

SUITCEYES Scoping Report on Law and Policy on Deafblindness, Disability and New Technologies

Working Paper

Country	Netherlands
Author(s)	Jose Smits
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Executive Summary

People with deafblindness are not formally recognised as a distinct group in Dutch legislation, eligibility criteria, for provision of equipment, benefits or support and care. Eligibility criteria for all these kinds of provisions usually use the general term disability, or, if a more specific disability is required, refers only to people who are deaf or who are blind.

Care providers, including providers of equipment, specialise mostly in either people who are deaf or people who are blind, but they do offer care, support and information on deafblindness and have initiated a joint information centre on deafblindness. The University of Groningen maintains a Masters course and a research centre on deafblindness. There are some small disabled people's organisations that represent people with deafblindness.

There is no specific legislation in the Netherlands for access to technology. As of July 2018, a Temporary Decree on Digital Accessibility Government was implemented (as a result of the European directive on digital accessibility). The European Accessibility Act is to be implemented in the Netherlands but an implementation plan is not yet known. The Code on General Accessibility and the implementation plan of national Government of the UNCRPD Netherlands assume that voluntary action plans, rather than imposed legal requirements, will improve accessibility of services and goods. The Act on Equal Treatment on the Ground of Disability or Chronic illness states that lack of accessibility can be regarded as discrimination. Individual citizens are to file complaints on specific incidents on the lack of accessibility.

It is reported¹ there is no sense of urgency to enhance general accessibility of goods, services and products such that individual adaptations would be less needed. Yet, new technologies and especially introduction of accessibility of the internet and applications are considered to be of great value for enhancing participation and inclusion of individuals with disabilities, both by users, producers and by policymakers. There is a readiness to provide individual persons with disabilities with equipment, adaptations and apps that make communication easier and that would facilitate participation.

People with deafblindness are entitled to benefits, provisions (sign language interpretation services) and individual equipment that enable their participation in society, work and education. Eligibility criteria, conditions and funding are based on several laws. Technical equipment can be provided to people with deafblindness either by municipalities, health care insurers or the employee insurance authority UWV.

¹ Alternative report on the CRPD Netherlands: J.C. Smits, J. Schoonheim, Schaduwrapport Verdrag inzake de rechten van personen met een handicap, Iederin December 2019. <https://iederin.nl/wp-content/uploads/2019/12/Schaduwrapport-VN-verdrag-Handicap.pdf>

All new technologies and use of these technologies should comply with privacy regulations. The Dutch act General Regulation of data protection² is based on European Union Privacy legislation.

There are no known campaigns or initiatives to increase disabled people's participation in education, training, or developing new technologies. Debate on cyber security does not focus specifically on people with disabilities.

1. People with Deafblindness

1.1 Official recognition of people with deafblindness as an eligible group

There is no official or formal recognition of people with deafblindness as an eligible group (for care, provisions or policies). Eligibility criteria for benefits or provisions in the Netherlands usually do not require specific disabilities as ground for eligibility. Anyone who has a chronic illness or a disability can be eligible for provisions regardless the type of disability. In specific regulations a more specified disability ground is used as an eligibility ground for provisions, for instance for receiving a type of long term care or the use of a sign language interpreter. In such cases, there can be mention of either deafness or blindness, but not the combination of the two. People who are deafblind can thus opt to be perceived as deaf or blind, not both at the same time. The one formal exception is that people who are deafblind are entitled to 168 hours per year of sign language interpretation services (for activities not being work or education), while people who are deaf only receive 30 hours per year sign language interpretation.³

National government traditionally subsidises care providers, who also serve as expert centres for people who are either deaf or blind. Five of these national expert centres⁴ have, at the request of national Government, formed a joint expert centre on deafblindness. This new expert centre, called DB connect⁵, was founded in 2017.

1.2 National data on people with deafblindness

In the Netherlands, the definition of deafblindness is based on medical diagnostic criteria. People who have a hearing loss of more than 35% in their 'best' ear are

² Algemene verordening gegevensbescherming (AVG).

³ See explanation of regulation by the council of municipalities:

https://vng.nl/files/vng/20141212_landelijke-regeling-tolkdiensten.pdf

⁴ These five care providers and expert centres are Bartiméus, GGMD, Kalorama, Kentalis en Visio.

⁵ DB Connect. <https://dbconnect.info/over-db-connect/>

considered deaf. People who have vision below 30% of the norm or a field of view less than 30% are considered blind. Those that combine the two criteria are considered deafblind.⁶

It is estimated⁷ that around 2000 people in the Netherlands are born with deafblindness. Some researchers state⁸ that this group with congenital deafblindness is underestimated because children with deafblindness may be mistakenly diagnosed as severely intellectually disabled, as they cannot easily communicate. A second group of around 1000 to 1500 people have developed deafblindness at later age but before their 65th birthday. The third group of people who are deafblind are people who have become deafblind at old age (above 65th year). This group is estimated around 35.000⁹ to 80.000 people¹⁰. They are mostly above 80 years of age.

In policy reports and annual budgets from the national Government, care providers and schools for special education, data is collected on people with “sensory disabilities”. This term is used to refer to people who are deaf, blind and deafblind. If in these reports a further distinction is being made (in data) it would only be the distinction between being either deaf or blind. Two examples illustrate this. Eligibility criteria for long-term residential care are based on distinctions between types of disability: physical disabilities, intellectual disabilities, people with mental health problems, people with somatic disabilities (meaning elderly people who are dependent on intensive care) and people with sensory disabilities. If people have multiple disabilities, they are placed in the category of disability that is regarded as having the most impact for the particular person. Data on people receiving long-term residential care is based on these distinctions only; therefore, statistics show only the number of people with ‘sensory disabilities’ in long term care.

The second example is a policy report, commissioned by the national Government on the need to establish an expert centre on sensory disabilities.¹¹ In this report, there is only one mention of the word deafblind, where authors consider that more coordination may be needed for specific groups, such as people with deafblindness, if the organisation of the expert centre is based on a division of deaf and blind people.

⁶ DB Connect. <https://dbconnect.info/over-doofblindheid/>

⁷ See for estimations DB Connect: <https://dbconnect.info/over-doofblindheid/>

⁸ Prof.dr. M. Janssen, University Groningen on her webpage introduction of deafblindness states: “Due to a lack of knowledge, many deafblind people in the Netherlands are mistakenly treated as if they can hear and see.” <https://www.rug.nl/about-ug/latest-news/press-information/scientists-in-focus/mjanssen>. And by: Vaal, J., Gussekloo, J., De Klerk, M., Frijters, D., Evenhuis, H., Van Beek, A., & Deeg, D. (2007). Combined vision and hearing impairment: In an estimated 30,000-35,000 people aged 55 years or over in the Netherlands. *Nederlands Tijdschrift Voor Geneeskunde*, 151(26), 1459–1463.

⁹ Estimation by Vaal e.a.

¹⁰ Estimation by DB Connect.

¹¹ Adviestraject Expertisefunctie Zintuiglijk Gehandicapten. Zonmw 2017. [Adviestraject_Expertisefunctie_Zintuiglijk_Gehandicapten._Eindadvies.pdf](#)

1.3 National law and policies specific to people with deafblindness / sensory impairment

We could not find laws and policies specific to people with deafblindness, with one exception. There is a provision for the use of sign language interpretation¹² for leisure activities (any activity outside formal work or education) where people with deafblindness are permitted 168 hours per year, compared with people who are deaf who receive 30 hours per year.

All other laws, regulations, eligibility criteria and policy reports either mention disability in general or refer to 'sensory disabilities' meaning people who are deaf, blind or deafblind.

Sign language interpretation for people who are deaf or deafblind can be provided for leisure activities, education and work. Applications for sign language interpretation can be submitted to a national central agency.¹³ Regulations for these provisions are based on five separate laws aiming at providing support and care for people with disabilities in general. These laws are: the Social Support Act 2006¹⁴, Participation Act 2003¹⁵, a series of laws on education known as Appropriate Education 2015¹⁶, Healthcare Insurance Act 2005¹⁷ and the Act on Reintegration of Labour-disabled 2005¹⁸. These five laws have their own criteria for eligibility and provision. For instance: sign language interpretation in education can be provided for up to 100% of time spent in schools, whereas the maximum time for sign language interpretation in work environments is 15% of working time. Since 2019, a central agency has dealt with all applications based on these five laws and it mediates between users of sign language interpretation and interpreters, and pays interpreters.¹⁹ Applications for these laws are the responsibility of either municipalities, school boards or the Administrative authority UWV.

¹² Landelijke regeling tolkvoorziening voor mensen met een zintuiglijke beperking 2015.VNG. https://vng.nl/files/vng/20141212_landelijke-regeling-tolkdiensten.pdf

¹³ The administrative authority UWV decides on all applications and provisions for sign language interpretation. It has delegated applications and mediation between persons who are deaf or deafblind and sign language interpreters to the national organisation Tolkcontact.

¹⁴ Wet Maatschappelijke Ondersteuning 2015
<https://wetten.overheid.nl/BWBR0035362/2020-03-19>

¹⁵ Participatiewet 2003. <https://wetten.overheid.nl/BWBR0035362/2020-03-19>

¹⁶ Passend Onderwijs. <https://www.rijksoverheid.nl/onderwerpen/passend-onderwijs>

¹⁷ Zorgverzekeringswet 2005. <https://wetten.overheid.nl/BWBR0018450/2020-03-19>

¹⁸ Wet Werk en inkomen naar arbeidsvermogen 2005.

<https://wetten.overheid.nl/BWBR0019057/2020-03-19/0/informatie>

¹⁹ The organisation UWV decides on all applications and provisions of sign language interpretation based on the laws mentioned. Tolkcontact deals with applications:

<https://www.tolkcontact.nl/>

1.4 Important bodies that represent, report on or have responsibility for people with deafblindness

The University of Groningen appointed in 2008 prof. dr. Marleen Janssen to a professorship in deafblindness, where she leads a Masters course in communication and congenital deafblindness. In 2017, Dr. Janssen founded the Institute for Deafblindness, dedicated to research and teaching on both congenital and acquired deafblindness. This interdisciplinary institute focuses exclusively on deafblindness,²⁰ exploring communication, language and cognition among people with congenital and acquired deafblindness.

There are several not for profit organisations that provide long-term care, special education and ambulatory support for people with deafblindness. These providers mostly originated as either providers for people who are deaf or blind, but they do provide care and education for people with deafblindness as well. These organisations are: Bartiméus²¹ (focus on blindness), GGMD (focus on supporting deaf people)²², Kentalis (focus on deaf people)²³ and Visio²⁴ (focus on blind people). The care provider Kalorama²⁵ combines care for elderly people and end-of life care with care and support for people with deafblindness. These five care-providers together founded in 2017 a joint expert centre on deafblindness, called DB Connect.²⁶

The Centre for Consultation and Expertise (CCE) on behavioural problems with people with severe disabilities, can since 2006 be consulted on issues concerning people with deafblindness and behavioural issues.²⁷

There are some small disabled people's organisations that represent people with deafblindness. Those are: the group Oog en Oor (eye and ear) a subdivision of the association Oogvereniging (eye association)²⁸; the foundation Usher Syndroom.²⁹ the Dutch foundation Doofblindenstichting;³⁰ and an informal group Het Slakkenhuis, which publishes a website with newsletters for people with deafblindness³¹.

²⁰ <https://www.rug.nl/gmw/pedagogical-and-educational-sciences/news/opening-ug-institute-for-deafblindness>

²¹ <https://www.bartimeus.nl>

²² <https://www.ggmd.nl>

²³ <https://www.kentalis.nl>

²⁴ <https://visio.nl>

²⁵ <https://kalorama.nl>

²⁶ <https://dbconnect.info/over-dooftblindheid/>

²⁷ Centre for Consultation and Expertise (CCE). <https://cce.nl/over-cce>

²⁸ https://www.doofblinden.net/?page_id=171

²⁹ <https://ushersyndroom.nl/wie-zijn-wij/>

³⁰ <http://doofblindenstichting.nl>

³¹ Doofblindennieuws. <https://doofblindennieuws.nl>

The Dutch association for professional sign language interpreters³² organises sign language interpreters who work specifically for people who are deafblind.

2. Overview of Law and Policy on New Technologies and Disabled People

2.1 Overall legal and policy framework for access to technology

The national Government published in October 2019 a policy letter to ameliorate access to digital technology in the Netherlands.³³ Analysis carried out for this letter noted that around 2.5 million persons in the Netherlands have problems in accessing new (digital) technologies. According to the analysis the 2.5 million people do not sufficiently understand new digital technologies or have difficulty in reading and writing such that they cannot understand written information by government agencies. People with (mild) intellectual disabilities are specifically mentioned as being part of this group. No other types of disabilities are mentioned in this policy letter.

The Government has formed and financed a public private partnership³⁴ of Government, NGOs and private companies aimed at improving accessibility. Measures taken are: improving easy to read language by government agencies via an awareness raising campaign and (free of charge) offer of easy read coaches; providing meetings, coaching and tools to help government agencies to make their websites accessible and easy to use; providing easy accessible courses for citizens in their own neighbourhood (in public libraries) to learn to use digital information and commissioning research at universities to find out how people can get more effective support in learning to use digital information. The general information of the public-private partnership does not report on specific projects, tools and initiatives aimed at people with disabilities.

There is no specific legislation in the Netherlands for access to technology. There is however a Code on general accessibility, introduced as a result of implementing the Convention on the Rights of People with Disabilities. This code addresses accessibility in the delivery of all goods and services for people with disabilities. See section 2.2 for further information.

³² Nederlandse beroepsvereniging Tolken gebarentaal. <http://www.nbtg.nl/over-het-beroep/wat-doet-een-tolk>

³³ Letter to Parliament on policies to inclusion in digital affairs, by the Minister of Internal Affairs, 23 October 2019. <https://www.rijksoverheid.nl/documenten/kamerstukken/2019/10/22/kamerbrief-over-voortgang-digitale-inclusie>

³⁴ The public private partnership is called Digital Samenleven (digital community). <https://digitaalsamenleven.nl/over-de-alliantie/>

2.2 Overall legal and policy framework for accessibility

The first Article of the Dutch Constitution (1983)³⁵ is a clause on equality and anti-discrimination. This article names several grounds on which discrimination is prohibited (such as sex and race). The ground of disability is not one of them. The Council Directive 2000/78/EC establishing a general framework for equal treatment in employment and occupation led to the adoption of the Dutch Act on Equal Treatment on the Ground of Disability or Chronic illness in 2003³⁶. The Act offers protection against discrimination on any type of disability or chronic illness. Its scope was initially confined to employment, occupation, and vocational education and, since 2009, to education and housing. It has been extended to public transport as of October 2012, and as of 2017 to delivery of goods and services as a consequence of ratifying the UNCRPD. A blind customer of a bank who could not use a bank app had success with his complaint based on the Act on Equal Treatment on the grounds of disability. The Dutch Human Rights Institute judged in 2017 that the bank was guilty of discrimination for not making the app accessible.

Legal requirements to provide accessibility or provisions that enable people with disabilities to participate are: the Building Code 2012, the Social Support Act 2015, the Mediawet 2008 (subtitling), Act on Reintegration of Labour Disabled 2005, the Participation Act 2017 and the act on Appropriate Education 2012³⁷.

As of July 2018, a Temporary Decree on Digital Accessibility Government³⁸ was implemented (as a result of the European directive on digital accessibility). This decree makes it mandatory for all websites by Government and Government agencies to be accessible for people with disabilities as of September 2020 and for mobile apps from government agencies to be accessible as of June 2021.

In a Code on General Accessibility³⁹, the legal duty to gradually provide general accessibility is introduced. The Government stated in this Code that the general comment on Article 9 of the UNCRPD is to be used as a 'guideline' and action plans on accessibility are to be prepared by NGOs and DPOs by sector. Some action plans have been agreed on. An example is an action plan for small businesses

³⁵ In Dutch Grondwet.

³⁶ Wet gelijke behandeling op grond van handicap of chronische ziekte.
<https://wetten.overheid.nl/BWBR0014915/2017-01-01>

³⁷ In Dutch: Bouwbesluit, WMO, Mediawet, WIA, Participatiewet, wetgeving passend onderwijs.

³⁸ Tijdelijk besluit digitale toegankelijkheid overheid.
<https://wetten.overheid.nl/BWBR0040936/2018-07-01>

³⁹ Besluit algemene toegankelijkheid voor personen met een handicap of chronische ziekte.
<https://wetten.overheid.nl/BWBR0039653/2017-06-21>

providing the businesses with knowledge and tools for making their shops more accessible.⁴⁰

The National Government has several policies aimed at improving accessibility. These include, for instance, providing video and text services for telephone services (including the use of the emergency number), financing provisions of accessible library books (Braille books, spoken books) and several regulations and funding systems for provision of individualised adaptations of all possible kinds at workplaces, in schools and at home. Adaptations include sign language interpretation, adaptations of computers, communication aids and apps, and technical adaptations.⁴¹

The Code on General Accessibility and the implementation plan of national government for the UNCRPD Netherlands assumes that voluntary action plans, rather than imposed legal requirements, will improve accessibility of services and goods.

The alternative report on the UNCRPD⁴² exposed some failures of this approach. The national emergency phone number is not 24/7 accessible via a sign language interpreter and technical malfunction is reported.⁴³ Sign language interpretation is seldom available on national news (until the beginning of 2020 not even in emergency situations). People with disabilities have complained about the quality of subtitling and audio description, which is not as a rule available. A guide on accessible building is available but is not usually used in education and training of architects and builders. Education and training of ICT experts or other technical professionals do not have standard courses on accessibility.⁴⁴

Another complaint is that in 2015 provision of technical adaptations or provisions for social support for people with disabilities were decentralised from national Government and national insurers to municipalities. That has led to a breakdown of national rules for providing adaptations, transport aids, technical equipment and so on, in favour of discretionary freedom for municipalities to decide on what is to be

⁴⁰ MKB Nederland. <https://www.mkb.nl/weekbulletin/actieplan-voor-betere-toegankelijkheid-voor-gehandicapten>

⁴¹ More information on policies on accessibility can be found in the alternative report on the CRPD Netherlands: J.C. Smits, J. Schoonheim, Schaduwrapport Verdrag inzake de rechten van personen met een handicap, Iederin December 2019. <https://iederin.nl/wp-content/uploads/2019/12/Schaduwrapport-VN-verdrag-Handicap.pdf>. More information on specific laws and eligibility criteria can be found in several national reports on accessibility by the Academic Network European Disability Experts ANED. <https://www.disability-europe.net/theme/accessibility?country=netherlands>

⁴² Schaduwrapportage Verdrag inzake de rechten van personen met een handicap in Nederland. <https://iederin.nl/wp-content/uploads/2019/12/Schaduwrapport-VN-verdrag-Handicap.pdf>

⁴³ <https://iederin.nl/maak-112-volledig-toegankelijk-en-bereikbaar-voor-iedereen/>

⁴⁴ Schaduwrapportage Verdrag inzake de rechten van personen met een handicap in Nederland. <https://iederin.nl/wp-content/uploads/2019/12/Schaduwrapport-VN-verdrag-Handicap.pdf>

provided and what conditions (from providers) apply. People with disabilities have complained further about the technical quality and maintenance of provisions since then.⁴⁵

3. Regulation of New Technologies

As a result of the European Accessibility Act 2019, regulations will apply for all those products and applications that fall under its scope. Dutch regulations will implement the minimum standards as laid down in the European Accessibility Act. Not much is known about exact implementation of this act in the Netherlands at the time of writing this report.

All new technologies and use of these technologies should comply with privacy regulations. The Dutch act General Regulation of data protection⁴⁶ is based on European Union Privacy legislation. Under the Dutch regulation it is permitted for private citizens to use cameras and sensors for private use. This means that it is permitted to make images and other recordings of oneself and of other persons around oneself provided these recordings will not be published.

For companies who record images or sounds it is obligatory to ask permission from every person who is being recorded, whether or not recordings are published.

The use of face- and object recognition is not allowed in the Netherlands unless these are being used for purposes of identification and security reasons. Companies who want to use biometric identification processes are expected to make sure to comply with specific rules set out to protect privacy and ask permission by the independent Authority Privacydata,⁴⁷ which oversees the General Regulation of Dataprotection. All handling and ownership of data and data analysis must be done according to privacy protecting rules of the General Regulation of Dataprotection.

The Authority Privacydata publishes a guide for costumers on 'the Internet of Things' and how companies use all kinds of technologies to gather data from their consumers.⁴⁸ The Authority published rules about privacy protecting and general exceptions on the rules (such as that passenger data on intercontinental flights may be exchanged with the USA and can be kept 5 years by USA authorities whereas European countries may only keep passenger data for 24 hours.

⁴⁵ Schaduwrapportage Verdrag inzake de rechten van personen met een handicap in Nederland. <https://iederin.nl/wp-content/uploads/2019/12/Schaduwrapport-VN-verdrag-Handicap.pdf>

⁴⁶ Algemene verordening gegevensbescherming (AVG).

⁴⁷ Autoriteit Persoonsgegevens. <https://autoriteitpersoonsgegevens.nl>

⁴⁸ Internet of things en smart home? Bescherm uw privacy! Guide on IoT and protecting privacy.

https://autoriteitpersoonsgegevens.nl/sites/default/files/atoms/files/handleiding_privacybescherming_internet_of_things_februari_2020.pdf

There are also warnings for consumers to read privacy regulations from every company whose products and apps are being used and to be aware that web shops with their main office outside the European Union are not easily affected by complaints and judgments by the Authority Privacydata.

4. Ethical frameworks relevant to disabled people and new technologies in place or under development

The Dutch government has released a strategic action plan for artificial intelligence with a range of policy initiatives and action plans to strengthen Netherlands' competitiveness in artificial intelligence on the global market.⁴⁹ There is no specific mention of disability rights but the strategy does refer to inclusion and calls for specific action to combat abuse and discriminatory aspects of the use of algorithms.

An important part of the strategy is to ensure that artificial intelligence is deployed such that human rights are respected and defended, that all citizens are included in the development of AI, that consumer's rights are protected and that safety of citizens is guaranteed.⁵⁰ Concrete actions include:

- the Ministry of Social Affairs is seeking a method to detect and combat possible discriminatory aspects of the use of algorithms by companies in selecting candidates for job vacancies;
- research has been commissioned on the impact of artificial intelligence on public values;
- research has been commissioned on opportunities and risks and legal implications of decision - making algorithms;
- research on the risks of privacy breaches via face recognition technology;
- the ministry of Justice is considering a certification system by an organisation at EU level for all uses of artificial intelligence in the justice system;
- The Ministry of Home Affairs is organising a national platform to exchange knowledge and support in transparency and accountability by government agencies in the use of artificial intelligence;
- all companies that unite on the platform digital.nl are to work according to guidelines. The guidelines ask all companies working with artificial intelligence to take into account public values such as honesty, justness, fairness, inclusion, accountability and rights on the use of data. Further requirements are: transparency; that companies communicate fairly on the opportunities, risks and limitations of the use of artificial intelligence; that they minimise unwanted bias and promote inclusive representation and that they provide all

⁴⁹ Strategisch Actieplan voor Artificiele intelligentie. (Netherlands AI Strategy Report). Oct 2019 Ministry of Economic Affairs. https://ec.europa.eu/knowledge4policy/ai-watch/netherlands-ai-strategy-report_en

⁵⁰ Strategisch Actieplan voor Artificiele intelligentie. (Netherlands AI Strategy Report). Oct 2019 Ministry of Economic Affairs, page 42 https://ec.europa.eu/knowledge4policy/ai-watch/netherlands-ai-strategy-report_en

means necessary to provide insight into their use of data and feedback opportunities for users of artificial intelligence.⁵¹

New technologies and especially the introduction of accessibility of the internet and applications are considered to be of great value for enhancing participation and inclusion of people with disabilities. There is a readiness to provide individual persons with disabilities with equipment, adaptations and apps that make communication easier and that would facilitate participation. The Social Support Act 2015, the Mediawet 2008 (subtitling), Act on Reintegration of Labour Disabled 2005, the Participation Act 2017, Long Term Care Act 2014⁵² and Basic Health insurance Act 2005⁵³ all in their own way grant the right of people with disabilities to provisions that would enhance both their health and participation.

Yet, there is no sense of urgency to enhance general accessibility of goods, services and products such that individual adaptations would be less needed. The implementation of the UNCRPD has been long postponed in the Netherlands out of fear that enhancing general accessibility would lead to high costs for both government and companies, while the proposal of a European directive for equal treatment outside labour was not accepted by Dutch government due to the cost argument.⁵⁴

The Code on General Accessibility and the implementation plan of national government of the UNCRPD Netherlands assume that voluntary action plans, rather than imposed legal requirements, will improve accessibility of services and goods. The alternative report on the UNCRPD⁵⁵ cites several reports by disabled people's organisations that general accessibility in buildings and the built environment has declined rather than improved and that accessibility of websites by government agencies other than national Government is very poor. See also section 2.2.

Interviews of groups of blind and deaf people by rapporteurs of the Alternative report UNCRPD⁵⁶ gave anecdotal evidence about the lack of general accessibility among government agencies and employers. For example, a deaf person complained that he could never go independently to an appointment at his town hall or with other government agencies such as tax revenue offices, because there was never a way to communicate in writing at the reception desks.

⁵¹ Ethische Code Artificial Intelligence (ethical code AI) NL digital.

<https://www.nldigital.nl/ethischecodeai/>

⁵² Wet Langdurige Zorg. <https://wetten.overheid.nl/BWBR0035917/2020-02-01>

⁵³ Zorgverzekeringswet. <https://wetten.overheid.nl/BWBR0035917/2020-02-01>

⁵⁴ Gevolgen VN verdrag IVRPH voor het Nederlands onderwijssysteem, page 30.

https://in1school.nl/images/kennis-opinie/onderzoeken-in1school/GevolgenVNVerdrag_IVRPH_Voor_Het_Nederlandse_Onderwijssysteem.pdf

⁵⁵ Schaduwrapportage Verdrag inzake de rechten van personen met een handicap in Nederland. <https://iederin.nl/wp-content/uploads/2019/12/Schaduwrapport-VN-verdrag-Handicap.pdf>

⁵⁶ Schaduwrapportage Verdrag inzake de rechten van personen met een handicap in Nederland. <https://iederin.nl/wp-content/uploads/2019/12/Schaduwrapport-VN-verdrag-Handicap.pdf>

In another instance, a blind person lost his volunteering job at an institution for the blind. He worked at a reception desk and used a computer to read text messages aloud. He was asked to leave that post once the General Regulation of Data protection was introduced and the institute for the blind considered reading out loud text messages at the reception desk to be a continuous breach of privacy.⁵⁷

People with sensory impairments who live independently (as opposed to in residential care) have to ask for assistance to participate at their municipalities. This may be support in communication, equipment and assistance for homework, leisure activities and travel etcetera. It is reported⁵⁸ that municipalities often do not recognise the specific needs of people with sensory impairments who need a variety of assistance in seeking an active social life. Municipalities are mainly focused on providing assistance to the much larger group of elderly people who need help in staying safe at home.

People with sensory impairments find that it seems much easier to be provided by municipalities with technical equipment (as this incurs incidental costs for municipalities) rather than personal assistance.

We could not find other references to codes of ethics in relation to disabled people in the Netherlands, nor specific references to topics such as (protection from) cyber bullying of disabled people.

5. Disabled People's Access to Information

Care providers (as outlined in section 1.4) and their joint NGO DB Connect provide information on new technology. Information is usually provided on their websites. Medical professionals and therapists provide information on new technologies as well. Once a year there is a fair on support and technology aimed at people with disabilities.⁵⁹ People with disabilities who apply for support based on the Social Support Act and the Act Long Term Care are entitled to independent client support advisers who could inform on new technologies.

6. Access to Equipment

6.1 Public Sector

Provision of equipment at home is mainly based on the Social Support Act 2015 (WMO), and is under the responsibility of municipalities. The autonomous administrative authority UWV will decide and pay for adaptations of the workplace

⁵⁷ Anecdote told to reporters of the alternative report UNCRPD Netherlands 2019 by a blind representative of a group of workers at an institution for the blind.

⁵⁸ Reported by people with sensory impairments in meetings with DB connect and interview with the rapporteur.

⁵⁹ Supportbeurs. <https://www.supportbeurs.nl>

(and in schools and higher education institutions). The relevant act is the Act on Reintegration of Labour-disabled 2005.⁶⁰ Some equipment is provided based on the Health Insurance Act.

Municipalities have large discretionary freedom to decide on allocation of equipment, costs and conditions. Municipalities are not obliged to publish lists or guidelines. They give out tenders for contracts with manufacturers and in these tenders agree on maximum costs. Procedures for adding or removing new equipment may vary. Usually it is up to negotiations between municipalities and manufacturers if new technology will be added and what conditions apply for updating, repair and replacement. The Social Support Act gives people with disabilities the right to apply for a direct payment to be able to choose freely on the market for alternative equipment. The municipality has the right to cap the direct payment to the cost level of their own price agreement with their preferred provider.

The UWV uses a list of adaptations and equipment to use. Health care insurers care insurers may decide what precise equipment can be provided in order to compensate for specific imitations. All new technology must be tested and approved by the national Health Care Insurance Institute⁶¹ to see if they are proven (cost) effective to compensate for specific limitations.

6.2 Private Sector

Private foundations enhance accessibility of websites and apps. An important one is the foundation Accessibility.⁶² This is an expert centre and research institute that focuses on accessibility of websites, especially for people with a visual disability.

A smaller one is the company Digitaal Toegankelijk.⁶³

Some network organisations have formed which stimulate knowledge exchange between private and public initiatives on digital innovations for enhancing accessibility and health solutions. An example is Health Valley Netherlands,⁶⁴ which is a partnership between companies, care providers, expert centres and Government. The organisations work on themes such as personalised medicine, robotics & medical devices, e-health and designing and constructing buildings for care purposes. Examples of products that are developed by partners in the network are the use of a robot in providing nursing tasks and a smart watch that is able to detect if a patient falls down.

⁶⁰ ANED. <https://www.disability-europe.net/dotcom>

⁶¹ Zorginstituut Nederland. Explanation about admittance procedures for new technologies. <https://www.zorginstituutnederland.nl/over-ons/werkwijzen-en-procedures/adviseren-over-en-verduidelijken-van-het-basispakket-aan-zorg/beoordeling-van-nieuwe-zorg>

⁶² <https://www.accessibility.nl/over-accessibility>

⁶³ <https://digitaaltoegankelijk.com/over-digitale-toegankelijkheid/>

⁶⁴ <https://www.healthvalley.nl/over-ons>

In 2017, 40 cities together with 60 employees and 30 scientists working in companies and universities presented a national smart city strategy.⁶⁵ The strategy emphasises preconditions that are to be met to improve quality of life, economic opportunities and inclusion of all citizens. Use of data and digital techniques are explored. Smart cities are not specifically aimed at improving accessibility for people with disabilities. Nevertheless, we found an example in the city of Breda, which tested an app at the end of 2019, with which disability cardholders can easily find designated parking places in the city.⁶⁶

Some examples of Dutch providers of apps with specific accessibility features are:

Assistive Ware, a Dutch company developing accessibility hardware such as Keystrokes and text-to-speech and symbols-to-speech apps such as proloquo2go.⁶⁷

Procit is a company based in the Netherlands and Asia producing and implementing ibeacon for navigation within buildings.⁶⁸

Symbaloo, a web application that enables users to design a personalised webpage with visual tiles for applications or webpages and search function.⁶⁹

Dedicon is a Dutch Foundation providing daisy books, Braille products and hardware and software (developed by themselves or by other companies) for people with visual disabilities.⁷⁰

Berengroep BV provides under the name Tolkcontact sign language interpreters and a sign language interpretation app (Tolkcontact app⁷¹) for people who are deaf or deafblind.⁷²

GTX Medical is developing a device to provide neuro-stimulation to people with spinal cord injury.⁷³

Ongehinderd, is a non-profit company which offers an app to assess the accessibility of public spaces, such as restaurants.⁷⁴

The company Hable provides an add-on keypad for smartphones for people who are blind.⁷⁵

⁶⁵ <https://www.nextgeneration.city/news/smart-city-strategy-the-netherlands.html> The strategy itself (digitale steden agenda) can be found here: <http://digitalestedenagenda.nl/wp-content/uploads/2017/01/NL-Smart-City-Strategie-.pdf>

⁶⁶ <https://www.gemeente.nu/ruimte-milieu/den-bosch-test-slimme-parkeerplekken-voor-gehandicapten/>

⁶⁷ <https://www.assistiveware.com/nl/over-assistiveware>

⁶⁸ <http://website3.procit.com/>

⁶⁹ <https://www.symbaloo.com/home/mix/13eP6j7Cfq>

Tolkcontact provides sign language interpretation and an app to provide this.

⁷⁰ <http://website3.procit.com/>

⁷¹ <https://www.tolkcontact.nl/tolk-app>

⁷² <https://www.berengroep.nl/>

⁷³ GTX Medical. <https://www.gtxmedical.com/development/>

⁷⁴ Ongehinderd <https://www.ongehinderd.nl/over-ons/>

Snoozy designed and produces mobility scooters with advanced features such as four wheel drive enabling off road trips.⁷⁶

Vertiwalk is an initiative by Rombout Frieling enabling people with a physical disability who cannot access stairs, to move vertically.⁷⁷

Berkelbike produces alternative handbikes for people in wheelchairs.⁷⁸

7. Accessibility measures in the built environment

I have found no references to personalised digital equipment in built environments. Accessibility measures in the built environment are usually aimed at providing low-tech measures such as Braille signs (at the entrance of buildings), ridged guidelines on pavements etcetera.

8. Skill Development and Work Opportunities

I have found no campaigns or initiatives to increase disabled people's participation in education, training, or developing new technologies.

Training in disability is not part of education of engineers, ICT specialists or any other profession in the Netherlands.

9. Cyber security and Safeguards against hate crime and abuse

We could not find any references to (protection from) cyber bullying of disabled people. Mind, an advocacy organisation for people with mental health problems cooperates with other NGOs in setting up a website to inform about and to report on cyber bullying.⁷⁹

All new technologies and use of these technologies should comply with privacy regulations as laid down in the General Regulation of Data protection⁸⁰ which is an implementation of the European Union General Data Protection Regulation (GDPR). The independent authority Privacydata⁸¹ oversees the regulation. For specific

⁷⁵ Hable. <https://www.iamhable.com/about>

⁷⁶ Snoozy. <https://scoozy.nl/>

⁷⁷ Vertiwalk: <http://www.vertiwalk.com/> and Rombout Frieling Lab: <http://www.rombout.design/>

⁷⁸ <https://berkelbike.nl/over-ons/>

⁷⁹ Website Meldknop (translates as report button) <https://www.meldknop.nl>

⁸⁰ Algemene verordening gegevensbescherming (AVG).

⁸¹ Autoriteit Persoonsgegevens. <https://autoriteitpersoonsgegevens.nl>

details, see above. Neither the regulation itself, nor information aimed at producers or consumers by the authority Privacydata make mention of cyber bullying and hate crime nor of any aspects specifically concerning people with disabilities. An example is for instance that the Authority explains the basic regulation for making video or pictures in public⁸² and the rules that apply but makes no specific mention about the consequences of these rules for people with visual impairments.

The EU Directive (EU) 2016/1148 concerning measures for a high common level of security of network and information systems across the Union (NIS Directive) is in the Netherlands implemented in the Cyber Security Law⁸³. The EU directive calls out for Governments to explicitly list in their legislation vital sectors for which strict cyber security rules apply, such as the health sector and digital infrastructure.

The Dutch national Government omitted the health sector from their list of vital sectors with the result that obligations resulting from the EU directive do not apply for breaches of cyber security in the health sector.⁸⁴

The Criminal Code contains two articles that criminalise insults and inciting hatred, violence or discrimination against a person on the grounds (among other grounds) of disability. Police forces in the Netherlands recorded 61 incidents of discrimination on the grounds of disability in 2015 and 27 in 2016.⁸⁵ It is not known whether the incidents led to prosecution.

A source for hate crime recordings in the Netherlands is offered by the OSCE Office for Democratic Institutions and Human Rights (ODIHR). The OSCE data (year 2018) show 3299 hate crime offences (including on line hate speech incidents). In 16 cases of the total bias against people with disabilities was noted.⁸⁶

⁸² the rule is: it is permitted for private citizens to use camera's and sensors for private use. This means that it is permitted to make images and other recordings of oneself and of other persons around oneself provided these recordings will not be published.

⁸³ Wet beveiliging netwerk- en informatiesystemen 2018.

<https://wetten.overheid.nl/BWBR0041515/2019-01-01>

⁸⁴ Decree of 4 December 2017 designating providers, products and services who are obligated to report on serious incidents in ICT. <https://zoek.officielebekendmakingen.nl/stb-2017-476.html>

A critique of the omission is mentioned in an online article by Pieter Kalis, PhD Candidate in Telecommunications Law, University of Leiden. <https://leidenlawblog.nl/articles/nis-directive-update-for-the-netherlands>

⁸⁵ Hate crime recording and data collection practice across the EU. European Union Agency for Fundamental Rights, 2018

https://fra.europa.eu/sites/default/files/fra_uploads/fra-2018-hate-crime-recording_en.pdf

⁸⁶ OSCE ODIHR Hate Crime Reporting <https://hatecrime.osce.org/netherlands>

10. Conclusions

The group of people with deafblindness does not get much attention in policies in the Netherlands. They are indistinguishable as part of the larger group of people with sensory impairments and in policies and regulations regarded and mentioned as people who are either deaf or blind. Legislation, regulation, administration and the provision of equipment and support and care only recognise people under the general term sensory impaired or, if a distinction is made, either deaf or blind.

The consequence is that it is not known how many children and adults in the Netherlands are deafblind. Rough estimations are made by care providers. Administration only give accounts of how many people have a sensory impairment and who have requested for a provision, care or support. A further consequence is that policies and regulations rarely take the specific needs of people with deafblindness into account.

A start has been made to raise more awareness by initiating a small expert centre (by five national care providers for people who are deaf or blind) and a research centre on deafblindness by the university Groningen.

There are no specific policies, campaigns or programs to raise awareness on the needs of people with deafblindness.

There is general readiness to provide people with all kinds of disabilities with individual support, care, equipment and provisions to facilitate participation in society. Yet there is no sense of urgency to enhance general accessibility in society and to enhance accessibility in general technology. Legislation to enhance accessibility in the Netherlands is induced by European legislation and the CRPD.

11. Recommendations

Make an inventory of the number of people in the Netherlands who are deaf and blind according to an international definition of deafblindness, and distinguish whether deafblindness is congenital or acquired later.

Commission research, in cooperation with the existing Dutch expert centre and Dutch research centre, on the specific needs of people with deafblindness.

Set up a taskforce which is to formulate what adaptations would work for people with deafblindness in enhancing accessibility in digital products, apps, buildings, the built environment, in education and in work.

Engage people with deafblindness systematically in the education of architects, product designers, app and website builders.

Private initiatives for e-health or other innovation networks such as 'smart cities' could be made aware of the need to incorporate design that recognises the specific

needs of people with disabilities and the specific opportunities that innovative digital technology could bring for this group of citizens.