



SUITCEYES

1 Jan 2018 - 31 Dec 2020

Smart, User-friendly, Interactive, Tactual, Cognition-Enhancer, that Yields Extended Sensosphere
Appropriating sensor technologies, machine learning, gamification and smart haptic interfaces

[D2.4]

Comparative Policy Report

Courtesy of LightHouse for the Blind and Visually Impaired, see <http://lighthouse-sf.org>.



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Authors	
Partner	Name(s)
UNIVLEEDS	Sarah Woodin

Contributors		
Partner	Contribution type	Name
UNIVLEEDS	Preparation of National Report: Netherlands	Jose Smits
UNIVLEEDS	Preparation of National Report: Greece	Eleni Strati
UNIVLEEDS	Preparation of National Report: Sweden	Moa Wahlqvist , Johanna Gustavsson
UNIVLEEDS	Preparation of National Report: Germany	Sabrina Weller, Friederike Rausch-Berhie, Tim Komorowski, David Samray
UNIVLEEDS	Preparation of National Report: UK	Sarah Woodin
HB	Review of this report	Jan Nolin
HB	Review of the deliverable template, guidance document and this report	Nasrine Olson
HB	Review of this report	Thomas Bebis
LDQR	Review of deliverable template, guidance document and this report	Mauricio Fuentes

Glossary	
Abbr./ Acronym	Meaning
AI	Artificial Intelligence
CCTV	Closed-circuit television
CRF	Charter of Fundamental Rights of the European Union
CRPD	Convention on the Rights of Persons with Disabilities
DPO	Disabled Persons' Organisation

EDF	European Disability Forum
EDbU	European Union of Deafblind
HIPI	Haptic Intelligent Personalised Interface
IoT	Internet of Things
OPD	Organisation of Persons with Disabilities
TBL	Taubblind (German for Deafblind). An official designation in Germany that permits access to certain services
UN	United Nations
WFDB	World Federation of Deafblind

History of changes		
Page no.	Previous Text	New Text
P3 Introduction	None: the text on the right is an addition.	This report assumes a certain level of knowledge and commitment to key aspects of human rights law, especially the CRPD, and the historical processes underpinning it. It also assumes that readers are familiar with aspects of commonality and difference concerning people with deafblindness and disabilities and where they are not, can gain access to it. Nevertheless, we aim to provide an overview for technical designers rather than human rights experts, in recognition of the essential role of designers in contributing to effective person centred technology. Effecting social change through law and policy is most incisive where all the relevant parties are involved in the process.
P5 A Note on Terminology	However, we recognise the differences in meanings across countries and the messages sent by using certain terms.	However, we recognise the differences in meanings across countries and the messages sent by using certain terms and in this report, we use the term ‘people with disabilities’.
Throughout	Disabled people	People with Disabilities
P5 A Note on Terminology	In writing this report we have aimed to use the most respectful terms in our culture; readers should substitute other terms (such as people with disabilities) if these are preferred by the people referred to.	In writing this report we have aimed to use the most respectful terms in our culture; readers should substitute other terms (such as disabled people) if these are preferred by the people referred to.
P6. Part 1 – People with Deafblindness	Recognition of disability is a complex area of law and policy and this report does not aim	Recognition of disability is a complex area and this report does not aim to offer a detailed picture. Broadly, we can distinguish between legal

History of changes		
Page no.	Previous Text	New Text
- Official Recognition of People with Deafblindness	to offer a detailed picture. Broadly, we can distinguish between legal definitions of disability (where a definition is written into law), administrative definitions (where definitions are often tied to eligibility for services and may change depending on how much money is in a budget) and self – identification, whereby people consider themselves to be disabled or not.	<p>definitions of disability (where a definition is written into law), administrative definitions (where definitions are often tied to eligibility for services and may change, for example depending on how much money is in a budget) and self – identification, whereby people concerned consider themselves to be disabled or not.</p> <p>Recognition that a person has a specific impairment is usually just the first step to gaining support or adjustments from official sources. Determining the <i>actual</i> assistance that a person will receive is often a second step that may or may not be linked to the specific impairment of the individual. These second assessments may consider functional capacity, i.e. the kinds of things that a person can and cannot do. A third step may sometimes involve a financial assessment that determines how much money an applicant has and what they should contribute to the agreed support.</p> <p>Governments rarely allocate resources solely on the basis of recognising that a person belongs to a particular disability category, without these additional assessments. This is often because it offers administrators very little flexibility. For example, if applicants' impairments remain the same over time, and assessment of people as belonging to a particular disability category is used as a passport to resources, problems may arise for administrators with controlling overall expenditure if budgets alter as a consequence of changing political priorities¹. Linking the capacity to carry out certain tasks to eligibility allows subtle adjustments to be made to procedures, while the basic system can remain in place. Further control over processes is often maintained through maintaining different assessment procedures for different types of support and fragmentation of systems between departments. It should be noted however, that directly allocating resources on the basis of impairment has been the main system in some EU countries (notably central and eastern European countries) but payment rates to recipients have typically been set at a very low level.</p>

¹ Arnould, C., Barral, C., Bouffioulx, E., Castelein, P., Chiriacescu, D., Cote, A. (undated), Disability Assessment Mechanisms: Challenges and Issues at Stake for the Development of Social Policies in light of the United Nations Convention for the Rights of Persons with Disabilities: https://www.firah.org/upload/notices2/novembre-2013/synthese_rapport_firah_-12p-engl.pdf

History of changes		
Page no.	Previous Text	New Text
		In consequence, although this is counter intuitive, establishing that a person belongs to a particular impairment category is not necessarily on its own a clear passport to state support.
P6 Official Recognition of People with Deafblindness	This section discusses the question of recognition and the actual definitions of deafblindness used.	This section discusses the question of recognition and the actual definitions of deafblindness used. It also notes some basic features of the subsequent assessment processes for applicants for support. Readers who are interested in further details about assessment processes should also look beyond this report to other publications that address this issue explicitly.
	In the Netherlands, impairment <i>per se</i> does not form the basis of eligibility for many benefits or provisions, although it is recognised for certain specific instances such as long-term care and access to interpreters. In the latter instance, applicants for particular forms of assistance must opt to be either counted as deaf or blind for the purposes of assessment. People with deafblindness are entitled to 168 hours per year of sign language interpretation services (for activities other than work or education), while people who are deaf only receive 30 hours sign language interpretation per year. ²	In the Netherlands, deafblindness <i>specifically</i> does not form the basis of eligibility for many benefits or provisions, although it is recognised for certain specific instances such as long-term care and access to interpreters. In the latter instance, applicants for particular forms of assistance must opt to be either counted as deaf or blind for the purposes of assessment. People with deafblindness are entitled to 168 hours per year of sign language interpretation services (for activities other than work or education), while people who are deaf only receive 30 hours sign language interpretation per year. ³ Structured assessments ⁴ are characteristic of procedures in the Netherlands, where, (for example, in relation to employment), the functional demands of jobs across the national economy are compared with the functional capacities of claimants. Similar, wider criteria for defining impairment apply to applicants for long-term support. ⁵
P7	Impairment is also not the basis for eligibility to services in Sweden.	Impairment is also not the sole basis for eligibility to services in Sweden.

² See explanation of regulation by the council of municipalities: https://vng.nl/files/vng/20141212_landelijke-regeling-tolkdiensten.pdf

³ See explanation of regulation by the council of municipalities: https://vng.nl/files/vng/20141212_landelijke-regeling-tolkdiensten.pdf

⁴ Baumberg Geiger, B., Garthwaite, K., Warren, J., and Bamba, C. (2017), 'Assessing work disability for social security benefits: international models for the direct assessment of work capacity', *Disability and Rehabilitation*, 40 (24): 2962-2970.

⁵ The Netherlands, Article 3.1.5, b Long Term Care Act, <http://wetten.overheid.nl/BWBR0035917/2018-01-01> and Beleidsregels indicatiestelling Wet langdurige zorg (Wlz) 2021 (Policy rules assessment Long Term Care Act 2021)

History of changes		
Page no.	Previous Text	New Text
P15 Table 2: National Support Organisations for People with Deafblindness	<p>DB – Connect (umbrella group for organisations connected with deafblindness). This organisation includes the following groups:</p> <ul style="list-style-type: none"> - Bartiméus (focus on blindness) - GGMD (Mental Health Care and Social Services) (focus on supporting deaf people) - Kentalis (focus on deaf people) - Visio (focus on blind people) - Kalorama (combines care for elderly people and end-of life care with care and support for people with deafblindness) 	<p>DB – Connect (umbrella group for organisations connected with deafblindness). This organisation includes the following groups, all of which provide services to people with deafblindness as well as a broader group of people with sensory impairments:</p> <ul style="list-style-type: none"> - Bartiméus (focus on blindness and deafblindness) - GGMD (Mental Health Care and Social Services) (supporting deaf and deafblind people) - Kentalis (deaf people and people with deafblindness) - Visio (blind people and people with deafblindness) - Kalorama (combines care for elderly people and end-of life care with care and support for people with deafblindness)

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Executive Summary

New technologies have generated considerable interest and controversy and they have particular relevance for people with disabilities and people with deafblindness. We report on three aspects relevant to the SUITCEYES project in this deliverable: a) the situation of people with deafblindness, b) human rights law in respect of access to personal technology and environmental accessibility, and c) the regulation of new technologies. The report is presented in three parts for easy reference.

We consider law and policy on access to devices, accessibility and regulation of new technologies that had come into effect, were planned or were being implemented by May 2020, when this report was compiled. Some updates have been added to cover the period from May 2022 to May 2021.⁶

There are several rationales for this report. First, when considering accessible technology for disabled people, it is not really feasible to avoid questions of policy. Many people with disabilities, including many with deafblindness, have little option but to gain access to technology through statutory services, charities or NGOs. This is because they are often disadvantaged in the labour market and so have lower incomes compared with the general population. Further, access to assessment services is often governed by various authorities who may also be gatekeepers to resources. This kind of law and policy is often local and carried out by municipalities or regional organisations, even if governed at national or international level.

Another rationale for this report is that new technologies are highly political. Few would argue against people with deafblindness having access to haptic technologies to provide environmental information but deployment of the technologies across society can be highly contested, depending on the use. As evidence of discrimination against people with disabilities through algorithms emerges, as well as evidence of surveillance and attempts to manipulate the population, there are campaigns to ban technology that recognises persons and aggregates data. These concerns are relevant to the population as a whole, including people with deafblindness. However, such developments have the potential to also impact on the availability of useful new technologies to people with deafblindness. For this reason, designers need to be aware of policy developments and policy makers must be informed about the potential beneficial (and harmful) uses of new assistive technology, in order that people with deafblindness do not lose the benefits of new technologies.

This executive summary aims to provide a broad overview of the main issues. References and further details are provided in the main report that follows.

Scope and Methods

We report on global, EU level and national measures across five countries participating in the SUITCEYES project: Germany (DE), Greece (EL), the Netherlands (NL), Sweden (SE) and the United Kingdom (UK). The aim is to provide an analysis of the context for the SUITCEYES project as well as to

⁶ A few updates have been added to recognise some major policy developments, but not all issues are covered. Although the deliverable was completed in May 2020 the review process for the SUITCEYES project as a whole was delayed by a year owing to the coronavirus pandemic.

inform a wider audience of stakeholders about the cross-cutting issues in developing new technologies with and for people with disabilities.

We recruited researchers in five countries to carry out a scoping exercise on relevant topics in their countries. The University of Leeds developed a template and guidance for the reporting on relevant law and policy, which was reviewed by colleagues from the SUITCEYES project and subsequently edited to incorporate suggestions. Researchers from four countries were recruited through open tender, while the author of this report carried out research on the UK situation and compiled this report.

People with Deafblindness

Recognition of deafblindness is not uniform across Europe. While some European countries conceive of deafblindness as distinct from blindness and deafness combined, in others, people who wish their impairment to be recognised must choose if they want to be considered blind or deaf. Official recognition may be important as a pre-requisite for social support such as interpreters and technology, and also the monitoring of progress in relation to certain indicators of well – being and equality, as long as comparable statistical data is available.

The European Parliament issued a declaration on the “rights of the deafblind” in 2004, which set out a limited set of rights. While an important marker, it was not binding on member states (by virtue of being a declaration rather than other type of legal instrument).

Definitions of deafblindness also vary across countries. The Nordic Model (see main report) is widely recognised as important for pointing out the serious consequences of combined sight impairment and Deafness; however, there is not a consensus. The most detailed definition and the one used in this report has been developed by the World Federation of the Deafblind (WFDB):

Deafblindness (is) a distinct disability arising from a dual sensory impairment of a severity that makes it hard for the impaired senses to compensate for each other. In interaction with barriers in the environment, it affects social life, communication, access to information, orientation and mobility. Enabling inclusion and participation requires accessibility measures and access to specific support services, such as guide interpreters, among others. (p.4)

Data on people with deafblindness is limited and inconsistent. The most systematic study in Europe, carried out in 2014⁷, gives a European prevalence rate of between 0.2% and 2.0%, with the lower figure given for people under 65 and the higher figure for those over 65. This age distinction is often made in research on deafblindness. It may be noted that the figures are calculated from a more limited prevalence study carried out in the UK in 2010⁸, because the study was not comprehensive across Europe. Despite these limitations, based on extrapolating from the smaller study to Europe, the European Deafblind Network estimates that there may be 3 million people with deafblindness in Europe.

⁷ European Deafblind Network (2014) *European Deafblind Indicators: mapping opportunities for deafblind people across Europe* http://deafblindindicators.eu/wp-content/uploads/2016/06/1_1Final-report-Mapping-opportunities_0315.pdf

⁸ Robertson, J & Emerson, E (2010) Estimating the number of people with co-occurring vision and hearing impairments in the UK, Centre for Disability Research, Lancaster University, Lancaster.

A distinction is also often made between levels of impairment with similar prevalence rates given: people with congenital deafblindness 0.2% and people with acquired deafblindness 2.0%.

SUITCEYES researchers looked into national data on deafblindness to try to gain more up to date and specific information. A summary of the data is as follows:

Table 1 Data on Prevalence of Deafblindness in Germany, Greece, the Netherlands, Sweden and the UK

Countries	Data from SUITCEYES national reports
Germany	Publications usually assume that the number of people is between 2,500 and 10,000. Other research has suggested over 400,000. (These numbers equate to 0.003%, 0.01% and 4.77% of the population in 2020).
Greece	No disaggregated data on impairment. In 2017 24.7% of the population declared an activity limitation due to health and 11.2% severe limitations. The parents' organisation of people with deafblindness estimates 50 households in Greece.
Netherlands	Estimated 2000 people with congenital deafblindness, 1000 to 1500 people with acquired deafblindness and 35,009 to 80,000 people with deafblindness in old age. (Approximately 0.35% of the national population in 2020).
Sweden	Swedish National Resource Center for Deafblindness estimates 2,000 people with deafblindness under 65 and 30,000-40,000 over 65 years (approximately 0.37% of population)
UK	Main charities for people with deafblindness, Sense and Deafblind UK, estimate an average of 390,500 people with deafblindness in the UK (approximately 0.57% of population in 2020). An incidence of 0.31% is given for the UK in 2014 by Sense, as part of a commissioned research report.

Note: For more details on this data please refer to the national country reports at:

<https://suitceyes.eu/policy-reports/>

We can see from this data that prevalence (roughly) is around 0.35%. There are several important considerations regarding the data however. Issues include:

- The diversity of people with deafblindness. There may be up to 80 causes of deafblindness and impairments may be recognised differently in different countries. A person with several impairments may be counted as being in another officially recognised group (rather than as having deafblindness).
- For accessibility reasons it may not be easy to reach people with deafblindness through commonly used means of communication.
- Assessments of impairment may be generated for specific purposes, such as for measuring the status of students, workers or eligibility for benefit payments. Therefore they may be limited to one sector of society or to a limited geographical area.
- Definitions of impairment may vary according to policies or budgets, so people may move in or out of categories.
- Many of areas such as welfare benefits or education are competencies of national governments who at present are largely are not under an obligation to report on deafblindness.

We also identified organisations of and for people with deafblindness. Groups of people with deafblindness do exist but they are mostly small, have few resources and aim at self-help rather than

social and political action. Organisations of people who are Deaf⁹ or blind are more organised, have more resources and tend to be more active on wider social issues.

Not surprisingly, laws and policies on people with deafblindness are limited, although there have been some measures in Germany and the UK. Legislation and policies on people with disabilities in general do however apply to people with deafblindness, and these are much more influential compared with impairment – specific measures.

Overview of Law and Policy on New Technologies

All of the countries taking part in this review are parties to the UN Convention on the Rights of Persons with Disabilities (CRPD) (2006), which places wide-ranging obligations on those that have signed and ratified it. The CRPD is specific to people with disabilities and builds on earlier human rights instruments, such as the Charter of Fundamental Rights of the European Union (CFR) (2000). Likewise, the Sustainable Development Goals, set in 2015, provide a framework for measuring progress towards ending poverty, along a number of dimensions. The CRPD, the EU Charter and the SDGs present requirements of governments with regard to technology (see further details in the main report).

Two broad aspects of law and policy are evident related to people with disabilities and new technologies. These are an important basis for people with disabilities' entitlements and are complementary rather than mutually exclusive. First, some measures are concerned with individuals' rights to support and equipment. These national and local measures give people with disabilities specific rights to support, funding and technology for a variable range of circumstances. In the majority of instances law and policy on access to devices is a competence of national governments rather than the EU and efforts to increase interchangeability between countries have been limited so far.

Second, other laws aim to make the environment accessible to all. Universal design is part of this accessibility approach, reflecting an anticipatory duty on organisations to accommodate people with disabilities. Rather than waiting to see if an individual customer requires adjustments in order to take part in an event or setting, organisations are required to arrange accessible environments in advance, open to all, in order that all may take part if they so wish. Recent EU directives on digital accessibility have been particularly important in this area for people with disabilities in recent years.

Although legislation is wide ranging, implementation problems in all countries taking part in this research can mean that legislation is not always as effective as it might be. Systems for administering grants and allowances are frequently complex and new technologies are not always readily added to the available devices that people with disabilities are entitled to claim. In other words, from the point of view of engineers and designers, the process for getting technology to people with disabilities may not be completely straightforward unless the cost is so minimal that those on low incomes can reasonably afford to pay for items themselves. Relatedly, regulation of accessibility is subject to the different requirements of national, regional and municipal governance: examples are discussed in the section *Access to Equipment* in the main report. While this can work effectively, it can also lead to lack of coordination and poor implementation.

⁹ See the later in this report 'A Note on Terminology'

Regulation of New Technologies

While early priorities for AI, IoT and machine learning centred on the potential for expansion and the boosting of growth and jobs, more recent attention has been paid to the potential of new technology to do harm. Following criticism of bias in algorithmic training and concern about breaches of data privacy, as well as other examples of exploitation, the EU has stated that AI must be regulated if it to gain acceptance and the trust of the general public. To this end, a series of policy documents have been released for consultation, prior to the expected development of legislation.

Organisations of people with disabilities have also so far been largely supportive of new technologies. The European Disability Forum of (EDF) states that new technology has enabled people with disabilities to overcome a range of barriers to taking part in society. Noting that people with disabilities are often early adopters of technology, they emphasise AI's potential for a wide range of important activities. These include communication, reality technologies for exploring the environment, learning and rehabilitation, robotics and smart environments for assistance. Nevertheless, they also have concerns. As well as access to and usability of the technology, the evidence of bias and discrimination in algorithms as well as lack of privacy are major problems potentially limiting adoption.

People with disabilities have not been included in the consultations, especially at national level (with a few exceptions). It is clearly important that such a dialogue is developed in the near future as there are many aspects that may have a profound effect on people with disabilities' quality of life. Issues include the use of personal cameras and sensors, which have generated controversy because their use in the public space is often associated with surveillance rather than communication. Ownership of data is also important – people with disabilities should not have to trade off privacy in order to gain the assistance of technology. If use of face recognition technology is banned, it is important that exemptions are sought to enable people with deafblindness to gain access to information about the environment (with the consent of those concerned). Distinctions therefore need to be made concerning the various uses of technology. People with disabilities stand to gain most and lose most depending on how opportunities are used.

Looking to the future, training is needed, of scientists in disability equality and awareness, and also of people with disabilities and care professionals in the potential and use of technology. There should also be further work to develop effective opportunities for smart cities to embed the use of technology for accessibility into infrastructure developments, while implementing safeguards against cybercrime and insecurities. These are clearly not the only opportunities but they are important examples of where dialogue could be developed further.

We conclude the report with a number of recommendations that are aimed at developing dialogue and co-operation between all stakeholders.

Main Report

Introduction

In this deliverable we discuss legal and policy developments connected to the use of new technologies relevant to people with disabilities. We report on global, EU level and national measures across five countries participating in the SUITCEYES project: Germany (DE), Greece (EL), the Netherlands (NL), Sweden (SE) and United Kingdom (UK). The aim is to provide an analysis of the context for the SUITCEYES project as well as to inform a wider audience of stakeholders about the cross-cutting issues in developing new technologies with and for people with disabilities. In so doing, we recognise that in a fast – changing field it makes sense for the view to be broad rather than overly focussed on the production of one device.

This deliverable is the fourth and last in the work carried out in Work Package 2 (WP2). We draw connections to the previous deliverables¹⁰ by relating findings to some data from the user interviews and other reports. However, this deliverable also introduces a new approach, a macro level view of structures and processes.

As this work is part of WP2, law and policy on new technologies are considered mainly from the perspective of people with disabilities. This is a very dynamic, energetic and fast moving field, covering several academic disciplines. Rather than seeking to be comprehensive, we instead describe the main issues and explain progress to date. Inevitably this is a broad brush overview and a scoping exercise rather than a detailed explanation of all legal and policy instruments. Many sources are available and wherever possible the reader is directed to these whenever possible.

This report has three main sections, linked to aspects of the SUITCEYES project as a whole. Following a discussion of the rationale for this report and methods, the first part is concerned with evolving policy recognition of people with deafblindness because they are the specific focus of SUITCEYES. The second part discusses existing law and policy as it relates to disabled people in general and the third part recent law and policy on aspects of new technology and artificial intelligence, machine learning and IoT in particular. Again, where available, we include research evidence and links to further information.

Rationale and Scope of this Report

New technologies have the potential to greatly enhance the lives of people with deafblindness though enabling access to better information about the environment. Missing out on incidental information restricts knowledge, with serious detrimental effects that are critical issues for people with

¹⁰ D2.1, D2.2 and D2.3

deafblindness¹¹. With the use of sensors, signal and image processing, as well as object and face recognition the deafblind person's perception of the environment can be extended and enhanced.

There are several rationales for this report on law and policy. First, when considering accessible technology for people with disabilities, it is not really feasible to avoid questions of policy. Many people with disabilities, including many with deafblindness, have little option but to gain access to technology through statutory services, charities or NGOs. This is because they are often disadvantaged in the labour market and so have lower incomes compared with the general population. Further, access to assessment services is often governed by various authorities who may also be gatekeepers to resources. This kind of law and policy is often local and carried out by municipalities or regional organisations, even if governed at national level. If designers aim to be relevant to the needs of users, they need to be aware of the means by which users will get hold of their products. For example, if an assessor will reject out of hand an assistive device on the basis that it is too expensive, it is useful to know this, either so an affordable design can be made, or so the restrictive purchasing policy can be changed.

Another rationale for this report is that new technologies are highly political. Few would argue against people with deafblindness having access to haptic technologies to provide environmental information but deployment of the technologies across society can be highly contested, depending on how they are used. As evidence of discrimination against people with disabilities through algorithms emerges, there are campaigns to ban technology that recognises persons and aggregates data. Such developments have the potential to impact on the availability of new technologies to people with deafblindness. For this reason, designers need to be aware of policy developments and policy makers must be informed about the potential beneficial uses of new assistive technology, in order that people with deafblindness do not lose access to these.

Engineers and designers typically do not receive education about the needs or circumstances of people with disabilities or about inclusive design in their professional training.¹² There are recent moves to improve this¹³ but designers often have limited knowledge about the processes that may affect the availability of the technology they produce to users.

Ethics have become a major issue in relation to new technologies. Risks associated with artificial intelligence (AI), machine learning and the Internet of Things (IoT) are widely recognised and there is increasing agreement that measures that need to be taken in order to safeguard the population. People with deafblindness are at even greater risk than the general population and it is imperative that designers develop a greater consciousness of the issues involved.

¹¹ Jaiswal, A., Aldersey, H., Wittich, W., Mirza, M., and Finlayson, M. (2018) Participation experiences of people with deafblindness or dual sensory loss: A scoping review of global deafblind literature in *Plos One* September 13, DOI: <https://doi.org/10.1371/journal.pone.0203772>

¹² European Commission *Commission Staff Working Document SWD (2020) 291 final. (27.11.2020) Evaluation of the European Disability Strategy 2010 – 2020* [Accessed 18.2.21] Available from:

<https://ec.europa.eu/social/main.jsp?langId=en&catId=89&furtherNews=yes&newsId=9835>

¹³ For example, European Accessibility Standard EN 17210 linked to Standardisation Mandate 420 on accessibility to the built environment. See:

https://standards.cen.eu/dyn/www/f?p=204:110:0:::FSP_PROJECT,FSP_LANG_ID:65077,25&cs=1B1F504D7DC F7711690E22BAE7CED456A and

<https://www.cencenelec.eu/standards/Topics/Accessibility/Pages/Builtenvironment.aspx>

Human rights law also provides a legal context for the SUITCEYES project. It is no longer acceptable to design technologies that might just ‘keep an eye on’ or ‘keep safe’ people with disabilities. The right to live independently in the community and experience a full life with required assistance underpins national governments’ agreements to international treaties, and is the outcome of decades of campaigning by people with disabilities. It is vital that this historical context is recognised, in order to safeguard against harm. Technology for people with disabilities should therefore be compatible with this purpose.

This report assumes a certain level of knowledge and commitment to key aspects of human rights law, especially the CRPD, and the historical processes underpinning it. It also assumes that readers are familiar with aspects of commonality and difference concerning people with deafblindness and disabilities and where they are not, can gain access to it. Nevertheless, we aim to provide an overview for technical designers rather than human rights experts, in recognition of the essential role of designers in contributing to effective person centred technology. Effecting social change through law and policy is most incisive where all the relevant parties are involved in the process.

Methods

We invited researchers from five countries to carry out a scoping exercise on relevant topics in their countries: Germany, Greece, the Netherlands, Sweden and the United Kingdom. The University of Leeds developed a template and guidance for the reporting on relevant law and policy, which was reviewed by colleagues from the SUITCEYES project and subsequently edited to incorporate suggestions. Categories for reporting on were selected for their pertinence for SUITCEYES work and known areas of risk (such as hate crime) were included, as well as critical issues likely to affect the availability of devices to people with deafblindness (such as processes for securing technology through public services).

Researchers for Germany, Greece, the Netherlands and Sweden were recruited through advertisement, while the author of this report carried out research on the UK situation.

The invitation to tender was circulated through academic discussion groups, including the Disability – Research and European Social Policy Jiscmail groups, which between them have over 3,000 members. Experts in the field, both academics and project managers, were also contacted, with a view to enlisting qualified applications and several assisted by circulating details through newsletters and among colleagues. All successful candidates were recruited by December 2019.

We did not anticipate that applicants would have knowledge of all of the specialist areas covered in this report but sought to recruit people with in-depth knowledge of at least one aspect. In the event, we were able to recruit four experienced researchers with substantial experience in complementary relevant fields. In three countries research was carried out by a team of people (DE, EL and SE) and in two instances reporting was carried out primarily by individual researchers (NL and UK). Researchers were provided with the template for reporting and individual briefing sessions were held with the people soon after appointment. Two additional online group meetings were held with all researchers in January and February 2020, to exchange information about emerging findings, answer questions and share insights.

Most of the research was desk based, involving review of academic literature, grey literature and legal and policy documents. Draft reports were prepared for the end of March 2020 and reviewed by mid-April. Additional information was requested and provided as necessary during the drafting of this synthesis report.

There were some challenges involved with mapping relevant literature. Very little information was available at the start of the review and we therefore chose a wide scope for the reports. However, the amount of literature and initiatives expanded exponentially after this, especially during the early part of 2020, such that any review was likely to become out of date within a few months. To the greatest degree possible, we have included the most recent information that we were able to find, up to the report submission date. Despite the increasing volume, we found information gaps in some areas (notably references to people with disabilities were lacking in more general technology initiatives). To augment the available data, researchers in each country carried out interviews with experts and used their insights to fill in missing information. Three interviews were carried out in Germany and two each in Greece, the Netherlands and the UK.

Results from the national reports were used to compile the information in this synthesis report and context was provided by the inclusion of EU level law, policy and evidence. It is important to note that international comparative data is very limited. Although Article 31 of the CRPD¹⁴ requires disaggregated data on disability, it is rarely available to the extent needed. The complaint about lack of international comparative data is widespread and well known¹⁵ and it is the reason why the European Commission's Disability Unit has resorted to looking to national data, for example. National data that is available is not usually comparable though, for methodological reasons. Data on new technologies is also limited because of the speed of change and the novelty of the field. Due to these issues, in this report we have avoided drawing comparisons that may not be sufficiently grounded in evidence, while also making tentative comparisons wherever possible.

A Note on Terminology

Different cultural meanings are associated with terminology and we recommend that the terms used should always be those chosen by disabled people themselves and their organisations and not by non-disabled people. Given a history where scientific terms describing disabled people have over time become used as terms of abuse by the general population, it is important that disabled people have choice over how they are described and represented.

In many European countries the term 'people with disabilities' is preferred as the more respectful option that emphasises the person rather than the disability or impairment. In the UK the term preferred by the people concerned is 'disabled people'.

¹⁴ Article 31 of CRPD <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-31-statistics-and-data-collection.html>

¹⁵ See for example: International Disability Alliance (2017) *Joint Statement by the Disability Sector: Disability Data Disaggregation* <https://www.internationaldisabilityalliance.org/data-joint-statement-march2017>

In the UK, disabled people make a clear distinction between the concepts of impairment and disability. For example, Greater Manchester Coalition of Disabled People¹⁶ refers to impairment as:

when part of a person's body, mind and/or emotions works differently to what is considered 'normal' by society.

Disability is described as:

the barriers, discrimination and prejudice disabled people face. It is not our bodies or minds which 'disable' us, it is society.

In this context, which underpins the social model of disability, it does not make sense to talk of people with disabilities. However, we recognise the differences in meanings across countries and the messages sent by using certain terms and in this report, we use the term 'people with disabilities'.

The terms 'Deaf' and 'deaf' have important and different cultural meanings. The term Deaf is used by people who are pre-lingually deaf, who mainly use sign language and for whom oral or written communication are second languages. The term deaf refers to people who have acquired severe hearing impairment¹⁷.

In writing this report we have aimed to use the most respectful terms in our culture; readers should substitute other terms (such as disabled people) if these are preferred by the people referred to.

PART 1

People with Deafblindness

Official Recognition of People with Deafblindness

Official recognition of an impairment or disability category is important because it indicates a regard for the practical effects of the impairment for individuals and groups¹⁸. This may be a precondition for the allocation of resources (whether in cash or kind) and environmental adjustments that are often vital to the people concerned. Further, recognition can be a point of reference for monitoring of disadvantage or discrimination, for which redress may be sought.

Recognition of disability is a complex area and this report does not aim to offer a detailed picture¹⁹. Broadly, we can distinguish between legal definitions of disability (where a definition is written into law), administrative definitions (where definitions are often tied to eligibility for services and may

¹⁶ GMCDP *Social Model of Disability* <https://gmcdp.com/beliefs-values-aims/social-model>

¹⁷ For an explanation, see *Signhealth* <https://signhealth.org.uk/resources/learn-about-deafness/deaf-or-deaf/>
Both terms are often used: see *EDF* <https://www.edf-feph.org/our-members/european-union-of-the-deaf/>

¹⁸ Thomas, C. (1999). *Female Forms: Experiencing and Understanding Disability*. Buckingham: Open University Press

¹⁹ Further information on this is available, for example, through reports on the website of the Academic Network of Disability Experts (ANED) <https://www.disability-europe.net/>

change, for example depending on how much money is in a budget) and self – identification, whereby people concerned consider themselves to be disabled or not.

Recognition that a person has a specific impairment is usually just the first step to gaining support or adjustments from official sources. Determining the *actual* assistance that a person will receive is often a second step that may or may not be linked to the specific impairment of the individual. These second assessments may consider functional capacity, i.e. the kinds of things that a person can and cannot do. A third step may sometimes involve a financial assessment that determines how much money an applicant has and what they should contribute to the agreed support.

Governments rarely allocate resources solely on the basis of recognising that a person belongs to a particular disability category, without these additional assessments. This is often because it offers administrators very little flexibility. For example, if applicants' impairments remain the same over time, and assessment of people as belonging to a particular disability category is used as a passport to resources, problems may arise for administrators with controlling overall expenditure if budgets alter as a consequence of changing political priorities²⁰. Linking the capacity to carry out certain tasks to eligibility allows subtle adjustments to be made to procedures, while the basic system can remain in place. Further control over processes is often maintained through maintaining different assessment procedures for different types of support and fragmentation of systems between departments. It should be noted however, that directly allocating resources on the basis of impairment has been the main system in some EU countries (notably central and eastern European countries) but payment rates to recipients have typically been set at a very low level.

In consequence, although this is counter intuitive, establishing that a person belongs to a particular impairment category is not necessarily on its own a clear passport to state support.

This section discusses the question of recognition and the actual definitions of deafblindness used. It also notes some basic features of the subsequent assessment processes for applicants for support. Readers who are interested in further details about assessment processes should also look beyond this report to other publications that address this issue explicitly.²¹

It is important to also bear in mind the different levels of competence between the European Union and member states, as responsibilities vary at different levels and in different policy areas.²² Legal and administrative recognition of persons with deafblindness is also not uniform within and across European countries.²³ A further issue is that definitions are not always considered appropriate from

²⁰ Arnould, C., Barral, C., Bouffioulx, E., Castelein, P., Chiriacescu, D., Cote, A. (undated), Disability Assessment Mechanisms: Challenges and Issues at Stake for the Development of Social Policies in light of the United Nations Convention for the Rights of Persons with Disabilities:

https://www.firah.org/upload/notices2/novembre-2013/synthese_rapport_firah_-12p-engl.pdf

²¹ See for example, Waddington, L., Priestley, M. and Sainsbury, R. (2018) Disability Assessment in European States: ANED Synthesis Report (December 1, 2018). Available at

SSRN: <https://ssrn.com/abstract=3320419> or <http://dx.doi.org/10.2139/ssrn.3320419>

²² Division of competences within the European Union <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=LEGISSUM%3Aai0020>

²³ Dammeyer, J (2014). Deafblindness: A review of the literature. *Scandinavian Journal of Public Health*, 42(7) 554-562

the point of view of people with the impairment and the World Federation of the Deafblind has commented on problems in this respect²⁴.

The European Parliament issued a declaration on the “rights of the deafblind” in 2004, which set out a limited set of rights.²⁵ While an important marker, it was not binding on member states (by virtue of being a declaration rather than other type of legal instrument²⁶) and national differences remained.

Differences are also apparent from the national reports prepared for the SUITCEYES project. In Greece, the Netherlands and Sweden, deafblindness is not officially recognised. In Greece, people with disabilities’ conditions and impairments are grouped under 19 chapters for assessment. Visual impairments (chapter 17) are assessed separately from hearing impairments (chapter 14), without acknowledging deafblindness as a distinct category. Eligibility assessment for accessing multiple disability benefits and services in the country is carried out at national level, by the Centre for Certification of Disability (KEPA²⁷) as part of the Social Security Agency (EFKA²⁸) and the Ministry of Labour. Assessment is based on the Barema scale (percentage)²⁹.

In the Netherlands, deafblindness *per se* does not form the basis of eligibility for many benefits or provisions, although it is recognised for certain specific instances such as long-term care and access to interpreters. In the latter instance, applicants for particular forms of assistance must opt to be either counted as deaf or blind for the purposes of assessment. People with deafblindness are entitled to 168 hours per year of sign language interpretation services (for activities other than work or education), while people who are deaf only receive 30 hours sign language interpretation per year.³⁰ For people with disabilities as a whole, structured assessments³¹ are characteristic of procedures in the Netherlands, where, (for example, in relation to employment), the functional demands of jobs across the national economy are compared with the functional capacities of claimants. Similar, wider criteria for determining eligibility, based on structured functional assessments apply to applicants for long-term support.³²

²⁴ WFDB (2018) *At risk of exclusion from CRPD and SDGs implementation: Inequality and Persons with Deafblindness*, World Federation of the Deafblind:

http://www.internationaldisabilityalliance.org/sites/default/files/wfdb_complete_initial_global_report_september_2018.pdf

²⁵ Declaration of the European Parliament on the rights of deafblind people

<https://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//EP//TEXT+TA+P5-TA-2004-0277+0+DOC+XML+V0//EN>

²⁶ For details of types EU legal instruments see

https://eurlex.europa.eu/summary/glossary/community_legal_instruments.html

²⁷ ΚΕΡΑ Άτομα με Αναπηρία: Νομοθετικό Πλαίσιο - ΟΠΕΚΑ (opeka.gr)

²⁸ EFKA <https://www.efka.gov.gr/el>

²⁹ For further details: ANED (2018) Disability Assessment Method Country Report (p. 6) <https://www.disability-europe.net/downloads/907-country-report-on-disability-assessment-greece>

³⁰ See explanation of regulation by the council of municipalities: https://vng.nl/files/vng/20141212_landelijke-regeling-tolkdiensten.pdf

³¹ Baumberg Geiger, B., Garthwaite, K., Warren, J., and Bamba, C. (2017), ‘Assessing work disability for social security benefits: international models for the direct assessment of work capacity’, *Disability and Rehabilitation*, 40 (24): 2962-2970.

³² The Netherlands, Article 3.1.5, b Long Term Care Act, <http://wetten.overheid.nl/BWBR0035917/2018-01-01> and Beleidsregels indicatiestelling Wet langdurige zorg (Wlz) 2021 (Policy rules assessment Long Term Care Act 2021)

Impairment is also not the sole basis for eligibility to services in Sweden. Assistance is allocated differently according to the form of support. For personal support, for example, services may be received on the basis of a serious and permanent functional impairment, which is not the result of usual ageing. Allocation is made to people who have considerable difficulties in everyday life and who need substantial assistance. However, the Nordic definition of deafblindness has been influential (see below)³³.

Deafblindness has been legally recognised officially in Germany and to some extent in the UK. In Germany, people with deafblindness were usually categorised as either blind or deaf until 2016. In 2012, members of all parliamentary parties in the German Bundestag expressed their support for the introduction of a separate category³⁴ and deafblindness was finally legally recognised as a distinct type of impairment with entry into force of relevant parts of the Federal Participation Act (Bundesteilhabegesetz, BTHG) passed on 30 December 2016.³⁵ The German definition is narrow, and the degree of disability (DoD)³⁶ relating to loss of vision must be 100, whilst the degree of hearing impairment needs to be at least 70.

In the UK, deafblindness is recognised to a greater extent in relation to eligibility for services rather than for general accessibility. The UK government developed a definition of deafblindness in 1995,³⁷ and has published specific guidance for local authorities.³⁸ The Scottish government takes a broader view however and publishes guidance in relation to rights to participate in society as well as access to services and equipment.

Beyond variations in the extent to which deafblindness is recognised, there are a number of definitions of deafblindness. These reflect different understandings of the implications of deafblindness at the time they were written. The Nordic network has been influential because it recognised the distinct rather than additive nature of the impairment. In 1980 it stated that:

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 disability³⁹

³³ Nordic Definition of Deafblindness <https://nkcdb.se/dovblindhet/fakta-om-dovblindhet/nordisk-definition/>

³⁴ Bundesarbeitsgemeinschaft der Taubblinden (BAT) (2012) <http://bundesarbeitsgemeinschaft-taubblinden.de/?p=1130> See links on the page to statements by political parties. http://bundesarbeitsgemeinschaft-taubblinden.de/Dokumenten/Berichte/TBL_Merkzeichen/1711676_SPD.pdf

³⁵ Federal Participation Act (BTHG) Article 18, Section 3; Ordinance on Passes for Disabled Persons (SchwbAwV), § 3

³⁶ The purpose of the degree of disability (DoD) is to provide an indicator for the extent of the impairment a person experiences as the result of a disability. This figure is entered into his or her disability pass. The lowest DoD is 20, and the highest figure is 100. In Germany, those with a DoD of 50 or more are considered to be severely disabled (German Social Security Code (SGB) IX, § 151 and 152).

³⁷ Department of Health (1995) *Think Dual Sensory*, London: Department of Health

³⁸ Department of Health (2014) *Care and Support for Deafblind Children and Adults Policy Guidance*, https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/388198/Care_and_Support_for_Deafblind_Children_and_Adults_Policy_Guidance_12_12_14_FINAL.pdf

³⁹ Nordic Welfare Centre (2018) *Nordic Definition of Deafblindness* <https://nordicwelfare.org/wp-content/uploads/2018/03/nordic-definition-of-deafblindness.pdf>

Further implications were drawn out from this definition in 2016, using the World Health Organization's International Classification of Functioning, Disability and Health (ICF) as a framework.⁴⁰ Notably, the revised definition draws attention to issues such as difficulties gaining access to information at a distance and the problems of drawing conclusions from fragmented information. Responsibility for accessibility lies with society, requiring available competent communication partners, specialised interpretation, environmental description and guiding, environmental adaptation and human and technological support.

The World Federation of the Deafblind offered a similar but briefer definition in 2018, as follows:

Deafblindness (is) a distinct disability arising from a dual sensory impairment of a severity that makes it hard for the impaired senses to compensate for each other. In interaction with barriers in the environment, it affects social life, communication, access to information, orientation and mobility. Enabling inclusion and participation requires accessibility measures and access to specific support services, such as guide interpreters, among others.⁴¹

It is important that definitions are accepted by the people to whom they refer and for this reason we use the WFDB definition in this report. The two aspects of action needed identified by the WFDB, of access to individual supports and accessibility measures, are also used as the basis for our reporting in Part 2 below.

National Demographic Data on People with Deafblindness

All national reports from the SUITCEYES study drew attention to limitations in available data⁴². The lack of recognition of people with deafblindness, differences in characterising impairment according to age, differences in definitions (for example, assessment of impairment levels or of functional abilities), the difficulties of identifying people with deafblindness and lack of comprehensiveness and comparability of data mean that it is difficult to draw definitive comparisons at an international level. Bearing these issues in mind, we consider the available findings in this section.

The World Federation of the Deafblind (WFDB) (2018)⁴³ has carried out analysis of survey data on people with deafblindness and reports a general prevalence rate of between 0.2% and 2.0% for the global population. This study is one of the few to use the Washington Group questions.⁴⁴ The two figures are used because surveys use different levels of severity of deafblindness: 0.2% is the rate usually given for people with "severe" levels of deafblindness, used by many countries. Others take a wider view and the WFDB maintains that 2.0% is a more accurate figure because it "includes a vast number of people with milder forms of deafblindness who experience barriers to participation and discrimination." (p16).

⁴⁰ Nordic Leaders' Forum (2016) *Developing a New Nordic Definition of Deafblindness*
[file:///C:/Users/lifslw1/Downloads/Developing-a-New-Nordic-Definition-sample-article%20\(1\).pdf](file:///C:/Users/lifslw1/Downloads/Developing-a-New-Nordic-Definition-sample-article%20(1).pdf)

⁴¹ WFDB (2018) *The Diversity of Persons with Deafblindness* **Error! Hyperlink reference not valid.** <https://www.wfdb.eu/introduction/> accessed on 30th of March 2020

⁴² National reports are available at: <https://suitceyes.eu/policy-reports/>

⁴³ WFDB (2018) *At risk of exclusion from CRPD and SDGs implementation: Inequality and Persons with Deafblindness*, World Federation of the Deafblind:
http://www.internationaldisabilityalliance.org/sites/default/files/wfdb_complete_initial_global_report_september_2018.pdf p16

⁴⁴ Washington group on disability statistics <https://www.washingtongroup-disability.com/>

Rates of deafblindness vary markedly according to age; for example, the WFDB notes that for most countries, a usual prevalence rate of 0.1% of the population under age 40, compares with 6% for the population aged over 75. A 2014 study by the European Deafblind Network (EDbU) similarly reported a rate of 5.9% people over 50 who experienced both vision and hearing impairments.⁴⁵

Regarding Europe specifically, the Declaration of the European Parliament on the rights of deafblind people P5 TA (2004) 0277, which represented a landmark in terms of recognition, noted that there were 150,000 people with deafblindness in Europe.⁴⁶ The report by the European Deafblind Network in 2014, based on a survey of 27 countries, 11 of which were European, estimates that there were a total of 2.7 million Europeans with deafblindness. The disparity with data from the Declaration of the European Parliament is again the outcome of narrower and wider definitions, the lack of widespread official recognition of deafblindness and differences in reporting methods. It is for this reason that there have been continuing calls for consistency in how data on deafblindness is generated, for example through the use of Washington Group questions⁴⁷.

Using the 2014 EDbU data, a rough overall calculation can also be made based on population: 446 million EU inhabitants and 2.7 million people with deafblindness gives a rate across all age groups of 0.6%.

SUITCEYES researchers investigated current national demographic data on people with deafblindness. The following table summarises data provided from each country, as available. Again it is not comparable internationally due to methodological differences. There are further details on the data in the SUITCEYES national reports.⁴⁸

Table 1. National Level Demographic Data on People with Deafblindness

Country	Summary of Demographic Data	Percent of Population	National Population in 2020 (rounded)
Germany	Publications usually assume that the number is between 2,500 and 10,000. ⁴⁹	0.003% - 0.01%	82,887,000

⁴⁵ Viljanen, A., Törmäkangas, T., Vestergaard, S. and Andersen-Ranberg, K. (2014) Dual sensory loss and social participation in older Europeans. *European Journal of Ageing*, 11(2): 155-167

⁴⁶ Declaration of the European Parliament on the rights of deafblind people P5 TA (2004) 0277 <https://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//EP//TEXT+TA+P5-TA-2004-0277+0+DOC+XML+V0//EN>

⁴⁷ Washington group on disability statistics <https://www.washingtongroup-disability.com/>

⁴⁸ SUITCEYES Policy reports: *Scoping Papers on Deafblindness, Disability and New Technologies* <https://suitceyes.eu/policy-reports/>

⁴⁹ de Oliveira (2015) *Was ist Blindheit. Eine Reise in die Welt der Nicht-Sehenden*. Norderstedt, BoD , p.15; Stiftung Taubblind Leben (2015) https://stiftung-taubblind-leben.de/public/dateien/jahresbericht_2015_stiftung_taubblind_leben.pdf p. 4; Bieling, Joost (2018) Talk to the Hand! Digitale Inklusion von Taubblinden. *IT für soziale Inklusion*. A. U. Burchardt, Hans. Berlin/Boston, Walter de Gruyter: 77-88; Bieling, T. and Joost, G. (2018) p.78

Greece	Estimated to be around 53,676 people with deafblindness in 2014 ⁵⁰ . Further data was not found.	0.08%	66,435,550
Netherlands	Estimated 2000 people with congenital deafblindness, 1000-1500 people with acquired deafblindness under 65 and 35,000 ⁵¹ to 80,000 ⁵² people with deafblindness who are over 65 (and mostly over 80).	Congenital 0.011% Acquired under 65 0.006% - 0.009% Acquired over 65 0.2% - 0.46 %	17,417,600
Sweden	Estimated to be 2,000 people with deafblindness under 65. ⁵³ 6-8 children born with deafblindness each year, and approximately 20 who acquire deafblindness later in life. Estimates from 2011 are of 30,000-40,000 individuals over the age of 65 with age related dual sensory impairment. A 2020 study found 1581 people over 65 with severe dual sensory loss. ⁵⁴	Under 65: 0.02% Over 65 age related: 0.3% - 0.39% Over 65 with severe dual sensory impairment 0.02%	10,319,601
United Kingdom	Sense states that there were an estimated 433,561 ⁵⁵ people with deafblindness in the UK in 2020. The estimated calculation is extrapolated from 2010 research, again based on estimates ⁵⁶ and related to the total population.	Age 0-19: 0.03% Age 20-69: 0.17% Age: 70+: 0.42% Total number of people with deafblindness: 0.64%	67,886,011

Please note: Population estimates are national estimates and may not equate to the year research was carried out. The figures are provided for rough comparison only.

In summary, considerable variations in definition, as noted in the previous section, lead to different estimates of people with deafblindness. A narrow definition in Germany leads to small numbers, while higher numbers in the Netherlands, Sweden and UK reflect wider definitions. In Greece, lack of recognition of deafblindness leads to a lack of estimated figures.

⁵⁰ European Deafblind Network (2014) *European Deafblind Indicators: Mapping Opportunities for Deafblind People Across Europe* http://deafblindindicators.eu/wp-content/uploads/2016/06/1_Final-report-Mapping-opportunities_0315.pdf p.17

⁵¹ 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

⁵² DB Connect: <https://dbconnect.info/over-dooftblindheid/>

⁵³ Swedish National Resource Center for Deafblindness www.nkcdb.se

⁵⁴ See Lundin, E., Elin, Stephen E. Widén, S.E., Wahlqvist, M., Anderzén-Carlsson, A. and Granberg, S. (2020) Prevalence, diagnoses and rehabilitation services related to severe dual sensory loss (DSL) in older persons: a cross-sectional study based on medical records, *International Journal of Audiology*, 59:12, 921-929, DOI: 10.1080/14992027.2020.1783003

<https://www.oru.se/english/research/research-teams/rt/?rdb=g252>

⁵⁵ Sense, UK <https://www.sense.org.uk/get-support/information-and-advice/conditions/deafblindness/>

Personal Communication 20.5.21. Estimated figures provided on the basis of Office for National Statistics data

⁵⁶ Robertson, J. and Emerson, E. (2010) *Estimating the number of people with co-occurring vision and hearing impairments in the UK*. Centre for Disability Research, Lancaster University: Lancaster

Law and Policies Specific to People with Deafblindness

International Treaties, such as the United Nations Convention on the Rights of Persons with Disabilities (CRPD) are key points of reference but they will be discussed in the following section because they apply to disabled people generally.

The European Parliament recognised the rights of deafblind people in 2004⁵⁷. A limited set of rights were set out, including the right to a democratic life, to work and access to training, to adaptations, to person-centred health and social care, to lifelong learning and the right to receive one-to-one support where appropriate from communicator-guides, deafblind interpreters and/or intervenors. However, as has been noted above, this was a declaration that was not binding on member states and therefore did not require action to be taken.

Over the past decade, the European Union has been guided by the EU Disability Strategy 2010 – 2020⁵⁸ and following its conclusion a motion for new strategy was approved by the European Parliament on the 2 March 2020.⁵⁹ Recommendations made by people with disabilities' organisations (OPDs) in the preparatory phases (although no longer part of the document) included references to the situation of people with deafblindness: specific mention of the need for 'additional care provided by professionals with specialist and qualified knowledge' as well as deafblind interpreters. There was a call for Member States to recognise the red-white cane as the symbol of the deafblind pedestrian in order to make deafblind people with deafblindness more visible in traffic and a call for Member States to incorporate the recognition of specific impairments into national legislation, "in order to address and cover their specific needs (e.g. deafblindness)".

For the SUITCEYES research, we found very little national law and policy specific to people with deafblindness. It was more often the case that people with deafblindness were included in general law and policy on people with disabilities (discussed in Section 2). However, a few specific initiatives are described next.

The "TBL" (short for "Taubblind") marker was introduced in 2016 in the German Ordinance on Passes for Disabled Persons. While this designation recognised deafblindness, it was not linked to comprehensive nationwide services for deafblind persons and they were not necessarily better off as a result. Compensation is still linked to designation as either blind or deaf⁶⁰

In the Netherlands, just one instance is noted. Sign language interpretation is available for leisure activities (any activity except formal work or education) and for this people with deafblindness may receive 168 hours per year compared with people who are deaf, who receive 30 hours per year.

In the UK deafblind children and adults were recognised in the 2009 Department of Health publication '*Social Care for Deafblind Adults and Children*' (The Deafblind Guidance).⁶¹ This placed legal duties on

⁵⁷ Declaration of the European Parliament on the Rights of Deafblind People
<https://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//EP//TEXT+TA+P5-TA-2004-0277+0+DOC+XML+V0//EN>

⁵⁸ European Disability Strategy 2010 – 2020 <https://ec.europa.eu/social/main.jsp?catId=1484>

⁵⁹ European Parliament resolution on the European Disability Strategy post-2020 (2019/2975(RSP))
https://www.europarl.europa.eu/meetdocs/2014_2019/plmrep/COMMITTEES/EMPL/RE/2020/01-22/1196563EN.pdf

⁶⁰ Bundesministerium für Arbeit und Soziales (BMAS) (2018b), p. 53

⁶¹ Department of Health (2009) Series number LAC(DH) (2009) 6 Social Care for Deafblind Adults

all English local authorities to identify deafblind people living in the administrative area, to provide specialist assessments and to deliver support to meet the needs identified. This included: provision of a specialist assessor, provision of appropriate services, trained one-to-one support services where assessed as necessary, accessible information about services and senior management responsibility for services for deafblind people. Although limited to two years, the Coronavirus Act 2020⁶² has weakened these rights in that the obligation on local authorities and health services to provide support to people with disabilities has been downgraded to a power to do so. Deafblind people are also recognised in the British Sign Language Act 2015 and in the Scottish BSL National Plan 2017 – 2023.⁶³

From this we can see that people with deafblindness are only sporadically recognised in national legislation and policy. Although some links are drawn between identification of people with deafblindness and the provision of support, this is limited and in many cases discretionary. Our findings indicate that more specific acknowledgement and support measures are required.

Organisations of and for People with Deafblindness

Organisations of and for people with deafblindness in the reporting countries are smaller and more fragmented compared with the larger, more organised associations associated with people with visual impairments or who are D/deaf. In some instances, organisations of people with deafblindness are part of these larger organisations.

At national level there are few representative organisations run by people with deafblindness themselves. Where organisations exist, there is a tendency for them to be local, with members focussed on self-help. Many are under-resourced and have a low profile. Activity has nevertheless increased in recent years, at least in terms of information on web sites and involvement in higher profile projects.⁶⁴

In Greece, we identified two small organisations concerned with individuals with deafblindness, the *Heliotrope* and the *Association of Parents, Tutors, and Friends of Deafblind Children*⁶⁵. However, due to their greater size, many tend to enrol with the representative associations of people with either visual or hearing impairments”: the Panhellenic Blind People’s Association and / or the Hellenic Federation of the Deaf⁶⁶.

In Germany, the *Bundesarbeitsgemeinschaft der Taubblinden* (BAT) (National Deafblind Working Group) comprises self-help groups from several German cities and regions.⁶⁷ Members largely communicate via sign language but spoken language is also supported. Their main objectives are the strengthening of members’ social status, social integration and activities include the creation of opportunities for social connection, national and international networking, and setting up a central office for deafblind assistants. The BAT also helps deafblind persons to assert their rights to assistance, information, education and training and work. Several organisations representing people with sensory

⁶² Coronavirus Act 2020 <https://www.legislation.gov.uk/ukpga/2020/7/section/11/enacted>

⁶³ BSL National Plan 2017 - 2023 <https://www.gov.scot/policies/languages/british-sign-language/>

⁶⁴ See for example the SHAPES project involves the WFDB as a partner organisation

<https://www.maynoothuniversity.ie/all-institute/all-projects/shapes>

⁶⁵ Websites are not currently available for most organisations in Greece.

⁶⁶ Hellenic Federation of the Deaf <https://www.omke.gr/>

⁶⁷ Members of the BAT http://bundesarbeitsgemeinschaft-taubblinden.de/?page_id=3

impairments include people with deafblindness and there is a greater number of support organisations: please see the national report for Germany for further details⁶⁸.

In the Netherlands, there are again some small organisations of people with disabilities that represent people with deafblindness. These include: *Oog en Oor* (Eye and Ear) a subdivision of the association *Oogvereniging* (Eye Association)⁶⁹; the foundation *Usher Syndroom*,⁷⁰ the Dutch foundation *Doofblindenstichting*;⁷¹ and an informal group *Het Slakkenhuis*, which has a website with newsletters for people with deafblindness⁷².

In Sweden, the *Förbundet Sveriges Dövblinda* (FSDB), the Association of the Swedish Deafblind, is a member driven organisation for people with deafblindness and their families⁷³. Founded in 1959, it has regional sections as well as sections for parents of children who have deafblindness, for parents with deafblindness and their families and one for young people with deafblindness. The FSDB organises activities to counter isolation, work to raise public awareness and aims to influence the political sphere on issues important to people with deafblindness.

The *British Deafblind Association* (BDBA) represents people with deafblindness in the UK. It has a close association with Deafblind UK, one of two charities that are active in raising money and providing services to people with deafblindness. Deafblind UK⁷⁴ and Sense⁷⁵ are both based in England and each has teams in the other three countries of the UK: Scotland, Wales and Northern Ireland as well as local organisations. The organisations provide services and support directly to people with deafblindness and their families, including residential housing, individual support, advocacy and advice. Sense provides day centre facilities in three locations.

Organisations Offering Support to People with Deafblindness

Further details of support organisations are provided in national reports for the five countries. A summary of relevant organisations is provided below, for easy reference.

Table 2 National Support Organisations for People with Deafblindness

Country	Organisations
Germany	Arbeitsgemeinschaft der Einrichtungen und Dienste für taubblinde Menschen [<i>Association of Institutions and Services for the Deafblind</i>] (AGTB) ⁷⁶ Deutsche Gesellschaft für Taubblindheit [<i>German Deafblindness Society</i>] (DGfT) ⁷⁷

⁶⁸ SUITCEYES Scoping Report on Law and Policy on Deafblindness, Disability and New Technologies: Working Paper, Germany <https://suitceyes.eu/wp-content/uploads/2021/02/SUITCEYES-Law-and-Policy-report-Germany-1.pdf>

⁶⁹ Oogvereniging https://www.doofblinden.net/?page_id=171

⁷⁰ Usher Syndroom <https://ushersyndroom.nl/wie-zijn-wij/>

⁷¹ <http://doofblindenstichting.nl>

⁷² Doofblindennieuws. <https://doofblindennieuws.nl>

⁷³ Förbundet Sveriges Dövblinda <http://www.fsd.org/>

⁷⁴ Deafblind UK <https://deafblind.org.uk/>

⁷⁵ Sense UK <https://www.sense.org.uk/>

⁷⁶ AGTB <https://agtb-deutschland.de/>

⁷⁷ DGfT <https://www.gesellschaft-taubblindheit.de/startseite>

	<p>Gemeinsamer Fachausschuss Hörsehbehindert/Taubblind [<i>Joint Committee for the Hearing and Visually Impaired and the Deafblind</i>] (GFTB)⁷⁸</p> <p>Kompetenzzentrum Selbstbestimmt Leben für Menschen mit Sinnesbehinderung Nordrhein-Westfalen [<i>North Rhine-Westphalia Centre of Excellence for Self-Sufficient Living for Persons with Sensory Impairment</i>] (KSL-MSi-NRW)⁷⁹</p> <p>Stiftung Taubblind Leben [<i>Foundation for People Living with Deafblindness</i>]⁸⁰</p> <p>Taubblindendienst der Evangelischen Kirche in Deutschland [<i>Deafblind Service of the Protestant Church in Germany</i>]⁸¹</p> <p>Taubblindenassistentenverband [Deafblind Assistants' Association] (TBA-Verband)⁸²</p>
Greece	<p>The Hellenic Association of Deafblind 'The Heliotrope'⁸³</p> <p>The Association of Parents, Tutors, and Friends of Deafblind Children⁸⁴</p>
Netherlands	<p>DB – Connect (umbrella group for organisations connected with deafblindness).⁸⁵ This organisation includes the following groups, all of which provide services to people with deafblindness as well as a broader group of people with sensory impairments:</p> <ul style="list-style-type: none"> - Bartiméus (focus on blindness and deafblindness)⁸⁶ - GGMD (Mental Health Care and Social Services) (supporting deaf and deafblind people)⁸⁷ - Kentalis (deaf people and people with deafblindness)⁸⁸ - Visio (blind people and people with deafblindness)⁸⁹ - Kalorama (combines care for elderly people and end-of life care with care and support for people with deafblindness)⁹⁰ <p>Nederlandse beroepsvereniging Tolken gebarentaal (<i>Dutch association for professional sign language interpreters</i>)⁹¹</p>

⁷⁸ GFTB <https://www.dbsv.org/>

⁷⁹ KSL-MSi-NRW <https://ksl-msi-nrw.de/de>

⁸⁰ Stiftung Taubblind Leben <https://stiftung-taubblind-leben.de/>

⁸¹ Taubblindendienst der Evangelischen Kirche in Deutschland <https://agtbd-deutschland.de/taubblindendienst-der-evangelischen-kirche-in-deutschland-ekd-e-v-radeberg/>

⁸² TBA-Verband <https://www.tba-verband.de/>

⁸³ No website. Email: diamatsa@gmail.com

⁸⁴ Association of Parents, Tutors, and Friends of Deafblind Children. No website. Contact: Tel/Fax +30 169 177 74

⁸⁵ DB-Connect <https://dbconnect.info/>

⁸⁶ Bartiméus <https://www.bartimeus.nl/>

⁸⁷ GGMD <https://www.ggmd.nl/>

⁸⁸ Kentalis <https://www.kentalis.com/>

⁸⁹ Visio <https://www.visio.org/home/>

⁹⁰ Kalorama <https://www.kalorama.nl/>

⁹¹ Nederlandse beroepsvereniging Tolken gebarentaal <https://www.nbtg.nl/>

Sweden	<p>The Swedish National Resource Center for Deafblindness⁹²</p> <p>The National Agency for Special Needs Education and Schools⁹³</p> <p>Upper secondary school, Riksgymnasiet för döva och hörselskadade, for young people with hearing impairment, deafness and deafblindness⁹⁴</p> <p>Mo Gård⁹⁵</p>
UK	<p>Deafblind UK⁹⁶</p> <p>Sense⁹⁷</p> <p>National Registers of Communications Professionals working with Deaf and Deafblind People (NRCPD)⁹⁸</p>

There are therefore organisations concerned with deafblindness in all countries taking part. However we can see differences in resources and patterns of provision. In the Nordic countries, the National Resource Centre for Deafblindness in Sweden has been active in developing understanding of deafblindness, as seen with the Nordic definition, research, training expert support. There are established support organisations in Germany, the Netherlands and the UK and these support people with deafblindness and their families, and to a greater or lesser extent initiate research, training and associated activities. Greece has the least number of organisations and these are mostly underfunded and focused on self-help and support to families. People with deafblindness and their organisations have taken a more active role in recent years, especially through participation in research and projects. However, in comparison with organisations of and for people with visual impairments or D/deaf people, activity remains low.

Recommendations: People with Deafblindness

Based on the review in this section, we make the following recommendations:

- A consistent definition of deafblindness should be adopted by national governments in agreement with organisations such as the European Deafblind Union (EDbU) and the World

⁹² The Swedish National Resource Center for Deafblindness www.nkcdb.se

⁹³ The National Agency for Special Needs Education and Schools <https://www.spsm.se/>

⁹⁴ Riksgymnasiet för döva och hörselskadade

https://gymnasieskolor.orebro.se/tullangsgymnasiet/studerahososs/riksgymnasietfordovaochhorselskadade.4_639484fa14f307c14aeff1.html

⁹⁵ Mo Gård <https://www.mogard.se/>

⁹⁶ Deafblind UK <https://deafblind.org.uk/>

⁹⁷ Sense <https://www.sense.org.uk/>

⁹⁸ NRCPD <https://www.nrccd.org.uk/index.php>

Federation of the Deafblind (WFDB) as well as national organisations of persons with deafblindness.

- The definition should recognise deafblindness as a distinct impairment and not simply the sum of deafness and blindness. It should recognise the diversity of the population of people with deafblindness.
- Accessibility measures that enable equal participation of people with deafblindness in society should be adopted, especially measures concerned with communication.
- Sign languages, including haptic languages, should have legal status.
- Official statistics and other data on people with deafblindness should be generated, regularly updated and used to inform progress on important indicators of equality.
- Recognising the value of peer support, adequate assistance should be provided for organisations of and for people with deafblindness to participate in civil society to represent their interests.

PART 2

Overview of Law and Policy on New Technologies and People with Disabilities

Most law and policy on disability is general, applying to all people with disabilities rather than particular groups. Such general legislation often has much more impact on the situations of people with deafblindness than impairment – specific legislation and the rest of this report considers this wider picture. In a review of this size and scope it is not possible to consider *all* relevant instruments but we have aimed to ensure that we cover those that are decisive for people with sensory impairments and to include a representative sample of measures.

Two aspects of law and policy are considered. First, some measures are concerned with disabled people's individual rights to personal support, equipment and aids. Second, other laws relate to universal design and making the environment accessible to all. Universal design is defined in Article 2 of the CRPD (see below) as follows:

“Universal design” means the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or

specialized design. “Universal design” shall not exclude assistive devices for particular groups of persons with disabilities where this is needed.⁹⁹

Of course there are overlaps between the two categories: in some ways the distinction between individual access to technology and universal design is artificial because technology is always employed in context. However, the distinction can be important from a practical point of view: it shows where the responsibility for measures lies and provides guidance for designers thinking about how the technology they develop may be used in practice.

Before considering legislation at European and Member State level, some overarching international instruments are discussed. Brief information is provided here and more detailed information is available through the sources provided.

The Convention on the Rights of Persons with Disabilities (CRPD) and the Sustainable Development Goals (SDGs)

All of the countries taking part in this review, as well as the EU itself, are parties to the UN Convention on the Rights of Persons with Disabilities (2006), which places wide-ranging obligations on those signing and ratifying it. The CRPD is specific to people with disabilities, linking to and operating with other international human rights instruments.¹⁰⁰ Signing and ratifying the Optional Protocol of the CRPD permits individuals, groups of people with disabilities or a third party representing them, to directly bring a complaint to the CRPD Committee regarding violation of their rights under the CRPD, providing all available and effective domestic remedies have been exhausted¹⁰¹.

Increasingly, many aspects of EU policy are becoming aligned with the Convention and it is therefore an important point of reference although not the only one. The General Principles of the CRPD are set out in Article 3 as follows:¹⁰²

- Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons;
- Non-discrimination;
- Full and effective participation and inclusion in society;
- Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
- Equality of opportunity;
- Accessibility;
- Equality between men and women;

⁹⁹ Article 2, CRPD: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-2-definitions.html>

¹⁰⁰ United Nations Office of the High Commissioner, *The Core International Human Rights Instruments and their monitoring bodies*
<https://www.ohchr.org/en/professionalinterest/pages/coreinstruments.aspx>

¹⁰¹ United Nations Office of the High Commissioner, *Optional Protocol to the Convention on the Rights of Persons with Disabilities*
<https://www.ohchr.org/EN/HRBodies/CRPD/Pages/OptionalProtocolRightsPersonsWithDisabilities.aspx#1>

¹⁰² CRPD Article 3: General Principles <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-3-general-principles.html>

- Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

The CRPD includes rights to assistive technologies. Article 19: Living independently and being included in the community¹⁰³ provides context as it requires the availability of personal assistance needed to support living and inclusion in the community, in order prevent isolation or segregation. Article 20: Personal mobility¹⁰⁴ specifies “quality mobility aids, devices, assistive technologies and forms of live assistance and intermediaries, including by making them available at affordable cost.” In Article 26: Habilitation and Rehabilitation¹⁰⁵, States Parties are required to promote the development of initial and continuing training for professionals and staff working in related services.

Accessibility relatedly appears in Article 19 on Living independently and being included in the community, Article 20 on Personal mobility and Article 21 on Freedom of expression and access to information. It is also the subject of General Comment 9, of the Committee on the Rights of Persons with Disabilities, which provides further guidance and interpretation on accessibility.¹⁰⁶ States Parties have a general obligation to undertake or promote research and development of universally designed goods, services, equipment and facilities, which should require the minimum possible adaption and the least cost to meet the specific needs. They should also promote their availability and use and promote universal design in the development of standards and guidelines.

UN General Assembly Resolution 48/96, Standard Rules on the Equalization of Opportunities for Persons with Disabilities, of 20 December 1993¹⁰⁷ predated the CRPD. Aimed at ensuring disabled people’s equal access, participation and inclusion in mainstream society, policies were introduced on access to assistive technology. They included “development, production, distribution and servicing of assistive devices and equipment and the dissemination of knowledge about them”. Rule 4 notes that devices should be affordable or free of charge and it is also stated that “persons with disabilities themselves could be involved in the production of those devices” as well as the formulation of policy regarding these. While not legally binding, the Rules present a strong moral and political commitment to governments and are an instrument for policy making and technical co-operation.

Further context for ICT and disability is provided by the United Nations 2030 Agenda for Sustainable Development (2014).¹⁰⁸ This provides a global framework for development, with 169 targets for 17 goals on a wide range of issues. Each target has one or more indicators that are used to measure progress and SDG 10 *Reduce inequality within and among countries* specifically refers to the social, economic and political inclusion of people with disabilities. People with disabilities are also mentioned in Goal 4 - *Ensure inclusive and equitable quality education and promote lifelong learning*

¹⁰³ CRPD Article 19 <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-19-living-independently-and-being-included-in-the-community.html>

¹⁰⁴ CRPD Article 20 <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-20-personal-mobility.html>

¹⁰⁵ CRPD Article 26 <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-26-habilitation-and-rehabilitation.html>

¹⁰⁶ Committee of the CRPD (2014) *General Comment 9*, <https://g3ict.org/publication/committee-on-the-rights-of-persons-with-disabilities-general-comment-no-2-2014-on-article-9-accessibility>

¹⁰⁷ Standard Rules on the Equalization of Opportunities for Persons with Disabilities <https://www.ohchr.org/EN/ProfessionalInterest/Pages/PersonsWithDisabilities.aspx>

¹⁰⁸ 2030 Agenda for Sustainable Development http://www.un.org/en/ga/search/view_doc.asp?symbol=A/RES/70/1

opportunities for all ; Goal 8 - Promote sustained, inclusive and sustainable economic growth, full and productive employment and decent work for all and Goal 11 - Make cities and human settlements inclusive, safe, resilient and sustainable.

Persistent inequalities are still in evidence in the 2018 UN report *Realization of the Sustainable Development Goals by, for and with persons with disabilities*¹⁰⁹, which provides details of persistent inequalities due to discrimination in many life spheres, including ICT.

European Legislation on Equality

While there is not space in a report of this size to discuss all relevant European legislation, this section notes some key instruments that provide the basis for recognition and enforcement of the rights of people with disabilities. The Treaty of Amsterdam¹¹⁰ amended in 2009 the Treaty on the Functioning of the European Union (TFEU), to include the aim to ‘*combat discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation.*’ The European Charter of Fundamental Rights (CFR)¹¹¹ also contains references to people with disabilities in relation to non-discrimination and integration.

The 2000 Employment Equality Directive¹¹² is the only non-discrimination directive that specifically applies to people with disabilities (as well as other groups). Member States and employers are required to develop coherent policies to prohibit direct and indirect discrimination and harassment on the ground of disability (among other grounds) with regard to employment. This directive is important in that it is the basis for requirements that employers provide reasonable accommodation, including compensation for disadvantage. An Equal Treatment Directive, proposed as early as 2008, has yet to be decided, despite some efforts to reach agreement.

As noted above, the EU has signed and ratified the CRPD in its own right¹¹³, with the provisions entering into force on the 22 January 2011. It has not signed the Optional Protocol but has established a Code of Conduct¹¹⁴. The CRPD Committee published its Concluding Observations on the European Union in 2015,¹¹⁵ with the next report due in 2021.

¹⁰⁹ United Nations (2018) *Realization of the Sustainable Development Goals by, for and with persons with disabilities* <https://www.un.org/development/desa/disabilities/wp-content/uploads/sites/15/2018/12/UN-Flagship-Report-Disability.pdf>

¹¹⁰ Treaty of Amsterdam <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A11997D%2FTXT>

¹¹¹ Charter of Fundamental Rights of the European Union <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX:12012P/TXT> The Charter was declared in 2007 and came into force in 2009 with the treaty of Lisbon.

¹¹² Council Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=celex%3A32000L0078>

¹¹³ Council Decision 2010/48/EC concerning the conclusion by the European Community of the United Nations Convention on the Rights of Persons with Disabilities. <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A32010D0048>

¹¹⁴ Code of Conduct between the Council, the Member States and the Commission setting out internal arrangements for the implementation by and representation of the European Union relating to the United Nations Convention on the Rights of Persons with Disabilities [https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A42010Y1215\(01\)](https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A42010Y1215(01))

¹¹⁵ Committee on the Rights of Persons with Disabilities (2015), Concluding observations on the initial report of the European Union [file:///C:/Users/lifslw1/Downloads/UN%20Concluding%20observations%20on%20EU_Disability%20Convention_final%20edited%20version%20\(1\).pdf](file:///C:/Users/lifslw1/Downloads/UN%20Concluding%20observations%20on%20EU_Disability%20Convention_final%20edited%20version%20(1).pdf)

The European Disability Strategy 2010 – 2020 has provided direction for EU disability policy over the past ten years. Having concluded, progress was evaluated in 2019-20 and a report was completed in 2020¹¹⁶. Agreement was reached that a new strategy would be developed and this was published in March 2021¹¹⁷.

These legal instruments show the EU’s general direction and priorities in respect of the rights of people with disabilities. Legislation consistently emphasises that people with disabilities should participate in society on equal terms with others. Older practices, such as requiring people with disabilities to live in institutions are now seen as problematic.¹¹⁸ In line with this, it is essential that technology should be developed that supports people with disabilities’ full participation in community life and society. This requirement has implications for the design of technology. If devices are developed that cost so much that only by pooling their resources can people afford to use them, this will provide an impetus towards group living and institutionalisation.

National Level Equality Law and Policy

The table below describes some basic legislation in each country that underpins arrangements for people with disabilities to get access to equipment and for environmental accessibility. This legislation is concerned with equality between citizens and in some instances involves transposition of UN or EU legislation into domestic law.

Table 3 National Level Equality Legislation

Country	Legislation	Provisions
Germany	Basic Law for the Federal Republic of Germany ¹¹⁹ Book IX of the Social Code ¹²⁰ Act on Equal Opportunities for People with Disabilities ¹²¹	The Basic Law states that no person shall be discriminated against because of disability. Equality rights are extended through further legislation. The Social Code is concerned with rehabilitation and the Act on Equal Opportunities with equal opportunities and accessibility of the public service sector.
Greece	Law 4488/2017 ¹²²	This seeks to promote implementation of the UN CRPD, and makes explicit references to new

¹¹⁶ European Commission, *Commission Staff Working Document Evaluation of the European Disability Strategy 2010-2020 {SWD(2020) 291 final}*
file:///C:/Users/lifslw1/Downloads/SWD_2020_289_F2_SWD_EVALUATION_EN_V5_P1_1105823.pdf

¹¹⁷ European Commission, *Union of Equality: Strategy for the Rights of Persons with Disabilities 2021-2030*
https://www.edf-feph.org/content/uploads/2021/03/KE0221257ENN_002-proof-2.pdf

¹¹⁸ For example, the Committee on the Rights of Persons with Disabilities (2015) has recommended that EU funds are used to develop mainstream support services, not institutions.

¹¹⁹ Basic Law for the Federal Republic of Germany http://www.gesetze-im-internet.de/englisch_gg/index.html

¹²⁰ Book IX of the Social Code
http://www.ilo.org/dyn/natlex/natlex4.detail?p_lang=&p_isn=60647&p_classification=08.01

¹²¹ Act on Equal Opportunities for People with Disabilities
http://www.ilo.org/dyn/natlex/natlex4.detail?p_lang=en&p_isn=61882

¹²² Law 4488/2017 “[Public Sector Pension reforms, employees protection, the rights of people with disabilities and other regulations](http://www.gesetze-im-internet.de/englisch_gg/index.html)”

		technologies and their potential in enhancing accessibility, participation and social inclusion
Netherlands	Act on Equal Treatment on the Ground of Disability or Chronic Illness 2003 ¹²³	The Act offers protection against discrimination on grounds of any disability or chronic illness. Its scope was initially confined to employment and work but it has since been extended to education, housing, public transport and delivery of goods and services as a consequence of ratifying the CRPD.
Sweden	Discrimination Act ¹²⁴	The Discrimination Act (2008:567) prohibits direct or indirect discrimination due to a disability, against a person in work or education. Since January 1 2015, lack of accessibility has also been considered discrimination, which means that a person with a disability must not be disadvantaged through lack of accessibility measures.
UK	Equality Act 2010 ¹²⁵	Protected characteristics include: disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex and sexual orientation. The legislation provides the legal basis for equality and non-discrimination in the UK for people with disabilities. The Equality and Human Rights Commission has responsibility for enforcement.

Overall Legal and Policy Framework for Access to Technology

All countries in the SUITCEYES project have existing systems for individuals to make claims to public authorities for personal equipment. As provision is publicly funded in various ways, there are indications that they have recently been put under strain by the costs of the coronavirus pandemic. However, clear data on this was yet to emerge at the time of writing this report and so is not included here.

Most legislation on personal access to technology is specific to Member States and there are some aspects that fall into the area of competence of the EU. Examples are summarised below and more details are provided in the national reports:

Table 4. Examples of National Law and Policy on People with Disabilities' Access to Technology

Country	Examples of Law and Policy	Main points
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¹²³ Act on Equal Treatment on the Ground of Disability or Chronic Illness 2003

<https://wetten.overheid.nl/BWBR0014915/2017-01-01>

¹²⁴ Discrimination Act https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfortssamling/discrimination-law-2008567_sfs-2008-567

¹²⁵ Equality Act 2010 <http://www.legislation.gov.uk/ukpga/2010/15/contents>

Germany	<p>§33 SGB V (Social Security Code V)¹²⁶</p> <p>National Action Plan¹²⁷</p> <p>Artificial Intelligence Strategy¹²⁸</p>	<p>Legal basis for a catalogue that specifies aids for health care. Innovative technology is included but aids are not for general everyday use.</p> <p>National Action Plan for implementing the CRPD. This includes funding of projects to develop new technologies for people with disabilities.</p> <p>The Strategy aims to establish Germany as a leader in AI and IoT. No apparent legislation or regulations that explicitly have the goal of making artificial intelligence (AI) or Internet of Things (IoT) technologies accessible to people with disabilities.</p>
Greece	<p>Single Organisation for Provision of Health Services (established by Law 3863/2010)¹²⁹</p> <p>The Single Regulation of Health Provisions (last modified in 2018)¹³⁰</p> <p>Law 4488/2017¹³¹</p>	<p>Health-related provisions for people who are insured. This includes rehabilitation measures, medical supplies and provision of assistive equipment.</p> <p>This defines eligibility and costs for assistive devices among other medical goods and services. Notable points are: a) devices only cover basic rehabilitation aids (e.g. wheelchair, prosthetics, hoists, etc.); b) provisions in cash (contribution), rather than in kind; c) eligibility is based on medical assessment and diagnosis rather than need.</p> <p>Disability legal rights strategy that aims to implement the CRPD. Requires public administration to undertake equal treatment measures, including reasonable adjustments such as assistive technology, personal assistance, individualised adjustment of processes or practices and specialised services for communication.</p>
The Netherlands	Social Support Act 2015 ¹³²	Municipalities have responsibilities for provision of assistive devices at home with the aim of the aim of facilitating a person to participate in society.

¹²⁶ Bundesministeriums der Justiz *Social Code – Book 5 - Statutory Health Insurance*

https://www.ilo.org/dyn/natlex/natlex4.detail?p_lang=en&p_isn=43202

¹²⁷ National Action Plan <https://www.bmas.de/DE/Schwerpunkte/Inklusion/nationaler-aktionsplan-2-0.html>
The current plan runs until 2021 coordinated by with the Federal Ministry of Labour and Social Affairs (BMAS) as the governmental focal point responsible for implementation.

¹²⁸ German Artificial Intelligence Strategy <https://www.de.digital/DIGITAL/Redaktion/DE/Publikation/strategie-kuenstliche-intelligenz-der-bundesregierung.html>

¹²⁹ Law No. 3863 of 2010 concerning the New Social Security System

https://www.ilo.org/dyn/natlex/natlex4.detail?p_lang=en&p_isn=86883

¹³⁰ Single Regulation of Health Provisions (last modified in 2018)

<https://www.eopyy.gov.gr/law/details/496fe7d2-e19a-4216-8adf-6ec7816c8c95>

¹³¹ Law 4488/2017 [Public Sector Pension reforms, employees protection, the rights of people with disabilities and other regulations](#)

¹³² Social Support Act 2015 <https://wetten.overheid.nl/BWBR0035362/2018-11-17>

	<p>Provisions based on Healthcare Insurance¹³³</p> <p>Wet Werk en Inkomen naar Arbeidsvermogen (WIA) 2005 (Act on Reintegration of Labour-disabled)¹³⁴</p> <p>Digital Samenleven¹³⁵</p>	<p>Healthcare insurance system that will fund certain assistive devices, e.g. communication aids, wheelchairs, daisy readers, special beds, alert devices and sign language interpreters.</p> <p>Equipment and adaptations for work life. This includes interpretation services.</p> <p>Public – Private Partnership aimed at improving digital accessibility. Measures include easy courses on digital information for citizens in local public libraries. Also commissioning university research on effective support for digital learning. Data on specific projects, tools and initiatives aimed at people with disabilities is not publicly available.</p>
Sweden	<p>Patient Act (2014: 821)¹³⁶</p> <p>The Health Care Act¹³⁷</p>	<p>Patients should be informed about available aids, be able to choose a device they prefer and receive it if it is justified in view of their needs and the costs involved. Health care regions should offer habilitation and rehabilitation, assistive devices for persons with disabilities, and interpreting services for everyday interpretation for deaf, deafblind and hearing impaired people.</p>
UK	<p>The Care Act 2014¹³⁸</p> <p>Disabled Facilities Grants¹³⁹</p>	<p>Local authorities must undertake an assessment for any adult who appears to have needs for care and support. They have a duty to provide support if needs are eligible. This includes equipment and adaptations to the home.</p> <p>Grants are provided to adapt housing for those eligible. This includes technology in the home and installation and adaptation of controls.</p>

¹³³ Provisions based on Healthcare Insurance https://wetten.overheid.nl/BWBR0018715/2019-02-13/#Hoofdstuk2_Paragraaf1_Sub-paragraaf1.4

¹³⁴ Workers with Disabilities Reintegration Act [Wet REA] (Stb. 290) <https://wetten.overheid.nl/BWBR0019057/2019-01-01>

¹³⁵ Digital Samenleven (digital community). <https://digitaalsamenleven.nl/over-de-alliantie/>

¹³⁶ https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/patientlag-2014821_sfs-2014-821

¹³⁷ https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/halso--och-sjukvardslag_sfs-2017-30

¹³⁸ Care Act 2014 <http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>

¹³⁹ Disabled Facilities Grants <https://www.gov.uk/disabled-facilities-grants>

The list of legislation and policies mentioned above is not intended to be comprehensive, but to provide a point of reference for designers and others in thinking about how users might access their products. While there are different systems for funding and applying for equipment and devices, at national, regional and local levels, in all instances there is an application process and a judgement made about eligibility. Frequently, people with disabilities are not in a position to purchase equipment themselves, especially if it is expensive. This is because they are often poorer than the general population due to underemployment and unemployment and also because of the costs and practicality of making environments accessible. Typically, at national level there is variation in eligibility criteria, levels of allocation and different means of distribution. If they are not universal, (available to all) the procedures can be highly complex, very diverse and often bureaucratic. These points are discussed further in Part 3 *Access to Equipment*, below.

Overall Legal and Policy Framework for Accessibility

In contrast with law and policies on the rights of people with disabilities to access support, devices and aids to facilitate independent living, there are many hard and soft legal instruments concerned with the need for environments to be inclusive of people with disabilities in general. Universal design is part of this approach, reflecting an anticipatory duty on organisations with regard to people with disabilities. Rather than waiting to see if an individual customer requires adjustments in order to take part in an event or setting, organisations are required to arrange accessible environments in advance, open to all, in order that people with disabilities may take part if they so wish.

In this section, we briefly review legal and policy instruments that have particular applicability to people with disabilities. Again, it is not possible to cover all measures, which are summarised in more detail on EU websites.¹⁴⁰ After describing the EU developments, we consider some important national developments.

European Digital Law and Policy

*European Accessibility Act: Directive (EU) 2019/882 of the European Parliament and of the Council of 17 April 2019*¹⁴¹

This directive applies to a range of ICT products and services, requiring accessibility measures to be taken in respect of people with disabilities. It covers computer hardware and operating systems, self-service and payment terminals, telephony services, audiovisual services, e-books in respect of air, bus, rail and waterborne passenger transport services. Functional requirements are specified in the Act, based on existing accessibility standards, such as Standard 301 549¹⁴² and these apply to the design of future technology, including new technologies.

¹⁴⁰ Digital Single Market Sitemap: <https://ec.europa.eu/digital-single-market/en/sitemap>; Electronic Communications Laws: <https://ec.europa.eu/digital-single-market/en/policies/telecom-laws>

¹⁴¹ Accessibility Act <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=COM%3A2015%3A0615%3AFIN>

¹⁴² Standard 301 549 <http://mandate376.standards.eu/standard>

The Act has been welcomed by DPOs / OPDs but there have also been comments on shortcomings.¹⁴³ It does not apply to health care services, education, transport, housing, and household appliances and clearly, these are significant limitations. There are lengthy transposition timescales before Member States must put the Directive into effect and smaller companies are exempt from the requirements. Nevertheless, the Directive represents an important landmark in accessibility legislation.

*EU Directive 2016/2102 on the accessibility of the websites and mobile applications of public sector bodies (European Commission (EC), 2016)*¹⁴⁴ supports the Digital Agenda for Europe as well as the implementation of the CRPD in Member States. It requires that EU countries ensure that the websites and mobile apps of public sector bodies meet common/harmonised European accessibility standards. The Directive states that public sector organisations must work to make their “websites and mobile applications more accessible by making them perceivable, operable, understandable, and robust.” These are the same principles as for the international voluntary consensus standard Web Content Accessibility Guidelines 2.1 (“WCAG”)¹⁴⁵. EU Directive 2016/2102 is also aligned to the draft harmonised standard EN 301 549 V3.1.1 (2019-06)¹⁴⁶ Accessibility requirements for ICT products and services.¹⁴⁷ All websites created after 23 September 2018 had to be accessible by 23 September 2019 and existing websites had to comply by 23 September 2020. All mobile applications will have to be accessible by 23 June 2021. This directive has been transposed into national law in European countries.

The EU General Data Protection Regulation came into force in May 2018 and provides a high standard of personal data protection, including the principles of data protection ‘by design and by default’. The EU has high standards in terms of safety and product liability but it is not yet clear whether these are sufficiently robust for emerging technologies. As noted, it is essential for citizens and businesses alike to be able to trust the technology they interact with, to have a predictable legal environment and rely on effective safeguards protecting their fundamental rights and freedoms.

The *European Electronic Communications Code (EECC)*¹⁴⁸ is one of the key initiatives of the Digital Single Market Strategy and relates to the rollout of 5G communication. Rules that will apply to all across Europe are set out in order to support the single market.

*Audiovisual Media Services Directive*¹⁴⁹ amendments of the Directive 2010/13/EU entered into force in 2018 and at the time of writing this report the legislation is in the transposition period. Member States are required to complete this by September 2020. Harmonisation of services in each country is mandated and the provider is responsible for ensuring compliance: this also includes video-sharing

¹⁴³ See European Disability Forum *EDF analysis of the European Accessibility Act* <http://www.edf-feph.org/newsroom/news/our-analysis-european-accessibility-act>

¹⁴⁴ EU directive 2016/2102 on the accessibility of the websites and mobile applications of public sector bodies (European Commission (EC), 2016) <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A32016L2102>

¹⁴⁵ Web Content Accessibility Guidelines 2.1 <https://www.w3.org/TR/WCAG20/>
<https://www.w3.org/TR/WCAG21/>

¹⁴⁶ EN 301 549 V3.1.1 (2019-06)
https://www.etsi.org/deliver/etsi_en/301500_301599/301549/03.01.01_20/en_301549v030101a.pdf

¹⁴⁷ Accessibility requirements for ICT products and services
https://www.etsi.org/deliver/etsi_en/301500_301599/301549/01.01.02_60/en_301549v010102p.pdf
https://www.etsi.org/deliver/etsi_en/301500_301599/301549/02.01.02_60/en_301549v020102p.pdf

¹⁴⁸ EECC <https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:32018L1972&from=EN>

¹⁴⁹ Amendments to the Audiovisual Media Services Directive <https://eur-lex.europa.eu/eli/dir/2018/1808/oj>

platforms. The provisions strengthen protection of certain groups (e.g. protection of minors) and among other measures strengthen rules on accessibility and against hate speech. Independence of regulators is re-affirmed.

EU Standards

The EU Standard *Design for All*¹⁵⁰ aims to ensure that there is access to products and services for people with disabilities on equal basis with others. The intent is to ensure recognition of variations between users and achievement of accessibility to the greatest extent possible. As an EN Standard, it is automatically an obligation that applies to all Member States and conflicting standards must be withdrawn.

By way of example, in Greece, implementation of the Design for All standard is recognised in the building regulations.¹⁵¹ Here, requirements are that entrances must be accessible to disabled people, there should be accessible toilets and room layout should be accessible. Although the emphasis is on physical layout and mobility impairments, guidelines are given for improving signage for blind visitors to buildings of public interest. However, there is no particular reference to deafblind users.

Examples of National Level Law and Policy

There is an extremely large body of legislation and policy at national level that is concerned with accessibility. Where governments have signed and ratified the CRPD, national legislation should be in line with the treaty. Again, it is not the intention to cover all aspects in this report and readers should consult national reports and the links given other sources of expertise for more details. The table below is indicative and broad in scope rather than fully comprehensive. Some of the instruments listed below apply only to one country, while others transpose EU and other international measures into national law.

Table 5 National Level Law and Policy on Accessibility

Country	Law	Comments
Germany	Equal Opportunities for Disabled Persons Act (BGG) 2002 ¹⁵² Act on the Further Development of the Equal Opportunities for Disabled Persons Act 2016 ¹⁵³	Defines the concept of accessibility. Further amendment in 2018 transposed Directive (EU) 2016/2102.

¹⁵⁰ CEN standard: EN 17161:2019 on Accessibility https://www.cencenelec.eu/News/Brief_News/Pages/TN-2019-019.aspx

¹⁵¹ Greek Parliament https://www.hellenicparliament.gr/Nomothetiko-Ergo/Anazitisi-Nomothetikou-Ergou?law_id=3dc4f0f3-36b8-4431-92d2-4ade78c39705

¹⁵² <https://www.bmas.de/EN/Our-Topics/Participation-of-Persons-with-Disabilities/disability-policy.html> Bundesfachstelle Barrierefreiheit: https://www.bundesfachstelle-barrierefreiheit.de/DE/Ueber-Uns/Definition-Barrierefreiheit/definition-barrierefreiheit_node.html;jsessionid=F899A99F744DA2C6FBB6AECA4DB472B8

¹⁵³ BGG <https://www.bmas.de/DE/Presse/Meldungen/2016/gesetz-zur-weiterentwicklung-des-behindertengleichstellungsrechts-in-kraft.html>

	Free Information Technology Ordinance (BITV) ¹⁵⁴	Contains technical details on accessibility relevant to implementing the requirements of EU Directive 2016/2102.
	Online Access Act (OZG) ¹⁵⁵	Administrative services available digitally via portals.
	Federal Participation Act (BTHG) ¹⁵⁶	Simplifies funding application process, which can facilitate access to new technologies for people with disabilities, and reduce barriers.
Greece	Law 4591/2019 (Government Gazette 19 A / 12-2-19): Incorporation into Greek law of : a) Directive (EU) 2016/2102 of the European Parliament and of the Council of 26 October 2016 on accessibility of websites and applications for mobile devices of public sector organisations and (b) Article 1 of Council Directive (EU) 2017/2455 of 5 December 2017. ¹⁵⁷	Transposition of EU directive into Greek law.
	Law 2621/ 2009 Special arrangements for servicing people with disabilities in areas of public use that are intended for pedestrian traffic.	Specification of tactile guides for the safe movement of people with vision impairments. Indicative uses are described.
Netherlands	Act on Equal Treatment on the Ground of Disability or Chronic illness in 2003. ¹⁵⁸	Establishes of a general framework for equal treatment of people with disabilities in employment and occupation. Transposition of EU Directive 2000/78/EC of 27 November 2000.
	Mediawet 2008 ¹⁵⁹	Transposition of Audiovisual Media Services Directive 2010/13/EU.
	Code on General Accessibility ¹⁶⁰	A legal duty to gradually introduce general accessibility. Article 9 of the CRPD is to be used as ‘guideline’ and action plans on accessibility are to be prepared by NGOs and DPOs per sector.

¹⁵⁴ Bundesfachstelle Barrierfreiheit https://www.bundesfachstelle-barrierefreiheit.de/DE/Themen/EU-Webseitenrichtlinie/BGG-und-BITV-2-0/Die-neue-BITV-2-0/die-neue-bitv-2-0_node.html

¹⁵⁵ OZG ¹⁵⁵ <https://www.bmi.bund.de/DE/themen/moderne-verwaltung/verwaltungsmodernisierung/onlinezugangsgesetz/onlinezugangsgesetz-node.html>

¹⁵⁶ Federal Participation Act <https://www.bmas.de/DE/Schwerpunkte/Inklusion/bundesteilhabegesetz.html>

¹⁵⁸ Wet gelijke behandeling op grond van handicap of chronische ziekte.

<https://wetten.overheid.nl/BWBR0014915/2017-01-01>

¹⁵⁹ Mediawet 2008 <https://wetten.overheid.nl/BWBR0025028/2020-04-01>

¹⁶⁰ Besluit algemene toegankelijkheid voor personen met een handicap of chronische ziekte. <https://wetten.overheid.nl/BWBR0039653/2017-06-21>

Sweden	Swedish Language Act (Språklagen SFS 2009:600) ¹⁶¹	People who are deaf and / or need sign language should be able learn, develop and use Swedish sign language. Authorities are responsible for protecting and to promoting use.
	EU Accessibility Directive ¹⁶²	Sweden has started the process of transposing the EU Accessibility Act although concrete measures have not been completed.
United Kingdom	The Public Sector Bodies (Websites and Mobile Applications) (No. 2) Accessibility Regulations 2018 ¹⁶³	Transposition of EU Directive 2016/2102 into UK law.

Despite such advances in legislation, substantial problems are reported in relation to accessibility in practice. In the Netherlands, people with disabilities have complained about the quality of subtitling and audio description, which is not generally available. In England, lack of sign language for emergency TV announcements¹⁶⁴ resulted in a legal challenge to the government by deaf campaigners. In contrast, sign language interpreters are present for announcements in Scotland and Wales, illustrating divergence between UK countries.

A guide on accessible building has been produced (NL), but it is not usually used in education and training of architects and builders. Education and training of ICT experts or other technical professionals does not include standard courses on accessibility.¹⁶⁵ This issue remains a problem across Europe and is one of the areas where not much progress has been made in recent years.¹⁶⁶

Co-ordination and enforcement across sectors remain difficult. In 2015 in the Netherlands, provision of technical adaptations or social support for people with disabilities was decentralised from national Government and national insurers to municipalities. This led to a breakdown of national rules for providing adaptations, transport aids and technical equipment among other measures, in favour of discretionary freedom for municipalities to decide on what was to be provided and what conditions (of providers) applied. People with disabilities have complained more about the technical quality and maintenance of provisions since this change was implemented.¹⁶⁷

¹⁶¹ Swedish Language Act https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/spraklag-2009600_sfs-2009-600

¹⁶² EU Accessibility Directive 2019 <https://www.mfd.se/verktyg/lagar-och-regler-om-tillganglighet/eus-tillganglighetsdirektiv/>

¹⁶³ The Public Sector Bodies (Websites and Mobile Applications) (No. 2) Accessibility Regulations 2018 <http://www.legislation.gov.uk/ukxi/2018/952/made>

¹⁶⁴ BBC Ouch 28.4.20 *Coronavirus: Lack of sign language interpreters leads to legal case against government* <https://www.bbc.co.uk/news/disability-52323854>

¹⁶⁵ 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>

¹⁶⁶ Evaluation of European Disability Strategy 2010 – 2020 <https://ec.europa.eu/social/main.jsp?langId=en&catId=1484&furtherNews=yes&newsId=9835>

¹⁶⁷ 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>

Overall, better accessibility has resulted from law and policy addressing the barriers faced by people with disabilities. However, substantial inequalities remain, often with some very basic issues, such as accessible communication for people with deafblindness. In general, it is not always easy to seek redress when the law has been broken. Access to justice often is an individual matter in law, requiring a person to challenge potentially more powerful and well-resourced organisations for redress. Nevertheless, the law remains a vital reference point for the implementation of rights.

Recommendations: Human Rights Law and Policy and People with Deafblindness

- Recognition of people with deafblindness is incomplete in human rights law, especially on communication. People with deafblindness should be adequately recognised and represented. Sign languages should have legal status in all countries.
- People with deafblindness and disabilities should be meaningfully and routinely involved in the development and transposition of accessibility law and policy. Adequate financial and other support should be available. There is scope for development especially at national level.
- Technology should be deployed in ways that support disabled people's full participation in society, as set out in the CRPD. It should not be used to shore up service models opposed by people with disabilities, such as institutional living. To support this, people with disabilities, with the assistance of service organisations, should have control of technology and how it is used.
- Technology for people with disabilities should be part of a wider range of types of assistance. Service users should not have to choose between only access to technology or access to personal support – there should be access to both.
- Service professionals should have access to training in the ethics and practicalities of new technologies and their potential for supporting independent living.
- New technologies should be made available and offered where they can improve circumstances and increase quality of life of users. This may involve active searching out of new devices.
- All technologies should be offered in the context of a robust ethical framework that includes maximum regard for safety, security of data and personal privacy.
- Support for installation of technology and training for users should be specified when assessing the needs of people with disabilities. It should be available and offered. Processes for repair and upgrade must be user friendly and include accessible support information.

PART 3

Regulation of New Technologies

New technologies, including artificial intelligence, the Internet of Things and machine learning are being implemented rapidly and developments described in this report are likely to be superseded in the near future. For that reason, we again aim to discuss the general issues rather than detailed developments where possible. We begin with a review of EU initiatives and continue with a comparison of national developments.

European Developments

New technologies have largely been valued for their value to the economy as a driver of growth and jobs, while other human benefits were initially seen to be cost savings to the public and private purse. However, evidence of the potential harms has led to a recognition of the need for a legal and policy framework, considered necessary for technology to gain social relevance and support. Consequently, the EU has developed a series of policy measures that specifically address the broader human implications of AI. Regulations take a rights-based approach and are in line with an emerging global consensus on the need for effective regulation.

Disabled people's organisations have so far been largely supportive of new technologies. The European Disability Forum of (EDF)¹⁶⁸ points out that new technology has enabled people with disabilities to overcome a range of barriers to taking part in society. Noting that people with disabilities are often early adopters of technology, they emphasise AI's potential for a wide range of important activities, including communication, reality technologies for exploring the environment, learning and rehabilitation, robotics and smart environments for assistance. Nevertheless, they also have concerns. As well as access to and usability of the technology, evidence of bias and discrimination entering into algorithms are major problems that potentially limit adoption. More recently, the European Disability Forum (EDF) signed up to the European Digital Rights (EDRi)¹⁶⁹ campaigns to ban the use of AI for biometric identification and mass surveillance.

On 7 December 2018 the European Commission published a Strategy and a Coordinated Plan on Artificial Intelligence¹⁷⁰, calling on Member States to develop national AI strategies by mid-2019. Three priorities were identified: boosting technological and industrial capacity and AI uptake across the economy; modernisation of education and training systems to prepare for labour market changes; and ensuring an appropriate ethical and legal framework based on the CFR. Other developments include AI Watch¹⁷¹, which provides information on developments, including at country level. In 2018 the Commission also published a White Paper: *On Artificial Intelligence - A European approach to*

¹⁶⁸ Marzin, C. (2018) *Plug and Pray: A disability perspective on artificial intelligence, automated decision-making and emerging technologies*, European Disability Forum, <http://www.edf-feph.org/sites/default/files/edf-emerging-tech-report-accessible.pdf>

¹⁶⁹ EDRi <https://edri.org/>

¹⁷⁰ AI for Europe, COM/2018/237 final <https://ec.europa.eu/transparency/regdoc/rep/1/2018/EN/COM-2018-237-F1-EN-MAIN-PART-1.PDF>

¹⁷¹ AI Watch https://ec.europa.eu/knowledge4policy/ai-watch_en

*excellence and trust*¹⁷² with the main policy measures proposed open for consultation. The White Paper set out some important recommendations on safeguards for the use of AI some of which will be described further below.

However the White Paper contains few references to people with disabilities. It recognises that people with disabilities and other groups may be at risk of discrimination from misuse of AI and widespread data breaches,¹⁷³ but it is not acknowledged to the same extent as for gender and ethnicity, where there have been several well publicised incidents. These involved the transfer of discriminatory practices in society to AI systems that learned to discriminate against certain populations, notably women and ethnic minorities.¹⁷⁴

On the 8 April 2020 the Council of Europe adopted Recommendation CM/Rec(2020)1 of the Committee of Ministers to member States on the human rights impacts of algorithmic systems,¹⁷⁵ which recommends that member states review their legislation as well as consult widely, including with civil society. However, this recommendation still does not recognise a need to safeguard the rights of people with disabilities, in contrast to other groups, only including mention that private sector organisations should not develop technology that discriminates against people with disabilities.

Draft regulations on AI¹⁷⁶ were published on the 1 June 2021. These state the intention to regulate AI, striking a balance between promoting the use of AI and addressing the associated risks, through EU level legal means. The regulations were published after this report was initially submitted and therefore it is not possible to discuss them in detail here. However, they are mentioned as they are a very important development, for SUITCEYES and society as a whole. The central role given to human rights legal frameworks and a sectoral and risk-based approach is welcome. The rights of people with disabilities are mentioned once and human rights legal instruments underpinning the regulations apply to people with disabilities. However, there is ambiguity in that the regulations refer more than once to voluntary accessibility agreements for people with disabilities and it is not clear that existing accessibility legislation has been sufficiently taken into account. Accessible AI technology should be a legal requirement. There is also reference to the vulnerability of people with disabilities, which is a controversial term for many people with disabilities who may prefer the emphasis to be directed towards dealing with those perpetrating harm. It is also not evident how implementation will be handled, for example, how the intended purpose of AI will be determined in relation to actual use. Clearly there is still scope for further refinements.

¹⁷² European Commission White Paper, On Artificial Intelligence - A European approach to excellence and trust https://ec.europa.eu/info/sites/info/files/commission-white-paper-artificial-intelligence-feb2020_en.pdf

¹⁷³ Access Now (2020) *Two Years under the EU GDPR an implementation progress report* <https://www.accessnow.org/cms/assets/uploads/2020/05/Two-Years-Under-GDPR.pdf>

¹⁷⁴ AI Now Institute (2019) *Discriminating System: s Gender, Race, and Power in AI* <https://ainowinstitute.org/discriminatingystems.pdf>

¹⁷⁵ Recommendation CM/Rec(2020)1 of the Committee of Ministers to member States on the human rights impacts of algorithmic systems

¹⁷⁶ European Commission (1.6.21) Proposal for a Regulation of the European Parliament and of the Council Laying Down Harmonised Rules on Artificial Intelligence (Artificial Intelligence Act) and Amending Certain Union Legislative Acts <https://digital-strategy.ec.europa.eu/en/library/proposal-regulation-laying-down-harmonised-rules-artificial-intelligence-artificial-intelligence>

The EU is collaborating with the OECD and others in seeking to regulate AI and develop a legal and the policy framework for its development. OECD.AI¹⁷⁷ provides a site for monitoring developments in AI policy, including at a national level through links to documents. The EU also provides information on national level policy developments via AI Watch, through the links below.

Table 6 National Strategies on Artificial Intelligence

Country	Link
Germany	https://ec.europa.eu/knowledge4policy/ai-watch/germany-ai-strategy-report_en
Greece	https://ec.europa.eu/knowledge4policy/ai-watch/greece-ai-strategy-report
Netherlands	https://ec.europa.eu/knowledge4policy/ai-watch/netherlands-ai-strategy-report_en
Sweden	https://ec.europa.eu/knowledge4policy/ai-watch/sweden-ai-strategy-report_en
UK	https://ec.europa.eu/knowledge4policy/ai-watch/united-kingdom-ai-strategy-report_en

In the rest of this section, we look at some aspects of new technology of relevance to the SUITCEYES project, the extent to which they are regulated and current debates where they apply.

Use of Personal Cameras and Sensors for Data Processing

The GDPR, which is incorporated into national laws in Europe, allows 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. Dash cams in cars are mostly legal although there are some differences between countries, primarily concerning identification of pedestrians.

Public space use of cameras and sensors by the police and other authorities beyond the home is more controversial and is governed by different laws. Surveillance of public spaces is becoming more widespread through closed-circuit television (CCTV) cameras in many EU countries. In areas where use is widespread (DE, UK) the possibility of public monitoring is often unwelcome, especially as it is often associated with greater intrusion and the possibility of restriction. In Sweden, where use is lower, research shows greater public support.¹⁷⁸

The EU White Paper on AI¹⁷⁹, (published 19 February 2020), which aims to develop a Europe – wide ‘human – centric approach’ to AI, points out several issues concerning legality of the processing of data. EU data protection rules do not allow the processing of biometric data for identifying people, except under specific conditions linked to the public interest. The GDPR permits such data processing on a limited number of grounds, mainly where there is a substantial public interest. Processing may only be carried out on the basis of EU or national law, be proportional, and be aligned to the right to

¹⁷⁷ OECD.AI <https://oecd.ai/>

¹⁷⁸ Lusax, Lund University http://lusax.se/Pressrelease_LUSAX_ENG_april2018.pdf

¹⁷⁹ European Commission White Paper, On Artificial Intelligence - A European approach to excellence and trust https://ec.europa.eu/info/sites/info/files/commission-white-paper-artificial-intelligence-feb2020_en.pdf

data protection and safeguards. The *EU Law Enforcement Directive*,¹⁸⁰ concerned with data processing for criminal investigations, states that data processing must be strictly necessary, with authorisation by EU or national law as well as appropriate safeguards. Processing of biometric data for the purpose of identification of individual people would be against a prohibition laid out in EU law and would be subject to the CFR. Therefore, AI may only be used for remote biometric identification purposes where such use is justified, proportionate and subject to adequate safeguards.

While all countries have passed related legislation¹⁸¹ there are some important differences. In Greece, processing of personal data, including through cameras and sensors, is regulated by the recently transposed GDPR Directive to Greek law (L.4624/2019).¹⁸² However, face and object recognition are not explicitly addressed in the current legal framework in Greece.¹⁸³ Other countries' legislation is more explicitly aligned to the EU Directive. In the Netherlands the use of face and object recognition is not permitted, unless used for identification and security reasons. Companies who want to use biometric identification processes are expected to comply with specific rules set out to protect privacy and ask permission by the independent Authority *Privacydata*,¹⁸⁴ which oversees the General Regulation of Data Protection. In the UK, the use of face recognition is highly contested too, both in terms of general data and for the purposes of criminal investigation. At times these purposes can be blurred, as when used for crowd surveillance. An important judgement supported use of live face recognition by the police in South Wales¹⁸⁵ but a successful appeal was launched by Liberty, a national human rights organisation.¹⁸⁶ In Germany too, it is reported that there was seen to be a high need for regulation. It is clear therefore that the area is highly contested.

Related to these uses, the Fundamental Rights Agency (2019)¹⁸⁷ has discussed violation of human rights through face recognition and notes important ways that rights may be infringed. However, use of face recognition for communication is not mentioned and it is important that legitimate uses of this technology are discussed and taken into account, for example as with the SUITCEYES project. While use of cameras and face recognition is most effective in and around the home, often for technical reasons related to what is currently possible, it is important to plan for the longer term, when it may become easier to use the technology outside the home. The EU White Paper on AI is a potentially helpful development for disabled people using of AI and other technologies. It is important that

¹⁸⁰ Law Enforcement Directive <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX:02016L0680-20160504>

¹⁸¹ For example: the German Data Protection Act, (Bundesdatenschutzgesetz) (BDSG), the GDPR Directive to Greek law (L.4624/2019), the Netherlands General Regulation of Dataprotection, the Swedish Camera Surveillance Act (2018: 1200) and the UK Data Protection Act,

¹⁸² <https://www.e-nomothesia.gr/kat-dedomena-prosopikou-kharaktera/nomos-4624-2019-phek-137a-29-8-2019.html>

¹⁸³ A full review of legislation addressing rights in the digital world (including Greek Constitution): <https://www.homodigitalis.gr/%ce%b5%ce%bd%ce%b7%ce%bc%ce%b5%cf%81%cf%89%cf%84%ce%b9%ce%ba%cf%8c-%cf%85%ce%bb%ce%b9%ce%ba%cf%8c/%cf%83%cf%87%ce%b5%cf%84%ce%b9%ce%ba%ce%ae-%ce%bd%ce%bf%ce%bc%ce%bf%ce%b8%ce%b5%cf%83%ce%af%ce%b1>

¹⁸⁴ Autoriteit Persoonsgegevens. <https://autoriteitpersoonsgegevens.nl>

¹⁸⁵ R -v- The Chief Constable of South Wales Police and others <https://www.judiciary.uk/judgments/r-v-the-chief-constable-of-south-wales-police-and-others/>

¹⁸⁶ R (on the application of Edward Bridges) v The Chief Constable of South Wales Police [2020] EWCA Civ 1058 <https://www.judiciary.uk/wp-content/uploads/2020/08/R-Bridges-v-CC-South-Wales-ors-Judgment.pdf>

¹⁸⁷ FRA <https://fra.europa.eu/en/publication/2019/facial-recognition-technology-fundamental-rights-considerations-context-law>

fundamental rights are taken into account because the purposes of deployment vary so greatly. Although there is justified concern about unwelcome intrusion of cameras and data processing, technology can be a very important enabler when used with appropriate safeguards. The Commission has stated that it intends to launch a debate on where and when AI could be used and it is vital that people with disabilities and with deafblindness are part of this.

By way of a brief update, the AI regulations developed from the White Paper may offer some way forward through their adoption of a sectoral approach. However, it is essential that there is further input from people with disabilities on this.

Ethical Frameworks Relevant to People with Disabilities and New Technologies

The European Commission set up the High-Level Expert Group on Artificial Intelligence (AI HLEG) in June 2018. The group was tasked with drafting two deliverables: AI Ethics Guidelines and Policy and Investment Recommendations. Ethics Guidelines for Trustworthy AI was published in on 8 April 2019 and there are three components. Actors and processes involved in the development, deployment and use of AI should be: (1) lawful - respecting all applicable laws and regulations, (2) ethical - respecting ethical principles and values, and (3) robust - resilient and secure. Seven further imperatives are given: human agency and oversight, technical robustness and safety, privacy and data governance, transparency, diversity, non-discrimination and fairness, societal and environmental well-being and accountability.

This report will not describe all developments in relation to ethics, which are now fast moving and extensive¹⁸⁸. However, it is worth noting that the ethics guidelines proposed by the AI HLEG have been piloted as a way of gathering more feedback and further developing the guidelines. Broader discussions with the G7 and the G20, and with the OECD, the Council of Europe and UNESCO have also taken place and these are part of a continuing effort to develop an ethical approach to AI that extends beyond Europe. The White Paper on AI (2020: 9) also states that the EU will “finance a €2.5 million project that will facilitate cooperation with like-minded partners, in order to promote the EU AI ethical guidelines and to adopt common principles and operational conclusions.”

Most countries have taken some actions to develop AI, IoT and the digital economy at national level. However, in many cases, the response to the situation of people with disabilities is under-developed and not yet thought through.

The Netherlands developed a digital strategy in 2018¹⁸⁹ that includes a commitment to “making efforts to ensure the use of ethical guidelines (European and otherwise) for AI applications by companies and public organisations.”¹⁹⁰ As yet, we were not able to find explicit reference to people with disabilities as participants in drawing up an ethical approach to AI. This is also the situation in Greece, where law

¹⁸⁸ For an account of the process, see also Smuha, N.A. (2019) The EU Approach to Ethics Guidelines for Trustworthy Artificial Intelligence *Computer Law Review International*, 20(4), 97 – 106.

¹⁸⁹ Netherlands Digital Strategy <https://www.nederlanddigitaal.nl/nederlandse-digitaliseringsstrategie>

¹⁹⁰ Netherlands Digital Strategy p7

and policy on new technologies remain underdeveloped. There was no legal framework in Greece for AI at the time of compiling the report, and it may be that if principles are advanced in other member states and at EU level, that developments in Greece will follow.

In Germany, while there was at the time of writing the report no framework for research using artificial intelligence, systems were under development. The German Federal Government set up the *Datenethikkommission*¹⁹¹ (*Data Ethics Commission*) as an independent and autonomous body of experts with the task¹⁹² of proposing ethical standards and guidelines, making concrete recommendations for the protection of individuals and society and the promotion of prosperity. Ethical boundaries for the use of AI and robots are under the auspices of the Commission, especially for social care and support and for particularly vulnerable groups (children, older people and disabled people). The brief also included questions about how responsibility is allocated for systems that fail to work. Special attention should be paid here to vulnerable groups, including people with disabilities.¹⁹³

The Committee's final report was submitted in October 2019.¹⁹⁴ The regulatory system was still at a theoretical stage at the time of writing this report. It proposed a criticality pyramid and a risk-adapted regulatory system for using algorithmic systems, including AI. It distinguished five levels, each of which requires specific regulatory measures. The German Interviewee 1 thought that smart clothing, depending on its design, could range anywhere between level 2 and 5.¹⁹⁵ Under the system, Level 2 refers to 'Applications with some potential for harm' and formal regulation is required (e.g. transparency obligations or publication of a risk assessment), or monitoring procedures (e.g. disclosure obligations towards supervisory bodies, ex-post controls, audit procedures). Level 5 refers to 'Applications with an untenable potential for harm' and imply complete or partial ban of an algorithmic system.

The Swedish government established the Committee for Technological Innovation and Ethics (KOMET¹⁹⁶) in August 2018, to place a special focus on ethical and social aspects of AI. An AI sustainability hub¹⁹⁷ has also been founded by companies, universities and public authorities. In 2019 a report that was "an inventory of the state of knowledge of ethical, social, and legal challenges related to artificial intelligence" was published. However, disability¹⁹⁸ was not mentioned. The authors of the SUITCEYES Swedish national report point out that although AI will affect many people with disabilities, there is no special focus on this target group, either by AI's sustainability Centre or at KOMET.

The UK has developed a strategy for the development of AI and allocated funding and resources for development. As part of the strategy, the Centre for Data Ethics and Innovation has been set up as part of the Department for Digital, Culture, Media & Sport.¹⁹⁹ The organisation states that its role is to

¹⁹¹ Datenethikkommission (2019) *Gutachten der Datenethikkommission* www.bmi.bund.de/DE/themen/it-und-digitalpolitik/datenethikkommission/datenethikkommission-node.html accessed on 27th January 2020.

¹⁹² Bundesministerium des Innern, für Bau und Heimat (BMI), and Bundesministerium der Justiz und für Verbraucherschutz (BMJV) (2018), 2.

¹⁹³ Interview with Respondent 1, 2020.

¹⁹⁴ Datenethikkommission der Bundesregierung (DEK) (2019).

¹⁹⁵ Interview with Respondent 1, 2020

¹⁹⁶ <https://www.kometinfo.se/in-english/about-us/>

¹⁹⁷ <http://www.aisustainability.org/about-us/>

¹⁹⁸ The report has been searched, where the words disability, disabilities and disabled have been used.

¹⁹⁹ Centre for Data Ethics and Innovation <https://www.gov.uk/government/organisations/centre-for-data-ethics-and-innovation>

advise the government about measures needed to ensure safe and ethical innovation in data and AI. The Centre is not itself a regulator of AI but aims to help ensure that those who govern and regulate the use of data across sectors do so effectively. At the time of writing this report, a number of publications had been produced, including a report concerned with bias and other problematic issues in AI, notably, a review of bias in algorithmic decision making.²⁰⁰ This review picks up on some well-known examples of discrimination based on race and gender but does not have any comment on disability beyond its mention as a protected characteristic.

It is evident from these examples that there is recognition in all countries that AI, machine learning and IoT can be discriminatory but very little attention as yet has been paid to the problems faced by disabled people. There is no evidence that the omission of disability is deliberate in these reports, which tend to respond to some specific issues such as reports of financial discrimination against people from minority ethnic groups and employment discrimination against women, following energetic lobbying by these groups. However, omission can have serious consequences. With daily discrimination a continuing problem for people with disabilities it is essential that steps are taken to prevent that transfer of discrimination into the data used for training AI systems and uses of AI. Additionally, cybersecurity and privacy are particularly important for people with disabilities because of known risks of hate crime, stalking and abuse.²⁰¹

There is a need for more discussion about ethical use and control of technology and data by people with disabilities. Most (with some notable exceptions) have been only marginally involved in the current discussion about AI and there should be greater focus on ensuring participation. It can be particularly difficult for people with disabilities to defend themselves against discrimination caused by decisions of algorithmic systems and privacy breaches if these are part of a technology system that is needed for communication or other essential everyday functions. Systems have to reliably work well and do no harm. By way of an example of harm, a study from the search engine Brave in 2020²⁰² uncovered widespread surveillance of UK citizens by private companies embedded on UK council websites. The report highlights that people seeking help for addiction, disability, and poverty on council websites were specifically targeted. Brave noted that there is a tendency for governments to assume that developers will abide by existing legislation and this will be sufficient to cover breaches. However, this is clearly not always the case and the opacity of AI is a problem for many seeking redress, who may be unaware of the harms involved. Such issues point to the need for robust legislation rather than overreliance on voluntary agreements by the public and private sectors.

²⁰⁰ Centre for Data Ethics and Innovation *Review on bias in algorithmic decision making* (2019) <https://www.gov.uk/government/publications/the-centre-for-data-ethics-and-innovation-calls-for-evidence-on-online-targeting-and-bias-in-algorithmic-decision-making/centre-for-data-ethics-and-innovation-review-on-bias-in-algorithmic-decision-making>

²⁰¹ European Network on Independent Living (ENIL) *Disability Hate Crime* http://www.enil.eu/wp-content/uploads/2012/06/Disability_Hate_Crime_Guide-FINAL-ENG.pdf

²⁰² Brave https://brave.com/wp-content/uploads/2020/02/Surveillance-on-UK-council-websites_compressed_version.pdf

People with Disabilities Access to Information

In this section we discuss the extent to which people with disabilities have access to information about new and developing technologies. There are particular problems for people with sensory impairments due to communication barriers, over and above the more general challenges in understanding the implications of new technologies that affect the general population. As noted in the European Union’s White Paper, there are opacity difficulties with artificial intelligence due to its technical nature and the fast pace of developments. First, we discuss the findings from the national reports and then consider the results of interviews carried out for the SUITCEYES project in the five countries.

A summary of sources of information about new technologies is given in the table below.

Table 7 National Sources of Information on Technology

Country	Sources of Information
Germany	Independent advisory centres: under the Federal Participation Act (BTHG) ²⁰³ Supplementary Independent Participation Guidance Agency (EUTB) ²⁰⁴ : runs 500 guidance centres Rehadat Information System ²⁰⁵ – provides online advice NGOs e.g. Aktion Mensch ²⁰⁶
Greece	Information available via various organisations but no overall system. These include private organisations, DPOs / OPDs, online platforms in the field of education and some accessibility units in higher education.
Netherlands	Privacydata ²⁰⁷ publishes a guide to the IoT and how companies use various technologies to gather data from consumers.
Sweden	Mainly via municipalities but some lack of clarity exists about legality and ethics.
United Kingdom	No single source of information about new technologies. Organisations include: charities e.g. AbilityNet ²⁰⁸ , Scope ²⁰⁹ and others.

National reports indicate that there are sources of information latest developments in technology but systems are patchy and fragmented in all countries. Despite some innovative projects, it is often not straightforward for people with disabilities to know where to find information about new technologies and they have less access to the internet compared with the general population. Communication barriers often present difficulties. A number of additional issues were raised in interviews with 79 people with deafblindness carried out by the SUITCEYES project between June 2018 and October 2019.

²⁰³ Independent Advisory Centres, <https://www.betanet.de/unabhaengige-teilhabeberatung.html>

²⁰⁴ EUTB <https://www.teilhabeberatung.de/>

²⁰⁵ Rehadat Information System <https://www.rehadat-hilfsmittel.de/de/informationen/ueber-uns/>

²⁰⁶ Aktion Mensch <https://www.aktion-mensch.de/>

²⁰⁷ Autoriteit Persoonsgegevens. <https://autoriteitpersoonsgegevens.nl>

²⁰⁸ AbilityNet <https://abilitynet.org.uk/about-abilitynet>

²⁰⁹ Scope <https://www.scope.org.uk/news-and-stories/artificial-intelligence-disabled-people/>

Interviews were carried out in the same five countries. Details about the process and personas, scenarios, use cases and methods are documented respectively in D2.1, D2.2 and D2.3 of the SUITCEYES project and more detailed analysis of the results will be given in future publications.

Many people with deafblindness did not have access to information about state of the art technology. A small number of people were well informed and they were often connected to leading NGOs concerned with disability. Some worked in or had connections to the fields of accessible technology, in which case they were particularly well informed. However, this was not the case for most.

Our interviews indicated that many people with deafblindness needed information in a different form from that usually presented on websites and this is often needed to be personalised to their own requirements. Not just written or spoken, but also tactile information, in terms of being able to try out technology, was essential. Much information on the Internet assumes that people are able to read, generalise and appreciate what technology might do from reading information on the page. Participants we talked to wanted to try out technology to find out what it felt like and very importantly how it interacted with other aids and devices they were using already.

Often people we interviewed had clear ideas about the functions they wanted the technology to fulfil. Examples included identifying important things in the environment, identifying people and objects and gaining information to help with journeys. They wanted to know about the degree of personalisation that might be possible and the range of options. This indicates that people with disabilities need to be involved at the design and development stages and not merely offered information about a device that has been finalised.

Beyond individual involvement there is considerable scope for scientific research to be carried out with groups that are more closely allied to people with disabilities. This includes groups of people with disabilities involved in making their own assistive technology²¹⁰ and organisations that represent users of assistive technology. This is potentially more difficult with AI, IoT and machine learning because the technology is developing quickly and is more difficult to understand; nevertheless, this exchange of information is vital for effective, relevant and cost-effective solutions. This represents a research opportunity for the future.

Access to Equipment

Public sector

Access to equipment is a national rather than EU competence. Often linked to personal human support, decisions are usually made following individual application to an authority. As noted earlier, in each of the countries, there are specific systems for allocating equipment to people with disabilities and in the majority of cases allocation is carried out by municipalities or regional authorities. Some examples follow.

In the Netherlands, provision of equipment at home is based on the Social Support Act 2 and municipalities have freedom to decide on the allocation of equipment, costs and conditions although

²¹⁰ See for example, Hamraie, Aimi and Kelly Fritsch. 2019. "Crip Technoscience Manifesto." *Catalyst: Feminism, Theory, Technoscience* 5(1): 1-33.

they are not obliged to publish lists or guidelines. Contracts are issued to manufacturers via competitive tendering and these may specify the maximum amounts to be paid. In the UK, small equipment and minor adaptations for use in daily living are also usually provided by local social service authorities but certain kinds of devices are funded or prescribed by health authorities. A similar situation applies to Sweden where most devices or aids are prescribed by Health Care Services for habilitation and rehabilitation. Responsibility here is shared between the counties and municipalities. In Greece, the types of technical aids or technology are defined by the single organisation for the provision of Health Services. In Germany, a whole series of stakeholders are involved in the financing of aids and equipment (so-called rehabilitation providers). These include pension insurance providers, the Federal Employment Agency, the statutory accident insurance companies, the integration offices and health insurance companies.²¹¹ This is a complex system with overlaps and certain areas of uncertainty in respect to the fields of responsibility. The stakeholders involved have come together to form the *Bundesgemeinschaft für Rehabilitation (National Rehabilitation Alliance)*, which aims to improve the situation.

People with disabilities are often disadvantaged in dealing with these systems. Evidence shows that people with disabilities are likely to be poorer, with fewer resources and more likely to require assistance from the state.²¹² They often also have lower digital literacy compared with the general population.²¹³ Inequalities persist even in Sweden, where the population is considered to be highly digitally literate as almost all the population has access to smart phones, with people with visual impairments relatively disadvantaged.²¹⁴ Our desk research found that systems for obtaining equipment often presented difficulties from the point of view of users. These problems concerned difficulties with both the formal ways that allocation systems were meant to work and the actual practice of carrying out the rules.

Limitations placed on eligibility were particularly problematic in Germany and the UK,²¹⁵ with high levels of refusals and legal appeals evident. The type of equipment made available to applicants often depended on the sphere of operation of the funder and the national, regional and municipal administrative area. Some devices could only be used for specific purposes, e.g., when at school, work or at home (NL, UK) and could not be taken to another place by the user. Some equipment could not be used if it was intended for general daily use (DE). Age and diagnosed impairment could also limit eligibility (DE). A lack of orientation to the needs of users of assistive technology was evident in Greece.

²¹¹ <https://www.rehadat-literatur.de/de/rehabilitation-und-teilhabe/rehabilitationstraeger/> accessed on 11 April 2020.

²¹² See ANED reports on Statistical Indicators <https://www.disability-europe.net/theme/statistical-indicators>

²¹³ Scholz, F., Yalcin, B., & Priestley, M. (2017). Internet access for disabled people: Understanding socio-relational factors in Europe. *Cyberpsychology: Journal of Psychosocial Research on Cyberspace*, 11(1), <https://doi.org/10.5817/CP2017-1-4>; in the UK, Office for National Statistics (2019) *The Digital Divide* <https://www.ons.gov.uk/peoplepopulationandcommunity/householdcharacteristics/homeinternetandsocialmediausage/articles/exploringtheuksdigitaldivide/2019-03-04>

²¹⁴ Johansson, S., Gulliksen, J. & Gustavsson, C. Disability digital divide: the use of the internet, smartphones, computers and tablets among people with disabilities in Sweden. *Univ Access Inf Soc* 20, 105–120 (2021). <https://doi.org/10.1007/s10209-020-00714-x>

²¹⁵ See for example, UK Work and Pensions Committee (2018) <https://www.parliament.uk/business/committees/committees-a-z/commons-select/work-and-pensions-committee/news-parliament-2017/pip-esa-full-report-17-19/>

Another question concerns whether innovative devices incorporating new technologies could be included in the list of permitted devices produced by authorities.

In Sweden, the way that new technology becomes available in practice provides a clear example of the difficulties that can often beset the approval of new products, but similar problems are often found in other countries as well. In Sweden, in order for innovations to be introduced as aids, they must be thoroughly evaluated. Testing and evaluation puts demands on health care services and bureaucratic requirements can result in lengthy delays. If other (older) aids already meet the same needs, there is no incentive in the system to introduce innovation, even if these show user benefit and better safety. The Aid Investigation²¹⁶ has reported, for example, that the lack of an ISO code for a product can mean that the innovation is not classified as an aid and therefore not made available. With the present rapid technological development, there are often new, modern and useful products on the market that are not included in the Swedish health care service's procurement range and the Swedish researcher concludes that there is no "freedom of choice" for new technologies as aids.

Some initiatives to improve the situation and examples of better practice are reported. In the Netherlands, the national Government published a policy letter in 2019, with the aim of improving access to digital technology. In two countries (DE, EL), new technologies were indeed made available to people with disabilities for enhancing accessibility although in Greece this was quite limited (the technology was not available for many purposes and there were delays with availability in schools). For a number of reasons, not least savings to taxpayers and insurers, it was generally more likely that technology would be adopted by authorities and made available to people with disabilities if it could be applied to many situations, was robust and not expensive.

In recent years people with disabilities have successfully argued for the availability of personal assistance, a funding stream that often includes aids and adaptations. Direct payments involve the allocation of funds to disabled individuals for buying in or arranging their own assistance, as long as they are deemed eligible to receive this from the relevant authorities. There is substantial evidence that this is preferred by many people with disabilities, resulting in better outcomes. In these instances, people with disabilities are the purchasers rather than the local authorities or municipalities, even if they are funded by them. The right to independent living in the community is established in Article 19 of the CRPD, described above, and these arrangements offer an alternative, more personally responsive system for many. Getting equipment in this way can mean it is more flexible and personalised, although it is also essential that the costs of installation, repair and upgrades are also included. For people with deafblindness, assistance to deal with upgrades and learn to use new devices is essential.

Private Sector

Direct access to technology without the need to make a request through municipalities and local authorities is an alternative route for people with disabilities. It is clearly preferable that technology has accessibility features built in from the start, using universal design, and there is evidence of substantial progress in recent years. In Europe, the market is dominated by American companies, such as Microsoft and Apple, which have led the way in developing accessible software, much of which is very useful for people with sensory impairments, especially blind and partially sighted people.

²¹⁶ <https://www.regeringen.se/rattsliga-dokument/statens-offentliga-utredningar/2017/05/sou-201743/>

Despite their usefulness however, smartphones are rarely made available as devices to recipients of social care services.

From a policy perspective, the private sector is considered an important partner for the development of new technologies. The European Union White Paper on Artificial Intelligence states under Action 5:

In the context of Horizon Europe, the Commission will set up a new public private partnership in AI, data and robotics to combine efforts, ensure coordination of research and innovation in AI, collaborate with other public-private partnerships in Horizon Europe and work together with the testing facilities and the Digital Innovation Hubs mentioned above.

Evidence of European national level activity is variable so far. In Greece and Sweden there is not much evidence of private sector innovation and partnership with people with disabilities. Although social inclusion for people with disabilities is politically uncontested in Sweden and resources are provided for innovation in this area, public information about private sector initiatives was not readily available. In Greece, activity is limited. The National Strategy for Smart Specialisation 2014-2020²¹⁷ identifies low levels of innovation in the country overall, as well as “a clear lack of orientation towards the real needs of society and especially of youth and vulnerable groups”. Poor development of infrastructure is considered to be hampering the foundation for universal design.

<https://ec.europa.eu/digital-single-market/en/news/staff-working-document-guidance-sharing-private-sector-data-european-data-economy> More initiatives were identified in the Netherlands, Germany and UK. In the Netherlands the foundation Accessibility²¹⁸ is an expert centre and research institute that focuses on website accessibility for people with visual impairments and a smaller company, Digitaal Toegankelijk, assists with implementation.²¹⁹ There are also network organisations for knowledge exchange between private and public initiatives on digital innovations for enhancing accessibility and health solutions.

In Germany, a large number of initiatives involve the private sector and many of these are pilot projects developing specific devices. The authors of the German report note that in consequence, prototypes are developed that subsequently need to be adapted in order to meet special requirements. This process is in turn associated with a high level of cost, exacerbated by the fact that such items are niche products, which do not have a large sales market. When AI is involved then there is an additional cost linked to regulation in respect of aspects such as the use of cameras and many prototypes are not pursued to the point of market maturity. This situation (which also applies in other countries) is regrettable because products and technologies that have been well adapted to the requirements of users can make a significant contribution towards improving participation and can thus have an impact on quality of life.²²⁰

The UK Government states that the AI sector has agreed a £1 billion package of support from government and industry to boost the development of new technology. The Office for Artificial Intelligence has been founded and a strategy for development established. Overall however, there is

²¹⁷ National Strategy for Smart Specialisation 2014-2020

<http://www.gsrt.gr/Financing/Files/ProPeFiles19/Executive%20Summary-2015-09-17-v04.pdf>

²¹⁸ <https://www.accessibility.nl/over-accessibility>

²¹⁹ Digitaal Toegankelijk <https://digitaaltoegankelijk.com/over-digitale-toegankelijkheid/>

²²⁰ Respondent 2 2020, Germany

very little mention of people with disabilities and indeed reference to equality issues. The Alan Turing Institute, a national research centre, has taken the most initiative in terms of its work on AI and inclusion but this is not seen across the sector.²²¹ <https://www.turing.ac.uk/research/research-projects/ai-and-inclusion> In the UK there is a potential for considerably more work of benefit to people with disabilities.

There is clearly some variation in the extent to which general awareness of the importance of accessibility is being translated into specific work that may benefit people with disabilities in Europe. High levels of activity in Germany, the Netherlands and the UK do not necessarily mean a corresponding focus on people with disabilities and development of usable products on the market. Lower levels of activity in Greece reflect inequalities between European countries.

However, given the importance of universal design for people with disabilities' participation in everyday life and the lead taken by the private sector, it is clearly crucial that the private sector is involved further in developing new technological solutions.

Accessibility Measures in the Built Environment

New technologies have led to a growing interest in smart cities that make use of IoT technology, broadband, big data and other technologies to increase efficiency and connectedness. The potential of new technologies to add to accessibility by designing in useful features is noted in the SDGs. SDG Goal 11 (Sustainable cities and communities) specifically mentions people with disabilities:

11.2. By 2030, provide access to safe, affordable, accessible and sustainable transport systems for all, improving road safety, notably by expanding public transport, with special attention to the needs of those in vulnerable situations, women, children, persons with disabilities and older persons" (United Nations, 2015) , and..

11.7 By 2030, provide universal access to safe, inclusive and accessible, green and public spaces, in particular for women and children, older persons and persons with disabilities.

The European Union is currently supporting work on smart cities and communities (EIP-SCC)²²², bringing together cities, industry, small business (SMEs), banks, researchers and others to increase communication, effectiveness and community cohesion based on place. Increasing digital connectedness of cities is also prioritised at national and city levels, involving a number of partners and aiming to use digital technologies to enhance communication and connectedness. While these initiatives are general and not specifically to do with people with disabilities, there potentially are opportunities to increase the accessibility and use of public space by people with disabilities and this

²²¹ Alan Turing Institute <https://www.turing.ac.uk/research/research-projects/ai-and-inclusion>

²²² Smart cities https://ec.europa.eu/info/eu-regional-and-urban-development/topics/cities-and-urban-development/city-initiatives/smart-cities_en <https://eu-smartcities.eu/>

has recently been recognised, in a growing number of projects.²²³ Notably, Smart Cities for All²²⁴ promotes universal design and inclusion.

There has also been interest and support from organisations of persons with disabilities. The World Blind Union is actively engaging in a number of programmes, including the Global Compact on Accessible and Inclusive cities and is taking part in the Disability Inclusion and Accessibility in Urban Development Network in the Cities 4 All Campaign, launched by G3ICT.²²⁵ Concerning the integration of technologies, The Danish Association of the Blind has investigated the potential of integrating RFID tagging in public space to indicate locations,²²⁶ finding it a useful development.

National researchers for SUITCEYES have identified a number of relevant initiatives.

In Greece, several projects may be useful to people with disabilities. These include “Developing a Strategy for Smart Cities and Implementation of a National Parking Management System”²²⁷, which aims to reduce anti – social parking, including illegal parking over access points for people with disabilities. In Athens, parking places for people with disabilities will also be safeguarded. Wheelroute²²⁸ is an application being developed by Greek start-up “AccessLab” with the support of the “Invent ICT” incubator²²⁹. This is an online GIS platform with open accessibility and mobility data that enables the user to gain information about accessible ramps and pavements in specific areas of Athens and also navigate through suggested routes from one point to another, measure a distance and report an obstacle, such as illegal parking. E-vision²³⁰ is a research project in progress at the time of writing this report, led by the ICT Institute of the National Centre for Research and Technological Development²³¹, aiming to create a system for assisting people with reduced vision to identify people and objects. Please see the national report for Greece for further details of this, and other work.

In the Netherlands, there has been a co-ordinated approach. In 2017, 40 representatives of cities, 60 company employees and 30 scientists presented a national smart city strategy.²³² This 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. Although smart cities are not specifically aimed at improving accessibility for people with disabilities, it may be noted that the city of Breda, which tested an app at the end of 2019 that enabled disability cardholders to easily find designated parking places in the city.²³³

²²³ For example: Trips project <https://trips-project.eu/>; Shapes project shapes2020.eu/ and others

²²⁴ Smart Cities for All: <https://smartcities4all.org/>; <https://smartcities4all.org/wp-content/uploads/2017/06/Smart-Cities-for-All-A-Vision-for-an-Inclusive-Accessible-Urban-Futur...-min.pdf>

²²⁵ Cities for All <http://www.cities4all.org/>

²²⁶ Danish Association of the Blind dkblind.dk

²²⁷ Parking Management System <https://www.akep.gr/AkepFiles/QHEM465X00-N47.pdf>
<https://www.akep.gr/AkepFiles/632H465X00-KPQ.pdf>

²²⁸ Wheelroute <https://webgis.accesslab.gr>

²²⁹ Invent ICT Incubator <https://webgis.accesslab.gr>

²³⁰ <https://evision-project.gr>

²³¹ <https://www.certh.gr/>

²³² <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>

²³³ <https://www.gemeente.nu/ruimte-milieu/den-bosch-test-slimme-parkeerplekken-voor-gehandicaptent/>

In the UK there has been acknowledgement of the potential for smart cities to enhance accessibility, even if these have not all been explicitly realised as yet. Tech UK²³⁴ notes the Mayor of London's recognition of the Global Disability Hub²³⁵ as a contributor to developments for example and there has been recognition for developments in London, Bristol²³⁶, Manchester and Edinburgh. The UK government points out that there is not as yet a national level initiative but a number of city level initiatives exist.²³⁷ One example in London has been the re-design of ticketing for public transport systems so that passengers may pay for use of all forms of public transport with a smart card, making payment easier across the board and removing the need for use of ticketing machines. This system had yet to be introduced in other cities.

The Swedish Government has commissioned to Vinnova, the Swedish innovation agency to carry out a special investment in research and innovation for accessible design. This involved continuing investment between 2017-2020²³⁸, with the aim of developing inclusive cities in relation to disability, age, sex and ethnicity.

In Germany, the *Smart City Charta*²³⁹ was developed in 2016 by the Dialogue Platform Smart Cities consisting of 70 experts from communities and cities, federal government departments, departments of the German states responsible for city development, science, civil society as well as economic and social associations. It appears that no representatives of people with disabilities participated in this dialogue process. The overall goal of the Smart City Charta is to use and shape the digital transformation in such a way that city planning and development is sustainable, citizens as well as economy and politicians are involved in the process, better governance and better access to services including public transportation as well as more equal access to education is reached.

Also in Germany, the *Standardization Roadmap Smart City*²⁴⁰ aims to identify the need for norms and standards for Smart Cities. To this end, the *Deutsche Institut für Normungen e.V. - DIN* (German Institute for Standardization) and the *Deutsche Kommission Elektrotechnik Elektronik Informationstechnik - DKE* (German Commission for Electrical, Electronic & Information Technologies)²⁴¹ are working together with experts from politics, society, industry, the research community and German Cities.²⁴²

A consultation of stakeholders of the EU's disability strategy 2021 – 2023 noted that many measures concerned with accessibility of the built environment often focus on adjustments in relation to visible or evident impairments. Detailed evidence on the situation is not available with regard to people with

²³⁴ Tech UK *London Open for Smart City Investment*

<https://www.techuk.org/insights/news/item/10919-london-open-for-smart-city-investment>

²³⁵ Global Disability Hub: <https://www.ucl.ac.uk/ucl-east/academic-vision/global-disability-innovation-hub>

²³⁶ Bristol City Council

https://www.connectingbristol.org/wpcontent/uploads/2019/11/Connecting_Bristol_300819_WEB.pdf

²³⁷ See UK Government <https://innovateuk.blog.gov.uk/2019/10/08/smart-cities-how-do-the-uk-and-south-korea-compare/>; <https://www.gov.uk/government/speeches/the-uks-leadership-in-smart-cities>

²³⁸ Vinnova <https://www.vinnova.se/m/smarta-stader/tillganglighetsdesign/>

²³⁹ Bundesinstitut für Bau-, Stadt- und Raumordnung (BBSR), (2017).

<https://www.bbsr.bund.de/BBSR/EN/Publications/SpecialPublication/2017/smart-city-charta-de-eng.html>

²⁴⁰ VDE (2014). <https://www.din.de/blob/67300/3a779a8629784919e0b92ff12fc6d9c1/smart-city-standardization-roadmap-smart-city-data.pdf>

²⁴¹ For more on DIN and DKE check also chapter 3 of this report.

²⁴² DIN e. V. and Deutsche Kommission Elektrotechnik Elektronik Informationstechnik (DKE) (2015), p. 7.

deafblindness but the opportunities for building in universal design and communication technologies should be kept under active review.

Skill Development and Work Opportunities

New technologies require new skills and this is especially so in the field of new accessible technologies and people with disabilities. In this section we consider developments in two areas: disability equality and awareness training for designers, engineers and other professionals and training in new technologies for people with disabilities, their assistants and care professionals. A challenge in this is that traditionally the fields of disability studies and engineering and design have been very separate fields to date and there is some way to go in bridging the gap.

CRPD Article 4: General Obligations, requires States Parties to promote training of professionals and staff working with people with disabilities in human rights and the services they guarantee. The European Disability Strategy 2010 – 2020²⁴³ included a commitment to “support design for all in general curricula for architects and engineers to prevent barriers when exercising their professions”. This is important for ensuring that new accessibility barriers do not become part of new designs. However, not much, if any progress has been made on this issue and most training for engineers does not yet routinely include disability equality or awareness training.²⁴⁴

The EU’s White Paper on AI (2020) also states that upskilling is needed for Europe and that this will be a focus of their revised Coordinated Plan on AI. Because it is envisaged that ethical approaches will be taught, there is an opportunity to raise the issue and to include people with disabilities, which is not the case at the moment. It states that:

Developing the skills necessary to work in AI and upskilling the workforce... will be a priority This could include transforming the assessment list of the ethical guidelines into an indicative “curriculum” for developers of AI that will be made available as a resource for training institutions. Particular efforts should be undertaken to increase the number of women trained and employed in this area.

People with disabilities themselves remain severely disadvantaged in education and employment and are disproportionately less likely to become engineers or designers compared with the general population.²⁴⁵ SUITCEYES researchers looked at these issues in the preparation of material for this deliverable. They found small projects, however no national level programmes were identified.

²⁴³ European Disability Strategy 2010 – 2020

<https://eurlex.europa.eu/LexUriServ/LexUriServ.do?uri=SEC:2010:1324:FIN:en:PDF>

²⁴⁴ See ANED entries in DOTCOM: the Disability Online Tool of the Commission, under Theme H. Awareness and External Action – Training for Engineers.

²⁴⁵ For example, see WFDB (2018)

http://www.internationaldisabilityalliance.org/sites/default/files/wfdb_complete_initial_global_report_september_2018.pdf

In Greece there are some vocational training programmes for people with disabilities run by the Public Employment Organization (OAED), which include training in ICT for people with various impairments (although blind people are trained separately in specialised premises)²⁴⁶. Interestingly, there was a recent announcement by the Minister of Education that it is in the government's plans to include new technologies in mainstream primary and secondary school education curricula²⁴⁷.

With regard to training for engineers, the revised Greek disability rights framework (Law 4488/2017) has specified that Universities are responsible for running training modules related to the rights of persons with disabilities according to the UN CRPD. The content and technical specifications of these programmes is to be defined by the respective Ministries in cooperation with the national Coordination Mechanism and Focal Point for the implementation of the UN CRPD (Law 4488/2017 Art. 66, para. 2).²⁴⁸ However, it should be noted that the latter bodies have not been formed to date.

In Sweden, Certec is part of the Department of Design Sciences at Lund University of Technology. Certec conducts research and education on rehabilitation technology and design²⁴⁹ from a disability perspective and on designing technical and human support for everyday living. Technology courses are aimed at civil engineers and industrial designers. Other independent courses are aimed at people working in disability services, such as housing, daily activities, habilitation, psychiatry, and schools.

In Germany, the Federal Ministry of Education and Research (BMBF) has a funding stream for *Inclusion in vocational education and training via digital media*, which forms part of the programme *Digital media in vocational education and training (2017–2022)*. Funded projects include those that adapt education and training provision to the communication requirements of individual people with disabilities.²⁵⁰

In the UK a number of bodies are concerned with professional development of engineers but orientation to people with disabilities tends to be sporadic rather than systematic. The Cambridge University Inclusive Design group²⁵¹ has developed a toolkit that aims to support inclusive design²⁵², which emphasises orientation to user needs. The UK government is committed to the development of AI technology and intends to invest heavily in increasing and developing the workforce. Greater diversity is mentioned as an important aspect with the recommendation that: "Government, industry and academia must embrace the value and importance of a diverse workforce for AI, and should work together to develop public information aimed at breaking down stereotypes and broadening participation." It is not clear however, that people with disabilities are considered part of this more diverse group.

No particular initiatives were identified in the Netherlands.

²⁴⁶ <https://agan.gov.gr/articlesview.php?id=2084>

²⁴⁷ https://www.alfavita.gr/ekpaideysi/ypoyrgeio-paideias/307561_n-kerameos-sto-programma-spydon-oi-nees-tehnologies-diarkis

²⁴⁸ Extract from the DOTCOM Greece H.5 <https://www.disability-europe.net/dotcom>

²⁴⁹ <http://www.certec.lth.se/>

²⁵⁰ <https://www.qualifizierungdigital.de/de/inklusion-durch-digitalisierung-3353.php> accessed on 31th of March 2020.

²⁵¹ Cambridge University Inclusive design group <https://www-edc.eng.cam.ac.uk/>

²⁵² Inclusive Design Toolkit <http://www.inclusivedesigntoolkit.com/>

Equally important is the lack of knowledge of many health and social care professionals. Many are not routinely informed about technology or its potential uses and this can limit it being offered to people with disabilities as part of habilitation and rehabilitation. This is especially so with new technologies, which are difficult to understand for people with little previous training.²⁵³ In consequence, lists of available equipment produced by municipalities may not include latest equipment. Given that our research has shown a low level of awareness of the potential of new technologies by people with deafblindness, there may not be much pressure to update them.

Finally, while there are clearly many difficulties, there are also opportunities. With large training programmes envisaged at national and international levels, it is timely to ensure an affective exchange of knowledge.

Recommendations: Regulation of New Technologies

- Safeguarding of privacy and well-being in relation to use of personal data is as important to people with deafblindness and people with disabilities as it is to non-disabled people. For this reason, effective legal remedies against exploitation and abuse via new technologies are essential.
- AI should be designed in ways that people can explain how decisions are made, and so that people are accountable for the ways AI is used.
- Direct consultation with people with disabilities should take place during the development and production of technology. It should not be left until the phase of testing devices, when it may be difficult to implement changes.
- Accessibility and the principles of Universal Design should be part of the curriculum for courses in computer science, engineering, business etc., as well as mainstreamed in industry as part of continuing professional development.
- Training for designers of accessible technology should include orientation to ways of discovering the needs of people with disabilities and people with deafblindness from a human rights perspective.

²⁵³ UK: All Party Group for Assistive Technology and Policy Connect (2019) *Roundtable, Outcomes: Smart homes and the future of social care*, available from <https://www.thedtgroup.org/media/163670/smart-homes-briefing-outcome-report.pdf> and Sweden: *Personal Communication* to SUITCEYES researchers from Karin Jönsson, National Resource Center for Deafblindness, Sweden, 20200330.

- Training for designers should include information on how people with deafblindness and people with disabilities can access their products in practice, with a view to making access easier wherever feasible.
- It should be required that data for training AI systems needs to be inclusive, accurate, ethical and reflect human worth. Algorithms must be properly scrutinised for evidence of bias and discrimination and remedial steps taken as soon as problems occur.
- Many policy reviews favour wider diversity of personnel in technology industries. This diversity must also include people with disabilities, with proactive steps taken to achieve this.

Conclusions

People with deafblindness have been relatively neglected in the policy field. In many countries there is limited recognition for people with deafblindness as a group and this has led to under-resourcing of assistance and often lack of adjustments for accessibility. Organisations of people with deafblindness do not have resources to organise as effectively as larger organisations of people with visual impairments or who are deaf, often due to communication barriers. This situation is changing to some extent but there is a widespread information deficit about the situation of people with deafblindness and better data is necessary for effective policy planning.

In all European countries reviewed for this deliverable, there are legal and policy measures in place to support non-discrimination, disability equality and accessibility. To a greater or lesser extent they are a result of UN and EU – level law and policy. These human rights measures are a vital point of reference for supporting people with disabilities’ right to participate in the community on an equal basis with others and for reasonable adjustments. As such, they indicate the need to develop technology that supports individual participation in society rather than management of groups for the purpose of administering care. Nevertheless, there is not universal good practice and barriers to taking legal action can mean that access to justice may be difficult for individuals to secure.

There is a great deal of work underway to place the new technologies of AI, IoT and machine learning within a new ethical framework of regulation. At EU level it is recognised that for AI to be adopted widely, it must be trustworthy, human – centric and backed by the rule of law. These developments are very welcome in relation to people with disabilities but at the same time there are many everyday instances of non-compliance and breach of privacy, raising questions about enforcement. Cybersecurity and privacy are particularly important for people with disabilities because of known risks of exploitation, hate crime and abuse. Following some publicised examples,²⁵⁴ steps are also

²⁵⁴ See for example: Brave (2000) *Surveillance on UK council websites*, https://brave.com/wp-content/uploads/2020/02/Surveillance-on-UK-council-websites_compressed_version.pdf; Judgement by the Hague District Court on the *Systeem Risico Indicatie*, (SyRI) [ECLI:NL:RBDHA:2020:1878](https://eclj.europa.eu/eur-lex/en/doc/2020/1878/), [Rechtbank Den Haag, C-09-550982-HA ZA 18-388 \(English\) \(rechtspraak.nl\)](https://rechtspraak.nl) Algorithm Watch (6.10.19) *Austria’s employment agency rolls out discriminatory algorithm, sees no problem* <https://algorithmwatch.org/en/austrias-employment-agency-ams-rolls-out-discriminatory-algorithm/>

needed to counter the negative portrayal of people with disabilities through algorithmic bias and discrimination.

People with disabilities are rarely seen in policy as active users of new technologies. Clearly face and object recognition are potentially very valuable to people with deafblindness as a means of discovering what is happening in the environment. Gaining access to this information could help people with deafblindness to achieve greater equality with non-disabled people. At the same time, concerns about the infringement of privacy and exploitation of individuals via face recognition are warranted. There is a case to be made for a specific legal exemption to allow people with deafblindness to use face recognition software.

People with disabilities are only marginally part of the conversation about regulation of new technologies. While there have been some important initiatives, there is an urgent need for participation on multiple fronts. First, there is scope for much greater involvement in product design. People with disabilities are often involved at the testing rather than initial stages of product design, when it may be too late to make changes. There is still a gap between the potential of smart technology to support social care and independent living and the role that products currently are capable of performing. If this gap is to be bridged effectively, as it is hoped can be done in the future, an understanding of context is vital, as is an orientation to the critical issues that are important to people with disabilities. In a changing environment this needs to be a continuing process rather than a one – off event.

Appendix 1: Summary of Recommendations

The following recommendations may also be found in the text of the main report at the end of the relevant sections. They are summarised here for easier reference.

Regarding People with Deafblindness and People with Disabilities

- A harmonised definition of deafblindness should be adopted by national governments and European level organisations, in collaboration with representatives, such as the European Deafblind Union (EDbU) and the WFDB as well as national organisations of persons with deafblindness.
- Disaggregated official administrative statistical and other data on people with deafblindness should be generated and used to inform progress on key human rights indicators.
- Training in the opportunities and risks presented by new technologies should be made available to people with disabilities, together with greater access to digital technologies, using a range of means. Targeted efforts should be made to include people with disabilities who are likely to be excluded, such as people with congenital deafblindness and older people.
- There should be substantial increase in the involvement of organisations of people with deafblindness and other potential users, in technology development programmes and policies. People with disabilities should be equal partners and recipients of funding to adequately support participation.
- Opportunities for trying out new digital technologies should be expanded where they are scarce. This might include the setting up of centres where people with disabilities can try different sorts of technologies to see how they might work in practice.

Regarding Human Rights Law and Policy on New Technologies and People with Disabilities

- Recognition of people with deafblindness is incomplete in human rights law, especially on communication. People with deafblindness should be adequately recognised and represented. Sign languages should have legal status in all countries.
- People with deafblindness and disabilities should be meaningfully and routinely involved in the development and transposition of accessibility law and policy. Adequate financial and other support should be available. There is scope for development especially at national level.

- Technology should be deployed in ways that support people with disabilities' full participation in society, as set out in the CRPD. It should not be used to shore up service models opposed by people with disabilities, such as institutional living. To support this, people with disabilities, with the assistance of service organisations, should have control of technology and how it is used.
- Technology for people with disabilities should be part of a wider range of types of assistance. Service users should not have to choose between only access to technology or access to personal support – there should be access to both.
- Service professionals should have access to training in the ethics and practicalities of new technologies and their potential for supporting independent living.
- New technologies should be made available and offered where they can improve circumstances and increase quality of life of users. This may involve active searching out of new devices.
- All technologies should be offered in the context of a robust ethical framework that includes maximum regard for safety, security of data and personal privacy.
- Support for installation of technology and training for users should be specified when assessing the needs of people with disabilities. It should be available and offered. Processes for repair and upgrade must be user friendly and include accessible support information.

Regarding the Regulation of New Technologies

- Safeguarding of privacy and well-being in relation to use of personal data is as important to people with deafblindness and disabilities as it is to non-disabled people. For this reason, effective legal remedies against exploitation and abuse via new technologies are essential.
- AI should be designed in ways that people can explain how decisions are made, and so that people are accountable for the ways AI is used.
- Direct consultation with people with disabilities should take place during the development and production of technology. It should not be left until the phase of testing devices, when it may be difficult to implement changes.
- Recent campaigns against the gathering of biometric information, especially through face recognition software, threaten to make illegal the kind of devices being developed by SUITCEYES. We recommend an exemption from these restrictions for people with deafblindness. Biometric identification, with appropriate privacy safeguards, can compensate for sensory impairments and increase accessibility and equality for people with deafblindness.

- Accessibility and the principles of Universal Design should be part of the curriculum for courses in computer science, engineering, business etc., as well as mainstreamed in industry as part of continuing professional development.
- Training for designers of accessible technology should include orientation to ways of discovering the needs of people with disabilities and with deafblindness from a human rights perspective. This should include information on how people with deafblindness and disabilities can access their products in practice, with a view to making this easier wherever feasible.
- It should be required that data for training AI systems is inclusive, accurate, ethical and reflects human worth. Algorithms must be properly scrutinised for evidence of bias and discrimination and remedial steps taken as soon as problems occur.
- Many policy reviews favour wider diversity of personnel in technology industries. This diversity must also include people with disabilities in regulating new technologies, with proactive steps taken to achieve this.