

Assistive technologies for people with disabilities

Part IV: Legal and socio-ethical perspectives

IN-DEPTH ANALYSIS

Science and Technology Options Assessment

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Abstract

As assistive technologies (ATs) continue to be introduced in many areas of public and private life the need has arisen to assess the aptness of the EU legal framework to cope with the ethical and regulatory challenges they present.

The key question is to what extent ATs may affect or reshape the existing norms regarding liability, privacy and autonomy that often feature as the major issues requiring regulatory attention. Technology in itself is neither good nor bad, it is the way it is used that determines its effect. The main challenge is therefore to develop a framework that can cope with potential threats to the privacy, integrity, safety and autonomy of disabled people in an inclusive and dynamic manner.

The project concludes with a series of social, ethical and legal reflections on the role of current and future European Parliament initiatives in the context of trends in the AT field. The analysis identifies various legal challenges that ATs raise in the context of EU law, including the coordination of the various competence layers, the lack of a commonly accepted definition, and the variety of risks ATs pose for the human rights, privacy, dignity, access to technology, autonomy and social inclusion of people with disabilities.

The analysis illustrates the various ways in which the current EU legislative framework may be affected by technological trends, analysing the legal and socio-ethical challenges that might have to be dealt with, especially in the light of the European Accessibility Act currently under discussion. It also provides a series of overarching recommendations for EU actors to take into account when dealing with ATs.

The study also identifies wider concerns, including the changing concept of what constitutes a healthy human body, medical classifications, social stigma and financing the development and provision of ATs. In response, several options for responsive policy action are suggested. These include securing accessibility as a human right, promoting privacy by design, improving the informed consent process, bringing in a user-centred model of technology design, allowing freedom of choice to use ATs, maintaining the availability of human care, developing appropriate ethics oversight structures, introducing a new classification system for ATs and ensuring safety in their use.

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1. Introduction

Evidence provided by various agencies demonstrates that people with disabilities face extensive discrimination and a wide range of barriers to exercising their rights and remain one of society's most vulnerable groups. Assistive technologies (ATs), namely those whose primary purpose is to maintain or improve an individual's functioning and independence to facilitate participation and to enhance overall well-being, have traditionally approached disability as a medical condition that needs to be cured or managed. However, over the last few years, certain technological developments commonly defined as accessible technology have been approaching disability not only as a functional limitation but also as an obstacle to societal integration. In that respect, technology is primarily seen as a factor in facilitating and normalising the life of disabled people in terms of reducing certain barriers especially in the field of employment. In fact, access to assistive devices and technology derives from the basic principles of human rights, such as dignity, autonomy, equality, non-discrimination, participation and inclusion. The topic of accessibility has generated considerable debate and activity over the last few years at European Union level.

Even though ATs do not in themselves suffice to reduce all barriers, they can certainly become a means for people with disabilities to retain choice and autonomy in their lives. Their gradual extension to all aspects of life along with the entry into force of the UN Convention on the Rights of People with Disabilities (CRPD, or simply 'the Convention') have sparked the interest of legal scholars worldwide. The Convention, as one of the most ground-breaking pieces of legislation in the field of human rights, has in fact become the benchmark against which to assess national and European Union legislation. Being the first legally-binding international human rights instrument to which both the EU and its Member States are party, it is the first international legal instrument to aim to ensure the active participation of people with disabilities in political, economic, social and cultural life. By accommodating their difference, the Convention has in fact provided the basis for the development of an EU accessibility policy and has attempted to mainstream disability in different areas under its competence. The Convention affirms that assistive technology is essential to enable persons with disabilities to live independently (Article 19) and to participate fully in all aspects of life (Article 29).

It emphasises that affordability and accessibility are necessary to ensure that assistive technology is available on an equal basis to everyone, everywhere. Under Article 20 of the Convention, states have an obligation to take effective measures to ensure personal mobility with the greatest possible independence, including by facilitating access by people with disabilities to assistive technology. States should also promote the availability of assistive technology, giving priority to technologies at an affordable cost; undertake research in this area; and provide relevant accessible information for people with disabilities (Article 4). On the basis of the principle of universal design, under Article 2 in conjunction with Article 9 of the Convention, technologies must be accessible to everyone on an equal basis. Furthermore, under the Convention, States are requested to engage in knowledge transfer through international cooperation.

The conclusion of the CRPD by the EU has boosted the move towards a review of the relevant EU rules and the drafting of new legislation to prepare the way for the implementation of certain provisions of the Convention in the EU and remove those barriers that prevent individuals with disabilities from achieving equality of opportunity and full participation in all aspects of life. It has served as a catalyst for the Union to claim additional competences in this newly emerging cross-cutting domain of public policy. In compliance with the UNCRPD, the European disability strategy for 2010 to 2020, adopted by the European Commission in November 2010, sets forth an ambitious policy framework to achieve full equality for people with disabilities in Europe and pays particular attention to the principle of accessibility. The disability strategy is centred on eight interconnected thematic areas that affect (or coincide with) different EU competences (exclusive, shared or supporting): accessibility, participation, equality, employment, education and training, social protection, health and external action. This strategy is not the first comprehensive policy framework on disability that the EU has designed. Before the strategy, the EU had a disability action plan that covered the period between 2004 and 2010. The purpose of this plan was to mainstream disability into relevant Community action and to design measures to improve the lives of people with disabilities. Moreover, over the last few years, a series of disability-related provisions has been introduced in various domains of EU legislation, such as personal mobility, transport and electronic communications. As a result of the Convention's normative effect, EU secondary legislation must be interpreted in the light of the Convention's provisions.

The involvement of the EU in the domain of ATs and disabilities and its efforts to mainstream disability in various areas under its competence is a recent phenomenon. The Union gained the right to legislate against discrimination on the basis of disability through the adoption of the Treaty of Amsterdam, which requires the Union to combat discrimination based on disability when defining and implementing its policies and activities (Article 10) and gives it the power to adopt legislation to address such discrimination (Article 19). The 1997 Treaty of Amsterdam, which entered into force on 1 May 1999, introduced legislative competence for the European Community in the area of non-discrimination and equality: Article 13 of the Treaty establishing the European Community (TEC) (now Article 19 of the Treaty on the Functioning of the European Union) authorises the EU Council of the European Union to adopt measures to combat discrimination on grounds of sex, racial or ethnic origin, religion or belief, disability, age, or sexual orientation. The introduction of these provisions as well as of a declaration stating that EU institutions must take account of the needs of people with disabilities in drawing up measures signified a qualitative and quantitative change in EU's disability policy. Declaration No 22 annexed to the Treaty of Amsterdam stipulates that in drawing up measures under what is now Article 114, 'the institutions of the Community [now Union] shall take account of the needs of persons with a disability'.

Following up this constitutional development, the Employment Equality Directive¹ became the first piece of EU secondary legislation to make explicit reference to the need to address discrimination on the grounds of disability. Based on Article 13 TEC, the Council of Ministers adopted a series of directives covering discrimination on various grounds: race and ethnic origin within and outside working life (Racial Equality Directive, 2000/43/EC),² religion or belief, disability, age, and sexual orientation, in employment, occupation, and also in vocational training (Employment Equality Directive, 2000/78/EC),³ on grounds of sex within and outside working life (Gender Equality Directive on Goods and Services, 2004/113/EC,⁴ Gender Equality Directive 2006/54/EC (recast)⁵). The Commission has also promoted accessibility in its digital agenda, provided passengers with reduced mobility with assistance, and has contributed to the development of common voluntary standards on accessibility in specific areas, such as information and communication technology and the built environment.

It should be mentioned that Article 1 of the Charter of Fundamental Rights of the EU (the Charter) states that: 'Human dignity is inviolable. It must be respected and protected'. Article 26 meanwhile states 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'. In addition, Article 21 prohibits any discrimination on the basis of disability. In view of the recently attributed legally binding value of the Charter of Fundamental Rights of the European Union,

¹ Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation, OJ L 303, 2.12.2000, pp. 16-22.

² Directive 2000/43/EC of 29 June 2000 implementing the principle of equal treatment between persons irrespective of racial or ethnic origin, OJ L 180, 19.7.2000, pp. 22-26.

³ Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation, OJ L 303, 2.12.2000 pp. 16-22.

⁴ Directive 2004/113/EC of 13 December 2004 implementing the principle of equal treatment between men and women in the access to and supply of goods and services, OJ L 373, 21.12.2004, pp. 37-43.

⁵ Directive 2006/54/EC of 5 July 2006 on the implementation of the principle of equal opportunities and equal treatment of men and women in matters of employment and occupation (recast), OJ L 204, 26.7.2006, pp. 23-36.

which brings together in a single text all the personal, civic, political, economic and social rights that people enjoy within the EU, the legal terms of reference concerning the use of ATs may have to be reconsidered.

Although the ethical implications of ATs have been addressed systematically by academics, little attention has been paid to the legal and regulatory dimensions of their use and application. By presenting socio-legal reflections that are of relevance to the work of the European Parliament, the analysis illustrates the different ways in which the current EU legislative framework may be affected by technological trends in the field of ATs, listing the issues that might have to be addressed, especially in the light of the European Accessibility Act that is currently under discussion. To this end, the current legislation has been scanned for areas of EU law that may need to be adjusted or revised owing to the ongoing deployment of ATs and their increased capacity to collect and process a massive amount of human data. Although the regulatory implications of ATs can be approached from a variety of legal perspectives, there are also issues that can be dealt with only by means of ethical analysis. This could feed into the EU policy-making process through both codes of conduct and ethical impact assessments. It is hoped that this briefing will give Members of the European Parliament a better overview of the various questions they are likely to be confronted with in the coming years in the domain of assistive technology.

2. Legal challenges

The adoption of technologies for disabled people challenges the suitability of existing EU legislation to cope well with a wide range of legal questions in an efficient manner. Until recently, very little consideration had been given to legal issues, to how these technologies could or should be regulated, or to the measures that may need to be taken to ensure their use is consistent with human rights obligations and with social citizenship rights of participation in civil society. Despite the gradual involvement of the European Union in the domain of ATs and disability, a series of important structural challenges still persist when it comes to the protection of the rights of people with disabilities, making the accessibility and affordability of ATs a complex socio-political endeavour. It should be noted that the accessibility of workplaces, the built environment, ICT, websites and transport services has not been the principal focus of accessibility debates at the EU level. As a result, employment has been an issue of marginal importance and there are no disability-specific indicators in the Europe 2020 strategy or within the framework of EU state aid law and policy. For the purposes of the study, accessibility refers to the fair and just distribution of resources to ensure individuals have equitable opportunities to obtain appropriate products or services based on their needs and is directly linked to the accessibility of goods and services, transport, information and communication technologies and access to information and justice.

In the EU context, disability policy stretches across all categories of EU-related competence (shared, exclusive and parallel). The main challenge lies in 'fitting' the horizontal issue of disability into the realm of EU exclusive and shared competences as EU competence on this matter is wide-ranging. Most of the components of disability-related action - especially those that relate to the use of ATs - fall outside the scope the current EU legal framework however, raising serious legal challenges and questions regarding the limitations of the EU law approach. For instance, the organisation of social security systems, education, employment, healthcare, housing and the terms of participation in political and public life belong to the exclusive competences of the Member States. Thus, Member States are responsible for the organisation and delivery of health services and medical care. Each Member State is however responsible for establishing its own national healthcare policy and social services; that is, defining policies and organising the provision of such services. Across Europe countries differ in the kinds of welfare models used for healthcare and social services. EU law does not harmonise national social security systems, but coordinates them with regard to insured persons in cross-border situations, thus the social security protection of a person with disabilities is assured by Member States, under national law. Member States are also responsible for the organisation of their education systems. As a result, the EU cannot enact legislation on inclusive education but can only support and supplement the efforts of Member States to develop inclusive education systems.

It should also be mentioned that the legal status of Braille and sign language in the EU Member States is also a matter of national competence and the situation is very diverse. The use of Braille is regulated at EU level only for the packaging of medicines. Moreover, competence with respect to ensuring the right of people with disabilities to participate in political and public life rests mostly with the Member States, and EU law does not harmonise Member States' electoral procedures. However, significant challenges to participation on an equal basis with others remain, including: legal obstacles; inaccessible environments, processes and information; a lack of awareness about the right to political participation; and a lack of reliable and comparable data. As not all legislation affecting people with disabilities makes reference to them, the lack of a mainstreaming approach at the EU level prevents the EU administration from providing a definitive Declaration of its competences across the diverse policy fields covered by the UN CRPD. When the EU concluded the CRPD in 2010, by Council Decision, an initial 'declaration of competence' was provided in the form of an illustrative list of relevant EU legislation. Most of the human rights covered by CRPD articles relate to areas of shared competence between the EU and its Member States (e.g. combatting discrimination on the grounds of disability, co-ordinating employment and social policies, free movement, transport, the internal market, or the collection of statistics). In some areas the EU has exclusive competences (e.g. state aid, common customs tariffs, or the administration of EU institutions themselves, including procurement, staffing and the accessibility of EU buildings or communications).

As a result of the exclusivity of national competences in these domains, there is wide variation in the delivery systems for assistive technology in Europe in terms of the established information, prescription, assessment, delivery, and financing mechanisms and procedures. There are also structural differences in the way social protection schemes are designed at national level and a lack of coordination, classification, sharing and validation of any information concerning the assessment and market use of assistive technology products. The fragmentation of legislation regarding access to products and services has also arisen as a result of the fact that Member States have different accessibility requirements. Currently, the implementation of accessibility criteria in public procurement also varies enormously across Member States. In practice, in most Member States, contracting authorities do not make sufficient use of the possibilities offered under Article 23 of Directive 2004/18/EC, as this article does not currently include a clear requirement for goods and services to be accessible. Furthermore, cost criteria have often been an overriding concern to the detriment of accessibility criteria.

It should also be noted that according to the EU Agency for Fundamental Rights, 21 out of 28 Member States still impose restrictions on the full exercise of legal capacity. The regulatory fragmentation with regard to accessibility requirements and specifications across Europe is primarily an obstacle for disabled citizens intending to travel across borders and presents a number of uncertainties for manufacturers and suppliers of goods and services in the single market, as well as for those in public procurement. As a result of this fragmented legal landscape and the various ways adopted by individual European countries to incorporate the main principles and provisions of the UNCPRD, compliance with norms on antidiscrimination is patchy. The diversity between Member States in terms of providing assistive technology (for instance eligibility and entitlement requirements for receiving assistive technology, provision of AT through the health system or insurance schemes). The patchwork of interpretations not only undermines the respective harmonisation efforts but also prevents the portability of services across Europe and in effect the relocation of persons with disabilities to other Member States for employment purposes.

How can EU law ensure that assistive devices are easily accessible to all people with impairments given the complexity of the health care and social systems that organise and regulate the provision of assistive devices? Is the EU's legal system paving the way for a one-stop shop for people with disabilities without necessarily removing the various national procurement systems for example? How can regulatory bodies and authorities ensure transparent acceptance procedures for assistive devices or even introduce standards on quality levels that could apply across all EU Member States? Given the wide range of concerns with regard inter alia to setting high standards of quality and safety for assistive technology, the question is whether it is feasible, in legal terms, to have uniform testing procedures for assistive technology products. Or should policy-makers move forward through softer approaches that are based on an exchange of best practices, data and experience or even through the compilation of regulatory EUwide databases and catalogues? When approaching ATs from a legal or regulatory point of view, it is important to assess whether the current EU product liability and product quality standards fit well with the particular challenges associated with these advanced technological devices.

Beyond the structural limitations attached to the current allocation of competences, the lack of a horizontally accepted definition of disability raises questions as to efforts to shape a common EU approach towards the use and application of ATs. Related to that, the traditional classification of ATs as medical devices no longer corresponds to technological and social reality in this domain. As a result, the definitions of disability adopted across the EU vary widely, juxtaposing different national disability provisions in various areas, such as social security, employment and anti-discrimination. The absence of a definition of disability as grounds for discrimination has proven particularly problematic. This is because a uniform definition of disability across the EU is of paramount importance in determining the scope ratione personae of Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation (the Employment Equality Directive). The absence of

a definition of disability also creates uncertainty as regards the scope of the protection afforded in the EU legal order. Do the definitions offered in the context of the EU Employment Equality Directive also suffice for other legal contexts where ATs are gradually being introduced? In this context, additional supportive measures designed to ensure the independence, social and occupational integration and participation of disabled people in the life of the community need to be considered from a horizontal legal perspective. Similarly, rapid technological developments in the field of ATs raise multiple questions regarding the shaping, application and eventual interpretation of concepts such as autonomy and integrity and the potential ramifications of the latter upon the development and implementation of the relevant pieces of EU secondary legislation.

Despite embracing the social model, which is evident in the cornerstone document of EU disability policy, i.e. the European Disability Strategy 2010-2020 (EDS 2010-2020), EU legislation does not yet include a unique prescriptive definition of disability or of what constitutes an assistive technology. In state aid law, namely in the 2014 General Block Exemption Regulation (GBER),⁶ a definition of 'workers with disabilities' hasbænincluded. However, while this definition is clearly inspired by the social model, it still refers to national legislation in an attempt to respect the diversity of legal cultures and approaches to disability across the Member States. Disability-related provisions in other areas of EU legislation, such as transport, lifts, public procurement, and electronic communications networks and services do not purport to offer a definition of what constitutes a disability. The uneasy task of identifying the criteria for determining disability has been left to national legislation, clearly resulting in a sort of patchwork.

In fact, there is much controversy and many practical problems connected with the criteria of disability and age. The separation of disability from sickness is particularly important – in principle, disability is long term. Sickness in the understanding of EU law should be understood as a short term inability to provide work. In the case of disability there is permanent impairment of a person's physical, mental or psychological capability, which makes participation in social life, including employment, impossible or considerably restricts it. An additional problem is connected with the degree of disability as well as with the occurrence of specific disabilities that, although they may impair the capabilities of the body permanently, do not have to lead to exclusion from or considerable restriction of participation in social life (hearing or visual impairment). It is more restrictive than the approach adopted in the CRPD as it requires claimants to have an impairment that, in interaction with social barriers, hinders their participation in professional life.

Could ATs be considered as falling within the scope of measures destined to safeguard independence, integration and social participation? If so, would that trigger any legal effects on the way the use of these technological products has been approached in a medical or employment context? Additionally, Article 35 of the Charter of Fundamental Rights provides for everyone to have the right of access to preventive healthcare and the right to benefit from medical treatment under the conditions established by national laws and practices. Could certain AT applications of a primarily medical nature benefit from the enforcement and placing of this right in terms of its legal integration within the rules on social policy and equal access to these technologies at EU level?

Moreover, given the variety of personalised data that AT devices involving a monitoring dimension may collect, data protection, safeguarding the privacy of their users and the security of information available to the devices are all major issues that require special legal attention. AT devices and robots will collect, process and store unprecedented amounts of data so as to function properly. The use of information will increase in volume and complexity as ATs carry out more and more autonomous functions and ATs have gradually become capable to extract, measure, store and decode potentially sensitive information about

⁶ Commission Regulation (EU) No 651/2014 of 17 June 2014 declaring certain categories of aid compatible with the internal market in application of Articles 107 and 108 of the Treaty Text with EEA relevance, OJ L 187, 26.6.2014, pp. 1-78.

their users. Ambient intelligence can make information and communication technology invisible and uncontrollable. Various types of information about an individual and their behaviour can be collected without the person even noticing. Understanding the risks posed by autonomous robots to the right to informational self-determination and privacy requires an appreciation of the ways in which data are, and will be, utilised by the technology. The existing normative framework including the principle of data minimisation, continues to provide essential guidance even though robots and artificial intelligence, by definition, require vast amounts and new forms of data that is often private and sensitive and can potentially be used by malevolent external agents for immoral purposes.

The use of assistive technology and robotics will have an impact on the right to privacy, namely the protection of personal data, and informational self-determination in a significant and unparalleled manner and may even restrict freedom of privacy, without fully involving or obtaining the consent of the person, given that this technology will be able to generate, centralise and share vast and unprecedented amounts of data on health and other sensitive information through the undesired access by other people to a personal space. Information gathered through the use of assistive technology will be particularly sensitive as it pertains to the health of individuals, their life choices, political, philosophical and religious beliefs, sexual habits, etc. This may concern people with disabilities, their caregivers, family or friends and raises various questions as to who is and should be responsible, how their behaviour should be monitored and controlled and what is the hierarchy of responsibilities? This is not usually inherent in the design as the information could be organised in a number of different ways.

Moreover, informal carers are not always able or willing to take on the responsibility for instance of looking for the person if and when he or she gets lost. Their consent to becoming involved in the functioning of the system cannot be presumed. Privacy issues include issues such as personal privacy, surveillance, as well as searching and combining data. Additionally, as the devices become more autonomous and since these systems function on the basis of data collection and analysis, it is likely that increasing data collection will be associated with risks of monetisation of valuable personal data as well as of risks of criminal hacking. Challenges for privacy will further increase as devices communicate with each other, particularly in home care, and as assistive technology and care robots intersect with assisted-living technologies and other electronic devices such as smartphones or tablets. A collateral privacy-related concern relates to information, such as algorithms, about the functioning of devices, particularly in the event of their potential misuse or malfunctioning, which could cause harm to users.

How would the privacy policies for each device apply and how could a user be expected to keep track of these? As EU data protection legislation is currently under revision, the issue of secondary use or of the definition of the owner or processor of data in the context of the operation of AT is crucial. Medical negligence is also of relevance to policy-makers and legislators if the delivery of patient care changes significantly owing to greater use of ATs. Would a technological fault still lead to liability for negligence? How would technology impact upon the legal standards that professionals, such as doctors, should adhere to? In case of the use of drones or automatically driven vehicles as forms of assistive technology, a multiplicity of legal and ethical questions come to the fore including issues of liability and privacy. In the case of implanted devices that can track an individual who is in need of constant surveillance and care, issues of informed consent and the appropriate means to guarantee that the individual rights involved, such as physical integrity, liberty, identity and privacy, are well protected come into play. As far as brain-computer interfaces (BCI) are concerned, the main legal issue concerns whether and to what extent the will expressed by the individual through these biomedical 'media' can be considered legally relevant and valid; or in the case of the use of cybernetic devices for disabled people, policy-makers may need to reconstruct or redefine key legal concepts of personhood, identity and autonomy. On the latter point, legal questions arise concerning the use of robots as companions for disabled people, mostly in terms of the robots' legal status and to allotment of liability for the damages caused to their users and to third parties.

Other challenges include the absence of any provision in the EU Equal Treatment Directives (Council Directives 2000/43, 2004/113 and 2006/54) that would explicitly prohibit discrimination on the grounds of disability and to provide reasonable accommodation to persons with disabilities in the areas of social protection, health care, (re)habilitation, education and the provision of goods and services, such as housing, transport and insurance.⁷ For transport, although the EU has passed legislation to improve accessibility of vehicles (and of infrastructure in the case of rail transport) for persons with disabilities, there is no specific EU legislation for air transport. Furthermore, EU copyright law, as long as the EU does not ratify the Marrakesh Treaty, does not provide ad hoc exceptions for the non-commercial transformation of protected works in an accessible format. As a result, the patchwork of national exceptions is extremely fragmented in terms of scope and content, making the cross-border circulation of works in an accessible format highly problematic. Moreover, the European Union has yet to mainstream a disability perspective into all its gender policies, programmes and strategies and has not acceded to the Council of Europe Convention on preventing and combating violence against women and domestic violence (Istanbul Convention) as a step to combating violence against women and girls with disabilities. Although harm prevention is one of the fields of application of assistive and robotics technology, such technology also raises some safety concerns. Assistive robots operate side by side with humans in an environment that is not usually well defined, such as the home, and are used by nonspecialists, who may in addition have declining abilities or cognitive impairments. Malfunctioning technology can also constitute a hazard for disabled people. Damage caused by assistive devices or robots can usually be attributed either to a machine defect or to faulty usage. With progress in machine learning, the risks of that technology are hard to predict. Another potential source of harm are cyber-attacks, which could have an impact on the system and indirectly cause harm. Safety regulations and premarket assessments need to take account of these specificities so as to protect disabled people's physical integrity.

Last but not least, research funded by the EU is not accompanied by ethics guidelines to ensure that all people with disabilities involved in such research are enabled to give their informed consent. In the field of EU-funded research involving people with disabilities, the European Union has not developed ethics guidelines or consent forms in accessible and easy-to-read formats, or prevented substituted decision-making in this area. Additionally, the barriers faced by people with disabilities and people with family members who have disabilities when moving to live or work in another European Union Member State, irrespective of the length of the stay still persist, including with regard to the portability of social security benefits in a coordinated manner across Member States. Given the fragmentation of the EU market for assistive devices and the dynamic interface between market innovation and ethical considerations, no measures have been adopted to prevent austerity measures from having further adverse and retrogressive effects on the standard of living of people with disabilities, for instance by setting a social protection floor to uphold the core content of the right to an adequate standard of living and to social protection.

Therefore, given the aforementioned enduring challenges, the existing EU legal landscape still seems incoherent and lacks the coordination that is necessary to enhance the active involvement of people with disabilities in all aspects of life. The adoption of several international instruments in the AT domain may

⁷ In 2008, the European Commission presented a proposal for a Council directive on implementing the principle of equal treatment outside the labour market, irrespective of age, disability, sexual orientation or religious belief. The proposed directive is aimed at extending protection against discrimination by means of a horizontal approach. However, as unanimity is required in the Council, the draft has remained blocked at that stage since then. The European Parliament has issued several resolutions asking the Council to adopt the directive, including a 2014 resolution on the mid-term review of the Stockholm programme, a 2016 resolution on the situation of fundamental rights in the European Union in 2015 and a 2017 resolution on equality between women and men in the European Union in 2014-2015, which urges the Council to reach a common position as soon as possible.

have provided the necessary legal impetus for EU action but the EU is still falling short of expectations for it to actively involve representative organisations of persons with disabilities and harmonise EU secondary legislation with the provisions of the Convention in a cross-cutting and comprehensive manner. The European Commission proposal for a European Accessibility Act, which is still under interinstitutional discussion, may help to tackle the challenges under consideration by paving the way towards safeguarding the full participation of people with disabilities in society and reducing the fragmentation of legislation governing access to products and services, as it provides for a common EU definition of and implementation framework for accessibility requirements for certain products and services. The proposal for a European Accessibility Act aspires to provide an EU-wide horizontal framework on disability that would act as an authoritative point of reference for all disability-related initiatives.

3. Socio-ethical challenges

Although assistive technology is full of promise for sustaining disabled peoples' independence and improving their quality of life, it also has the potential to intrude upon the rights, privacy and freedom of people with disabilities. Additionally, the introduction and use of ATs risks exacerbating social exclusion (if assistive technology is used as a way to cut services and reduce human contact), may become a potential threat to the independence of disabled people or may even complicate their lives (given the technical requirements required).

More specifically, ATs may pose new risks, undermining a person's **autonomy and independence – including the right to refuse a certain form of support, such as a robot –** by fostering **new forms of isolation and abandonment**, given that these new technological artefacts may lessen people's ties with the community. AT **might sustain a dependency culture**, **as w**here ATs such as robots remain the only form of interaction for disabled people, technology may even become incapacitating and disempower them. **People with disabilities may not be able to be truly independent** as they may rely – in technological terms – on family members and caregivers for technical matters that are beyond their abilities, in effect making people's lives and living environments more complicated. The use of algorithms embedded within ATs may further restrict autonomous decision-making.

Additionally, ATs **may perpetuate the view that disabled people are inert and in need of protection**, thereby damaging self-esteem, as some devices may be used to do things a person is still able to do for themselves, which may increase dependency and exacerbate their problems. While such tools can increase individual autonomy, **there are risks of abuse as there is a fine line between suggesting action and directing the person into a specific activity.** The use of ATs might also compromise disabled people's dignity especially via the use of restraints, disempowering practices, and neglect of the users' needs and preferences. Beyond the aforementioned concerns about autonomy, the issues of privacy, reliability (including manageability, predictability and dependability), delegation of control, accountability, and social compatibility (including transparency, fairness, universal access and acceptance) raise questions as to the ethical soundness of AT.

The use of robots and assistive devices **may potentially lead to a reduction in the amount of human contact** if ATs are used to cut back services. Although during the introduction of new systems interaction with health workers may increase, the use of robots for tasks such as lifting, carrying or even cleaning might ultimately reduce a disabled person's social contact with humans. Even if interaction with robots, for instance social companion robots, could be potentially beneficial for the physical and emotional wellbeing of disabled persons, the extent to which they may replace reduced or missing interaction with other people and any potential risks of **social exclusion** in this regard should be assessed thoroughly.

Moreover, the use of AT may change our understanding about what constitutes a healthy human body. ATs can be worn directly on or implanted in the human body, giving rise to questions such as whether embedded technology should be considered part of the body and what might be the potential effects upon the intellectual rights of the owner. One of the most important socio-ethical concerns regarding the deployment of ATs relates to the fact that the term 'disability' is not accepted by a wide range of individuals and communities that reject dominant definitions of disability as posing problems for individual and group identity and/or remain close to **medical classifications of disease – disability – handicap.** Questions arise as to whether or not there should be limits to the integration of technologies into human bodies and the blurred distinction between assistance and enhancement. Within this context, it should be mentioned that people who acquire disabilities later life may find the use of AT shameful and **stigmatising.** Particular concerns have been expressed about the possible stigmatising impact of tagging on people with dementia. The use of AT may, in some cases, draw attention to the fact that a person has a disability.

Given that the human touch is considered an important part of caring, a model paradigm of care that solely or primarily relies on AT entails the risk of dehumanising care practices. The result is that

individuals might risk losing their sense of identity, self-esteem and control over their lives, and raises overall raises concerns about human dignity. Views diverge on the extent to which robots can compensate for human contact, also considering that loneliness is a common source of distress and suffering for disabled people and impairs their quality of life. User acceptance depends on a variety of factors, including the characteristics of the technology itself, and also on the availability of alternatives, personal preferences and social and cultural circumstances. Assistive technology cannot substitute for human care. The extent to which it is appropriate to rely on a machine as opposed to human will, however, will vary depending on the context, task and individual concerned.

The introduction of assistive technology and care robots raises questions about the kind of care society seeks to offer disabled people as well as about the objectification of disabled people, as it is not clear if the care provided respects the person's dignity. Independent living must not be understood as absence of support given that assistive technology may infantilise the people concerned and also take away their choice and control, therefore breaching their autonomy. The promise of independence should be balanced with other human rights. The introduction of advanced assisted technology might amplify the existing gap in access to such forms of support and also create new inequalities in view of the risk that artificial intelligence might reproduce human bias and as a result discriminate against some people. Biased datasets and algorithms may be used in judicial decision-making, medical diagnoses and other areas that have an impact on disabled people.

The affordability of the system will have an impact on the uptake of technology and therefore equality, inclusion and the enjoyment of all other human rights (i.e. autonomy) that such technologies are supposed to enhance. Lack of access to assistive products and services restricts the enjoyment of human rights that are dependent on support through technology. Special attention must also be paid to vulnerable population groups that are disproportionately disadvantaged in terms of access to support, such as migrants, refugees and asylum seekers, indigenous peoples, ethnic, racial and cultural minorities, stateless people, those in conflict or humanitarian situations, and other marginalised segments of the population. One further challenge lies in the fact that **funding and services are either difficult to access or highly fragmented**, with ATs provided through both public and private insurance providers.

Fragmentation and variation in EU policies and services may result in the failure of systems to provide for those who need assistance, to meet societal obligations for equity of access to ATs and opportunities including comprehension of user needs, and to address economic concerns. Drawing the line between necessary therapy and enhancement is genuinely problematic. Augmentation technologies will increasingly blur the border between alleviating the effect of disabilities and enhancing the human body, raising questions about whether embedded artefacts are considered to be part of the body and/or the effects this could have for the intellectual property rights of the owner. Indeed, a purely technical repair of disability (age-related or not) is ethically problematic, because any disability is always the result of concurring physical, environmental and social conditions. To improve impaired human performance, it is necessary to define the intertwined concepts of normality, disease, disability and defect. Who decides what constitutes a disability, disease or defect? Who establishes what is normal?

4. Options

In view of the legal and socio-ethical questions raised by the potentially wide-scale application of ATs in Europe, the case for public intervention with regard to the elements listed above is clear. This intervention should take place swiftly and primarily in the form of standards and safeguards so as to enable people with disabilities to live independently and to participate fully in all aspects of life. The purpose of the overarching policy options is to provide a series of suggestions that EU actors can take into account when dealing with ATs, including the need to ensure an understanding and use of the human-rights-based approach to disability at all levels of the EU.

4.1. Ensuring accessibility as a human rights obligation

First of all, EU law needs also to ensure that discrimination on the grounds of disability is prohibited and to introduce an obligation to ensure access to a wide range of support services for people with disabilities. Full inclusion and equal participation of people with disabilities can only be achieved by taking a human-rights-based approach to disability at EU level. The accessibility obligation is a human rights obligation that supports a more inclusive approach that will contribute significantly to the protection of the right to an adequate standard of living, the right to social protection, the right of everyone to enjoy the highest attainable standard of physical and mental health and the right to education. In view of this suggestion, various pieces of EU legislation that impose obligations on operators to provide assistance for passengers with disabilities or reduced mobility (such as the Air Passengers Regulation, the Rail Passengers Regulation, the Sea and Inland Waterways Regulation and the Bus and Coach Regulation) may have to be reconsidered in view of the increasingly important role that ATs may play in relation to the enhancement of personal mobility in various transport contexts.

This review process could take into account the novelties contained in the horizontal directive on equal treatment currently under negotiation, extending protection against discrimination to people with disabilities, including the provision of reasonable accommodation in all areas of EU competence. The transposition of the Employment Equality Directive into the domestic law of the Member States should also take place paying the utmost attention to the duty of reasonable accommodation in the public sector, accessibility of workplaces and inclusive employment. The introduction of assistive technology must not lose sight of social inequalities. To avoid generating further inequalities, the equal access to ATs must be ensured for all people with disabilities regardless of their level of income, ethnic or cultural origin, religion, physical or mental ability, gender or place of residence.

Within this context, there is a need to enhance transparency when it comes to the procurement of AT products. The current proposal for a directive on public procurement introduces an obligation for contracting authorities to draw up technical specifications that must 'take into account accessibility criteria for people with disabilities or design for all users ..., except in duly justified cases'. Accessibility should be a key regulatory outcome in all ongoing and future efforts to enhance standardisation and the formulation of specific standards for the improvement of the proper functioning of the internal market for accessible assistive technology products and services. The Digital Agenda and Innovation Union initiatives may also have to be viewed through the prism of the European disability strategy especially with regard to its regulatory and legislative components. The legal 'accommodation' of AT within the EU legal framework will be further enhanced through the upcoming accession of the EU into the Marrakesh Treaty to facilitate access to published works for persons who are blind, visually impaired or otherwise print disabled. This treaty was agreed in 2013 under the auspices of the World Intellectual Property Organisation (WIPO) and sets out exceptions and limits to copyright rules so that people unable to use print media (including blind, visually impaired and dyslexic people) can access a far greater range of books and other written materials in accessible formats. Furthermore, legislative initiatives need to be taken in order to ensure that all EU citizens with disabilities enjoy the equal rights to vote and stand for elections at national and European levels and that a strategy on the implementation of the UN Convention within the EU, including all its institutions is developed. The Convention also stipulates that the design of products, environments, programmes and services should enable their use by all people, to the greatest extent possible, without the need for adaptation or specialised design. Such 'universal design' should not exclude assistive devices for particular groups of people with disabilities, where this is needed. According to the UN Convention, people with disabilities include those with long-term physical, mental, intellectual or sensory impairments that may, in conjunction with other barriers, hinder their full and effective participation in society on an equal basis with others. Guaranteeing equal access for all people to such technological innovations, tools and intervention should be of primary importance for all institutional actors involved in the shaping of disability-related policies.

4.2. Making sure assistive technology is affordable

Assistive technology must be available in sufficient quantity, affordable and accessible to all disabled people, without discrimination, especially for the most disadvantaged disabled people and those with high support needs. It should be tailored to the diverse spectrum of the needs of disabled people and be easily available, based on individual circumstances. Solutions that are only available in certain geographical areas, such as cities, or that are offered in specific settings only, such as homes for disabled people, do not comply with the principle of accessibility. The affordability of assistive services and robotics is a key element in ensuring access to such devices. While it will be a gradual process, States should include the provision of essential assistive devices and technology in national health insurance and/or social protection scheme coverage, on the basis of the World Health Organisation's priority assistive products list, and should also consider waiving import duties and taxes on assistive devices and technology that are not produced domestically. The adequacy of support may depend on the prevailing social, economic, cultural, climatic, ecological and other conditions. Gender, income and housing disparities that impede access to adequate support must also be addressed.

Further, in order to ensure universal access, Member States should integrate assistive technology into health and social protection schemes, making it available at affordable prices and offering financial assistance to those who need it. While promoting effective assistive technology, Member States must also retain other support options, including traditional care, and not create disproportionate disadvantages for individuals who may prefer, or whose needs would be better catered for through, other forms of support. States should also establish monitoring and accountability mechanisms regarding the provision of assistive technology in order to evaluate the adequacy of support arrangements and prevent human rights abuses. There is also the need to examine the ethical concern of fairness in the availability of new assistive products to address the need for the implementation of the human rights of people with technology needs in our society, including people acquiring disability as they age, aging with a disability, and aging well. AT should be acknowledged as an essential measure to enable disabled people to live independently and to participate fully in all aspects of life, on an equal basis with everyone, everywhere. The promotion of advanced technology, such as robotics, should complement and not detract from efforts to ensure that basic low-technology assistive products are available to everyone. Moving in this direction, there is a need for a fair distribution of technologies - via the implementation of reimbursement plans and other welfare mechanisms - so as to prevent the emergence of a technological divide that could exacerbate pre-existing economic inequalities and the availability of ATs to wealthy users only.

A non-discriminatory interpretation of the provisions entitles all people with disabilities to a right to demand available and affordable assistive technology. Securing this right is both a national and an international responsibility. Additionally, thorough consideration must be given to the question of what employment provisions might be necessary in terms of the labour force if the artificial or genetic development or supplementing of existing human capabilities results in people with extraordinary abilities. This would fundamentally alter the meaning of the term 'disability' and confer an unassailable advantage on people with access to such technological innovations, tools and interventions, naturally raising delicate ethical and moral questions. Furthermore, there is also a need to foster the use of ATs in

a way that enhances autonomy and independence but without increasing social exclusion. The introduction of an EU-wide accessibility labelling scheme might provide a means of ensuring that people living with functional limitations are able to find reliable and easily available information about the accessibility of products and services. Accessibility should have a social or attitudinal aspect. This form of accessibility refers to the removal of stigma and other negative forms of behaviour that people with disabilities, their families and their caretakers experience throughout their lives. Second, accessibility includes an affordability aspect. This aspect refers to the need to make everything affordable to persons with disabilities, from flight tickets to new information and communication technologies.

Applying a human-rights-based approach, support should be available as a means to expand opportunities and not as a method of maintenance. Assistive technology should enable human capabilities and enhance human dignity. This aim should be integrated from the conception to the application of assistive devices and robotics. Robotics and other types of assistive technology should not prioritise certain forms of participation, i.e. they should not merely seek to facilitate remote interaction from home, and should not create distraction as a form of respite for caregivers. The right to an adequate standard of living requires, at a minimum, that everyone should enjoy the necessary conditions of support they need. That involves the availability of support services and assistive devices. Unless disabled people have access to the support they require, they will not be in a position to fully enjoy their human rights, such as the right to an adequate standard of living. Not only should such services and devices be generally available in the market, they should also comply with the principles of availability, acceptability and quality.

4.3. Privacy-by-design approach

Privacy should not be used by developers and companies as a pretext for not disclosing information on the grounds that it is sensitive, if it is required to establish responsibility, including negligence or to challenge driven or automatic decision-making. Again, personal information should only be disclosed if necessary for a specific, well-defined purpose, bearing in mind that not every investigation of every form of malfunctioning would justify interference with privacy rights and that it would be necessary to strike a balance among conflicting rights. It is crucial to ensure inclusive and equal access to these technologies taking into account the impact of ATs on user privacy owing to their access to traditionally protected spaces and sensitive personal information and the need to ensure the principles of medical ethics, safety of patients, and integrity of care provided.

Against this backdrop, there is a need to ensure that users be given the options to prevent data archiving, delete historical data, and amend incorrect or misinterpreted data over the lifespan of the robot, but also to operate in a transparent research data sharing environment that provides users with information about the data inputs, outputs, and algorithmic decisions presented to them. Additionally, a privacy-by-design approach needs to be introduced so as to enable data to be collected in an ethical manner. Such an approach should be proportionally designed to accommodate sensitive settings and promote transparency, access permissions, privacy policies, user consent, and privacy controls.

Beyond shedding light on the terms of applicability of the new General Data Protection Regulation in the domain of ATs, the European Data Protection Supervisor might have to adopt a series of initiatives in order to address the relevant privacy risks. Given that certain assistive technology devices have the capacity to extract, collect and share sensitive information independently, the process by which robots and artificial intelligence collect, use and process personal data must be transparent and comprehensible. Users should be able to understand fully the extent of monitoring, including how data are gathered and processed, by whom, for what purpose, for how long and where they are stored, and with whom they are or can be shared. Monitoring technologies could result in unwanted supervision and could even take place without a disabled person being aware.

4.4. Establishing a fair and tailor-made informed consent process

Data gathering and other forms of invasion of personal and domestic privacy must take place only after obtaining the informed consent of the individuals concerned (i.e. the disabled individuals and others whose information may be collected). The right to free and informed consent is enshrined in Article 25 of the Convention on the Rights of Persons with Disabilities. It is necessary to obtain the specific consent of a person in advance of every intervention. This requirement needs to be extended to support given to disabled people through technological means, including robots. Others should not be allowed to give consent on their behalf. The obligation to obtain consent needs to include a duty to consult disabled people appropriately and to ensure that they are not unduly influenced in their decision on the use of technology. As technology acceptance may fluctuate over time, disabled persons should also be able to change their minds and opt out of technology at any time. Unless there are viable alternatives, the disabled person does not, however, have a real choice. Consent should not merely be either an administrative requirement or binary decision: instead there is a need for dynamic consent models that allow for the user to change his/her mind and the terms of involvement, and to select more nuanced participation choices.

Informed consent is an essential element of a rights-based approach and is paramount in the introduction of assistive technology. Information must be given in an understandable way and language, bearing in mind individual personal circumstances and cognitive abilities and in effect in such a manner that potential users will understand the risks and not overestimate the benefits of technology. Simple and accurate information needs to be provided, in order for people with disabilities to be able to assess the implications and possible risks as well as benefits properly. Further human rights requirements imply that disabled persons keep control over information collected through technologies, e.g. on health conditions and living habits. Depending on the personal circumstances and needs of a disabled person, diverse levels of support may be required to obtain consent. Particular safeguards are required for people with severe cognitive difficulties, including disabled persons with dementia. The process followed to obtain consent, including the manner in which people are consulted, determines the extent to which disabled persons can make informed and autonomous choices. Even if disabled persons consent to the use of monitoring devices, they must remain in control of what information will be gathered, how it will be used and with whom it will be shared. For example, can a surveillance system put in place to detect failures collect also data about the user's habits?

The right to autonomy also extends to the withdrawal of technology. Technologies should be flexible enough ('self-learning') to adapt to disabled persons' preferences and lifestyles. The paradigm of choice and control includes the right to opt out of the assistive device at any time. Withdrawal of the system must not take place without the explicit consent of the user. A prerequisite is that simple and accurate information about the technology be provided for every disabled person — not just to those with cognitive impairments — in order for them to be able to assess the implications of the use of assistive and robotics technology prior to giving their consent. When technology has been applied for a long period, the impact on the disabled person's rights must be closely evaluated. This is especially important for robots, with which users may develop close bonds owing to their anthropomorphic features and functionalities. The right of disabled people to autonomy is at times limited on the ageist assumption that because someone is disabled, has declining mobility or worsening memory, they are not able to make decisions. Safeguards are needed so that the choice of a person, for instance not to take prescribed medicine or follow a certain regime, is respected and to prevent the robot from coercing the disabled person into adhering to the caregiver's instructions.

Not only must disabled people retain the whole range of decision-making powers other adults have, but they should also not be penalised for their decisions. Systems may for, instance, signal a deviation from prescribed or expected behaviour to other actors, such as caregivers, health professionals or even insurance companies. It is important in this regard to clarify that robots should not be able to substitute themselves for the decision-making of a disabled person. The human control paradigm implies that it should not be possible to delegate a decision with legal effects to an automated process. Last but not least, the implications of the use of assistive and robotics technology on the informational self-determination of disabled persons needs to be better understood and assessed.

4.5. Disabled people should retain control over the use of technology

If a person prefers not to use technology or feels overly restricted, alternative measures must be provided. Participation begins with the direct involvement of disabled people in the design and development of assistive products and extends to the planning, delivery and evaluation of services. A participatory or user-centred design could ensure their inclusion at all levels of decision-making. This is about making disabled persons equal partners in the process, using genuine bottom-up approaches (i.e. co-design or co-construction). Specific efforts must be made to include marginalised groups and those not adequately covered in representative organisations of disabled persons. Such groups might include indigenous people, migrants and refugees, ethnic, cultural or linguistic minorities, and those with complex support needs. Furthermore, to be truly inclusive, technology must reflect the diverse preferences and lifestyles of disabled people based on age, disability, nationality, ethnicity, religion, gender, status, etc. Within this framework, there is, moreover, a need to build the capacity of people with disabilities to engage with assistive technology through targeted training. Information and training should be aimed at helping disabled people develop the digital skills necessary to use the technology and develop technological literacy to understand and evaluate the benefits and risks of technology.

There is a need to further explore appropriate mechanisms of accountability and monitoring of assistive technology and in particular of robots, including by engaging in discussions about the establishment of a dedicated watchdog on artificial intelligence, and ensure that such mechanisms adequately address the situation of disabled people and are grounded in human rights standards. People with disabilities should be actively involved in the design and development of assistive technology and robotics. They must also participate in all aspects of decision-making about the introduction of assistive technology through public policies, including design, provision and monitoring. All necessary measures need to be taken so as to ensure the active participation of disabled people in research, development and policy-making, including by addressing structural barriers to their involvement. Robotics research activities should be conducted in accordance with the precautionary principle, anticipating the potential impact, while encouraging progress for the benefit of disabled persons and society at large. ATs and robotics should support disabled people's participation in social and public life – namely in decision-making processes e.g. through online surveys, consultations, voting systems – and in other everyday activities (online shopping, government or banking services, leisure, etc.). The principle of participation also implies the direct involvement of disabled persons in the design and development of assistive solutions.

Adequate support is a precondition for the effective exercise of all human rights on an equal footing with others and therefore for the possibility to live with dignity. Attention must be paid to ensuring that technology targeting disabled people does not stigmatise disabled people as frail and as needy of assistance. Technologies that reinforce stereotypical images of disabled people, exclusion and segregation do not comply with human dignity, despite their promise to enhance autonomy and independence. In this context, there is a need to introduce universal health coverage and develop a transparent regulatory environment where assistive products and services can be tested in a real environment, to make a non-discriminatory interpretation of the scattered disability-related EU provisions – that might entitle all people with disabilities to the right to demand available and affordable assistive technology –, and to introduce a requirement that these technologies be developed collaboratively with people with disabilities. In relation to the latter, it should be mentioned that users' needs and preferences and the individual decision-making process regarding whether or not to start using AT are important factors to consider for effective AT use and, consequently, more effective use of public resources.

4.6. Developing ethics oversight structures

The EU institutions might need to consider the development of an ethics-by-default framework for researchers, academia and engineers to ensure that these technological solutions do not hinder research and technological developments but are in compliance with existing Union and national ethical practices and codes. The technologies must also uphold the rights and principles enshrined in the Charter of Fundamental Rights, in particular human dignity, respect for and protection of private and family life, security and safety, the protection of personal data, protection of intellectual property, freedom of expression and information, equality and non-discrimination, solidarity, and citizens' rights and justice, and should be subject to proportionality. As technology becomes more sophisticated and autonomous, a people-centred approach to independent living and a human rights-based approach needs to be embedded in the design, planning and implementation of assistive technology systems. A rights-based design ensures that technology will take account of people's diverse needs and preferences, paying due attention to vulnerable groups, including those with high support needs, the cognitively and otherwise impaired. Human rights impact assessments of assistive should be undertaken to address human rights concerns and ensure compliance with international standards. The auditing of machine-based decisions and algorithms, and their compliance with human rights standards, is essential in avoiding discriminatory treatment, including through biased algorithms. In this context there is a need to develop concrete guidelines for such human rights impact assessments in consultation with developers and manufacturers, but also service providers, procurers and civil society.

The gradual application of ATs is triggering the need to establish appropriately staffed committees on robot ethics at the EU and national levels tasked with considering and assisting in resolving unusual or complicated ethical problems. The role of these ethics committees would be to address the psychological and societal impact of human-robot interaction with special attention to vulnerable groups, in particular children, to avoid creating harmful dependence on robots, for instance through the evocation of an emotional response, or the isolation of these individuals from reality. In this connection, the European Commission may need to develop specific guidelines to support the functioning of such committees but also develop the necessary guiding ethical principles for the design, engineering, testing and use of ATs to ensure that such technologies really can improve the quality of human life. There is also a need for ethical monitoring, to protect people's fundamental rights against the potential risk of threats to respect for human dignity, autonomy and personal identity. Such risks need to be assessed and compared with the opportunities for promotion of dignity and personal identity development that are made possible by these devices through the restoration of lost functionalities and the chance of recovering effective interaction with the external environment.

4.7. The need to introduce a new classification structure for ATs

There is clearly an urgent need for a coordinated research, implementation, and policy response to assistive product access and procurement. It must be proactive, responsive, and sustainable, so as to match technology advancement but also to develop a more nuanced classification system that departs from the medical/non-medical dichotomy. The auditing of machine-made decisions, and their compliance with human rights standards, is therefore considered necessary to avoid discriminatory treatment. This response should be tailored to the particularities of ATs and allow the appropriate classification and regulation of mainstream devices that are 'disability inclusive' as well as ATs that are also intended for mainstream markets. There is a need for a broad conceptualisation of ATs that would allow the EU to include any type of assistive, adaptive and rehabilitative device aimed at compensating for functional limitations, given that disability is an evolving concept that results from the interaction between people with impairments and attitudinal and environmental barriers that hinder their full and

effective participation in society on an equal basis with others and with the same dignity. Against this backdrop, EU legislators need to perform a social fitness test of the current framework mostly in terms of whether it manages to reflect the needs of people with disabilities adequately in the fields of product and service development.

4.8. The need to ensure that human care remains irreplaceable

The introduction of technology cannot substitute for the State's obligation to support disabled people or lead to a collective disengagement from the duty to support them. Evading social responsibility for this group, as in practice society discounts disabled people's inherent worth, breaches the universality of the right to support. The use of these technologies should not replace human care or substitute States' obligation to support disabled people by creating the necessary structures and services, and allocating a budget for long-term care. States must ensure that all disabled people enjoy equal access to assistive technology without discrimination. Eligibility criteria for the provision of assistive devices must follow a human rights-based approach to ensure that they are not discriminatory. Human caregivers will still be needed and will continue to provide an important source of social interaction for them that is not totally replaceable.

4.9. Need to ensure safety

Any EU-wide regulatory initiative in the field of ATs must take into account the risks associated with the possibility that assistive technology artefacts integrated into the human body may be hacked or switched off or have their memories wiped, because this could endanger human health, and in extreme cases even human life. In view of these risks, special attention should be attached to protecting such systems. The vulnerability of patients with special needs, including children, the elderly and people suffering from disabilities in combination with the potential that any user may develop an emotional connection with robots, should be acknowledged. Within this context, the EU should open discussions on how to ensure that ATs will not impact negatively on the autonomy and independence of vulnerable people, and their implications for human rights in terms of improving the lives of people with disabilities. Moreover, special safeguards should be introduced to limit the access to this information to professionals and other relevant stakeholders while restricting access to malevolent agents and third-party companies interested in the data. At the same time, there is a need to ensure continuous and sustainable access to maintenance, enhancement and, in particular, software updates that fix malfunctions and vulnerabilities. It is also necessary however to create independent entities to retain the means necessary to provide services for people using vital and advanced assistive appliances, especially cases where such services are no longer carried out by the original supplier.

5. Conclusions

Accessible technology as such is not an autonomous object or essential element of EU legislation. Law in the area of ATs needs to keep up with technological advances, to strike a balance between stimulating innovation and protecting fundamental rights and values, including protecting people with disabilities from discrimination, safeguarding access to public services and benefits, and supporting both the independence and care of disabled people. The wide variety of ATs available raises the question of whether there should be a normative classification of their relevant challenges and the relevance of the latter to the reshaping of legal concepts such as legal capacity and competence, identity, privacy, health and bodily integrity.

The myriad ethical, legal and social effects of the commercial development and use of these technologies may signify a paradigm shift of civil law, insurance law, equal recognition before the law, participation in criminal proceedings, consumer affairs, political, social and cultural life, equality and nondiscrimination (employment, education and training, social protection, health), and freedom of movement and may even affect the interactions between science, ethics and law. The involvement of the EU in the domain of disability has not led to the creation of new rights for disabled people; but rather to the elaboration and clarification of existing human rights within the disability context. Despite a number of initiatives to promote and harmonise accessibility requirements in a range of areas (e.g. transport, built infrastructure, ICT or ATs), the EU's regulatory environment has remained fragmented. The EU-wide regulatory framework on disabilities that sets the rules for the facilitation of the social inclusion of people with disabilities and the protection of their rights remains rather insufficient in many ways and for several reasons.

Although EU law is important in affecting and shaping the accessibility and availability of ATs at national level, public provision of these technologies falls mostly outside the scope of EU law. The limited role of EU law in that respect could be attributed to the fact that ATs are provided through the social security or public health systems of the Member States with the EU limiting itself to a coordinating role. Beyond the structural limitations attached to the current allocation of competences (areas such as the organisation of social security systems, education, employment, housing, and healthcare belong to the exclusive competences of the Member States), the 'accommodation' of ATs within EU law depends largely on how disability is defined. Such a definition comes with complex social, ethical and also with legal consequences. As a result of the wide variety of approaches and interpretations of the main tenets of the framework, implementation has been problematic within Member States and a serious regulatory fragmentation in the EU market seems to persist.

The framework's failure to approach ATs as enablers of people's equal participation in society, to render them affordable and accessible and to make use of their end products so as to promote civil rights, such as the right to equal recognition before the law and the right to support the exercise of legal capacity will remain a major challenge. Moving in this direction, several steps need to be taken so as to address these multilevel structural and conceptual challenges. Could the use of ATs eliminate disabilities in the eyes of the law? Should people be permitted to retain their 'disabled' status after a functional 'elimination' of their disability under EU law? At what point would it be proper to consider a person no longer disabled, despite their history? Should mobility assistive devices be treated as part of the owner's body? If a device that permits its user to function at the same level as people who do not have histories of disability can be fairly considered part of the body, should that user no longer be considered disabled? How integrated into the body would that device need to be? Developments in the field of ATs are changing the way people with disabilities live, as well as how society thinks about disabilities. Additionally, several other challenges of legal nature still persist. Among them are those that relate to the lack of ratification of the Optional Protocol to the CRPD⁸ by the European Union and its failure to conduct a cross-cutting, comprehensive review of its legislation aimed at harmonising it with the Convention, and to the fact that no strategy on the implementation of the Convention across all its institutions exists. Moreover, the proposed European Accessibility Act has not yet been adopted by the EU (in fact the adoption of this act was an explicit recommendation of the UNCRPD Committee in 2015 but the legislative process has been subject to extensive delays, ongoing since 2011)⁹ and the current EU acquis has not been sufficiently assessed in respect of accessibility for persons with disabilities. At this stage, it is more than necessary for the EU to revise its disability strategy so as to align it with the implementation of the CRPD as well as with requirements for disability mainstreaming in the UN 2030 Agenda and Sustainable Development Goals. The principle of mainstreaming (including the intersection of gender mainstreaming) needs to be embedded in all EU policies and new monitoring tools and indicators need to be developed. The alignment of strategic priorities needs to maintain a balance between the comprehensive scope of the UNCRPD and the actual scope of EU competence.

Last but not least, all efforts to shape a human rights-driven EU approach might have to take into account the likelihood of accessibility features in mainstream products gradually setting aside special AT products, assistive technology products being dealt with as common consumer goods, purchased directly by users without the intermediation of service delivery systems, and the need to decide when a medical, a social, or a consumer model should be considered appropriate. A broader question that needs to be discussed is whether the EU legislator should start reflecting on the potential of the rules under discussion to reflect a social as opposed, or in addition, to a medical 'reading' of disability. A transition to a human-centred approach as well as a user-centred model for technology design and development could facilitate the proactive involvement of target users in the design and development process. Special attention should be paid to the impact of austerity measures upon the accessibility of ATs, which may in effect have an adverse impact on the situation of people with disabilities, and also to whether technological accommodations – despite their clear benefits – depart from the ideal of mainstreaming disability across all EU policies.

⁸ The <u>Optional Protocol</u> was adopted on 13 December 2006 during the 61st session of the General Assembly by resolution A/RES/61/106. In accordance with its Article 10, the Optional Protocol has been open for signature by all signatory States and regional integration organisations of the Convention on the Rights of Persons with Disabilities at United Nations Headquarters in New York since 30 March 2007.

⁹ Accessibility requirements for products and services, Legislative Observatory (OEIL), European Parliament.

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The ongoing introduction of assistive technologies to many areas of public and private life has triggered the need to assess the aptness of the EU legal framework to cope with the ethical and regulatory challenges they present.

This, the final part of the project, offers social, ethical and legal reflections on the role of current and future European Parliament initiatives in the context of trends in the field of assistive technologies. The analysis identifies various legal challenges that assistive technologies raise in the context of EU law, including the coordination of the various layers of competence, the lack of a commonly accepted definition, and the variety of risks posed for human rights, privacy, dignity, access to technology, freedom, and the social inclusion of people with disabilities.

In response, several policy options are discussed. These include securing accessibility as a human right, promoting privacy by design, improving the informed consent process and focusing on a user-centred model of technology design. They also include allowing freedom to choose whether or not to use assistive technologies, maintaining the availability of human care, developing appropriate ethics oversight structures, introducing a new classification system for assistive technologies, and making sure devices are safe to use.

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