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

Working Paper

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Contents

Executive Summary

Sweden's population is considered to be among the most digitally experienced in the world and the society has a high degree of digital literacy. Digitalisation is expected to enable large benefits for society and create a more inclusive society. However, for some groups the accessibility of new technologies is not in place and they are at risk of being left behind. People with deafblindness are among these groups. Legislators' and professionals' lack of knowledge often results in barriers to the inclusion of people with deafblindness in the development of policies on accessible technical aids and consumer products.

People with deafblindness in Sweden are not recognised as an eligible group for services and there is no national register of how many individuals live with deafblindness in Sweden. The estimated number of individuals with deafblindness is 2000 up to the age of 65. The group is very diverse and their support needs are very individual.

Several legal frameworks and policies are in place for developing accessibility and new technologies. However, due to the premises of deafblindness the demands for accessibility are often not met. Adaptations often meet the needs for single sensory loss (i.e. hearing or vision), but not for the complexity of dual sensory loss as it is defined in the Nordic Definition of Deafblindness.

The support system in Sweden is spread over several authorities and agencies. Counties, as well as municipalities, have responsibility for meeting the needs of people with disabilities, including deafblindness. They have a high degree of autonomy, while some other parts of the support system are regulated at a National level. This means that information, prescription of and training to learn new technology and other technical devices is unequally distributed within Sweden. It also means that there are many different actors involved when a person with deafblindness gets the support and rehabilitation needed. There are also some agencies that have a specific remit to assist people with deafblindness. Within the health care services there are Deafblind teams or networks of professionals and there are also special resources for support in schools. The Swedish National Resource Center for Deafblindness has the responsibility for collecting, developing and spreading knowledge about deafblindness to professionals.

Ethical dimensions of new technology are currently being discussed in relation to human enhancement, gene editing, foetal diagnostics and robotics. The emphasis is on the need for a multidimensional perspective when introducing new technology. In Sweden issues are also being raised about how health care can keep up with the fast developing new technologies.

Regarding the involvement of people with disabilities in policy development in accessibility and new technology, we present information from the Association of the Deafblind in Sweden who have been a consultative body when the authorities have

conducted different inquiries. These inquiries were not about new technology explicitly but touched on equality and participation for people with disabilities, which also includes technology, information and living conditions.

1. People with Deafblindness

1.1 Official recognition of people with deafblindness as an eligible group

People with deafblindness in Sweden are not recognised as an eligible group within law and policy. The system in Sweden is structured with different laws and regulations concerning people with disabilities and not specifically organised around distinct disability groups.

However, in Sweden the Nordic Definition of Deafblindness[1] is applied and this is used when addressing people with deafblindness and their needs. The last revision of the definition was accepted in 2016 by the Nordic leader forum. The initial section is as follows:

> "Deafblindness is a combined vision and hearing impairment of such severity that it is hard for the impaired senses to compensate for each other. Thus, deafblindness is a distinct disability."

The definition is followed by main implications and a five-point list of further clarifications[2]. The main implications are social life, communication, access to information, orientation and mobility in a safe and secure way. Sometimes physical and psychological health issues are also included. Further, the importance of the tactile sense for being able to compensate for the loss in vision and hearing is emphasised.

People with deafblindness are a heterogeneous group who have very different needs depending on the onset and cause of deafblindness. This also depends on the resources and the social networks that they have. However, most people with deafblindness need lifelong support from society and special adjustments are needed to make information about and learning of new technical aids.

1.2 National data on people with deafblindness

No comprehensive national register of people with deafblindness exists in Sweden. However, various data is of interest and will be mentioned in this section.

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[1] https://nkcdb.se/dovblindhet/fakta-om-dovblindhet/nordisk-definition/
[2] https://nordicwelfare.org/wp-content/uploads/2018/03/nordic-definition-of-deafblindness.pdf

The Swedish National Resource Center for Deafblindness[3], estimates the number of people with deafblindness under 65 years of age to be 2000 individuals. The estimated number of children born with deafblindness is 6-8 each year, and approximately 20 will develop deafblindness later in life. No figures on the number of individuals over 65 years who develop age-related hearing and vision loss exist in Sweden today. Estimates from 2011 indicate that around 30,000-40,000 individuals over the age of 65 had age-related dual sensory loss[4]. Research at the Audiological Research Centre in Örebro is ongoing and results from the prevalence estimates for severe dual sensory loss in older adults over 65 years of age will be published during 2020.

The Association for the Swedish Deafblind (Förbundet Sveriges Dövblinda, FSDB) has approximately 800 members. The membership is not solely restricted to individuals with deafblindness; it also includes family members, relatives, and professionals from different disciplines[5]. About 350 of the members have deafblindness[6] themselves.

A Swedish research register on individuals with Usher syndrome was founded in Sweden about 30 years ago and today it includes data from approximately 275 individuals. The register was founded by Prof Claes Möller, and with the aim to conduct clinical and genetic research in Usher syndrome. The Swedish estimates of how many living with Usher syndrome is 800 individuals[7] and the figure is based on prevalence studies conducted in Sweden in the beginning of the millennium[8].

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

In Sweden, there are no national laws or policies specific to people with deafblindness. There are however, several laws and policies that are applicable for the group, but they are formulated to meet the rights and the needs of people living in Sweden, regardless of disability or not.

In Sweden, the municipalities and the counties have a high degree of autonomy to organise health care services and social services provided to citizens, including people with disabilities. The municipalities have the responsibility to organise among other things, care for elderly and people with disabilities and this is obliged in law[9]. There are several laws that the municipalities must respond to: the Local

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[3] www.nkcdb.se

[4] https://nkcdb.se/dovblindhet/fakta-om-dovblindhet/forekomst/

[5] www.fsdb.org

[6] Personal communication Linda Eriksson, 20200408.

[7] https://www.socialstyrelsen.se/stod-i-arbetet/sallsynta-halsotillstand/ushers-syndrom/

[8] Sadeghi M, Kimberling WJ, Tranebjœrg L, Möller C. The prevalence of Usher syndrome in Sweden: a nationwide epidemiological and clinical survey. Audiol med 2004; 2: 220-228

[9] https://skr.se/tjanster/lattlast/vadgorkommunerna.596.html

Government Act (2017:725)[10], the Social Services Act (2001:453)[11] as well as the Support and Services Act for persons with disabilities (LSS 1993:387)[12]. The 21 counties in Sweden are required to provide citizens with health care and this is funded by taxes paid by citizens[13]. There are also some parts of the support system within social services that are governed by the state, for example, the National Insurance Office[14] and the Swedish Employment Service[15].

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

No authority or body has the full responsibility to report on or have responsibility for people with deafblindness. The responsibility to meet the needs of people with disabilities, including deafblindness, is spread between different authorities and bodies within the social services, health services, and the educational system[16]. This section will focus on people with deafblindness.

The Swedish National Resource Center for Deafblindness[17] is a state funded organisation that was founded in 2003. They have the assignment from the Social Welfare Department to collect, develop and spread information and knowledge about deafblindness to professionals working in the field. They are also responsible for the development of methods in the field as well as giving courses, seminars and so on.

The National Agency for Special Needs Education and Schools[18] in Sweden is another state funded organisation with the responsibility for supporting and supervising teachers and other staff in the educational system with regard to children, youth and adults with disabilities to fulfil their educational goals. They have a special unit that is responsible for people with deafblindness[19].

There is an upper secondary school, Riksgymnasiet för döva och hörselskadade, for youngsters with hearing impairment, deafness and deafblindness. The students come from all over Sweden and have needs for communication adjustments such

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[10] https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/kommunallag-2017725_sfs-2017-725

[11] https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/socialtjanstlag-2001453_sfs-2001-453

[12] https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/lag-1993387-om-stod-och-service-till-vissa_sfs-1993-387

[13] https://skr.se/tjanster/lattlast/vadgorregionerna.494.html

[14] https://www.forsakringskassan.se/

[15] https://arbetsformedlingen.se/

[16] www.nkcdb.se

[17] www.nkcdb.se

[18] www.spsm.se

[19] https://www.spsm.se/funktionsnedsattningar/syn--och-horselnedsattning-eller-dovblindhet/

Swedish Sign language (SSL), loop systems or other technical solutions for hearing impairments, to be able to take part in education[20].

Mo Gård is a non-profit organisation that provides services, such as support, education, treatment and residential homes to people who have Swedish sign language (SSL) as their main communication and have additional needs or disabilities, including deafblindness[21].

The Swedish Public Employment Service[22] has overall responsibility for people who have difficulties entering the labour market. They have had special support units for people with deafblindness; these were organised within support services for people with deafness, vision- and hearing impairment and deafblindness. However, the Swedish Public Employment Services have recently gone through re-organisation and it is unclear whether the special units will remain in the future. This could have a great effect on the possibility to get support from professionals with knowledge about deafblindness.

The 21 counties (Regioner) in Sweden, have broad responsibilities for citizens. There are also special units or networks within the health care services, often organised within the rehabilitation and habilitation sector, which have a special responsibility for meeting the needs of people with deafblindness and their families. These are called Deafblind teams or Deafblind networks. Every county has their person to contact but the organisation, resources and knowledge to meet the needs differ from county to county[23]. These teams or networks also differ in their target groups, whether it is to support persons with deafblindness of all ages, restricted to adults of working age, or also include elderly people who acquire their vision- and hearing impairments due to old age.

The counties also have responsibility for providing people with deafblindness with interpreter services[24]. They provide interpreters to enable people with deafblindness to participate and to be active in society and in everyday living. The right to interpreter services is regulated in the Health Care Act (2017:30)[25]. Interpreter services may prioritise the assignments that are received, depending on their resources. There is a need for more interpreters who can interpret for people with deafblindness in Sweden. The service is free of charge for the individual.

There are 290 municipalities in Sweden. They have responsibility for social services that are to be provided to the inhabitants, including care for elderly people and people with disabilities. This is regulated in the Social Services Act (Socialtjänstlagen

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[20] https://www.orebro.se/omriksgymnasiet/omriksgymnasiet.4.5b96647312226a30526800017074.html

[21] https://www.mogard.se/

[22] https://arbetsformedlingen.se/

[23] https://nkcdb.se/dovblindhet/samhallets-stod/behov-av-specifika-tjanster/

[24] https://www.tolkcentralen.se/vartuppdrag

[25] https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/halso--och-sjukvardslag_sfs-2017-30

2001:453)[26] and in the Support and Services Act for persons with disabilities (LSS 1993:387)[27]. For example, the municipalities provide personal assistants, contact persons and group homes to those who have the right to this kind of support.

The Swedish Social Insurance Agency (Försäkringskassan)[28] has responsibility for different issues concerning additional costs for people with disabilities. There are several allowances that may be applied for, such as disability allowance in the case of additional expenses or help with daily activities and attendance allowance for adults who have needs for personal assistance. People with disabilities may also apply for assistive devices to be used when working. These may be devices such as listening devices to complement hearing aids or assistive vision devices such as a Braille display or video magnifier. It is not possible to receive allowances for equipment that is normally required in a proper working environment as these costs are to be covered by the employer. To get access to the allowances from the Social Insurance Agency the individual needs a statement from a medical doctor, to document the disabilities.

The Association for the Swedish Deafblind (Förbundet Sveriges Dövblinda, FSDB) is a member driven organisation for people with deafblindness and their next of kin[29]. It was founded in 1959. The FSDB is divided into regional sections and there is also a section for parents with children who have deafblindness, a section for parents with deafblindness and their families and one for young people with deafblindness. The FSDB organises activities to break isolation, provide fellowship and other activities to people with deafblindness. They also work to raise awareness in the public and political sectors about questions important to people with deafblindness.

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

2.1 Overall legal and policy framework for access to technology

A few laws and regulations can be considered to be the main laws and policies determining accessibility and access to new technologies.

Convention on the Rights of Persons with Disabilities[30]

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[26] https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/socialtjanstlag-2001453_sfs-2001-453

[27] https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/lag-1993387-om-stod-och-service-till-vissa_sfs-1993-387

[28] https://www.forsakringskassan.se/

[29] http://www.fsdb.org/

[30] https://www.regeringen.se/rattsliga-dokument/departementsserien-och-promemorior/2008/04/ds-200823/

Sweden ratified the UN Convention on the Rights of Persons with Disabilities in 2008.

Discrimination Act[31]

The Discrimination Act (2008:567) prohibits direct or indirect discrimination due to a disability, against a person in work or education. In January 1, 2015, an amendment was made and lack of accessibility is now also seen as discrimination, which means that a person with a disability cannot be disadvantaged by not taking accessibility measures.

The Health Care Act[32]

Chapter 8 of the Health Care Act (2017: 30) states that the health care region shall offer habilitation and rehabilitation, assistive devices for persons with disabilities, and interpreting services for everyday interpretation for the deaf, deafblind, adult deaf and hearing impaired. Chapter 10 describes that the region should allow the patient possibility to choose between aids (as stated in Chapter 7 § 2 of the Patient Act (2014: 821).

Patient Act [33]

The Patient Act (2014: 821) Chapter 3 states that the patient should be informed about the aids available to persons with disabilities. Chapter 7 states that when different aids are available for people with disabilities, the patient should be given the opportunity to choose the alternative he or she prefers. The patient should be given the chosen aid, if it is justified in view of his or her needs and the costs of the aid.

The Public Procurement Act[34]

The Public Procurement Act (2016-1145) applies to procurement carried out by a contracting authority (public procurement). The law specifies that when an item procured is to be used by natural persons, the technical specifications shall be determined taking into account the needs of all users, including availability to persons with disabilities.

Working Environment Act[35]

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[31] https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/diskrimineringslag-2008567_sfs-2008-567

[32] https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/halso--och-sjukvardslag_sfs-2017-30

[33] https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/patientlag-2014821_sfs-2014-821

[34] https://riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/lag-20161145-om-offentlig-upphandling_sfs-2016-1145

[35] https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/arbetsmiljolag-19771160_sfs-1977-1160

The Work Environment Act (1977-1160) states that the employer must take into account the employee's need for special conditions at work by adapting the working conditions or taking other appropriate action. When planning and arranging work, the employer must take into account that people's requirements regarding conditions for performing tasks are different.

The Swedish government and the Swedish Municipalities and Regions have decided to develop the e-health area. They jointly strive for a vision that Sweden will be the best in the world in using the possibilities of e-health and digitalisation by the year 2025[36]. E-health work is being developed from laws and perspectives in health care services based on equality, efficiency and security. For example, digital services should be designed on the basis of universal design to ensure equal service. This means that IT support should be useful and accessible to all, regardless of other factors such as age or disability.

Sweden's population is considered to be among the most digitally experienced in the world since almost all residents have access to smart phones and virtually the entire society has been digitally developed[37]. Digitalisation is expected to enable large benefits for society, as digital visits, among other things, enable patients and caregivers to maintain contact regardless of distance.

One concept in digitised care is welfare technology. Welfare technology is defined by the National Board of Health and Welfare as the digital technology used to improve or maintain participation, independence, security or activity to compensate for a disability[38]. Welfare technology means the knowledge and use of that technology. In laws and regulations and two different lines around accessible welfare technology can be discerned. In healthcare, accessible welfare technology is often linked with aids and / or various digital solutions. In other areas, such as social design and technology, the concept of universal design has instead become an increasingly common starting point when designing various services in society.

By ratifying the CRPD, Sweden has undertaken to carry out or promote research and development and to promote access to and use of new technologies (Article 4). New technologies include both information and communication technologies as well as aids for people with disabilities. Most of the aids prescribed through health care are medical technology products.

Aids and welfare technology are available to users and patients in different ways. Assistive products are prescribed to individuals according to the Health Care Act

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[36] Vision e-health 2025: Common starting points for digitalisation in social services and health care. Stockholm: Ministry of Social Affairs, Sweden's Municipalities and County Council. https://www.regeringen.se/4a1f04/contentassets/79df147f5b194554bf401dd88e89b791/vision-e-halsa-2025.pdf

[37] Digital healthcare services aimed at patients: Survey and follow-up. Stockholm: The National Board of Health and Welfare. From https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2018-6-15.pdf

[38]National board of Health and welfare (2019) https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/dokument-webb/ovrigt/terminologi-resultat-av-remiss-valfardsteknologi-2015.pdf

(2017:30) while welfare technology is mainly provided through decisions under the Social Services Act (2001: 453) or the Act (1993: 387) on support and services for persons with certain disabilities. Changes in the Patient Act (2014: 821) have given increased opportunities for patients and users to participate in the choice of aids: when different aids are available for people with disabilities, the patient should be given the opportunity to choose the alternative he or she prefers. However, even though some regions have introduced "free choice" of aids, the individual may not be offered a total freedom of choice as aids are usually procured at several year intervals.

In order for innovations to be introduced as aids, they must be thoroughly evaluated. However, rapid technological development places high demands on health care when it comes to assessing which innovations and new products should be provided as aids or not. If other (older) aids already meet the same needs, there is no incentive for the health care services to introduce innovations, even if these show high user benefit and patient safety. It is also not uncommon for innovations to be designed to meet more than one need. Further, according to the Aid Investigation[39] , such an elementary thing as the lack of a natural ISO code for the product can mean that the innovation is not classified as an aid. New products also need to be tested and evaluated before being included in the procured product range, which can result in long lead-in times before the product is procured, and thus can be prescribed as aids. With the rapid technological development that is taking place today, there are often new, modern and useful products on the market, which are not included in the health care service´s procurement range. Overall, it can be concluded that it is not simply "freedom of choice" for new technologies as aids.

In the Aid Investigation, a number of other problems with access to aids were also highlighted. One of the major problems is that there are no regularly produced comprehensive national statistics on assistive technology. Therefore, it is difficult to know what types of aids are prescribed (and how much concerns new technology) and whether individuals are given access to the aids that they need.

The National quality plan for care and care for the elderly (SOU 2017:21[40]) points out that there is a great interest in municipalities to use welfare technology in health care and care, but there are uncertainties regarding the legal conditions for the use of technology, as well as difficult ethical issues to deal with. There is also a need to clarify the boundary between aids and welfare technology, which is not limited to a particular area such as disability, but encompasses a wide range of services in the entire public sector. The question of individual consent and the influence of the individual has also been raised. The ethical issues have also been pointed out in the

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[39] https://www.regeringen.se/rattsliga-dokument/statens-offentliga-utredningar/2017/05/sou-201743/
[40] https://www.regeringen.se/rattsliga-dokument/statens-offentliga-utredningar/2017/03/sou-201721/

Integrity Committee's interim report[41] where it is considered doubtful how people with reduced decision-making capacity can be offered services with welfare technology.

2.2 Overall legal and policy framework for accessibility

Sweden has legislation regarding accessibility in several different laws and regulations. The laws and regulations that mainly involve transposition into other national laws and regulations are the Discrimination Act (2008: 567) and the Convention on the Rights of People with Disabilities (CRPD) (described above).

Other central regulations concerning accessibility are the accessibility directives, which quite recently have come into force in Sweden:

Web Accessibility Directive[42]

In 2018, the Web Accessibility Directive came into force in Sweden. The law covers the entire public sector and means that websites, extranets, intranets, documents and applications (apps) must meet the requirements for accessibility in EN301549.

EU Accessibility Directive

In 2019, the EU Accessibility Directive came into force and this is to be implemented by the Swedish Constitution by June 28, 2022[43]. The Accessibility Directive deals with common accessibility requirements for products and services, such as computer hardware systems, payment terminals and electronic communications services. Products and services released on the market must meet the requirements of the directive no later than June 2025 and a process will be started with the aim of deciding how Swedish constitution should be designed to comply with the directive's requirements.

3. Regulation of New Technologies

Depending on the type of technology used, different legislation may need to be considered. Individuals usually gain access to welfare technology through decisions on assistance under the Social Services Act (2001: 453)[44] and with regard to

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[41] https://www.regeringen.se/4ac6ee/contentassets/56e701d354824bcb9826ea0839ab28f3/sa-starker-vi-den-personliga-integriteten-sou-201752
[42] https://eur-lex.europa.eu/legal-content/SV/TXT/?uri=CELEX:32016L2102
[43] https://www.mfd.se/verktyg/lagar-och-regler-om-tillganglighet/eus-tillganglighetsdirektiv/
[44] https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/socialtjanstlag-2001453_sfs-2001-453

technology, different laws may be applicable depending on the type of technology concerned, e.g. the Camera Surveillance Act (2018: 1200)[45].

3.1 Use of personal cameras and sensors
The purpose of the Camera Surveillance Act (2018: 1200)[46] is to meet the need for camera surveillance for legitimate purposes, while protecting individuals from undue intrusion on personal privacy. The Camera Surveillance Act applies both to using surveillance cameras and to the subsequent processing of recorded material. The Camera Surveillance Act does not apply to places where the public does not have access, that is, if a natural person conducts the surveillance as part of private activity.

3.2 Face and object recognition
Biometric data is regarded in Swedish legislation as particularly worthy of protection and the processing of sensitive personal data, such as biometric data, is generally prohibited. The General Data Protection Regulation (GDPR)[47] contains specific provisions on biometric data that must be taken into account when using face recognition technology.

3.3 Handling and ownership of data
The General Data Protection Regulation (GDPR) contains provisions designed to protect people from violence of personal privacy when processing personal data. In the Patient Data Act (2008: 355)[48], there are supplementary rules that apply to health caregivers' processing of personal data in health care.

3.4 Data Analysis
Regulations on how data may be handled in research are found in both the Data Protection Regulation (2018: 218)[49], the Ethics Review Act (2003: 460)[50] and the Publicity- and Secrecy Act (2009: 400)[51].

[45] https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/kamerabevakningslag-20181200_sfs-2018-1200
[46] https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/kamerabevakningslag-20181200_sfs-2018-1200
[47] https://www.datainspektionen.se/lagar--regler/dataskyddsforordningen/
[48] https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/patientdatalag-2008355_sfs-2008-355
[49] https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/lag-2018218-med-kompletterande-bestammelser_sfs-2018-218
[50] https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/lag-2003460-om-etikprovning-av-forskning-som_sfs-2003-460
[51] https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/lag-2003460-om-etikprovning-av-forskning-som_sfs-2003-460

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

In 2018, the Swedish government came up with an AI strategy, National Approach for Artificial Intelligence[52]. The strategy draws the general direction for AI in Sweden. When it comes to ethical issues, the strategy points out "it is important to develop ethical guidelines to ensure a transparent, explainable, and non-discriminatory development of AI. This is particularly important in systems that may affect the physical world, such as self-driving vehicles or AI applications in health care". In order to develop the field of ethics and AI, the Swedish government established a Committee for Technological Innovation and Ethics (KOMET[53]) in August 2018. In order to place a special focus on ethical and social aspects of AI, a hub, AI's sustainability Center[54], was founded by companies, universities and public authorities. AI´s sustainability centre wrote a report in 2019 "An inventory of the state of knowledge of ethical, social, and legal challenges related to artificial intelligence". However, disability[55] was not mentioned in this report. Although AI will affect many people with disabilities, no special focus is described on this target group, either at AI's sustainability center or at KOMET. Given that there is no particular focus, it is difficult to find knowledge or ethical discussions that specifically concern people with disabilities, in their reports and other writings.

With regard to ethics in health care, the Swedish Medical Ethical Council (abbreviated in Swedish SMER) has been appointed by the government with the task of elucidating medical-ethical issues from a societal perspective. In their analyses, SMER applies a humanistic view of people; that every human is a subject with freedom, responsibility and dignity and must never be regarded or treated solely as a means to an end[56]. This view of humanity is linked to the perception of human dignity, which means that all people have certain fundamental rights that must be respected and apply equally to everyone. Human value is linked to human existence, not to what she owns, does or can do.

In SMER's reports, disability does not constitute a specific focus area[57] and in searches on SMER's website with the words "impairment" (funktionsnedsättning) and "disability" (funktionshinder) respectively 14 and 11 hits occur. The hits that can be linked to new technology concern human enhancement, gene editing, fetal diagnostics and robotics. The ethical reasoning on these phenomena is more or less developed and includes either how disability can be affected by new technology or how the use of technology can affect people with disabilities. SMER emphasises that

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[52] https://ec.europa.eu/knowledge4policy/ai-watch/sweden-ai-strategy-report_en
[53] https://www.kometinfo.se/in-english/about-us/
[54] http://www.aisustainability.org/about-us/
[55] The report has been searched, where the words disability, disabilities and disabled have been used.
[56] http://www.smer.se/om-smer/uppdrag/
[57] http://www.smer.se/rapporter/

it is important to have a multidimensional ethical perspective when introducing new technology[58]. They question for example whether it is ethically acceptable to put a GPS transmitter on a person with dementia or to monitor a person with a camera in their home. At the same time, they believe that for the individual, robots and surveillance technology can be valuable tools that contribute to increased independence. The new technology can also mean cost savings and relieve healthcare staff from heavy work tasks. However, if technology increasingly replaces staff, there is a risk that the individual's need for social stimulation and human contact will not be met. When it comes to robotics, camera surveillance and GPS transmitters in healthcare, the importance of analysing the benefits to the individual as well as safety and ethical aspects is emphasised before new technology is introduced.

SMER also states that the legislation in the healthcare area is well written, but that it does not keep up with the rapid development of technology. An example is the Act on Genetic Integrity[59], from 2006 where some of the technology that exists today was not even conceived when the law was written. Regarding the benefits of new technology and its benefits, there are different perspectives depending on the context and whose perspective is represented. In health care, the ethical issues may be about human rights as well as efficiency and economy.

The National Board of Health and Welfare has prepared information- and discussion material[60] on ethical issues in the introduction of welfare technology, which they use in education aimed at municipalities, companies and non-profit organisations that provide care. The material is divided into three main groups; the user, the user's relatives and the profession where ethical questions are discussed from each perspective.

5. Disabled People's Access to Information

The possibility to access information about new technology is restricted for people with disabilities, including individuals with deafblindness. For people with deafblindness, society needs to put special efforts into making information about new technologies available because one of the fundamental difficulties when living with deafblindness is the lack of information or fragmented information. The overall situation is that people with deafblindness receive less information than others. This also applies to information about new technology regardless of whether it is "ordinary" consumer technology such as mobile phones, computers or if it is

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[58] State Medical-Ethical Council (2014). Robots and supervision in the care of the elderly - Ethical aspects. http://www.smer.se/rapporter/robotar-och-overvakning-i-varden-av-aldre-etiska-aspekter/
[59] https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/lag-2006351-om-genetisk-integritet-mm_sfs-2006-351
[60] https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/dokument-webb/kunskapsstod/e-halsa-valfardsteknik-etik-sammanstallning-2017.pdf

technical aids which are adjusted for individuals with deafblindness. Where a technical aid is provided for individuals with deafblindness, often in reality this means a technical aid that either compensates for the hearing loss or the vision loss and not for the combination effect of the loss of both senses[61].

The Swedish National Resource Center for Deafblindness has from the Ministry of Social Affairs, the assignment to "identify and work for the development of technology and services for information and communication"[62]. This has been prioritised since 2014 and the work is done in close collaboration with the Association of the Deafblind in Sweden.

There is also an "expert group" on technology within the Swedish National Resource Center for Deafblindness[63]. They focus on issues concerning technology, technical aids, information and communication. The group pays close attention to accessibility questions relevant to people with deafblindness and can provide support to professionals in special questions concerning technology. Together with a similar corresponding group at Bartimeus in the Netherlands they are in the process of starting up an international network on technology and technical aids through the International organisation of Deafblind International (DBI) although further details were not confirmed at the time of writing this report.

The Swedish Post and Telecom Authority (Post och Telestyrelsen, PTS) monitors the electronic communications and postal sectors in Sweden[64]. They are one of the key authorities responsible for ensuring the Swedish Government's Disability Policy is realised. Their main task is to fill the gap where communication solutions available on the market are not accessible and they provide support and information. For example, they are responsible for relay services in video and text telephony, free dispatch of literature in Braille and postal services for elderly and people with disabilities in rural areas[65]

The Agency for Digital Government (Myndigheten för digital förvaltning, DIGG)[66], has the responsibility for the development of digitalisation of the public sector and this is regulated by the Regulation with instructions for Digital Management Authority (SFS 2018:1486)[67] . They are also the agency that defines the meaning of digital accessibility. They provide information on how accessible websites are to be structured and also act as a regulator for the follow up of accessibility of websites and other digital platforms within the public sector[68]. The requirements in the Act for Web Accessibility Directive are that the information provided should be perceivable, manageable, understandable and robust.

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[61] https://nkcdb.se/forskning-och-utveckling/ikt-projektet/
[62] https://nkcdb.se/forskning-och-utveckling/ikt-projektet/
[63] https://nkcdb.se/expertstod/ikt/
[64] https://pts.se/en/english-b/internet/usefulness-and-accessability/
[65] https://pts.se/en/english-b/internet/usefulness-and-accessability/
[66] https://www.digg.se/
[67] https://svenskforfattningssamling.se/sites/default/files/sfs/2018-07/SFS2018-1486.pdf
[68] https://www.digg.se/utveckling--innovation/digital-tillganglighet/tillganglighetsredogorelse

The Equality Ombudsman (Diskrimineringsombudsmannen)[69] is the authority to whom restrictions in accessibility are reported. They have the power to initiate a process and investigate if accessibility requirements are not met and if this is considered to be discrimination against an individual. This is not restricted to accessible environments in public buildings, but also includes restrictions in accessible information, personal service, or at the workplace. People with disabilities have the right to put demands on accessibility in for example, restaurants, shops, education, work and health care.

6. Access to Equipment

6.1 Public Sector

The National Board of Health and Welfare states that for individuals with disabilities an aid is "for daily life or aids for care and treatment". Further, the definition states that "an aid is an individual product with the aim of preserving or increasing activity, participation or independence by compensating for the impairment"[70]. This definition can then be further divided in aids for care and treatment, welfare technology and medical technology.

Most of the devices or aids are prescribed by the counties or regions, for the health care services of habilitation and rehabilitation, but the responsibility is shared between the counties and the municipalities. The process for prescription of an aid includes testing, adjustments if necessary, information, skill training and follow up[71]. The prescription of aids is regulated by the Health Care Act (2017:30) [72]. The responsibility for aids for hearing and vision is placed within health care services in rehabilitation settings for hearing and vision respectively, for example audiological clinics or low vision clinics[73]. The person can refer him or herself without a referral from a medical doctor and this is regulated by the Act on Freedom of Choice (LOV, 2008:962)[74].

In procurement each health care manager, county council or municipality decides on which regulations and type of technology should be offered to the target groups. This is then formulated within the respective aid policy or manual. The type described is

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[69] https://www.do.se/om-diskriminering/vad-ar-diskriminering/bristande-tillganglighet/

[70] https://termbank.socialstyrelsen.se/?TermId=768&SrcLang=sv

[71] https://termbank.socialstyrelsen.se/?TermId=178&SrcLang=sv

[72] https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/kunskapsstod/2016-8-2.pdf

[73] https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/kunskapsstod/2016-8-2.pdf

[74] https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/kunskapsstod/2016-8-2.pdf

then what is offered to the user. If what is selected does not meet the needs of the person, the health care manager may arrange an individual direct procurement based on the person's individual needs[75]. This means that what is provided in by one health care manager in one part of the county differs from what is procured in other counties.

Each health care manger within the counties has their own list of aids that are available and getting an individual direct procurement is not always easy, even if the possibility is there.

In general, there is not sufficient knowledge among those making the procurements or setting the criteria for what can be on the list of aids and devices. However, this is to some extent compensated by professionals' advice and meeting individuals with deafblindness, who can make individual adjustments.

The process has been that the individual borrows the aids needed and if they are not needed anymore, s/he returns them. However, this is changing since some counties have introduced rental cost for the aids. The introduction of rental cost for aids has been criticised for leading to inequality for users. You pay the same monthly amount regardless of how many aids you have, and the user also has to pay additional costs for visiting the service that provides the aids and start up fees. There are also differences between the counties in terms of charges and in how high the fees are. Various user organisations have strongly criticised these developments and the introduction of rental costs has also lead to some individuals with disabilities returning their aids, because they cannot afford the costs.

New technologies, including AI, IoT and haptic technology, can be available through the procurements. Whether this is the case is probably more a question of knowledge about what is needed than regulations about what may be included. Some confusion about what an aid is also exists, and things that are referred to as consumer or welfare technology are not regarded as aids. Updates to the list of available aids are produced every so often, depending on the length of contacts given to organisations for providing aids.

The individual's participation and self-determination, is also severely limited by procurement processes that lead to a supplier and/or a product becoming a preferred supplier. In this area, it should be a requirement that all procurement results in several suitable options for the end user. Another aspect that has been identified is that sometimes it is not the introduction of new technologies that is the problem. Rather, at issue is the possibility of keeping the technical devices that one is used to using. Learning how to use a new device takes a lot of time and effort for an individual with deafblindness. Some counties have decided to limit the time a person can get support for learning a new device or function. It is also difficult for professionals to keep up with the development of new technologies and to keep their

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[75] https://www.vardhandboken.se/vard-och-behandling/hjalpmedel/hjalpmedel-vid-fysiska-funktionsnedsattningar/forskrivning/

knowledge up to date[76]. Support for updates, repairs and replacements is part of the support system and is one of the main tasks for professionals.

No research has been identified which address these issues with regard to persons with deafblindness.

6.2 Private Sector

In the searches for the report and in discussion with personnel at the Swedish National Resource Center for Deafblindness, no such initiatives have been identified or are known of[77].

6. Accessibility measures in the built environment

The National Board of Housing, Building and Planning (Boverket)[78] has responsibility for some of the laws and regulations concerning the built environment. Other authorities also share responsibility for accessibility issues in buildings. The laws, regulations and recommendations concern public buildings as well as private houses and apartments and they also refer to plots. The National Board of Housing, Building and Planning say that buildings and plots should be accessible and useful for individuals with mobility or orientation issues. The accessibility requirements address site, design and technical property requirements. Two laws are applicable: the Planning and Building Act (PBL) and in the Planning and Regulation Act (PBF), and in addition to the laws there are recommendations that are clarified in implantation regulations[79].

The Swedish Government has commissioned Vinnova, the Swedish innovation agency, to carry out a special investment in research and innovation for accessible design. This is an ongoing investment between 2017-2020[80]. The aim is to develop the city to be inclusive regardless of disability, ages, sex or ethnicity. This special investment is further divided into different research programmes or initiatives, which also include smart city initiatives in digitalisation. Another programme concerns the Internet of Things (IoT) with the aim of increasing the public sector's possibility to

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[76] Personal communication, Karin Jönsson, National Resource Center for Deafblindness, Sweden, 20200330.
[77] Personal communication, Karin Jönsson, National Resource Center for Deafblindness, Sweden, 20200330.
[78] https://www.boverket.se/
[79] https://www.boverket.se/sv/PBL-kunskapsbanken/regler-om-byggande/boverkets-byggregler/tillganglighet/
[80] https://www.vinnova.se/m/smarta-stader/tillganglighetsdesign/

use IoT that is inclusive for all[81]. Sweden is considered to be well developed when it comes to technology and digital solutions, but one of the challenges is to keep up with the rapid development of new technology in the future.

7. Skill Development and Work Opportunities

The Swedish Public Employment Service (PES) has a government mission to support people with disabilities in skill development and work opportunities. PES offers a variety of support to people with disabilities, both upon entry into the labour market and during employment[82]. The PES has a number of specialists who work with rehabilitation support for job seekers, employees and employers and the specialists have different professional backgrounds such as physiotherapy, occupational therapy, audiology and psychology. Work-related aids and technology are not a responsibility within health care. The responsibility to assist people with disabilities with the technical aids is the responsibility of PES and they can decide on a financial contribution to provide someone with a technical aid. The PES website describes various successful technical aids and innovations, which have given opportunities for persons with a disability in working life[83]. Schools are responsible for technical aids that pupils or students need within the school setting.

Also other actors touch on technology and its opportunities to promote participation of people with disabilities in society.

For example, in 2020 the Nordic Welfare Center will carry out a project - The future of working life; technology and digitalisation for increased inclusion - which is about how the Nordic countries can overcome differences in labor force participation between people with disabilities and others in the population, with the help of technology, digitalisation and innovations[84]. The project will investigate, gather and disseminate knowledge about digital and technical solutions and consists of four parts:

1. A literature review based on research, research needs and evidence-based knowledge of digital and technical solutions

2. Provide examples of digital and technical solutions implemented in the Nordic countries

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[81] https://www.vinnova.se/e/strategiska-innovationsprogrammet-for-sakernas-internet/iot-sverige-varen-2020/

[82] https://arbetsformedlingen.se/sok?q=funktionsneds%C3%A4ttning%20samt%20teknikutveckling

[83] https://arbetsformedlingen.se/for-arbetsgivare/nyheter/nyheter/2019-12-03-robothandske-och-anpassad-arbetsplats-losningen-for-joakim

[84] https://nordicwelfare.org/projekt/framtidens-arbetsliv/

3. A toolbox for implementing digital and technical solutions. The main target group is employers, employees and relevant professional groups.

4. Dissemination of knowledge through webinars, seminars and other information efforts.

Another central actor in the area of technology and disability is Certec, which is part of the Department of Design Sciences at Lund University of Technology. Certec conducts research and education in Rehabilitation Technology and Design[85]. The research is about technology and design from a disability perspective with the purpose to create knowledge about designing technical and human support in everyday life. Certec's courses are technology-related and are aimed at, for example, civil engineers and industrial designers. They also have independent courses aimed at those working in disability services, such as housing, daily activities, habilitation, psychiatry, and schools.

Whether people with disabilities and their knowledge are utilised in different education programs in technology, or in technology education, is difficult to know. For example, the Royal Institute of Technology's curriculum for a civil engineer with a focus on design and product development does not describe universal design or disability[86].

8. Cybersecurity and Safeguards against hate crime and abuse

No information about personal safety or cybersecurity concerning hate crime and abuse has been identified which specifically address persons with disability. This is regulated within the Swedish penal code[87], and public prosecution. The Swedish Discrimination Act[88] could be applicable also when experiencing exposure due to harassment on the internet.

9. Examples of good practice in inclusion of disabled people in developing policy on new technologies

The Association of the Deafblind in Sweden survey the development of new technology in Sweden and take part in discussions and development around

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[85] http://www.certec.lth.se/

[86] https://www.kth.se/utbildning/civilingenjor/design-produktframtagning/kurser-masterprogram-1.517694

[87] https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/brottsbalk-1962700_sfs-1962-700#K5

[88] https://www.do.se/

accessibility and new technology. The association regularly responds to letters and inquiries that have been initiated by various authorities in Sweden[89]. For example they have been a consultative body for; the Aid Investigation (SOU2017:43); the Swedish Agency for Participation's[90] suggestion to the Government about a new strategy for a disability policy for an equal and sustainable society (2016/04598/FST)[91]. They have also written a letter on the memorandum Expanded Protection Against Discrimination in the form of Non-discrimination (Ds 2016:26)[92] that was initiated by the Swedish Government. The Association of the Deafblind has also responded to the Interpreter service memorandum for everyday interpreting (Ds 2016:7)[93].

The examples presented above do not explicitly deal with policies on new technology. However, they all concern accessibility and equality concerns for people with disabilities. Another example is that the Association of the Deafblind, together with representatives from the IKT group (Information, Communication and Technology) within the National Resource Center for Deafblindness, has been involved in discussions with Swedish government and the Swedish Municipalities and Regions about E-health and how this can be accessible to people with deafblindness. At present, there are many shortcomings in the accessibility of the web platforms of E-health[94].

The Association of the Deafblind in Sweden also takes part in reference groups where the Swedish Post and Telecom Authority ask their users for feedback on the services they provide within electronic communication.

Another example of involvement in development of new technology is from 2016 when the National Bank of Sweden changed the format of money in Sweden. They had developed an application for people with visual impairments that gave audio description of the paper money and coins. However, this was useful if using a Braille script reader with a mobile phone. This was observed by a person with deafblindness who at the time was working at the National Resource Center for Deafblindness. The company who developed the application was approached, and a new version of the application was produced after raising awareness about deafblindness.

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[89] http://www.fsdb.org/Skrivelser.html

[90] https://www.mfd.se/

[91] https://www.regeringen.se/contentassets/cee47abfd1ba49bb96542024b6d625c6/en-funktionshinderspolitik-for-ett-jamlikt-och-hallbart-samhalle-mfds-forslag.pdf

[92] https://www.regeringen.se/4a0426/contentassets/fad33077df9347faba3c01a716951d43/utvidgat-skydd-mot-diskriminering-i-form-av-bristande-tillganglighet-ds-201626

[93] https://www.regeringen.se/496acd/contentassets/fd0d8dc158d04e97ab31138c1f20497d/tolktjanst-for-vardagstolkning-ds-20167.pdf

[94] Personal communication, Karin Jönsson, 20200330.

10.   Conclusions

In Sweden, people with deafblindness are not recognised as a unique group within law and policy. The structure of law and policies in Sweden are on the contrary organised on the basis of accessibility, discrimination, integrity and such concepts.

There is a high degree of self-government by the counties, who have the main responsibility for providing health care, which also includes technology and technical devices to people with disability. As a consequence, the distribution of technology is uneven and fragmented. The legislation to meet needs seems to be in place and is developing to meet the new technology, AI and IOT, but the administration is not responding to this. Probably this is because of limited resources, lack of knowledge from professionals and other structural issues. There is a national register for aids prescribed by the health care service, however, the reporting from the counties is not adequate.

Lack of information is one of the key features of living with deafblindness. This means that the possibility to get access to information about new technology is often fragmentary and even haphazard depending on who you meet (professionals as well as your social network) and where you live.

The Swedish society and its citizens use digital solutions and different technologies to a great extent. However, accessibility is insufficiently inclusive and development concerning both public environments and websites is too slow. This means that people with disabilities, including deafblindness, are excluded from society when accessibility requirements are not met. One example of this is the access to health care resources through e-health, which is not met for people with deafblindness.

11.   Recommendations

Some recommendations can be made from the results presented in this report.

National guidelines for procurement of technical aids are needed. This could facilitate effectiveness for customers, purchasers and providers, as well as lead to cost reductions and improved knowledge at national level.

There are no national comprehensive statistics on the use of technical devices, including the use of new technologies for people with disabilities today. This would be helpful to be able to identify needs and restrictions in the accessibility of both existing technology and new technology. Support, installation and training all need to be addressed when describing the requirements for people with disabilities.

In Sweden today there is legislation and policies that are in place and under development with regard to accessibility of new technology. However, there is a

need to further develop access to the information about new technology to people with disabilities, including people with deafblindness.

To be able to use consumer products such as smart phones as aids, further work should be developed. However, this also comes with challenges for professionals, who need knowledge of the new technologies. Minor updates of a device can create great challenges for individuals with deafblindness, which is time consuming and takes a lot of energy.