example of such a Guideline is the *Handreiking Bezoek en logeren* (guideline visitors and staying over) published by the association of Care Providers VGN, October 2020 https://www.vgn.nl/documenten/handreiking-bezoek-en-logeren-28-oktober-2020.

- an adequate number of protective materials and tests on COVID-19 will be made available for people with disabilities and their families and carers, and people with disabilities who run a higher health risk will get priority in the vaccine programme;
- adequate support will be provided for families and carers of people with disabilities such as providing respite care;
- a policy will be developed to reduce the risk of loneliness.

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

People with disabilities are not structurally involved in disaster planning and recovery planning. It is up to the mayors of municipalities to decide on involvement in the planning process. We have found no evidence of structural involvement in the process at local level or at the level of the regional safety regions.

At the start of the COVID-19 pandemic the DPO organisation lederin was not immediately and spontaneously consulted by national Government or the outbreak management team. Iederin criticized many measures as having severe social-emotional effects on people with disabilities. Once lederin changed their public critique into the offer: 'How can we help set up better measures for people with disabilities' the organisation got more regularly consulted at ministerial level. In May 2020, the Minister of Health had taken to consulting the disabled people's organisation lederin on a biweekly basis.¹⁷

The consultation resulted in a specific COVID-19 strategy for people with disabilities, published in June 2020.¹⁸

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

In 2016 research was commissioned concerning the situation of persons with disabilities to inform disaster and recovery planning. This research was by the Institute of Physical Safety on the strategy to protect people who are considered less able to take care of themselves.¹⁹ The subsequent report criticised the lack of attention for people with disabilities in all disaster and recovery planning.²⁰

The Netherlands Institute for Social Research has published several reports on the impact of the COVID-19 measures and one specifically in June 2020 on the impact of

Interview with CEO of lederin in magazine communicatie-vakblad C 'In crisistijd verdwijnt de samenspraak' https://iederin.nl/in-de-media-communicatie-vakblad-c-in-crisistijd-verdwijnt-de-samenspraak/.

Report by the Institute Physical Safety. *Verminderd zelfredzamen ten tijde van rampen en crises: de overheid een zorg?* (less able to take care during disaster and crisis, does government care?'). Instituut Fysieke Veiligheid (2018) https://www.ifv.nl/kennisplein/Documents/20181203-IFV-Verminderd-zelfredzamen-ten-tijde-van-rampen-en-crises.pdf.

Report by the Institute Physical Safety. *Verminderd zelfredzamen ten tijde van rampen en crises: de overheid een zorg?* (less able to take car during disaster and crisis, does government care?'). Instituut Fysieke Veiligheid (2018) https://www.ifv.nl/kennisplein/Documents/20181203-IFV-Verminderd-zelfredzamen-ten-tijde-van-rampen-en-crises.pdf.

Letter to parliament, Betreft commissiebrief inzake SO COVID-19 Update paragraaf 8 Zorg voor kwetsbare mensen (update on COVID-19 care for vulnerable people). 28 May 2020 https://www.rijksoverheid.nl/documenten/kamerstukken/2020/05/28/commissiebrief-inzake-so-COVID-19-update-paragraaf-8-zorg-voor-kwetsbare-mensen.

lock down measures on people with disabilities.²¹ The main recommendation in the report was that because people with disabilities are disproportionately affected their interests should be taken into consideration more deliberately.

2.4 Use of disaster management and recovery planning funds

Funds have been made available (EUR 460 million in total) to continue payment for care providers who had to shut down day care centres and special schools.²² Care providers were thus protected against bankruptcy. People with disabilities living independently and receiving direct payments for their care, were also compensated for extra costs if they were forced to hire extra hours of assistance, for instance if they had to stay more hours at home while day care centres were closed down.

Report Beleidssignalement: *Mensen met een verstandelijke beperking*. (policy brief: people with a disability) National Institute Social research SCP. June 2020 https://www.scp.nl/binaries/scp/documenten/publicaties/2020/06/15/beleidssisgnalement-mensen-met-een-verstandelijke-beperking/SCP-

Beleidssignalement+Mensen+met+verstandelijke+beperking.pdf.

Letter to parliament about the budgetary consequences https://www.rijksoverheid.nl/binaries/rijksoverheid/documenten/kamerstukken/2020/04/20/kamerbrief-wlz-kader-2020.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?

There are no statistics available concerning the overall mortality of people with disabilities. However, there are statistics available on the mortality rate of people who are eligible for long term residential care compared to the general population.²³ In the Netherlands 300 000 people are eligible for long term care.²⁴ Of this group eligible for long term care, 170 000 are above retirement age. All others are younger people with (mostly intellectual) disabilities.²⁵

During COVID-19 the mortality rate among people eligible for long term care has been higher compared to the general population. The following graph shows the number of people deceased per week from all causes for the general population and for people in long term care. Dark blue represents people receiving long term care. The light blue is the expected number of people with long term care deceased and with a 95 % confidence interval. The green lines represent the number of deceased per week in the general population. In both groups the mortality rate in 2020 was higher than is to be expected (based on former years) but mortality is even higher among people receiving long term care. Especially in week 52 of 2020 the mortality rate among people receiving long term care was 40 % higher than among the general population.

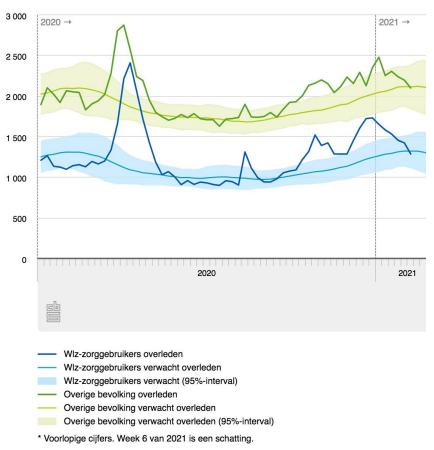
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²³ Statistics Netherlands (CBS), *Overledenen per week, provincie en gemeente, week* 6, 2021 https://www.cbs.nl/nl-nl/maatwerk/2021/07/overledenen-per-week-provincie-en-gemeente-week-6-2021.

Residential long-term care is based in the Act Long Term Act (Wet Langdurige Zorg 2014: https://wetten.overheid.nl/BWBR0035917/2021-01-01). The main eligibility criterion is that one needs support and surveillance 24 hours a day. People who are eligible usually receive residential care but can opt to receive a direct payment as well and live in their own home.

Schaduwrapportage Verdrag inzake de rechten van personen met een handicap in Nederland (Alternative report on the CRPD) Alliantie VN-verdrag Handicap, December 2019 https://iederin.nl/wp-content/uploads/2019/12/Schaduwrapport-VN-verdrag-Handicap.pdf.

Overledenen per week*



Source: Netherlands Statistics. StatLine: number of deceased per week and Number of deceased according to regions, sex, age and long-term care use).

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

Yes, a specific recent project by the Radboud University of Nijmegen monitors mortality due to COVID-19 among people with intellectual disabilities living in residential care. The mortality rate by COVID-19 is 3 to 4 times higher among people with intellectual disabilities compared to the general population and mortality is increased from a younger age. The higher mortality rate is said to be caused by a less effective immune response, premature ageing and a combination of chronic illnesses combined with obesity. The Case Fatality Rate is higher than 1 % from 30 years of age upwards among people with intellectual disabilities whereas a Case Fatality Rate higher than 1 % among the general population starts from 60 years of age. The higher mortality rate

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The Academic Collaborative 'Sterker op eigen benen' of Radboud university medical centre made an on-line registration system available in which 72 care providers, representing 75 % of people with intellectual disabilities living in residential group homes or apartments with support provided by care providers. The findings of the registration system are presented in factsheets. The most recent one cited in this report is from 29 January 2021.

Registratie COVID-19 in database. (registration COVID-19 database) by Academic Collaborative 'Sterker op eigen benen' of Radboud university medical centre https://oda93f8e-6ee7-45d9-be21-eecb55ca3e69.filesusr.com/ugd/d45b6c 31e956195d884b74b08f0362e4cc2893.pdf.

Registratie COVID-19 in database. (Registration COVID-19 database) by Academic Collaborative 'Sterker op eigen benen' of Radboud university medical centre https://oda93f8e-6ee7-45d9-be21-eecb55ca3e69.filesusr.com/ugd/d45b6c 31e956195d884b74b08f0362e4cc2893.pdf.

among people with intellectual disabilities occurred also during the influenza epidemic in 2017-2018.²⁸

Other relevant findings in the monitoring project of people with intellectual disabilities in residential care are that the mortality rate in people with intellectual disability and a confirmed COVID-19 infection is 5 %; 57 % of confirmed COVID-19 infections in this group occur in the 40 to 69 age group and 13 % in the 70+ age group. The mortality rate in patients with intellectual disabilities with a confirmed COVID-19 infection was 14 % in the first wave and 2 % in the second wave.²⁹

There are no data available on what proportion of the total population dying from COVID-19 are people with disabilities. Netherlands Statistics does register cause of death but does not register if people have a disability. Netherlands Statistics does register if people receive long term care (see section 3.1).

The National Institute on Health and Environmental Matters provides data on COVID-19 (contagion and number of people dying) with three specific groups: people living in residential care homes for the elderly; people living in residential care for people with disabilities and on people older than 70 years living in their private home.³⁰ Based on the data of RIVM (who started recording this as of 1 July) it is possible to see the number of people who died from COVID-19 while living in residential care homes for the elderly (9 415) and how many people older than 70 years died from COVID-19 while living in their own home (6 139).31 The number of people with disabilities who died from COVID-19 while living in residential care was 6 165.32 The total number of people who died of COVID-19 in the Netherlands is 136 840 according to the registration by the National Institute on Health and Environmental Matters.³³ It is not possible to know how many people with disabilities living in their own home died from COVID-19. The National Institute on Health and Environmental Matters does not register having a disability, but only registers age and whether people live in residential settings. Netherlands Statistics also does not register disability when registering deaths. Netherlands Statistics does register if people were receiving long term care

Mortality of people with intellectual disabilities during the 2017/2018 influenza epidemic in the Netherlands: potential implications for the COVID-19 pandemic. M. Cuypers, B. W. M. Schalk, M. C. J. Koks-Leensen. M. E. Nägele. E. J. Bakker-van Gijssel, J. Naaldenberg. G. L. Leusink 26 May 2020 https://doi.org/10.1111/jir.12739.

Factsheet nr 14. Registratie COVID-19 in database. (Registration COVID-19 database) by Academic Collaborative 'Sterker op eigen benen' of Radboud university medical centre https://oda93f8e-6ee7-45d9-be21-eecb55ca3e69.filesusr.com/ugd/d45b6c b07081e61e81430f9a776a5048a67360.pdf.

National Institute on Health and Environmental Matters. RIVM Corona dashboard https://coronadashboard.rijksoverheid.nl/.

National Institute on Health and Environmental Matters. RIVM Corona dashboard. Numbers recorded from 1 July 2020 up until 22 February 2021. Webpage with numbers on people living in care homes for the elderly: https://coronadashboard.rijksoverheid.nl/landelijk/verpleeghuiszorg. Webpage with numbers on people older than 70 living in their private home https://coronadashboard.rijksoverheid.nl/landelijk/thuiswonende-ouderen.

National Institute on Health and Environmental Matters. RIVM Corona dashboard. Numbers recorded from 1 July 2020 up until 22 February 2021. Webpage with numbers on people with disabilities living in residential care: https://coronadashboard.rijksoverheid.nl/landelijk/gehandicaptenzorg.

National Institute on Health and Environmental Matters. RIVM Corona dashboard. Numbers recorded from 27 February 2020 1 July 2020 up until 22 February 2021 https://coronadashboard.rijksoverheid.nl/landelijk/sterfte.

but not all people with disabilities receive long term care and not all people who receive long term care live in residential setting.

4 Access to health

<u>Article 25 – Health</u>

4.1 Emergency measures

Neither disability, age nor living arrangements are being used as criteria to prioritise entitlement to general health care. The National Government formally rejected in January 2021 a new triage protocol proposed by two main Dutch associations of medical specialists to prioritise younger patients over older patients in the case of a capacity shortage in intensive care units.³⁴

A medical assessment is a regular part of the triage protocol for admittance to an intensive care unit.³⁵ The Clinical Frailty Scale (CFS) is part of this triage protocol, but an explicit exception is made for the use of the CFS on people with intellectual disabilities. The use of the CFS has been criticised³⁶ because the scale places people with for instance reduced mobility or with support needs in daily life activities in categories less likely to be admitted to intensive care. The Dutch triage protocol states explicitly that the CFS is not to be used for people with intellectual disabilities and is not to be used with people below 65 years of age. The Dutch triage protocol advises intensive care specialists to use for this pandemic a specifically designed additional protocol for people with intellectual disabilities designed by the Dutch association of doctors specializing in care for people with intellectual disabilities.³⁷ This protocol or guideline explicitly refers to the right to equal treatment and access to health as laid down in the Convention on the Rights of Persons with Disabilities. The protocol gives guidelines on how to act when patients with an intellectual disability are suspected of not being able to decide for themselves, how to consult with family or representatives of people with intellectual disabilities. The protocol also acknowledges that some people with intellectual disabilities may be dependent on trusted personal assistants who might not be admissible to intensive care units during lock down periods. The advice is to allow the trusted personal assistant or family to go with the patient to the intensive care unit for at least part of the day.

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triage-op-basis-van-niet-medische-overwegingen-voor-ic-opname-ten-tijde-van-fase-3-in-de-COVID-19-pandemie.

Letter to Parliament, 4 January 2021 on forbidding the use of the newly proposed triage proposal by medical specialists https://www.rijksoverheid.nl/documenten/kamerstukken/2021/01/04/kamerbrief-over-draaiboek-

The proposal itself was made by Federatie Medisch Specialisten en de Koninklijke Nederlandsche Maatschappij tot bevordering der Geneeskunst: Draaiboek Triage op basis van niet-medische overwegingen voor IC-opname ten tijde van fase 3 in de COVID-19 pandemie Criteria voor fase 3 stap C aansluitend op het NVIC Draaiboek Pandemie. November 2020 https://www.demedischspecialist.nl/sites/default/files/Draaiboek%20Triage%20op%20basis%20van%20niet-medische%20overwegingen%20IC-opnamettvfase%203 COVID19pandemie.pdf.

DRAAIBOEK PANDEMIE DEEL1 (Pandemic Guidelines) Nederlandse Vereniging voor Intensive Care (NVIC) Versie 2.0, May 2020 (Netherlands Association Intensive Care) https://www.demedischspecialist.nl/sites/default/files/Draaiboek%20pandemie%20deel%201.pdf.

³⁶ Inklusion in Zeiten der Katastrophen-Medizin BODYS-Stellungnahme zur gegenwärtigen Triage-Debatte, in der behinderte Menschen hin- tenangestellt werden sollen https://idw-online.de/de/attachmentdata79720.pdf.

Nederlandse Vereniging van Artsen voor Verstandelijk Gehandicapten, Leidraad verwijzing van de volwassen patiënt met VB en (verdenking op) COVID-19. April 2020 https://nvavg.nl/leidraad-verwijzing-van-devolwassen-patient-met-vb-en-verdenking-op-COVID-19/.

Some doubts have been raised among organisations of people with disabilities about the effectiveness of using this scale for people with intellectual disabilities because it does not apply to people with physical disabilities. It furthermore does not address experiences by people with disabilities who feel that doctors sometimes address the perceived quality of life of people with disabilities when discussing options for treatment.³⁸

4.2 Access to hospital treatment for COVID-19

The number of people hospitalised with confirmed COVID-19 was 127 436 between 27 February 2020 and 21 February 2021.³⁹ It is not known how many of them have a disability because disability or ethnicity is not registered in hospitals.

4.3 Treatment for COVID-19 in congregate settings

The larger residential care providers for people with disabilities and care providers for the elderly have set up specialised care units within their residential facilities. These care units provide basic and medium care (including oxygen supply) for people with confirmed COVID-19. The care units serve two objectives. One is to isolate residents with confirmed COVID-19 from other residents within the facility. The second objective is to provide care when hospitals are full or in order to spare the residents going to hospital as this can be deemed to be too much of a burden for some patients. An example of the latter is that some people with intellectual disabilities or dementia would panic if they are placed in unfamiliar surroundings of a hospital room with carers who are in protective gear. It is not known how many people have been treated in such residential care units, nor is there information on their effectiveness in infection control or saving lives. The units are not nationally registered.

4.4 Public health promotion and testing during the pandemic

National public health announcements on COVID-19 measures are made during live broadcasted press conferences by the Prime Minister and Minister of Health. A sign language interpreter is part of the broadcast. Transcripts and videos of the press conferences are also made available.

At the start of the COVID-19 pandemic in the Netherlands in early March 2020 no sign language interpretation was provided during live broadcast press conferences by the Prime Minister and Minister of Health.⁴¹ On 11 March 2020 a deaf man held up a protest sign during a live broadcast news item in national television with the text "where is the sign language interpreter during times of crisis?". A day after that protest a sign

National Institute on Health and Environmental Matters in coordination with organisation of Intensive Care Units NICE https://data.rivm.nl/geonetwork/srv/dut/catalog.search#/metadata/4f4ad069-8f24-4fe8-b2a7-

https://data.rivm.nl/geonetwork/srv/dut/catalog.search#/metadata/4f4ad069-8f24-4fe8-b2a7-533ef27a899f.

The special units are called Cohort care units. They are mentioned for the first time in a letter to parliament by the minister of Health Welfare and Sport, 9 April 2020 https://zoek.officielebekendmakingen.nl/kst-25295-219.html.

³⁸ Anecdotal evidence by author of report.

https://www.ad.nl/binnenland/dove-machiel-26-protesteerde-tijdens-journaal-gebarentolk-essentieel-bij-coronacrisis~a927c876/?referrer=https%3A%2F%2Fwww.google.com%2F&referrer=https%3A%2F%2Fiederin.nl%2F.

language interpreter was assigned to each live broadcast press conference on COVID-19 measures by the Prime Minister.

The national association of care providers for people with disabilities gathered and published information and several guidelines (some of them in easy-to-read) on COVID-19 health announcements and specific lockdown measures such as the rules on visiting residential facilities and care homes, the locking down of day care centres, and vaccine programmes.⁴²

National Government publishes regularly easy to read information on COVID-19 measures.⁴³ Some publications by national Government are more visual, such as information on vaccination.⁴⁴ The library service for people who are blind provide their own auditory publications on COVID-19.⁴⁵

Testing of care workers had as of March 2020 initially been made available only for people working in institutions or small group homes, but not so easily for care workers who worked for people with disabilities who lived independently and contracted care workers with a direct payment. The advocacy organisation for people using direct payments to provide for their care, pushed to get testing available for this group of care workers as well and this was done within a month.⁴⁶

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

From the start of the pandemic fewer people sought treatment or medical advice in hospitals or with general practitioners. This was partly out of fear of being contaminated in hospitals or out of consideration for doctors who were deemed to be busy with COVID-19 patients and partly because hospitals, treatment centres and general practitioners closed down for face-to-face contacts.⁴⁷ The number of referrals to hospital care decreased from the start of the pandemic in February 2020 with 1.1 million and with 80 000 to mental health care.⁴⁸ Various specialists have warned that people in the first stages of cancer or heart diseases have missed out on the chance to have their illnesses diagnosed in early stages.

The national federation of providers of mental health care noted that waiting lists for acute treatment of patients with mental health problems have increased intolerably as a result of the COVID-19 pandemic, partly because more young people suffer from

⁴² National association of care providers for people with disabilities VGN https://www.vgn.nl/achtergrond/informatiemateriaal-over-corona.

Webpages national Government on easy-to-read information on COVID-19 https://www.rijksoverheid.nl/onderwerpen/coronavirus-COVID-19/uitgelicht-corona/persconferenties-corona-in-eenvoudige-taal.

Praat plaat: Prik tegen Corona (visual information on vaccination) https://www.rijksoverheid.nl/documenten/publicaties/2021/01/13/praatplaat-prik-tegen-corona.

Library service Anders Lezen (read differently) https://www.passendlezen.nl/iguana/www.main.cls?surl=home.

Advocacy organisation direct payment Per Saldo on COVID-19 measures https://www.pgb.nl/hulp-en-advies/slimme-lijstjes/slim-lijstje-pgb-en-corona/.

In the Dutch care system medical specialists, hospital care and mental health care can only be accessed via a referral from the general practioners.

⁴⁸ News release December 2020 by the National Health Authority NZA (Nederlandse Zorg Autoriteit) https://www.nza.nl/actueel/nieuws/2020/12/15/aanvullende-maatregelen-noodzakelijk-om-zorgvoor-covid--en-non-covid-patienten-toegankelijk-te-houden.

serious mental health problems as a result of lockdown measures, and partly because hospitals and treatment centres were closed down during the initial period of the pandemic.⁴⁹

Face to face therapy and treatment for people with mental health problems has been replaced by digital contact sessions during lock down periods. Specialists in the mental health field have differing opinions on the effects. Some say that digital sessions can work as effective as face-to-face contact or are even a stimulus to work on different tactics such as organizing peer support. Other specialists argue that digital sessions make it far easier for a sizable portion of people with mental health issues to dodge addressing their problems which cannot be avoided during actual house calls.⁵⁰

4.6 Vaccination programmes

Specific categories of people with disabilities and chronic illness are prioritised in the vaccine roll out programme. As of 6 January 2021, medical and nursing staff in hospitals, ambulances, care homes and general practitioners were given vaccines.⁵¹ This prioritization is intended to protect both workers and the people they support.

While vaccination of health and care professionals continue, a second vaccination programme started as of 18 January 2021 for, in order of priority, people living in larger residential care homes for the elderly and residential institutions for people with disabilities; people with disabilities living in small group homes; elderly people (starting with people over 90 living in their own home; elderly people between 90-65 and people below 65 considered to be at high risk.⁵² When all these groups have been vaccinated the general population will follow, starting with older before young people.

Among people considered at high risk to be vaccinated before the general population are people with Down syndrome, along with people with obesity, kidney failure, diabetes and respiratory diseases. People with Down syndrome have recently (March 2021) been added to the list of people at high risk by the national advisory council on health⁵³ on request of the University of Utrecht and the Dutch Down Syndrome association and vaccination of this group started as of mid-February.⁵⁴ According to research done by Pediatric infectiologist L. Bont of the University of Utrecht, people with Down syndrome are at higher risk of respiratory disease due to a less effective

Rapport Uitvraag Acute Jeugd-ggz (report on acute mental health care for youth). GGZ Nederland, March 2021 https://www.denederlandseggz.nl/getmedia/0e75f613-bd1b-4559-a815-808cbdd67be7/210310-Rapport-uitvraag-acute-jeugd-ggz-DEF(1).pdf.

The debate among professionals is summed up in the web article 'Van face to face naar zorg op afstand. De ggz na de coronacrisis' (from face to face contact to care at a distance. Mental health after the corona crisis) https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7215121/.

Government webpage with priority in vaccine roll out programme https://www.rijksoverheid.nl/onderwerpen/coronavirus-vaccinatie/volgorde-van-vaccinatie-tegen-het-coronavirus/volgorde-vaccinatie-zorgmedewerkers.

https://www.rijksoverheid.nl/onderwerpen/coronavirus-vaccinatie/volgorde-van-vaccinatie-tegen-het-coronavirus/volgorde-vaccinatie-voor-mensen-die-niet-in-de-zorg-werken.

The national advisory council on health, in Dutch Gezondheidsraad. Announcement in a letter to parliament by the minister of Health, 'Reactie advies inzet AstraZeneca-vaccin tegen COVID-19'. 5 February 2021 https://www.rijksoverheid.nl/documenten/kamerstukken/2021/02/05/kamerbrief-over-reactie-advies-inzet-astrazeneca-vaccin-tegen-COVID-19.

⁵⁴ Stichting Down Syndroom https://www.downsyndroom.nl/veelgesteldevragen/het-coronavirus-en-downsyndroom/.

immune system.⁵⁵ For the same reason people with Down syndrome are at higher risk of catching COVID-19 and will become more ill according to Dr. Bont. Based on his recommendation all people with Down syndrome over 18 years, living at home will be given priority in the vaccine roll out program. The University of Utrecht received finances by the ministry of Health to research the effectiveness of the vaccine with people with Down syndrome.⁵⁶

In vaccination programmes priority is given to support workers for people with disabilities but invitations are only sent out via care institutions or via foundations running group homes. Staff working on a personal contract with someone with a disability and direct payment budget cannot formally be reached via the vaccination programme and are not offered a possibility to present themselves.⁵⁷

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⁵⁵ Verhoogde kans op luchtweginfecties bij kinderen met downsyndroom: het gevolg van een afwijkend afweersysteem, RIVM 16-09-2011 https://www.rivm.nl/verhoogde-kans-op-luchtweginfecties-bij-kinderen-met-downsyndroom-gevolg-van-afwijkend.

Website article University of Utrecht. 01-02-2021. *COVID-vaccinatiestudie bij down syndroom gestart* https://www.umcutrecht.nl/nieuws/covid-vaccinatiestudie-bij-down-syndroom-gestart.

Procedure to get vaccinated for care professionals https://www.rijksoverheid.nl/onderwerpen/coronavirus-vaccinatie/vraag-en-antwoord/hoe-maak-ik-een-afspraak-voor-vaccinatie-tegen-corona.

5 Income and access to food and essential items

Article 28 – Adequate standard of living and social protection

5.1 Emergency measures

All employers and all self-employed people who are economically hit by orders to close down economic activities during lockdown measures, receive payments by the national Government to (partly) compensate for lost revenue and to prevent employers firing their employees. The self-employed receive these payments up to the level of net minimum wage benefit level.

There have been no measures relating to an adequate standard of living and social protection, focussing particularly on income and on access to food, that have an explicit disability or older age dimension.

In June 2020, the national Government announced they would pay a EUR 1 000 net bonus to care workers in hospitals and residential care homes who worked exceptionally hard during the pandemic.⁵⁸ This offer led to protests by workers and family members of people with a disability living independently and paying for care out of a direct payment scheme. They felt they worked exceptionally hard as well supporting people with disabilities living in their own home, especially because all day care centres closed down in the initial months of the pandemic. In November the national Government decided to partly honour the protests and offered the bonus payment to care workers on a direct payment scheme. Family members who work for a relative with a disability and who are being paid out of the direct payment scheme have specifically been exempted from receiving this bonus.

There have been no specific government measures to support people during lockdowns in terms of getting access to food or other essentials.

5.2 Impact of the COVID-19 crisis

There is no direct evidence that the COVID-19 crisis has impacted people with disabilities disproportionately on income and poverty. Employers who are affected by lockdown measures receive compensatory payments on the condition they do not fire employees. Many employers downsized nonetheless by not extending temporary working contracts. People with disabilities work disproportionately more often on temporary contracts and have more often lost their jobs. This has been noted in a report on the impact of COVID-19 by the National Institute for Social Research SCP. ⁵⁹ of the crisis. The majority of people with disabilities tend to be hired on a temporary status.

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Letter to parliament. June 2020 https://www.rijksoverheid.nl/actueel/nieuws/2020/06/25/bonus-voor-unieke-inzet-zorgpersoneel-tijdens-coronacrisis.

Report Beleidssignalement: Mensen met een verstandelijke beperking. (policy brief: people with a disability) National Institute Social research. June 2020 https://www.scp.nl/binaries/scp/documenten/publicaties/2020/06/15/beleidssisgnalement-mensen-met-een-verstandelijke-beperking/SCP-Beleidssignalement+Mensen+met+verstandelijke+beperking.

6 Access to transportation and the public spaces

Article 9 – Accessibility

6.1 Emergency measures

During the first wave of the pandemic in the Netherlands part of the lockdown measures was to close down public transport for all non-essential travel, including adapted public transport for people with disabilities who are unable to travel via regular public transport.⁶⁰ This adapted transport service was closed down during the first lockdown period (March until the end of May 2020), and in the second lockdown period starting 14 December until the time of writing the report (end of February 2021). In the first lockdown period non-essential shops, all public buildings such as museums and theatres, and all sports facilities such as swimming pools were closed. Such facilities specifically for people with disabilities (such as therapeutic horse riding or swimming lessons) were also closed down.

Everyone in the public realm is required to maintain a 1,5-meter distance since March 2020. This includes public transport and all public transport for people with disabilities. Everyone entering a public building is required to wear a facemask and keep a distance. People with a disability are exempted from the duty to wear a facemask if they cannot wear one due to their disability.

People who belong to one household are not required to maintain that distance between household members. Personal assistants of someone with a disability are not required to maintain the 1.5-meter distance to the person they assist and will have to provide some evidence if they are spoken to by law enforcement.

During the lockdown periods⁶¹ (March-June 2020 and December 2020-until now) supermarkets and other essential shops that were allowed to stay open introduced rules on routing within shops and the rule to enter the shop only when pushing a trolley. The trolley serves as a way of maintaining a 1.5-meter distance from other customers.

The National Human Rights Institute monitored problems people with disabilities were experiencing in the public realm. Complaints were made about the inaccessibility of shops due to for example non-visible routing instructions; the obligations to use a trolley for people who could not handle a trolley; and partitioning boards and face masks that made it difficult for deaf people to communicate. Complaints were also made to the Human Rights Institute by people with disabilities who felt unprotected and unsafe in shops and the public realm because not all people kept to the rules of distancing or wearing facemasks.⁶²

6.2 Impact of the COVID-19 crisis

Passengers in public transport are required to wear a facemask. People with disabilities who cannot wear a facemask due to their disability are exempted from that

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⁶⁰ The service is called Valys https://valys.nl/.

The first lock down period was from March until end of May 2020. The second lockdown period started 14 December until time of writing the report (end February).

National Human Rights Institute https://mensenrechten.nl/nl/na-sluiting-van-het-meldpunt-goed-toegankelijk-werk-aan-de-winkel.

duty. In such cases passengers should maintain a distance of 1.5 meters. We have found no evidence of problems as a result of this rule. Trains and buses are less packed due to the lockdown measures requiring people to work at home as much as possible and the closing down of schools during lock down periods.

The duty to wear a facemask also applies to adapted transport for people with disabilities, including transport to special schools. In the case of bus transport to special schools and the public adapted transport service for people with disabilities, the buses are so small that maintaining a distance of 1.5-meter results means losing the ability to transport more than two or three passengers at a time (where regularly eight would be possible). This has led to the practice that parents were asked to provide transport for their children with disabilities with their own cars.

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

<u>Article 17 – Protecting the integrity of the person</u>

7.1 Emergency measures

There are no known measures of reduction in prior procedural requirements and safeguards relating to subjecting people with disabilities to involuntary detention or treatment.

The Health Inspectorate remarked in January 2021 that it receives mixed findings from care providers on increases or decreases in involuntary treatment or detention. 'Some care providers reported they were compelled to keep more residents forcibly in their rooms or to administer more often drugs to keep residents calm. Other (care providers) not.'63

On 19 March 2020 the National Government decided to forbid all access of family and friends to people living in care institutions.⁶⁴ As a rule any visit was forbidden unless a resident was dying. The only way to see family or friends as of that date was visiting from behind windows.⁶⁵ Although not specifically mentioned in the decision, residents were not allowed to go out of the residence to visit family or friends, not even if residents were living in their own apartment within the residential institution.

The national umbrella organisation of DPOs lederin protested the total ban on visits during the first lockdown period. Residents of a specific care home for the elderly in Amsterdam and their families challenged before the court on 16 June 2020 the no visit rule and the rule to prohibit leaving the care home for even a few minutes. In reaction to the lawsuit the care provider relaxed the no visit and no going out rule. Two further litigation cases were started. One was by an association founded to fight unnecessary restrictions within care homes. Another litigation case was started by a group of family members who hired in June 2020 a Dutch human rights lawyer to litigate the National Government and Health Inspectorate stating that human rights were violated by the no visit, no going out rule in care homes. In reaction to this threat of litigation

Monitoring effects of COVID-19 by the Health Inspectorate. *Zorgsignalen tijdens coronacrisis*. Edition January 2021 https://www.igi.nl/actueel/nieuwsbrieven/zorgsignalen-tijdens-coronacrisis.

See guideline by the association of care providers for people with disabilities May 2020 https://www.vgn.nl/nieuws/advies-bezoekregeling-gehandicaptenzorg.

Stichting Stop Onnodige Vrijheidsbeperking In De Zorg (SOVIDZ) https://sovidz.nl/ and news item on national television on the arguments of the foundation: https://eenvandaag.avrotros.nl/item/nederlandse-staat-voor-de-rechter-gesleept-opsluiten-bewoners-verzorgingshuis-gaat-in-tegen-mensen/.

General press clippings mention the lawsuit such as in the national newspaper De Volksrant https://www.volkskrant.nl/nieuws-achtergrond/advocaat-stelt-zorgminister-ultimatum-gun-verpleeghuisbewoners-meer-vrijheden~bf7ca71c/.

The lawyer in this case that was hired was Liesbeth Zegveld, human rights lawyer https://www.prakkendoliveira.nl/nl/wie-zijn-wij/advocaten/prof-liesbeth-zegveld.

Letter to parliament, 19 March 2020. *Aanscherping bezoek verpleeghuizen ivm COVID-19* (scharpening of visiting rules to care homes due to COVID-19) https://www.rijksoverheid.nl/documenten/kamerstukken/2020/03/19/kamerbrief-over-aanscherping-bezoek-verpleeghuizen-in-verband-met-COVID-19.

the National Government agreed with care providers on relaxing the rules and the lawsuits were suspended. The relaxation of the visiting rules fitted in with the general easing of lockdown measures in that period.

As of July 2020, new guidelines (for which DPOs were consulted) were published in which a balance has been sought between the explicitly written down right for people with disabilities to receive visitors and the necessity of taking precautionary measures to prevent infection. As a rule, visits are allowed but only after agreement each time with the management of the location and visitors must maintain distance to the person they visit. If a resident with a disability visits family or friends outside the institution or participate in leisure or sports activities outside the institution, the management may reserve the right to place the resident in quarantine after returning.

On 1 December 2020, a new Temporary Act Measures COVID-19 was implemented.⁶⁹ This act gives residents of care homes and institutions for people with disabilities the right to receive at least one family member or friend. The act further commands the management of institutions to set rules in consultation with the client council of the institution. The outbreak management team advised to allow each resident in a care institution to receive each a bubble of 2 or 3 visitors.⁷⁰

The Health Inspectorate reported in February 2021 that some care homes do not allow any visitor and some only one per day.⁷¹

7.2 Impact of the COVID-19 crisis

There is no clear information on increases or decreases in institutional living during the COVID-19 pandemic. It was reported in May 2020 that family or friends who decided to take their loved ones out of institutions to provide care at home, were told they would not be able to return as the rooms they occupied would have to be registered after 14 days as having been vacated. Care institutions are required to report vacated rooms after 14 days of absence and are not permitted to claim any finances for a vacated room. The Minister of Health then decided to grant extra payments for care institutions in just such cases so rooms could stay reserved for people who would want to leave temporarily due to the fear of contracting COVID-19 within the institution.⁷²

Handreiking bezoek en logeren gehandicaptenzorg voor verantwoord bezoek en logeren in coronatijd 28 October 2020 VGN (association of care providers for people with disabilities.) https://www.vgn.nl/system/files/2020-10/Handreiking%20Bezoek%20en%20logeren%2028%20oktober%202020%20.pdf.

⁶⁹ Tijdelijke wet maatregelen COVID-19 2020 https://wetten.overheid.nl/BWBR0044337/2020-12-01.

Aanvulling op handreiking 'Bezoek en sociaal contact; corona in verpleeg-huizen. (addition to guidelines visit and social contact, corona in care homes)

https://www.clientenraad.nl/nieuws/aanvulling-op-handreiking-bezoek-en-sociaal-contact-corona-in-verpleeghuizen/.

Monitoring effects of COVID-19 by the Health Inspectorate. Zorgsignalen tijdens coronacrisis. Edition 10 February 2021 https://www.igj.nl/actueel/nieuwsbrieven/zorgsignalen-tijdens-coronacrisis.

Letter to parliament, Betreft commissiebrief inzake SO Covid 19 Update paragraaf 8 Zorg voor kwetsbare mensen (update on COVID-19 care for vulnerable people). 28 May 2020 https://www.rijksoverheid.nl/documenten/kamerstukken/2020/05/28/commissiebrief-inzake-so-COVID-19-update-paragraaf-8-zorg-voor-kwetsbare-mensen.

It was reported in December 2020 that care homes and rehabilitation centres were forced to decline any new clients, as they were short staffed due to the pandemic (many staff being sick or in quarantine).⁷³

For restrictions on access to family or friends for people living in institutional care see 7.1.

Monitoring effects of COVID-19 by the Health Inspectorate. Zorgsignalen tijdens coronacrisis. Edition, 30 December 2021 https://www.igj.nl/actueel/nieuwsbrieven/zorgsignalen-tijdens-coronacrisis.

Violence, exploitation or abuse 8

Article 16 – Freedom from violence, exploitation and abuse

Emergency measures

Schools and day-care centres were closed (during first and second lockdown period).⁷⁴ Schools and day-care centres were asked to stay open for 'emergency shelter'75 for either children of parents doing essential work or for children in situations at risk or in situations where family could not provide adequate care. In May 2020, it has been reported that day care centres for children with severe disabilities received up to 30 % of the children that would normally be present. 76 There were no general measures or changes to policies relating to domestic violence. The justice department (prosecution) issued a general call to the public in April 2020 in which it warned the general public that the lockdown might increase the risk to domestic violence and called out the public to report any incidents they might notice.⁷⁷

8.2 Impact of the COVID-19 crisis

The Health Inspectorate reported in February 2021 that not enough emergency places were made available for children. It has been reported that youth care professionals had to place 47 telephone calls in order to find a suitable place for two children who were abused and who had to leave their home instantly. They were placed eventually in an institution that had placed beds in the hallway.⁷⁸ A youth protection agency for children with intellectual disabilities reported that not all special schools would provide enough emergency shelter.⁷⁹ The Health Inspectorate noted during three recent inspections of a mental health institute, an organisation who provides a combination of education and care and a Youth Protection Agency that all three institutions reported more emergency situations around young people in their home, including domestic violence. The emergency situations were deemed so acute that intervention would be needed within five days to protect the young people. The report by the Health Inspectorate noted that municipalities do not seem to realise that more funds would be needed to finance the increasing call for intervention to protect youth.⁸⁰

Youth protection agencies reported to the Heath Inspectorate that the general rule in the Netherlands during lockdown to restrict families to have just one visitor a day is potentially endangering children in at risk families, as it diminishes the possibility of calling persons from the regular social network (grandparents for instance) to help within these families and it diminishes the possibility by social networks to make notice

⁷⁴ The first lock down period was from March until end of May 2020. The second lockdown period started 14 December until time of writing the report (end February).

⁷⁵ In Dutch noodopvang.

The Letter to parliament, Betreft commissiebrief inzake SO COVID-19 Update paragraaf 8 Zorg voor kwetsbare mensen (update on COVID-19 care for vulnerable people). 28 May 2020 https://www.rijksoverheid.nl/documenten/kamerstukken/2020/05/28/commissiebrief-inzake-so-COVID-19-update-paragraaf-8-zorg-voor-kwetsbare-mensen.

Webpage https://www.om.nl/actueel/nieuws/2020/04/17/grote-zorgen-over-huiselijk-geweld-tijdenscoronacrisis-%E2%80%9Chet-zicht-vertroebelt%E2%80%9D.

Monitoring effects of COVID-19 by the Health Inspectorate. *Zorgsignalen tijdens coronacrisis*. Edition 3 February 2021 https://www.igj.nl/actueel/nieuwsbrieven/zorgsignalen-tijdens-coronacrisis.

⁷⁹ On average special schools receives 20 to 25% of students with disabilities during lock down periods. Monitoring effects of COVID-19 by the Health Inspectorate, edition 27 January 2021.

⁸⁰ Monitoring effects of COVID-19 by the Health Inspectorate, edition 3 February 2021.

of potential abusive situations. The tendency by professionals to limit face to face contact to digital calls adds to the danger of not noticing potentially abusive situations within families. ⁸¹

Several mental health institutions for youth reported an increase of suicidal behaviour and eating disorders among young people. For some institutions the increase was so huge combined with staffing problems that they reported they could not provide adequate help anymore.⁸²

⁸¹ Monitoring effects of COVID-19 by the Health Inspectorate, edition 3 and 10 February 2021.

⁸² Monitoring effects of COVID-19 by the Health Inspectorate, edition 20 January 2021.

9 Independent living

Article 19 – Living independently and being included in the community

9.1 Emergency measures

People living in their own room or apartment within a residential institution reported not to be able to leave their home for leisure activities or to stay over at the homes of friends or families. The management of the residential institutions had closed down for visits or formally prohibited residents to go out. This situation formally ended at the end of May 2020. After May care institutions still restricted visiting rules if management deemed the infection risk too high. See also section 7.1.

Providing protective tests, protective gear and vaccinations to family, friends and professional personal assistants working for people with disabilities living independently consistently has lagged behind offering the same to staff working in institutions. Providing protective gear to personal assistants working for someone living independently started off as late as May 2020.⁸³ See also section 4.3.

The National Government offered a bonus of EUR 1 000 extra to all professionals who had to work extra hard during the first wave of the pandemic in hospitals, care homes or institutions. This bonus was initially not available to people working for people using a direct payment and living independently. In January 2021, it was decided that the bonus will become available for this group after all.⁸⁴

Confirmed COVID-19 patients with a disability living independently were offered to be placed temporarily in care homes if support at home was not deemed possible due to a shortage of staff with at home care agencies. Home care agencies did experience shortage of staff due to increased sick leave.⁸⁵

9.2 Impact of the COVID-19 crisis

During the periods March-May 2020 and especially around December 2020 several problems were reported about a lack of adequate support for elderly people in need of support and for people with disabilities. In the first lockdown period people living in their own room or apartment within a residential institution reported not to be able to leave their home for leisure activities or to stay over at the homes of friends or families. Residential institutions had closed down for visits or formally prohibited residents to go out. See also section 7.1.

Because day care centres were closed, people with disabilities and mental health problems were not able to spend their day at day care centres. Residential institutions offered very limited day activities at home, sometimes digitally, sometimes via ambulant services. It has been reported by care providers that for some people with

Richtlijn Persoonlijke Beschermingsmiddelen (PBM) voor mantelzorgers, *PGB-gefinancierde zorgverleners en vrijwilligers in palliatieve zorg*https://www.rijksoverheid.nl/documenten/richtlijnen/2020/05/19/richtlijn-persoonlijke-beschermingsmiddelen-voor-mantelzorgers-pgb-gefinancierde-zorgverleners-en-vrijwilligers-in-palliatieve-zorg.

Per Saldo, advocacy organisation for people using direct payment https://www.pgb.nl/zorgbonus-nu-ook-voor-pgb-zorgverleners/.

⁸⁵ Monitoring effects of COVID-19 by the Health Inspectorate, edition 28 October 2021.

disabilities this brought boredom, depression and stress. For others it meant less stress as they were not required to go to their regular day care centres which they had been experiencing as stressful.⁸⁶

Providing support for people with disabilities living at home in the community has been under severe pressure. Personal assistants were not until May 2020 able to get protective gear and clothing.⁸⁷ As it is impossible to maintain a distance of 1.5 meters while providing care and support to people with disabilities, staff feared being contaminated. In many cases support workers stopped working or had to take sick leave. Family or friends mainly took over the work. Sometimes families took over the work as a form of shielding their family member with a disability as letting in support workers increases the chance of contracting COVID-19. The Health Inspectorate⁸⁸ and the Netherlands Institute for Social Research both reported that family and friends of people with disabilities living independently were under huge strains to continue adequate support for months on end.⁸⁹

Another problem occurred when providers of day care for children and adults with disabilities were forced to close down during lockdown periods. Care providers are paid per day per person who actually show up at the day care centres. Closing down would mean that care providers were not allowed to claim their costs. The National Government guaranteed continuous payment for those care providers who work for people eligible for long term care (mostly adults with severe disabilities). Those care providers that offer day care activities for children with disabilities or adults with less severe disabilities are being paid by municipalities based on the Social Support Act. Not all municipalities would pay during lockdown periods. It has been reported that as a result especially the smaller organisations providing care for children with disabilities within the community faced considerable financial difficulties.

⁸⁶ Several editions of Monitoring effects of COVID-19 by the Health Inspectorate.

Monitoring effects of COVID-19 by the Health Inspectorate. *Zorgsignalen tijdens coronacrisis*. Edition 3 February 2021 https://www.igj.nl/actueel/nieuwsbrieven/zorgsignalen-tijdens-coronacrisis.

⁸⁷ Richtlijn Persoonlijke Beschermingsmiddelen (PBM) voor mantelzorgers, PGB-gefinancierde zorgverleners en vrijwilligers in palliatieve zorg https://www.rijksoverheid.nl/documenten/richtlijnen/2020/05/19/richtlijn-persoonlijke-beschermingsmiddelen-voor-mantelzorgers-pgb-gefinancierde-zorgverleners-en-vrijwilligers-in-palliatieve-zorg.

Several editions of Monitoring effects of COVID-19 by the Health Inspectorate.

Several editions in the Monitoring effects of COVID-19 by the Health Inspectorate. And also the impact has been noted in the Report Beleidssignalement: Mensen met een verstandelijke beperking. (policy brief: people with a disability) National Institute Social research SCP. June 2020 https://www.scp.nl/binaries/scp/documenten/publicaties/2020/06/15/beleidssisgnalement-mensen-met-een-verstandelijke-beperking/SCP-Beleidssignalement+Mensen+met+verstandelijke+beperking.

⁹⁰ Wet Maatschappelijke Ondersteuning of Jeugdwet.

10 Access to habilitation and rehabilitation

<u>Article 26 – Habilitation and rehabilitation</u>

10.1 Emergency measures

Access to habilitation and rehabilitation support and services were partly closed during lockdown periods⁹² but exceptions were being made for essential services. Professionals who worked in 'direct contact' with other people (such as hairdressers and masseurs) were not allowed to work during lockdown periods, but exceptions were made for medical professionals. For instance, a physiotherapist could continue to work, but a chiropractor could not. Rehabilitation services are offered to children via special schools. In periods when special schools were closed, they could not continue to offer their services.

The adapted public transport service for people with disabilities was closed down during March until end of May 2020. There was no closing down in the second lockdown period. Exceptions to the use of this transport were only allowed to attend weddings and funerals, but not to go to rehabilitation services.

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

There is no specific information reported on the impact of measures in access to habilitation and rehabilitation, not in general reporting and not in the reports by the Health Inspectorate.

The first lock down period was from March until end of May 2020. The second lockdown period started 14 December until time of writing the report (end February).

11 Access to justice

Article 13 - Access to justice

11.1 Emergency measures

Access to justice was limited to digital hearings in the first wave lockdown period. There is no evidence on the impact of this.

11.2 Impact of COVID-19 crisis

There is no specific information reported on the impact of measures on access to justice for people with disabilities.

12 Access to education

Article 24 – Education

12.1 Emergency measures

Special schools and day care centres for children with and without disabilities were closed down during general school closing in the first and second lockdown periods. Schools and day care centres could offer online lessons or online activities.

Both regular and special schools and all-day care centres maintained the option to provide 'emergency shelter' for children of parents doing essential work or children in at risk situations. Those that did attend 'emergency shelter' were required to wear facemasks during transport (not in class) and to keep distance if possible. It has been acknowledged that keeping distance was not a realistic option for many people with disabilities and their personal carers and it was not required if it was deemed impossible.

During the first lockdown period around 20 % of pupils in day care or schools kept on attending under the emergency shelter rule. During the second lockdown over a third of pupils went to day care or schools.⁹³

Funds have been made available (EUR 460 million in total) to continue payment for care providers who had to shut down day care centres and special schools.⁹⁴ Care providers were thus protected against bankruptcy. People with disabilities living independently and receiving direct payments for their care, were also compensated for extra costs if they were forced to hire extra hours of assistance, for instance if they had to stay more hours at home while day care centres were closed down. There were no other measures to support families who needed to shield or to provide equipment.

12.2 Impact of the COVID-19 crisis

There is no formal reporting known on the impact of the COVID-19 crisis on education for children and adults with disabilities. Parents report very mixed experiences about the quality of online lessons offered by special schools. Some parents report positive experiences. Other parents report that online lessons were of poor quality or were completely absent. 95

Children with disabilities in special education are usually offered internships as of the age of 16. These internships have not been offered during lockdown periods and have been severely reduced in periods outside formal lockdown. There is no evidence about the impact on families of the closure of schools and day care centres.

According to a national organisation of day care providers https://www.parool.nl/nederland/meer-kinderen-in-noodopvang-scholen-tijdens-tweede-lockdown~b5daa874/?referrer=https%3A%2F%2Fwww.google.com%2F.

Letter to parliament about the budgetary consequences <u>https://www.rijksoverheid.nl/binaries/rijksoverheid/documenten/kamerstukken/2020/04/20/kamerbrief-wlz-kader-2020/kamerbrief-wlz-kader-2020.pdf.</u>

⁹⁵ Informal reports in Facebook groups by parents of children with disabilities.

13 Working and employment

Article 27 – Work and employment

13.1 Emergency measures

Employees who are affected by lockdown, receive payments to compensate for loss of revenue on the condition not to fire employees. Self-employed people who cannot work are compensated up to net minimum wage level.

There are no known specific measures relating to work and employment that have an explicit disability dimension. See also section 5.1.

13.2 Impact of the COVID-19 crisis

There is no direct evidence that the COVID-19 crisis has impacted people with disabilities disproportionately on work and employment. Indirectly the effect shall be that more people with disabilities lose their job as a result of the crisis, according to a warning by the National Institute for Social Research SCP. 96 The research agency based this conclusion on the fact that the number of temporary jobs has been reduced in the Netherlands as a result of the lock down measures. The majority of people with disabilities tend to be hired on a temporary status. See also section 5.1.

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Report Beleidssignalement: Mensen met een verstandelijke beperking. (policy brief: people with a disability) National Institute Social research. June 2020, https://www.scp.nl/binaries/scp/documenten/publicaties/2020/06/15/beleidssisgnalement-mensen-met-een-verstandelijke-beperking/SCP-Beleidssignalement+Mensen+met+verstandelijke+beperking.

14 Good practices and recommendations

14.1 Examples of good practice

The regular consultation by the Minister of Health with the organisation of people with disabilities lederln, as of May 2020, can be counted as good practice. The consultation led to the adoption of a strategy especially for people with disabilities in which the rights as described in the CRPD were taken into account with all new COVID-19 measures. The specific strategy led to an obligation for care providers to consult with a representative council of residents in their care facilities on each change in Covid-measures, such as the rules for allowing visitors.

The interests of people with disabilities were also taken more into account in parliamentary debates on the COVID-19 measures. The prioritization of adults with Down syndrome in the vaccination roll out programme and to research the effect that vaccination would have on this group can also be counted as a result of the stronger focus on people with disabilities.

Good efforts have been made to make information accessible for different groups of people with disabilities. The pandemic had led to the regular participation of a sign language interpreter during live broadcasted announcements, something that had not been done before April 2020. The sign language interpretation drew exceptional praise from the general public as many people were impressed and amused by the facial expressions and hand gestures of the interpreters.⁹⁷ The sign language interpretation led to more awareness by the general public of the necessity to make all emergency information accessible to people with disabilities. The National Government also invested more than usual in making information more visually available and in easy read formats.

The vaccine roll-out strategy has taken the more vulnerable health condition of people with Down syndrome into account. This group has been prioritised compared to the general population in vaccination as part of the larger groups of people considered to be more vulnerable such as people with respiratory disease, kidney failures etc. Professionals working in care homes and institutions for people with disabilities also have priority in the vaccination roll out partly to protect the workers themselves but also to protect people they care for. See section 4.6.

14.2 Recommendations

Disabled people's organisations, the National Human Rights Institute and the Ombudsman had warned about violating human rights by refusing all visitors to care homes and institutions. They all recommended to consult with disabled people's organisations at a national level and with client councils in all care homes and institutions about more flexible rules about visiting. After that the national Government indeed took up more intensive consultations, not only with disabled people's organisations but also with organisations of companies (such as the organisation of shop owners) and with care providing organisations. The main umbrella of disabled people's organisation lederin recommended to consult more with people with

⁹⁷ The interpreter who started in the first weeks of the pandemic became very popular and is generally known by name in the Netherlands. Her work led to an increased influx in training to become sign language interpreter https://www.pgb.nl/zorgbonus-nu-ook-voor-pgb-zorgverleners/.

disabilities, not on finding problems but on the question of how to help. This recommendation led to formulating a disability specific strategy plan.

The Health Inspectorate monitors impact of the COVID-19 measures by collecting notifications and publishing them in regular monitoring reports. Their reports were used to adapt COVID-19 measures. It can be recommended to more actively seek information about the impact by either gathering more actively information during regular inspections or to commission research.

Closing down all schools is considered to be of huge impact on pupils of primary and secondary schools. The organisation of secondary schools recommended amending exams and recommended more lenient ways of grading exams so students who have missed months of lessons would more easily pass exams. The impact on regular students will be made visible by monitoring study results per schools and possible decline in exam results. Such monitoring is not possible for students with disabilities as they visit in majority segregated special schools where only a minority if students do exams. It is recommended to commission research on the quantity and quality of online lessons for students with especially intellectual disabilities.

The closing down of schools and day care centres had huge impacts on family life as family members were supposed to provide day care for family members with disabilities. It is recommended to commission research on the impact this had on families with children and dependent adults with disabilities.

The prioritization in the vaccination roll-out programme of people in residential care is based on the assumption that living in residential care homes increases the risk of infection and on the assumption that mortality rate is higher among people living in residential care. This assumption is not thoroughly tested. The specific registration of contamination and mortality rates within care homes, institutions for people with disabilities and elderly people above 70 years of age started as of July 2020. The registration is not compatible with the registration of causes of death which is supplied by Netherlands Statistics as Netherlands statistics only registers people eligible for Long Term Care, not the actual place of residence. A recommendation is to commission research on infection rate and mortality of people actually living in residential care compared to people with disabilities living in their private home.

14.3 Other relevant evidence

No information on this point.

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