

**Technology in Social Care** and Support Services A policy paper from the Person-centred **Technology** Membership **Forum of EASPD** 



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| Index  |
|--|
| Preface4   |
| Foreword5  |
| Executive summary 7  |
| 1. Introduction 8  |
| 2. Trends in society that impact the social services sector 10 |
| 3. Policy frameworks15   |
| 4.Technology shaping the services of the future 17             |
| 5. Barriers to change  |
| 6. Recommendations   |
| 7. Concluding remarks29  |
| References   |

Editors: Sharon Borg Schembri and Evert-Jan Hoogerwerf

**Contributing authors:** Thomas Bignal, Sharon Borg Schembri, Emmanuel Fragniere, Evert-Jan Hoogerwerf, Konstantina Leventi, Silvia Muñoz, Benjamin Nanchen, Yousra Sandabad.

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### **Preface**

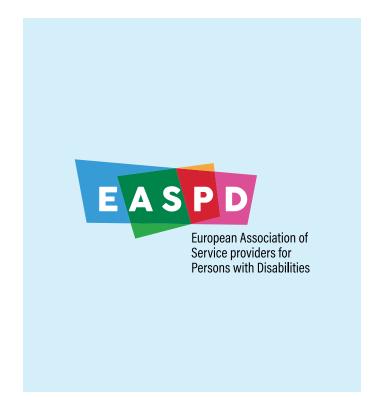
It is a truth that looking to the past, to history, can often help us look forward. Viewed through this perspective, the digital and technological revolution described in this paper is not unprecedented, nor are some of the challenges in coming to terms with it.

Readers may know of the Luddites. They were a clandestine, shadowy, loosely organised movement of English textile workers in the early 19th century. They feared that new machinery and methods of production in cotton and woollen mills would threaten their jobs so they tried to destroy these machines and stem the tide of industrial change. Their actions were futile. 'Luddite' has entered the English language as a noun to describe 'a person opposed to new technology or ways of working.'

Of course the parallel with the challenges we face today in riding the tide of digital and technological change is not perfect. Whilst many of us may have misgivings about how life is changing around us, there is no organised opposition to this new revolution. What stands out, too, is that the scale and transformative impact of the digital and technological revolution utterly dwarfs the mechanical innovations of the 19th century Industrial Revolution.

In the field of providing support to people with disabilities, there has not been any real opposition to embracing the digital and technological revolution in recent years, but just, well, an inertia. Much as newspapers have stood still, bemused as their business model and sales have been rapidly destroyed by the impact of web based news and information, we in social care and support have often sat passively, doing little to change our approach.

Thankfully, there have been exceptions. Some of our member organisations have been alert for several years to the challenges and opportunities that this revolution is creating, and have been changing their services. EASPD had Assistive Technology as the theme for the conference we held in Barcelona in 2018 and this year (2021) the theme for our 25th anniversary conference in Brussels is 'The future is now: Person Centred Technology to empower people and disability services.' We established the Person Centred Technology (PCT) Interest Group some years ago and very interestingly whilst for too long its members numbered no more than 4 or 5, as the Person Centred Technology Member Forum it now has 28 active members and a wider network of 39 followers. Also very importantly, colleague networks, like Association for the Advancement in Assistive Technology in Europe (AAATE) have been dedicated to drawing attention to the opportunities that PCT offer and providing assistance and support.



Yet we all have to do far, far more. This comprehensive and insightful policy report makes it very clear that a digital and technological revolution is happening all around us, and that the pace of change is accelerating rapidly. It expertly identifies the range of factors that are brewing to create a perfect storm. As we all know, the COVID pandemic was a powerful accelerant, forcing service providers to rethink how we support persons with disabilities, but many other factors are contributing.

What is critically important now, today, is that we embrace this revolution, recognise the great opportunities that it can give to empower persons with disabilities and to help us improve our services. We must also influence the direction of these huge changes, so that mainstream initiatives are designed from the beginning to benefit persons with disabilities and the services that support them.

I offer my sincere thanks to the authors of this expert policy report, who have given generously of their time and knowledge. I give special thanks to the members of the PCT Member Forum for initiating this work and to Evert-Jan Hoogerwerf and Sharon Borg Schembri who have coordinated the work leading to this report. I also thank our EASPD Project Officer, Magdalena Verseckas, who did so much to facilitate and support the work of the PCT Member Forum.

**James Crowe**President EASPD

### **Foreword**

There are over 100 million persons with disabilities in Europe. Many persons with disabilities live full and active lives in society, in part due to recent advances in social support and attitudes. For many others, however, empowerment and social inclusion is an uphill battle. Recent data shows that 28.4% of the EU population with disabilities is at risk of poverty or social exclusion, some 10 percentage points higher than those without a disability (Eurostat, 2021a). The employment situation is no better with only 50.8% of persons with disabilities of adult age employed (European Disability Forum, 2020), and children and adults with disabilities continue - in their thousands - to be excluded and/or segregated from mainstream education settings (Bertana, 2021). These statistics paint a rather bleak picture for many persons with disabilities across the continent. The situation of support services for persons with disabilities is no better, with the sector experiencing under-funding and staff shortages for over a decade.

There is a new hope: that digitalisation can revolutionise social inclusion; offering up new opportunities and solutions to employment, education and inclusive living for persons with disabilities, including through more effective and digitalised support services.

For instance, new digital technologies can help to reduce the barriers that some persons with disabilities face in coming to work; either by allowing people to work from home and still be digitally connected to the office or by facilitating the accessibility of the transport routes to and from the office. New technologies are also helping persons with disabilities to live independently through - for instance - new "support robots" or online platforms (Rosken, Crosby & Fuzesi, 2021). If developed in the right way, these technologies will mean that support services are only a simple click away; bringing persons with disabilities much closer to inclusive living and enjoying their human rights.

Technology will also transform how social care and support services are developed and implemented. Such technologies can for instance be beneficial for the professionals who support persons with disabilities on a day-to-day basis. For instance, through distance care apps, or electronic files to better manage workload and optimise work flows and processes. This means that we can create better jobs for the 11 million care and support workers in Europe (Turlan, 2019). It is no exaggeration to say that digitalisation can really revolutionise social inclusion. Yet, as the statistics show, we are still far from making this a reality for all. There is a clear digital divide for persons with disabilities and support workers. As tech enterprises, policy makers and other stakeholders move forward, they will need to consider how to make the digital transition inclusive for all.

Many questions remain to be solved:

- How will the digital revolution change the social care and support sector?
- What will services of the future look like, and how do we want them to look?
- How can we assure a full and beneficial alignment of the social care and support sector with the digital transformation process leaving no one behind?

This excellent policy report brings many initial answers to these questions and paints a picture on how we can – collectively – make the most of digitalisation to promote social inclusion; both for persons with disabilities and through tech-savvy support services.

The Future is Now: we need to take advantage of the opportunities it offers!

#### Luk Zelderloo

Secretary General EASPD



#### What are social care services?

Social services play an essential role in caring for and supporting all people who may need such help. For the purpose of this paper, social services should be understood as care and support services for people with disabilities of all ages and older people.

#### Social services can include (among others)

- > Employment and training services, such as supported employment, vocational education and training, sheltered workshops, etc.
- ➤ Education services, such as special schools for persons with disabilities, or specialised support in mainstream schools, etc.
- > Child care and early intervention services
- > Short, medium and long term care, such as independent living services, supported living, semiresidential care, residential care, respite care, day care, shelters, etc.
- Social housing
- Social assistance services

(Ref. Bignal, T & Vaughan, R. Investing in Social Care & Support A European Imperative. EASPD, 2017)



# **Executive summary**

This paper reflects on the impact of the ongoing digital transformation process in society on organisations providing social care and support services to people with disabilities and older people. It does so by recognising the empowering role of technology for persons with disabilities or functional difficulties. A major challenge is to understand what the support services of the future could look like and what different stakeholders can do to assure that the transformation process is increasingly an opportunity for service users and providers and not a pitfall.

The digital revolution must not be seen as an isolated phenomenon or trend. Its challenges interact with the challenges caused by other trends in society, such as demographic and social-economic trends, as well as the changing perception of disability, which must be analysed as well, to get the picture right of what, as a sector, we can expect or aim for.

The way services are provided to people with disabilities has been undergoing substantial change over the past decades. Many services are moving towards the human rights-based approach supported by the UN Convention on the Rights of Persons with Disabilities. This fundamental change brings to the core of service provision the needs and preferences of each individual and their self-determination. At the same time, the changes in the design and delivery of services are clearly yet to be fully accomplished, at policy and at practical level. This represents a challenge for the service provision of tomorrow as well as for policy makers at EU and national level. Important policy frameworks such as that provided by the UN Convention, by the European Disability Rights Strategy 2021-2030 and by the EU Digital Agenda, require further action at national and local level, typically the level at which support services operate.

Technological progress impacts in different ways on social care and support providing organisations. A distinction can be made between assistive technologies empowering the individual and which can boost their independence, and person-centred technologies allowing organisations and their staff to provide better services. The use of both technologies has to be fostered by using appropriate strategies for their adoption that take into account a wide range of factors and quality indicators such as interoperability, accessibility, usability, compatibility, cost-benefits, quality of life, quality of work, user acceptance or abandonment, etc.

Combining the trends in technological development, wider societal trends and the opportunities provided by technology, it is possible to imagine what the services of the future ideally should look like: personcentred, personalised, flexible, adaptive and resilient, digitally connected, integrated and interconnected, hybrid and co-produced.

To steer this process in the right direction and to create the services of the future that are respectful for the rights of the individual, empowering, effective and efficient, whilst valuing the role of staff, different barriers have to be overcome, at societal, community and personal level. This requires a holistic approach and a vision shared by all stakeholders that move in the same direction, although with different roles and responsibilities. Key-players in this process are policymakers, commissioners of services and care providers themselves. To help each stakeholder to understand its possible contribution to the development of the services of the future, recommendations are formulated and included in the paper.



#### 1. Introduction

The digital revolution is progressing rapidly and like any revolution it is impacting the way people perceive life and consequently their behaviour. The success of digital technologies is related to their enabling and enhancing power expressed at both individual and organisational level, with processes in all sectors being faster, more efficient and effective and, very often, also cheaper.

The key questions this policy paper aims to respond to are:

- ➤ How will the digital revolution change the social care and support sector?
- > What will services of the future look like, and how do we want them to function?
- > How can we assure a full and beneficial alignment of the social care and support sector with the digital transformation process leaving no one behind?

A major policy objective is to capture the benefits of technological development so as to strengthen social service providers to fulfil their mission. That is to empower and to support, where needed, people with disabilities and older people to have equal access to opportunities and to fully enjoy their human rights in an inclusive but rapidly developing society. Strengthening the sector is therefore important, as technological development can be an opportunity or a threat; it can broaden or reduce the gap between people, it can create exclusion or inclusion. Technological development that "leaves no one behind" could potentially lead to happier and fulfilled lives and more sustainable, safer and wealthier communities in which all members have a role and contributions are valued. The social service sector, just like the world of education, policymaking and research has a key role to play in making that vision true. All contributions are welcome in addressing these challenges and collaboration and coordination is needed between sectors and stakeholders.



#### A note on terminology

In preparing this paper the authors found different and sometimes overlapping definitions of "digitalisation", "digitisation" and "digital transformation".

Generally speaking...

"Digitisation" refers to the conversion of data to a digital format. It is a technical, often company internal, process.

"Digitalisation" refers to the transformation of a process, for example the way services are delivered. It is a deliberate process of change that involves organisations and their clients or service users.

"Digital transformation" is a broad term mainly used to refer to a process that is going on in society and that impacts on the lives of people.

The authors have tried to use these terms as coherently as possible throughout the text.

Persons with disabilities claiming independence over the last decades have significantly contributed to technological innovation. Where researchers with and without disabilities have studied together, solutions to overcome barriers and to foster accessibility, often innovative results have been obtained (e.g., speech recognition, eye gazing, the touch paradigm, brain-computer interaction, screen-reading software, etc.). The same process should be envisaged for the definition and production of the services of the future that should be empowering, accessible, personalised, and inclusive.

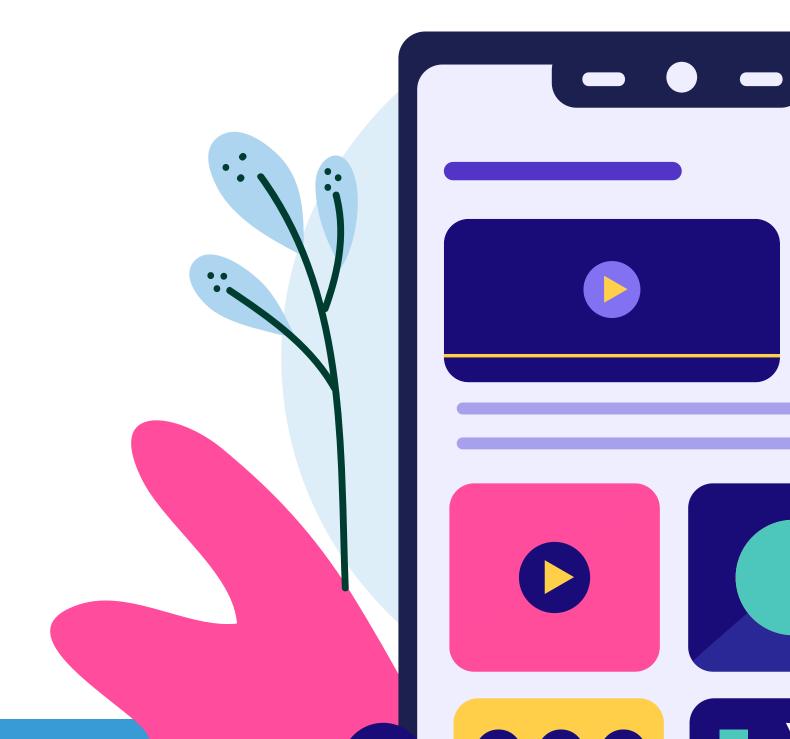
In this paper the authors make a distinction between technologies used by individuals to increase their independence and to undertake activities that without those technologies they could not do, so-called assistive technology, and then technologies proposed by care providers to better manage and deliver care and support in care ecosystems. Both can be considered **personcentred technology** if the core objective of their use is the empowerment of the person. Both uses are important for service providers who should be aware that technology

adoption processes might quite radically change the relationship between care and support receivers and providers.

Social care and support services are delivered in a changing context determined by societal mega trends such as demographic change, cultural, economic and technological developments. In Section 2 we will look at those trends and describe their (possible) impact on the sector. Section 3 deals with the most relevant policy frameworks in place at the moment: collective attempts to organise or direct change towards predetermined goals. Section 4 describes the impact of technology on the empowerment of people and organisations and how technology will help to shape the future of social care and support services. The

barriers to change are addressed in Section 5. The document concludes with recommendations for all stakeholders involved in technology uptake in the social care and support sector (Section 6). As all stakeholders should synergically work in driving the digital transformation in the right direction, the recommendations address each stakeholder directly.

"Digital transformation is the profound and accelerating transformation of business activities, processes, competencies and models to fully leverage the changes and opportunities of digital technologies and their impact across society in a strategic and prioritized way." (Demirkan, Spohrer & Welser, 2016)



### 2. Trends in society that impact the social services sector

Authors: Emmanuel Fragniere, Benjamin Nanchen, Silvia Muñoz

This section will look at megatrends that are impacting and projected to continue to influence the provision of social care and support services and what the service users expect from these social care services. Identifying these megatrends is important to inform thinking about the development of future social care services and related policies.

#### 2.1. Megatrends

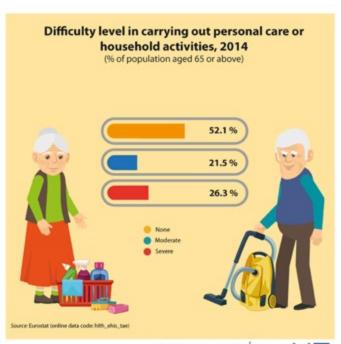
#### 2.1.1. Demographic changes

Europe is undergoing major demographic changes that will have an impact on its society and its economy.<sup>1</sup>

Less people forming increasingly multicultural societies. The European population continues to grow but it is expected to reach its peak, 447 million (EU-27), in 2025. Then, and for the first time in its history, it is expected to start decreasing due to a low birth rate. It takes 2.1 children per woman to maintain a population size stable, however in Europe, this rate is stagnating at around 1.5. According to many, Europe could therefore only grow through an active immigration policy, which is seen as a resource for Europe. Nevertheless, there are various challenges for the receiving societies. These include assuring access to services in case of language and cultural barriers. Digitalisation can support the provision of social care services in multiple formats and languages.

Living longer but with assistive technology and support. Eurostat predicts a European population of 424 million in 2070. Moreover, it is estimated that 30% of this European population will be aged 65 and over, compared to about 20% in 2021. For a large part, this is the result of improved healthcare. Most of the aged population will be active and healthy. However, almost half is expected to experience some kind of functional difficulty, most of the time leading to reduced mobility (Eurostat, 2020).

The increasing burden of informal care on increasingly smaller households (Eurostat, 2021b) will require significant

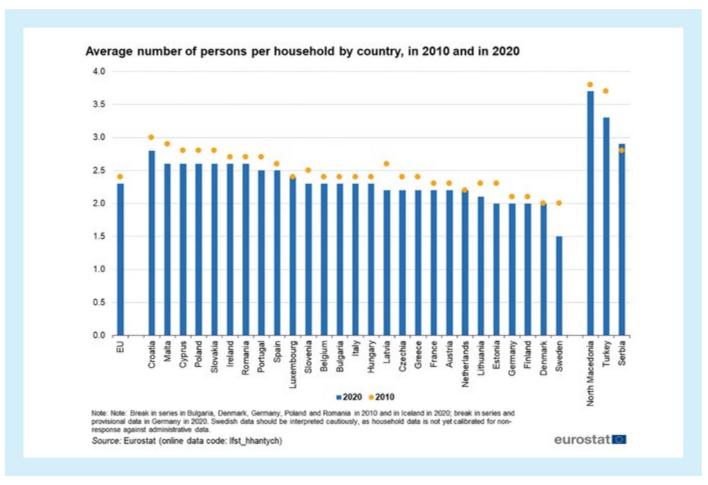


ec.europa.eu/eurostat

protection plans and additional investments in formal social care and support services that are accessible and sustainable, and which will improve the work-life balance of informal caregivers (Social Services Europe, 2018). The expectation is that the demand for assistive technology will increase, as well as the demand for remote health monitoring. Politicians, policymakers and social care services will feel pressure to ensure a high quality of life for everyone within the community, including formal and informal care providers.

<sup>&</sup>lt;sup>1</sup> Data for this section is taken from the Eurostat and the European Commission Report on the Impact of Demographic Change (https://ec.europa.eu/info/sites/default/files/demography\_report\_2020\_n.pdf)





Households are increasingly smaller in Europe, due to demographic and wider social phenomena.

Urbanisation and poverty show less obvious trends. Until recently people were increasingly living in cities. In 2019 in the EU-27, 21% of the population lived in rural areas, 40% in urban areas and 39% in intermediate areas. The pandemic, however, seems to have inverted this trend since several people returned to their home village and started working from home. Services (transport, banking, internet access, health, housing, education, etc.) are generally numerous and accessible in urban areas compared to rural areas. However, as we have seen during the pandemic, digitalisation of services might reduce this gap. According to Eurostat, 31 million people, or 7% of the EU population, live in a region with rapid demographic decline and low GDP per capita, which constitutes a double challenge.

#### 2.1.2. Social and economic megatrends

#### From "experience economy" to "convenience economy".

The service economy has been characterised over the last 30 years by the experience economy (Pine & Gilmore, 2011), with the consumption of products and services being influenced by the values attributed to them by consumers. Nowadays the convenience economy is rapidly gaining importance, with changing expectations from consumers. Due to their busy lives in urban areas consumers want

rapid retail solutions, that are of good quality and value for money and delivered where and when needed, with free or almost free home delivery. The reason for this change is part of the shift towards digitisation and automation which both enhance convenience. In fact, a lot of people find digital products and services very convenient to them and are very likely to opt for these services (Fromm, 2019). Therefore, social care services have to move with this trend, offering quality services when the service user requests it and within their community. The latter is very convenient for service users living in rural areas. Digitalisation of services is one way to improve the efficiency and accessibility of the services, and will allow service users to ask for help when issues arise. This is very true for Assistive Technology services, where technical issues are constant and need to be dealt with immediately. It is also worth keeping in mind that experience is sometimes lost at the expense of convenience. The use of Virtual Reality and hybrid services enable social services to be convenient and at the same time experiential.

#### Uberisation in the field of social care

Perhaps the most recognisable element to the economy of convenience is the explosion of online platforms (such as Uber, etc), replacing the more traditional ways of operating services. Such online platforms connect consumers with (often independent) professionals willing to perform such a service for a certain price. These online platforms are generally seen as more convenient for consumers as they can access services that are generally cheaper, more flexible and quicker than through traditional enterprises. Online Platforms are also developing their market share in the field of social care by connecting people with support needs with people willing to provide support work. This process means that such a rapport is only a click away, rather than traditionally going through a service provider. It is however important to note and reflect upon the criticisms of online platforms regarding quality assurance, long-term impact, profit-making and working conditions for workers.

#### Mary's urgent need for support

Mary has tetraplegia and her service provider assisted her to access a computer via the use of eye gaze technology. One day, the eye gaze stopped working and Mary's carer called the service provider to ask for their help. He highlighted the urgency of a solution as Mary is stranded without the eye gaze technology. This technology has opened a myriad of opportunities for Mary, including supporting her in her job. The staff understood the urgency and immediately connected to Mary's computer remotely to solve the problem, helping her to gain access to the computer again.

Millennials and Gen Z forces. The generation of millennials constitutes a large section of the workforce. Surveys report that they are much more connected and socially responsible than previous generations. They have technological intuition and a heightened awareness of the products and services they consume (DeVaney, 2015). It is important to understand that the millennials are the current driving force when it comes to service planning and digital innovation. However, in a decade's time Gen Z will be shaping the social and economical situation. Gen Z are digitally immersed and have been greatly impacted by the COVID-19 pandemic. This knowledge and experience will influence technological innovation that can assist in preventing crises, improving health and managing communicable diseases.

In the case of millennials and Gen Z, there is a risk of a generation gap in expectations regarding care. Most of the older generation naturally relies on the notion of family to take care of them. This reliance risks disappearing with the younger generations. Through the use of technology they are able to develop digitized services while also obtaining products and services in the comfort of their own home, thus fostering independence (Clark, 2009).

#### 2.1.3. Digitalisation - Digital trust and digital divide

Digital innovations change work environments, the qualifications that are needed to perform certain jobs, the way people are trained and educated, and it also impacts the way services are provided. Automation puts at risk a lot of jobs, including those performed by people with support needs, but it may also create new ones. This requires the development of training that addresses the digital skill needs of workers. Accordingly, digitalisation of care services may limit the significant job creation potential in the care sector. However, with 8 million new jobs expected to be created in the next decade (European Commission, 2021a), digital skills will be needed more than ever and new technologies can improve the attractiveness of jobs in the care sector (e.g. by improving working conditions).

Yet, the rapid digital transformation does not align well with the slow development of digital skills, leaving digitally illiterate people behind. This phenomenon of digital poverty is a major concern of our society and particularly affects people with disabilities, the elderly and illiterate people. In France, the digital divide appears to affect 23% of the population and 58% of people over seventy. Additionally, one in five young people in Europe lack basic digital skills (European Commission, 2021a). With the rise of eGovernment, people that are digitally illiterate will not be able to access these newly formed public services. Authorities should take this phenomenon into account in their public policies regarding digital transformation.



#### **Digital divide**

A service provider in Malta, who offers therapy and leisure services, interviewed 20 families of persons with disabilities. 12 of these families reported that their children do not use technology to support them in their daily lives due to a number of reasons. These include: financial limitations, severe disability affecting access, long waiting lists to access assessment services, have never tried technology or do not see the need for technology. 3 of these individuals are over the age of 25 years, 5 between the ages of 6-11 years and 4 between the ages of 2-5 years.

A foundation in Poland, involved in the management of projects concerning social inclusion through education and training, many of which are organised for people with disabilities, interviewed 20 of their customers whose ages range between 25 to 55 years old. 5 of these service users reported that they do not own or use a mobile phone. The mobile phone was rated as the most available technology amongst the other participants, who reported that it helps them to connect with their families and move around in their community.

The digital divide affects countries in Europe differently. In Utrecht (the Netherlands) and Övre Norrland (Sweden), 19 out of every 20 adults used the internet for banking in 2019. The share was less than 1 out of every 10 adults in the majority of Bulgarian and Romanian regions. The development of the required infrastructure to improve connectivity in rural areas is a challenge, as identified by the World Bank. To avoid the digital divide, efforts from different stakeholders should be taken as soon as possible (Van Deursen & Van Dijk, 2019).

The abundance of data (big data) leads to a more in-depth knowledge of consumers. This does not come without problems. Ethical aspects are involved, that are related to the notion of data ownership, data protection and privacy issues (e.g. the European GDPR law). It also requires improved cybersecurity preventive measures, to prevent personal data from being stolen for malicious use.

The storage of data and ensuring that the servers used are secure is an increasingly important issue that many citizens are aware of and concerned about. Many citizens might reject innovations due to their lack of trust in the digital processing of data.

#### Issues of digital trust

When 87 years old Clara was asked to participate in an innovative project deploying digital health solutions for remote monitoring of her vital parameters, she simply said "No". "You are very nice young girls", she said to the researchers, "just like my granddaughters, and I won't have difficulties giving you the key to my house. But I am not going to share my data with multinational companies that will make profit out of them."





# 2.2 Turning points and their impact on future services

Turning points are more or less disruptive events or rapidly evolving trends with high impact on the way we live, produce, consume. They help us to imagine possible future scenarios (Hillgren, Light & Strange, 2020). Climate change, the COVID-19 pandemic and digitalisation are to be considered turning points. The Conference on the Future of Europe has also listed core topics that will have an impact on the future, such as developments in health, community living, social justice, jobs, values, rights, rule of law and security, digital transformation, democracy, migration, education, culture, youth and sports. These themes have to be considered when imagining a more inclusive future world with better and easier lives for all.

#### 2.2.1. Climate change

Stopping climate change requires committed action. The vision of the European Union is to be climate neutral by 2050. If measures are taken, the shape of the social and economic relationships will radically change at international level. Public transport, technology, industry, energy, and construction sectors are pointed out as most affected by those changes. The vision includes the promotion of a circular economy, boosting biodiversity and protecting nature, an economic growth decoupled from resource use and, finally, that no person and no place is left behind. To foster social inclusion, principles of Universal Design must accompany public policies and innovation in domains related to climate neutrality.

Social services are closely connected to environmental challenges. On one hand the space and buildings needed to support people with care and support needs, their energy consumption, and emissions related to transportation, have a significant impact on the environment. In this domain, smart home/building technology and mobility management apps will allow for important energy savings. On the other hand, climate change influences the sector significantly due to the growing number of people in vulnerable situations and the increasing prevalence of weather-related incidents.

#### 2.2.2. Sustainable development

Service providers can act as a catalyst and trigger for people's personal involvement in collaborative projects linked to sustainable development. Essentially there are two co-production configurations: enabling services (active co-production) generating a high perception of value; and supporting services (passive co-production) generating a low perception of value. In future services the user might be increasingly involved in co-production and co-creation, which might lead to higher awareness of

the link between services and environmental impact. The megatrend of a convenience economy will also influence the users of services, and active co-production will be influenced by it, developing services with more involvement and consciousness of well-being and climate care (Brink & Wamsler, 2018).

#### 2.2.3. The pandemic

The coronavirus pandemic has made it evident that joint action is necessary to protect people's health and that more coordination and preparation for future crises are necessary. The pandemic also highlighted how essential care services are to society, as well as the structural weaknesses the sector is experiencing (underfunding, staff shortages, etc). The goal is to be protected with high-quality care in the event of a crisis, and receive the tools needed to prevent and manage health emergencies. The increased funding for innovation and research in the health sector, proposed after the COVID crisis, will very likely boost technology uptake in preventive care interventions. Healthier and longer lives are expected, at least in developed countries. The focus on preventive care should provoke changes in people's lifestyles and relationships. Furthermore, this focus might lead to new industry developments. Again, accessibility and social inclusion must be the "standard" in these domains and not merely be "nice to have".

#### 2.2.4. A new Europe

Europe is facing a crisis concerning some of its fundamental values, such as solidarity, respect for diversity and inclusion. For a unified Europe not to end only as a dream, the vision for the economy should be built on a more inclusive and fair model, leaving no one behind (including people with disabilities), boosting jobs, growth, and investment from governments in order to reduce poverty and inequality. Social justice must be driven by the Human Rights approach, preventing the violation of rights and abuses globally. High participation and involvement should be on the rise, to ensure healthy democracies. Decision making and policy development must be part of these developments, and technology can be a tool to boost participation. To take up these challenges, accessibility and social inclusion must be the "standard". Furthermore, steps need to be taken to win the support of young people for these developments and to educate them to safeguard the cultural heritage, diversity, innovation so that citizens can participate fully in all areas of society.



### 3. Policy frameworks

#### 3.1. Introduction

Policy frameworks should support the reform of existing systems to ensure their effectiveness in responding to future needs and challenges. As we live in an era of digitalisation, policy frameworks should help to achieve sustainable change leaving no one behind. This requires taking into account the special needs, wishes and challenges of persons with disabilities and older people and of the social care sector that supports them in reaching life goals important to them, aided by technology.

Policy frameworks exist and are relevant at all levels: international, national and regional. Because of the international focus of this paper, we will present the major international frameworks relevant for the scope of this paper. Very often these international frameworks have equivalents or complements at national and sometimes even regional level. Within the scope of this paper it has not been possible to provide an overview of all these frameworks, but readers are invited to reflect on how the main international policy frameworks are transposed into their national or regional policies and the impact of these policies on the lives of people and organisations.

#### 3.2. International policy frameworks

# A: The UN Convention on the Rights of Persons with Disabilities <sup>2</sup> :a guide for inclusion

Main articles of the UN Convention on the Rights of Persons with Disabilities related to assistive technology, accessibility and universal design: Article 3. General principles, Art. 9. Accessibility, Art. 19. Living independently and being included in the community, Art. 24. Education, Art. 27. Work and employment.

The UN Convention on the Rights of Persons with Disabilities introduces a holistic and integrated human rights approach to address barriers faced by persons with disabilities. It does not introduce new rights, but highlights how to apply in practice existing human rights to all persons with disabilities. The CRPD calls for the removal of all socially constructed barriers which are the main cause of the social exclusion of persons with disabilities.

One of the main barriers to human rights enjoyment for persons with disabilities is the issue of accessibility. Digitalisation has the power to increase accessibility of a number of products and services for persons with disabilities across their life; be -for instance- it to live independently, to gain employment or to be in education. Equally possible is that digitalisation creates new barriers for persons with disabilities if the digital products & services that are developed are not accessible. For this reason the Convention highlights, beside accessibility, the importance of Universal Design, Accessibility and access to Assistive Technology.

**Universal design:** the design of products, environments, and services usable by all people, to the greatest extent possible, without the need for adaptation or specialized design.

**Reasonable accommodation:** making necessary and appropriate modifications and adjustments so that persons with disabilities can enjoy and exercise on an equal basis with others all human rights and fundamental freedoms.

**Assistive Technology:** any product or technology-based service, specifically designed to enable individuals with disabilities to participate equally in any aspect of life.

# B: The Strategy of the rights of persons with disabilities 2021-2030 <sup>3</sup>

As a signatory of the UN Convention, the European Union must develop its own integrated Strategy on how it will help to implement the UN CRPD within the European Union. For this reason, the European Commission launched the Strategy on the Rights of persons with Disabilities 2021-2030. It includes the following initiatives:

- > The AccessibleEU flagship initiative will launch a European resource centre bringing together representatives from national authorities, experts, and professionals to increase coherence in accessibility policies and facilitate access to relevant knowledge.
- ➤ New Guidance on independent living and inclusion in the community will provide recommendations to Member States to enable persons with disabilities to live in accessible,
- > supported housing in the community or to continue living at home. This will also be followed by a European Framework for social services of excellence for persons with disabilities.
- > Inclusive and accessible VET programmes and targets to further support the participation of adults with disabilities in learning.
- ➤ A package of initiatives to strengthen labour market outcomes for persons with disabilities.
- A blueprint for sectoral cooperation on skills, under the Pact for Skill is intended to 'lead the way' in identifying digital skills needs within the social economy sector and applying assistive technology for better employability.
- ➤ Other relevant initiatives that focus on human-centric and user-friendly digital public services across Europe include:
- > the evaluation of the Web Accessibility Directive;
- > increasing accessibility on transportation, mobility, and movement of persons with disabilities and other groups;
- → the European Disability Card initiative which is intended to further promote labour mobility and service provision for persons with disabilities across the EU.
- > The Commission says that it will lead by example. Examples highlighted include adoption of an Action Plan on web accessibility and work to improve accessibility across its audiovisual communications and graphic design as well as in its offices and other buildings.

All these initiatives are required to facilitate the use of digital technologies as a way to help persons with disabilities access their rights.

#### C: The EU's Digital Strategy 4

The European Union also has its own European Digital Strategy which aims to make the digital transformation work for people and businesses. This includes persons with disabilities.

It includes actions in the fields of

- > Artificial Intelligence
- > European Data Strategy
- > European Industrial Strategy
- > High performing computing
- > Digital Markets Act
- > Digital Services Act
- > Cybersecurity
- > Digital Skills
- > Connectivity
- > European Digital Identity

All of these initiatives will require measures to ensure that persons with disabilities also benefit from the digital transformation taking place in Europe.

An example is the **Digital Education Action Plan 2021-2027** which will ensure that Member States are supported in securing assistive technologies and in providing accessible digital learning environments and content. This plan focuses both on fostering the development of a high-performing digital education ecosystem; and enhancing digital skills and competences for the digital transformation.

#### **EU Legislative Instruments**

- European Accessibility Act: requirements to ensure the accessibility of mainstream digital services and products for persons with disabilieties
- **Web accessibility Directive:** requirements for public bodies to make websites ant mobile applications or communications more accessible.
- European Electronic Communications Code: covers telecommunication services (e.g. internet connection, European emergency number 112, public warnings, etc) and includes obligations for good quality, affordability, public availability, and accessibility of services
- European Standard on Accessible ICT Services: requirements to make ITC products and services, such as websites and applications, accessible.

Accessibility is also at the forefront of the EU's digital strategy in the following legislation:

Last but not least, to help the implementation of the EU's Digital Strategy, the European Disability Rights Strategy and the UN CRPD, the European Union also has several funding programmes:

- ➤ The Recovery and Resilience Facility is made up of approximately €672.5 billion worth of investment for Member States with more than 50% earmarked for modernisation (including digitalisation)
- ➤ The European Social Fund + with €99.3 billion (in current prices) worth of investment including in the field of digitalisation
- ➤ The European Regional Development Fund with €226 billion (in current prices) worth of investment including in the field of digitalisation
- ➤ The Digital Europe programme, with €7.5 billion directly focused on bringing technology to businesses, citizens and public administrations.

All these programmes and policies can - in their own way provide opportunities to invest in accessible, useful digital products and services that will help to implement the UN CRPD and the EU Strategy on the Rights of Persons with Disabilities.

#### 3.3. From policy to practice

Both politicians and policymakers have an important responsibility in converting high level policy objectives into reality. To achieve this, appropriate legislation needs to be complemented by the development of standards, guidelines, recommendations, and procedures.

Often this will have to happen at national, regional or local level and will involve different levels of decision making. Different policy sectors might be involved, such as education, health, social inclusion, employment, culture, sports, public finances, ICT infrastructure, etc. Very often the agencies responsible for policy work rather independently one from each other, or act at different administrative levels. What most countries have in common is that persons with disabilities need to engage with different agencies to see their rights for full participation being fulfilled. For example, funding for assistive technology in education might be decided at national level by the Ministry of Education, while adaptation of the classroom might be the task of the local authorities. Especially where interventions with technology need to be coordinated between different agencies, important delays can occur, leading to frustration and the non-optimal use of resources. Such barriers, and others, will be addressed in Section 5 of this document.



 $<sup>{\</sup>tt 2.www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html}$ 

<sup>3</sup> www.ec.europa.eu/commission/presscorner/detail/en/ip\_21\_810

<sup>4</sup> www.digital-strategy.ec.europa.eu/en

### 4. Technology shaping the services of the future

# 4.1. The changing role of service providers supporting persons with disabilities

It is difficult to reflect on the way technology will shape the future of services without considering wider changes in the way services are developed and delivered. The way service providers have perceived and interpreted their role in time is subject to change. Drivers for change have been different in nature, and most of the time connected to wider political and societal beliefs and developments.

For many ages the way people with disabilities have been treated and the attitude towards disability, has been marked by societal fears, prejudice, and ignorance (Marini, 2017). After the Second World War, in most European countries these perceptions started to change. Initially, organisations of parents claiming services for their children, and later the disabled people's rights movement and the independent living movement, driven by persons with disabilities themselves, changed the way disability is perceived. The adoption by the World Health Organization of the International Classification of Functioning and Disability in 2001 and then the adoption of the UN Convention on the Rights of Persons with Disabilities in 2006, have opened up the eyes of many service providers. The Convention marks an important milestone for persons with disabilities and the disability rights community. Persons with Disabilities are no longer seen as passive recipients of services but as subjects with rights, who should be supported, if needed, to make decisions, and in contributing and participating equally in society.

As a result, the traditional medical approach to disability and paternalistic attitudes towards people with disabilities have been challenged. Although rejection and traditional stigmatic and discriminatory attitudes towards people with disabilities survive in the personal culture of a significant part of the population, most organisations supporting people with disabilities in Europe are aware of the rights of persons with disabilities to be respected and fully included in society and advocate for a change in the way services are designed, planned, and delivered.

Goal setting in supporting services has become a personcentred and shared process, involving the person, their family and professionals. It is also broader in scope with a long-term perspective. Services are "co-designed" and "co-created" with deinstitutionalisation as an important driver of change. De-institutionalisation plans are thus being introduced to facilitate the transition from large residential institutions to services based in the community. For all of these to become a reality we need a systemic change, a change not only in the way services are provided but also in the way

# Authors: Evert-Jan Hoogerwerf and Sharon Borg Schembri

services are developed and funded. Care has evolved over the last 60 years from "making sure the person is safe in a protected environment" to enabling people to live their lives as much as possible as anyone else, with the same rights and opportunities.

This latter development has three important implications: 1) the person supported has to be seen in a broader bio-psycho-social-tech perspective with resources and constraints in each domain and empowerment as the goal; 2) removing barriers in the physical, institutional and cultural environment is fully part of the care function; 3) the unique relationship between care receiver and care provider has evolved to a caring ecosystem based on a network of different people and organisations with different roles enabling an individual or a family to live like anyone else. This requires all actors in the ecosystem to engage in responsible collaboration, coordination and communication. It further requires the flexibility to change the types and amount of care and support when needed and asked for and to scale it up or down, based on the evolving needs of the enabled person. No care should be delivered if there is no need, and no support should be provided when a person feels confident to do things independently. In all these processes technology is providing unique opportunities.

Services should be provided to the individual with disabilities following person-centred principles, where each person is recognised as an individual with needs, wishes and preferences. This indicates a shift from a medical approach, where the individual is perceived as an object of charity and protection, to a more social human-rights approach, where the individual is an integral part of the planning of the services they will receive and the way they will be helped.

#### Mark, as a service user is a member of the AAC team

Mark, a 22-year-old with athetoid Cerebral Palsy is nonverbal and wishes to use an AAC device to be able to communicate his ideas. He does prefer to use his hands to access the device and makes sure he communicates this to the team he is working with. The team took this wish into consideration and provided different technologies so that Mark could try to use the device with his hands. Mark together with the other members of the team concluded that accessing the AAC device with his hands is hard work and thus Mark decided to try the suggestion of one of the members; that of trying a head pointer.

Co-production in policy planning and service delivery is a way forward. This is an inclusive working practice between experts by experience (users), organisations offering support, public authorities and, if relevant, families and other stakeholders. All these people are working together with the ultimate goal to deliver a service, policy or activity that is responsive to the individual's needs and preferences in line with the 'nothing about us, without us' principle and the UN Convention of the Rights of Persons with Disabilities. This practice puts the person with care and support needs in the driver's seat where the person is meaningfully and in an ongoing manner involved at all stages in the design,

Technology, because of its enabling and empowering nature, is an important ally in supporting personcentred and codesigned scenario's.

development, and delivery of the relevant service. This indicates that people should be supported in an empowering way, which requires ongoing training and retraining of the staff working in these services.

# **4.2.** Person-centred technology and the role of service providers

Technology is rapidly changing the way people live. The digital revolution is progressing and shaping the future faster than ever. The impact of technological development in areas such as artificial intelligence, the internet of things, big data, 5G connections, GPS, augmented reality, brain-computer interaction, just to name a few, is already apparent in applications such as self-driving cars, intelligent information systems, obstacle detection, object recognition, humanmachine interaction techniques (e.g. touch, movement, speech, gaze, thought), home automation appliances, rehabilitation techniques, training software, etc. Many of these technologies will be mainstreamed in our home appliances, our learning and working tools and environments, and in our social and free time activities. For those that can cope with these developments and that have the flexibility to change their lifestyles, life will be easier in terms of physical and mental stress. For others it will be exactly the opposite (Harrison & Luccassen, 2019). The issue is therefore not to be "in favour" or "against" the use of technology in social services, but to ensure that technology adoption creates added value for the individual and the organisation and that it is sustainable and smoothly integrated in recognisable human controlled and supervised processes and environments.

It is difficult to distinguish between different categories of person-centred technology that are relevant for persons with disabilities and service providers. The distinction between categories is often blurred. Nevertheless we make an attempt to highlight issues that require attention from service providers.

#### 4.2.1. Assistive technology for individual use

Assistive Technology (AT) is a broad umbrella term that embraces technology based assistive solutions (low- and high-tech hardware, software and services) for the individual, but whose use brings benefits also to his or her environment. Examples of products and their add-ons include, for those designed to support mobility e.g. (powered) wheelchairs, walking aids, car adaptations, white canes, seeing e.g., glasses and magnifiers, screen readers, braille keyboards, etc., hearing e.g., acoustic aids, visual and tactile feedback, etc., communication e.g., smartphones and their apps, communication devices, AAC systems, etc., independent living e.g. smart home applications, environmental control systems, etc., and cognition e.g., memory aids, pill dispensers, localisation apps, etc.

Assistive technology can come in the form of mainstream products with accessibility features e.g., PCs, smartphones, tablets, home automation systems, etc. or products and services especially designed for persons with disabilities e.g. special input devices, communication boards, wheelchairs, screen readers, remote sign language translation services, etc.. As a strategy, using technology for enhancing human potential, is as old as the stone age and it is typical for human beings to improve their quality of life by using aids or tools. Due to permanent or temporary health conditions, everyday functions can be challenged and consequently people might experience limitations in activities and restrictions in participation. Like all technology-based solutions that make our lives easier, for persons with disabilities, assistive technology can help to bridge that gap between personal limitations and environmental restrictions.

Access to AT is considered by the international community as a human right.

#### The right assistive technology

Supporting a person in identifying the right assistive technology (the mix between mainstream and specially designed hard- and software, products and services), is not an easy task, as it requires the assessment of many factors, such as the wishes and preferences of the person, the goals and expectations, the functional difficulties of the person and the environmental constraints, the setting of intended use, the availability and accessibility of products and support services, the available funding, etc. Some service providers operate Assistive Technology Centres where people looking for tailor-made solutions can receive assistance.

The use of assistive technology is not limited to a restricted group of people with life-long or permanent disabilities. While ageing, most people will find benefits from using assistive technologies. This includes persons with non-communicable diseases or mental conditions such as dementia, who might also use assistive products and services. Furthermore, those affected temporarily by limitations in functioning due to trauma may also make use of these products and services. Basically, nobody can do without assistive technologies, sooner or later in life.

Service providers have an important responsibility in making sure that the people they support have access to the most appropriate assistive technology for their independence, activities, participation, for making choices and to express consent or dissent.

#### AT supports return to work after trauma

James is a 36-year-old man who loves his job as an architect. He loved designing new buildings using ACAD software, until one morning when he was involved in an accident during one of his site visits. He fell from some distance and had a spinal cord injury. He lost some hand function to the point that he could not use the standard mouse to continue to design and so he inquired about alternative mouse control. He found out that with the use of a trackball with panning features he could return to work.

#### AT enables independence and well-being

Giovanna has recently been diagnosed with dementia. Her son was concerned that she was forgetting to take her pills at the correct time and thus he advised her mother to discuss this with her occupational therapist. The occupational therapist suggested that she uses an electronic pill dispenser that reminds her to take her pills with an alarm and visual marks indicating which slot to open.



### **Understanding Assistive Technology**

Over the years many other different definitions or conceptualisations of assistive technology have been produced. Some focus on categories of products and services, others on the capacity of the technology to compensate for impairments, others again on the impact on the user and their participation in all realms of life. In whatever way we define assistive technology, some fundamental concepts are key to understanding assistive technology.

**Assistive technology is enabling technology.** It maintains or increases people's independence and self-determination. It has the force to unlock human potential, to empower people, to allow for choice and control over one's life, to boost self-esteem and dignity, to maintain or increase wellbeing and quality of life.

Assistive technology brings radical change. Once Assistive Technology is adopted the perception of life and what is possible will change and new goals will emerge. This effect is relevant for the individual user, their families, their communities, and societies as a whole. All involved should be open to address the new goals, especially when these lead to new areas of independence. This might involve the development of a strategy or a plan for further personal development and participation in different areas of life. In the development of such plans, the person should be at the centre, as much as possible driving the process, with the support of assistive technology experts and other professionals.

Assistive technology is constantly innovating. Although some assistive products are relatively unaffected by technological progress (e.g., walking sticks) others have been outdated by innovation or even substituted by new paradigms in human-machine and human-environment interaction. Being a field of technology, assistive technology benefits from, adapts to, sometimes even drives innovation. Eye gaze technology, brain-computer interaction, voice-input techniques, text messaging, have all been influenced by research involving persons with disabilities wanting to find new solutions to overcome disabling barriers. This is an on-going process.

#### 4.2.2. Accessible mainstream technology

Accessibility is a broad term that refers to the usability by people in different conditions of products, environments, and services. If designed according to Universal Design principles, many products, environments, and services would have significantly less intrinsic barriers and be accessible for people with disabilities. To a certain extent, this would also reduce the need for assistive technologies. Mainstreaming accessibility in our thinking about environments and services and in the acquisition of products, is a cultural and moral obligation for all, nowadays. Accessibility is about the whole of life, and the whole person. In addition, the economic added value of implementing accessibility right from the start compared to retrofitting or making special adaptations, is evident.

When it comes to the digital world, accessibility can be defined as all individuals being able to use Information Communication Technology (ICT) systems, hardware, software and tools, perform services and understand content. All printed and digital information should as far as possible be made accessible. This starts with using simple language (e.g. easy to read, plain language), but includes multimedia communication (text, images, subtitles, signlanguage interpretation, multilingual, etc.), accessible digital content (e.g. websites, documents, information kiosks, cash dispensers, smart tv's, etc.). Service providers to persons with disabilities have a leadership role to play in making society more inclusive for all. Support services should be accessible, affordable, adaptable, and available to ensure they fully incorporate the human rights approach.

#### The ENTELIS network

Accessibility has been on the agenda for more than four decades but still it is not properly integrated into the education of caregivers, managers, administrators, educators and policy makers in the disability domain. Promoting and facilitating digital accessibility is the aim of the ENTELIS' network. Members share expertise and experience, develop and implement innovative methods and practices to foster inclusive education and promote common values, as well as enhance the digital skills and competences of digitally excluded groups, particularly persons with disabilities of all ages, through strategic public and private partnerships (e.g. ENTELIS+ project).



#### 4.2.3. Technology in person-centred care and support

Technological development has provided care and support providing organisations with opportunities to develop new ways of delivering their services and for their service users to benefit from them. In particular the large-scale diffusion of Internet connectivity and the possibility to connect devices that gather independently (without human intervention) data as part of wider interrelated networks, the so-called "Internet of Things", have opened up different possibilities in the areas of communication, counselling, data acquisition and elaboration, remote monitoring and support, etc.

#### Internet connectivity increased independence for Esther and Ron

Esther and Ron have managed to realise their dream of living together as a couple. The circumstances were not favourable, as their parents had strong concerns about the feasibility of their plans. But both Esther and Ron were convinced that with some support they could manage, and they talked about their plans with the organisation that had been supporting them for years. Advice was sought in the local assistive technology centre. After visiting the apartment and meeting the persons involved, the team recommended installing some environmental safety sensors (gas, smoke, flood alarms and video entrance control based on face recognition) and a communication app to retrieve relevant information and to stay connected with the organisation's service centre for remote support in case of need.

It is not difficult to imagine a care ecosystem where all actors are connected, share data and coordinate activities, while interventions are only planned and delivered where and when needed. Wearable sensors, sensors installed in the environment and active data entry by care receivers and providers produce a wealth of data that provide in real time a more complete picture of the situation and its development. Data travels fast and algorithms based on big data processing and artificial intelligence can fulfil important roles in filtering information, raising an alarm, predicting future developments, and elaborating best-choice scenarios. The same communication channels can be used to send reminders, provide information, propose exercises, and connect people with a community.

From the point of view of service users there are important benefits to gain, especially in the areas of independence and self-management, safety, determination of one's own care and support plan, and social connectedness.

#### **Remote monitoring care solutions**

Magdalena, who is in her fifties, lives in a residential setting with other persons with disabilities where she is supported by care workers for her daily living activities. Recently her father has developed a chronic illness that requires him to reduce his activities and keep his vital parameters under control. As a consequence, he can't visit Magdalena as often as before. She is seriously worried for him and would like to help him to adopt an adequate lifestyle and diet. Thanks to a project funded by the local health authorities, Magdalena and her father are equipped with a remote care solution. On her tablet Magdalena can now see how her father is doing, his daily physical activity and vital parameters. They remain in contact through video calls, provided on the same platform.

From the point of view of staff, this might open new areas of professional development, new job opportunities and, if implemented appropriately, better working conditions and more teamwork.

From the point of view of the social service provider, the benefits mainly relate to efficiency and quality of service provision, although, due to the difficulties in technology adoption many organisations refrain from taking this step into the future.

#### 4.2.4. Remote interpersonal communication

The recent COVID-19 pandemic has forced many social service providers to rapidly move their services online. This has involved coping with difficulties and it has required making adaptations to traditional models of interventions in face-to-face mode. The difficulties were mostly related to the absence of tools and strategies, but also to the lack of the necessary digital skills among service users and staff.

What has worked best is interpersonal communication. Many people had experience with mobile devices and PC's and social media applications such as Facebook, Instagram and Whats'App. The step to video conferencing platforms was therefore not too big to make. Nevertheless, many users of day care centres or students with disabilities were left unsupported and were further isolated from the community during this emergency transition to digital ways of support and education. Although the hope for many is to return to normal, it is difficult to imagine that the use of digital tools for remote interpersonal communication in social services will disappear. The advantages are simply too big and for many it perfectly fits a new lifestyle based on the smooth integration between "remote" and "in presence" modalities for learning, work, supporting and socialising. Digital communication tools and media can support people with disabilities to build or join networks of peers, bringing them closer.

# Digital tools support interpersonal communication

Service users with cognitive difficulties who were supported to install an online meeting application by the staff of a foundation in Poland, made it clear that by being able to talk and share their difficulties in this way, they did not feel lonely, and their stress levels were significantly reduced. Additionally, a 53-year-old man with intellectual disability stated that the pandemic has forced him to obtain and learn to use a mobile phone and this has improved his life. He uses it for cooking channels, to listen to music and to text his assistant.

#### Service development: introducing telehealth

The staff of an assistive technology assessment service in Malta had to solve the problem of how to continue to support their service users at the start of the COVID-19 pandemic. No policies were available to guide how services could be provided online whilst ensuring the team continues to offer a good quality service that also protects the client's privacy. The staff took the initiative to take online courses and research other countries who had been offering telehealth prior to the pandemic. Protocols were written and users were assisted to download the required software to be able to participate in the online sessions.

Those service users who did not own or could not afford to buy a computer, smartphone or tablet or lacked digital skills were the most affected as they could not be assisted during the lockdown periods.



#### 4.3. Services of the future

The pervasiveness of the digital revolution leaves no doubt that the social care and support sector will also be increasingly influenced by it (Deloitte Centre for Health Solutions, 2015).

Part of these changes will come automatically and will be driven by mainstream developments in society, almost without people noticing or perceiving the sector specific change. Novelty will be embraced and smoothly integrated in the daily practice of all, as has happened with smart phones and global positioning systems. However, a major concern will be the level of inclusiveness driven by innovation. For example, the introduction of new technologies and services might reduce or increase barriers for certain people who have difficulties in touching, seeing, hearing, dragging, speaking, or understanding. The social care sector has a role to play in making sure that innovations are evolving towards inclusion leaving no one behind. At all costs we should avoid that technology adoption in the sector leads to the dehumanisation of care (Allwood, 2017; Baily, 2011).

Indeed, part of this can be determined by ourselves and by our organisations. The adoption of technology should not be an aim in itself but based on a careful assessment of factors that have to be considered in different stages of the adoption process. For example, in the phase of conceptualisation of a solution, not only the problems or needs of the individual or the service provider will have to be considered, but also the opportunities provided by technology to further enhance lives and services. What is essential is that the values at the basis of the social care and support sector are not affected and that these values provide guidance to assess the impact of technology driven innovation. These values include individuality, rights, choice, privacy, independence, dignity, respect, partnership, self-determination, participation, inclusion, equal opportunities, respect for diversity, and confidentiality. 5

Based on the above, we can define key features of the support services of the future.

| Feature   | Description   |
|---|---|
| Person-centred                                      | Services should be person centred, supporting the individual to overcome all barriers that restrict his or her right to live like anyone else.  |
| Personalised  | Because all persons have the same rights but live different lives, support services by default should be personalised and tailored to the individual needs of a person.   |
| Flexible,<br>adaptive and<br>resilient              | People change and also the external conditions are subject to change. For that reason it is important that services are constantly reviewed, adapted and if needed, renegotiated. Allowing for flexibility in service design, will make services more resilient and useful for the person supported.                |
| Digitally con-<br>nected                            | Services will increasingly be digitally connected, sharing in real time data among professionals and service users. Large amounts of data will be collected through sensors and IoT devices, elaborated and shared with those authorised to see them.   |
| Integrated and interconnected                       | Artificial intelligence, big data management and better communication among professionals and with service users will allow for more integrated services, able to respond in real time to requests for information or intervention and will allow the services to better and more rapidly cope with changing needs. |
| Connecting dif-<br>ferent levels of<br>intervention | Services will provide data for analysis at different levels in order to better define individual support, but also community development and regional or national data of use to the health and social care system for planning and prevention.   |
| Hybrid  | Hybrid services are services that integrate human intervention with technology-based interventions in a smooth and effective way, without reducing the perceived quality of care.   |
| Co-produced   | Care providers and service users will collaborate in defining the main characteristic of the services. They will agree what personal data will be shared, in the best possible interest of all and how users will be protected from abuse and their privacy protected.  |

<sup>5 -</sup> European Care Certificate. (2021, September 27). retrieved frpm ww.eccertificate.eu.

### 5. Barriers to change

Authors: Sharon Borg Schembri and Evert-Jan Hoogerwerf

#### 5.1. Introduction

The participation of persons with disabilities in all realms of life and society has gained significant importance within disability policy and it was emphasized by the publication of the UN Convention and its emphasis on a rights-based model. The UN Convention stresses that persons with disabilities have the right to "effective participation and inclusion in society" (UN, 2011).

Societal participation can be defined as the participation of persons in the public sphere and this spans across social and cultural participation to economic and political participation (Pietilä et al., 2021). It involves having access and being included in community settings such as schools, sport clubs, local events.

The digital revolution has affected the way participation is expressed in many areas of life. Doing things differently, or simply, "change", hides huge opportunities, but also risks. Society as a whole, but also, or maybe especially service providers, should make sure that persons with disabilities not only do not remain behind, but capture the opportunity to foster their participation through the widespread and intelligent use of enabling technologies. Everything must be done to make sure this "historic" opportunity is not lost (Hoogerwerf et al, 2016).

For that reason, the barriers to change have to be addressed with increasing determination.

In the following paragraphs the existing barriers at societal, community and individual level that require attention will be discussed and suggestions on how these may be addressed will be presented.

#### 5.2. Societal level

The main barrier at political level is the lack of enforcement among European Union Member States of existing E.U. laws and regulations guiding accessibility of products, internet and services for persons with disabilities. There is reluctance on the part of European countries to create implementation mechanisms such as the procurement of (innovative) assistive technology from government funded schemes. The latter is becoming even more urgent to meet the UNCRPD Convention that accentuates the provision of AT for all. Adding to this is the uninformed prejudice that the costs of AT outweighs the benefits and thus real commitment to provide ICT-AT has not been realised in many of the European Member States. Research has demonstrated

that investing in AT has a transformative impact on people's wellbeing and makes financial sense for funders and governments (Blauwet et al., 2020).

Public procurement rules need to be modified to ensure ICT accessibility in public services as well as to ensure the provision of AT in education. It is also important to facilitate the employment of persons with disabilities within public services. Accessibility criteria should be included in government purchasing policies. Laws and policies on inclusive education and employment should include the use of accessible ICTs and ICT-AT as reasonable accommodations to eliminate barriers and thus facilitate participation for students and employees with disabilities.

Availability and access to ICT-AT is also affected by lack of available funds to purchase the necessary resources including devices, assessment and support services and training for persons with disabilities and professionals. Current estimates indicate that only 5% -15% of the global population has access to AT (Pietilä et al.,2021) . This is resulting in a financial burden for families and individuals who will end up looking for funds or relying on charity, thus encouraging charity-based models rather than human rights-based models. Other issues at the national level include the limited accessibility of applications in the national language. Also, 90% of those who require AT do not have access to it (WHO, 2020).

Another barrier is the **unavailability of specific devices** in some local markets. Thus persons with disabilities have to purchase equipment from other countries with less pre- and post-sales services and higher risks of buying the wrong technology. Moreover, ICT-AT equipment is not protected by a fixed price across all European countries and thus providers may double the cost of the equipment since the market is small and the conditions regarding tax and other duties are not very transparent.

A further aspect that needs to be tackled is the level of accessibility and usability of future ICT-AT systems. At the moment we lack mainstream technology that is designed for all people, using universal design principles. Lack of interoperability between technologies is a continuous issue. E-accessibility is also not fully implemented in some of the countries although the Web Accessibility Act stated that public websites should be made accessible by the end of 2015. The latter affects access to digital content. Moreover, accessibility to social care services is the result of lack of personnel to manage services effectively without delays. Finally, cultural barriers still dominate in European countries where persons with disabilities are seen as incompetent and perceived as definitely dependent on their families and the community. Media often do not help in this regard as it continues to portray a stereotyped view of disability and also pushes sensationalism. Some cultures reinforce this dependency due to the use of overprotection

rather than promoting self-determination. Discrepancies exist in awareness and education and proficiency levels in relation to ICT/ICT-AT policy and practice. Moreover, differing or incorrect terminology is used in different countries when discussing AT and disability issues and this may lead to misunderstandings and inaccuracies.



#### 5.3. Community level

Poor knowledge of ICT-AT opportunities and digital competencies are the main barriers reported as affecting the participation of persons with disabilities in their community. In some countries ICT-AT services are either not available, or not provided within the communities where they are most needed. Many students are still experiencing poor opportunities to develop digital skills within educational institutions. Educational systems are not fully prepared to empower learners with disabilities in developing their ICT and ICT-AT skills especially those with complex communication and physical disabilities. Very often the hardware and software that is required to facilitate access to digital literacy and the development of ICT-AT skills is not available (Hoogerwerf, Mavrou & Traina, 2020). The result is a mismatch between what is required for the labour market and what digital and employability skills the students are gaining from education. As a consequence, persons with disabilities are experiencing higher unemployment rates and due to poor digital skills and lower levels of education, they experience difficulties in obtaining employment in the open labour market. Restructuring of current educational systems is required, in order to address the issue of qualifications and skills properly. This needs to be done as early as possible. Employability skills training should be considered at secondary level whilst also providing guidance and support to the parents of students with disabilities to be in a better position to guide their children. Career guidance professionals should also be trained on how to guide persons with disabilities in the best job path according to their competencies and skills whilst taking into consideration the interest of the persons with disabilities (Sainsbury, 2018).

Other barriers that are affecting employment include the poor availability of accessible technology in the workplace, poor knowledge on how to identify skills and abilities of persons with disabilities, or not hiring people because of the extra cost to buy equipment. Employment quotas is one of the frequently used policy measures to end underemployment of persons with disabilities and increase working opportunities for persons with disabilities. Currently, 103 countries globally provide for employment quotas in their national legislation (International Labour Organisation, 2019). Although such measures are in place in many European countries, they are not always enforced and when they are enforced, they lack the substance to make a difference (Sainsbury, 2018). These measures must be reinforced by other strategies such as funding for employers training, to address the knowledge gap about the benefits that are linked to employing persons with disabilities and to generate awareness on disability at a wider national level so as to contribute to a wider change in perception on disability. Additionally, financial support is also important to cover costs required to employ persons with disabilities, including the provision of necessary technology (Business Leaders Malta, 2015).

Other barriers affecting participation of persons with disabilities in their community are related to the **insufficient** preparation of public health and social services to support persons with disabilities in their technology needs. For interventions with AT to be successful it is fundamental that a holistic approach is adopted, which means that services in health and the social domain collaborate and put the interest of the end user first. Additionally, existing services are not fully equipped with the latest AT equipment to be able to provide their service users' assessments and trials on a variety of available solutions. In some countries, there is a lack of centres that offer assessment and advice on ICT-AT. These services are needed to support clinicians, social workers, and education professionals in defining better personalised plans because technology is an integral part of it. The provision of AT is less effective and efficient without their advice, with the risk that the wrong equipment is prescribed, leading to abandonment, waste of money and frustration. The WHO reports that fragmented delivery systems and lack of interagency collaboration interferes with the efficient provision of AT within reasonable timescales. (WHO, 2020).

The intention to introduce person-technology in the delivery of services may meet resistance among staff that might fear job loss or that do not feel comfortable in dealing with new technologies or lack digital skills. Recently, within the context of COVID-19, which has accelerated the technology uptake in services, we may experience further **resistance amongst professionals** to adapt to this the 'New Normal'. These concerns emphasise the importance of correct information and the need for continuous professional development of all staff members.

#### 5.4. Personal level

Various barriers at personal level have been identified in a study conducted by the ENTELIS project consortium (Kharki & Sallinen, 2016). Respondents indicated that user and family training on how to use AT-ICT to meet life goals is lacking and results in abandonment of technology. Also fear or anxiety towards the use of technology and the internet, especially amongst the elderly population, is another barrier that needs to be addressed especially now that Europe is facing an aging population. The WHO estimates that by 2030, older people may be needing two or more assistive technological products due to acquired conditions and chronic conditions. Some of these will be based on digital technologies. Therefore digital skills should be encouraged amongst this population to facilitate access to and usability of AT. Additionally, research (Raja, 2016) keeps on showing that the use of AT enables older people as well persons with disability to continue to live in the community and thus minimise institutionalisation. The WHO estimates that 2 billion people will require assistive technology by 2050 (WHO, 2020).

The advancement of the internet comes with security challenges such as safety and data protection issues. Some people, and not only the most vulnerable, are cheated over the internet, abusing their lack of familiarity with data protection procedures, or their good faith. Children might be involved in age-inappropriate activities on the internet. Particularly, persons with intellectual disabilities are more prone to cyberbullying. As mentioned earlier, the COVID-19 pandemic has pushed the use of the internet and social media amongst persons with disabilities as it was the only access to socialisation. This has made the sector more aware of the challenges related to it and the need to develop policies and strategies around the safe use of digital technologies. Some persons with disabilities, on the other hand, are reluctant to use the internet and ICT due to fear of these mentioned risks, depriving them of the important opportunities it can offer. One way of addressing these issues is to educate and guide persons with disabilities in using the internet safely. The issuing of a set of guidelines would be helpful to guide European countries to implement education programs and strategies to increase safety in this regard.

#### The lesson learned by Karel

Karel has always controlled his bank account with great care. His pension is not very high, so he needs to make sure that it doesn't turn red, while his savings are there for extraordinary expenses. Karel is proud of his achievements in "getting digital". His 87 years haven't stopped him from trying out new things, such as tablets and smartphones and online banking and shopping. Recently he received a WhatsApp message from someone who he thought was his daughter, so friendly were her words. She wrote to "her daddy" that she was in financial difficulties at the end of the month with a dentist's bill to pay. She asked her father to lend her the money by transferring 1.865,00 euro to the dentist's account. Later that evening Karel called his daughter and they discovered that they were the victims of a fraud. The fraud helpdesk of the bank couldn't do more than confirm that the bank account was not that of a dentist and in the meantime had been closed.

Another barrier that can affect the use of AT is if the person lacks **self-determination or self-confidence**. This can be addressed by making sure that social care services use a person-centred model during the ICT-AT assessment process so as to increase their motivation through their participation in the decision-making process. Additionally, social care services should create support programs to keep on educating service users and empower them to keep abreast with new developments in AT. Public awareness and mainstreaming of technology will also reduce stigma, another barrier that limits the utilisation of ICT-AT products.



#### 6. Recommendations

What follows are recommendations that will help the social care and support sector (and its various actors and stakeholders) to align their ambitions with the digital transformation of society. To increase their impact they are written as "personal messages" directly addressing the reader.

#### 6.1. Persons with disabilities

- Technology is a pathway that can help you to reach your goals. It is your right to be helped in having access to the most appropriate technology that will allow you to have the same opportunities as anyone else in life, especially in access to information, education, employment. Discuss your needs and wishes with those closest to you and ask for expert advice if you feel you need it.
- When you ask for expert advice, be part of the process, state what you would like to participate in and achieve. Ask to try out the equipment so that you can identify the right equipment that will make a difference in your life.
- Use technology in a responsible way, like everybody should do, learn about its functions, consider its constraints. Reflect on how the use of technology is changing your life and what further steps you envisage. Share your findings with others. Protect your digital identity and your personal data from abuse.

#### 6.2. Professional care workers

- Be open to change. Technology will change the way services are organised and delivered. Develop interest in technology, explore how it can make your work more effective and efficient and keep up to date with new developments. Encourage, shape and take part in the uptake of technology by your employer.
- Understand the potential impact of technology on the life goals of the men and women you support and make sure that they can make use of their personal equipment. Encourage and facilitate their use of technology for their activities and participation. If you think their technology is not appropriate or broken, report this to your managers.
- If you identify that a person you support may benefit from the use of technology, bring this to the attention of supporting professionals and managers.

# **6.3.** Professionals in health, education, and social institutions

- Understand the potential impact of technology on the life goals of your service users. Develop your own digital interests and skills. Seek training or support in case you need it. Encourage, shape and take part in the uptake of technology by your employer.
- Adopt an integrated approach when it comes to supporting service users in their technology needs. Seek collaboration with professionals from other disciplines or multidisciplinary teams that can support you and your client in finding the right technologies for their needs and in the definition of user strategies.
- For those working in education, make sure your institution is prepared to support students with disabilities and teachers to make effective use of technology in the classroom and beyond. You can start by ensuring that all staff are aware and knowledgeable about accessibility features in mainstream software and hardware that can be taught to students such as text to speech, dictate, display enhancements and adjustments to mouse/keyboard control. Make sure the digital skills development of persons with disabilities is high on the school's/college's priority list. It is important to include digital skills in a wider and comprehensive skills strategy, which encompass other transversal skills (e.g. soft skills, communication skills) considered as highly relevant to employers.
- For those working in health, embrace a multidisciplinary/ transdisciplinary approach to technology and disability. Recognise the role of multidisciplinary/transdisciplinary expert teams, involving ICT-AT experts, engineers, therapists (e.g. OT's, FT's, SLT's), educators, social workers. In many countries only doctors have the authority to prescribe AT, mainly as budgets for AT are located under Public Healthcare systems, but funding should be integrated with additional sources, as the outcomes of successful AT adoption are in the social and educational domain as much as in the health domain. Additionally, the assessment and prescription of AT involves the simultaneous contribution of different professional expertise.



# **6.4.** Managers in social care and support providing organisations

- Embrace technological innovation proactively in the best interest of your service users, staff and your organisation. Technology is never an aim in itself, but it is the medium that facilitates participation. Make sure you get the right guidance from experts who do not have a commercial interest.
- Make yourself familiar with existing tools that might guide you through the technology adoption process. The solutions that you might adopt should perfectly fit your organisation, the needs of your service users and the capabilities of your staff. Make sure the solution is compatible with all elements in your wider care system-thinking.

#### Compatibility core items in technology adoption for person-centred integrated care and support services

#### **Conceptualisation phase**

The envisaged solution responds to the identified needs of the target users The envisaged solution is compatible with relevant policy frameworks The envisaged solution reflects the values of Integrated Care

#### **Contextualisation phase**

The solution is compatible with existing IC care pathways

The solution enables new IC care pathways

The solution is compatible with the existing Health and Care system

The solution is compatible with the existing funding models for care provision

#### Implementation phase

The build solution is compatible with the skills of the users

The build solution is compatible with the expectations of the users

The build solution is compatible with the environment of use

The build solution is compatible with other technologies

The build solution is compatible with legislation/regulations (e.g., safety, privacy, etc.)

The build solution is compatible with the care management procedures

#### **Evaluation phase**

The solution is compatible with the evaluation practices in the organisation

The solution can cope with larger numbers of users

The solution is interoperable with different care contexts and cultures

Source: Hoogerwerf, E.J. et al. 2021. Scaling-up Improved Integrated Care Service Delivery. D3.2., SHAPES project (H2020-GA 857159).

- Allocate resources to change management. Involve all stakeholders, starting from your service-users and staff. Involve them actively in the process and make sure their input and feedback guide you. Value early adopters, "ambassadors" and digital tutors in your organisation.
- Invest in the development of the professional skills of your staff. Not just in digital skills development, but also in coping with new service delivery models. It is a long-term investment in the quality of life of all actors in the care network.

# **6.5. Commissioners (those paying for the services)**

- Apply different cost-benefit criteria and different parameters to technology related investments, including the long-term impact on the costs of care, the independence and quality of life of the people supported, and the quality of jobs in the care sector. Aim for win-win scenarios.
- Invest more in digital services and provide adequate resources for assessment procedures, procurement and maintenance of technology and training. Consider the development of Assistive Technology Centres in your area, competence centres and knowledge hubs that can drive and accompany the change.
- Make "accessibility" a formal requirement of the services that you tender out.
- Welcome the use of digital technology in the services that you have already tendered out.
- Adopt a perspective in the provision of care and support services that is based on a holistic and flexible approach to needs and an even broader perspective on solutions responding to those needs.

#### 6.6. Policymakers and politicians

- Create legislative frameworks that foster the full participation of persons with disabilities in all realms of life in an enduring way. Involve them directly in all phases of the process. Remove barriers and make sure that the policies that you propose are inclusive and do not leave anyone behind. The best way to do this is to adopt a Universal Design approach in shaping innovation and to develop inclusive thinking skills.
- Approach this field as a potential win-win challenge. Research has shown that investing in the independence of people with technology leads to important social cost savings and a higher quality of life (Bensi, Bitelli & Hoogerwerf, 2011).
- Make "accessibility" a touchstone for policy development. If barriers are irremovable, provide alternative solutions, reasonable accommodation or empower support.
- Value the role of civil society and of service providers. Many of them are real laboratories of innovation and inclusion. Support them in picking up the challenges of the digital society and introduce structural and project funding for development, training and outcome assessment. Consult with the professionals providing these services when it comes to policy making and research.

- Digitalisation is a cross-cutting political issue involving several actors. Consequently a coordinated approach needs to be adopted to bring together politicians, administrations, unions and employers' associations, industries, research and civil society, including disabled persons organisations (DPOs) so that persons with disabilities are fully involved in the process.
- Increase budgets for training on the use of digital technology. Some companies may find that the investment in the development of digital skills represents a loss of productive time and economic resources. Financial incentives can help to overcome this barrier.
- Increase budgets for the employment of professionals providing services in the field of Assistive Technology so they can support their service users efficiently, reduce their waiting lists and thus meet the values of a convenience economy.
- Make sure that your policy objectives and strategies aimed at facilitating the use of inclusive ICT are cross-sectorial and are reflected in all relevant policy domains. A cross-referenced and coherent policy context will allow investments in AT and AT provision and improving accessibility of ICTs in one sector to impact positively on other sectors. Help to expand funding opportunities for AT and support services, especially in those situations where funding is solely provided by the health care system.
- Do not forget that to favour the uptake of technology in the sector, more resources are needed for research and development of innovative solutions for inclusion. National and European funding programmes that support financially innovative projects aimed at developing new technologies and assistive digital devices are fundamental.
- Also, provision programs of ICT-AT need to be supported fully by the government to ensure that all persons with disabilities have access to AT which is their right and leads to important long-term savings. This will reduce the reliance on charity.
- Accompany any policy initiative in this field with an accessible information campaign, providing correct and accurate information.



#### 6.7. Researchers

- More information is needed on AT Outcomes and impact. A lot of anecdotal evidence is available about the benefits of AT for individuals and digital technologies in care and support pathways but there are still many open questions. This information is relevant for designing policies that aim at higher results. Please, make this part of your research agenda.
- More information is needed on the connection between digitalisation in care and support services and the ecological transition, and how both trends can strengthen each other.
- All research investigating technology and services need to reflect on the involvement of persons with disabilities, both as informants and as researchers. Accessibility in all its facets needs to be taken into account (e.g. websites, surveys, reports, conferences and workshops, etc.).
- Research activities should also study and analyse the type of initiatives and measures that are most effective when addressing digital inequalities for people with disabilities.

#### 6.8. Developers

- If you are a developer of new technology-based solutions you should take accessibility, usability, aesthetics, affordability, scalability and transferability into account. "Design for all" principles should be at the basis of any design effort of consumer goods and services. The best way to do this is to involve potential users right from the start and to adopt a user-centred approach.
- Refer to standards in the field of accessibility and keep yourself updated on the European accessibility standardisation process.

### 7. Concluding remarks

The digital revolution has taken a big leap during the last decade transforming various sectors including social services. The emergent technological trends will definitely continue to change how we think, function, and live. It will continue to transform disability management, opening up the learning opportunities for persons with disabilities to fully access and participate in all aspects of life, including cultural, economic and political life.

Access to assistive technology and accessible (digital) environments is a human right as delineated by the UN Convention and thus, the majority of the EU member states have committed to address these barriers to enable persons with disabilities to access technology and reduce the digital divide. In response to this, the European Union worked hard

to put disability matters high on its agenda through the issuing of the European Disability Strategy 2010-2020, which builds upon the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), and complements Europe 2020 (the EU's strategy for smart, sustainable and inclusive growth) and the European Charter of Fundamental Rights of the Lisbon Treaty (European Commission, 2021b).

The aim of this strategy was to remove barriers across 8 areas, reflecting the rights enshrined in the CRDP: accessibility, employment, inclusion education and training, equality, participation (including access to quality community-based services), health, social protection and external action (development and enlargement programme). Despite all these efforts not all EU countries have fully implemented the accessibility related legislation and thus persons with disabilities in various countries across Europe are still at risk of discrimination, social exclusion and poverty.

The COVID-19 pandemic, inevitably, continues to affect persons with disabilities disproportionally with the introduction of social distance measures and self-isolation. Those persons with disabilities who had access to ICT-AT were able to reduce the feeling of loneliness, by connecting socially through the internet and by engaging in online leisure activities, such as games and reading e-books, whilst those who did not have access were even more isolated. Social services were halted and persons with disabilities residing in countries who lacked digitisation of services were even more neglected.

On the other hand, the COVID-19 pandemic has pushed service providers to utilise digital technology and use it creatively to keep on delivering services, and coach persons with disability to utilise assistive technologies to meet their special needs. Regardless of all these efforts, barriers to access digital technology in EU countries still exist as has been reported in several studies and reports (Karki & Sallinen, 2016; Mavrou & Meletiou-Mavrotheris, 2015). The aim is to push all member states to reduce the digital gap by addressing these gaps. The new European Disability Strategy 2021-2030 strives to achieve this.

Advancements in ICT-AT on their own are insufficient to bridge the gap in the socioeconomic inclusion of persons with disabilities and the elderly. Changes in the organisational aspects are required at policy, cultural, financial and accessibility level. Additionally, stakeholders' knowledge and awareness of the ICT solutions available and the capacity of various stakeholders to support accessible ICT services is important to reduce barriers that impact on the success of using the internet and ICT for the inclusion of persons with disabilities (Raja, 2016).



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EUROPEAN ASSOCIATION OF SERVICE PROVIDERS FOR PERSONS WITH DISABILITIES Handelsstraat / Rue du Commerce 72 | B- 1040 Brussels - Belgium +32(0) 2 233 77 20 | info@easpd.eu | www.easpd.eu

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