



Assistive technologies for people with disabilities

Part I: Regulatory, health
and demographic aspects

STUDY

Science and Technology Options Assessment

EPRS | European Parliamentary Research Service
Scientific Foresight Unit (STOA)

PE 603.218

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Part I: Regulatory, health and demographic aspects

Study

IP/G/STOA/FWC/2013-001/LOT 6/C3

January 2018

Abstract

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) constitutes a significant step, marking a paradigm shift in the way people with disabilities are seen and leading to important legislative and policy changes. This report analyses first the regulatory frameworks for assistive technologies (ATs) that have been established in four countries to further the inclusion of people with disabilities. Several years after the ratification of the UNCRPD by the EU, these four countries are representative of European diversity: Germany, Hungary, Portugal and Sweden. The report identifies a number of positive examples and good practices as well as difficulties and bottlenecks in the implementation of the UNCRPD. All four countries have successfully adopted the UNCRPD. There are already very positive examples of a favourable regulatory framework for furthering inclusion with the help of AT. However, while different laws (e.g. national anti-discrimination laws) seem to be well integrated into the existing national level legal systems, there are major gaps in everyday practice and significant variations within and between countries. Emphasis could now be placed on raising awareness of such examples, to ensure that the laws are actually put into practice and to help other countries adopt similar legislation and policies.

The report, furthermore, analyses the causes, risk factors and the prevalence for three common types of disability: deafness and hearing impairments, blindness and visual impairments and autism spectrum disorder. The causes of these disabilities are manifold. In the case of autism spectrum disorder, they are currently not very well understood, but genetics are thought to play an important role. While some visual and hearing impairments are also congenital, the majority are acquired and many, especially in developed countries, occur later in life. The ageing population with a higher rate of chronic disease is therefore a key driver of an increasing demand in AT.

PE 603.218

The STOA project 'Assistive technologies for the inclusion of people with disabilities in society, education and jobs' was requested by the European Parliament's Science and Technology Options Assessment (STOA) Panel. It was carried out by the European Technology Assessment Group (ETAG), led by the Institute for Technology Assessment and Systems Analysis at Karlsruhe Institute of Technology (ITAS/KIT) and including Fraunhofer ISI, The Institute of Technology Assessment (ITA) and Responsible Technology (RT), and managed by the Scientific Foresight Unit (STOA) within the Directorate-General for Parliamentary Research Services (DG EPRS) of the European Parliament.

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LINGUISTIC VERSION

Original: EN

ABOUT THE PUBLISHER

To contact STOA or to subscribe to its newsletter please write to: STOA@ep.europa.eu
This document is available on the Internet at: <http://www.ep.europa.eu/stoa/>
Manuscript completed in December 2017
Brussels, © European Union, 2018

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PE 603.218
ISBN 978-92-846-2356-3
doi: 10.2861/364554
QA-06-17-412-EN-N

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List of abbreviations

ANED	Academic Network of European Disability Experts
ASD	Autism spectrum disorder
ATs	Assistive technologies
CANS	Central auditory pathway
DOTCOM	Disability online tool of the Commission
EU	European Union
EAM	External auditory meatus
ICT	Information and communication technologies
ISS, I.P.	Institute for Social Security (PT)
MSESS	Ministry of Solidarity, Employment and Social Security (PT)
NCD	National Council on Disability Affairs (HR)
NDP	National Disability Program (HR)
NGO	Non-governmental organisation
NHS	National Health Service
NPD	National Disability Program
OEP	National Health Insurance Fund
PNPA	National Plan for the Protection of Accessibility (PT)
ROP	Retinopathy of prematurity
RP	Retinitis Pigmentosa
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UN	United Nations
VHI	Voluntary health insurance
WHO	World Health Organization

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Executive Summary

Introduction

This stocktaking paper provides an overview of the context within which assistive technologies (ATs) for the inclusion of people with disabilities exist in Europe. For this purpose, two important aspects are investigated: Firstly, the regulatory environment for the inclusion of people with disabilities at EU and national level, the latter represented through the examples of Germany, Hungary, Portugal and Sweden and secondly the health- and demography-related causes of visual and hearing impairments as well as of autism spectrum disorder (ASD).

The paper is based on a review of relevant academic literature, the DOTCOM database of the Academic Network of European Disability experts (ANED) and regulatory documents at the national and European levels. In order to compensate for language barriers and for cases of incomplete or out-of-date documents, additional interviews with national experts were carried out for the regulatory part. These also proved useful in gaining insights into the extent to which the regulation had been implemented and how successful it had actually been.

Regulatory perspective

The purpose of the regulatory section is to map and analyse the regulatory landscape depicting the inclusion of people with disabilities in Europe. Regulation can be seen as the backbone of ensuring inclusion as it sets the rules for the inclusion of people with disabilities and defines their rights in terms of not being discriminated against and receiving the necessary support for living a life that is as normal as possible.

The United Nations Convention on the Rights of People with Disabilities (UNCRPD) was the first legally-binding international human rights instrument to which the EU and its Member States are parties. It opened for signature in March 2007 and came into force in May 2008, once it had been ratified by the twentieth party. Fifty specific articles and general principles build a comprehensive framework for the empowerment and non-discrimination of people with disabilities. It also includes articles on monitoring and mechanisms for reporting on the progress of implementation. The UNCRPD was an important step in marking a “paradigm shift” in the way people with disabilities are seen. The perception has been gradually moving away from viewing people with disabilities as “objects” of charity, medical treatment and social welfare towards viewing them as “subjects” with rights and who can be active members of society if the right provisions are made. Additionally, the UNCRPD has promoted the approach that the problem is not a disabled person's impairment, but rather the disabling barriers put up by society, which need to be removed to achieve inclusion.

Actions undertaken to achieve the rights of persons with a disability and to implement the UNCRPD are defined in the European Disability Strategy 2010-2020. The Strategy is a comprehensive framework committing the Commission to the empowerment of people with disabilities to enjoy their full rights and to removing everyday barriers in their lives. It builds upon the experience of the Disability Action Plan (2004-2010).

The non-discrimination of people with disabilities is also embedded in key legal pillars of Europe. This includes the Charter of Fundamental Rights of the EU, which was proclaimed in December 2000 and was required because the European Economic Community Treaty from 1958 did not make any references to fundamental human rights. It addresses equal rights for persons with a disability in several articles. The EU is obliged to respect the Charter of Fundamental Rights in all its activities.

The Treaty on the Functioning of the European Union addresses non-discrimination, committing itself to mainstreaming the disability perspective, among others, in all policies and activities. The power to pass laws against discrimination on various bases, including disability, in all areas of EU competence is also stipulated in the Treaty.

Beyond these general legislations, there is also legislation concerning the rights of persons with a disability in specific areas of life, covering areas of EU-competence or shared competence. This includes transport networks, telecommunications and the labour market. Other areas are exclusively managed by the individual Member States, for example social security systems and education.

The comparison of the four countries shows a diverse regulatory landscape. All four countries have successfully adopted the UNCRPD. Anti-discriminatory and other legislation for the inclusion of people with disabilities is included at the highest level of the legal framework, containing detailed rules on definitions, remedies and legal procedures. There are also specific prohibitions in several fields, such as employment, housing, and healthcare. Nonetheless, there are still cases of non-compliance with the UNCRPD and of laws and regulations which discriminate against people with disabilities. Also, there are great variations between countries, for example Sweden has taken the approach that people with disabilities possess full legal capacity and if necessary are supported in decision-making, whereas in Portugal, for example, persons under guardianship have very limited rights to enter into legal commitments, regardless of the presence of mental handicaps.

In general, the move away from a “one size fits all” approach towards a more individual one, taking into account the wishes and abilities of people with disabilities and viewing them as valuable members of society, is evident in various pieces of legislation and is likely to become increasingly prominent in the future. However, a problem evident in all countries, which also has an impact on the availability and usability of ATs, is that the alignment between the regulatory measures in place and their implementation in practice is sometimes poor.

Germany and Sweden seem to have a more decentralised and flexible policy frameworks to better address the requirements of people with different disabilities as well as the needs of the individual. Although the legal framework is also well adapted in Hungary and Portugal, the lack of resources seems to be a hindrance keeping the state from playing a stronger role in arranging suitable living conditions and a better integration of people with disabilities into society. In Hungary, ATs are mainly provided by NGOs and the budget available is a fixed amount. In Portugal very little public funding is available for ATs, and people with disabilities and their families are expected to cover the costs. In Germany and Sweden financial resources dedicated to ATs are not limited per person, but dependant on the needs of the individual.

Overall, there are already very positive examples of favourable regulatory frameworks for furthering inclusion with the help of AT in different countries. There may be benefit in raising awareness of such examples to support other countries in developing their own measures.

Health and demographic perspective

The health and demographic section describes the causes and risk factors for the three types of disabilities and discusses their current and future prevalence. This provides the basis for exploring which impairments are likely to play the greatest role in the future, and for reflection upon how ATs could support inclusion in society, education and employment.

Hearing loss is a reduced ability to hear sounds in comparison to normal hearing, which can range from slight to profound. Loss of the ability to hear sound frequencies in the normal range of hearing is called

hearing impairment. Several disorders can occur that affect the auditory system. In Europe, hearing impairments rank on place 12 (Central Europe) to place 18 (Western Europe) of the most common causes for years lived with disability. The global number of years lived with disability due to hearing impairments increased substantially from 1990 to 2010; a suggested reason for this increase is the ageing population.

Blindness is defined as a presenting visual acuity of less than 3/60 or a corresponding visual field loss to less than 10° in the better eye. If visual acuity is less than 6/60 and more or equal to 3/60, it is considered as a severe visual impairment, but if the presenting visual acuity is less than 6/18 to 6/60, visual impairment is moderate. Only an estimated 3% of people classified as blind are functionally blind, and most blind people have some degree of useful vision. According to 2014 data from the WHO, 80% of all causes of visual impairment are preventable or curable. In Europe, vision loss ranks among the 30 most common causes of years lived with disability. In some causes (refraction and accommodation disorders and cataracts) prevalence is higher in Eastern compared to Western Europe, most likely due to less advanced treatment options. As loss of vision is most common in older age, the number of persons with visual impairments is consequently also expected to rise.

ASD is considered a lifelong neurodevelopmental disorder. It usually manifests itself early in life, and comorbidities (for example with learning difficulties or epilepsy) are possible. Symptoms of ASD and their severity vary widely. For someone on the high functioning end of the autism spectrum, they may only result in relatively mild challenges. For others, symptoms may be more severe, for example when repetitive behaviours and a lack of spoken language greatly reduce the ability to participate in everyday life. The causes of ASD are not yet understood well but genetics are thought to play an important role. Data on the prevalence of ASD in the EU is quite heterogeneous, with some studies citing 1% or more of the population being affected.

While the causes of ASD are not very well understood to date and some visual and hearing impairments are congenital, the majority are acquired and many, especially in developed countries, occur later in life. The ageing population with a higher rate of chronic disease is therefore a key driver for an increasing demand in ATs.

In terms of inclusion in society, there are crucial differences between these disabilities. People with a hearing impairment have a better position in the labour market than those with a visual impairment or ASD. The reason for this is that acquired hearing impairments often appear by the late 40s, by which time people have already established themselves in the labour market. Also, there are more ATs developed for people with hearing impairments than for people with visual disabilities or ASD, and hearing impairments can be easier to compensate than visual impairments. In general, people with congenital disabilities can find it harder to enter the labour market in the first place. This also applies to autistic people, who in addition can be faced with prejudice.

1. Introduction

This stocktaking paper aims to provide an overview of the context within which assistive technologies (ATs) exist in Europe. For this purpose, the regulatory environment for the inclusion of people with disabilities at EU and national level is considered in the following part of the paper (Sect. 2), the health- and demography-related causes of visual and hearing impairments as well as of autism spectrum disorder (ASD) are then presented (Sect. 3). To represent the diversity of different European regions, four countries are examined at a national level in Sect. 2: Germany, Hungary, Portugal and Sweden.

The paper is based on a review of relevant academic literature, the DOTCOM database¹ of the Academic Network of European Disability experts (ANED) and regulatory documents at the national and European levels. In order to compensate for language barriers and for cases of incomplete or out-of-date documents, additional interviews with national experts were carried out. These also proved useful in gaining insights into the extent to which the regulation had been implemented and how successful it had actually been.²

The paper is structured as follows: Section 2 begins with an outline of the relevant European legislation and then describes how the four countries studied in detail have implemented the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in general as well as have handled key issues for disabled people such as voting and education for living independently. This section ends with a summary of good practices, difficulties and open questions. Section 3 presents the causes and risk factors for deafness and hearing impairments, blindness and visual impairments, and ASD as well as their prevalence. Further information is provided in the annex.

2. Regulatory perspective

The purpose of this section is to map and analyse the regulatory landscape depicting the inclusion of people with disabilities in Europe. It includes a section on regulation at the European level and then compares regulation in four countries representative of different regions in Europe: Germany, Hungary, Portugal and Sweden. These countries were chosen as they reflect European diversity in terms of the following aspects: old and new Member States, region, size, culture and economic performance as well as approaches to AT and regulatory processes. The countries selected are Germany as a Central European country, Hungary as an Eastern European country, Portugal as a Southern and Sweden as a Northern European country.

2.1. Regulation at European level

One key factor in measuring a society's degree of development is in how it deals with its disabled people and to what extent it strives and succeeds in including them in society, education and employment. Discriminating against disabled people has serious and damaging consequences for them as individuals (Green et al., 2005; Pascoe and Smart Richman, 2009) as well as for society more generally as it deprives itself of the full contribution of a significant proportion of people. The backbone of ensuring inclusion is the regulatory framework. It sets the rules for the inclusion of disabled people and defines their rights in terms of not being discriminated against and receiving the necessary support for living a life that is as normal as possible.

It should be borne in mind that the majority of disabled or impaired people are elderly and have acquired their limitation as they have grown older. As the groups of disabled and elderly people often

¹ Available at <http://www.disability-europe.net/de/dotcom>

² When not otherwise specified, the source of the information in Sect. 2 is ANED. Personal assessments of the national situations come from the national experts interviewed.

overlap, regulatory measures that are designed to support the rights of elderly people can benefit disabled people and vice versa.

2.1.1. Regulation for the general inclusion of disabled people

The UNCRPD was the first legally-binding international human rights instrument to which the EU and its Member States are parties. It was an important step in marking a “paradigm shift” in the way people with disabilities are seen. The perception has been gradually moving away from viewing disabled people as “objects” of charity, medical treatment and social welfare towards viewing them as “subjects” with rights and who can be active members of society if the right provisions are made (Lansdown, 2009). Additionally, the UNCRPD has promoted the approach that the problem is not a disabled person's impairment, but rather the disabling barriers put up by society, which need to be removed to achieve inclusion (European Union Agency for Fundamental Rights, 2013).

While the EU did not undertake a comprehensive review of existing legislation to determine its conformity with the UNCRPD prior to concluding (or ratifying) the Convention, it did determine the extent of its competence to act. The Declaration of Competences identifies those areas where the EU has exclusive competence (this applies to all rules previously established by the European Community, e.g. equal treatment in employment), those areas where it has shared competence with Member States (e.g. action to combat discrimination on the ground of disability) and areas in which Member States have exclusive competence (e.g. state aid).³ Underlying is the principle of subsidiarity, which means that the EU has a subsidiary function and is only responsible for those areas, which have transnational component and cannot be performed at national level. Action at EU level therefore focuses on areas where an internal market problem is evident, e.g. when trade is hindered due to a lack of standardisation of products and services.

The UNCRPD opened for signature on 30 March 2007 and came into force on 3 May 2008, once it had been ratified by the twentieth party. Fifty specific articles and general principles build a comprehensive framework for the empowerment and non-discrimination of persons with a disability. The Convention also includes articles on monitoring and mechanisms for reporting on the progress of implementation. Most parties also signed the Optional Protocol, entitling the UN Committee on the Rights of Persons with Disabilities to monitor violations of the rights of persons with a disability (ANED, 2016).

A Code of Conduct between the European Council, the Member States and the European Commission provides internal arrangements for the implementation of the UNCRPD and representation of the European Union (EU) (European Union, 2010). Pre-existing coordination and monitoring bodies concerning disability play an important role; the Disability High Level Group, for example, was set up in 1996, consisting of representatives of the Member States, the Commission and civil society. Its tasks include monitoring policies for persons with a disability and advising the European Commission. The implementation of UNCRPD-relevant law in Member States is monitored by the European Commission.

The first official report of the EU on the implementation of the UNCRPD was published in 2014, while internal reports on policy for and situation of persons with a disability are issued annually by the Disability High Level Group. Shadow reports to the first official report were submitted to the UN by a number of civil society organisations and advocacy organisations representing persons with a disability, for example the European Disability Forum.

Actions undertaken to achieve the rights of persons with a disability and to implement the UNCRPD are defined in the European Disability Strategy 2010-2020. The Strategy is a comprehensive framework committing the Commission to the empowerment of people with disabilities to enjoy their full rights

³ For details see Annex II (declaration of competence) of the Council Decision of 26 November 2009 concerning the conclusion, by the European Community, of the United Nations Convention on the Rights of Persons with Disabilities.

and to removing everyday barriers in their lives. It builds upon the experience of the Disability Action Plan (2004-2010). The strategy identifies eight areas of action; the most notable of these are an accessibility initiative (e.g. promoting the market for AT), participation (e.g. web accessibility and mutual recognition of disability cards), funding (e.g. allocation of EU funds taking accessibility into account) and awareness-raising (e.g. European Award for accessible cities).

The need for reliable data on the regulatory framework for persons with a disability in the EU and its Member States as a basis for policy development and implementation of the UNCRPD has been met since 2007 by the Academic Network of European Disability experts (ANED). The network was established by the European Commission, working together with existing disability research centres and national organisations. ANED set up the Disability Online Tool of the Commission (DOTCOM) in 2012, providing detailed information on policies, laws and strategies concerning the rights of persons with a disability and implementation of the UNCRPD in the EU, its Member States and associated countries. In addition, ANED regularly publishes reports on different topics concerning the situation of persons with a disability, for example statistical indicators, EU law and policy, employment or political participation. The latest detailed review of the role of European laws and policies in supporting disabled people was provided in the 2014 ANED report “Annotated review of European Union law and policy with reference to disability”.⁴

The non-discrimination of people with disabilities is also embedded in key legal pillars of Europe. This includes the Charter of Fundamental Rights of the EU, which was proclaimed on 7 December 2000 and was required because the European Economic Community Treaty from 1958 did not make any references to fundamental human rights. It addresses equal rights for persons with a disability in several articles: Article 1 states that “human dignity is inviolable. It must be respected and protected”. Discrimination on various bases, including disability, is prohibited according to Article 21. Article 26 addresses inclusion and assistance for persons with a disability, stating that “the EU recognises and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community.” The EU is obliged to respect the Charter of Fundamental Rights in all its activities.

The Treaty on the Functioning of the European Union addresses non-discrimination in Article 10, committing itself to mainstreaming the disability perspective, among others, in all policies and activities. The power to pass laws against discrimination on various bases, including disability, in all areas of EU competence is stipulated in Article 19 of the Treaty.

2.1.2. Regulation concerning specific areas of life

In accordance with the principle of subsidiarity, specific legislation promoting the rights of persons with a disability are either managed by the individual Member States or are of exclusive or shared competence with the EU, as described above. Examples of exclusive competence are social security systems and education, although the EU might influence these issues with position papers or by funding allocation (e.g. non-discrimination and respect of accessibility is required for all projects receiving EU funding). while the internal market or transport are of shared competence.

One example of an area of EU competence is that of European transport networks. For transport accessibility, there are four main EU regulations: the Air Passengers Rights Regulation (from 2006), two regulations on the rights of rail passengers (2007) and regulation concerning the rights of passengers when travelling by sea and inland waterway (2010). The main points of these regulations include protection from being denied boarding because of disability, provision of qualified assistance, accessibility of essential information and provision of a complaints mechanism. For the trans-European

⁴ See <http://www.disability-europe.net/theme/eu-law-and-policy/reports-law-and-policy>.

conventional rail network, a set of technical rules, the technical specifications on interoperability, aim to ensure structural accessibility (e.g. wheelchair-accessible seats).

A second example of EU competence is the telecommunication sector and, to some extent, the media. The Audio-visual Media Services Directive includes an article encouraging Member States to adopt ICT accessibility legislation for people with a visual or hearing disability. The European Commission has issued two mandates, one in 1998 and the other in 2005, to the European Standardisation Organisations. The first mandate addressed ICT accessibility for elderly and disabled persons on the bases of the principles "design for all" and "AT". The second mandate called for EU standards on e-accessibility, which can be used in public procurement. Concerning telecommunications, user rights are stipulated in the regulatory framework for electronic communications: The Users Rights Directive, for example, stipulates equal access for users with a disability to all services available to other end-users and encourages Member States to use European standards for e-accessibility.

A third and very important area of European competence concerns the rights of persons with a disability in the labour market. The Employment Equality Directive was adopted in 2000 and prohibits discrimination regarding employment and occupation on various grounds, including disability. According to the directive, employers are obliged to provide reasonable accommodation for persons with a disability. The directive allows for positive action to prevent discrimination or for compensation for disadvantages experienced by persons with disabilities in the labour market.

While, according to the Treaty on the Functioning of the European Union, Member States are not allowed to give aid to companies which could distort competition in the European common market, certain exceptions including aid for training or employment of disabled persons are made.

2.2. Comparison of the level of implementation and operationalization of key European legislation in Germany, Hungary, Portugal and Sweden

2.2.1. Overview of social care systems

The four countries under study not only differ in their location within Europe, their size and their economic performance, but also in terms of how social welfare is organised. A country's social care system is an important factor in the provision of AT and the following sections give details on the chosen case studies.

Germany

Germany's population was 81.8 million people in 2015 (German Federal Statistical Office, 2016). The country has an ageing society and approximately 17 million people (21%) are aged 65 and above. Roughly 9% of the population suffer from a severe disability (defined as being registered as disabled to 50% or more),⁵ and the proportion of disabled people is highest in the older age groups. The German social security system is fairly comprehensive and consists of five main branches: health insurance, long-term care insurance, pension insurance, accident insurance and unemployment insurance. It is financed by contributions by employers and employees as well as taxes. Public health insurance is compulsory for all persons, apart from a few exceptions, for example the self-employed or persons with wages above the annual assessment ceiling. State supervision is conducted by the Federal Ministry of Health in the case of sickness and long-term care insurance and by the Federal Ministry of Labour and Social Affairs in the case of pension, accident and unemployment insurance. Competence is shared between federal and state authorities, generally depending on the size and location of the insurance institution. For some situations, there is additional state social support; examples are basic provision for jobseekers, in old age and in the event of reduced earning capacity or family benefits. The needs of persons with a

⁵ The proportion of disabled people in the total population varies in the four countries. A likely reason is that there is no common method of counting those with disabilities, leading to such different results.

disability may be covered by different insurance systems. Rehabilitation and AT, for example, can be provided either by the health insurance (in the case of an acute medical condition), by the long-term care insurance (in the case of long-term care) or by the accident insurance (if disability is due to an accident). It is not always clear which insurance system is responsible, which can lead to delays for people seeking support. Some disabilities are also addressed by specific laws: deaf and blind persons, for instance, receive a monthly sum according to the Assistance for Blind and Deaf Persons Law.

Hungary

Hungary's population stood at approximately 9.8 million people in 2015. The country has an ageing society and 1.7 million people (18%) are aged 65 and above (World Bank, 2015). Around 70% of the population live in urbanised areas (Központi Statisztikai Hivatal, 2013), and around half a million in deep poverty (especially in the Southwestern part of the country). Roughly 6% of the population suffer from a disability, and this number is likely to increase to up to 10% by 2021 (Könczei, 2009). The Ministry of Human Resources (*Emberi Erőforrások Minisztériuma*) is responsible for the health sector, including health insurance. The healthcare system is tax-funded; revenue comes from compulsory health insurance contributions and taxation, and is organised by the state-owned National Health Insurance Fund (OEP), which is free for disabled people, including those with physical and mental disorders (OEP, 2013). The OEP operates via its central service and the devolved health insurance funds in the country's 19 counties (European Commission, 2013a). The law determines the legal status and guarantees *ipso facto* compulsory insurance coverage. Employers must pay national insurance contributions for their employees to the competent tax authority, which transmits the data relating to their insurance rights to the competent county-level health insurance funds. Healthcare services can be received from specialised healthcare providers, including private providers that are contracted by the OEP (European Commission, 2013a). To receive a disability pension in Hungary, the insured person must have a loss of working capacity of at least 40% and at least 1,095 days of coverage during the last five years before the claim, may not receive any regular cash benefit, and must be incapable of any gainful employment. The National and the County Medical Expert Committees of the OEP assess the disability. Depending on the disability, the monthly pension is between 30% and 150% of the monthly minimum wage (€300) (SSPTW, 2012). The Hungarian social security system offers protection in the case of sickness, maternity, old-age, invalidity, occupational disease and injury, accidents at work, survivorship, children's education and unemployment (European Commission, 2013a). However, the social security system in Hungary is still far behind Western European countries and Scandinavia, and is considered to be aligned with the overall level of economic development in the country.

Portugal

According to the latest estimates, the total population of Portugal was 10.4 million in 2015 (National Statistics Office Portugal, 2015). The population aging index in Portugal was 128, which means that for each 100 young people there are 128 elderly⁶. About 82% of the population aged 5 or above are not thought to have difficulties performing daily activities with regard to vision, hearing, mobility, memory or concentration, or hygiene and personal care as well as understanding others or making themselves understood. About 18% of the population aged 5 or above reported having a lot of difficulty or being unable to perform at least one of these activities. In the population aged 65 or above, this indicator exceeded 50%.⁷ Currently the Portuguese healthcare system is characterised by three coexisting, overlapping systems: the universal National Health System (NHS); special public and private insurance schemes for certain professions (health subsystems), covering about a quarter of the population; and private voluntary health insurance (VHI), with estimates of coverage ranging from 10% to 20% of the

6 https://www.ine.pt/xportal/xmain?xpid=INE&xpgid=ine_destaquas&DESTAQUESdest_boui=107624784&DESTAQUESTema=55466&DESTAQUESmodo=2 (accessed in July, 2016).

7 <http://www.inr.pt/content/1/2841/ine-publica-resultados-definitivos-do-censos> (accessed in July, 2016).

population. Most of the population is entitled to choose between two health care insurers (or can use both): NHS and VHI. Part of the population, approximately 20–25% according to the most recent National Health Survey (2005/2006), is also covered by a health subsystem. Health services are delivered through a mix of public and private providers, with public provision dominant in the primary care and hospital sectors. Access to hospitals and publicly covered specialist services is controlled by gate-keeping at primary care. The Ministry of Labour and Social Solidarity is responsible for social benefits such as pensions, unemployment benefits and disability benefits. The Ministry's collaboration with the Ministry of Health has improved in recent years. Joint projects include a review of certification for absence from work, a programme to improve coordination between health and social care services and an initiative to improve the continuity of long-term care for older people and people with disabilities (Barros et al., 2011). The Portuguese healthcare system is funded mostly by taxes, but also with a relatively considerable rate of cost-sharing through co-payments⁸. The health subsystems (providing comprehensive or partial coverage) are financed by employee and state contributions. Co-payments for healthcare services are relatively high in Portugal.

The social welfare system for people with disabilities is fragmented and discriminatory⁹ and does not promote independent living. The system is based on the idea that families should provide for their relatives with disabilities and that they have to help and support them and that the state only plays a supplementary role.

Sweden

Sweden is a Northern European country with more than 9.8 million inhabitants out of which around 85% live in urbanised areas. The country has an ageing society; approximately 20% of the Swedish population are over 65 years old. Around 20% are considered to have a disability, and around half of the disabled people use ATs. Among the disabled persons in Sweden, 70% are 65 years old or older. Therefore, an aging society and disability are both emerging topics for the Swedish social system (Blomquist & Richter, 2012; Swedish Agency for Participation, 2016). The Swedish social security system is fairly comprehensive and consists of six main branches: health insurance, invalidity insurance, parental insurance, pension insurance, accident insurance and unemployment insurance. Responsibility for the social security system and health care provision in Sweden is decentralised and shared by the Ministry of Health and Social Affairs together with other government bodies, 20 county councils and 290 municipalities. It is supervised by the National Board of Health and Welfare (Socialstyrelsen). The Health and Medical Service Act regulates the duties of county councils and municipalities. The country has a government-funded social welfare system, which provides universal health care for its citizens. Both the Swedish healthcare system and social assistance are financed mainly by taxes. Persons who have a permanent loss of functional capacity receive a disability allowance (*handikappersättning*) (European Commission, 2013b). A disabled person who requires daily assistance receives assistance allowance (*assistansersättning*) or personal assistance (*personlig assistans*) (European Commission, 2013b). These allowances amount to €32–€35 per hour (European Commission, 2013b). If a disabled person needs assistance with everyday life for more than 20 hours/week, assistance allowance is provided by the State. If fewer than 20 hours are necessary, the allowance is the responsibility of the local municipalities under the designation of personal assistance (European Commission, 2013b). To be entitled to a disability allowance, the person must be categorised, for example, as suffering from a

⁸ Co-payments (or user charges) refers to a fixed amount charged for a service. These exist in most public health care services. User charges exist for consultations (primary care and hospital outpatient visits), emergency visits, home visits, diagnostic tests and therapeutic procedures. When compared to the cost of the service, the values set for co-payments are typically smaller. There is no annual ceiling on co-payments (Barros et al., 2011).

⁹ Since the disabled have to be able to prove their own disability by means of a medical consultation in order for the physician to prescribe a certificate of incapacity and the needed AT. The next step is to go to Social Security and ask for the support, by presenting three different quotes (prices) for the needed technology.

mental disability such as ASD or suffering from physical disability that is not a normal consequence of ageing and that causes significant difficulties in the person's daily life (e.g., visual or hearing impairment) (European Commission, 2013b). The overall situation of a disabled person, the various forms of assistance required and the extra costs are all taken into account in determining the amount of the disability pension, which can be a maximum of € 3,527 per month (European Commission, 2013b).

2.2.2. Implementation of the UN Convention

All four countries included in this study signed the UNCRPD at the same time, namely on the 30th of March 2007. After a ratification procedure in the national parliaments, the UNCRPD came into force in 2008 (Hungary and Sweden) and in 2009 (Germany and Portugal). All four countries have also appointed a specific ministry as an official focal point for matters concerning the implementation of the UNCRPD. In Hungary it is the Ministry of Human Capacities, in Germany the Federal Ministry for Labour and Social Affairs, in Portugal the Ministry of Foreign Affairs and the Ministry of Solidarity, Employment and Social Security and in Sweden the Ministry of Health and Social Affairs. Furthermore, a coordination mechanism according to Article 33 of the UNCRPD has been established in all four countries.¹⁰

National focal point

According to Article 33, all Parties to the CRPD need to assign national focal points responsible for persons with disabilities. In **Germany** it is the Federal Ministry for Labour and Social Affairs, with each federal state also having its own focal point, while in **Hungary** the Ministry of Human Resources has been assigned this role. However, in Hungary the Office for the Secretary of State for Social Inclusion is responsible for disability affairs in general, including the UNCRPD. This shared responsibility aims to reflect the fact that improvements must be made in several fields simultaneously, which requires collaboration. In **Portugal**, responsibility is also shared: the Directorate General of Foreign Policy of the Ministry of Foreign Affairs and the Office of Strategy and Planning of the Ministry of Solidarity, Employment and Social Security have been appointed. In **Sweden**, the Family and Social Services Division of the Ministry of Health and Social Affairs is the official focal point.

Coordination of implementation

Article 33 of the UNCRPD also stipulates that a coordinating mechanism needs to be implemented by each country. In **Germany**, the coordination mechanism consists of the Federal Government Commissioner for Matters Relating to Persons with Disabilities and the Advisory Council on Inclusion. It is supported by four specialist committees, which provide reports on various topics related to the UNCRPD. Furthermore, an independent Monitoring Body of the UNCRPD (independent mechanism, in accordance with Article 33) was established in Germany as a separate department at the German Institute for Human Rights. In **Hungary**, a formal coordination mechanism was not established until 2015, when the inter-ministerial Committee on Disabilities was set up (UN OHCHR, 2015). The National Council on Disability Affairs (NCD) fulfils the role of the independent mechanism (appointed by the government). Within the NCD a number of disabled people's organisations are represented. In **Portugal**, the National Institute for Rehabilitation, from the Ministry of Solidarity, Employment and Social Security, acts as a coordination mechanism at the governmental level. An independent mechanism has been set up and consists of ten different members, but has not yet met or taken up its work. In **Sweden**, the coordination mechanism is composed of representatives from various ministries, headed by the Ministry of Health and Social Affairs that also has the task of wider coordination of the work of the

¹⁰ Sections 2.2.2 until 2.2.4 are primarily based on information provided by ANED through the DOTCOM database and other sources. For the sake of readability we reference these sources only in the bibliography and refrain from referencing them in the chapter.

government on disability policy and is also the focal point as described above. An independent mechanism does not exist in Sweden.

Reporting on implementation progress

According to Article 35 of the UNCRPD, every country that has signed the Convention is expected to submit a report on progress toward implementing the convention within two years of its taking force. In addition to these official reports, advocacy organisations publish their own shadow reports.

As for **Germany**, the first report was due in March 2011. The official state report was submitted to the UN in September 2011 and published in May 2013. Additionally, the first shadow report for Germany was released in January 2013. For this purpose the German UNCRPD Alliance was founded by civil society organisations and organisations of persons with a disability to enable them to participate in the review of the official state report. In April 2014 the UN sent a “List of Issues” to the German government, which consists of open questions on the state report, for example regarding UNCRPD implementation in the German Federal states. The German government responded to the List of Issues in August 2014. Concluding observations and recommendations on the first country report of Germany were published by the UN in May 2015. It is interesting to note that in Germany, some civil society organisations submitted their own statements to the UN. A self-help organisation of autistic persons (*Enthinderungsselbsthilfe von Autisten für Autisten*), for example, did not feel adequately represented by the UNCRPD Alliance, and claimed that it was not allowed to contribute to the official state report or the shadow report of the UNCRPD Alliance. It criticised other autism advocacy groups (who are active in politics) for being led by parents and therapists who in their view lack an understanding of the needs of autistic persons. The organisation published a parallel shadow report and its own statement regarding the List of Issues.

For **Hungary**, this first state report was due in June 2010. The official state report was submitted to the UN in October 2010 and published in its final version in June 2011. The first shadow report from Hungary was released in August 2010. It was produced by the Hungarian Disability Caucus, which had been established by civil disability organisations earlier in 2010. Several NGOs and the Ombudsman are the members of the Civil Caucus.

In **Portugal**, the first state report on the implementation of the UNCRPD, written by a Working Group of the National Human Rights Committee, was due in October 2011 and was presented to the UN in August 2012. Reacting to the official report, the Disability and Human Rights Observatory, in cooperation with a large number of civil society and disability organisations, submitted a shadow report¹¹ in June 2015. In April 2016, the UN published an assessment report which concluded that despite the efforts made by Portugal in certain areas, the country had still not carried out a comprehensive cross-cutting review of the legislation in order to harmonise it with the Convention and, therefore, laws, regulations, customs and practices that discriminate against disabled people are still in place. A large number of persons with disabilities are subjected to total or partial guardianship and, as such, deprived of certain rights. Although a review of the Civil Code is taking place, there continue to be restrictions on legal capacity. A lack of a national policy for independent living was also criticised. Austerity measures have led to cutbacks, for example in social services. In Portugal, people with disabilities lack access to information and communication because of a lack of accessible formats and appropriate AT for different types of disabilities.

In **Sweden**, the first state report was due in January 2011, was initially submitted to the UN in February 2011 and was published in its final version in September 2012. Sweden has been criticised because the state report focuses on activities for which no outcome indicators have been defined, making it very difficult to assess whether the UNCRPD has been well implemented or not. The first shadow report was released by the Swedish Disability Movement in 2011. Additionally, other organisations such as the

¹¹ This shadow report was signed by 32 entities in Portugal, representing 241 disabled people organisations.

Forum Women and Disability, Swedish Disability Federation, Association for Relatives of Psychically Disabled Persons, Swedish Federation Human Rights for Persons with Disabilities and the Disability Council International have submitted their own reports. Furthermore, the Anti-Discrimination Law and Anti-Discrimination Ombudsman in Sweden have proved to be very useful in monitoring the implementation process of the Convention, with the Ombudsman regularly receiving reports about violations of the Convention in Sweden.

The following figures illustrate how the UNCRPD has been implemented in the four countries:

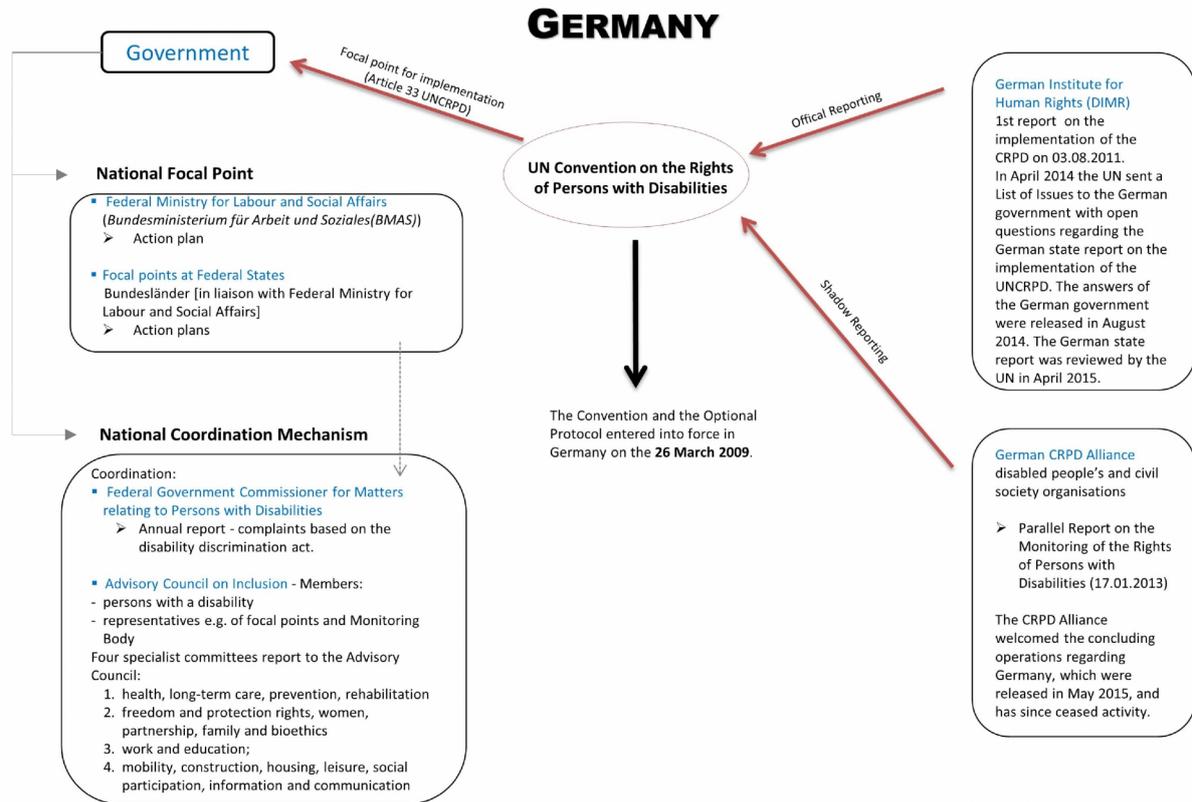


Figure 1- Organization of UNCRPD implementation in Germany*

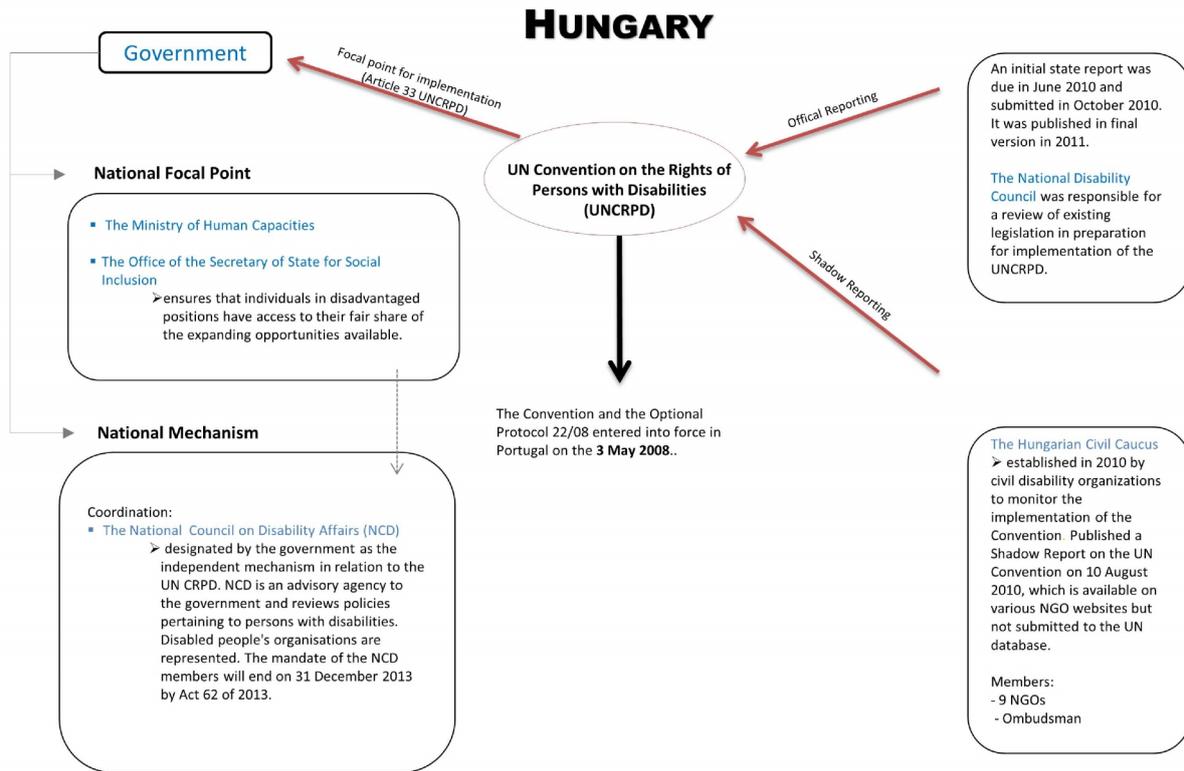


Figure 2- Organization of UNCRPD implementation in Hungary*

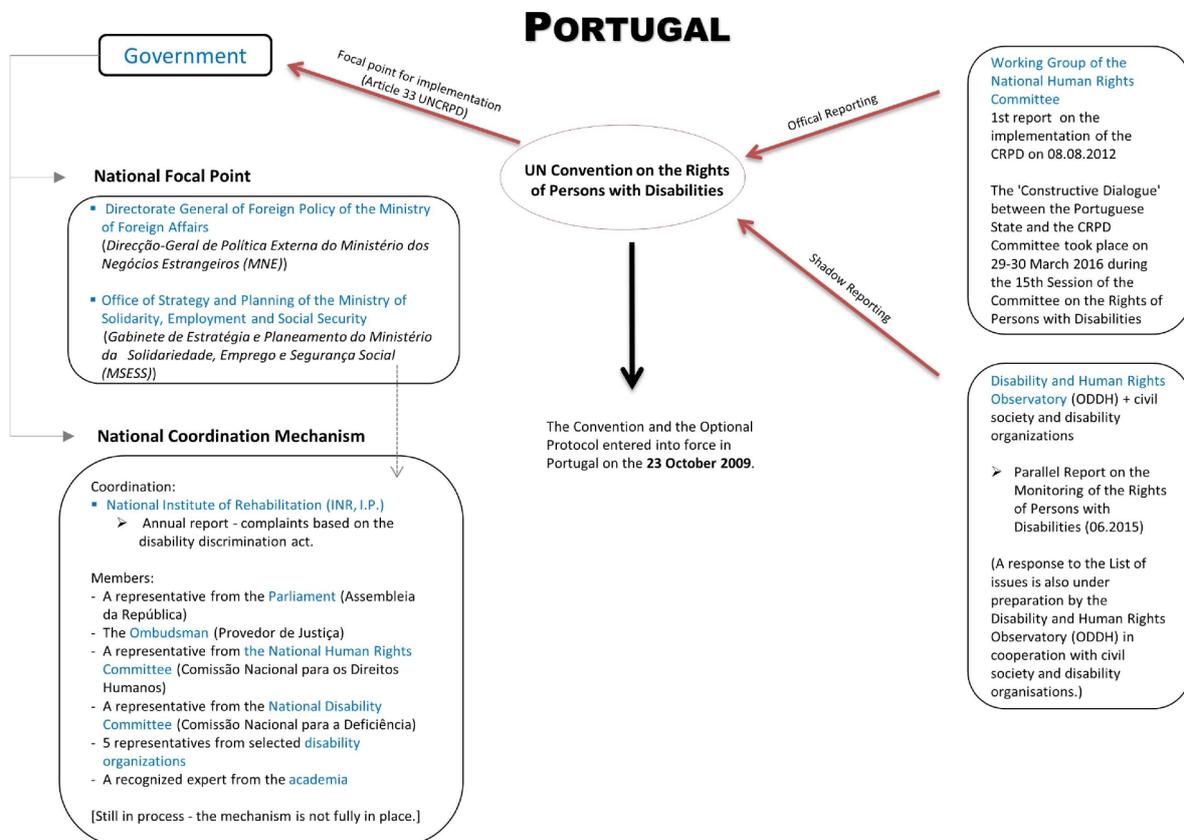


Figure 3 - Organization of UNCRPD implementation in Portugal*

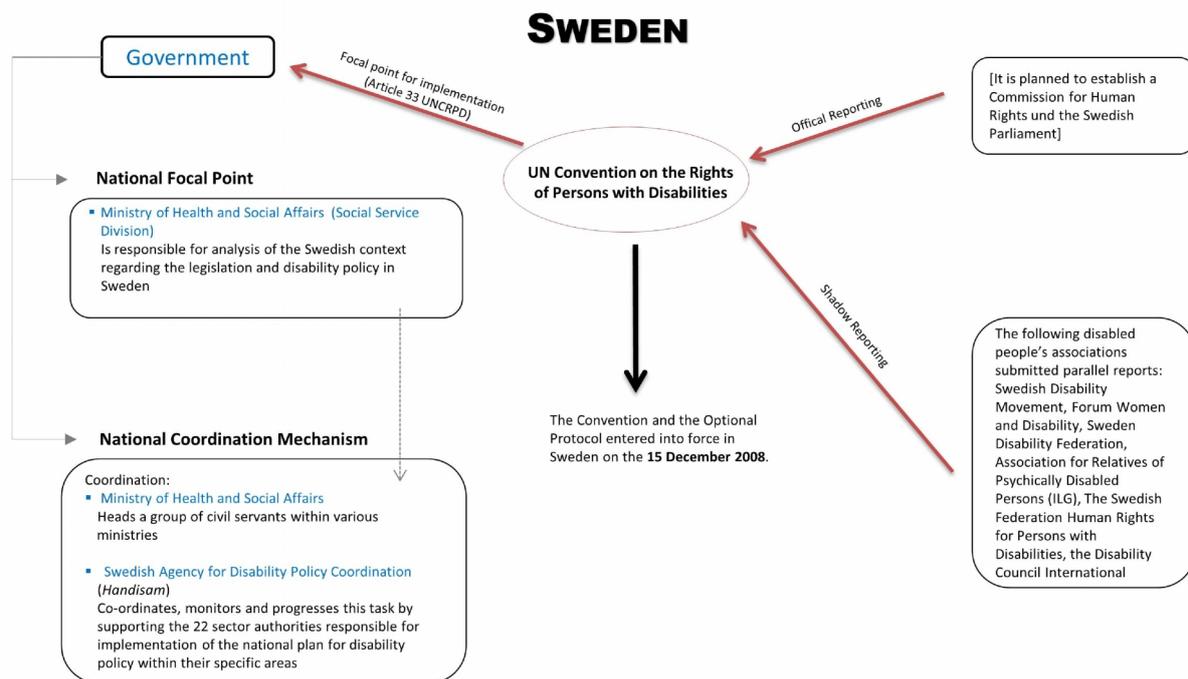


Figure 4 - Organization of UNCRPD implementation in Sweden*

*Source: These figures are based on information from the DOTCOM database and were developed by the research team

2.2.3. Comparison of the general legal frameworks

Anti-discrimination

In **Germany** a ban on discrimination on the basis of disability was added to the German Constitution (*Grundgesetz, Article 3, §3*) in 1994. Later on, a separate legal code for rehabilitation and participation of persons with disabilities, the Social Code Book IX, was adopted (in 2001). Among other things, the Social Code Book IX regulates benefits for persons with a disability in the areas of rehabilitation and working life. In 2002, the Disability Equality Act (*Behindertengleichstellungsgesetz, BGG*) took force with the main goal of providing accessibility for disabled persons. Protection from discrimination in the workplace and in civil law was given a legal basis in the General Equality Act (*Allgemeines Gleichbehandlungsgesetz, AGG*) in 2006. This law prohibits discrimination on different bases, including various forms of disability.

In **Hungary**, the general legal framework is very similar to that of Germany: the Fundamental Law (the new Constitution) contains a general clause against discrimination (*Article 15*) and the Hungarian Equal Treatment Act (*Law 125/2003*) describes rules on anti-discrimination, including remedies and legal procedures. Specific provisions on the equal treatment of disabled people are made in the Equal Opportunities Act (*Act 26 of 1998*). Furthermore, the Hungarian Parliament has approved a National Disability Program (NDP), to establish measures for creating equal opportunities for disabled persons (UN OHCHR, 2015). Hungary also is one of very few states in the EU that has adopted autism plans and strategies (Della Fina & Cera, 2015). In Hungary, the 5-year National Autism Strategy (2008–2013) was initiated by the Ministry of Social Affairs and Labour and prepared by experts under the supervision of the Hungarian Autistic Society. The Strategy was provided in Section IV/3 of Government Decree no. 1067/2007 on the implementation of the National Programme of Disability

Affairs. The purpose of the strategy is to improve care for persons with ASD by developing specific services, including those in the fields of education, training and employment (Della Fina & Cera, 2015).

Even though disability is not explicitly mentioned as a ground for discrimination in the **Portuguese** Constitution (*Art. 13*), the grounds listed are not considered to be exhaustive and it is therefore usually assumed as also including disability. Article 71 of the Constitution affirms the equal rights of persons with disabilities, requiring the state to carry out a national policy of prevention, rehabilitation and integration. Two other legal documents have also addressed the prohibition of discrimination because of disability more recently: the 2004 Disability Act (*Law 38/2004*) and the 2006 Anti-discrimination Law (*Law 46/2006*). Both prohibit direct and indirect forms discrimination based on disability and promote the principle of affirmative action (also called positive discrimination) in order to compensate disabled people for structural inequalities. In addition, the Anti-discrimination Law (*Article 4*) defines what constitutes discriminatory practices, for example “the denial or imposition of limitations in the provision of goods and services, the built environment, sign language, education, healthcare and information technologies” (ICT) (ANED, 2016).

In **Sweden**, the constitution states that all official bodies must treat all people equally and strive for full equality. The constitution also entitles all citizens to vote and to participate in politics without discrimination. The constitution further determines that the European Convention for the Protection of Human Rights and Fundamental Freedoms should have the status as constitutional Swedish law. In 2009, the Discrimination Act (*2008:567*) came into force, thereby replacing the former Equal Opportunities Act and six other anti-discrimination laws. It prohibits discrimination based on several grounds (among them disabilities). It is fairly comprehensive and covers areas such as the workforce, the education system and the possibility to buy and sell services or/and products, for instance, as well as national military service. It does not, however, mention access to civil and political participation.

In all four countries, legislation against discrimination against disabled people, along with other possible causes of discrimination, is embedded in the constitution. These countries also have further acts prohibiting discrimination or stipulating equal treatment of disabled people. Hungary, in addition, placed special emphasis on coordinated action regarding ASD, as shown by their national autism strategy.

Guardianship and supported decision-making

In **Germany**, if a person is not able to manage their everyday affairs because of disability, a legal custodian can be appointed, according to the German Civil Code Book. The guardianship court determines the areas of agency for the custodian, depending on the person's condition. For certain far-reaching decisions, the legal custodian always needs the consent of the guardianship court, for example to abandon a rented home or for measures associated with the deprivation of liberty. In Germany the institution of supported decision-making (Article 12 UNCRPD) has not yet been implemented into Civil Law.

In **Hungary**, the general rules on legal capacity, guardianship and supported decision-making are regulated by the new Civil Code (*Act 5 of 2013*), which took force in March 2014 to achieve conformity with Article 12 of the UNCRPD. According to Article 21 of the new Labour Code, people under partial guardianship in terms of labour affairs are allowed to enter into a labour contract with the consent of their legal representative while people under plenary (i.e. full) guardianship can also enter into such contracts, but only their legal representative is entitled to make legal statements on their behalf. Both groups are allowed to enter employment contracts only for jobs which, considering their condition, they are capable of handling on a regular basis.

In **Portugal**, legal capacity, as defined by the Civil Code, is the ability to enter a legal relationship (*Art. 67*). The Civil Code also defines two means of limiting or suppressing legal capacity. The regime of *interdiction* constitutes a severe abridgement of rights. Irrespective of age, persons subject to interdiction are assigned the status of minors. This means that they do not have the right to vote. If interdiction is

mandated because of a mental anomaly, there are further severe restrictions: The exercise of parental responsibilities and testifying in court are also removed and, while they are allowed to marry, the marriage can be declared invalid. A guardian (“tutor”, usually a family member) and a pro-tutor to supervise the tutor are assigned to assist the person under interdiction. For certain activities (e.g. dealing with property and inheritances) the guardian requires permission from a court. The regime of *interdiction* (Article 138(1)) can be assigned by a court to people with mental anomalies but also to those with deaf-muteness and blindness who are considered to be unable to govern their lives. Examples of this include addictions or financially ruinous behaviour. Interdiction involves the suppression of the right to manage property. A “curator” is assigned to help or act on behalf of the person under interdiction in aspects related to property. In the latter case a family council is created to supervise the curator. Both interdiction and “inabilitation” are assigned by a court. Revision of the Civil Code to reform the system of full and partial guardianship is currently in progress. However, this matter is still the object of public debate, and to date no changes to the Civil Code have been made.

Sweden abolished total guardianship already in 1989 (European Union Agency for Fundamental Rights, 2013). In a Memorandum (Ds 2008:23 FN) of the Ministry of Health and Social Affairs it is stated that, according to Swedish law, people with disabilities obviously have the same legal capacity as others. For disabled people who require assistance, two alternative measures and less intrusive forms of assistance have been in place since January 1989. A trustee (*förvaltare*) can be appointed by the court as the person’s guardian who does not need consent by the disabled person to make a legally binding decision. Also, a mentor (*god man*) system is implemented, which provides assistance to persons with a disability in legal and other matters. However, unlike trustees, mentors need the consent of the disabled person to make a legally binding decision (Code on Parenthood and Guardianship (SFS: 1949:381), Chapter 11, Article 7).

The approach to legal capacity differs greatly in the four countries studied. While all the countries have different levels of guardianship to reflect the capabilities of people in need of support, the system currently in place in Portugal makes it possible for people to be assigned the status of a minor because of deaf-muteness or blindness. In Sweden, total guardianship has been abolished, and the basic assumption is that disabled people are no different in terms of legal capacity than the rest of the population. Accordingly, two degrees of assistance are available. Hungary has also made the shift to supported decision-making (article 12 of the UNCRPD) while Germany has yet to implement it.

Voting

According to the constitutions of Germany, Hungary, Portugal and to the Memorandum of the Ministry of Health and Social Affairs in Sweden, every person has the right to vote in general, direct, free, equal and secret elections.

In **Germany**, accessibility in elections is covered by the Disability Equality Act. However, according to the German Electoral Law (§13 *Bundeswahlgesetz*) a person is automatically deprived of the right to vote if they have a legal custodian covering all areas of life or if they have been sentenced to stay in a forensic institution because they committed a crime they cannot be held responsible for. If the guardianship does not cover all areas of life, they are eligible to vote if they wish. The UNCRPD Monitoring Body has criticised this practice, amongst other things pointing out that the ability to vote is not examined in the guardianship procedure and that plausible arguments for the denial of the right to vote are lacking. Disabled people who are not excluded from voting have the right to vote by post (all citizens are eligible) and to be accompanied to the polling station by a person of their choice to support them. However, polling stations are not always wheelchair accessible. Blind people can request they be sent a Braille voting template to use at the polling station or for voting by post. Electronic voting is not available in Germany.

In **Hungary**, the right to vote can be removed by a judicial decision on the grounds of restricted mental capacity (Fundamental Law, article 23). A court deciding on placing an individual under guardianship

specifically needs to consider the question of the deprivation from the right to vote (Act on the Electoral Procedure, No. 36 of 2013, sec. 17/A. §). Human Rights Watch has criticised Hungary for routinely excluding people with mental disabilities from exercising their right to vote. As of January 2014, disabled voters who are eligible to vote can request notification in Braille, in simple language and the use of a Braille voting template. They can also make use of a mobile ballot box and can receive help from a person of their choice or alternatively have two members of the polling station fill in the ballot paper for them (Human Rights Watch, 2013). Electronic voting is not available in Hungary.

In **Portugal**, Article 2 of the Electoral Law (Law 14/79) specifies that citizens who have been assigned the status of interdiction, or persons with intellectual impairments under the regime of full or partial guardianship and those living in psychiatric institutions are unable to exercise their voting rights (Law 14/79, Decree-Law 319-A/76 and Organic Law 1/2001). Article 97 of the Electoral Law entitles persons with visible physical disabilities or illnesses to be assisted at the voting booth by a person of their choice. Persons without visible disabilities are required to provide medical evidence in order to benefit from this. Alternative means of voting, e.g. through electronic voting or ballot papers in Braille, are not available. This means that the Portuguese Electoral Law discriminates against disabled people by compromising their right to a free and secret vote. As a result of a complaint by the Portuguese Association of Disabled People, the National Elections Commission released recommendations for improving accessibility of polling stations in 2009. However, accessibility is still not considered to be ideal.

Sweden guarantees the right to vote for all persons with disabilities, including those without legal capacity. The Swedish Election Act (*Vallagen SFS 2005:837*) makes various provisions for people with disabilities, including that those who are unable to place the ballot in the envelope behind the voting screen are entitled to receive help from election officials. If a disabled person is not able to enter a polling station, election officials may also receive the envelope with the ballot outside the polling premises provided that this can be done safely. Electronic voting is not available in Sweden. Disabled persons who cannot come to the polling station due to their disability may vote through a “messenger”, which includes relatives, carers, people appointed by the municipality for this purpose and rural postal workers. Furthermore, local municipalities are required to ensure that voting premises give voters a good opportunity to vote. If the chosen premises do not fulfil the requirements for accessibility, officials need to explain the reason for their choice and what measures will be taken in order to offer accessible premises in future elections. The county administrative board (*länsstyrelsen*) then needs to decide if the premises in question can be used in the next election.

In terms of allowing disabled people without full legal capacity to vote, the four countries differ greatly in their approach. Portugal excludes disabled people under full or partial guardianship or in psychiatric institutions from voting altogether, while Germany excludes those who have a guardian covering all areas of life. In Hungary, the right to vote is at least examined as part of the guardianship process. Only Sweden fulfils the requirements of the UNCRPD by giving full voting rights to disabled people. Accordingly, the countries also vary in the provisions they make in facilitating easy access to polling stations and offering disability-friendly ways of voting.

Sign language

Broadly speaking, each spoken European language has a sign language equivalent. However, countries that share a language do not necessarily use the same sign language (e.g. Austria and Germany). Sign languages were recognised as official national languages at different points. In addition, there is "international sign", as international sign language is now mostly called. It is a set of internationally recognised signs and less complex than national sign languages, for example it is more limited in terms of vocabulary. Often it is used in combination with national signs. Its main purpose is to facilitate international communication between deaf people (European Union of the Deaf, 2017).

In **Germany**, the 2002 Disability Equality Act already recognised German sign language as an official language. Users of the language are therefore entitled to be provided with a translator when they need

to appear in front of public authorities (mentioned in Social Code Book IX). Children with hearing impairments can choose between bilingual and mainstream schools, although parents tend to prefer them to be schooled within the mainstream education system (German Association of the Deaf, 2016) and integrated education is generally being promoted.

In **Hungary**, according to Act 125 (2009), users of Hungarian sign language are members of a linguistic minority. The Act defines the right of deaf and deaf-blind people to use and learn how to use special communication systems. This Act also promotes users of sign language taking active part in society and participating equally in the political decision-making process. An important novelty of the Act is that the parent of a hearing impaired or deaf-blind child may choose freely between a bilingual and a traditional auditive-verbal education method (UN OHCHR, 2015) and from 2017 bilingual education will become compulsory for deaf children in special schools. In Hungary, a particularly innovative approach to facilitating the use of sign language and other suitable forms of communication in everyday life is available and is worth mentioning. The Hungarian Association of the Deaf and Hard of Hearing has implemented a live “translation” service, offering voice, video and text message translation free of charge to registered users.¹²

The **Portuguese** Constitution states that Portuguese sign language must be considered as a means of cultural expression and a tool for accessing education and facilitating equal opportunities. Portuguese sign language also features in the Anti-Discrimination Law (Law 46/2006). According to it, denying access to sign language is defined as a discriminatory practice. According to Article 43 of the 2004 Disability Act (Law 38/2004), the State and other private and public stakeholders are required to provide information to disabled people in accessible formats, which include sign language.

In **Sweden**, by a 1981 Parliamentary resolution, Swedish Sign Language became the official language for hearing impaired persons, with the right to practice sign language, just as is the case for persons who speak other recognised minority languages in Sweden. Later, the Swedish Language Act (Språklagen SFS 2009:600) stated that people who are deaf or hard of hearing, or persons who for other reasons need sign language, shall be given the opportunity to learn, develop and use the Swedish sign language. Children are expected to attend mainstream schools, and sign language is taught as an optional third language. For those who are unable to be schooled within the mainstream system, there are six specialist schools available across the country, out of which one caters for pupils with learning difficulties.

Recognition of national sign language as an official language has been accepted in all four countries under study, as early as in 1981 in Sweden and more recently (2009) in Hungary. In Portugal and Hungary, sign language is recognised by the constitution and in Germany and Sweden by separate acts. While this recognition by itself primarily has symbolic character, it has important implications for the right to use sign language in different areas of life (and to be provided with translation if necessary) and therefore for inclusion and participation.

2.2.4. Comparison of regulation concerning specific areas of life

Regulation concerning public spaces (transport, buildings)

Accessibility to public spaces is regulated in all four countries under study.

In **Germany**, accessibility of public transport and public buildings was made a requirement by the Disability Equality Act (2002). This obligation applies to new large-scale public buildings and to renovated ones. All 16 federal states (*Länder*) have similar laws and regulations on accessibility in buildings which are open to the public. Institutions can be fined for non-compliance. However, this does not apply to private buildings that are accessible to the public. Although the general equality law

¹² Further details are available on the website of the Hungarian Association of the Deaf and Hard of Hearing: <https://www.skontakt.hu/english/>.

does stipulate that people may not be discriminated against because of a disability, it does not appear to be adequate to instigate sufficient action.

The Disability Equality Act also applies to transport and stipulates that at the national level transport needs to be accessible. This has caused changes in various specific acts, for example the national passenger transport law. Full accessibility of public transport for persons with reduced mobility or impaired senses needs to be accomplished by 2022. Public transport is also mentioned in the Social Code Book IX, stipulating that persons with a recognised severe disability or who are deaf or blind are entitled to use public transport free of charge.

The Disability Equality Act is currently under amendment. Planned changes include a more individualised approach to what is required for accessibility, the requirement that accessibility also be provided for non-large-scale building projects and the increased availability of official communication in an easy-to-read style (BMAS, 2016).

In **Hungary**, all buildings in which services to the public are provided are required by the Equal Opportunities Act (26 of 1998) to be accessible to disabled people. This applies to public and private buildings, whether old or new. The Equal Treatment Act (125 of 2003) can be applied for legal procedures in case of any breaches. Transport providers are also required by the Equal Opportunities Act (26 of 1998), to provide accessibility for disabled passengers, which applies to all forms of public transport. Initially a deadline was set for the latter in 2013, which was later deleted by an amendment. In general, implementation in both buildings and transport has been slow. In practice accessibility is often neglected in large infrastructural or other investment projects and is generally weak in transport due to a lack of resources.

In **Portugal**, the Disability Act (2004) stipulates the right of people with disabilities to access transport, including the use of public transport, special transport and other means of appropriate transport, as well as to receive forms of social support. The law requires that public buildings and public-use facilities are made accessible to disabled persons. Deadlines depend on the year of construction. The National Plan for the Promotion of Accessibility, 2007/2015 (PNPA) (Resolution of the Ministers Council 9/2007) establishes a set of measures to remove barriers to accessibility in transportation and the built environment, in workplaces, housing and ICT.¹³ Furthermore, the National Disability Strategy, 2011-2013 (Resolution of the Ministers Council 97/2010) also included measures to remove obstacles and promote accessibility in public transportation.¹⁴ However, a study of Lisbon city centre in 2010 concluded that only 12.4% of the bus stops were accessible and only 4 out of 13 underground stations

¹³ The application of the PNPA considers two temporal phases. The period up to 2010 sets out the concrete measures and actions, indicating their completion deadlines and promoters. The actions for the period 2011-2015 will be set during the 2nd half of 2010 due to a current status of the implementation of PNPA.

INR published the evaluation of the first phase in the report "National Plan for Accessibility Promotion: Progress Report Phase 1 (2007-2010)". In resume, 11 from the 68 measures were accomplished. The second phase 2012-2020, was approved in Resolution of the Ministers Council which took place on the 24th August 2012.

¹⁴ In the Final Report of the Implementation of the National Disability Strategy, (INR, 2013) the final assessment of the National Disability Strategy is very positive, since from the 133 implementing accountability measures by various agencies, in the 5-axis strategic intervention, the percentage of accurate overall implementation was 75.93%, which demonstrates accountability and a commitment by services, central government bodies, regional and local, as well as the various entities and civil society organizations, for its implementation and enforcement.

Some measures, successfully implemented were identified in such as:

Measure 89: Increase the number of Carris buses equipped with adapted vehicles.

Measure 91: Install a written message and audio system inside the Carris buses with information on stops.

Measure 92: Introduce cards with raised characters in Braille for people with low vision, with the existing information in the stops of Carris buses

Measure 93: Provide descriptive information of Carris buses itinerary in audio format.

Measure 95: Install a referral system with touch pavement in the Lisbon Metropolitano

Measure 97: installing the system for fixing the wheelchair in the carriages of the Lisbon Metropolitano.

had an elevator, although none fulfilled the accessibility standards (Teixeira, 2010). These findings may be illustrative of the wider reality in Portugal.

In **Sweden**, the Special Transport Act of 1979 and the Special Transport Regulation of 1980 established the right of access to public transport for persons with disabilities. These acts allocated responsibility to the Swedish Transport Administration (*Trafikverket*), the Swedish Maritime Administration (*Sjöfartsverket*) and the Swedish Transport Agency (*Transportstyrelsen*), with the Swedish Transport Administration also having a coordinating role. The efforts appear to have been quite successful, with 92% of Sweden's public transport having dedicated wheelchair spaces, 90% being equipped with a ramp or lift, and 76% having audio-visual announcements (Swedish Institute, 2016).

Various general rules for the physical environment were established by the Planning and Building Act of 2010. It specified that in built-up areas the environment needs to be adapted to accommodate the requirements of disabled people. This applies to both public and private buildings. In addition, accessibility for people with disabilities already needs to be taken into account in technical specifications (Law on Public Procurement (SFS 2007:1091)).

Accessibility of buildings open to the public, whether privately or publicly operated, is stipulated by acts in Hungary, Portugal and Sweden, while in Germany this regulation only applies to publicly operated buildings. Except for Sweden, the implementation of accessibility still appears to be a challenge, with factors such as lack of regulation, incentives and deadlines, commitment and resources contributing to the situation. Sweden has promoted accessibility since the late 1970s and has therefore benefitted from a longer timeframe to implement it.

Information and Communication Technologies (ICT)

In **Germany**, section 11 of the Disability Equality Act of 2002 provides the basis for ICT accessibility. It requires the public sector to ensure its websites are accessible. This includes interoperability with ATs and the provision of information in German sign language.

Consequently, other changes have been made, for example in the Telecommunications Act (*Telekommunikationsgesetz*), which mandates that people with disabilities must have equal access to broadcasting and telecommunication systems. The Regulation on Barrier-Free Information Technologies specifies the criteria that need to be fulfilled, which are similar to the content accessibility guidelines of the World Wide Web Consortium. Commercial internet providers are not obliged to provide barrier-free websites but are asked to negotiate their accessibility standards in goal agreements with Disabled People's Organisations. Germany, unlike Hungary, Portugal and Sweden, has already signed the Marrakesh Treaty in 2014 (WIPO, 2016), which aims to create a set of mandatory limitations and exceptions for the benefit of the blind, visually impaired, and otherwise print disabled persons.

While in **Hungary** ICTs and websites are not subject to the Equal Opportunities Act (26 of 1998), the Provision on Accessibility of Information stipulates that they need to be accessible to disabled people. The act did not define a transitional period; instead accessibility was to be achieved immediately. Sanctions are possible for breaching this obligation (e.g. by the Equal Treatment Act 125 of 2003). Government Decree 305/2005 applies to websites providing information of public interest. These websites are required to be accessible to visually impaired and blind people. However, the 2011 report "Monitoring eAccessibility" found that despite policy efforts, "levels of accessibility achieved are generally low[er] and are poorly correlated with the efforts made in the implementation of accessibility policies" (European Commission, 2011).

In **Portugal**, the Action Plan for Information Society, adopted by Resolution of the Council of Ministers 107/2003, demands that ICT and websites are accessible. Accessibility is also promoted through the National Programme for the Participation of Citizens with Special Needs in the Information Society (Resolution of the Council of Ministers 110/2003). The measures proposed include the accessibility of public television channels and training on internet skills for disabled people. A special programme (ACCESS) has been established by the Ministry of Education and Science to enable disabled people to

overcome difficulties in using ICT. One part of the programme is the Solidarity Network, which has offered internet access, web hosting and electronic communication to non-governmental disability organisations (NGOs) since 2011. In addition, the Resolution of the Council of Ministers 155/2007 approved the Guidelines for the Accessibility of Government and Central Administration Websites.¹⁵ The “Monitoring eAccessibility” report however does not rate Portugal’s success in achieving actual improvements highly: “[...] efforts to implement accessibility policies have not been matched with a corresponding level of accessibility” (European Commission, 2011).

In **Sweden**, information and activities related to the government must be accessible to disabled people by law (Regulation SFS 2001:526). However, a disabled person is not entitled to receive information from government or municipal authorities in an accessible format of their choice, such as Braille. The Swedish e-delegation has produced guidance for web pages in terms of accessibility, however there is no such obligation for municipalities. The Swedish Administrative Development Agency (*Veroa*) published guidelines for public sector websites but was shut down in 2008 and has not been replaced. The “Monitoring eAccessibility” report also does not commend Sweden for its rate of accessibility.

None of the four countries studied can serve as a prime example of ICT accessibility. However, implementation levels across Europe are low despite policy efforts (European Commission, 2011). As these focus mainly only on public sector websites, the majority of websites are not included and private providers do not appear to voluntarily follow the requirements set out for the public sector. Another cause of regulations not being taken up appears to be a lack of transitional periods and sanctions for non-implementation.

Independent living

In **Germany**, community-oriented assistance and care is a basic principle of the social security system (Social Code Book XII) and of long-term care insurance (Social Code Book XI). According to the Social Code Book XII, persons with a disability can receive *integration support*, for example assistance to adapt their home. Deaf and blind persons are entitled to receive a monthly sum on the basis of the Assistance for Blind and Deaf Persons Law. All people who have been assigned to one of four care levels (*Pflegestufen*) are entitled to financial assistance and payments in kind. The financing of AT at home depends on the situation in which the need for the technology arises. For a therapeutic reason, the health insurance will provide the assistive devices, while long-term care insurance is responsible in a situation of long-term care (six months and longer). If an accident at work or an occupational disease has caused the disability, the accident insurance is responsible for providing AT. However, it is not always immediately clear which insurance system is responsible, and time and resources can be lost in the process of working this out. While the level of funding available is not abundant, it does cover many expenses. In general, enabling disabled people to live at home rather than in institutionalised care is a driver for the use of AT.

The Equal Opportunities Act prescribes that long-term institutions must be closed gradually (article 17 as amended in 2013) and that 1500 persons living with a disability but capable of independent living with personal help must be housed in residential homes for small communities by 31 December 2013, which is to be financed by EU Funds. The rest of the institutions not affected by the above mentioned change in 2013 will be replaced by residential homes according to a schedule defined by the government. There is a strategy on de-institutionalisation approved by the Government on 21 July 2011 (Government Resolution 1257/2011). The strategy's time frame is 2011-2041. From January 2011 new institutional places can only be created in community-based forms. Institutions housing more than 50 persons gradually have to be transformed into community-based services.

¹⁵ The final report "Study on Assessing and Promoting e-Accessibility" (from 2013) shows that the Portuguese public administration sites are in the average of the EU Member States. The overall score for Portugal is slightly above 50%, similar to the EU27 average.

In **Hungary**, independent living is supported by personal assistance (social) services, regulated by Act 3 of 1993 on Social Governance and Social Benefits. Assistive equipment, as well as information and services, are mostly provided by NGOs in Hungary. Several forms of allowance in kind are available from the government. This includes a free medication card to receive therapeutic equipment and medicine, car purchase and car conversion support, different forms of transportation support and home adaptations. However, conditions of entitlement and administrative processes are complex, and ATs provided by the state are very basic. NGOs in Hungary therefore have an important role, and people who can afford more sophisticated devices usually access them via NGOs (or often also via private firms). Another emerging issue for Hungary is accessibility of information. Very little information is available in Hungarian, and there are not enough resources available to translate all the necessary information into Hungarian. However, since very few disabled people in Hungary speak English, there is a knowledge gap regarding the possibilities that new and innovative AT can offer.

In **Portugal**, disabled people have traditionally lived with their families, except in the case of mental disabilities. The 2004 Disability Act (Article 32) calls attention to the need on the part of the state to take the necessary measures to ensure the right to housing for persons with disabilities. Nevertheless, according to Order 28/2006, persons with disabilities can be obliged to live in a residential facility if they participate in education, training or other activities located in an area far from their home or if the family cannot guarantee proper accommodation for them. Persons in Portugal with disabilities of 60% or more incapacity can have access to a special house credit. Also, disabled people with low income can benefit from government support with the cost of rent. Decree-Law 8/2010 has established the creation of new types of services providing community care for persons with psychosocial disabilities to reduce institutionalisation. The 2004 Disability Act (Article 31) states that the provision of appropriate means of compensation for people with disabilities is the state's responsibility to improve autonomy and adequate integration into the community. The National System for the Ascription of Assistive Devices, established by Decree Law 93/2009 and Decree Law 42/2011, operationalizes the act. Disabled people with an incapacity level of 60% or more can have free access to AT. Nevertheless, AT are provided only after the evaluation of the conditions of the applicant and of the importance of the device to the applicant's life, and a medical prescription is required. AT prescribed by a health or a rehabilitation centre is funded by the Institute for Social Security (ISS, I.P.) and the Ministry of Health. The process of obtaining AT is lengthy and bureaucratic. In Portugal, there is no national personal assistance scheme and, therefore, persons with disabilities are very dependent on the support of their families. At the national level, the family members who assist their disabled relatives (both children and adults) are entitled to an Allowance for Assistance by Third Person (€ 101.17 per month). If the disabled person is admitted to live in an institution, the institution receives € 915 from the state.

Sweden has a long history of de-institutionalising disabled people, ranging back to the 1970s. According to the Swedish Law on Grants for Housing Adaptation of 1992, municipalities approve grants for reasonable expenditure for the adaptation of housing accommodation to permit people with functional impairments to continue living in their own homes. According to the Code of Social Insurance, disabled people can apply for tax-free credit to cover specific additional costs of living. The cost for a municipality associated with a disabled person living in their own apartment is between €2000 and 2500 per month (whereas the cost of a special housing institution can be over €5000 per month). This makes a strategic housing plan a key issue in Sweden for local municipalities (Swedish Agency for Participation, 2016). Access depends on the onset of the disability. If onset is before the age of 65, benefits are maintained beyond the age of 65. If a disabled person's pension does not cover basic needs, the person may apply for additional support according to the Code of Social Insurance. The amount is not fixed (as for example in Hungary) but related to the needs of the individual person. The baseline legislation concerning social services for the entire population is the Social Service Act of 2001. AT is mainly provided in accordance with the Health and Medical Services Act of 1982. The AT provision in Sweden to disabled people is a responsibility of regional authorities (21 county councils) together with local authorities (290 municipalities) (Health and Medical Service Act §3b and §18b). According to the Act, ATs are obtained

either via healthcare providers or via employers, and a prescription by a healthcare professional is required. Every regional authority sets the fees and evaluates the need for ATs independently. This has led to very heterogeneous levels of access to ATs between different counties in Sweden. Work-related AT are the responsibility of social insurance offices and/or employment agencies.

In all countries under study, independent living is promoted as opposed to institutionalised care. While Germany provides a relatively adequate amount of funding for ATs necessary for independent living, responsibilities are divided between different insurance systems, which can lead to delays in granting the support needed. In Sweden, this responsibility rests with healthcare providers, but large regional variations exist because it is dealt with at a county level. In Hungary, ATs provided by the state are of very low quality, which is why NGOs play a major role. However, ensuring equal access this way is very difficult. Portugal still relies heavily on the support of the families of disabled people in terms of looking after them at home and access to ATs is lengthy and bureaucratic.

Education

In **Germany**, the constitution does not explicitly state that disabled children are entitled to be schooled in mainstream schools, but Article 3 (3) forbids discrimination because of disability. Beyond this, school and university education are the sole responsibility of the 16 federal states and each state has its own legislation and school authorities. These decide about individual cases, i.e. the type of special education (if any) and support needed as well as whether a disabled child is to attend a special needs school, a specialist school or a regular school. In some states, parents are involved in making this decision, in others it is made by the school authority alone, taking into account statements from parents, teachers and other experts. In the majority of states, integrative schooling is seen as the preferred option. However, the attendance at a mainstream school depends on the availability of AT and trained staff. Personal assistance to attend a mainstream school is financed through the “integration support for disabled people” (Social Code Book XII). There is a slight difference between states, with the northern states offering more opportunities for disabled children to be schooled in mainstream schools.

Regarding university education, the national Framework Act on Higher Education (*Hochschulrahmengesetz*) requires universities to ensure that students with disabilities are given access to all academic courses and services, receive need-based special support in order to take exams and in general do not suffer discrimination (section 2 paragraph 4 sentence 2 HRG; section 16 sentence 4 HRG). Respective provisions have been adopted by the German federal states in their higher education laws.

In **Hungary**, the Act on National Public Education (Act 190 of 2011) regulates the choice for children with disabilities between education in special schools and regular schools. However, the education system for disabled people in general in Hungary is lagging behind that in the Western European countries. On the one hand, different laws and regulations support inclusion of disabled children in the mainstream school systems, while on the other hand the daily practice is something very different and extremely variable. Many schools have serious infrastructure and accessibility problems. Additionally, the staff often lacks expertise, especially regarding the needs of autistic children.

In university education, the National Higher Education Act (204 of 2011) grants disabled students special rights such as special arrangements during examinations (e.g. use of ATs), as well as extra time or the exemption from being assessed altogether. They can also be exempted from taking certain course units or parts of units and educational funding from the state may be extended by up to four semesters. Disabled students are also granted 50 extra points on top of the maximum 480 points resulting from their secondary education, allowing them easier access to higher education (Government Decree 79/2006, article 18-20). Accordingly, the number of disabled students increased from 271 in 2002 to 1,176 in 2008.

In **Portugal**, the Disability Act (2004) states the right of disabled people to education. New legislation on inclusive education, introduced by Decree Law 3/2008 and amended by Law 21/2008, led to the closure of special education schools and the integration of disabled children into regular schools. For

deaf and/or blind or low vision students, so-called *reference schools* were established. These schools are public mainstream schools, which provide resources for the students to learn Braille or sign language from preschool to the end of compulsory education. Both laws refer to inclusive education and constitute efforts to integrate children with special needs into public mainstream schools in order to facilitate their integration into the community. Decree-Law 108/2015 introduced changes to Decree Law 290/2009 that initially created the Programme of Employment and Vocational Training of Persons with Disabilities. This programme aimed to support the training and employment of persons with disabilities who have difficulties being integrated into the labour market. Decree Law 108/2015 introduced the Inclusive Employer Brand, which is a public award that aims to promote inclusive practices by employers. Persons with disabilities can also participate in internship programmes by Ordinance 259/2014 and Ordinance 149-B/2014.

Universities in Portugal are not subject to legislation that imposes any kind of duties in relation to students with disabilities,¹⁶ other than the Anti-Discrimination Act, which prohibits discrimination in all areas of social life, including education. The Law on Higher Education Funding (Law 37/2003 of 22 August, paragraph 4, Article 20), however, states that universities should consider providing special support for students with disabilities. While this has been taken up by some universities (e.g. through developing guidelines for their staff, establishing support offices or providing accessible materials and equipment), other universities do not provide any support to disabled students. However, there is a quota of 2% for disabled students for the national application process to higher education (Ordinance 197-B/2015). In order to benefit from this quota, disabled students must fulfil all the requirements of regular applicants and provide evidence of their disability. However, the majority of disabled students enter higher education without using the quota.

In **Sweden**, all children must have access to an equal quality of education according to the Discrimination Act (SFS 2008:567). School Regulation (SFS 2011:185) requires schools to arrange for teaching in sign language if there are at least five pupils who choose it. There are special schools for students with various disabilities operated by the National Agency for Special Needs Education. According to Swedish School Law (SFS 2010:800) children who cannot meet the requirements of regular schools are admitted to a special needs school (*grundskolan*). An assessment is made prior to this decision. Local municipalities are in charge of compulsory schools for pupils with learning difficulties (therefore, it is not regulated at the federal level, just like in Germany).

At the higher education level, all universities and other institutions are required to establish a contact person or coordinator dealing with issues related to educational support for disabled students. Services that are typically available include sign language courses and translation, support with reading, note-taking and proofreading, personal assistance, the provision of certain ATs, for example in specially equipped rooms, alternative forms of examinations and/or extra time for exams, mentors and books in Braille.

A commitment to inclusive education has been made by all four countries. In reality, whether it is possible to educate a disabled child in a mainstream school very much depends on the availability of ATs and other facilities as well as of trained staff. Lack of funding can get in the way of providing these, and economically more advanced countries appear to fare better in implementing the regulation. There are also regional variations within countries, e.g. between the German states. Only Portugal has closed special education schools altogether.

¹⁶ In the Concluding Observations on the initial report of Portugal, the Committee recommends that the State party should pay attention to the links between article 24 of the Convention and SDG 4, targets 4.5 and 4(a) in order to ensure equal access to all levels of education and vocational training. It was also mentioned that the state should take steps to increase human and material resources and to facilitate access and enjoyment of a quality inclusive education for all pupils with disabilities, providing state schools with adequate resources to ensure the inclusion of all students with disabilities in mainstream classrooms.

In higher education, the situation is more varied. While in Germany and Hungary universities are obliged to provide special support to disabled students, in Portugal this is only suggested on a voluntary basis. Individual good practices such as a quota, additional financial support or dedicated contact persons have also been developed in some of the countries.

Employment

In **Germany**, persons with a disability are protected against discrimination in working life by the General Equality Act and Social Code Book IX. Social Code Book IX requires all private companies and public service providers with 20 or more employees to have at least 5% severely disabled staff (6% in case of private companies). Otherwise, a compensational tax applies, which is used for example to finance accessible workplaces. Supported employment has been possible since 2008, also on the basis of Social Code Book IX. Consequently, persons with a disability can receive individualised training and support when starting a job in the general job market; if required they are also eligible for continuous support. Individual adaptation of workplaces, provision of specialist equipment and adaptive technologies at work are available for persons with a disability on the basis of Social Code Book IX. The employer is required to facilitate the adaptation of the workplace within the scope of what is deemed reasonable and has to consider the health and abilities of a disabled employee in their tasks and responsibilities. Funding is dependent on the situation and may be provided by the accident insurance, long-term care insurance or the Federal Agency for Employment. Employers with five or more permanently disabled staff with a level of disability of 50% or above are required to facilitate the election and appointment of a disabled person's representative. There are also various awards for disability-friendly employers.

State subsidies for work place adaptation, adaptive technologies and personal assistance are guaranteed. All of these are available on a competition basis every year until the funds are exhausted. The legal basis for flexible employment contracts is set up, however distance work, for example, as a systemic factor of high impact is virtually non-existent

Also in **Hungary**, legislation on non-discrimination in occupation and employment is in place through the Equal Treatment Act (125 of 2003). The NDP also provides information on how to increase the rate of employment of disabled persons (UN OHCHR, 2015). Guaranteed state subsidies for workplace adaptation, AT and personal assistance are available, these are awarded on a competitive basis every year until no more funding is available. The legal basis for flexible employment contracts has been set up, however working from home, for example, as a systemic factor of high impact, is virtually non-existent. Financial incentives for companies to employ people with disabilities include personal income tax allowances. The activities carried out in the field of occupational rehabilitation since 2012 are deemed to have improved the participation of disabled people in the labour market and increased the number of those involved in supported employment: currently around 3000 employees with disabilities are working for more than 300 employers. Furthermore, in the National Reform Programme, €6.4 million have been allocated to improve the quality of life, social integration and employment rate for people with ASD. The same programme also supports infrastructure developments to promote the employment of people with ASD and other types of disabilities (European Commission, 2014). Furthermore, NGOs are very active in implementing programmes to integrate people with disabilities (especially ASD) in the labour market. However, there is a lack of experts who could facilitate and manage this process, e.g. in terms of advising companies on how to better integrate disabled persons.

In **Portugal**, the Disability Act (2004) announces the "right to employment, work and training" (Article 26). The Labour Code guarantees the right of employees and applicants to not be discriminated against directly or indirectly regardless of characteristics such as disability, reduced working capacity or chronic disease (Article 24:1). The Anti-Discrimination Law makes any actions of employers or recruitment agencies that limit access of disabled people to employment or result in dismissal a

discriminatory practice (Article 5).¹⁷ Within public administration, a mandatory quota of 5% for external admissions was established by Decree Law 29/2001. Financial support is also available to public employers that are not part of the state administration to compensate them for measures required to accommodate disabled staff, such as workplace adaptations, elimination of architectural barriers, wages and social security contributions (Decree-Law 108/2015). The law also introduced the Inclusive Employer Brand, allocated as a public award to honour and reward particularly successful cases of employers who have established open and inclusive practices for persons with disabilities in the areas of recruitment, retention, accessibility and community services (Article 78).

In **Sweden**, the Discrimination Act of 2008 covers all features of the relationship between employer and employee. An earlier important measure was the introduction of the “Prohibition of Discrimination in Working Life of People with Disability Act” (1999:132). The Swedish Public Employment Service was established to provide disabled people with personal employment advice. It also offers access to specialists for people with impaired sight or hearing. The provision of equipment is regulated by the Health and Medical Service Act of 1982. Support at the workplace in terms of AT or physical adaptation can be provided up to a certain amount of funding, either through the county governments or through the municipalities. Personal assistance is available to those with certain functional impairments needing assistance to communicate, leave their home, etc.

Employers who hire people whose work capacity is limited (for example due to disability) are sometimes entitled to wage subsidies (Swedish Institute, 2016). Sweden has also successfully implemented an approach called supported employment in a number of organisations through their close cooperation with the Swedish Institute for Disability Research at Örebro University. “Misa AB2, which stands for “Method of development, Individual support, participation in Society and sympathy at Work”, for example, offers work related activities to people who have experienced obstructions in joining or returning to the workforce. The aim is to provide individual, for example in the form of rehabilitation, assessment of work abilities and daily training in order to improve employability.

Discrimination of disabled people is prohibited in all four countries. To motivate employers to hire disabled staff, fines can be imposed in Germany for not meeting employment quotas, while in Hungary employers with disabled staff are entitled to tax relief and in Portugal to special payments. Quotas exist in both Germany and Portugal. In Portugal, these only apply to public organisations, while in Germany both public and private employers are included. Hungary places a special focus on ASD and provides funds for it through its National Reform Programme, in terms of which it is ahead of the other countries in utilising the capabilities of autistic people. In Germany and Portugal, employers who have demonstrated special efforts for disabled staff are recognised with rewards, which is a positive incentive. Sweden uses the approach called supported employment¹⁸ as an innovative evidence-based practice to help disabled people into paid employment.

2.3. Good practice, difficulties, open questions

Our research has identified a number of positive examples and good practices as well as difficulties and bottlenecks in the implementation of the UNCRPD in the four countries under study. We have also taken a closer look at some of the more general framework conditions that appear to have either a positive or negative influence on the overall situation of disabled people in Germany, Hungary, Portugal and Sweden. This section is structured analogously to the previous one, covering the general

¹⁷ According to the Annual Report – 2015 About Discriminatory Practice Acts towards Disability and Health Aggravated Risk, the Authority for Working Conditions informed of the existence of five (5) complaints concerning the adoption by an employer of a discriminatory practice against a worker at his service or in the context of employment, and all of these processes are in the regulatory phase until the present date,

¹⁸ Supported employment in different EU countries is also the subject of a report by consulting group COWI for the European Commission:

http://ec.europa.eu/justice/discrimination/files/cowi.final_study_report_may_2011_final_en.pdf.

UNCRPD implementation first and then the various areas of life that are relevant in terms of ATs. Finally, recommendations are made and open questions discussed.

2.3.1. Good practice in UNCRPD implementation and the general legal frameworks

Since the adoption of the UN Convention for the Rights of Persons with a Disability in 2006, there has been an emergence of a new generation of human rights guarantees for persons with different disabilities. Our findings indicate that all the countries under study have successfully adopted the UN Convention for the rights of persons with a disability. However, while different laws (i.e. the UNCRPD or national anti-discrimination laws) seem to be well integrated into the existing national level legal systems, our analysis indicates that there are major gaps in everyday practice and significant variations within and between countries.

All four countries have set up specific coordination and monitoring bodies and mechanisms.¹⁹ However, the submission of shadow reports by individual NGOs indicates that there may still be an unmet need for greater general involvement of NGOs in the official reporting process to the United Nations, as these NGOs consider it necessary to make their views heard through shadow reports. Greater involvement would make it possible for the majority of the criticism expressed in their shadow reports to already be included in the official reporting process.

While the adoption of legislation to comply with the UNCRPD is being monitored and also needs to be reported, evidence on the actual success of the measures is comparatively sparse. In particular the definition of indicators that allow tracking the effects over time and across countries is missing, which makes it difficult to identify examples of particularly effective regulation. The good practice examples suggested here need to be considered within these methodological constraints.

In Germany and Sweden, many areas of relevance to disabled people are regulated at the regional or municipal level. This has advantages and disadvantages: On the one hand it enables a more personalised and flexible approach to addressing the needs of disabled persons, while on the other it can lead to a great deal of variability between different municipalities or states, for example as witnessed regarding the access to ATs and quality of services in Sweden.

Anti-discrimination

Hungary has made a concerted effort with its national autism strategy, which places special emphasis on a disability that appears to be particularly affected by discrimination. The strategy focuses on improving inclusion in key areas of life such as education, training and employment and can be considered as a good practice example.

Guardianship and supported decision-making

Sweden leads the way in terms of giving disabled people as much say in their lives as possible, and has been at the forefront of promoting equality since abolishing full guardianship and explicitly stating in 1989 that disabled people have the same legal capacity as their non-disabled fellow citizens. Two concepts are in place for people who require assistance in managing their legal affairs and other decision-making, namely trusteeship and mentorship. Trusteeship is a form of substitute decision-making while mentorship facilitates supported decision-making. This serves as a good practice example. On the other hand, an area that is highly worrying and needs urgent attention is the current situation in Portugal: Even people who only have physical disabilities (deaf-muteness and blindness) are at risk of being assigned the status of minors. While this is also being criticised nationally, a swift

¹⁹ Hungary is an exception since it has not nominated a specific coordination entity on the Convention issues, although it nevertheless has a monitoring body in place.

solution is required to move away from denying a person's liberties and towards enabling full capacity or supported decision-making.

Voting

With voting rights closely linked to guardianship, it is not surprising that Sweden again has the most pioneering approach by giving disabled people full voting rights and making extensive provisions to ensure that people can participate if they wish to do so. This includes assistance by election officials for people who cannot access the polling station by receiving a paper ballot outside the station, voting via a "messenger" and duties to make polling stations accessible. In Germany blind people can request a Braille voting template to use in a postal vote or for voting at the polling station.

Difficulties still exist in countries where the right to vote is automatically taken away with full or partial guardianship (Germany and Portugal) as a person's ability to vote is not even examined separately before such a far-reaching step is taken (here Hungary serves as a better example).

2.3.2. Regulation concerning specific areas of life

Sign language

In all four countries included in this study, recognition of sign language serves as a positive example of policies designed to support disabled people. Sign language has been well taken up in all four countries in different schooling systems. This trend is closely connected with the integrated schooling system, which serves as another positive trend over the past years and demonstrates the success of flexible policy design that contributes to better meeting the needs of disabled children by integrating them into the mainstream schooling system.

Public spaces (transport, buildings)

Regulation concerning the accessibility of public spaces appears to be most successful when it defines a transitional period, offers funding for implementing the changes and does not distinguish between public and private buildings. A country such as Sweden, which has already been promoting accessibility for more than 35 years, is in a much better position than Portugal, for example, whose legislation on accessibility is much more recent. This illustrates how fundamental changes take a long time to implement and how important careful and long-term policy planning is.

Information and communication technologies

The measures that have been put in place to make public sector websites accessible to disabled people have achieved this goal; however, they have not led to voluntary action in the private sector. With the majority of websites being privately run, a large proportion of all websites are not accessible. Regulation should therefore be extended to also cover private sector websites and could include binding requirements combined with sanctions and incentives, which have been successful in the public sector.

Independent living

Enabling disabled people to live outside of institutions plays a major role in their inclusion in society and quality of life. It also requires commitment to support this choice, which has been officially made by all the countries under study. In Germany, the level of funding available ensures that disabled people can live an independent life and also have access to the necessary ATs. Access to financial support and ATs in Germany therefore can be seen as a good practice example. Less positive is the process required in order to receive this assistance, which can be a bureaucratic burden, as it is not always clear which insurance systems is responsible.

A mindset that the family of a disabled person is responsible for their care, as is the case in Portugal, can hinder policy progress in this area, can put the disabled person into a dependent role with little leeway for creating an independent life and can cause great inequalities in terms of living situations and quality of life. Policies enabling and honouring family involvement while not making it a necessity, as is the case in Germany, might be a good way forward.

Education

Portugal has taken its commitment towards inclusive education the furthest by closing special education schools altogether and making provisions in certain mainstreams schools to accommodate disabled pupils. The other countries under study have also implemented important measures to ensure disabled students receive the schooling they are entitled to, such as personal attendance to attend a mainstream school, classes to learn sign language or special help with sitting exams.

Overall, higher education institutions do not yet have the same provisions as schools, and this is an area that still requires attention. Sweden appears to be most advanced, with a wide range of support measures available such as sign language interpretation, help with reading, note-taking and proofreading, personal assistance, certain ATs, for example in specially equipped rooms, extra time for exams, alternative forms of examinations, mentors or other individualised support measures, talking books and books in Braille. Such measures could also be implemented in other countries.

Employment

Several measures taken in the four countries studied appear to represent good practice. These include quotas in the public and private sector to employ disabled people, financial support and advice on the one hand as well as sanctions on the other and awards recognizing particularly disability-friendly employers. To ease autistic people into employment and reduce the stigma and misconceptions about the condition, the Hungarian national reform programme can be highlighted as a potentially effective approach, as can the Swedish supported employment concept. In all these countries further awareness measures would probably be helpful to change the perception of disabled employees from being a burden towards being valued members of staff and promoting diversity in the workforce.

2.3.3. Options for future policy making

One of the main difficulties for policy makers regarding the overall national level process of implementing the UNCRPD is the lack of precise and robust indicators that would allow measuring the actual impact and benefit of this Convention on a national level in and across different countries. The DOTCOM database, developed by ANED, already includes a number of indicators and sources and provides a comprehensive overview of the UNCRPD uptake process in the countries which have signed the Convention. The same database could be developed further to also include reporting on respective indicators, which would enable policy makers to evaluate and compare the success of UNCRPD implementation better and to identify the actual success of particular policy measures.

Another possible step to improve the evidence base is the inclusion of more disability organisations in the national official reporting process. Currently shadow reports are published by disability organisations who feel that they cannot make their voices heard in the official reporting process.

In terms of guardianship, unnecessarily limiting disabled people's rights and taking away their right participate in the political process through voting are in breach of the UNCRPD. Action to eliminate such discriminatory practices is recommended.

Measures to improve the accessibility of ICT in the public sector, such as binding requirements, appear to be most successful and could be extended to the private sector. Furthermore, reasons for non-compliance could be investigated and technical and other solutions developed that make it easier to

develop accessible websites. Especially with IT-literate generations progressing into old age and continuing to rely on ICT, this will become an increasingly competitive factor in the future.

To promote independent living, policies enabling and honouring family involvement while not making it a necessity, as is the case of Germany, might be a good way forward for disabled people being able to choose how they want to live.

Concerted national efforts to promote education and employment, especially focusing on mental disabilities, could contribute to reducing the stigmatisation and exclusion of a significant proportion of disabled people.

Finally, there are a number of problems afflicting ATs in each of the different countries. The first major issue is heterogeneity. Within a country, people with disabilities may be afforded different degrees of access to ATs and services, depending on where they live, which is often referred to as a “post-code lottery”. This issue is especially evident in Hungary, Portugal and Sweden and seemingly less so in Germany. Another hindrance is a very long and bureaucratic process for obtaining ATs in general. Also, information on ATs is not always easily available, putting people who are unaware of what is available and what they are entitled to at a disadvantage. Efforts could therefore be taken to ensure that information and access to ATs is equal across individual countries and throughout Europe as it is a key enabler of inclusion.

2.3.4. Open questions

A number of open questions arise from our analysis. In Europe, the majority of social care and health care systems are funded through taxes. It remains to be seen how the quality of health care services can be maintained while facing current demographic trends, such as aging societies and an increasing number of people with disabilities on the one hand and on the other the increasing availability of expensive innovative ATs.

Secondly, we witnessed a general policy trend towards supporting and encouraging disabled persons to pursue a life as independent as possible, e.g. in terms of living in private accommodation instead of staying in large institutions and in terms of inclusive schooling and being in employment. However, questions arise as to how well these trends can be applied in practice, especially in countries where there are fewer resources available for individual support and assistance for disabled persons. For example, making provisions for students with different disabilities to be taught in most mainstream schools can be more costly than only equipping a small number of specialised schools with the necessary tools and resources.

Thirdly, unanswered is the question as to how well countries other than Germany, Hungary, Portugal and Sweden have adapted their legislation and regulations to better meet the needs of their disabled citizens. Further studies of a larger number of countries are necessary in order to determine whether more common patterns emerge and which European level policy incentives could be designed to better meet the needs of disabled persons in different EU Member States.

2.4. Conclusion on the regulatory environment for ATs and people with disabilities

In all four of the countries studied, anti-discriminatory and other legislation for the inclusion of people with disabilities is included at the highest level of the legal framework and contains detailed rules on definitions, remedies and legal procedures. There are specific prohibitions in several fields, such as employment, housing, and healthcare. Nonetheless, there are still cases of non-compliance with the UNCRPD and of laws and regulations which discriminate against disabled people. Also, there are great variations between countries, for example Sweden has taken the approach that disabled people possess full legal capacity and if necessary are supported in decision-making, whereas in Portugal, for example,

persons under guardianship have very limited rights to enter into legal commitments, regardless of the presence of mental handicaps.

In general, the move away from a “one size fits all” approach towards a more individual one, taking into account the wishes and abilities of disabled people and viewing them as valuable members of society, is evident in various pieces of legislation and is likely to become increasingly prominent in the future. However, a problem evident in all countries, which also has an impact on the availability and usability of ATs, is that the alignment between the regulatory measures in place and their implementation in practice is sometimes poor.

Germany and Sweden seem to have a more decentralised and flexible policy framework to better address the requirements of people with different disabilities as well as the needs of the individual. Although the legal framework is also well adapted in Hungary and Portugal, the lack of resources seems to be a hindrance keeping the state from playing a stronger role in arranging suitable living conditions and a better integration of people with disabilities into society. In Hungary, ATs are mainly provided by NGOs and the budget available is a fixed amount. In Portugal very little public funding is available for AT, and disabled people and their families are expected to cover the costs. In Germany and Sweden, on the other hand, financial resources dedicated to ATs are not limited per person, but dependant on the needs of the individual.

Overall, there are already very positive examples of favourable regulatory frameworks for furthering inclusion with the help of AT in different countries. There may be benefit in raising awareness of such examples to support other countries in developing their own measures.

3. Health and demographic perspective

The objective of this section is to provide information on three types of disability: deafness/hearing impairments, blindness/visual impairments and ASD. It describes the causes and risk factors for these disabilities and discusses their current and future prevalence. This provides the basis for exploring which impairments are likely to play the greatest role in the future, and for reflection upon how ATs could support inclusion in society, education and employment.

3.1. Deafness and hearing impairments

3.1.1. Definition

In order for a person to hear sounds, it is necessary to “have a source of sound, a mechanism for receiving this sound, mechanisms for relaying sounds to the central nervous system, and pathways in the central nervous system to deliver this sensory information to the brain where it can be interpreted, integrated, and stored” (Lucker and Hersh 2003, 2).

Anatomically, the ear can be divided into three main parts²⁰: the outer, middle and the inner ear, which includes the central auditory system (Figure 5).

²⁰ There are different approaches to the division of the compartments of the ear, for instance Heller and Kennedy (1994) take a four level division (outer ear, middle ear, inner ear and the central auditory system).

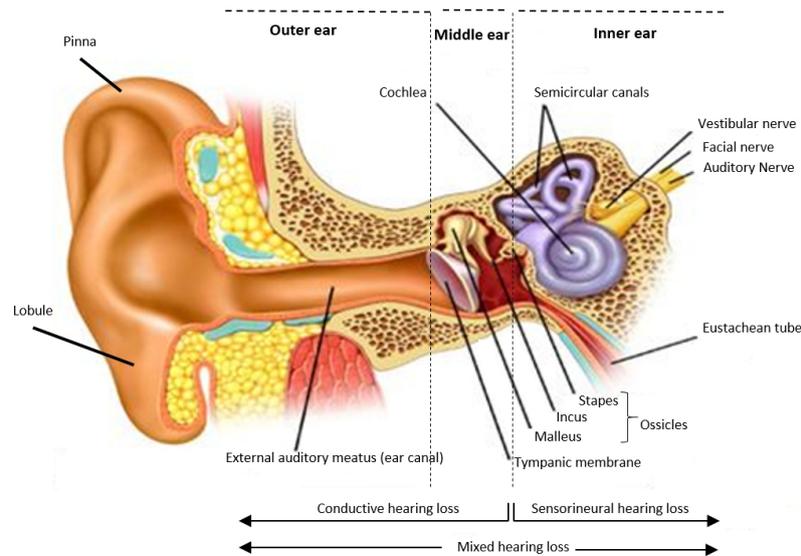


Figure 5 – Cross Section view of the ear

(Source: adapted from <https://virtualgardneranatphys.wikispaces.com/Equilibrium>.)

The outer ear consists of the pinna (or auricle) and the ear canal (or external auditory meatus (EAM)), which ends in the eardrum (or tympanic membrane). Its main function is to receive sound and funnel it down to the eardrum. The middle ear consists of three ossicles: malleus (hammer), incus (anvil) and stapes (stirrup) and the tympanic membrane. Its main function is to convert the acoustic energy of the sound received by the pinna and funnelled down to the eardrum into mechanical energy by the motions of the eardrum and the bones in the middle ear. The inner ear is composed of the cochlea and the auditory nerve (or eighth cranial nerve) (Lucker and Hersh 2003).

Hearing loss is a reduced ability to hear sounds in comparison to normal hearing, which can range from slight to profound. Loss of the ability to hear sound frequencies in the normal range of hearing is called hearing impairment. The WHO classifies hearing into five grades, from “no impairment” to “profound impairment”. There are, however, other classifications, such as the one adopted by ASHA (American Speech-Language-Hearing Association) provided by Clark in 1981, which has seven grades, from “normal” to “profound”. Both classifications can be found in the Annex.

3.1.2. Causes and risk factors

Several disorders can occur that affect the auditory system. Depending on the structure affected, the hearing loss can be designated as conductive hearing loss, sensorineural hearing loss and mixed hearing loss. The classification and characterisation has been further developed (if not otherwise mentioned the following sections are based on: Lucker and Hersh 2003, NHS 2015 and SCENIHR 2008):

Disorders of the Outer Ear: Conductive Loss

Conductive hearing loss only results from problems of the outer ear if they result in total blockage of the air conduction pathway, resulting in a loss that lasts only as long as the outer ear is totally blocked and prevents sound reaching the tympanic membrane. For this reason, most outer-ear problems cause temporary rather than permanent hearing loss.

There can be physical malformations such as congenital atresia (absence or closure of the external auditory canal) or obstruction in the external auditory canal from impacted cerumen (wax), foreign bodies, or a tumour. Infections such as *external otitis* (an infection of the skin of the external auditory canal, also known as swimmers ear) may also impede hearing. The tympanic membrane (eardrum),

bordering between the outer and middle ear, may become perforated due to an infection or a blow to the head.

Disorders of the Outer and Middle Ear: Conductive Loss

These occur whenever there is a problem in the conduction of the sound waves along the path through the outer ear, tympanic membrane (eardrum), or middle ear (ossicles). Since sound travels through air and bone, the presence of *conductive hearing loss* suggests there is an air-bone gap, which means that sound travelling through the bone conducting pathway will be heard better than sound travelling through the air conduction pathway (which includes the outer and middle ear). Consequently, air conduction thresholds will be raised, but bone conducting thresholds will be “normal”.

Disorders of the Middle Ear: Conductive Loss Otitis media

One of the most frequent causes of conductive hearing loss is *otitis media*, which is an inflammation of the middle ear that is frequently caused by a bacterial or viral infection. Often otitis media is accompanied by fluid in the middle ear, which restricts movement of the tympanic membrane. This restriction of movement can result in a moderate hearing loss and possible rupture of the tympanic membrane. Otitis media with effusion (fluid) is the most common cause of ear problems and temporary hearing loss in children. Many middle-ear problems are temporary and only cause hearing loss while they last.

Disorders of the Cochlea: sensorineural hearing loss

Problems involving cochlear structures cause *sensorineural hearing loss*. The most common congenital causes are related to hair cell and cilia abnormalities, due to abnormalities in the development of these sensorial cells during the embryonic and fetal stages, or due to hereditary/genetic factors leading to abnormal development of these structures.

The most common cause of hair cell²¹ damage is noise (noise-induced hearing loss) and ageing (the most common type of sensorial hearing loss due to aging is presbycusis). Since these cells cannot be regenerated, this damage is permanent, resulting in a decreased hearing sensitivity.

Disorders of the Inner Ear and VIII Cranial Nerve: Sensorineural Loss

A *retrococlear disorder* occurs when the auditory nerve is affected. Hearing loss due to a dysfunction of the inner ear on the pathway from the inner ear to the brainstem is referred to as a *sensorineural loss*. In this type of hearing loss, sound reaches the inner ear, but is not completely transmitted to the brain. Typically, the individual cannot hear high frequencies, which are the frequencies needed to understand speech. Most babies born with a hearing loss have a sensorineural loss. This is the case in such conditions as Usher syndrome and congenital infections which result in hearing impairment. However, a sensorineural loss may be acquired or stem from such causes as ototoxic drugs, trauma, and infections (meningitis) (Ludman (1988) cited in Heller and Kennedy (1994)).

Disorders of Outer, Middle, Inner Ear: Mixed Loss

A *mixed hearing loss* occurs when both conductive and sensorineural losses are combined, resulting in raised air and bone conduction thresholds, as well as an air-bone gap. Conductive hearing loss is usually temporary and can often be treated with medication or minor surgery.

²¹ Both the auditory system and the vestibular system in the ears have sensory receptors called hair cells. They are designated as such due to the fact that, when magnified, they have the appearance of fine hairs. The auditory hair cells are located within the spiral organ of Corti, on the thin basilar membrane in the cochlea of the inner ear.

Concerning sensorineural hearing loss, people with diabetes, chronic kidney disease and cardiovascular disease are also at increased risk of hearing loss. Sensorineural hearing loss is permanent, and hearing aids are often required to improve hearing in these cases (NHS 2015).

Disorders of Central Auditory System: Central hearing loss

A *central hearing loss* occurs if there are abnormalities in the auditory cortex or the pathways going from the brain stem to the auditory cortex. In rare cases, both are involved. Pathologies involving nerves cause problems with the normal transmission of neurochemical substances or with nerve impulse transmission. They are mostly related to tumours or growths on or that pinch nerves, problems with blood flow to the nerves and other central auditory pathway (CANS) structures, diseases (viruses or bacteria) that invade the nerves or CANS structures, or age-related degeneration of the nerve structures. Trauma and accidents can lead to the destruction of nerves or CANS structures.

Neurodegenerative diseases mean deterioration of nerves, *neural presbycusis* being the most common one, which is due to the natural changes and degeneration of the auditory nerves and CANS structures due to ageing.

Hearing problems involving the auditory cortex of the brain (part of the brain dedicated to auditory sense) are often called *central deafness*.

If the pathway from the VIII nerve to the brain is affected, a person's ability to process and understand auditory information rather than hearing itself is consequently also affected. This means that the person can hear sounds but is not able to understand or interpret them as speech. For this reason, if the problem is related to interpretation of the auditory information and no lesion has occurred, the problem is designated as an *auditory processing disorder*.

3.1.3. Prevalence

Worldwide, hearing impairments rank among the 25 most common causes for years lived with disability. In Europe, hearing impairments rank on place 12 (Central Europe) to place 18 (Western Europe) of the most common causes for years lived with disability. The global number of years lived with disability due to hearing impairments increased substantially from 1990 to 2010; a suggested reason for this increase is the ageing population (Vos et al., 2012). Data on the prevalence of hearing impairments is scarce and heterogeneous as a result of a variety of definitions and methodologies. A study on behalf of the Global Burden of Disease Hearing Loss Expert Group in 2008 estimated a global prevalence among adults (>15 years) of hearing impairment (≥ 35 dBHL) for males of 12.2% and for females a lower percentage of 9.8%. Differentiating the prevalence by region, the study found lower rates of hearing impairments in high-income regions with 8% for males and 7.3% for females, respectively. The study also found a clear correlation of hearing loss with age, with a sharp increase of the prevalence curve above 50 years of age, reaching an estimated global prevalence of 50% among 80-year-olds (Stevens et al., 2011).

As the most common causes of hearing impairments are acquired and age-related, prevalence is highest in the elderly population. Examples are age-related hearing loss (presbycusis) with an estimated European prevalence of 55% of men and 45% of women by the age of 80 (Roth et al., 2011), chronic otitis media and noise-induced hearing impairments. Congenital deafness or hearing impairments are less frequent and sometimes associated with syndromes, such as Down syndrome, Usher's syndrome, Treacher Collins syndrome, Crouzon syndrome, Alport's syndrome and Waardenburg's syndrome (Angeli et al. 2012). In children the most common cause of (temporary) hearing impairment are infections of the middle ear. Of note, the Scientific Committee on Emerging and Newly Identified Health Risks of the European Commission in 2008 published a report on the emerging risk for noise-induced hearing impairment in young people. As a result of a threefold increase of exposure to "social noise" (e.g. personal music players) since 1980, this population is increasingly at risk for noise-induced hearing

impairments. At the same time, noise exposure at the workplace has decreased because of better workplace safety regulations.

3.2. Blindness and visual impairments

3.2.1. Definition

In order for a person to be able to see, it is necessary that the structures of the eye collect and focus light energy into an image, and then convert the image into an electric-chemical impulse. The visual pathways transmit the electric-chemical impulses to the visual cortex, which is located in the brain. The visual cortex will then interpret the impulse and relay it to other higher cerebral centres (Heller and Kennedy, 1994).

The visual pathway can be divided into three areas: (1) the eye (and its muscles), (2) the visual pathways to the brain and (3) the visual cortex (Figure 6).

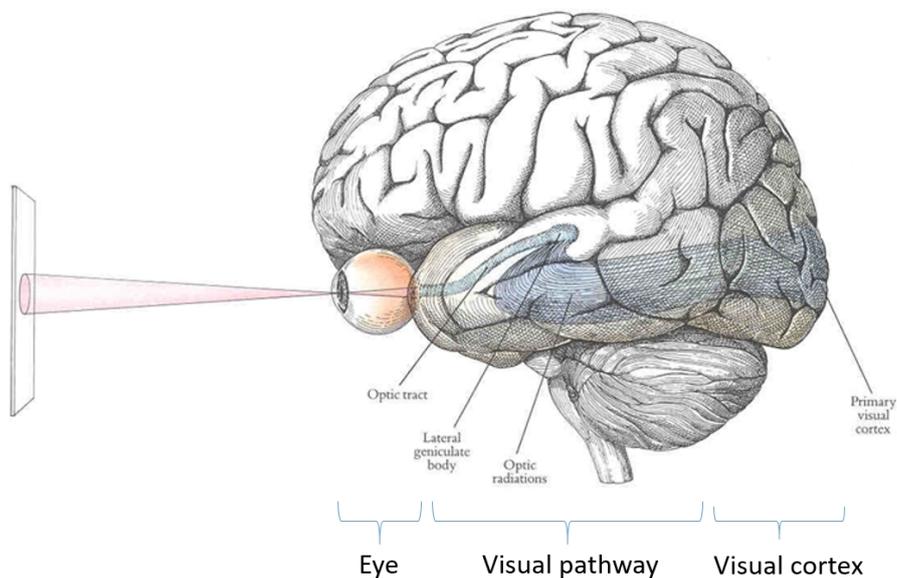


Figure 6 - Representation of the visual pathway

(Source: adapted from <http://www.cog.brown.edu/courses/cg0001/figures/visualpaths/lateral.jpg>)

Anatomically, a cross-sectional view through the eye presents the three layers, consisting of the external layer (fibrous tunic), formed by the sclera and cornea, the intermediate layer which contains the choroid, the pigment epithelium, the iris, and the ciliary body, and the inner layer, consisting on the retina which is the sensory part of the eye (Heller and Kennedy, 1994) (Hersh and Johnson, 2010). The macula is the most sensitive part of the retina, which is located at the back of the eye. The retina turns light into electrical signals and then sends these electrical signals through the optic nerve to the brain, where they are translated into the images we see. When the macula is damaged, the centre of the field of view may appear blurry, distorted, or dark (National Institutes of Health Medicine & Friends of the National Library of Medicine 2012) (Figure 7)

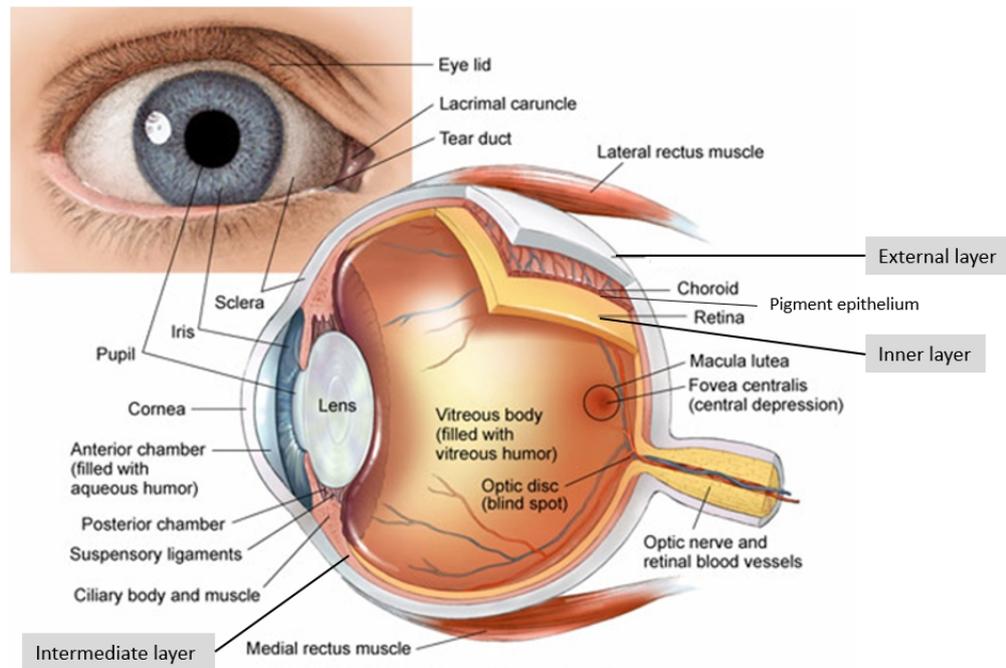


Figure 7 - Cross Section view of the eye

(Source: adapted from <http://neurobowe.wikispaces.com/Sensation+%26+Perception>)

Blindness is defined as a presenting visual acuity of less than 3/60 or a corresponding visual field loss to less than 10° in the better eye. If visual acuity is less than 6/60 and more or equal to 3/60, then it is designated as a severe visual impairment, but if the presenting visual acuity is less than 6/18 to 6/60, then it is a moderate visual impairment (WHO, 2015). The classification of severity of visual impairment is recommended by the Resolution of the International Council of Ophthalmology (2002) and the Recommendations of the WHO Consultation on "Development of Standards for Characterization of Vision Loss and Visual Functioning" (Sept 2003).

Only an estimated 3% of people classified as blind are functionally blind, and most blind people have some degree of useful vision (Hersh and Johnson, 2010). According to the WHO (2014), 80% of all causes of visual impairment are preventable or curable. There are several causes for visual disorders that can be classified according to the structure and function affected.

3.2.2. Causes and risk factors

Categories of disorder by structure include (if not otherwise mentioned the following sections are based on: Heller and Kennedy, 1994 and Hersh and Johnson, 2010):

Disorders of the external layer (cornea and sclera)

The function of the cornea is to refract light rays; therefore, a lesion on the cornea may result in blurred vision and, if scarring or perforation from *ulceration* occurs, blindness can result. *Infection of the cornea* can also occur, due mainly to a deficit on hand hygiene. *Trochoma* is a bacterial infection of the conjunctiva that leads to scarring of the cornea. Usually prompt medical treatment helps to avoid permanent damage. *Keratoconus* is a cone-shaped cornea that results in a distortion of the entire visual field. This rare disorder usually begins during adolescence, is slowly progressive, and usually occurs in individuals with congenital rubella and Down syndrome. Initially, a mild vision loss with myopia (near sightedness) and astigmatism occurs. If left untreated, this condition can slowly progress to the point that the cornea ruptures, resulting in blindness. Contact lenses may improve visual acuity in the early stages and surgery can be performed.

Disorders of the intermediate layer and surrounding chambers and fluids (aqueous humor, iris, ciliary body, lens and vitreous humor)

Glaucoma is an abnormal increase in intraocular pressure, which can damage the eye and visual functioning. There are several types of glaucoma, which all involve an imbalance between production and outflow of the aqueous humor.²² Secondary glaucoma occurs when there is an additional cause. This category of glaucoma is typically due to a blockage in the area of the eye in that the aqueous humor exits, resulting in increased intraocular pressure, which, if it persists and progresses, will damage the optic nerve, resulting in a loss of visual acuity, field loss, and/or blindness (Berkow, 1987; Martyn & DiGeorge, 1987, cited in Heller and Kennedy, 1994). Congenital glaucoma, which is glaucoma occurring from birth, is considered a primary type of glaucoma.

Glaucoma may be associated with other conditions such as congenital infections, adventitious conditions (e.g. trauma, tumours), retinopathy of prematurity and some syndromes. The major signs of glaucoma in infants include eye enlargement, tearing, photophobia, corneal clouding, twitching of the eye muscles and intense eye pain. After age three, the sclera and cornea are less expandable and the signs of pressure elevation are different. The child or adolescent may have no symptoms even with pressure high enough to cause visual loss. When the individual is born with glaucoma (congenital glaucoma), surgical intervention is necessary to correct the blockage and prevent optic nerve impairment. For glaucoma which develops after birth, eye drops can usually control the condition and may be all that is required. In a few cases, surgery may be necessary. For individuals who have secondary glaucoma, the other condition will need to be treated for glaucoma treatment to be successful. In this case, medication or surgery may be indicated.

Cataract refers to scattering of light rays, promoting a clouding of the lens in the eye (U.S. National Library of Medicine 2014). For this reason, if it progresses, it may become so dense that blindness results. They are very common in older people. As the cataracts develop, frequent changes in eyeglass prescription may help assist in maintaining useful vision. When cataracts progress to the point that useful vision is gone, surgery is performed to remove the lens. When an infant has congenital cataracts, surgery within a few months of birth is often advised to allow for proper development of visual responses. After cataract surgery, the individual will need to wear glasses, contact lenses or may have a prosthetic lens implant. Cataracts are present in a wide range of developmental disorders. Some of these include congenital infections (e.g. CMV²³, toxoplasmosis, rubella, and herpes) and syndromes (trisomy 18, trisomy 13, Down syndrome, Cockayne, Crouzon, Refsum and Usher syndromes). Cataracts may also occur from trauma or drugs (steroids) and are associated with metabolic disorders. A special type of lens abnormality called "cataract of prematurity" may occur in the newborn, but the cloudy areas usually disappear after a few weeks (Martyn & DiGeorge, 1987, cited in Heller and Kennedy 1994).

Cataracts are related to ageing factors and their prevalence is higher in women. Uveitis has been present in children with such congenital infections as herpes, rubella, syphilis, toxoplasmosis, and CMV. It is important to diagnose and treat uveitis in an early phase.

Disorders of the inner layer (retina)

Retinal dystrophies are lesions of the retinal cones, rods and pigments. The main group of retinal dystrophies are known as *retinitis pigmentosa* (RP) where retinal degeneration occurs and melanin pigment migrates into the retina and deposits itself. This results in night blindness and progressive loss of the peripheral field of vision.

Several atypical forms of RP have been found in which the symptoms and course of the condition differ from the classic form just described, namely when degeneration begins centrally. In this case, the macula

²² Aqueous humor is the watery fluid that fills the anterior and posterior chambers of the eye.

²³ Cytomegalovirus

is involved, which results in deficits of central vision, poor acuity and colour vision abnormalities. These may progress to the periphery and result in degeneration in that area as well.

Age is a major risk factor for age-related macular degeneration. Other factors include smoking, race (Caucasians have a higher prevalence) as well as family history and genetics. Certain syndromes may have typical RP (e.g. Usher syndrome) or atypical RP (e.g. Alstrom syndrome). There is no effective treatment at this time for either typical or atypical RP.

When the retina separates from its supporting structures and atrophies, a *detached retina* occurs. Depending on the cause of the detached retina, the early symptoms are usually minimal. Typically, the detachment occurs from fluid accumulating under the retina, which pushes it away from the choroid. This may occur from other ocular conditions such as retinopathy of prematurity, congenital infections (such as toxoplasmosis), general physical conditions (such as diabetes or head trauma) or after cataract surgery. When a retinal detachment occurs, the individual will need to have surgery as soon as possible to reattach the retina, since otherwise it will lead to blindness.

Retinopathy of prematurity (previously known as retrolental fibroplasia) consists of an abnormal growth of blood vessels, which occurs in the immature retina. The majority of the cases are mild and spontaneous regression of these abnormal blood vessels may occur with minimal scarring and little to no visual loss. However, in more severe cases, the abnormal blood vessels extend into the vitreous and may cause retinal detachment, severe visual loss and/or blindness. Children with retinopathy of prematurity have a higher risk of myopia, strabismus and glaucoma.

Diabetic eye disease is a group of eye conditions that can affect people with diabetes. Diabetic retinopathy affects blood vessels in the light-sensitive retina. Chronically high blood sugar from diabetes is associated with damage to the tiny blood vessels in the retina, leading to *diabetic retinopathy*. The retina detects light and converts it to signals sent through the optic nerve to the brain. Diabetic retinopathy can cause blood vessels in the retina to leak fluid or haemorrhage (bleed), distorting vision. In its most advanced stage, new abnormal blood vessels proliferate (increase in number) on the surface of the retina, which can lead to scarring and cell loss in the retina. Diabetic retinopathy is the most common cause of vision loss among people with diabetes and the leading cause of vision impairment and blindness among working-age adults. Diabetic macular oedema is a swelling in an area of the retina called the macula. Diabetic eye disease also includes cataract and glaucoma.

Besides the above-mentioned disorders, other factors can lead to visual disorders, such as eye malformation. Some children may be born with *microphthalmos*, which is extremely small eyeballs (associated with congenital rubella), *anophthalmus* (absence of eyes), or *aniridia* (partial or complete absence of the iris).

Disorders of the visual pathways can also occur, and therefore the visual pathways of the optic nerve, optic tract and optic radiations may be affected and result in visual impairment. When there is damage to the visual pathways or cortex of the brain, disorders of the visual cortex occur. Although the eye shows no pathology, the brain is unable to process the incoming visual information, resulting in visual impairment, ranging from partial loss of visual acuity to blindness. Possible causes can be closed head injury, drowning, prolonged convulsion, meningitis, and hypoxia resulting in brain damage.

Visual acuity refers to how clear or sharp an image is in terms of forms or patterns. When individuals cannot clearly see near objects due to an active error, this is known as hyperopia (farsightedness). Individuals with an active error affecting distance vision are considered to have myopia (nearsightedness). In astigmatism, there is an unequal curvature of the cornea or lens, which results in blurred or distorted images by itself or in combination with farsightedness and nearsightedness.

Impairments in ocular motility may also result in difficulties with tracking, convergence, gaze shift and scanning. Ocular motility refers to the movement of the eye by any of the six muscles surrounding each eye (i.e., extraocular muscles). Examples of ocular mobility are strabismus, amblyopia and nystagmus.

Some individuals may have difficulty perceiving colour, due to missing or damaged cones (colour receptors) in the eye. Disorders in colour perception can require environmental arrangements, such as controlling the amount of light, and presenting materials with textures or contrast are helpful.

3.2.3. Prevalence

According to a WHO report from 2010, globally 285 million people are visually impaired and 39 million are blind. The majority of visually impaired persons are found among the elderly population, with worldwide 65% of people who are visually impaired and 82% of all blind being 50 years and older. In Europe, the WHO estimates a prevalence of 2.9% for vision loss and 0.33% for blindness across all ages. The prevalence is higher in low- and middle-income countries (WHO, 2014).

In Europe, vision loss ranks among the 30 most common causes for years lived with disability. Interestingly, looking at blindness due to refraction and accommodation disorders and cataracts, a difference between Eastern and Western Europe can be found. While refraction and accommodation disorders are the 21st most common causes for years lived with disability in Eastern Europe, they seem less relevant in Western Europe, only ranking on place 60. The same trend can be found for visual impairments due to cataracts. A possible explanation may be better access to treatment in Western Europe, as vision impairments due to refraction and accommodation disorders or cataracts may be corrected with visual aids or cured by medical treatment. Generally, in high-income countries the most common causes of visual impairment are acquired, and related to age or chronic diseases. Examples are macular degeneration, glaucoma, diabetes and idiopathic diseases²⁴ (Vos et al., 2012).

The global as well as the European population is expected to see an increase in elderly citizens. According to the Population Reference Bureau, as many as 25% of the people in the EU will be above the age of 65 by 2030, up from about 17% in 2007. As loss of vision is most common in older age, the number of persons with visual impairments is consequently also expected to rise. An Australian study projected an increase from 575,000 persons over 40 years of age with a loss of vision in 2009 to 801,000 by 2020 (Economics, 2010).

3.3. Autism spectrum disorders

3.3.1. Definition

Autism is considered a lifelong neurodevelopmental disorder. It usually manifests itself early in life, and comorbidities (for example with learning difficulties or epilepsy) are possible (Joseph et al., 2014). In the current edition of the International Classification of Diseases (ICD-10), childhood autism is categorised under pervasive developmental disorders (DIMDI, 2016). This category also includes diseases presenting with similar clinical pictures, namely Asperger's syndrome and pervasive developmental disorder not otherwise specified. These three diagnoses are often referred to as "Autism spectrum disorders" (ASD).

The diagnosis of ASD is based on clinical features. Central symptoms are impairments in social interaction (e.g. facial expression or peer relationship) and communication (e.g. delay or total lack of language development), and, repetitive behaviour characteristic of autistic people. Many of those on the autism spectrum also have exceptional artistic or academic abilities. However, symptoms and their severity vary widely. For someone on the high functioning end of the autism spectrum, they may only result in relatively mild challenges. For others, symptoms may be more severe, for example when repetitive behaviours and a lack of spoken language greatly reduce the ability to participate in everyday life.

²⁴ That is, diseases that appear self-originated. They occur without a known cause.

3.3.2. Causes and risk factors

The causes of ASD are not yet understood well. Studies suggest that multiple genetic, biological and environmental factors modulate the likelihood of a child to be autistic. In the past, several misleading and disproved theories have attributed ASD to factors like poor parenting practices or vaccination, which slowed understanding of the disease and negatively affected autistic persons and their families.

Concerning ASD, most scientists agree that *genetic factors* play an important role (Huguet et al., 2013). This view is supported by a higher risk of ASD for siblings (Ozonoff et al., 2011) and especially twins (Rosenberg et al., 2009) of children diagnosed with ASD. Some genetic disorders are associated with ASD; examples are fragile X-syndrome and tuberous sclerosis (Cohen et al., 2005). Generally, boys are 4.5 times more likely to be autistic than girls (Christensen et al., 2016).

Data on acquired *risk factors* for ASD focus on congenital and developmental factors, as the disorder usually manifests itself early in life. Proposed congenital risk factors are higher parental age (Durkin et al., 2008), drugs taken during pregnancy, e.g. valproate (Christensen et al., 2013), congenital infections, for example with rubella virus (Chess, 1977) and various other environmental factors. Suggested developmental risk factors include complications or abnormalities at birth (reviewed by (Gardener et al., 2011), immune system disruption (Gregg et al., 2008) and association with intestinal abnormalities (Gilger and Redel, 2009).

3.3.3. Prevalence

Data on the prevalence of ASD in the EU is quite heterogeneous, as there are no official records of cases and scientific studies differ in methodology, study cohort (e.g. age of children screened) and the diagnostic criteria used to identify cases. In 2005, the European Commission published a report reviewing the available data on ASD prevalence in the EU (European Commission, 2005). The report states that early studies in the 1970s obtained a prevalence of ASD within 4.5-5.0 per 10,000 people, defining autism as a rare disease. These studies used narrow diagnostic criteria according to Kanner. Later studies in the 1990s found substantially higher rates of ASD of around 60 per 10,000 people, defining ASD as a more common health concern. For these studies, the broader DSM-IV criteria²⁵ were used. As a result of broadened diagnostic criteria and heterogeneous methods, it is difficult to draw conclusions on the trend of ASD prevalence. The report therefore states that it remains unclear if the major increase in prevalence rates also represents an increase in new cases (increased incidence).

More recent data suggests an ongoing increase in ASD prevalence. A British study of 56,946 children found a prevalence of 1% (100 per 10,000) for ASD, commenting that the disease is even more common than previously recognised (Baird et al., 2006). Other recent European studies have reported similar prevalences. A Finnish study of 5,484 children, for example, found a prevalence of 84 per 10,000 for ASD (Mattila et al., 2011) and an Icelandic cohort study of 22,229 children determined a prevalence of 120 per 10,000 (Saemundsen et al., 2013).

Globally, the prevalence of autistic spectrum disorders was estimated for the WHO Global Burden of Disease Study 2010. An overall prevalence of 7.6 per 1000 persons was obtained, with little regional variation. The study did not find clear evidence of a change in prevalence for ASD between 1990 and 2010 (Baxter et al., 2015). However, a more recent WHO meeting report states that the reported prevalence of ASD varies substantially across studies and that "prevalence of ASDs appears to be increasing around the world" (WHO, 2013). The report suggests factors like improved awareness, better diagnostic tools and improved reporting as possible explanations for the increase in prevalence of ASD. A different literature review obtained a global prevalence of 6.2 per 1000 persons for ASD. Again, the evidence did not support geographical, cultural or socioeconomic differences in prevalence. But the

²⁵ For details of the criteria see the website of the US Autism Research Institute: https://www.autism.com/tools_dsm4.

study states that prevalence estimates have increased over time, while a big variation among studies and a lack of data especially for low-income countries limit the power of the global statistical analysis (Elsabbagh et al., 2012). Suggested reasons for the increase in prevalence of ASD included broadening of diagnostic criteria, diagnostic switching from other developmental disabilities to ASD and increased awareness.

To obtain a clearer picture of ASD prevalence and socioeconomic implications, in 2015 the European Commission launched the project Autism Spectrum Disorders in the European Union. Aims of the project are, among others, estimation of ASD prevalence in 12 European countries and the proposal of policies and programmes for the early detection and better support of autistic persons. The first findings are expected to be published in June 2016²⁶.

3.4. Conclusion on the health/demographic drivers of visual and hearing impairments and autism spectrum disorder

The causes of visual and hearing impairments and ASD are manifold. In the case of ASD, they are not very well understood to date, but genetics are thought to play an important role. While some visual and hearing impairments are also congenital, the majority are acquired and many, especially in developed countries, occur later in life. The ageing population with a higher rate of chronic disease is therefore a key driver for an increasing demand in ATs.

In terms of inclusion in society, there are crucial differences between these disabilities. People with a hearing impairment have a better position in the labour market than those with a visual impairment or autism. The reason for this is that acquired hearing impairments often appear by the late 40s, by which time people have already established themselves in the labour market. Also, there are more ATs developed for people with hearing impairments than for people with visual disabilities or ASD, and hearing impairments can be easier to compensate than visual impairments. In general, people with congenital disabilities can find it harder to enter the labour market in the first place. This also applies to autistic people, who in addition can be faced with prejudice.

²⁶ To date no findings have been published, see <http://asdeu.eu/key-findings/>.

4. References

- ANED. 2016. "Academic Network of European Disability Experts." <http://www.disability-europe.net/>. Accessed August 25, 2016.
- Angeli, Simon, Xi Lin, and Xue Zhong Liu. 2012. "Genetics of Hearing and Deafness." *The Anatomical Record* 295(11):1812–1829.
- Baird, Gillian, Emily Simonoff, Andrew Pickles, Susie Chandler, Tom Loucas, David Meldrum, and Tony Charman. 2006. "Prevalence of Disorders of the Autism Spectrum in a Population Cohort of Children in South Thames: The Special Needs and Autism Project (SNAP)." *Lancet* 368(9531):210–215.
- Barros, Pedro Pita, Sara Ribeirinho Machado, and Jorge de Almeida Simões. 2015. "Portugal: Health System Review." *Health Systems Transition* 13(4):1–156.
- Baxter, A.J., T. S. Brugha, H. E. Erskine, R. W. Scheurer, T. Vos, and J. G. Scott. 2015. "The Epidemiology and Global Burden of Autism Spectrum Disorders." *Psychological Medicine* 45(3):601–613.
- Blomquist, Ulla-Britt, and Andreas Richter. 2012. "Service Delivery System for AT, AT in Sweden." http://portale.siva.it/files/doc/library/a410_1_RICHTER_BLOMQUIST_aaate2012.pdf. Accessed July 14, 2016.
- BMAS – Bundesministerium für Arbeit und Soziales [eng.: German Federal Ministry of Labour and Social Affairs]. 2016. "Entwurf eines Gesetzes zur Weiterentwicklung des Behindertengleichstellungsrechts" [eng.: Draft on the Revision of the Law for the Equality of Disabled People]. http://www.bmas.de/SharedDocs/Downloads/DE/PDF-Meldungen/2016/gesetzentwurf-zur-weiterentwicklung-des-behindertengleichstellungsrechts.pdf;jsessionid=D616BD3F6A2D959CF7D244B7DA2149AD?_blob=publicationFile&v=3. Accessed August 24, 2016.
- Chess, Stella. 1977. "Follow-up Report on Autism in Congenital Rubella." *Journal of Autism and Childhood Schizophrenia*, 7(1):69–81.
- Christensen, Jakob, Therese Koops Grønberg, Merete Juul Sørensen, Diana Schendel, Erik Thorlund Parner, Lars Henning Pedersen, and Mogens Vestergaard. 2013. "Prenatal Valproate Exposure and Risk of Autism Spectrum Disorders and Childhood Autism." *JAMA* 309:1696–1703.
- Clark, John Greer. 1981. "Uses and Abuses of Hearing Loss." *Asha* 23: 493–500.
- Cohen, David, Nadège Pichard, Sylvie Tordjman, Clarisse Baumann, Lydie Burglen, Elsa Excoffier, Gabriela Lazar, Philippe Mazet, Clément Piquier, Alain Verloes, and Delphine Héron. 2005. "Specific Genetic Disorders and Autism: Clinical Contribution towards their Identification." *Journal of Autism and Developmental Disorders*, 35(1):103–116.
- Della Fina, Valentina, and Rachele Cera (eds.). 2015. *Protecting the Rights of People with Autism in the Fields of Education and Employment. International, European and National Perspectives*. Heidelberg / New York / Dodrecht / London: Springer.
- Deutscher Gehörlosen-Bund e.V. [eng.: German Association of the Deaf]. 2016. "Hörbehinderte Kinder an Regelschulen: Was für den erfolgreichen Besuch einer Regelschule wichtig ist." [eng.: Hearing Impaired Children in Mainstream Schools: What it takes to Succeed]. http://www.gehoerlosenbund.de/index.php?option=com_content&view=article&id=1561%3Ahoerbehindertekindernregelschulenwasfuerdenerfolgreichenbesucheineregelschulewichtigist&catid=83%3Ameinkind&Itemid=129&lang=de. Accessed August 25, 2016.

- DIMDI, 2016. "Verhaltens- und fertigkeitenbasierte Frühinterventionen bei Kindern mit Autismus" https://portal.dimdi.de/de/hta/hta_berichte/hta248_bericht_de.pdf. Accessed 5 October 2016
- DOTCOM. 2016. "The Disability Online Tool of the Commission." <http://www.disability-europe.net/de/dotcom>. Accessed August 25, 2016.
- Durkin, Maureen S., Matthew J. Maenner, Craig J. Newschaffer, Li-Ching Lee, Christopher M. Cunniff, Julie L. Daniels, Russell S. Kirby, Lewis Leavitt, Lisa Miller, Walter Zahorodny, and Laura A. Schieve. 2008. "Advanced Parental Age and the Risk of Autism Spectrum Disorder." *American Journal of Epidemiology*, 168(11):1268–1276.
- Economics, A. 2010. "Clear Focus – The Economic Impact of Vision Loss in Australia in 2009." *Report for Vision 2020*:1417–1436.
- Elsabbagh, Mayada, Gauri Divan, Yun-Joo Koh, Young Shin Kim, Shuaib Kauchali, Carlos Marcín, Cecilia Montiel-Nava, Vikram Patel, Cristiane S. Paula, Chongying Wang, Mohammad Taghi Yasamy, and Eric Fombonne. 2012. "Global Prevalence of Autism and Other Pervasive Developmental Disorders." *Autism Research: Official Journal of the International Society for Autism Research* 5(3):160–179.
- European Commission. 2005. "Some Elements about the Prevalence of Autism Spectrum Disorders (ASD) in the European Union." http://ec.europa.eu/health/ph_information/dissemination/diseases/autism_1.pdf. Accessed September 23, 2016.
- European Commission. 2011. "Monitoring eAccessibility." <http://www.eaccessibility-monitoring.eu/researchResult.aspx>. August 25, 2016.
- European Commission. 2013a. "Your social security rights in Hungary." http://ec.europa.eu/employment_social/empl_portal/SSRinEU/Your%20social%20security%20rights%20in%20Hungary_en.pdf. Accessed July 14, 2016.
- European Commission. 2013b. "Your Social Security Rights in Sweden." http://ec.europa.eu/employment_social/empl_portal/SSRinEU/Your%20social%20security%20rights%20in%20Sweden_en.pdf. Accessed July 14, 2016.
- European Commission. 2014. "National Social Report – Hungary." <http://ec.europa.eu/social/keyDocuments.jsp?policyArea=750&subCategory=758&type=0&country=0&year=0&advSearchKey=SPCNationalSocialReport&mode=advancedSubmit&langId=en>. Accessed September 29, 2016.
- European Union Agency for Fundamental Rights. 2013. "Legal Capacity of Persons with Intellectual Disabilities and Persons with Mental Health Problems." <http://fra.europa.eu/sites/default/files/legal-capacity-intellectual-disabilities-mental-health-problems.pdf>. Accessed July 14, 2016.
- European Union. 2010. "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." Accessed 5 October 2016 <http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A42010Y1215%2801%29>
- European Union of the Deaf. 2017. "International Sign." <http://www.eud.eu/about-us/eud-position-paper/international-sign-guidelines>. Accessed June 14, 2017.
- Gardener, Hannah, Donna Spiegelman, and Stephen L. Buka. 2011. "Perinatal and Neonatal Risk Factors for Autism: A Comprehensive Meta-Analysis." *Pediatrics*, 128(2):344–355.

- Gilger, Mark A., and Carol Anne Redel. 2009. Autism and the Gut. *Pediatrics* 124(2):796–798.
- Green, Sara, Davis, Christine, Karshmer, Elana, Marsh, Pete, Straight, Benjamin. 2005. "Living Stigma: The Impact of Labeling, Stereotyping, Separation, Status Loss, and Discrimination in the Lives of Individuals with Disabilities and Their Families." *Sociological Inquiry*, 75(2):197–215.
- Gregg, Jeffrey P., Lisa Lit, Colin A. Brown, Irva Hertz-Picciotto, Wynn Walker, Ryan A. Davis, Lisa A. Croen, Sally Ozonoff, Robin Hansen, Isaac N. Pessah, and Frank R. Sharp. 2008. "Gene Expression Changes in Children with Autism." *Genomics* 91(1):22–29.
- Heller, Kathryn, and Cheryl Kennedy. 1994. *Etiologies and Characteristics of Deaf-Blindness*, edited by Louis Cooper, Lawrence T. Eschelmann, James W. Long, and Rosanne K. Silbermann. Monmouth: Teaching Research Publications.
- Hersh, Marion. 2008. "Perception, the Eye and Assistive Technology Issues." In *Assistive Technology for Visually Impaired and Blind People*, edited by Marion A. Hersh and Michael A. Johnson, 51–102. London: Springer London.
- Huguet, Guillaume, Elodie Ey, and Thomas Bourgeron. 2013. "The Genetic Landscapes of Autism Spectrum Disorders." *Annual Review of Genomics and Human Genetics* 14:191–213.
- Human Rights Watch. 2013. "Hungary: Change Discriminatory Voting Laws." <https://www.hrw.org/news/2013/10/01/hungary-change-discriminatory-voting-laws>. Accessed August 24, 2016.
- Instituto Nacional de Estatística [National Statistics Office Portugal]. 2015. https://www.ine.pt/xportal/xmain?xpgid=ine_main&xpid=INE. Accessed September 22, 2016.
- Könczei, György (ed). 2009. "Disability: Good Practices (Hungary)." <http://mek.oszk.hu/09700/09751/09751.pdf>. Accessed July 14, 2016.
- Központi Statisztikai Hivatal. 2013. "2011 – Évi Népszámlálás – 3. Országos adatok." http://www.ksh.hu/docs/hun/xftp/idoszaki/nepsz2011/nepsz_orosz_2011.pdf. Accessed July 14, 2016.
- Lansdown, Gerison. 2009. *See Me, Hear Me: A Guide to Using the UN Convention on the Rights of Persons with Disabilities to Promote the Rights of Children*, Save the Children: London.
- Lucker, Jay, and Marion A. Hersh. 2003. "Anatomy and Physiology of Hearing, Hearing Impairment and Treatment." In *Assistive Technologies for Hearing-impaired, Deaf and Deafblind*, edited by Marion A. Hersh and Michael A. Johnson, 1–39. London: Springer-Verlag London Limited.
- Mattila, Marja-Leena, Marko Kielinen, Sirkka-Liisa Linna, Katja Jussila, Hanna Ebeling, Risto Bloigu, Robert M. Joseph, and Irma Moilanen. 2011. "Autism Spectrum Disorders according to DSM-IV-TR and Comparison with DSM-5 Draft Criteria: An epidemiological Study." *Journal of the American Academy of Child and Adolescent Psychiatry* 50(6):583–592.e11.
- National Institutes of Health Medicine & Friends of the National Library of Medicine. 2012. "Leading Causes of Blindness." *NIH MedlinePlus: the magazine* 6(4):12–13.
- NHS. 2015. "Causes of Hearing Loss." <http://www.nhs.uk/Conditions/Hearing-impairment/Pages/Causes.aspx>. Accessed July 14, 2016.
- OECD. 2013. "OECD Better Life Index." <http://www.oecdbetterlifeindex.org/about/better-life-initiative/>. Accessed July 14, 2016.
- OEP. 2013. "Aufgaben der Nationale kasse für Gesundheitsversicherung (Ungarische Akronym: OEP)."

- http://www.oep.hu/pls/portal/docs/PAGE/LAKOSSAG/OEPHULAK_EBELLAT/ELLA_TASMO/KIZAROLAG_EU_SZOLG_JOGOSULTAK_2013_01.pdf. Accessed July 14, 2016.
- Ozonoff, Sally, Gregory S. Young, Alice Carter, Daniel Messinger, Nurit Yirmiya, Lonnie Zwaigenbaum, Susan Bryson, Leslie J. Carver, John N. Constantino, Karen Dobkins, Ted Hutman, Jana M. Iverson, Rebecca Landa, Sally J. Rogers, Marian Sigman, and Wendy L. Stone. 2011. "Recurrence Risk for Autism Spectrum Disorders: A Baby Siblings Research Consortium Study." *Pediatrics* 128(3):e488-495.
- Pascoe, Elizabeth, Smart Richman, Laura. 2009. "Perceived Discrimination and Health: A Meta-Analytic Review." *Psychological Bulletin*,135(4):531-554.
- Rosenberg, Rebecca E., J. Kiely, Gayane Yenokyan, John McGready, Walter E. Kaufmann, and Paul A. Law. 2009. "Characteristics and Concordance of Autism Spectrum Disorders among 277 Twin Pairs." *Archives of Pediatrics & Adolescent Medicine* 163(10):907-914.
- Roth, Thomas Niklaus, Dirk Hanebuth, and Rudolf Probst. 2011. "Prevalence of age-related Hearing Loss in Europe: A Review." *European Archives of Oto-Rhino-Laryngology* 268(8):1101-1107.
- Saemundsen, Evald, Páll Magnússon, Ingibjörg Georgsdóttir, Erlendur Egilsson, and Vilhjálmur Rafnsson. 2013. "Prevalence of Autism Spectrum Disorders in an Icelandic Birth Cohort." *BMJ open* 3(6).
- SCENIHR. 2008. "Potential Health Risks of Exposure to Noise from Personal Music Players and Mobile Phones including a Music Playing Function."
http://ec.europa.eu/health/ph_risk/committees/04_scenihhr/docs/scenihhr_o_018.pdf. Accessed September 27, 2016.
- SSPTW. 2012. "Hungary." <https://www.ssa.gov/policy/docs/progdesc/ssptw/2012-2013/europe/hungary.pdf>. Accessed July 14, 2016.
- Statistisches Bundesamt [eng.: German Federal Statistical Office]. 2016. "Bevölkerungsentwicklung, Demografischer Wandel."
<https://www.destatis.de/DE/ZahlenFakten/GesellschaftStaat/Bevoelkerung/Bevoelkerung.html>. Accessed August 26, 2016.
- Stevens, Gretchen, Seth Flaxman, Emma Brunskill, Maya Mascarenhas, Colin D. Mathers, and Mariel Finucane. 2011. "Global and regional Hearing Impairment Prevalence: An Analysis of 42 Studies in 29 Countries." doi: <http://dx.doi.org/10.1093/eurpub/ckr176>
- Swedish Agency for Participation. 2016. "Assistive Technology in the Home."
<http://www.mfd.se/other-languages/english/assistive-technology-in-sweden/assistive-technology-in-the-home/>. Accessed July 14, 2016.
- Swedish Institute. 2016. "Facts about Sweden – Disability policy." http://sharingsweden.se/wp-content/uploads/2016/06/Disability-policy_low_res.pdf.) Accessed September 24, 2016.
- Teixeira, Diana. 2010. "Igualdade de Oportunidades: Um Olhar Sobre as Barreiras Arquitetónicas À Acessibilidade." Instituto Superior de Ciências Sociais e Políticas.
<https://oatd.org/oatd/record?record=oai%5C%3Awww.repository.utl.pt%5C%3A10400.5%5C%2F3018>. Accessed September 29, 2016.
- The World Bank. 2015. "Country Overview." <http://data.worldbank.org/indicator/SP.POP.TOTL>. Accessed September 09, 2016.
- U.S. National Library of Medicine. 2014. "Cataract." <https://medlineplus.gov/cataract.html>. Accessed July 14, 2016.

- UN OHCHR. 2015. "The response of the Hungarian government to the UN special rapporteur's questionnaire on the right of persons with disabilities to participation in decision making." http://www.ohchr.org/Documents/Issues/Disability/DecisionMaking/States/PM%20-%20Hungary_ENG.doc. Accessed July 14, 2016.
- United Nations. 2015. "Human Development Reports: Hungary." <http://hdr.undp.org/en/countries/profiles/HUN>. Accessed July 14, 2016.
- Vos, Theo. et al., 2012. "Years lived with disability (YLDs) for 1160 sequelae of 289 diseases and injuries 1990-2010: a systematic analysis for the Global Burden of Disease Study 2010". *Lancet*, 380(9859):2163-2196.
- WHO. 2013. "Autism Spectrum Disorders & other developmental Disorders - From raising Awareness to building Capacity." http://apps.who.int/iris/bitstream/10665/103312/1/9789241506618_eng.pdf. Accessed September 27, 2016.
- WHO. 2014. "Visual Impairment and Blindness - Fact Sheet N°282." <http://www.who.int/mediacentre/factsheets/fs282/en/>. Accessed September 23, 2016.
- WHO. 2015. "International Statistical Classification of Diseases and Related Health Problems - 10th Revision (ICD-10)-2015." <http://apps.who.int/classifications/icd10/browse/2015/en#/H53-H54>. Accessed July 24, 2016.
- WHO. 2016. "Prevention of Blindness and Deafness - Grades of Hearing Impairment." http://www.who.int/pbd/deafness/hearing_impairment_grades/en/index.html. Accessed July 14, 2016.
- WIPO. 2016. "WIPO-Administered Treaties." http://www.wipo.int/treaties/en/ShowResults.jsp?treaty_id=843. Accessed July 14, 2016.

Annex: Background information on impairments

Table I-1: World Health Organization Grades of hearing impairment (WHO 2016)

Grade of impairment*	Corresponding audiometric ISO value**	Performance	Recommendations
0 – No impairment	25 dB or better (better ear)	No or very slight hearing problems. Able to hear whispers.	
1 – Slight impairment	26–40 dB (better ear)	Able to hear and repeat words spoken in normal voice at 1 metre.	Counselling. Hearing aids may be needed.
2 – Moderate impairment	41–60 dB (better ear)	Able to hear and repeat words spoken in raised voice at 1 metre.	Hearing aids usually recommended.
3 – Severe impairment	61–80 dB (better ear)	Able to hear some words when shouted into better ear.	Hearing aids needed. If no hearing aids available, lip-reading and signing should be taught.
4 – Profound impairment including deafness	81 dB or greater (better ear)	Unable to hear and understand even a shouted voice.	Hearing aids may help understanding words. Additional rehabilitation needed. Lip-reading and sometimes signing essential.

* Grades 2, 3 and 4 are classified as disabling hearing impairment (for children, it starts at 31 dB)

** The audiometric ISO values are averages of values at 500, 1000, 2000, 4000 Hz.

Table I-2: Degrees of hearing loss according to Clark (1981, 497)

Degree of hearing loss	Hearing loss range (dB HL)
Normal	-10 to 15
Slight	16 to 25
Mild	26 to 40
Moderate	41 to 55
Moderately severe	56 to 70
Severe	71 to 90
Profound	91+

Table I-3: Common problems and causes of conductive hearing loss (Outer ear) (Lucker and Hersh 2003, 32)

Problem	Structure involved	Causes and treatments
Cerumen	EAM	Cerumen softeners, ear washing (irrigation) or removal by doctor
Foreign objects in EAM	EAM	Irrigation or removal by doctor
Congenital atresia	EAM	Birth defect in which the ear canal does not form. Surgery is done for cosmetic purposes only.
Otitis externa, outer ear infection (sometimes referred to as swimmer's ear)	EAM	Antibiotics and sometime anti-inflammatory medication to reduce swelling of EAM

Table I-4: Common problems and causes of conductive hearing loss (Middle ear) (Lucker and Hersh 2003, 33)

Problem	Structure involved	Causes and treatments
Perforated tympanic membrane (hole)	Tympanic membrane	Medicine to heal; time needed for hole to close; in some cases, surgery is required to close the hole
Infection/inflammation of tympanic membrane	Tympanic membrane	Antibiotics and anti-inflammatory medicines to reduce swelling
Otitis media	Middle-ear cavity	Antibiotics if infection is present; decongestants; allergy medications if related to allergens; surgery to drain fluid
Otosclerosis	Stapes mostly footplate	Bony growth around oval window causes footplate to be immobilized; surgery to remove stapes and bony growth and replace with artificial device
Ossicular fixation	Any middle-ear ossicle	Two or more ossicles are fused or "stuck" together and cannot move; sometimes congenital; surgery to "unstuck" the ossicles; sometimes surgery removes one ossicle and replaces it with artificial device
Ossicular discontinuity	Any middle-ear ossicle	Joints between ossicles break; can sometimes be congenital; surgery or device to connect ossicles

Table I-5: Common problems and causes of sensorineural hearing loss (Lucker and Hersh 2003, 34)

Problem	Structure involved	Causes and treatments
Congenital	Hair, cells, cilia, entire cochlea	Birth defects; problems picked up by the mother transmitted to the foetus; hereditary factors; rhesus factor; trauma
Neonatal	Hair cells; cilia	Infections picked up by the newborn; birth trauma
NIHL	Hair cells; cilia	Permanent hearing loss due to noise exposure
Temporary threshold shift	Hair cells; cilia	Temporary hearing loss due to noise exposure
Presbycusis	Hair cells; cilia; blood supply to cochlea	Normal changes in cochlea due to ageing
Ototoxicity	Hair cells; cilia; other cochlear structures	Drugs that are toxic to the cochlea, such as some mycin antibiotics and drugs used in cancer treatment, cause permanent hearing loss
Temporary ototoxicity	Hair cells; cilia	Drugs that are toxic to the cochlea only when high doses of the drug are in the person's system; most common is aspirin
Viruses and bacteria	Hair cells; cilia	Some viruses and bacteria can invade the cochlea and do permanent or temporary damage; one common bacterium is a form of streptococcus that leads to permanent hair cell damage and can also lead to encephalitis
Viruses and bacteria	Cochlear fluids	Some viruses and bacteria invade the intracochlear fluids, leading to dizziness and hearing loss, often temporary, only while disease is present in inner ear; sometimes referred to as labyrinthitis
Perilymphatic	Perilymph fluid	Hole (called a fistula) in the ligament holding footplate in the oval window or a hole in the membrane of the round window; loss of perilymph through the hole causes temporary hearing loss and dizziness; once hole is closed (spontaneous or by surgery), fluid returns to normal, as does balance and hearing
Ménière's syndrome or disease	Endolymph fluid	Improper absorption of endolymph leads to pressure build up in membranous channels of the inner ear, leading to dizziness and hearing loss that fluctuates with pressure changes
Advanced Ménière's	Perilymph and endolymph fluids, Reisner's membrane and hair cells	Advanced stages of Ménière's can lead to rupturing of Reisner's membrane, allowing perilymph and endolymph fluids to mix and cause ionic imbalance in cochlea that can cause permanent hair cell destruction
Cochlear otosclerosis	Perilymph, basilar membrane, hair cells	In some cases of otosclerosis the bony growth moves into the cochlea, invading the perilymph fluid and basilar membrane; can lead to damage to hair cells

Table I-6: Pathologies of the auditory nerve and CANS leading to hearing or auditory problems (Lucker and Hersh 2003, 35)

Pathology	Structure involved	Causes and treatments
Eighth nerve tumours	Auditory nerve	Abnormal cell growth of structures surrounding the auditory nerve; leads to sensorineural hearing loss; usual treatment is surgical removal, but radiation may be used to shrink them
Auditory neuropathy	Auditory nerve	Abnormal development or lack of development to the eighth nerve; wait to see if nerve pathway develops or permanent problems mostly with auditory processing
Congenital	Auditory nerve and CANS structures	Rare, but child could be born without an eighth nerve or other CANS structure including cortical; wait to see if nerve pathway develops or permanent problems, mostly with auditory processing; eighth nerve causes sensorineural hearing loss as well
Trauma/accidents	Auditory nerve, CANS structures, brain (auditory cortex)	Blows to the head; traumatic brain injury; depends on amount of injury, could be temporary, but is often permanent; auditory processing problems
Tumours of the CANS structures	Any structures in the CANS including the cortex, but excluding the auditory nerve itself	As with eighth nerve tumours, only these grow on the nerves of CANS or in the brain (auditory cortex); surgical removal of tumour or growth; radiation of chemotherapy to shrink; leads to auditory processing problems
Cerebral vascular accidents (or stroke)	Burst blood vessel in CANS structural area or in brain (auditory cortex)	Leads to pressure in area, damage of cells in area; must wait to assess extent of damage; surgery may be tried to reduce swelling; leads to auditory processing problems

Table I-7: Categories of visual impairment (WHO 2015)

Category	Presenting distance visual acuity	
	Worse than:	Equal to or better than:
0 Mild or no visual impairment		6/18 3/10 (0.3) 20/70
1 Moderate visual impairment	6/18 3/10 (0.3) 20/70	6/60 1/10 (0.1) 20/200
2 Severe visual impairment	6/60 1/10 (0.1) 20/200	3/60 1/20 (0.05) 20/400
3 Blindness	3/60 1/20 (0.05) 20/400	1/60* 1/50 (0.02) 5/300 (20/1200)
4 Blindness	1/60* 1/50 (0.02) 5/300 (20/1200)	Light perception
5 Blindness	No light perception	
9	Undetermined or unspecified	

*Or counts fingers (CF) at 1 metre.

By analysing first the regulatory, health and demographic aspects of assistive technologies, this report prepares the groundwork for a scientific foresight study on the subject. The regulatory analysis focuses on four countries that have successfully adopted the UNCRPD but that have experienced varying levels of success in its implementation. The analysis of disabilities focuses upon three common types of disability: deafness and hearing impairments, blindness and visual impairments and autism spectrum disorders. It also considers the demographic context in terms of an ageing population, which could be a key driver for increasing demand for assistive technologies in the future.

This is a publication of the Scientific Foresight Unit (STOA)
EPRS | European Parliamentary Research Service, European Parliament



PE 603.218
ISBN 978-92-846-2352-5
doi: 10.2861/42217
QA-06-17-411-EN-N

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