12 Personal autonomy in elderly and disabled: How assistive technologies impact on it

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Abstract

Technological change has been notable in recent decades, including the field of assistive technologies aimed at promoting the autonomy of the elderly and disabled people. Personal autonomy is possible thanks to ethical-juridical protection through reciprocally recognized human rights (civil and political, economic, social and cultural, third generation). The current technological change could produce an alteration in the exercise of personal autonomy, putting at risk its normative protection, since some of these rights currently require technological mediations to be able to be carried out. Nowadays, the UN Convention on the Rights of Persons with Disabilities (CRPD) governs as the international normative framework that defines and protects the autonomy of people with disabilities, mostly elderly, and includes important references to technological developments. New assistive technologies, that can be used to record physiological variables or to monitor habitual patterns of life, are suggested as devices that promote personal autonomy. Health monitoring could impact privacy, identity, integrity, and the protection of personal data. Therefore, it is necessary to broaden the ethical reflection from the CRPD to the relevant regulations on privacy and data protection (General Data Protection Regulation [GDPR] and Draft Privacy Regulation ePrivacy) and the Data Protection Impact Assessment (DPIA) provided in Art. 35 GDPR, which is especially relevant for the realm of assistive technologies. In this contribution we show how technological change affects some aspects of personal autonomy, its normative protection, privacy, and care.

12.1 Introduction

In recent years, technological change has been notable, including the field of assistive technologies aimed at promoting the autonomy of elderly and disabled persons. In this contribution we show how this change affects some aspects of personal autonomy, its normative protection, privacy, and care.

Taken as the possibility of self-government, without illegitimate interference, to decide on and execute one's life plan, personal autonomy is possible thanks to ethical-juridical protection and through reciprocally recognized human rights (civil and political, economic, social and cultural, third generation, corresponding primarily to rights of a collective nature: rights to a healthy environment, economic development, self-determination). The current technological change could produce an alteration in the exercise of personal autonomy, putting at risk its normative protection, since

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carrying out some of these rights has followed a constant process of increasing need and dependence on technological mediations (Winner 2007). Nevertheless, the elderly and disabled have been absent from these reflections over time, assuming their limited ability to exercise autonomy. Nowadays, fortunately, the UN Convention on the Rights of Persons with Disabilities, (CRPD) (UN 2006) governs as the international normative framework that defines and protects the autonomy of people with disabilities, with the highest rates of disability among the elderly resulting from the accumulation of health risks over a lifetime of illness, injury and chronic illness, and includes important references to technological developments(see, for example, CRPD, arts. 2, 4 g, 4 h, 9, 20b, 20 d, 21a, 26.3, 29a.ii).

New assistive technologies, such as robot companions, smart screen assistants, or wearable technology with sensors that record physiological variables to monitor habitual patterns of life, are suggested as devices that promote personal autonomy. The recorded data, once processed, can offer information about health, habits, etc., and allow, in principle, to make more autonomous decisions about one's own well-being and quality of life, relying on the information provided by the processing of data obtained from personal patterns of behavior. But this technological scenario claims an extreme protection of personal autonomy too, since health monitoring could impact privacy, identity, integrity, and the protection of personal data. Therefore, it is necessary to broaden the ethical reflection: from the CRPD to the relevant regulations on privacy and data protection (General Data Protection Regulation [GDPR] and Draft Privacy Regulation ePrivacy) and the Data Protection Impact Assessment (DPIA) provided in art. 35 GDPR, which is especially relevant for the realm of assistive technologies. All these regulations have the essential goal to protect the affected individuals in the asymmetric power relations which they face with the organizations and governments that develop, implement, and manage assistive technologies. In this kind of relationship, it seems especially important to ensure the effective protection of the personal autonomy of the elderly and disabled.

The technological scenario, which affects rights such as privacy, identity, integrity, and data protection, requires new forms of "care". Not only traditional forms of personal and intersubjective care, but also social care, that is, normative measures that help secure those rights, so that new technological devices do not become instruments of surveillance and control, diminishing the autonomy they intend to promote. The basic ethical principle of non-maleficence involves the need to protect people from damage and harm in her interaction with assistive technologies. As in the case of medical iatrogenesis, the technological mediations could cause harms (on the people's privacy, identity, and integrity). This is the primary ethical duty about the use of assistive technologies: *primum non nocere*. Moreover, these technologies should be available without any kind of discrimination in order to fulfill an elemental ethical principle of justice.

To achieve this goal it is important to consider the "public" dimension of autonomy and its relational character, related to the social participation of the elderly and disabled in the public debate on assistive technologies, in all phases of their development, in terms of "social appropriation" of technologies or inclusiveness. Autonomy should be considered in an intersubjective and collaborative way instead of an individualistic and solipsistic one.

12.2 Technological mediation and the capability approach

Generally speaking, a community's approach and relationship to a certain technology can be viewed as mediated and filled with meaning by means of intertwining sets of values, representations and social practices. This way of understanding the relationship allows us to talk about the community's "discourse" (Lynch 1988) about this technology. But there is an analogous (instrumental) discourse (Winner 1980), linked to the whole set of characteristics of the technology in question, which also brings with it practices, representations and values coming from the communities responsible for its idea, design, development, manufacturing, marketing and commercialization.

Different environments for activities and social participation, such as: urban, domestic, educational or work environments; environments for public, political, social and economic participation; or environments for culture, leisure or health can be considered "functionings environments," in the sense of the capability approach developed by Amartya Sen and Martha Nussbaum. This concept deals with spaces (real or virtual) in which we carry out actions and practices we consider to be important and valuable for our well-being and quality of life (Sen and Nussbaum 1993). In this approach, well-being consists of evaluating life conditions defined by functionings. These represent what a person achieves or becomes in the course of their life, which can be considered a set of interrelated functionings (Sen 1987, 1998).

The introduction of technological elements into functionings environments condition the way in which these actions are carried out and, consequently, can modify the evaluation of the functionings mediated by such elements (Toboso 2010). If in a given environment the situation arises in which mediation from a device is obligatorily needed to perform a certain functioning, the limitations of this device will define the limitations of this act. In the most extreme case, if the device is not available, the performance of the functioning will be nullified, which will negatively affect the scope of well-being associated with its achievement. Barriers of access or use will create discrimination and inequality in the user communities, as a consequence of their technological dependence on such devices. The sum of inequalities of access and use may produce an inequality of greater importance: an inequality of opportunities for the affected people or communities, as a consequence of such barriers that restrict the opportunities to access the use of technologies (Toboso 2010).

Demanding genuine equal opportunities brings up important questions related to ethics, politics and social justice, and to the question which value frameworks should be considered the most relevant when considering what is needed for equality. The aspects that a community of users can evaluate in their relationship with any type of device are numerous. Among them we highlight some values (Echeverría 2003), in connection with access and use, and linked to security and privacy: availability, affordability, necessity, appearance, simplicity, ergonomics, accessibility, usability, versatility, efficiency, quality, reliability, security, intimacy and privacy.

The realization of values, such as those referred to, can be interpreted as the concurrence of the community's discourse and the instrumental discourse, and is the basic condition for "social appropriation" of the devices, which we should differentiate from the simple concept of "adopting" them (Salovaara and Tamminen 2009). Adoption happens through the practice of use, while appropriation happens by means of the co-constructive combination of practices and values, requiring realization of these values in practices, and also involves social representations that are favorable towards the device in question (Tiles and Oberdiek,1995; Oudshoorn and Pinch 2005).

12.3 Current frameworks on the rights of the elderly and persons with disabilities

More than mere instruments, assistive technologies are mediations which open up new possibilities in human functioning. Today, numerous functionings are mediated by them. In the environments in which people who are dependent, the elderly or those with disabilities are cared for, the introduction of assistive technologies is generally encouraged as a substitute for traditional human care (de Asís Roig 2014). Resorting to these devices should contribute to a "democratization of care" (Tronto 2013), that overcomes the enormous gender bias that has befallen this fundamental activity for social reproduction (Kittay 1999), and should not be a source of new discrimination regarding access to basic care and attention.

The Convention on the Rights of Persons with Disabilities (CRPD) is an international regulatory framework with legal repercussions in the majority of countries in the world. To responsibly advance the development of assistive technologies, in terms of well-being and justice, professionals involved should receive training in this legal document, given the importance socio-technical mediations have for the full enjoyment of human rights (Winner 2007). This technological development will have to take into account the regulatory framework of the CRPD, and prospectively orient itself towards facilitating autonomy in the achievement of human functionings in inclusive environments, guaranteeing conditions for good care, derived from an international human rights normative framework.

With respect to the values in the CRPD to be taken into account in developing assistive technologies, we point out the following: (1) Respect for every type of human functional diversity. Technologically assisted care must deal with the wide diversity of human functionings. (2) Inclusion requires universal accessibility and universal design. Assistive technologies must be accessible and promote, in addition to health, autonomy and social inclusion. (3) Social participation of people receiving assistance demands having a voice in all the phases of development and implementation of technologies. It is necessary to include these people from the first developmental phases of technological innovation (Chavarriaga and Millán 2016), in consonance with what is indicated in the CRPD (Preamble, Parts n and o, Art. 3.c). The importance of participation in the technological design process on the part of users with disability must be emphasized. The users themselves know best how technological devices can contribute to their greater autonomy, quality of life and level of participation in society, and can assist in evaluating their advantages as well as their drawbacks in the earliest phases of their development. As the ones most familiar with their own reality, users help to create technological solutions that are more feasible in not only their technical but also their financial and social aspects. User participation also contributes to generating demand for those solutions which, in turn, stimulates their introduction into the market and inspires new lines of research (Toboso 2010).

The underlying theoretical discourse of the CRPD, based on the social model of disability (Abberley 1987; Barnes, Oliver and Barton 2002; Swain et al. 2004), interprets disability as a result of the interaction between people with different bodily or mental functions and discriminatory social structures. The juridical-moral approach of the CRPD endorses overcoming the traditional medical-rehabilitation model, which limits disability to the individual sphere, and highlights society's responsibility to eliminate all social barriers – physical, legal, political, economic, cultural or attitudinal – that affect persons with disabilities. Accordingly, in the Preamble (section 5) the CRPD states that "disability is an evolving concept" and that "disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others".

Hence, speaking about "disability" and "persons with disability" we should henceforth consider that the current recognized normative framework is the CRPD and no longer about considering disability as conceived in the medical-rehabilitator model, even though it is still present to a large extent in the collective imagination and societal practices (UN 2006). As such, it should be concluded that implementation of socially appropriable assistive technologies must take into consideration the model underlying the CRPD.

12.4 Rethinking autonomy in technological functionings environments

According to what is expressed in Article 20.b, the CRPD recognises the right to have access to "assistive technologies, technical devices and quality mobility aids, including by making them available at affordable cost". Articles 4.g and 26.3 also call on the

States Parties to promote assistive technologies and devices for people with disabilities "as they relate to habilitation and rehabilitation". Nevertheless, the proclamation of such rights does not imply a relapse into traditional medical-rehabilitation model outlined above. Consequently, although assistive technologies may be focused on rehabilitation or assistance, they must be oriented, in accordance with the principles of the CRPD, towards the respect for and facilitation of individual autonomy (Art. 3a) in the usual spaces for activity and social participation of persons with disabilities (Art. 3c), and in concordance with the other relevant principles: dignity, non-discrimination, equality of opportunity, respect for differences, accessibility, equality between men and women, and respect for the evolving capacities of children with disabilities (Art. 3).

Assistive technologies are also used to improve the functional autonomy of people with some types of motor disorder or neurodevelopmental disorder. Some applications based on brain-machine interfaces allow motor pathologies to be restored, and to restore communication through writing on a computer screen (Hochberg et al. 2006) or as a physical response to control an effector (Wodlinger et al. 2015). Other applications that have been used for decades are stimulation interfaces such as cochlear implants (Gifford et al. 2008) and deep brain stimulation, which relieves symptoms for people with Parkinson's disease, dystonia (Arle and Alterman 1999) or depression (Trapp, Xiong and Conway 2018).

These techno-scientific artefacts require an ethical examination (Jonas 1997) that clarifies the risks involved in their use, determines morally acceptable conditions for their adaptation and helps to increase the level of commitment for responsible performance in techno-scientific work by designers and developers in the social framework (Agazzi 1996). Any reflection concerning change in the technological area should be accompanied by a parallel ethical reflection on the aspects affected by these technologies. Given the large amount of possibilities to use current technology, such a change creates the obligation to deal with important questions such as autonomy, privacy and data protection, as well as the new neurorights (see below) and cognitive liberty. The adoption of an ethical-legal framework should be aimed at providing technologies to support the autonomy of persons with disabilities. Moreover, it should guide techno-scientific work towards the purpose society as a whole should be committed: the inclusion of persons with disabilities into a variety of different social environments.

The change in discourse the CRPD has brought about allows the ideas of care, autonomy, dependence and vulnerability to be redefined. Care is now conceived as a right that is, in turn, reinforced by the set of rights promoted by the Convention and by technological mediation. Thus, what is stressed is a "public" vision of care, as opposed to another traditional vision that is benevolent and with an enormous gender bias (see Kittay 1999). Limitations on personal autonomy in dependent people are no longer conceived as pure destiny or as an inherent characteristic of these limitations, but rather as a contextual condition that can be modified or is the focus of attention in the framework of human rights. Furthermore dependence, as a situation that requires care, is no longer conceived apart from the possibility of an independent life. There is also a growing awareness that physical or mental vulnerability interacts with social vulnerability which in turn results from stigmatization and from the discriminatory configuration of the socio-technological environment (Nussbaum 2007).

Some implications of this conceptual redefinition for assistive technologies are: (1) The technologies in question need to contribute to improving the social task of caregiving; (2) They need to facilitate the autonomy of people receiving assistance in the social environments in which they develop; and (3) They need to be part of the socio-technological foundation that supports their rights as a whole.

12.4.1 Privacy and data protection

We begin by recalling an essential principle of privacy in continental Europe, starting from legislation on the subject in 1970 s Germany. This principle is called prohibition with the exception of authorization (*Verbot mit Erlaubnisvorbehalt*). This means that processing of personal data is prohibited unless there is an exception that authorises data processing. The traditional examples were that the affected person had given their consent or that a legal regulation authorized the data processing.

The GDPR (in Art.6.1.f) has introduced or extended the possibility of arguing for a legitimate interest on the part of the organization that is processing personal data. It is worth pointing out that it is necessary to be able to clearly document the existence of this interest, as well as that it does not imply a disproportionate risk to the rights of the people affected. If this documentation is impossible, it is likely that from the start of its implementation the processing implies a violation of privacy legislation. The point of this clause is to show that control regarding the subject of privacy should be done prior to implementation—in fact even prior to doing any test with real data or real subjects who will be affected by an assistive technology.

12.4.2 Data protection targets

To reflect on the essential points regarding privacy, we draw upon what are known as safety goals (in German, in the original: *Schutzziele*, Rost Op. Cit).

- Transparency. In the field of privacy, this concept (included in arts. 5, 25 and 32 of the GDPR) is understood as the possibility to control (from the point of view of those responsible for processing, as well as from the perspective of the subjects affected and from an external body such as a data protection authority) any processing of personal data. This control is usually guaranteed by means of documentation and different types of protocols.
- Unlinkability. Included, among others, in the GDPR articles mentioned above, this implies that in regard to privacy, personal data collection must be intended

for specified purposes and not further processed in a manner that is incompatible with these purposes. To be able to fulfill this goal, it is essential that the purpose of the processing is defined as precisely as possible, guaranteeing its legitimacy and legality.

- Integrity. (see GDPR articles mentioned above) This refers, on the one hand, to the requirement that information technology processes and systems continuously comply with the specifications that have been determined for the execution of their intended functions. On the other hand, integrity means that the data to be processed remain intact, complete, and up-to-date. Deviations from these properties must be excluded or at least ascertainable so that this can either be taken into consideration or the data can be corrected.
- Confidentiality. (Ibid.) This is guaranteed in the sense of the principle of Privacy by Design (Art. 24 GDPR), when processing of personal data has been planned and implemented in such a way that only authorized people can access the functions (this is a technical term, we may also write procedures) and systems related to it.
- Ability to intervene. In addition to the previously mentioned articles, arts. 18, 20 and 21 of the GDPR should also be noted. In regard to privacy, this implies that the processing of personal data, if necessary, can be modified or stopped.
- Availability. (see arts. 13 and 15 of the GDPR, among others). This is the requirement that personal data must be available and can be used properly in the intended process. Thus, the data must be accessible to authorized parties and the methods intended for their processing must be applied.

The data protection goals mentioned here establish a list of criteria to follow for the development and implementation of personal data processing that is easily interpretable, including for the use of assistive technologies, without delving too deeply into the legal aspects of the problems that may arise if the data protection goals are not implemented/respected (e. g. lack of confidentiality). Also implied is the possibility of implementing a control procedure that follows the principles in the PDCA cycle (Plan, Do, Check, Act) (Breut, 2017 Op. Cit) that allow regular controls to be done, in fact continually, on the processing that is developed and implemented.

12.4.3 Data protection impact assessment

Article 35 of the GDPR establishes that given the probability that processing “is likely to result in a high risk to the rights and freedoms of natural persons”, it will be necessary to carry out a DPIA before the processing is started. This obligation is aligned with the principle of privacy, which has the goal of analyzing processing from its design phase onwards and of guaranteeing proper management of the risks as well as the fulfillment of the principles of necessity and proportionality. A DPIA should include:

- a systematic description of the envisaged processing operations
- an assessment of the necessity and proportionality of the processing operations in relation to the purposes
- an assessment of the risks
- the envisaged measures to address the risks, including safeguards, security measures and mechanisms to ensure the protection of personal data.

It should be highlighted some types of personal data processing can involve high risks for the subjects affected and as such need a DPIA. The Article 29 working party (Art. 29 WP) was the independent European working party that dealt with issues relating to the protection of privacy and personal data until 25 May 2018 (after entry into application of the GDPR its new name is European Data Protection Board) issued a document in respect to this (European Commission 2017) in which they mention different criteria to follow in order to assess the risks involved with regard to certain forms of personal data processing. In the following we mention two that are relevant for assistive technologies:

- "A systematic and extensive evaluation of personal aspects relating to natural persons which is based on automated processing, including profiling, and on which decisions are based that produce legal effects concerning the natural person or similarly significantly affect the natural person" (Art. 35. 3 GDPR)
- Processing on a large scale of special categories of data referred to in Article 9, section 1, or of personal data relating to criminal convictions and offences referred to in Article 10.

It should be remembered that found among the types of data mentioned in Article 9.1 of the GDPR are data concerning health. The two points mentioned above indicate that any processing of personal data in which assistive technologies are used should be accompanied by a DPIA. Carrying out this assessment forms part of the legal basis for development and implementation of the processing, and not completing the assessment could imply that this processing constitutes, or could constitute, from the moment real personal data is utilized, a violation of current legislation on the subject of data protection.

12.5 On the recognition of new human rights: 'Neurorights' and cognitive liberty

The first step towards possible recognition of new human rights related to neuroscience take form in the debate on "cognitive liberty". According to Bublitz (2013), this concept, at times also called "mental self-determination", includes two closely-related aspects:

- The right of individuals to use emerging neurotechnologies
- The protection of individuals against coercive use of these technologies and the possibility that the technology could be used without their consent.

Bublitz (2013) summarizes this in the following manner: cognitive liberty is the principle that guarantees "the right to alter one's mental states with the help of neurotools as well as to refuse to do so". The second aspect of cognitive liberty is related to a reconceptualization of some already existing rights and to the creation of new fundamental "neurorights" (Ienca and Andorno 2017):

- The right to mental privacy
- The right to mental integrity
- The right to psychological continuity.

12.5.1 The right to mental privacy

If we consider the problems posed to reach adequate protection of the traditional right to privacy, it appears evident that it is necessary to adapt regulations to achieve the same type of protection for mental privacy. This protection should cover any type of information obtained from the brain by means of neurotechnologies and distributed by digital means. It means protecting people in the face of illegitimate use of for example their cerebral information and preventing possible filtrations of this data on the Internet.

12.5.2 The right to mental integrity

Intrusions or actions on a person's brain can create not only a violation of their privacy but also a damaging change to their neural computation. The presence of damage is a necessary condition for a violation of the mental integrity of the person to have taken place. Ienca and Haselager (2016) have introduced the idea of "malicious brain-hacking" to describe neurocriminal activities on the neural computation of users of neurotechnologies, just like what hackers do with computers. Focusing on brain-computer interface (BCI), which could also be used in conjunction with assistive technologies, they have identified four types of malicious brain-hacking on different levels or for different types of BCI. In three of these types the attack is done on the measurement, decoding and feedback levels and can cause manipulation of the person's neural computation if the attacker, without authorization or knowledge of the person, intercepts the signal sent by the BCI-controlled apparatus.

The rights that should arise from this new scenario must be the basis for a new regulation that provides adequate protection in the face of aggressions by means of neurotechnologies. The incorporation of neurotechnologies into the digital world and availability on the Internet of the information created can cause the mental integrity of the individuals to be subject to a higher level of risk if the appropriate protective measures have not been adopted.

12.5.3 The right to psychological continuity

In addition to mental privacy and mental integrity, the perception that an individual has of their own identity may also be affected by an incorrect use of neurotechnologies. These technologies can be used to monitor brain signals as well as to stimulate or modulate brain functions. As such, changes in brain functions produced by brain stimulation can, as a consequence, create changes in critical mental states for the personality (Decker and Fleischer 2008). Specifically, it has been observed that brain stimulation can have an impact on psychological continuity, that is to say, on the essential requirement for personal identity to perceive oneself as a continuous and persistent entity, and "as the same person", over time (Klaming and Haselager 2013).

This right implies protecting the personal identity and continuity of personal behavior in the face of non-consensual modifications by third parties. This is closely related to the right to mental integrity and, at times, they might overlap as both rights seek to protect individuals from non-consensual alterations of their mental dimension.

The subject of new fundamental neurorights has not been picked up, for the moment, in regulation or legislation, but we believe it should be taken into account as soon as possible in the development and implementation of neurotechnologies such as BCIs in order to be able to analyze and manage risks as comprehensively as possible.

12.6 Conclusions

The mediation of technological devices, such as assistive technologies, in functionings environments determine the character of the assisted functionings and the way they are carried out. This involves modification of the original functionings, which will transform into "mediated" ones. In general, this mediation implies adaptation of the users' discourse to the artefactual discourse materialized in the devices (Winner

2007), which produces a transformation not only in the landscape of practices in the environment, but also in the panorama of its values.

More than one hundred years ago, Schumpeter spoke about processes for innovation as “creative destruction” (Schumpeter 1934). Recently, Javier Echeverría has been reflecting on the good and bad of innovation, assuming that all innovation has its beneficiaries but also those who are harmed (Echeverría 2014). The question that concerns us is how to distribute the benefits and the harms. It would be desirable for this to be done in a just and equitable way toward the conditions of functionings environments, on which the well-being and quality of life of people may critically depend.

In caregiving environments, the supposed advantages of new assistive technologies such as affective robots, robotic assistants, caregiving robots and others are already being advertised. But this is being done without taking into account that caregiving relationships imply elements that are essentially human and intrinsically intersubjective, and to care for a person with Alzheimer’s, to name one case, the best “technology” is another human being (de Asís Roig 2014). As we indicated in the Introduction, the current technological scenario affects rights such as privacy, identity, integrity and data protection, and requires new forms of care. In addition to traditional and familiar personal care, appealing to normative measures, such as the CRPD, which help to guarantee these rights, we also raise the need for social care, which assumes the importance of the public dimension of autonomy, related to the social participation of older and disabled people in the public debate on assistive technologies. The last threshold is the prevention of harm and damage (by action or by omission) involved in the ethical principle of non-maleficence (primun non nocere). We should avoid the adverse effects of assistive technologies in elderly autonomy, identity, and integrity as a case of “iatrogenesis” by means of a social and participative appropriation of that device.

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