

Emerging Challenges and Future Potentials for Persons with Disabilities in the Digital Era

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1. Scrutinising the Road to an Inclusive Digital Society

This volume collects contributions reflecting on the main concerns emerging from the new challenges and future potentials of digital technologies on the protection of human rights for persons with disabilities. It lays its foundations on the assumption that, for persons with disabilities, Information and Communication Technologies (ICTs) can represent, on the one side, an opportunity to actively participate and be fully included in society and, on the opposite, a possible means of exclusion – since some digital tools are not accessible and usable yet – and a threat to the protection of sensitive personal data from cyber-attack and cyber-bullying. The ambition is to pave the way forward an inclusive digital society, thus collecting different expertise to identify critical legal and social policy responses grounded to a disability human rights perspective, notably suggesting legislative interventions and best practices to be implemented for achieving solid improvements of the current regulatory framework.

In this respect, due to the highly qualified scientific content and the strong social impact of the interface between the ICTs and the human rights of persons with disabilities, the Authors involved in this editorial project are both Scholars in different disciplines (public and private international law, EU law, administrative law, disability law and policy, engineering) and representatives of private sector and civil society working on the implementation of ICTs for persons with disabilities. The interaction between such a varied network of disability experts and relevant stakeholders has been the cornerstone for the development of an interdisciplinary and ‘participative’ research approach, crucial to deal properly with the issue at stake in a more effective way.

All the Authors took part to an international and interdisciplinary network created as one of the outcomes of the project «Building an Inclusive Digital Society for Vulnerable Persons: The Role of Social Media Tools in a Disability Human Rights Perspective» (hereafter, the ‘BIDS Project’), with the aim at improving new synergies, exchanges of ideas and awareness-raising on the cross-cutting issue under analysis.

Such a network has been consolidated on occasion of the international workshop, entitled «Building an Inclusive Society for Persons with Disabilities. New Challenges and Future Potentials in the Digital Era», organised within the context of the BIDS Project in Pavia at Palazzo Vistarino, on May, 20-21, 2019. The workshop resulted in an invaluable opportunity to foster the exchange of views among the involved Scholars, coming from around Europe and Italy, but also to consolidate the network created with the intention of enhancing future fruitful cooperation on common scientific projects. Most of the contributions collected in this volume have been presented during such event.

2. Structure and Contents of This Book

This volume is divided into three major Sections, which, respectively, set the scene of the relevant multilevel legal framework (Section I), focus on the major challenges emerging from the widespread of digital technologies (Section II) and, finally, analyse some of the best practices developed or to be developed to realize a ‘digital-inclusive society’, in compliance with the Sustainable Development Goals (SDGs) promoted by the United Nations (Section III).

2.1. Promoting Equality and Social Inclusion for Persons with Disabilities in the Digital Era: A Multilevel Approach

The first Section addresses the relevant legal and policy framework adopting a multilevel approach. In fact, it analyses the issue at stake from the perspectives of international law, EU law, and national law, while embracing a critical perspective.

Adopting such a multilevel approach, Lisa Waddington sets the scene of the relevant international and European legal framework referring to e-accessibility and digital equality, starting from the relevant provisions of the United Nations Convention on the Rights of Persons with Disabilities (hereinafter, ‘CRPD’). The Author sheds a light on the emergence of a multilevel regulation of e-accessibility and digital equality within Europe, developed in the last few years. Consequently, Andrea Broderick, who adopts a EU law perspective, focuses on one of these most recent legislative initiatives, *i.e.* the European Accessibility Act (Directive (EU) 2019/882 of the European Parliament and of the Council of 17 April 2019 on the accessibility requirements for products and services, hereinafter ‘EAA’), which contains several substantive provisions related to digital inclusion. This contribution examines the inter-relationship between the key CRPD norms of equality and accessibility, and assesses the provisions of the EAA, seeking to determine whether they embody inclusive digital equality for persons with disabilities. Finally, descending to the national level, Vittorio Pampanin focuses on the Italian legal framework, with the purpose of presenting a brief overview of the relevant legal and policy initiatives that contribute to the national implementation of web accessibility, with particular reference to the active role both assigned and recognized to public sector bodies. It analyses the so-called ‘Stanca Act’ (Law 9 January 2004, No. 4, recently updated by the Law Decree 10 August 2018, No. 106), along with other relevant regulatory references to accessibility, as well as the role of the Italian Agency for Digital (AgID) in the implementation of web accessibility in Italy.

2.2. Accessibility, Human Dignity and Privacy Concerns

The second Section focuses on the new challenges related to accessibility, human dignity and privacy concerns emerging with the widespread diffusion of digital technologies among persons with disabilities. It embraces international human rights law issues, also at the regional European level, as well as private international law related issues.

Deepening the analysis of the relevant international human rights legal framework, the co-investigator of the BIDS Project, Silvia Favalli, analyses the most relevant challenges

that the widespread use of social media by persons with disabilities generates for the protection of their human rights. This chapter focuses on social media accessibility, freedom of expression and opinion, privacy and data protection, human dignity and autonomy in the international legal order, with a special focus on the relevant provisions of the CRPD, suggesting the necessity of adopting a different general approach in the protection of human rights in the digital environment. With reference to the system of protection of fundamental rights provided for by the European Convention on Human Rights (hereinafter, ECHR) within the framework of the Council of Europe, Federica Falconi considers hate speech against persons with disabilities as a case-study to examine the current European Court of Human Rights' approach in respect of hate speech and its possible developments. The paper undercovers the emergence of an extensive body of case law by the Strasbourg Court reflecting a growing awareness of the need to combat hate speech in order to guarantee to all individuals the full enjoyment of the fundamental rights enshrined in the ECHR. To this goal, restrictions to freedom of expression may be allowed especially when vulnerable people, such as persons with disabilities, are the target of these hateful expressions which qualify as 'more than insulting', running counter the underlying values of the ECHR as a whole.

With the purpose to tackle related private international law issues, Stefano Dominelli explores whether EU law rules on international civil procedure are adequate to cope with the right of access to courts that persons with disabilities might encounter to seek reparation for cross-border online defamation. The Author highlights that, whereas the current legal framework is not free from critiques from a private international law perspective, nonetheless the application of the existing rules as interpreted by the Court of Justice of the European Union seems sufficiently adequate to settle the needs at hand, whilst the creation of new rules to specifically cover the matter appears unfeasible. Finally, addressing the relationship between disability and the protection of personal digital data in health sector, Federica Persano focuses on the different concerns related to the protection of health data in the EU legislation, with particular reference to the so-called General Data Protection Regulation (hereinafter, GDPR), namely Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC.

2.3. Realizing Disability-Inclusive Development Through ICTs

The final Section collects relevant best practices realized by members of civil society, including members of representatives' association of persons with disabilities, academics, and private sector experts in ICTs, adopting a multi-stakeholder approach. The necessity of such a 'whole-of-society' approach is described in the opening contribution by the principal investigator (PI) of the BIDS Projects, Carola Ricci, who underlines that, while States are the primary duty-bearer called to protect the human rights of all individuals, civil society is required to participate actively as well, in a sort of 'multi-stakeholder alliance', in order to implement the human rights standards set within the CRPD with the

further aim of realising the UN Development Goals *for and with* persons with disabilities. The same approach has been adopted under the framework of the BIDS Project for the planning and implementation of a pilot application, named «SI@unipv (Smart Inclusion at the University of Pavia)», a beacon-based navigation system connected to an easy-to-use app, with the purpose to ameliorate the access to the ancient courtyards of the University of Pavia by persons with visual impairment or low vision. The PI has realised SI@unipv together with the co-investigator and Fondazione ASPHI onlus, an association representing persons with disabilities, specialised in developing e-accessibility and usability solutions, as presented by Ennio Paiella and Roobi Roobi. In their contribution, they introduce the main goals achieved by Fondazione ASPHI onlus, active since 1980 with the aim of promoting the integration and improving the quality of life of persons with disabilities through ICTs; its main activities include research, development, testing, promotion of new solutions, working in cooperation with public and private institutions, universities and research centres. In the same vein, Donato Matturro and Vito Disimino present the mission of *Joomla!*, a free and open-source Content Management System (CMS) for publishing web content, in fostering digital inclusion. *Joomla!* is one of the most popular website software, thanks to its global community of developers and volunteers, who make sure the platform is accessible, user-friendly, extendable, multilingual, responsive and search engine optimised.

Under the same Section, additional best practices realized by members of civil society, private sector experts in ICTs and academia are presented as well. Cristian Bernareggi describes a project supported since 2013 by the Sustain for Life Foundation, which is providing assistive technologies and training teachers for students with sight impairments in Western Uganda schools. Sustain for Life's aim is to provide assistance, training and education to some of the poorest and most underdeveloped communities in the world, to help them become economically and sustainably self-sufficient.

Finally, Alessandro Greco and Valentina Giacometti describe two projects of tactile maps developed by a research team of the Department of Civil Engineering and Architecture of the University of Pavia. These represent other two examples of good practices chosen among several projects developed at the University of Pavia for its heritage: the team, coordinated by Professor Alessandro Greco, has been working on accessibility and usability since 2006, with experiences on research, design and training activities, on both buildings and urban spaces.

3. What is the Way Forward to Digital Inclusion?

As mentioned before, the main ambition of the BIDS Project is to identify critical legal and social policy responses grounded to a disability human rights perspective, notably suggesting legislative interventions and best practices to be adopted for achieving concrete improvements of the current EU regulatory framework. Such a mission has been achieved through the invaluable synergies developed among the international network of disability experts, including both Scholars and members of civil society, created within the activities of the Project. In particular, the search for 'a way forward' to build a fully inclusive digital

society and foster disability-inclusive development through ICTs resulted in the emerging need for further action on interrelated topics. These particularly refer to web accessibility and digital equality, on the one side, privacy, data protection and freedom of expression, on the other side. Additional engagement should be promoted in order to guarantee the respect for the inherent dignity and individual autonomy (including the freedom to make one's own choices) of persons with disabilities in the digital environment, requiring further specific action in the European area, using the suggested methodology of a participatory approach.

3.1. Web Accessibility and Digital Equality

Accessibility and privacy together are preconditions to achieving equality and non-discrimination, which are in turn essential principles for the recognition of the equal right of persons with disabilities to live independently and be included in the digital community. To this respect, in the last few years several steps in the direction of digital inclusion have been undertaken, where different legislative measures have been implemented at the international, European and Italian level. Nonetheless, more action is still needed to fully include all users, with and without disabilities, in the enjoyment of the digital environment. Moreover, one of the peculiarities of the virtual world resides in the fact that, besides the key role played by States, also Non-State actors are emerging as new addressees of human rights obligations.

Notably, at the global level, the CRPD has been interpreted as recognizing web accessibility within the realm of human rights for people with disabilities, where the CRPD lays down an international obligation for States to design accessible websites and to provide public information in accessible and usable online formats. Nonetheless, such a duty is frustrated by the absence of a definitive standard by which web accessibility is gauged. This is because, in this context, the self-regulation of private entities prevails. As a consequence, accessibility guidelines and standards are set by standardisation organisations and are, by definition, merely voluntary.¹

Also at the European level, it is possible to notice a major sensitivity and a growing interest towards digital inclusion and the accessibility of the digital environment. Hence, web accessibility has been prioritised within initiatives developed under the Digital Agenda, one of the seven flagship initiatives under the Europe 2020 Strategy. Accordingly, «a multilevel regulation of web accessibility and digital equality is emerging within Europe»,² where the EU has recently adopted a range of legal provisions addressing web accessibility and digital equality. Among these instruments, the most remarkable is the European Accessibility Act (EAA), which «has begun to pave the road towards digital inclusion and equality for European citizens with disabilities».³ Nonetheless, this Directive

¹ See *infra*, Favalli S., *Disability and Social Media: Paving the Road to a Different Approach in the Protection of Human Rights in the Digital Era*.

² See *infra*, Waddington L., *Regulating e-Accessibility and Digital Equality in Europe from a Multilevel Perspective*.

³ See *infra*, Broderick A., *The European Accessibility Act: A Paradigm of Inclusive Digital Equality for Persons with Disabilities?*

is still «somewhat deficient when compared to the CRPD's model of inclusive equality», with reference to some notable limitations and exceptions of its material scope.⁴

Finally, at the national level, a new sensitivity towards the necessity to guarantee to all citizens the accessibility to public bodies online resources arose. In the last few years, the legal framework on this issue has been developed throughout the adoption of a bunch of regulations and administrative acts. However, according to most recent statistics, the large majority of the Italian municipalities still present accessibility problems.⁵

Under such premises, it is argued that the adoption of the so-called 'nudging approach' in boosting both States and Non-State actors behaviours towards a 'virtuous' web accessibility-oriented policy and legislation represents the best way to really achieve digital inclusion. Hence, from the developed multilevel legal analysis it emerges that, despite the range of legislative initiatives adopted, it finally depends: (i) on the willingness of single States to recall as compulsory the international accessibility standards in its own legislation; (ii) on the sensitivity of private and public entities to address the accessibility concerns of their online platforms; as well as, (iii) on the awareness of individual users to adopt all the tips and methods able to improve the accessibility of their own accounts, especially with regards to social media platforms. To this extent, both the active involvement on the issues at stake of the civil society and the awareness-raising of private and public entities, as well as of all the citizens/users are crucial.⁶

3.2. Privacy and Data Protection

Privacy and data protection do constitute paramount concerns for all digital users. To date, in the digital environment, there are structural problems to the effective exercise of the principle of consent with reference to data protection, which may affect all digital contributors. In this context, the situation of users with disabilities is particularly delicate, due to security and anti-discrimination issues. Nonetheless, from the carried out analysis, it emerges that users with disabilities do not usually receive specific protection.

Within the EU legal order, a comprehensive reform of data protection rules is in due course, throughout the adoption of the so-called General Data Protection Regulation (GDPR), applicable as of 25 May 2018. The Regulation is aimed at ensuring the protection of natural persons with regard to the processing of personal data and on the free movement of such data. This is an essential step to strengthen citizens' fundamental rights in the digital age and facilitate business by simplifying rules for companies in the digital single market. In this fast-changing digital age, the right to protect personal data must be safeguarded. Nonetheless, up to now, the EU regulatory framework is not coherently providing a fair balance between the use of online resources to collect personal data and

⁴ *Ibidem*.

⁵ See *infra*, Pampanin V., *The Role of Public Administration in Promoting the Accessibility of Online Resources: The Italian Legal Framework*.

⁶ See *infra*, Ricci C., *Realizing the Sustainable Development Goals for and with Persons with Disabilities through ICTs*.

the respect of the right to privacy of vulnerable persons, such as persons with disabilities. Most notably, the EU General Data Protection Regulation does not contain any provision directly protecting personal data of persons with disabilities. More generally, data concerning disability are included in the terms ‘generic data’ and ‘health data’.⁷

Under such premises, the inclusion of the peculiar vulnerabilities of users with disabilities in the digital environment in the rationale of the progressive legislative reforms of privacy and data protection regulations in due course within the EU is crucial. In particular, consumers with disabilities must be actively involved in the relevant policy-making process in order to raise awareness on the specific threats to the protection of their data and ensure that the steps to effectively protect their privacy online are finally taken. In the same process, it is also necessary to duly take into consideration the provision of the CRPD, according to which the right to privacy of persons with disabilities must be read in combination with the recognition of the individual’s legal capacity and in the respect of the person’s autonomy, will and preferences, which is an essential part of the human dignity for persons with disabilities.

3.3. Hate Speech, Online Defamation and Freedom of Expression: A Wake-Up Call for Europe?

The analysis conducted by the PI and the co-investigator on freedom of expression and opinion in the digital environment related to the protection of the rights of persons with disabilities is twofold. On the one hand, this right is considered as strictly interconnected to web accessibility, as access to digital information and communication tools is considered as a precondition for the enjoyment of freedom of opinion and expression of persons with disabilities. In this vein, the CRPD encompasses in the freedom of expression and opinion, which is traditionally described as a ‘negative right’, also the States’ obligation to provide public information in accessible and usable formats. On the other hand, the exercise of this freedom is considered in contrast with the respect of human dignity of persons with disabilities in the increasing cases of online disability hate speech. Hence, «while on the one hand the Internet has given a voice to disabled people, it has also exposed them to greater abuse».⁸ In connection with this trend, an impressive increase in the phenomenon of online bullying against persons with disabilities has been also registered.⁹

In this delicate context, many questions are still pending as to the opportunity to enact legislative measures to prohibit hate speech, mainly referring to the need to counter-balance it with the exercise of the fundamental freedom of opinion and expression. Nonetheless, at the European level, a sort of ‘judicial activism’ is filling such a legislative gap. International legal standards have been judicially interpreted by the European Court of

⁷ See *infra*, Persano F., *Health and Disability in the EU General Data Protection Regulation*.

⁸ See *infra*, Falconi F., *Addressing Disability Hate Speech: The Case for Restricting Freedom of Expression in the Light of the European Court of Human Rights’ Case Law*.

⁹ See *infra*, Dominelli S., *Disabilities, Cyber-Bullying and Defamation: A Uniform International Civil Procedure Perspective*.

Human Rights to ensure that people with disabilities are protected against incitement to hatred on an equal footing with others. Accordingly, in the European judicial space, the peculiar vulnerability of persons with disabilities victims of online bullying and defamation has been duly taken into account whereas they have the possibility to seise their *forum actoris*. In this vein, the current rules on international civil procedure, as interpreted by the Court of Justice of the European Union, appear adequate to cope with the increasing problem under exam.

However, it is impossible not to stress the need to address the social roots of the widespread of this kind of hateful behaviour. To this extent, the involvement of civil society and the awareness-raising of all citizens on the risks of vulnerability for human dignity in the digital environment appears now more than ever crucial in our society.

From the foregoing it follows that, in the digital era, it is of utmost importance to guarantee the full enjoyment of the many benefits deriving from the widespread use of new digital technologies to the whole population, including persons with disabilities. Fostering digital inclusion and digital equality means to recognize the equal right of all persons with disabilities to live and actively participate in the community, also benefitting from the unprecedented opportunities deriving from new technologies. ICTs could represent a means to improve the inherent dignity of persons with disabilities, widening their opportunities and ensuring their independence and autonomy, including their freedom to make their own choices.

Web accessibility and data privacy are necessary preconditions to reach such an achievement. On the one hand, all the appropriate measures must be taken to ensure that people with disabilities can perceive, understand, navigate and interact with websites and tools on an equal basis with others. In addition, ensuring access to digital information is crucial to guarantee the full enjoyment of the freedom of opinion and expression for persons with disabilities, which is also a prerequisite to exercise the freedom to make their own choices and living independently. On the other hand, the peculiar vulnerability of persons with disabilities must be duly taken into account to provide a proper privacy protection within the digital environment. This not only offers safeguards against discrimination on the ground of disability, but it is also an invaluable ally to combat cyber-bullying and other online hateful behaviours against persons with disabilities.

To this extend, mainstreaming cornerstone concepts such as digital inclusion, e-accessibility and digital equality in the current legal and policy framework is both crucial and urgent to develop a fully inclusive society. In this respect, persons with disabilities along with civil society must be actively involved in a 'multi-stakeholder alliance' to participate in the policy-making process, in order to foster the adoption of appropriate legislative reforms, to spread existing best practices and to raise awareness on such emerging topics among the whole society.