

# **AUTONOMY IN THE AAL – BETWEEN LAW AND ETHICS**

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# ABBREVIATIONS

AAL	Active and Assisted Living
AI	Artificial Intelligence
CI	Contextual Integrity
CJEU	Court of Justice of the European Union
CNIL	Commission nationale de l'informatique et des libertés (FR)
DPD	Data Protection Directive
DPIA	Data Protection Impact Assessment
ECHR	European Convention on Human Rights
EDPS	European Data Protection Supervisor
EGE	European Group on Ethics
GDPR	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 (General Data Protection Regulation)
IoT	Internet of things
ICT	Information Communication Technology
MIPAA	Madrid International Plan for Action on Ageing
OEWG	Open-ended Working Group on Ageing
PbD	Privacy by design
RIS	Regional Strategy for the Implementation
TEU	Treaty of European Union
TFEU	Treaty on the Functioning of the European Union
UDHR	Universal Declaration of Human Rights
UN	United Nations
WP29	Article 29 Working Party

# 1 INTRODUCTION

## 1.1 *Technology for an active and assisted living*

### 1.1.1 Demographic changes and growth of Silver Economy

Silver Economy (the economy of the population over 50) is the third largest economy in the world, following only the US and China. It is going to grow going forward. In 2018 a study on the European Silver Economy has been conducted by the European Commission in collaboration with Technopolis and Oxford Economics. According to the Executive Summary of the research, by 2060 one in three Europeans will be over 65, and as soon as by 2025 the Silver Economy is projected to contribute over 5.7 trillion EUR to Europe's economy. One of the critical policy strategies that the research suggests is to not only embrace the tremendous financial and economic opportunities of the demographic change and Silver Economy growth but also to redefine the whole ageing experience. It will be achieved by creating a new identity of older individuals – one of healthy, active, independent and socially inclusive.<sup>1</sup>

### 1.1.2 Determining factors of active and healthy ageing

Ageing is a part of life, from the day we are born - we start our journey to ageing. There are many various perspectives on what it means to “age well”. The true meaning of “ageing

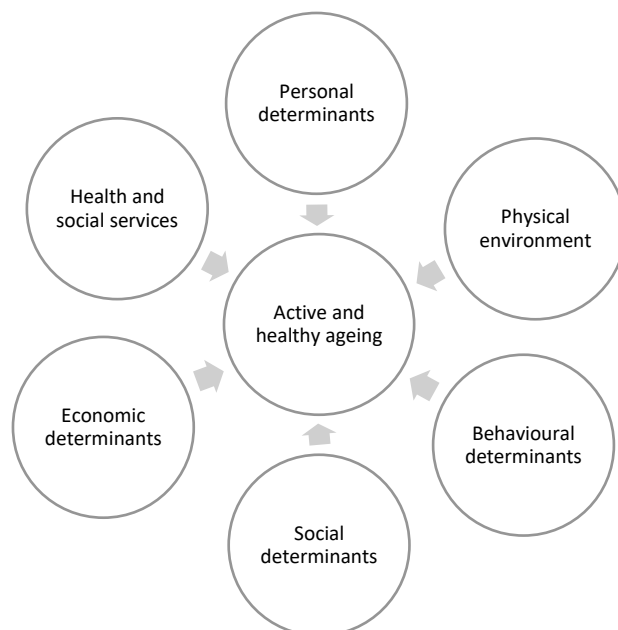


Figure 1 - Elements of Active and Healthy Ageing

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<sup>1</sup> The Silver Economy 2018.

well” is highly individual and will depend on the cultural background, education and the individual’s attitude to ageing.

Figure 1 above depicts the elements that cumulatively contribute to active and healthy ageing. Each of these elements benefits one way or another from new technologies. Below are some examples of how the technologies for Active and Assisted Living impact (AAL) every determining factor of healthy ageing.

*Health and social services* need to be improved in quality and affordability. For this, they need to be integrated and better coordinated. To help in the transformation of the health and care services and to speed up their integration, there is a need for including technological and digital solutions.

*Behavioural determinants* include healthy eating, physical activity, taking medication and preventive actions. Positive changes in lifestyle are bound to bring health benefits later in life.

*Personal determinants* for active and healthy ageing include biological and genetic features which make an impact on the person’s ageing experience overall and a person’s psychological and cognitive capacity. In this area, cognitive training games are designed to improve the older person’s memory and cognitive function.

*Physical environment* for active and healthy ageing includes transportation and housing. Here, technology can respond with driverless cars and smart homes that would facilitate and support the independent living of the older person for as long as possible.

*Social determinants* include the opportunities for education, training and social inclusion.

*Economic determinants* include income, employment opportunities and social protection.

By the above-presented determinants of the healthy and active ageing, the Report provided an overview of the case studies of potential technological solutions for seniors, which are presented in the next Section.<sup>2</sup>

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<sup>2</sup> The Silver Economy 2018, p. 27.

### 1.1.3 AAL technology – an overview

Below is a diagram that gives concise representation and explanation of the sector-specific technological aids that altogether constitute the AAL technology.

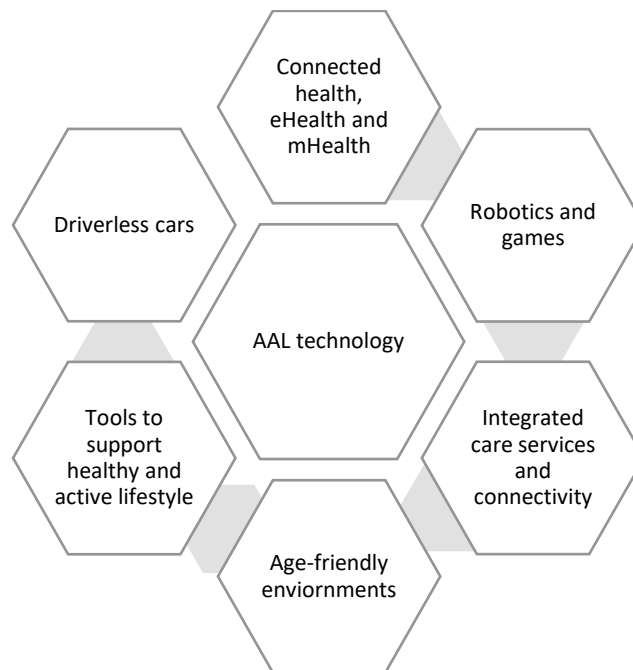


Figure 2 - Technologies that represent AAL

For the complete clarity as to what do these different sectors of the AAL include and to give a more clear and updated overview of the technologies discussed in this research, let us have a more detailed look at different groups of technological solutions and their functions.

*Connected health, including mHealth and eHealth solutions.* These technologies are primarily used to help in a healthcare setting, and their goal is to improve diagnosis and treatment of health conditions, manage disease prevention and conduct patient monitoring to speed up the recovery process and prevent or minimise disease recurrence. These can include neurological, cardiac and apnoea monitoring devices, devices for vital signs monitoring and medication reminders.

*Robotics and games.* The primary function of using robotics in senior care is to decrease the burden put on the care personnel and provide the older persons with the care and assist them in performing routine tasks while they are at home alone. Gaming technologies are aimed at the senior population that experience the onset of cognitive decline or have to face dementia. Developed gaming tools can help seniors keep a good memory function and train

their mind in an engaging way. Gaming solutions provide cognitive stimulation and rehabilitation.

*Integrated care services and improved connectivity.* These technologies are designed to help seniors take an active role in the care process. They include digital platforms that help seniors connect with the nurses and doctors and also with their relatives and other informal caregivers. This way seniors become central in the care management process.

*Age-friendly environments.* These solutions include smart homes that are designed utilising sensor and monitoring technologies to enable elderlies to live in their home independently for an extended period and feel safe and secure in their homes. This category also includes wearable and non-wearable devices for detection of falls and to ensure security and safety of the individual.

*Tools to support a healthy and active lifestyle.* These are apps and devices that harness the data analytics and machine learning to promote healthy and active life, including digital tools for preventive medicine, fitness wearables and trackers, nutrition trackers etc.

*Driverless cars.* This category represents cars that have smart monitoring solutions to track the driver's behaviour, driving habits, cognitive function and overall physical state. It would enable seniors to drive for an extended period. This technology will help increase the mobility of older persons and allow them to travel and visit their friends more frequently which will, in turn, decrease their social isolation and have a very positive impact on their overall well-being.<sup>3</sup>

Overall, AAL technologies have the potential to improve seniors' quality of life significantly. However, the uptake of the new AAL technologies is still not as rapid as would have been desirable. The main reason for this is the gap between technology and its target users. The gap presents itself in three dimensions: societal, legal and ethical.<sup>4</sup>

As can be seen, the term AAL includes a broad area of different technologies that aim at improving the ageing experience in all essential determinative factors that ensure healthy

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<sup>3</sup> The Silver Economy 2018, pp. 27-28, 35.

<sup>4</sup> Marcello - Ienca - Jotterand 2015.



and active ageing. The research will explore the AAL technology in its entirety without focusing on any specific tool or solution, methodology, sector or goal.

More precisely, the focus will be drawn to such features of the AAL technology as:

- Unobtrusive and ubiquitous monitoring.
- Data collection about the individual, his or her everyday life, daily activities, her environment and social interactions.
- Creation of profiles based on collected and analysed data.
- Broad utilisation of big data analytics, data mining and AI.

The AAL is enabled by the environment that uses unobtrusive computing devices, and its primary goal is to improve the quality of life and allow independence. It acknowledges individual needs, requirements and preferences based on the information it obtains through various environmental and wearable sensor equipment. The main attributes of AAL are *integration* – AAL is embedded in the environment, *adaptivity* – AAL is changing in response to the user preferences, *personalisation* – AAL is tailored to the specific user and *anticipation* – AAL may anticipate users' needs or predict changes in their behaviour, health and functioning.<sup>5</sup>

#### 1.1.4 AAL to promote individual autonomy

Living at home and in the environment of choice has proven to create benefits for the physical and mental well-being of the seniors, while being cost-effective for ageing societies. Health is an essential determinant for an independent life. Human health develops through the entire lifespan and is dependent not only on bodily functions or presence of the disease but also on the living environment and lifestyle. As people age, many health changes and challenges as people age are caused by habits and behaviours established during their lifespan. The overall goal of the AAL technology is to make seniors healthier, and subsequently, more independent and to increase their control over their own life – to promote their independence and autonomy.<sup>6</sup> Seniors highly cherish their independence, and they are willing to accept the AAL technology at home, as long as it helps them with

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<sup>5</sup> Mordini - De Hert 2010, pp. 167-168.

<sup>6</sup> Gomez - Montovani - De Hert 2013.

maintaining individual independence.<sup>7</sup> However, the relationship between the AAL and the autonomy of the individual is not linear.

On the one hand, the AAL technology has an increasing influence on the individual, and, therefore, decrease their ability to be genuinely autonomous in their decisions and actions. Moreover, the pace of technological development is so high that less tech-savvy seniors are less likely to follow-up with all new features, thus, losing their autonomous standing.<sup>8</sup> On the other hand, the autonomy of the individual in interaction with the AAL can be achieved when the individual is in charge of different configurations of the technology or in charge of taking certain decisions. Another autonomy-enabling example would be when a person with a chronic disease becomes free from the burden of thinking and making decisions related to their chronic condition and free from having to think about the disease all the time.<sup>9</sup>

There are many issues related to a person's ability to use AAL, their attitude to its presence in everyday life and the way it affects privacy.<sup>10</sup> The socio-technical infrastructure of the AAL technology may result in different vulnerabilities to older individuals. Seniors can be increasingly vulnerable to profiling inaccuracies, privacy breaches, autonomy trap, unfair discrimination and stigmatisation. According to *Nissenbaum*, there is a potential connection between data collection, aggregation and profiling and *subtle erosion of autonomy* which is a very different concept from that of open coercion, influence and limitation of individual autonomy.<sup>11</sup> This same idea coincides with the notion of "autonomy trap".<sup>12</sup> So while the AAL may enhance a person's safety and autonomy, the risk of subtle coercion and influence is still very high.

While being the central pillar in the development of the future European Silver Economy and having large promises as to enabling "healthy and active ageing", the role of the AAL in facilitating or inhibiting individual autonomy remains dubious. AAL users belong to a senior demographic – a vulnerable user group that is most likely to be challenged by

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<sup>7</sup> Ranchordás - Kaplan 2017, p. 51.

<sup>8</sup> Rouvroy 2009, p. 47, Gomez - Montovani - De Hert 2013, p. 151.

<sup>9</sup> Gomez - Montovani - De Hert 2013, p. 155.

<sup>10</sup> Bronfmant 2016.

<sup>11</sup> Nissenbaum 2010.

<sup>12</sup> Zarsky 2014.

physical, mental or sensory impairment, or require special attention considering their lifestyle, illness or frailty. Therefore, exploring the autonomy of AAL users is crucial.<sup>13</sup>

## *1.2 The research question, structure and scope*

The primary goal of this research is to examine the notion of autonomy and the way it manifests itself in the interaction of seniors with the AAL. In other words, to what extent does the AAL promote senior's autonomy or, on the contrary, inhibit it? This research will look at the autonomy in the AAL context as being enabled by two instruments: legal norms and ethical norms, and, therefore, two perspectives to the autonomy will be studied: legal perspective and ethical perspective. The overarching question of this research is: *How does legal and ethical can ensure that senior's autonomy is enabled during their interaction with the AAL technology?*

The research question will be analysed by exploring the notion of autonomy and its relation to privacy and what is the connection between these two concepts. The research will also separately look at the AAL technology and the way it threatens individual autonomy through the Contextual Integrity framework. Then the study will analyse the legal safeguards for autonomy and proceed to ethical principles and guidelines as autonomy enablers. Finally, legal and ethical approaches to the autonomy in the AAL will be analysed, and how they both can be efficiently utilised will be presented.

The structure of the thesis is based on the top-down approach. *Chapter 1* gives a general overview of the AAL technology and defines the types of technology that the thesis is focusing on. It also stresses the significance of technology in promoting active and healthy ageing. *Chapter 2* gives background to further research and defines in depth such concepts as “*privacy*” and “*autonomy*”, and also looks into the connection and interrelation between them. *Chapter 3* dives into the features of the AAL that are threatening individual autonomy and in *Chapter 4* the AAL is evaluated through the Contextual Integrity Framework. *Chapter 5* analyses the legal approach to autonomy and the way in which legal norms enable it in senior-AAL interaction. The Sections of this Chapter look into *the right to data protection* and the *right to private life* as the legal instruments to facilitate autonomy in the AAL. *Chapter 6* goes on to examine the ethical norms and principles applicable to the AAL.

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<sup>13</sup> Fisk - Rudel 2013, p. 212.

Finally, *Chapter 7* concludes the research and presents key findings and answers the primary research question.

The scope of the research is limited to the AAL technologies presented in Section 1.2 of this Chapter. It is important to mention that the possible applicability of the Medical Device Regulation to the AAL<sup>14</sup> is out of the scope of this research work. Also, the ePrivacy Directive was not examined since during the time this research work was written, the EU legislator was preparing a new ePrivacy Regulation to bring it in line with the GDPR. Seniors are defined as individuals aged 65+. This group will also include individuals with a physical and mental disability. Geographically, the research will focus on the legislation of the European Union. The context in which autonomy, privacy and ethics are explored will be solely limited to the AAL technology application in senior care. The areas of law studied in this research are data protection law, human rights law, information society law. Ethical norms include principles of biomedical ethics and ethics of care and standards of ethical technology design.

### *1.3 Methodology and source material*

Methodology primarily used in this research is legal doctrinal.<sup>15</sup> The research will be based on the law of the European Union. The sources of the hard law will be studied, such as *Treaty of European Union (TEU)*, *Treaty on the Functioning of the European Union (TFEU)*, *Charter of Fundamental Rights of the European Union*, Regulations and Directives (in particular – *General Data Protection Regulation*) and *CJEU* case law. Also, the Universal Declaration of Human Rights (**UDHR**), the *European Convention on Human Rights (ECHR)* and the jurisprudence of *the European Court of Human Rights (ECtHR)* as binding on the European Union will be studied. Soft law, such as opinions, law commentaries, policy reports, guidelines (Article 29 Working Party guidelines), codes of conduct, communications, codes of ethics and ethical guidelines will also be thoroughly analysed. Further, research articles and literature will be used to give a broader overview of the concepts and discussions around them.

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<sup>14</sup> Regulation (EU) 2017/745 of the European Parliament and of the Council of 5 April 2017 on medical devices, amending Directive 2001/83/EC, Regulation (EC) No 178/2002 and Regulation (EC) No 1223/2009 and repealing Council Directives 90/385/EEC and 93/42/EEC (Text with EEA relevance) OJ L 117, 5.5.2017, p. 1–175, Art.2(1), Rec. 19.

<sup>15</sup> MConville - Chui 2007, p. 19.

The research will also use the socio-legal methodology, in particular, “socio-techno-legal” approach which will analyse law, technology and ethics. Since this research is focused on the introduction and impact of novel technology, the *Synthetic Theory of Law and Technology (the Synthetic Theory)* will be utilised to analyse the intersection of law and technology. This theory is based on the combination of instrumental and substantive theories of technology. The *instrumental theory* defines technology as a neutral tool and does not consider it in the social, cultural and political contexts. On the contrary, *substantive theory* emphasises the way in which technology can control or influence individuals without their awareness of it. Synthesis of both theories helps eliminate their drawbacks if used separately. When new technological developments threaten legally protected values and interests, synthetic theory gives a new view on the relationship between law and technology.<sup>16</sup>

The legal analysis uses two approaches to examine the relationship between law and technology. *The liberal approach* is close to a substantive theory of technology, and it looks into how the law safeguards interests and values that are threatened by the new technology. This approach recognises that technology and its developments are engrained into economic, political, social and other processes and subsequently analyses the latest technology in all these different contexts. Another approach is *conservative*, and it follows a traditional doctrine not taking into consideration how law and technology influence interests and values.<sup>17</sup> The conservative approach is connected with the instrumental theory of technology that views the technology separately from economic, political, cultural and social processes.

The Synthetic Theory does not change the traditional legal analysis; it instead looks more into the way technology can have an impact on individuals and their legal interests apart from the technology intended use. This research will utilise the framework in the following way.

The first step in applying the Synthetic Theory of law and technology would be, through a legal doctrinal analysis applicable to the affected area of technology law, to identify if the traditional interest or value protected by law is affected. In the course of this research, through the legal doctrinal analysis of the European data protection and privacy law, and

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<sup>16</sup> Cockfield - Pridmore, 2007, pp. 475-476.

<sup>17</sup> Cockfield - Pridmore, 2007, p. 501.

ethical codes and standards, the traditional value of individual autonomy and how it is affected by the novel technology will be analysed. This step is in alignment with the instrumental theory of technology. Instrumentalism in this context sees individual playing an active role in the adoption or rejection of the new technology. It assumes that the purpose of the law is to provide a legal framework that promotes technological development by encouraging and rewarding innovation; and, thus, advances the common good.

The second step of analysis will use a contextual analysis to look into the broader context of AAL and its potential impact on the autonomy of the individual and suggest solutions from both legal and ethical perspective to protect individual autonomy in the AAL.<sup>18</sup> Due to the strong connection between the notions of privacy and autonomy,<sup>19</sup> in the second step of the Synthetic Theory, the research will also utilise the Contextual Integrity framework. Contextual Integrity is a step-by-step decision heuristic that is specifically designed to analyse the impact of the new technology on privacy, and it perfectly aligns with the second step of the Synthetic theory. In a nutshell, Contextual Integrity is a theory of privacy developed by *Nissenbaum*. The theory connects protection of personal information to the norms of the appropriate information flow within specific contexts. Contextual Integrity framework rejects the traditional distinction between private and public information and instead stresses on the preservation of informational norms within the contexts. The framework evaluates the flow of personal data between different actors and helps identify which information flows are appropriate in one context but are unacceptable in another.<sup>20</sup>

#### *1.4 Terminology*

This research operates with terms that are more common in computer science and enter the realm of privacy and data protection law when the new technologies are examined. Introducing and defining certain terminology that is less common in the legal field is necessary so that the reader can easily follow the arguments presented in this research.

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<sup>18</sup> Cockfield - Pridmore, 2007, pp. 503-505.

<sup>19</sup> Discussed in detail in Section 2.4.

<sup>20</sup> Nissenbaum 2010.

“*AAL technology*” or “*AAL*” means a broad area of different technologies that aim at improving the ageing experience in all essential determinative factors that ensure healthy and active ageing.

“*IoT*” means a network infrastructure, linking uniquely identified physical and virtual objects, things and devices through the exploitation of data capture (sensing), communication and actuation capabilities.<sup>21</sup>

“*Big data*” represents extensive datasets—primarily in the characteristics of volume, variety, velocity, and/or variability—that require a scalable architecture for efficient storage, manipulation, and analysis.<sup>22</sup>

“*AI*” means a branch of computer science dealing with the simulation of intelligent behaviour in computers or the capability of a machine to imitate intelligent human behaviour.<sup>23</sup>

“*Web 3.0*” means connective intelligence; connecting data, concepts, applications and ultimately people.<sup>24</sup>

“*Code as law*” is the main argument expressed by L.Lessig. It means that a code (the protocols and software) which makes the functioning of the Internet possible is also playing the regulatory role in the cyberspace.

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<sup>21</sup> Ebersold 2016, p. 145.

<sup>22</sup> NIST 2015, p. 4.

<sup>23</sup> As defined by the online version of the Merriam Webster Dictionary, See <https://www.merriam-webster.com/dictionary/artificial%20intelligence> [accessed 17 December 2018].

<sup>24</sup> ‘What Is Web 3.0? Webopedia Definition’ <[https://www.webopedia.com/TERM/W/Web\\_3\\_point\\_0.html](https://www.webopedia.com/TERM/W/Web_3_point_0.html)> [accessed 17 December 2018].

## 2 BACKGROUND

### 2.1 Introduction

This Chapter is going to explore the concept of “autonomy” so that the reader has a comprehensive understanding of what it is, what are its essential attributes and what are the different types of autonomy that are differentiated in the literature. Further, the definition of the concept of “privacy” and its importance to autonomy is discussed. And finally, the relationship between autonomy and privacy will be presented.

### 2.2 Autonomy concept

Let’s start with the definition of autonomy. *Dworkin* has defined autonomy as being equal to “*positive and negative liberty, dignity, integrity, individuality, independence, responsibility and self-knowledge, self-assertion, critical reflection, freedom from obligation, the absence of external causation and knowledge of one’s interests.*”<sup>25</sup> Quoting *Agich*, “*autonomy can be conceived as (a) self-reliance, i.e., the capacity to provide for one’s own needs; (b) personal preferences, the capacity to express your wishes, desires and impulses and make your own decision and choices; and (c) self-assertion, the pursuit of the fulfilment of one’s desires and goals.*”<sup>26</sup> *Raz* defines a person who is autonomous as being “*an author of her own life*”, and stresses that autonomy is a “*constituent element of the good life*”. *Raz* mentions that the ideal of personal autonomy is when individuals can, to a certain extent, control and influence their life path through decisions they make. Autonomy in his understanding also includes the freedom to be irrational which means freedom from being coerced, excessively and unfairly persuaded and unduly influenced. It considers the fact that the concept of autonomy recognises people as individuals and members of society – social beings. And the ability to make autonomous decisions is one of the forms of social freedom.<sup>27</sup>

Research literature contains a large variety of ways to define the notion of autonomy. However, most of these definitions circle around these critical attributes:

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<sup>25</sup> Dworkin 1988, p. 6.

<sup>26</sup> Agich 2003, p. 11.

<sup>27</sup> Raz, 1986, pp. 368, 408.



- Self-governance.
- Self-determination.
- Freedom (positive and negative).
- Decision-making governed by an individual's principles.
- Human dignity.

The freedom attribute of individual autonomy has an especially important role to play in the general context of senior care practices. The relationship between a caregiver<sup>28</sup> and a senior individual is not always horizontal but more often – it is a top-down relationship where a senior person partially or fully depends on the caregiver's decisions. The freedom aspect of autonomy manifests in the individual's ability to make choices, to have the opportunity to make choices and be properly informed about it. Also, the choices given to individual must be meaningful.<sup>29</sup> Freedom to choose also includes the opportunity to make “wrongful” choices, for example, the choice not to accept care.<sup>30</sup>

Autonomy can be distinguished into two types: moral and personal autonomy. Moral autonomy is when the individual can subject oneself to objective moral principles. Personal autonomy is a morally neutral trait that an individual can exhibit relative to any aspect of their life not limited to questions of moral obligation.<sup>31</sup> Moral autonomy is embodied in the individual actions that are governed by the principles that are her own and which are subject to a critical analysis.<sup>32</sup>

Two types of autonomy that are particularly relevant to the senior care were introduced by the Independent Living Movement: (i) decisional autonomy - the capacity to exercise control over any activity that is needed to fulfil one's desires, and (ii) executive autonomy - the ability to perform these activities for oneself without any assistance. Independent Living Movement holds decisional autonomy as the starting point of any caring relationship. If the need for care is entirely determined by the individual's incapability (i.e. lack of executive autonomy) and the experts or relatives who "knew better" are in control

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<sup>28</sup> Here the term caregiver is used broadly which includes institutions and individuals.

<sup>29</sup> Bernal 2014, p. 25.

<sup>30</sup> Hildebrandt - Koops 2010, p. 7.

<sup>31</sup> Marshall 2009.

<sup>32</sup> Nissenbaum 2010, p. 81.

of care relationship – it completely negates the decisional autonomy of the individual, and such care relationship should not take place.<sup>33</sup>

The ideal autonomous good life has two elements: i) quality of life and ii) autonomous capacity and opportunity to lead such life. Therefore, it is important to consider the capacity and the opportunity to be autonomous. Capacity relates to the physical ability to be autonomous, for example, all healthy adult people have the full capacity to be autonomous. However, if we take children, animals, mentally or physically impaired, their capacity to exercise autonomy is limited. But what about the opportunity to be autonomous? Should the limitation in the capacity to be autonomous due to impairment affect the opportunity to be autonomous? When considering someone who has limited capacity to exercise autonomy they should be allowed the opportunity for the autonomy as it is still an important element of the autonomous good life and should not be affected by the possible limitations in capability to be autonomous.<sup>34</sup>

In the realm where AAL technologies are used in home care and nursing homes, autonomy embodies itself in various engagements with technology, individuals, organisations, institutions and living environments. In this regard, for a senior individual, there are many ways of being autonomous. For example, the autonomy can be gained when the individual is an active user of the AAL technology and becomes the manager of her health, which otherwise, is fully managed by care personnel, doctors and relatives. In another situation, the autonomy is achieved when the individual is liberated from the need to think about her ailment and be completely autonomous from it negatively affecting their life experience.<sup>35</sup>

Individual autonomy is something that the state cannot provide only through the law. However, despite this, showing respect to individual autonomy and providing opportunities to the individuals to develop their capacity for the individual autonomy has nowadays become the most fundamental legal and ethical imperative.<sup>36</sup> The understanding of autonomy is different when looking at it from the legal perspective and the perspective of the ethics of specific care practices.<sup>37</sup>

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<sup>33</sup> Hildebrandt - Koops 2010.

<sup>34</sup> Hildebrandt - Koops 2010.

<sup>35</sup> Gomez – Montovani - De Hert 2013, p. 154.

<sup>36</sup> Rouvroy - Pouillet 2009.

<sup>37</sup> Gomez – Montovani - De Hert 2013, pp. 147-158.

### 2.3 Defining privacy concept

We have just explored the concept of autonomy, and now it's time to define the concept of privacy. In the same way as autonomy, privacy is related to the concept of individual freedom and human dignity. In this Section, we will focus on the concept of privacy overall, not on the right to private and family life. In Chapter 5, we will explore in depth the right to private life.<sup>38</sup>

There are different theories of privacy. Control theory is the major one. The well-known privacy scholars, such as *Miller* and *Westin* are the proponents of this theory. According to *Miller*, individual's ability to control the circulation of information about them is often a central part to maintain relationships and personal freedom, and it is also an attribute of an effective right to privacy. *Westin* defined the concept of privacy as “*the claim of individuals, groups or institutions to determine for themselves when, how and to what extent the information about them is communicated to others*”.<sup>39</sup> However, this theory of control falls short when the new ways of data processing come into play.<sup>40</sup>

Privacy is closely related to the notion of control. It may mean either limiting access to one's personal data or giving access to certain personal information. However, another understanding is that privacy is about setting the boundaries of the individual against others within different spatial, temporal and cultural situations. Privacy is a dynamic practice, not a static value which allows a person to build her personality free from negative stereotyping or social and public preconceptions that may influence individual and the development of her identity.<sup>41</sup> It helps to protect moral capital in the form of individual private information and share it with trusted persons that would help to forge trustful and close relationships. It also allows individuals to pursue activities that they would not otherwise be comfortable pursuing in public or when the level of expectation of privacy is rather low.<sup>42</sup> Privacy enables individuals to regulate their ability by selecting which personal information they share with others. The individual has certain vulnerabilities and weaknesses, and privacy helps to deal with them without causing individuals to feel intimidated by other people or

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<sup>38</sup> Marshall 2009, p. 4.

<sup>39</sup> Buitelaor 2012, p. 188.

<sup>40</sup> Pan - Martinson 2016.

<sup>41</sup> Hildebrandt 2015.

<sup>42</sup> Marshall 2009.

feel like they are held accountable in front of others for their vulnerabilities that they have no way of changing.<sup>43</sup>

Privacy is protecting individual independence, dignity and integrity; in this sense, it is closer to autonomy. Privacy can be divided into four different concepts: informational privacy, physical privacy, the privacy of communications and spatial privacy.<sup>44</sup> Another way to present different dimensions of privacy is to divide it into spatial, relational and informational privacy. Spatial privacy is the inviolability of home or other premises where the person expects to be private. Informational privacy relates to data protection.<sup>45</sup>

Another theory of privacy is Contextual Integrity framework. It was introduced by *Nissenbaum's* book "Privacy in Context". *Nissenbaum* argues that privacy is not limited to either limiting control to access to personal information or being in control of making the personal information accessible to others - it is much more than that. People care about the proper flow of the information. By introducing the Contextual Integrity framework, the author stresses the importance of following the informational norms. By focusing too much on the definition of what privacy is or is not is in practice halting the progress to address the challenges that are related to the protection of privacy.<sup>46</sup>

Privacy does not particularly hold universal importance as a central and fundamental value. There are many critiques to the concept of privacy. These critiques or challenges can be divided into the following groups: security critique, economic critique, communitarian critique, feminist and transparency critiques. Without going into much detail on all the critiques, let's focus on the ones that are the most relevant to the AAL application in the senior care: economic and transparency critiques.

The essence of the economic critique is that excessive support of privacy reduces business opportunities. Therefore, protecting the individual is less important for business progress than supporting a thriving economy. However, the benefits of abusing privacy and autonomy are rather short-lived. If the businesses want to enjoy sustainable economic benefits, the relationship between the needs and desires of individuals must be balanced,

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<sup>43</sup> Krausova 2009, p. 329.

<sup>44</sup> Marshall 2009.

<sup>45</sup> Hildebrandt - Koops 2010.

<sup>46</sup> Nissenbaum 2010, Hildebrandt 2015.

which means ultimately giving more respect for the privacy and autonomy of the individual. Where the needs of the individual are not respected, businesses are likely to suffer or even fail.

The economic challenges are very crucial especially in the AAL as the businesses are the key drivers of technological development and therefore it may be tough to persuade them to change their methods for the benefits that are very debatable and far-fetched. More to that, businesses would somewhat be convinced by the demands of finance or customer demands than philosophical or moral argumentation. It underlies the symbiotic regulation approach: to work precisely through the mechanism of symbiosis between businesses and their customers, their competitors, *etc.* It is vital that the rights of the individuals do not override the freedoms that companies require to develop new technologies and to thrive. When the competing rights and freedoms are kept in balance, the beneficial aspects of symbiosis will be achieved. Businesses often see data protection law as a bureaucratic burden. The consent is seen as an unnecessary intrusion in the service provision which delays the delivery of service to the customer and deprives the customer of good customer experience. Business lobby groups work hard to try and lessen the impact of data protection legislation.<sup>47</sup>

The transparency critique states that the idea of privacy is somewhat outdated and is not feasible today because of the fast advance of technological society and changed attitude to privacy. In the modern surveillance society, the expectation of privacy, especially in the online realm is very low. Additionally, individuals are engaging in ever more open sharing of every possible aspect of their private lives for the whole Internet to observe. There are three variants of the transparency critique: (1) the struggle for privacy is lost, (2) the battle for privacy is outdated, and (3) the struggle for privacy is wrong: we should embrace transparency and make the lack of it a virtue to be enjoyed. The weakness of these arguments is discussed in more detail in Chapter 4.

Web 3.0, as envisaged by Tim Berner-Lee, has the potential to grant us more autonomy and increase the freedom of choice by giving individuals more power over the information they share on the Internet. However, this same potential of the technology could turn to the opposite direction and rob us of the anticipated freedoms and become something that instead

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<sup>47</sup> Bernal 2014, pp. 43-52.

controls than empowers us. Privacy is crucial to ensure that the latter scenario does not materialise.<sup>48</sup>

## *2.4 The relationship between privacy and autonomy*

Privacy and autonomy are partners in protecting and supporting many human rights. Privacy as a protector of the autonomy<sup>49</sup> rather than privacy per se is the focus of this research. There are two rationales for privacy: privacy as seclusion, which is often spatial and privacy as freedom of action, self-determination and autonomy.<sup>50</sup> Privacy is a legal concept or an intermediate value for encouraging final values such as liberty, autonomy and self-determination.<sup>51</sup> The legal right upon which the autonomy rests is the right to respect one's private life."<sup>52</sup>

*Nissenbaum* gives three forms of relationship between privacy and autonomy that summarise and expand the above definitions of both concepts in their relation to one another.

First one is conceptual where privacy is partially constitutive of autonomy. In this form of relationship, the privacy is understood as the right to control or determine access to information about oneself. So, the relationship between the two is not causal, and privacy is understood as a form of autonomy, in particular, it is a person's self-determination concerning information about oneself. There is also a connection between privacy and individual's self-presentation and identity formation.

Second is when the privacy is viewed as a constraint on access to people through information and as such promotes our freedom of thought and action. When under observation people may feel that they need to act or not act in certain ways. When this is the case, it means that we have internalised the watcher and our behaviours are determined by the fact that we are being watched and they are no longer our own. In this relationship,

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<sup>48</sup> Bernal 2014, pp. 48-53.

<sup>49</sup> Bernal 2014, p. 10.

<sup>50</sup> Marshall 2009.

<sup>51</sup> Rouvroy - Pouillet 2009.

<sup>52</sup> Bernal, 2014, p. 49.

privacy and autonomy have a causal effect so that for the autonomy of the individual to exist, there needs to be privacy and the absence of the latter will undermine the former.

The third relationship between privacy and autonomy draws on the understanding of autonomy as not only the ability to review the principles critically and act on them but also the ability to follow through. In today's surveillance world of pervasive monitoring, data aggregation and mining, behavioural advertising and so on, the manipulation that deprives the person of the autonomy is much subtler than when the person's actions are explicitly manipulated in a coercive way. These technologies may influence people's weaknesses, and these may result in the fact that people make a choice that is not inherently their own. Such surveillance results in the "*subversive manipulation*" since it has very little to do with the goals that people have set for themselves, it is centred around the exploitation of people and their circumstances to benefit others. *Nissenbaum* states that there is a direct connection between the data collection, aggregation and profiling and "*subtle erosion of autonomy*". The author stresses that these practices lead to "*coercion, deception and manipulation*".<sup>53</sup>

## 2.5 Conclusions

Despite the varying definitions of the concept of "autonomy", all of them encompass its key definitive attributes, such as self-governance, self-determination, freedom, individual decision-making and human dignity. In the social care setting, there are two approaches to define individual autonomy. It is defined as decisional autonomy and executive autonomy or as the capacity and opportunity to be autonomous. Decisional autonomy is the starting point of any care relationship, meaning that even when the executive autonomy of the individual is limited, his or her decisional autonomy needs to be upheld even if it means making the "wrong" choice of not providing care to the individual if they have decided so. Similar idea surrounds the capacity versus the opportunity to be autonomous. Chance to be autonomous is still important even if capacity is limited.

Privacy and autonomy go hand in hand in protecting human rights. Privacy is an important value, and it is even more important as a protector of individual autonomy. There are many different theories of privacy. This research is based on the theories of privacy as control and privacy as contextual integrity which is explored in more detail in Chapters 3 and 4. Privacy is also a subject of various critiques with the economic and transparency critiques being the

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<sup>53</sup> Nissenbaum 2010.

most prominent. The economic critique points out that businesses are the key drivers of technological progress and the need to observe privacy stalls innovation. The transparency critique states that people do not care about privacy anymore and it is not relevant in light of widespread sharing of personal data on the Internet. While both critiques have their merit, this research stresses that privacy is a significant value to enable individual autonomy particularly in the age of emerging technologies that have a massive potential of depriving individuals of their autonomy as they become more sophisticated and autonomous.

The relationship between privacy and autonomy manifests in three ways. First is when privacy is a form of autonomy and is defined through the individual's ability to control the information about oneself. The second form is when privacy promotes individual freedom by constraining access by others to the personal information. Here privacy acts as a pre-condition to the autonomy. And the third form of relationship is when the autonomy act as a pre-condition to privacy. It is based on the person's ability to follow through on her wishes and desires. New technologies that are incorporating big data analytics, machine learning and ubiquitous surveillance affect our privacy and autonomy in a subtle way. While we may have a perceived control over personal information, our actions and decisions are influenced without us realising, thus, affecting our autonomy and, subsequently, privacy.



# 3 AAL AND ITS IMPACT ON INDIVIDUAL AUTONOMY

## 3.1 Introduction

New technologies undoubtedly disrupt existing legal and regulatory orders because they can disturb the values which lie in the core of current legal and regulatory frameworks.<sup>54</sup> Technology might strengthen the core values or weaken them, and quite often the impact of the technology is unclear or is determined much later, at the stage of its application.<sup>55</sup> Generally, it is very challenging to characterise technology in binary terms as “positive” and “negative” or “acceptable” and “unacceptable” as it has many complex and often unexpected dimensions and subsequent impacts.

Legal analysis of technological change can be broken into two categories: liberal – takes into account how technology affects interests, and conservative approach relies on a more traditional doctrinal analysis.<sup>56</sup> A critical review of the interplay between law and technology is fundamental since technological developments determine and influence human behaviours often in ways that cannot be anticipated in advance. The more technology penetrates different areas of our lives – the more it shapes our values, culture, norms and interests.<sup>57</sup> This feature of the technology is called – “*technological determinism*”.

Technological determinism is one of the critical concerns in the substantive theory of technology. According to it, technology to a certain extent produces a society that must act and exist in certain ways. Modern technologies especially enhance this determinism, and we – humans – are forced to keep up with the technology. We are also used as the resources for the technology, and we have a false sense of control over the technology while it controls us. Technological determinism highly depends on whether technological development is

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<sup>54</sup> Brownsword - Scotford - Yeung 2016, p. 5.

<sup>55</sup> Brownsword - Scotford - Yeung 2016, p. 17.

<sup>56</sup> Cockfield 2004, p. 383.

<sup>57</sup> Cockfield 2004, p. 385.

deeply embedded in our social structures. Once the technology is deeply ingrained in social practices – it shapes them.<sup>58</sup>

Technology is no longer a sole target of regulation but became a regulatory tool itself by incorporating legal compliance through risk assessment and risk governance. The concept of techno-regulation and “*code as law*” approach<sup>59</sup> present a different role of technologies – regulatory. The concept of “privacy by design”<sup>60</sup> is also a part of this approach. It is rather difficult to separate technological developments from legal developments. Law-making is a much longer process as compared to the process of technological advancement. This time gap has two significant impacts: 1) legal uncertainty where the involved parties do not know and understand their rights and obligations fully, and 2) the time gap allows momentum for consideration and analysis before legal regulation. Technology is the law – technology imposes limitations and constraints on individual and business behaviour. Control by law is the ability to enforce the law in a specific technological environment.<sup>61</sup>

Instrumentalist theory of technology states that technology is a neutral tool that serves the purposes of its users. This theory recognises human agency in technology in a sense that individuals direct the use of technology. Therefore, there is no danger in individual autonomy being limited or diminished by the technology.<sup>62</sup> On the contrary, the substantive theory of technology emphasises that technologies have an impact on society. When it comes to law and technology analysis – the instrumental theory is dominating, and a minimal account is taken of how technological developments interact with law and institutions that can have adverse outcomes.

Based on the theory of technological determinism, next Section will review how the AAL threatens the autonomy of the individual through its architecture.

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<sup>58</sup> Brownsword - Scotford - Yeung 2016, p. 397.

<sup>59</sup> Lessig 2006, See also Hildebrandt - Koops 2010, Hildebrandt 2015 where a concept of ambient law similar to “code as law” is explained.

<sup>60</sup> See more about “privacy by design” and the regulatory role of technology in Sections 5.3.7 and 3.1 respectively.

<sup>61</sup> Cockfield 2004, p. 397.

<sup>62</sup> Cockfield 2004, p. 480.

### 3.2 Restrictions and threats to autonomy

The balance between the different interests of individuals, governments and communities cannot be achieved without placing some limits on individual autonomy. Restrictions that are aimed at protecting the rights of others or the interests of the population are considered acceptable, necessary and appropriate. “*Razian*” understanding of autonomy, which was mentioned in Section 2.2, allows and even requires the intervention by governments to support autonomy. However, restrictions that result from asymmetrical informational relations are unacceptable. These types of restrictions are discriminatory and reinforce the imbalance of power. Restrictions to autonomy have many negative impacts and put at risk human rights, such as freedom of association, assembly, thought and religion, and other rights including social, cultural and economic rights.<sup>63</sup>

AAL brings three types of vulnerabilities that have a high potential to restrict autonomy: profiling, surveillance and involvement of third parties, the "autonomy trap" and behavioural nudging.<sup>64</sup>

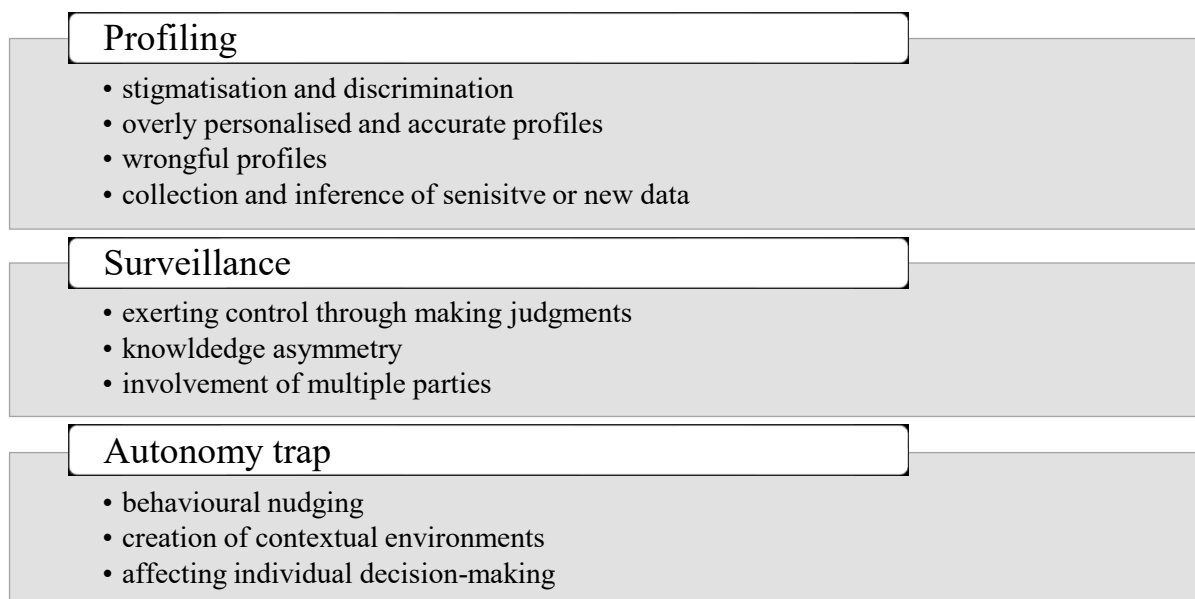


Figure 3 - Three groups of vulnerabilities brought by the AAL

<sup>63</sup> Bernal 2014, p. 31-32.

<sup>64</sup> Hildebrandt – Koops 2010.

### 3.2.1 Profiling

When an individual interacts with AAL technology, her autonomy is threatened by the profiling and its related processes. In the AAL context, the data collected about the individual and her environment is very sensitive and can reveal certain sensitive habits, patterns, preferences, physical conditions and other extremely unique information about the person.<sup>65</sup> Over time, the profiles can expand enormously through data enrichment mechanisms and unexpected insights could be drawn by combining different sets of data in the long run. Initially, mediocre data collected through a single device can, later on, be a missing puzzle complementing a big picture that would give completely unexpected and unpredicted results. Inferred data can become rather sensitive as compared to the one that was initially provided by the individual, and had this person known in the first place that such sensitive data would be inferred about them, they would not have provided any information to the service provider. AAL has an impact on autonomy either when the profiles are overly accurate or not. The negative impact of overly accurate profiling can manifest in revelations about an individual's sexuality or pregnancy (the well-known Target example)<sup>66</sup> or in the encouragement of the individual to react on their immediate impulses rather than future aspirations. Also, over-personalisation is resulting in the creation of filter bubbles - different universes of information provided to different individuals. These bubbles have an effect on individual autonomy and erode civic engagement; they also contribute to the polarisation of society.<sup>67</sup> Inaccurate profiling can result in inappropriate decisions made on its basis, thus, also negatively affecting the individual.<sup>68</sup> When the profiles are matching a specific ethnical background, the individual may face discrimination and stigmatisation due to possible third party access to the data generated on the ethnical group or due to possible correlations that are not necessarily correct.<sup>69</sup> Also, because AAL is ubiquitous and

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<sup>65</sup> Paez and La Marca 2016.

<sup>66</sup> 'How Target Figured Out A Teen Girl Was Pregnant Before Her Father Did' [accessed 16 December 2018].

<sup>67</sup> Pan - Martinson, 2016.

<sup>68</sup> Bernal 2014, p. 13.

<sup>69</sup> Rajaretnam 2014, p. 300., Generation of "new" information about the individual is the process when different data sets are combined and the new data is generated by means of inference from the combined data sets. The new data obtained by such means carries inherent inaccuracy. The results obtained by this means will not render completely accurate data in all cases. See also Wiedemann 2018, p. 11.

invisible, the individual is not aware of the profile content that is being generated about them in the real time.<sup>70</sup>

### 3.2.2 Surveillance and involvement of multiple parties

If surveillance is misused, the individual autonomy is reduced.<sup>71</sup> Individual's awareness of the fact that they are being observed limits their autonomy. AAL generates conclusions about people's attributes and behaviour and thereby makes judgements about them. It is very close to George Orwell's idea of Panopticon which exerts control over individuals not only through surveillance but also through making judgements about them.<sup>72</sup> Awareness that we are being scrutinised impinges our inclination for a free choice. Even though a person makes a conscious choice, this choice is invisibly influenced by the knowledge asymmetry between those who profile and those who are being profiled. The threat of scrutiny obstructs the emotional release that is available to individuals in the comfort of their privacy. Especially when it is unclear what data will be generated - any collected information has the potential to affect individual autonomy.<sup>73</sup>

The nature of senior care, one way or another requires the involvement of different parties in the care process, but the use of AAL extends their number even further. Among these parties are: doctors, caregivers, family members, technical or maintenance personnel, senior care managers, insurance companies and even possibly other AAL providers. Also, external agencies such as telecommunications and data storage and processing service providers, and patient monitoring companies. Considering the number of parties involved, the knowledge asymmetry threatens senior's autonomy.<sup>74</sup>

### 3.2.3 Autonomy trap and behavioural nudging

AAL technologies are real-time data-driven adaptive environments that transform the information output based on the profiles that they have generated about us. The generation and content of these profiles are challenging to predict and anticipate. The flow of information that is produced as an output influences our behaviour. And so the ability of the person to make her own choices becomes influenced by the information that the

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<sup>70</sup> Gadzheva 2008, p. 63.

<sup>71</sup> Fisk - Rudel 2013, p. 219.

<sup>72</sup> Orwell, 1984.

<sup>73</sup> Pan - Martinson 2016.

<sup>74</sup> Ranchordás - Kaplan 2017, p. 39.

individual has no control over and no way of anticipating what it may be like. Therefore, interacting with AAL technology from the standpoint of the senior individual in a way that would be respectful to her autonomy is very difficult.<sup>75</sup> Zarsky describes this phenomenon as an “autonomy trap”.<sup>76</sup> The origin of the autonomy trap lies within the mass media’s ability to shape human behaviour. Before the Internet, our tastes, views and perceptions were influenced by traditional media channels, such as newspapers and television. After the Internet has been created, the entry barrier, as well as the costs of media production, have become lower, thus, creating a less manipulative media environment. However, this scenario did not materialise to the full extent expected. Instead, the new content creators on the Internet could not gain as much attention and recognition on the World Wide Web as the mainstream media channels due to a large number of the creators. Additionally, the Internet markets were found to be extremely hard to penetrate. It led to the majority of the Internet content creators remaining unheard. However, thanks to the recent technological advances, Internet and traditional media content providers received access to a vast amount of personal data, and so the content providers can tailor content to serve the tastes and interests of a specific individual. This phenomenon brings to life the notion of “autonomy trap”, where

*“(a) Individuals inform the information providers which types of knowledge and information they are interested in and provide (both implicitly and explicitly) personal information such as their traits and interests;*

*(b) The content providers supply individuals with specific information “tailored” to the needs of every person, according to each provider’s specific strategy, and chosen on the basis of the personal information previously collected;*

*(c) The individuals require additional information. This time, however, the request is affected by the information previously provided;*

*(d) Again, the information providers supply information, in accordance with their policies and discretion;”<sup>77</sup>*

The vicious cycle of “autonomy trap” largely manifests in the online environment through targeted advertising and content targeting and impedes individual autonomy. In the case of the AAL, the technological environment would have the ability to intervene and affect an individual’s behaviour, direct it towards certain outcomes and decisions and influence the

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<sup>75</sup> Hildebrandt 2015, pp. 90-93.

<sup>76</sup> Zarsky 2014, p. 35.

<sup>77</sup> Zarsky 2014, p. 38.

course of her daily life. There is, however, an argument stating that we tend to tolerate certain behaviours online that we would not tolerate offline, like tracking of our online activities. In the case of AAL, we would have to tolerate this same online practice in a whole new, different realm.<sup>78</sup>

### *3.3 Conclusions*

Theory of technological determinism is based on the substantive theory of technology. It emphasises that technology shapes social practices and has become a regulatory tool itself. Modern technologies are enhancing the determinism and disrupt legal and regulatory orders and values that they are based on.

AAL technology is no different as it profoundly impacts individual autonomy and disrupts the efficiency of the legal and regulatory tools that are aimed at securing it. AAL creates asymmetrical informational relations which are already characterised by the imbalance of power (senior person vs others). AAL brings three types of vulnerabilities that restrict autonomy. These are profiling, surveillance and involvement of third parties, the "autonomy trap" and behavioural nudging. Profiling leads to stigmatisation and discrimination through the creation of overly personalised or wrongful profiles. Profiling also results in the creation of new, at times, even more sensitive data than the one that was initially provided. Surveillance is reinforcing control over seniors. It also brings new parties into the care setting enhancing the informational asymmetry and power imbalance even further. Autonomy trap and behavioural nudging is affecting seniors through the creation of a contextual environment that are highly personalised and adaptive. These environments subtly strip off the individual of her autonomy by directing her behaviour and decision-making.

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<sup>78</sup> Mik 2016, p. 26.

# 4 CONTEXTUAL INTEGRITY EVALUATION OF AAL

## 4.1 Introduction

In the previous Chapter, we have established that the AAL is threatening individual autonomy. In Section 2.4, we have discussed the interrelation and connection between privacy and autonomy. Based on either form of inter-dependence between the two, it is safe to say that when autonomy is threatened, privacy is threatened as well and vice versa. Considering the nature of the AAL technology and the way it can subtly manipulate and erode individual autonomy, privacy, when preserved and present, can prevent this from happening. This Chapter is going to evaluate the AAL technology through Contextual Integrity framework and see how the privacy of the AAL user is affected.

## 4.2 Contextual Integrity in a nutshell

The modern understanding of privacy had evolved in the 1960s when institutions started using computerised databases. Radical transformations of ways in which information is collected, aggregation of data, use of big data analytics, data mining and artificial intelligence; and distribution, communication and dissemination of the information – all pose a much more significant threat to privacy. The central disruption of the technology is that it has altered the information flows from the way that we have been used to.

In a world of new technologies, personal information is being generated, shared and inferred in new and unpredictable ways. And while the transparency critique holds true to a certain degree, especially considering how much more personal information we have knowingly or unknowingly volunteered about ourselves, privacy is even more important to be preserved and respected. In this regard, it is important to note that privacy is relational and contextual. Our vulnerabilities to privacy depend on the nature of the relationships to other people and contexts we are in, and they vary by degree of trust and behavioural norms. Information we would prefer to keep secret from one person can be freely shared with another person.

In Section 2.3, we have presented different theories of privacy, contextual integrity being one of them. Many argue that protecting privacy means either limiting access to personal data or giving individuals control over it. Contextual Integrity (CI) theory does not agree with the pre-conceived notion that all you must do to retain privacy is to introduce



procedural constraints to the access and dissemination of personal information. *Nissenbaum* states that people care about the appropriate flow of the information. Essentially, CI views privacy as a proper flow of information which conforms to the contextual information norms. The CI introduces a step by step guidelines to evaluate the disruptive technology regarding its impact on privacy. If the contextual integrity of the informational norms remains intact - according to *Nissenbaum* – privacy is preserved. CI evaluation serves two main purposes: locate and describe disruptive information flows and guide the assessment in moral terms. The first stage of the analysis through the CI framework requires identifying in the greatest detail possible: the prevailing context(s) and all informational norms of these context(s) – context-relative informational norms. The second stage moves towards critically evaluating information flow against the context's values, ends and purposes to determine whether context-relative norms are respected.<sup>79</sup> Context-relative norms govern the flow of information in a specific context. These norms can be implicitly integrated in the understanding of “normal” or acceptable behaviour or they can be explicitly in rules or laws.

### *4.3 CI decision heuristic - a step-by-step evaluation*

This Section will go through a step-by-step assessment of the AAL technology with the help of the CI decision heuristic. CI framework is about the full consideration of social settings in which new technological practices are situated. The approach is first to describe the new practice. The second step is to provide a normative evaluation of the practice in terms of individual interests, social values; and contextual goals, ends and purposes.

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<sup>79</sup> Nissenbaum 2010.

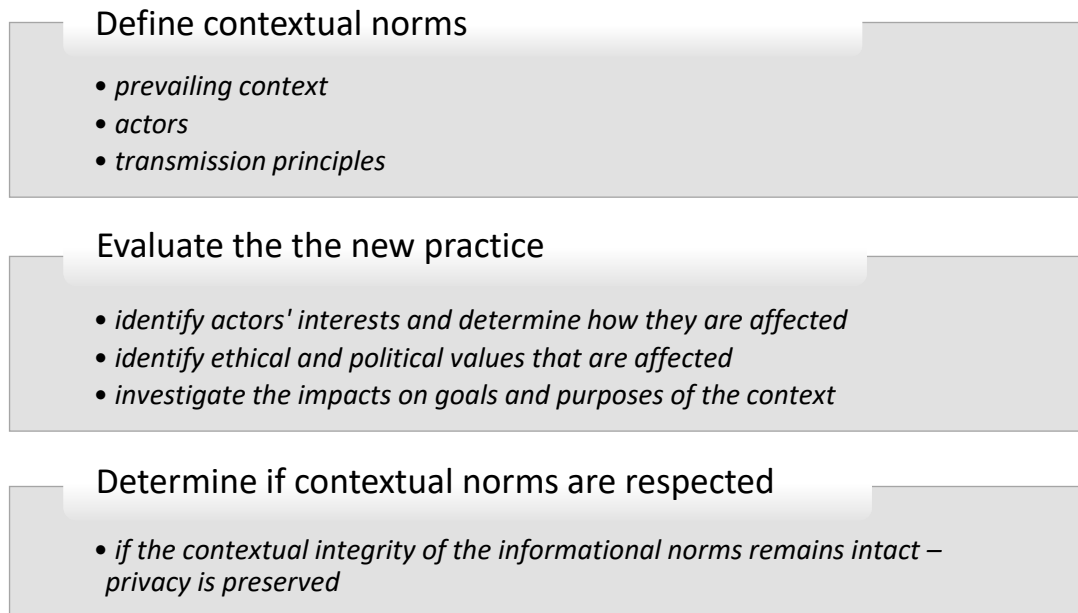


Figure 3 - Contextual Integrity evaluation flow

#### 4.3.1 Defining AAL context-relative information norms

The structure of the context-relative information norms consists of four key parameters: contexts, actors, attributes and transmission principles. All these parameters are equally important for the preservation of contextual integrity. The evaluation begins with establishing a prevailing *context*, then key actors and attributes are identified, and *transmission principles* that govern information norms are demonstrated. Next step of the evaluation consists of three layers that cover the assessment of *interests*, general *ethical and political values*, and *context-specific ends and values*.

*Step one - identify the prevailing context.*

CI framework has a clear definition of the term “context”. For *Nissenbaum*, contexts are “*the structured social systems that have evolved to manage and accomplish aspects of social life recognised as fundamental in a given society*”, like education, the use of libraries, healthcare or commercial transactions.<sup>80</sup> Contexts are characterised by roles, activities, norms and values (goals, purposes, ends). Contexts vary depending on the time, place, society, culture, history and politics. Another differential in contexts is whether they are institutionalised or recognised formally and explicitly (i.e. by law). Contexts can, of course,

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<sup>80</sup> Nissenbaum 2010, p. 132, Levy - Kilgour - Berridge 2018.

overlap, and that is when the main conflicts arise. It is crucial to recognise that the introduction of the AAL does not create the new context with its own rules but operates within the existing social context.

The prevailing context in the AAL is the context of social care services that are provided to the senior person at their home or in the senior care institution (service home, long-term care facility or hospital). Another context here is also the family relations with the spouse and relatives, friends. There can also be a commercial marketplace context when the service is being directly provided to the senior, or personal data is shared with the third parties, like insurance companies, security service providers, *etc.* Different contexts may overlap within the same practice and cause conflicts. In this evaluation, the AAL will be viewed from the perspective of the context of social care.

*Step two - identify actors.*

**Information subjects:** a senior, friends, spouse, other persons whose data is collected through AAL.

**Senders/initiators:** older person, formal and informal caregivers, care service provider.

**Recipients:** a senior, care personnel, doctors, AAL provider, social services provider (organisation), clinicians and other third parties, social care officials. After the AAL is taken in use, a new set of recipients of the personal data comes into play: AAL technology service provider, third parties like insurance companies, rehabilitation centres *etc.*

*Step three - Identify attributes or information types.*

Attributes correspond to the types of data processed in the context of the AAL technologies. The list below is non-exhaustive but gives an overall representation of the types of data that is processed, including health-related data and other kinds of sensitive personal data:

- Daily activities
- Health data
- Information about the living environment and surroundings
- Information about social activities
- Habits
- Routines

- Level of functioning
- Ability to complete daily tasks without help
- Meals
- Sleep quality
- Sleep schedule
- Exercise
- Mood

Also, the degree of the collected health-related and other sensitive information is unpredictable due to profiling and machine learning techniques. To compare the data that has been previously available to the care personnel – it may not be much broader per se. But what has changed, compared to previous data attributes shared with the care personnel is the possibility to infer new data and to profile individuals based on specific features.

*Step four - identify transmission principles.*

Transmission principles create a constraint on the flow of information from a party to party in a specific context. It expresses the terms and conditions under which the transfers of the information occur. For example, in the context of relationships between the client and their lawyer, the flow of information is governed by the principle of confidentiality. In the context of a consumer transaction, the consumer is entitled to the information about the product safety. Thus, the transmission principle here is that of entitlement. Other examples of transmission principles are reciprocity, need, voluntary disclosure of information, the notice and consent transmission principle, which requires the knowledge of the data subject (notice) and their consent to the processing of the personal data. In the context of family relationships, we might expect the information to be shared voluntarily (the subject decides what information to share) and reciprocally.

Confidentiality is the transmission principle in the context of social care. It does not apply to all information but to the information that the care personnel requires for performing their duties according to standards of their profession. The care personnel can mandate care on the fullness of the information received from the individual. Another difference is that the flow is unidirectional, the care person does not disclose any personal information.

When the AAL enters the social care context, transmission principles change. If previously information was obtained by the care personnel directly from the senior person or their

relative or guardian, now the information can be obtained through the middle-men – AAL technology provider. And even though the confidentiality rules still apply – there is a dramatic change in the method of information exchange. Also, the way the information is obtained is entirely different – data is collected 24/7, without manual input and in an unobtrusive or often subtle way. It is a completely different practice from the previous one, which was self-reporting by the individual. In Chapter 5, we will discuss the applicability of the GDPR data protection principles to the AAL. These principles can also be viewed as transmission principles of the data. In a way, the data protection principles are aimed at preserving the principle of confidentiality. However, as presented in Chapter 5, Section 5.4 – these principles are not effective when it comes to the AAL technology and ways in which it operates.

All three parameters of the contextual norms are important and independent, and therefore, privacy cannot be reduced to any one or two parameters. Reducing privacy only to the specific transmission principle, say notice-control, or to a particular type of information fails to preserve it.

#### 4.3.2 CI evaluation of the AAL in social care

CI evaluation phase consists of three layers:

**First layer.** Assessment of how novel flows of information affect the interests and preferences of the affected parties and stakeholders. It may include the evaluation of the benefits that they enjoy and the risks that they may suffer as a result of the new information flows. Interests and general ethical values are a subject of the growing literature on privacy; it also considers whether values are threatened - threats to autonomy for example.

The primarily affected parties are seniors, their family members, care personnel, social services providers and AAL service provider. Seniors and their family are mainly interested in preserving their individual autonomy, living as long as possible independently and staying in good health. Care personnel is seeking to provide care efficiently, ensure individual's safety and avoid adverse outcomes to their health and well-being. Social services providers are interested in ensuring that the care services are provided to those who require them, that the personnel job satisfaction rate is high, and the services are cost-

efficient.<sup>81</sup> When the AAL is entering the picture, primarily, it caters to the interests of the social services providers and care personnel. The senior person's interests are not fully met.

**Second layer.** Identification of the ethical and political principles and values that are affected in the context. The second layer of the CI analysis considers the impacts on ethical and political values. Autonomy and independence, human dignity, safety and security – are the central values pursued in senior care. Also, the ethical principles of beneficence and non-maleficence play a vital role in the provision of care.

**Third layer.** The third layer of the CI analysis investigates the impacts on goals and purposes in the selected contexts. The practice is evaluated regarding its contextual functions: goals and purposes. Like cure disease, alleviate suffering, provide equity, *etc.* In this layer, the new practice is evaluated in terms of its ability to fulfil and promote the end goals, values and purposes of the context.

In Chapter 3, we have identified how the use of the AAL negatively affects individual autonomy through profiling, surveillance and knowledge asymmetry, the creation of autonomy trap and behavioural nudging. Human dignity is also negatively affected when there is a restriction of the individual autonomy. The ultimate goal of introducing the AAL into social care is to ensure active and healthy ageing. However, this goal is compromised when the AAL fails to enable the individual autonomy.

#### *4.4 Conclusions*

As we can see from the above-presented analysis, the contextual norms of the social care are disrupted when the AAL enters it. The AAL technology inherently disrupts the entrenched information norms in the social care context. Because the sensors are unobtrusive and ubiquitous and perform tracking 24/7 - it allows for collection and logging of the user behaviours daily, for example, when they took a shower, had a meal, who has visited them etc. There is a significant change in type, frequency, breadth and depth of the information that is tracked about the individual, how this information is obtained and shared. Creation of individual profiles through utilising machine learning and other AI tools introduces new information into the context, which initially was not available. Social care service providers gain broader knowledge about the individual which is often unpredictable.

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<sup>81</sup> Palm 2014, p. 388.

And considering that the senior person is somewhat vulnerable and is dependent on the caregivers, it puts them at an even higher dependency and can potentially reduce their autonomy or completely deprive them of it. New actors enter the realm of social care: AAL service providers and third parties that previously played a limited role in the care provision (i.e. insurance companies, IoT providers, security companies). Also, the transmission principles have changed with the new methods of obtaining data.

At the same time, the fact that the contextual norms are disrupted does not automatically indicate the violation of privacy. However, it prompts to question whether the disruptive nature of the new technology is appropriate in this context. When we looked at the interests of the affected parties, we saw that the AAL is mostly beneficial to social care providers and the AAL service providers. The interest of the individual autonomy of the senior is infringed by the AAL, while the interests of security, care efficiency and cost-effectiveness are pursued. In terms of values and goals pursued by the social care, the AAL only nominally supports them, mainly because without individual autonomy, active and healthy ageing is not possible.

As a result of the evaluation through the CI framework, the conclusion is that the AAL violates the contextual integrity of the information norms in the social care context, thus, infringing privacy. The question remains, what are the tools that can bring the new practice in line with the contextual norms?

# 5 LOCATING AUTONOMY IN LAW

## 5.1 Introduction

The concept of autonomy manifests in AAL technology in three roles: autonomy of the person that is being cared for or is treated as a patient, autonomy of the citizen that resides in a democratic constitutional state and the autonomy of the data subject. Senior's autonomy, as a citizen of a democratic state, is represented through the human right to respect for private and family life and the right of older people to lead independent lives. When the senior is viewed in the role of a data subject – the autonomy is enabled through the right to data protection.<sup>82</sup> Autonomy of the patient and the person being cared for is facilitated through the principles of biomedical ethics and the ethics of care. This Chapter will focus on the autonomy of the citizen and data subject, and in Chapter 6, the principle of autonomy warranted by the ethical principles will be examined.

## 5.2 Autonomy of the citizen

From the legal philosophy perspective, autonomy has a very close connection to human rights. Autonomy is central to establishing human rights and exists to support them.<sup>83</sup> Universal Declaration of Human Rights (**UDHR**) refers to a human being as "born free" and that everyone has a 'right to liberty'.<sup>84</sup> European Convention on Human Rights (**ECHR**) does not mention anything that could have a direct resemblance to autonomy but includes specific rights that are very close to it: respect for family and private life, freedom of thought, conscience and religion; and freedom of expression, assembly and association.<sup>85</sup>

ECHR's Article 8 - the right to respect for private and family life in paragraph 1 reads as follows: "*Everyone has the right to respect for his private and family life, his home and his correspondence.*" The corresponding right to respect for private and family life is also included in Article 7 of the EU Charter of Fundamental Rights (**the EU Charter**). In *Tysiack v Poland* (para 107): "*Private life is expressly stated to be a broad term encompassing, among others, the right to personal autonomy, personal development and to establish and*

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<sup>82</sup> Gomez – Montovani - De Hert 2013, p. 148.

<sup>83</sup> Marshall 2009, pp. 28, 30-31.

<sup>84</sup> UN General Assembly 217 A (III) 1948, Articles 1, 3.

<sup>85</sup> Council of Europe ETS 5 1950, Articles 8-11.



*develop relationships with other human beings in the outside world.*<sup>86</sup> And while the ECHR does not have an explicit right to personal autonomy, the ECtHR jurisprudence has developed in such a way that the interpretation of the right to private life includes it.<sup>87</sup> In the legal scholarship, the right to privacy has been connected to the values of human dignity, liberty and autonomy.<sup>88</sup>

The rights of older persons guaranteeing their autonomy and independence<sup>89</sup> are recognised at the international level in soft law and positive human rights law. The first international initiative was the Vienna International Plan of Action on Ageing adopted by the UN General Assembly in 1982.<sup>90</sup> This instrument consists of 62 recommendations aimed to protect and promote the rights of older persons as part of the UDHR. Later, in 1991 the UN General Assembly adopted the United Nations Principles of Older Persons.<sup>91</sup> Lastly, in 2002 the second World Assembly on Ageing was held in Madrid, and the United Nations approved the Madrid International Plan for Action on Ageing (**MIPAA**).<sup>92</sup> The Regional Strategy for the Implementation (**RIS**) was adopted to implement the MIPAA in Europe. The right of older people to lead independent lives is recognised in Article 23 of the European Social Charter (1996).<sup>93</sup> and Article 25 of the European Union Charter of Fundamental Rights.<sup>94</sup> The Council of Europe's Recommendation CM/Rec(2014)2 on the promotion of the human rights of older persons makes recommendations on older people's autonomy and participation and their consent to medical care.

Despite all the available international instruments, the need for a Convention on the Rights of Older Persons has been broadly articulated. In 2010 the UN established the Open-ended Working Group on Ageing (**OEWG**) with the purpose of strengthening the protection of older person's rights. The gaps in the protection of an older person's rights by the existing

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<sup>86</sup> *Tysiac v Poland* No. 5410/03 2007, para. 107.

<sup>87</sup> *Marshall* 2009, p. 49.

<sup>88</sup> *Reagan* 2015, pp. 50-70.

<sup>89</sup> Autonomy is the *ability to make choices and decisions*, with support if necessary, according to one's will and preferences. Independence is the *ability to perform actions* of daily living and participate in society, with support if necessary, according to one's will and preferences.

<sup>90</sup> UN General Assembly No. E.82.I.16 1982.

<sup>91</sup> UN General Assembly 46/91 1991.

<sup>92</sup> United Nations A/CONF.197/9 2002.

<sup>93</sup> European Social Charter ETS 163 1996.

<sup>94</sup> EU Charter 236/02 2012.

instruments were identified, and the feasibility of introducing new regulatory tools was explored.<sup>95</sup> The need for the Convention on the Rights of Older Persons is a response to the failure of the existing human rights mechanisms to protect and promote the rights of seniors.

HelpAge International, a global network of organisations promoting the rights of older people, has recently issued a report addressing the problem of autonomy and independence of older persons concerning long-term and palliative care. The report highlighted the critical issues of senior people regarding autonomy and independence. There are no explicit standards in international human rights law on autonomy and independence in older age. While older persons highly value autonomous and independent life, many of them are not able to make autonomous decisions about different areas of their life. Deterioration in health or income, loss of a job or retirement and change in living circumstances – all these factors are preventing or interfering with older person's autonomy and independence. The government, local authorities, policy makers, various service providers and even family members are contributing to the loss of autonomy and independence by the older persons.<sup>96</sup>

### *5.3 Autonomy and a right to data protection*

In the process of the interaction with AAL, a senior person is viewed as a data subject, and her autonomy is enabled through the right to data protection and stemming from it data protection principles guaranteed in the European data protection legislation.<sup>97</sup> The right to data protection has been introduced in response to the technological developments which have threatened in new ways the value of personal autonomy. The goal of the right to data protection is to even out the informational power imbalance.<sup>98</sup> It is guaranteed in Article 8 of the EU Charter<sup>99</sup>, as well as in Article 16(1) of the TFEU.<sup>100</sup> The first EU data protection legislative instrument was adopted in 1995 in the form of the Data Protection Directive

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<sup>95</sup> 'Towards a UN Convention on the Rights of Older People', 'United Nations Open-Ended Working Group on Strengthening the Protection of the Human Rights of Older Persons'.

<sup>96</sup> 'Freedom to Decide for Ourselves', p. 4.

<sup>97</sup> Reagan 2015, pp. 150-151

<sup>98</sup> Rouvroy 2009.

<sup>99</sup> EU Charter, 2012/C 326/02, Art. 8.

<sup>100</sup> TFEU 2008/C 115/01, Art. 16(1).

(DPD). In May 2018, the new legal tool, General Data Protection Regulation (GDPR) has entered into force and replaced DPD.

The right to data protection is regulated at both levels: through primary law – EU Charter and secondary law – GDPR. It is called a “*human right with a regulatory character*”<sup>101</sup>. GDPR contains the set of data protection principles to ensure that the processing of the information about an individual remains fair and lawful and does not infringe other fundamental rights.<sup>102</sup>

The relation between the right to privacy and data protection has been broadly studied and discussed in the legal literature and CJEU case law.<sup>103</sup> For this research, it is important to clarify the difference in a nutshell. While the right to privacy and the right to data protection intersect, they are different concepts. From one point of view, the right to privacy is broader than the right to data protection as it protects not only data, but it also protects the inviolability of the human body, protects individual’s relationships with others and their emotions, and it also serves as a guarantee of spatial privacy.<sup>104</sup> Another point of view suggests that the right to data protection is wider than the right to privacy. The term “personal data” covers a much more extensive array of information about the individual as compared to the scope of the information covered by the Article 8 of the EU Charter, where the link to the sphere of the individual’s private life needs to be established and the individual needs to be identified.<sup>105</sup> This research argues that especially in consideration of the AAL technologies it makes no difference which right has a broader scope. The goal of enabling individual autonomy in the interaction with the AAL requires both rights to be viewed as complementing each other since they both serve the same end-goal. Therefore, this research adopts the view that the right to data protection is a positive tool of privacy that ensures that personal data is processed in a way that would render unlikely the infringement of an individual's privacy and personal integrity.

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<sup>101</sup> Gallert – de Vries - de Hert – Gutwirth 2013.

<sup>102</sup> Gomez - Mantovani - De Hert 2013.

<sup>103</sup> See Case C-73/07 Tietosuojavaltuutettu v Satakunnan Markkinapörssi OY, Satamedia, Case C-275/06 Promusicae, Case C-139/01 Österreichischer Rundfunk.

<sup>104</sup> Rouvroy 2009.

<sup>105</sup> Lynskey 2015, p. 38.

The main tools of the data protection framework to support individual autonomy are data protection principles and data subjects' rights guaranteed by the GDPR.<sup>106</sup>

### 5.3.1 What constitutes the “AAL data”?

Before delving into the data protection principles and data subjects' rights, it is crucial to discuss what constitutes the “AAL data”. AAL belongs to a broader category of the Internet of Things (**IoT**) and consists of Internet-connected objects that are equipped with sensors and are placed in the environment or are worn by the data subject. And while the data collected by the AAL may arguably not always be sensitive, WP29 in its Opinion on the Recent Developments on the Internet of Things, suggested that consent is the most appropriate basis for data processing due to the intrusiveness of the IoT.<sup>107</sup> Indeed AAL is highly intrusive and enables longitudinal tracking and linking of health and behavioural data, and it allows increased interactions between data representations of the user. Also, environmental monitors reveal a lot of information about a person's private space, creating a “public window” into the private window of the individual. Especially environmental sensors are harder to avoid or escape. Additionally, AAL data is very hard to render anonymous, and the risk of re-identification is very high.<sup>108</sup>

Data produced by AAL technologies is a “health-related” data since it contains different physiological measurements, data on a person's behaviour and psychological state.<sup>109</sup> GDPR defines data “related to health”, to fall into a “special category of personal data”. It is defined as: “*personal data related to the physical or mental health of a natural person, including the provision of health care services, which reveal information about his or her health status.*” Also, the GDPR includes in the concept of “data concerning health”: “*data about the health status of a data subject which reveal information relating to the past, current or future physical or mental health status of the data subject.*”<sup>110</sup> The mentioning of the “future” is especially relevant to the AAL since, at the time of the collection, data may not be sensitive, however, through data enrichment mechanisms, unexpected insights

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<sup>106</sup> Lynskey 2015, p. 179.

<sup>107</sup> WP29 0829/14/EN 2014.

<sup>108</sup> Paez - Marca 2016, p. 38-39.

<sup>109</sup> It is still unclear whether the AAL devices will be considered to fall in the same regulatory field as medical devices but, as mentioned in Section 1.2, this research will not delve into the analysis of the AAL as the medical device.

<sup>110</sup> GDPR, Article 4(15), Rec. 35.

may be drawn by combining a myriad of data sets. And originally insignificant data can later be used with other data to infer information with a different meaning.

Moreover, this definition makes stress on the purpose of the data processing, rather than the data source or the type of data. For instance, data which does not directly describe health but from which health-related conclusions can be made, or the data which assists in making such findings can fall in the scope of the health data. And, subsequently, be under a more stringent data processing rules.<sup>111</sup> WP29 also has given guidance on the concept of health data under the DPD. WP29 stressed that for a data to be considered as “health-related”, it does not necessarily need to be generated in a professional, medical context, which pertains to medical data. The health-related data does not necessarily have to be related to the disease or disability, possible diagnosis, treatment plan or prescription. It can also include data that is generated by the devices and apps used in the context of medical treatment, and they do not have to be necessarily considered as “medical devices”. The health-related data can also relate to the information of whether a person is wearing prescription glasses, information about an individual’s intellectual and emotional capacity. WP29 also suggests that data generated by the lifestyle apps and devices that do not give any information about the health status of the individual, and from which no conclusions about individual’s health status can be made – does not constitute sensitive data. For example, a specific medical context is missing if an app is only counting a number of steps someone took on the certain day, and this data is not combined with any other data about the individual.<sup>112</sup>

Therefore, AAL data can, for the most part, be considered as health-related data. It falls under the Article 8 GDPR since the data is used to make conclusions about the person’s health status, the sensor data is combined and matched to infer information about a person’s health risks or follow up on the progressing of certain health conditions. And as WP29 Opinion mentions, “*For data to qualify as health data it is not always necessary to establish ‘ill health’.*”<sup>113</sup> Therefore, AAL data can create a large volume of health data and be invasive, and subsequently, the Article 9(2)(a) of the GDPR should apply – the data subject should give explicit consent to the processing of their personal data.

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<sup>111</sup> GDPR, Art 4(15), Rec. 35, Art.9.

<sup>112</sup> WP29 0011 2012.

<sup>113</sup> WP29 0011 2012, p. 2.

### 5.3.2 Data processing principles

GDPR defines in Article 5 the following principles of data processing:

- lawfulness, fairness and transparency
- purpose limitation
- data minimisation
- accuracy
- storage limitation
- integrity and confidentiality

The first principle of lawfulness, fairness and transparency reads as follows: “*personal data shall be processed lawfully, fairly and in a transparent manner in relation to the data subject.*” Lawful processing entails that a data controller has a legal ground for processing personal data. Since the data processed in the AAL belongs to one of the special categories of data – data related to health<sup>114</sup> – Article 9 applies to determine the lawfulness of the data processing.<sup>115</sup> By default Article 9 prohibits the processing of the special categories of personal data unless one of the exceptions specified in paragraph 2 applies. There are two exceptions that are applicable to the AAL context. The first one is when the processing is necessary for “*...the provision of health or social care or treatment or the management of health or social care systems and services*”, and the processing is subject to “*the obligation of professional secrecy*”.<sup>116</sup> While the AAL is primarily used in the social care setting, the nature of the AAL differs from the information systems that are used by the health and social care providers. AAL extends beyond the pure social care setting, and the personal data within the same AAL ecosystem is available not only to social care providers but also to other stakeholders outside of the social care setting. Not to say that this exception is not applicable, in the situations when the AAL is solely taken in use by the social care provider, and it is managed in a centralised manner – this exception will suffice. However, the AAL ecosystem is more complex and involves many parties and other contexts than social care, for example, when used at senior’s home. The second exception applicable is when the data subject has given the explicit consent to the processing of personal data.<sup>117</sup> Using consent

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<sup>114</sup> More about the AAL data in Sections 5.3.1

<sup>115</sup> GDPR, Art. 9. Also other legal grounds for processing can be used for data processing but that would depend on factors, for example data pseudonimisation. Considering that the processing of health-related data

<sup>116</sup> GDPR Article 9(2)(h) and (3).

<sup>117</sup> GDPR Article 9(2)(a).

as a legal ground for processing is also a way to enable senior's autonomy in their interaction with the AAL.<sup>118</sup>

The principle of purpose limitation means that the controller can collect and process personal data only for a specified purpose. The principle of data minimisation means that data processed should be limited only to the personal information that is necessary and adequate to achieve the purposes of data processing. The principle of data minimisation and purpose limitation are contradictory to the nature of the big data analytics.<sup>119</sup>

AAL is heavily reliant on the big data, and machine learning and its untapped potential are driven by the ability to maximise the amount of available personal data for analytics and inferring new useful information about the individual. For instance, whether the person is exhibiting the early signs of cognitive decline. The principles of accuracy and storage limitation are also at odds with the AAL technology.

### 5.3.3 Consent

Consent is the critical element in the enablement of autonomy of seniors as data subjects when the AAL is in use. However, recent technological developments are challenging the functioning of consent as an act that is protective of individual autonomy.<sup>120</sup>

Under the GDPR consent is defined as "*freely given, specific, informed and unambiguous indication of the data subject's wishes by which he or she, by a statement or by a clear affirmative action, signifies agreement to the processing of personal data relating to him or her*" Therefore, the consent should meet the following conditions:

- Freely given
- Specific
- Informed
- An unambiguous indication of wishes<sup>121</sup>

AAL sparks controversy on the several criteria regarding consent. Interestingly, Recital 43 of the GDPR provides that the consent should not be relied upon when it is obtained in a

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<sup>118</sup> See Section 5.3.3.

<sup>119</sup> Hildebrandt - Koops 2010.

<sup>120</sup> Kosta 2013.

<sup>121</sup> GDPR Art. 4(11).

situation where there is an apparent imbalance of power between the data subject and controller. Like employer-employee relation that has been identified as posing a potential problem for demonstrating freely given consent, the power imbalance in the senior care also makes obtaining freely given consent difficult in the AAL.<sup>122</sup>

Nevertheless, AAL is putting a great emphasis on the autonomy of the older person via consent. It is expected that consent automatically guarantees autonomy. In the AAL consent serves as a "magic key" that would open the door to the legitimate processing of any category of personal data and opens enormous possibilities for a privacy trade-off. It is argued in the legal scholarship that establishing individual consent as a benchmark for individual autonomy is problematic. As consent can be used to legitimise any practice as long as the procedural aspect obtaining informed consent is satisfied.

The interaction of older persons with ICT technologies has three particular characteristics: 1. Older persons may have reduced capacity to give consent due to the chronic illness. So, the consent will often be provided by their guardian. 2. Seniors are quite often dependent on their caregivers, and the consent given by the party is pure fiction. Individuals do not have the freedom to choose. 3. Seniors are less competent in using new technologies, and it impairs their ability to give informed consent.<sup>123</sup>

As the European data protection legislation is currently built on the theory of "privacy as control", consent is sought as a crucial tool for enabling an individual to define the flow of personal data. The only problem is that in the realm of new technologies, the control theory of privacy is not relevant anymore, and so exercising control over personal data is challenging, if not impossible in the 21<sup>st</sup>-century data processing practices. Because most data processing operations nowadays are conducted by multiple controllers/processors, by using cloud computing, for multiple purposes, by means of automatic processing - how can someone, for example, be informed about the data processing activities if even the data controller might not know all parts of the story?<sup>124</sup>

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<sup>122</sup> WP29 WP259rev.01 2018 p. 7, WP29 WP249 2017 para. 6.2.

<sup>123</sup> Gomez - Mantovani - De Hert 2013, p. 151.

<sup>124</sup> Koops 2014.



#### 5.3.4 Capacity and competence to give consent

Informed consent is also an issue in case of cognitive decline or dementia as the seniors in this situation are not able to give informed consent. The notion of competence is used in evaluating whether a patient can give an informed and valid consent.<sup>125</sup> Demented patients may not be competent. Therefore, reliance on informed consent in case of AAL is a very ineffective practice of securing the right to data protection, privacy and autonomy.<sup>126</sup>

The general rule states that only legally capable individuals can give consent. The capacity to give consent emerges in the situation when an individual is, for instance, cognitively disabled or has another mental health issue that prevents him or her from giving informed consent. The main challenge is that a capacity to give consent is often specific to a certain decision, not to all decisions; it can also fluctuate throughout short periods. There are two problems related to this situation. The first problem concerns the declaration of legal incapacitation and the second problem is related to the kind of technological solution that can be applied. In most European countries declaring individual incapacitation is made following a medical model of capacity and, thus, it has substantial consequences. From a legal point of view, a legally incapacitated person is entirely deprived of the ability to make decisions on many different aspects of her life. And this view does not consider the fact that many people who suffer from mental disorders or cognitive impairment can still have the ability to decide on certain aspects and not others. Similarly, AAL solutions that are developed according to a medical-legal model of capacity often offer a one-way option. For example, wearables, such as security bracelets, which control and monitor individual behaviour may end up limiting the functions that the individual still has the capacity to perform.<sup>127</sup>

#### 5.3.5 Collaborative consent

A notion of collaborative consent states that consent should be viewed in the form of a dialogue, a process and not a one-off decision which is based on the limited information that is provided at one point in time. It should be taking a step further, for what is often being a consent to become a continuing process rather than a single event. Using AAL technological opportunities and advances, consent can become much more of a form of

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<sup>125</sup> European Commission 2017, p. 37.

<sup>126</sup> Ranchordás - Kaplan 2017, p. 53.

<sup>127</sup> Mordini - de Hert 2010, pp. 136 - 140.

collaboration between the and observed. The service provider can engage in a direct dialogue with the user and give her all the relevant information continuously and inform the user about the important changes in the real time as they happen to user's direct responses before taking any action. Collaborative consent is the key to enable those who are being monitored to influence the monitoring process actively. And this is a significant point: those who are monitoring have a constant need to explain the subjects the benefits of being monitored. To be able to explain these benefits, they would need to ensure that these benefits exist and that the symbiosis is rather beneficial than parasitical.<sup>128</sup>

### 5.3.6 Profiling

According to GDPR Article 4(4) profiling is perfectly legal as long as the principles for lawful processing are met. General data protection principles and the rights of data subjects should be observed.<sup>129</sup> Recital 71 has a guide on how profiling should be conducted and stresses, among others, the need for prevention of discriminatory effects of the profiling.

### 5.3.7 Privacy by design and by default

The term Privacy by design (**PbD**) has been first introduced by Ann Cavoukian, Information and Privacy Commissioner of Ontario, Canada.<sup>130</sup> The GDPR defines privacy by design and by default as different “*technical and organisational measures that a data controller is required to implement as part of its overall approach to protecting the rights and freedoms of individuals with respect to the processing of their personal data.*”<sup>131</sup> PbD means that privacy implications and core principles of data processing are considered at every step of technology development. In a nutshell, PbD approach is about embedding data protection into the design specifications of the technology which helps reduce the privacy risk from the onset. PbD does not apply only to the process of development of new technologies; it also applies to the ongoing operation and management of such technologies. Privacy by default means that whenever it comes to the processing of personal data, the least privacy invading option is the default one.<sup>132</sup>

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<sup>128</sup> Bernal, 2014, p. 40.

<sup>129</sup> WP29 WP251rev.01 2017.

<sup>130</sup> Cavoukian, 2009.

<sup>131</sup> GDPR, Article 25(1), Rec. 78.

<sup>132</sup> GDPR, Article 25.

Incorporation of privacy in the early stage of technology development is the best approach. Data Protection Impact Assessment (**DPIA**) is an effective tool to incorporate privacy throughout the whole technology development and implementation process. The important part of the whole DPIA is to identify and assess risks and vulnerabilities to privacy posed by the new technology. The GDPR allows data controllers to be flexible in determining the precise structure and form of the DPIA. However, it must be a genuine assessment of risks to allow controllers to take measures to address them. Risk assessment describes the processing activity and assesses its necessity and proportionality to help manage any resulting risks to the rights and freedoms of individuals. According to Article 35 GDPR, the DPIA is mandatory for controllers or processors acting on their behalf when data processing is “likely to result in a high risk”. Article 35(3) provides some examples of when processing is likely to result in high risk:

*“(a) 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;*

*(b) processing on a large scale of special categories of data referred to in Article 9(1), or of personal data relating to criminal convictions and offences referred to in Article 10(1); or*

*(c) a systematic monitoring of a publicly accessible area on a large scale”.*

According to paragraphs (a) and (b) of the above excerpt from Article 35, it is safe to assume that taking in use AAL technologies in the provision of senior care will require conducting DPIA. WP29 recommends carrying out a DPIA if the data processing is not “high risk” as it is a useful tool to help data controllers comply with data protection laws.<sup>133</sup>

DPIA should be started as early as possible even if some of the processing operations are still unknown. Every step of the DPIA process should be documented. The DPIA should include a description of the envisaged processing operations and the purposes of the processing. Assessment of the necessity and proportionality of the processing should be made. And most importantly, the risks to the rights and freedoms of data subjects need to be assessed.<sup>134</sup> The DPIA is not a one-off project, and the assessment of risks, threats and vulnerabilities needs to be done on a continuous basis.

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<sup>133</sup> WP29 2016/679 2017.

<sup>134</sup> GDPR, Art. 35(7), WP29 2016/679 2017.

The methods and approaches to conducting DPIA vary depending on the country and organisation. GDPR does not set the boundaries as to the methods, forms and methodologies to the ways in which the DPIA should be conducted, it is up to the organisation to determine it. A variety of tools and guidelines from the supervisory authorities is available. Most notable in this area is a French data protection supervisory authority CNIL which has issued a number of detailed guidelines for conducting DPIA.<sup>135</sup>

The crucial component of the DPIA is assessing the risks and vulnerabilities to privacy from the very beginning of the technology development. Various privacy risk assessment models have proven to be useful. *Breaux* suggests using Contextual Integrity Heuristic to identify the risks posed by the new technology. The CI helps identify privacy vulnerabilities in the system that help capture the threats that would seek to exploit those vulnerabilities and the adverse events that would materialize.<sup>136</sup>

#### 5.3.8 Data subject's rights

Data subject's rights along with data processing principles are another tool to guarantee the autonomy of the senior in their interaction with AAL. When personal data processing is based on consent, individuals have the right to access any stored personal information related to them. Moreover, they have the right to request corrections to the information that is being processed about them and the right to data portability (i.e. the right to obtain any personal data related to them in a structured, commonly used and machine-readable format, and transmit this data to another service provider). Also, data subjects have the right to withdraw consent at any time and request the deletion of their personal data.<sup>137</sup> Seniors should also be aware of where their sensitive personal data (health data) is stored and what safety and security safeguards have been taken to ensure the safety and integrity of their personal data. Data subjects should be given essential information about the data processing, and who are the data controller and processor. A layered approach is more feasible as it allows to avoid overwhelming the user with a large amount of information at once, providing data processing information according to a principle of "just in time knowledge".<sup>138</sup> Any personal data, including data concerning health, shall not be stored for

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<sup>135</sup> CNIL Publications.

<sup>136</sup> *Breaux* 2014, pp. 27-37.

<sup>137</sup> GDPR, Art. 12 – 20.

<sup>138</sup> European Commission 2015.

a more extended period than necessary. The clear criterion for the deletion of data should be established and informed to the user. Extended periods of retention shall be permitted in the situations when they are necessary and only after the relevant consent from the data subject has been obtained. Personal data may be retained for a longer period after it has been irreversibly anonymised or pseudonymised.<sup>139</sup> However, especially with regards to the health data, it may be challenging to do without the potential risk of re-identification.

### 5.3.9 Data security

One of the most critical pre-conditions of privacy protection is the security of data. In AAL, both physical and network security, including authentication and backup protocols should be considered. Distributed system and IoT present an extra level of security problems: from the device to the network to the collection or storage of data. Prevention of privacy violations and security breaches starts with implementing security by design in all of the envisaged use cases.<sup>140</sup> Insufficient security measures will result in the disclosure of sensitive information or leakage of sensitive data.<sup>141</sup>

The unobtrusive sensor network will have access to different types of information, such as physiological measurements, location, biological data (blood pressure, heart-beat rate *etc.*) This information may be accessed by the interested third parties, thus, compromising the integrity of the system. Necessary safeguards should be introduced to limit access to the sensitive data and restrict it only to authorised parties.<sup>142</sup> AAL should have appropriate technical and organisational measures to protect sensitive personal data against unlawful and unauthorised access or processing. Appropriate authentication mechanisms and access control are among the first measures to be introduced.<sup>143</sup> In every use case, data protection risks should be identified, and a respective risk management process should be developed to introduce appropriate mitigating measures. Risks to the protection of personal data should be assessed and re-evaluated frequently to ensure that the AAL provides security assurance that is appropriate for the risks involved.

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<sup>139</sup> GDPR, Rec.39, Art.5(1)(e).

<sup>140</sup> Juniper Research Mobile Ecosystem Forum *Whitepaper*, pp. 205, 220.

<sup>141</sup> Krausova 2009, p. 325.

<sup>142</sup> Marcello – Jotterand 2015.

<sup>143</sup> ‘Green Paper on Mobile Health (“mHealth”)’ 2014.

Also, where possible personal data will be pseudonymised or anonymised, and risks for re-identification will be identified and mitigated at an early stage. Especially in use on traffic and vulnerable road users monitoring, effective anonymisation techniques will be implemented.

## *5.4 Conclusions*

In this Chapter, we have explored how the autonomy in AAL is enabled when the senior is viewed in the role of a citizen in a democratic state or in the role of the data subject. The right to privacy and the right of older persons to lead independent lives as well as other rights of older persons guaranteeing their autonomy and independence are recognised at the international level, and there is a number of international instruments that are aimed at promoting the rights of older persons. Despite all the available international instruments, there is still a need for a Convention on the Rights of Older Persons. The gaps in the protection of the older person's rights still exist, and there are no international standards in the international human rights law on autonomy and independence in the older age.

The right to privacy and data protection are the principal instruments to counter the threats of the AAL. GDPR is a comprehensive instrument that contains a vast array of data processing principles and rules to enable the right to the protection of personal data. While the safeguards envisaged by the GDPR should not be dismissed, they may lead to over-proceduralisation of the data processing. Meaning that data protection principles may make any processing of data legitimate as long as procedural requirements of data protection are fulfilled, and yet privacy may be compromised, particularly, when the consent is relied upon as the safeguard of individual autonomy.<sup>144</sup> Informed consent may be very difficult to obtain due to the nature of the technology and lack of capacity and competency on the data subject side. In the face of the AAL threats to individual autonomy, the instrument of informed consent is ineffective. Not to say that it has no place in the data protection framework but to emphasise that it cannot bear the whole burden of protecting privacy and ensuring individual autonomy in the AAL.

Current legislative regulation is inadequate in the face of the new technology. A possible solution is to express the legal protection through embedding legal rules in the AAL. Privacy by design incorporates data protection into the design specifications of the

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<sup>144</sup> Barocas - Nissenbaum 2014, p. 32.

technology which helps reduce the privacy risk from the onset. DPIA is a useful tool to incorporate privacy throughout the whole technology development and implementation process, and it would be a much more effective way to avoid the over-proceduralisation and safeguard individual autonomy in the AAL.

## 6 LOCATING AUTONOMY IN ETHICS

### 6.1 Introduction

There is a divide on whether AAL technologies benefit older persons' lives. The main question is whether the AAL is respecting the main ethical principles as much as it should?<sup>145</sup>

When considering the ethical norms that are relevant and applicable to the AAL, there is no one main set of ethical standards. Biomedical ethics and ethics of care practices, ethics of technology and data ethics – are all useful to discern the guidelines for the ethical AAL technologies. In this research, we are going to utilise the applied virtue ethics – a moral theory on what kinds of individuals we should be and how we can lead a good life that is “most worthy of us”.<sup>146</sup> Other theories of ethics are utilitarian and deontological ethics. Utilitarian ethical theory “*places the locus of right and wrong solely on the outcomes (consequences) of choosing one action/policy over other actions/policies. As such, it moves beyond the scope of one's interests and takes into account the interests of others.*”<sup>147</sup> Deontology - moral theory on what choices are required or forbidden or what we ought to do. In other words, deontology is a study of (external or internal) moral obligations.<sup>148</sup> These ethical theories are not going to be covered in this work. Moreover, applied ethics provides the basis for the development of fundamental rights in Europe, and therefore is also more relevant to this research.<sup>149</sup>

The following Chapters will present different fields of ethics and corresponding ethical norms that are most relevant to addressing the notion of autonomy in the AAL.

### 6.2 Autonomy and a current model of senior care

Autonomy is crucial for older people. Seniors want to have control over their lives or their environment, and they do not want to become more dependent on the use of external aids,

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<sup>145</sup> Diaz-Orueta – Urdaneta 2013.

<sup>146</sup> ‘D2.2 Lists of Ethical, Legal, Societal and Economic Issues of Big Data Technologies’, p. 20, ‘European Textbook on Ethics in Research’ 2010, p. 25.

<sup>147</sup> ‘Online Guide to Ethics and Moral Philosophy’.

<sup>148</sup> Ponnambath - Parija 2016.

<sup>149</sup> ‘D2.2 Lists of Ethical, Legal, Societal and Economic Issues of Big Data Technologies’, p. 20.



in this case, AAL technology.<sup>150</sup> Therefore, the focus should be on maintaining autonomy and decision-making of the individual for as long as possible. The assumption should be that the person has autonomy, even though they may be physically or mentally impaired. Technology should take the role of supporter but not a performer or a substitute to autonomous actions of the person. Why is autonomy so significant? Many studies explain how crucial it is to allow older people to preserve control over their environment or decisions, for example over decisions about the decoration of their apartment or room in a nursing home, or the possibility of growing vegetables on a small piece of land etc. Seniors who can preserve control over their environment and the way it is built and configured have a higher rate of maintaining their current cognitive abilities, mood and longevity.<sup>151</sup> AAL technology constitutes the part of their living environment, and if the person has the feeling that the technology was installed there against their will or they do not trust that it does not violate their privacy, then it might do more harm than good.

There is a fine line between the environment that is safe and secure and the environment that promotes individual autonomy and human dignity. While the current model of senior care is constructed in a way that the restriction of the personal autonomy is justified for the sake of security and safety, technology should be more focused instead on preserving human dignity and inherent in it individual autonomy.<sup>152</sup>

AAL technologies are being introduced within the current framework of the health and social care systems where “*reduced autonomy is a norm*”. The term care in the true sense of this concept inevitably includes the notion of reciprocity as the act of caring is important for developing and maintaining relationships within families and communities and between the givers and receivers of care. The greatest value of care is in its reciprocity. As, over time, the act of caring has been taken over by institutions, certain conditions started to apply to the receipt of care. The understanding of “care” in the institutional regimes is covering a broad area of tasks that are involved in the provision of institutional care. In this type of care, the relationship between the caregiver and the recipient of care is unequal, and it lacks reciprocity which has a limiting impact on individual autonomy. On the other hand, the

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<sup>150</sup> European Group on Ethics in Science and New Technologies 2015, p. 161.

<sup>151</sup> European Group on Ethics in Science and New Technologies 2015.

<sup>152</sup> European Group on Ethics in Science and New Technologies 2015, p. 171.

supportiveness of the new technologies is evaluated by their ability to enable users to retain control over the important parts of their lives.<sup>153</sup>

The model of social care affects the way in which autonomy manifests in the older person's – user's - interaction with the technology. Now, the AAL technology is introduced in the context of current senior care model and incorporates the norms that apply within the health- and social care domains. When considering the healthcare domain and public social care domain, the model of service provision here follows the norms of the medical model of service provision. When AAL follows the medical model, older persons should comply with the treatments and care plans that are prescribed to them by the health- and care professionals and they exercise very little autonomy. *Fisk and Rudel* argue that instead of a medical model, the social model of care provision should be used. The social model of provision views older people as being able to make (or at least participate in the making) decisions about the services that are provided to them. Thus, the social model of care is more beneficial to enable user autonomy.<sup>154</sup> When it comes to applying the basic ethical principles that are relevant to the medical model of care provision, they are not necessarily well suited to the situation when care moves out of institutions or when the AAL augments it.<sup>155</sup>

The way the medical care model is interacting with user autonomy is somewhat restrictive on the individual autonomy. In the care setting, there is an apparent conflict between the autonomy of the senior and the duty of care by the staff. Autonomy is about self-control, freedom of choice and duty of care in this context is about the principle of beneficence - doing good and non-maleficence – causing no harm. These two principles mean for personnel that they should provide more care, security and safety. And it might be at the expense of the resident autonomy. It was established that professional caregivers were less tolerant to risk as compared to family members. Also, when it comes to demented older people, there is a tendency to infantilising them.<sup>156</sup>

The AAL technology should be configured in a way that allows different degrees of control over it. The social model of service provision will enable more personalised services and

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<sup>153</sup> Fisk - Rudel 2013, p. 216.

<sup>154</sup> Fisk - Rudel 2013, p. 213.

<sup>155</sup> Kubitschke *et al*, 2009.

<sup>156</sup> Niemeijer 2010, p. 1135.

more equality in the relationships between the caregiver and care recipient. Another area where autonomy can be limited is the surveillance conducted by the AAL technologies. Related to it is the notion of transparency where users will know how the information is collected, stored and used. AAL technologies are not neutral, and they are context-related. The ethical view on the AAL should consider its design choices and functionality as these can either enable or disable the autonomy of the user and impact the shift into the social model of care.<sup>157</sup>

### 6.3 *Ethical principles applicable to the AAL*

#### 6.3.1 Principles of biomedical ethics and ethics of care

This type of ethics focuses on relationships and emotions such as sympathy and solidarity.<sup>158</sup> *Beauchamp and Childress* outlined the four fundamental principles for biomedical ethics. These are autonomy, beneficence, non-maleficence and justice. These ethical principles have been recognised as particularly important in the biomedical ethics and ethics of care.<sup>159</sup>

**Autonomy** refers to the right of the patients to retain control over their body, and it also includes their ability to decide whether to receive care at home or in the long-term care facility and also whether they would like to take AAL technology in use or not.<sup>160</sup> Decisions of the senior person must be respected and may be restricted only to the extent necessary to ensure the success of treatment.<sup>161</sup> Informed consent from a moral point of view is closely related to the autonomous choices of patients and subjects. The self-determination of the patient characterises the relations between the physician and the patient. The ethical principle of autonomy includes three criteria of autonomous actions, according to *Beauchamp*: a person acts intentionally, with understanding and without controlling influences. It is important to note, however, that ideal or full autonomy cannot be achieved, the substantial autonomy, on the other hand, is more achievable.<sup>162</sup>

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<sup>157</sup> Niemeijer 2010.

<sup>158</sup> 'European Textbook on Ethics in Research', 26

<sup>159</sup> Beauchamp - Childress 2013.

<sup>160</sup> Fisk - Rudel 2013, p. 211.

<sup>161</sup> Old Age and Ethics of Care Report (ETENE) 2008.

<sup>162</sup> Kosta 2013.

**Beneficence** - the principle of beneficence is about the promotion of the interests and well-being of the people concerned. According to the principle of beneficence, senior care providers should do everything they can to benefit the senior person.

**Non-maleficence** - the principle of non-maleficence envisages that harm should be prevented wherever possible and where damage may be unavoidable, it should be minimised as much as possible. This principle requires the care personnel to consider every decision they make and whether these decisions would cause any harm to individual rights.<sup>163</sup>

**Justice** - the principle of justice is about promoting fairness and equality. This principle states that all decisions made on behalf of person should be fair and just. And there should be no discrimination against the person with regards to age, race, religion, sex, national origin or disability.<sup>164</sup>

### 6.3.2 Ethics of technology

In 1999 European Group on Ethics (**EGE**) issued an *Opinion on the Ethical Aspects of the Information Society*. The list of ethical principles relevant in the context of healthcare within the new information technologies was presented. Among them were:

- Respect for private life
- Confidentiality
- Trustworthiness
- Legitimate purpose for collection of data
- Explicit informed consent for the use of data by the patient
- Transparency of standards
- The right of citizens to participate in the design of ICT systems in healthcare; and
- Citizen education that includes ethical implications of ICT as a pre-condition of European democracy<sup>165</sup>

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<sup>163</sup> Old Age and Ethics of Care Report (ETENE) 2008.

<sup>164</sup> Old Age and Ethics of Care Report (ETENE) 2008.

<sup>165</sup> EGE, Opinion n 13 - 30/07/1999.

These ethical principles support the principle of human dignity as a basis for requirements of privacy, confidentiality and medical secrecy. Also, the principle of autonomy as a basis for requirements of self-determination and participation, beneficence and non-maleficence - the basis for the attempts to weigh anticipated benefits against foreseeable risks; and the principle of justice, serving as a basis for requirements of equitable distribution of limited resources were taken into account.<sup>166</sup>

In 2014, EGE issued Opinion on the Ethics of Security and Surveillance where it identified critical ethical principles of surveillance technologies: privacy and freedom, autonomy and responsibility, well-being and human flourishing, and justice.<sup>167</sup> In 2015, the European Data Protection Supervisor (EDPS) published an Opinion on new digital ethics, referring in the Preamble to the importance of the fundamental rights to privacy and the protection of personal data to the value of human dignity. EDPS stressed that: *“In today's digital environment, adherence to the law is not enough; we have to consider the ethical dimension of data processing.”*<sup>168</sup> The opinion introduced a four-tier *“big data protection ecosystem”* which consists of:

- Future-oriented regulation of data processing and respect for the rights to privacy and data protection.
- Accountable controllers who determine personal information processing.
- Privacy-conscious engineering and design of data processing products and services.
- Empowered individuals.<sup>169</sup>

The third tier on privacy conscious engineering and design of big data technologies is revolving around the idea that technology should be dictating our social interactions and the structure of our communities but should instead be supporting our values and fundamental rights.<sup>170</sup> In continuation of this idea, the next Section will present the principles of ethical technology design applicable to the AAL realm.

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<sup>166</sup> EGE 1999.

<sup>167</sup> Dratwa 2014, p. 71.

<sup>168</sup> EDPS, ‘Opinion 4/2015, p. 4.

<sup>169</sup> EDPS, ‘Opinion 4/2015.

<sup>170</sup> EDPS, ‘Opinion 4/2015, p. 10.

### 6.3.3 Principles of ethical AAL design

The social care is an area where ethics has gained a central position as a safeguard for the older persons' interests. However, taking in use, the AAL technology has brought forth new situations that the traditional ethics of care approach has not faced before. The AAL technology requires a new strategy for ethical norms that would cover the unique challenges posed by the latest technology.

*Mittelstadt* introduced ethical principles and guidelines for designing H-*IoT*<sup>171</sup> technology that combines the principles from data protection law and biomedical ethics:

1. Facilitate public health actions and user engagement with research via the H-*IoT*.
2. Non-maleficence and beneficence.
3. Respect autonomy and avoid subtle nudging of user behaviour.
4. Respect for individual privacy.
5. Respect for group privacy.
6. Embed inclusiveness and diversity in design.
7. Collect the minimal data required.
8. Establish and maintain trust and confidentiality between the H-*IoT* users, service providers and care personnel.
9. Ensure the transparency and accountability of the data processing protocols.<sup>172</sup>

Drawing from the above-presented set of principles let's see in more detail what some of them mean explicitly for the AAL technology design and for empowering individual autonomy in the AAL.

#### **Respect for individual privacy**

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<sup>171</sup> H-*IoT* – is health-related Internet of Things, under the term the author refers to technological applications that “can monitor health and well-being outside of formal healthcare systems”, See also Mittelstadt 2017, p. 1.

<sup>172</sup> Mittelstadt 2017, p. 2.

It must be a fundamental principle in the AAL due to its nature of being able to cross extremely sensitive areas of an individual's personal life. It should be a starting point when designing AAL devices since the amount of personal data and especially health-related data processed can reach an unprecedented scope and detail considering that older persons are particularly vulnerable to the risk of privacy loss with regards to using AAL, it is essential that they are provided with the information on what data is collected, which type of processing is done, and they also should be given access to the information that has been collected about them. Another important matter is when the person with limited capacity to understand the nature of data processing is involved, for example, persons with dementia, special attention must be paid to the ways to explain these aspects to them as they might be the most vulnerable and least likely to accept the new technologies. At the same time, these individuals may be needing the assistance the most.<sup>173</sup> For instance, in the BEDMOND project, which is developing a system for early detection of Alzheimer's disease and other neurodegenerative diseases in older persons who are living alone, the coordinators took all effort in describing to the participants (in the initial stages of dementia) the nature of the monitoring solution and the its benefits for dementia-related research. As it turned out, participants were willing to accept the new monitoring technology knowing that it is for the sake of helping others who might be able to benefit from it in the future.<sup>174</sup>

### **Non-maleficence and beneficence**

The principle of beneficence implies the need for a balance between the benefits of the use of AAL technology against the risks and costs involved. The principle of non-maleficence means avoiding the causation of harm. If it is not possible, the damage should not be disproportionate to the benefit of treatment. The AAL should be designed to be secure and reliable and not pose a threat to the user's health or safety. Also, the data generated using AAL should not be used to undermine the interests of its users.<sup>175</sup>

### **Respect for autonomy and avoiding subtle nudging of human behaviour**

As discussed earlier, the medical model of senior care puts senior's safety first and, in this case, the AAL technology would be adopted with the user's safety as the priority in mind.

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<sup>173</sup> Mittelstadt 2017, p. 160.

<sup>174</sup> 'BEDMOND - AAL Programme'.

<sup>175</sup> Mittelstadt 2017, p. 4.

However, the perception of the users to “need” the device can very well undermine their autonomy. When the senior is pressured to use the AAL, it has a negative impact on his or her autonomy. So, when it comes to the autonomy of the older persons, is it imperative that they are involved in the decision-making process about the changes and new technology that is going to be introduced in their living environment. It will give them the feeling of perceived and real control over the things that happen in their life.<sup>176</sup>

Users’ autonomy can be undermined by nudging their behaviour and “mummifying” their identity over time through storage and exchange of personal data over a long period of time. Personalised feedback and intelligent adaptive environment can affect user behaviour. The user can also start to behave differently in response to perceived expectations of the device. Particular attention should be paid to the nudging of user behaviour to satisfy the interests of third parties pursuing commercial interests.

### **Informed consent**

Informed consent has been a fundamental principle of biomedical ethics and historically was used to protect the autonomy and related interests of the participants in the research. However, when data is routinely gathered, generated and shared with third parties, the method of informed consent is not feasible. *“The uncertain value of H-IoT data, and what it can reveal about the user through novel and unforeseen analysis and linkage with other datasets, therefore challenges the protection normally afforded to autonomy through single instance consent”*<sup>177</sup> Also, data subjects cannot be informed in detail about the possible future uses of their aggregated data and so informed consent in such a situation is impossible. The principal purpose of the consent is to promote individual autonomy, encourage rational decision-making and protect patients’ safety and well-being. Informed consent must comprise of three elements: (1) disclosure of the sufficient information and enough time to make an informed choice, maybe in the language that is adapted to their level of understanding, (2) a person must be competent to understand the information presented; and consent must be given voluntarily.<sup>178</sup>

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<sup>176</sup> Mittelstadt 2017, p. 5.

<sup>177</sup> Mittelstadt 2017, p. 6.

<sup>178</sup> Mittelstadt 2017, p. 6.



Competence is one of the most crucial elements of informed consent in the AAL context. Competence requires that the participant has sufficient mental capacity to understand and retain relevant information about the new practice and communicate her views on this practice. In the context of taking the AAL technology in use, the principal users are vulnerable because of their unfamiliarity with new technologies and varying level of competence.<sup>179</sup> Every effort should be made to obtain valid consent from each user. Where a senior is not competent to consent, proxy consent should be sought from the most appropriate third party. The needs of the older person would also need to be addressed regarding their readiness and willingness to use specific technologies. User interface and service design would need to encompass the effective way to obtain valid consent from this group of users.

According to *Diaz-Orueta* and *Urdaneta*, the AAL technology should respect an older person's physical and psychological conditions. A person with cognitive decline who is still competent should be able to decide on the installation of the technology in their home. Technology should focus less on security and more on the preservation of dignity and autonomy of the persons. What is more important a safe living environment or the environment that preserves person's autonomy and dignity - is a tough question to consider and reach balance, especially that there are no definitive standards for competency assessment.<sup>180</sup>

### **Inclusiveness and diversity in design**

Given the sensitivity of data and different capacities of users, the subjectivity of the interests that are represented, the design process of the AAL should involve users whenever possible, since it enhances their agency. *“Devices can be designed that both align with the values and interests of specific user groups while allowing individual control of privacy policies and features.”*<sup>181</sup>

### **Trust and confidentiality between the AAL users and providers**

Trust is very closely connected to other values, including privacy, confidentiality, safety and efficacy. Trust is often a pre-requisite for the use of the AAL system, and lack of trust

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<sup>179</sup> If a participant is suffering from any form of mild cognitive impairment.

<sup>180</sup> Diaz-Orueta - Urdaneta 2013.

<sup>181</sup> Mittelstadt 2017, p. 8.

has been linked to the low level of AAL acceptance. Users want to trust the devices that handle highly sensitive data about them.

### **Accountability and transparency of the data processing protocols**

Transparency gives the users power to hold the providers accountable for the impact of the AAL on the care they receive and their quality of life. Goals and purpose of data collection need to be clearly explained to the user and family; it also includes the principle of informed consent.

*Kosta et al.* introduced that are complementary to the *Mittelstadt's* principles of ethical AAL design.

**Integrity and dignity:** technology should not violate the individuals' dignity as human beings.

**Reliability:** technical solutions should be reliable when used for the purposes that they were created for.

**E-inclusion:** services should be accessible to all user groups despite their physical or mental disabilities.

**The benefit to the society:** The society will use the technology for others benefit and make sure that it does not cause harm to others.

**Proportionality:** The level of intervention should be proportionate to what is necessary for the given situation.

**Justice:** For instance, with the case of dementia, the fact that the person will not remember everything when the sensors are installed - does not mean that everything is permitted.<sup>182</sup>

### **Human-centric approach**

Implementing a human-centric approach to data processing is aimed at supporting individual autonomy and digital dignity. Unobtrusive monitoring technologies are increasing the vulnerability of users through continuous monitoring of the most private spheres of their life. Ensuring the individual's control over the personal data he or she shares

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<sup>182</sup> *Kosta et al.* 2009, p. 5.

with the service providers has become more critical and at the same time much more challenging than ever. User control and oversight over their data is an essential aspect of autonomy. Data subject's rights of access and portability allow users to protect their privacy and be informed about what types of data about them are being collected and how they are used. Data portability enables users to choose with which parties to share their data, such as medical and social care providers and to have the freedom to select and move between different AAL service providers.<sup>183</sup>

Based on the above-presented principles of ethical AAL technology design, *Mittelstadt* proposes to follow the nine guidelines for ethical design and implementation of the AAL.<sup>184</sup>

1. Give users control over data collection and transmission. Participatory design methods can help strike an appropriate balance.
2. Iteratively adhere to industry confidentiality standards. At a minimum, de-identification or anonymisation of data should be required.
3. Design devices and data sharing protocols to protect user privacy by default. AAL should be designed to protect privacy by default. Clear guidelines to handle the legacy of the AAL data are required.
4. Use alternative consent mechanisms when sharing the AAL data. When informed consent is not feasible, alternative tools to protect user interests should be embedded in the AAL data protocols. These mechanisms should especially be integrated when the service provider is intending to use the data for secondary purposes or planning to share it with third parties for commercial purposes. Currently, the practice is to use "wide" or "blanket" consent for other purposes. However, tiered or dynamic consent is preferable. While consent should still act rather as an enabler than as a restriction of secondary uses.
5. Meet professional duty of care and facilitate the inclusion of medical and social care professionals in the AAL mediated care. The AAL technology should allow users to engage with the care personnel according to their wishes. Introduction of the AAL is often viewed as a means to reduce the reliance on care personnel as such, therefore putting the senior's

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<sup>183</sup> EDPS 2016.

<sup>184</sup> Mittelstadt 2017, p. 2.

well-being at risk. Therefore, the AAL should be designed to create opportunities for social care professionals to remain involved in the care process as they were before the AAL.

6. Include robust transparency mechanisms in the AAL data protocols to grant users oversight over their data. Quite often users do not have the necessary knowledge and capability to understand vast and complex data gathered by the AAL. Here, a trusting operational relationship is crucial.

7. Report the uncertain utility of the AAL data to users at the point of adoption. Users should be informed about data retention and processing aims, the scope of data collected and what collected data can foreseeably reveal about them.

8. Provide users with practically useful mechanisms to exercise meaningful data access rights. Giving access to raw data may be harmful if the data subjects cannot make sense of it due to the lack of expertise or resources.

9. Design devices to be unobtrusive according to the needs of specific user groups. AAL can create the feeling of “being watched”. It can also be physically obtrusive. These technologies can disrupt the user’s normal autonomy and behaviour, and impact the user’s identity, subjecting the user to stigma.<sup>185</sup>

## 6.4 Conclusions

Autonomy of the older person in the current model of social care is a balancing act between the duty of care of the personnel and the preservation of the control by seniors over their decisions and lives overall. At the moment, social care follows the medical model of service provision where reduced autonomy of the patient is a norm. *Fisk and Rudel* argue that a different model should be pursued instead – the social model of care which views older people as being able to make or participate in making decisions about the services that are provided to them, thus enabling individual autonomy. New ethical norms are necessary to promote the social model of care. The basic ethical principles that are relevant to the medical model of care are no longer suited.

At the moment, there is no single set of ethical norms or standards that would comprehensively cover the AAL technology. Being a novel practice in the context of social

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<sup>185</sup> Mittelstadt 2017, pp. 10-17.

care, the AAL resides on the border between the ethics of care principles and the norms of ethical technology design. Principles of biomedical ethics and ethics of care combined with the ethics of technology and data ethics render the new set of guidelines and principles of ethical AAL design.

Ethical AAL design incorporates the principles of data protection as guaranteed by the GDPR and the principles of the biomedical ethics. The principle of autonomy and enabling it instrument of informed consent belongs to both legal and ethical normative regulation. In fact, historically, the principle of informed consent came into the data protection from the norms of ethical research. Also, completely new and yet not less important principles enabling individual autonomy are: avoiding subtle nudging of user behaviour, inclusiveness and diversity in design and establishing and maintaining trust and confidentiality between the AAL users, AAL service providers and care personnel. Implementation of human-centric AAL allows users effectively exercise their rights to access personal data, be informed about the data processing practices and be able to control the flow of the personal information between different AAL service providers. It is another example when the technology design choices have a profound impact on the individual autonomy. Stemming from these principles, there are nine guidelines of ethical AAL design that are worth incorporating at the early stages of technology development and following when it is in use.

## 7 CONCLUDING REMARKS

In the face of growth and expansion of Silver Economy, the active and healthy ageing has become a primary goal. It also coincides with the rapid development of new technologies – AAL being one of them. The AAL employs the advances in the emerging technologies with the need to promote healthy and active ageing experience. Individual autonomy and independence are crucial constitutive elements of “ageing well”. The way AAL technologies influence individual autonomy is, however, rather ambiguous. On one side, its main goal is to enable independent and autonomous living for as long as possible, while on the other side, the methods it employs are by its very design limiting individual autonomy.

Following the theory of technological determinism, stating that technology shapes social practices, the AAL impacts all spheres of older person’s life. Senior’s individual autonomy is no exception. AAL also brings three types of vulnerabilities that restrict autonomy. These are profiling, surveillance and involvement of third parties, the "autonomy trap" and behavioural nudging. AAL creates asymmetrical informational relations which are at the onset characterised by the imbalance of power (senior person vs others).

Taking into account the nature of AAL technology, privacy is the key element enabling individual autonomy in the AAL and vice versa. Therefore, these two values are closely interrelated in the AAL context. To evaluate the AAL’s impact on individual privacy, we have used the CI framework. Analysis showed that the AAL disrupts the contextual information norms of the social care, thus, infringing privacy.

Next logical step was to evaluate the tools that could bring the AAL in line with contextual norms and enable individual autonomy.

### *7.1 Law*

From the legal perspective, the autonomy in AAL is enabled when the senior is viewed in the role of a citizen of a democratic state or in the role of the data subject. The right to privacy and the right of older persons to lead independent lives as well as other rights of older persons guaranteeing their autonomy and independence are recognised at the international level in a number of international instruments. However, the gaps in the protection of the older persons’ rights still exist, and there are no international standards in the international human rights law on autonomy and independence in the older age. For this

reason, a need for a Convention on the Rights of Older Persons is largely advocated. The right to data protection is the principal instrument to guarantee individual autonomy of a senior as a data subject. GDPR is a comprehensive tool containing data processing principles and rules to enable the right to the protection of personal data.

The right to privacy, data protection and the right of older people to lead independent lives – all build a solid base for ensuring that individual autonomy and human dignity are protected. However, the legal, regulatory methods and tools are not meeting the challenges of the AAL technology. Individual consent as autonomy enabler is not effective, especially considering the vulnerability of senior persons and the low likelihood of them giving free and informed consent, or when it is provided by their guardian. Reliance on consent may lead to “proceduralisation” of the AAL use. When merely ticking the box renders any practice possible as long as all procedural requirements are in place and all the formal conditions are met.

A possible solution to this is to express the legal protection through embedding legal rules in the AAL. Privacy by design incorporates data protection into the design specifications of the technology which helps reduce the privacy risk from the onset. DPIA is an effective tool to integrate privacy throughout the whole process of technology development, and it would be a much more adequate way to avoid the over-proceduralisation and will safeguard individual autonomy in the AAL.

## 7.2 *Ethics*

At the moment, there is no single set of ethical norms or standards that would comprehensively cover the AAL technology. Being a new practice in the context of social care, the AAL resides on the border between the ethics of care principles and the norms of ethical technology design. Principles of biomedical ethics and ethics of care combined with the ethics of technology and data ethics render the set of guidelines and principles of ethical AAL design.

As stressed by the EDPS: *“In today's digital environment, adherence to the law is not enough; we have to consider the ethical dimension of data processing.”*<sup>186</sup> With this statement in mind, the principles of ethical AAL design incorporate the principles of data

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<sup>186</sup> EDPS, ‘Opinion 4/2015, p. 4.

protection as guaranteed by the GDPR and the principles of the biomedical ethics. The principle of autonomy and enabling it instrument of informed consent belongs to both legal and ethical normative regulation. Also, completely new and yet not less important principles enabling individual autonomy are: avoiding subtle nudging of user behaviour, inclusiveness and diversity in design and establishing and maintaining trust and confidentiality between the AAL users, AAL service providers and care personnel. Implementation of human-centric AAL that allows users effectively exercise their rights to access personal data, be informed about the data processing practices and be able to control the flow of the personal information between different AAL service providers is another element where the technology design choices have a profound impact on the individual autonomy.

### 7.3 Architecture

Lessig famously stated that online, behaviour is predominantly structured by code, and that code is more effective in regulating behaviour than law or physical architectures. The abstract notion of ‘*code regulates*’ is embodied in the manner in which online businesses control the entire interaction through code. The underlying code defines the range of possible actions.<sup>187</sup>

In the same manner, AAL design choices can integrate privacy and autonomy of its users.<sup>188</sup> The technology needs to incorporate privacy values through “code”. It should be set by default and embedded in the technology architecture.<sup>189</sup> The concept of PbD and DPIA discussed in Section 5.3.7 are both mandated by the GDPR and are a great starting point for designing the technology that is respectful of legal requirements and takes into account the ethical norms of the specific context in which the technology is going to be applied. Also, the principles of ethical technology design are important as they allow autonomy and privacy to be embedded “through code”.

Following the ethical norms from the very beginning of the AAL introduction – from the moment the technology is being designed and taken in use ensures that the procedural constraints and data protection principles are observed and are being complied with, as they

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<sup>187</sup> Lessig 2006.

<sup>188</sup> Lessig 2006.

<sup>189</sup> Hildebrandt - Koops 2010.



serve as a pre-condition to meet all the legal and procedural restrictions imposed by the GDPR.<sup>190</sup>

#### *7.4 Final thoughts*

This research focused on the value of individual autonomy and its importance in the context of social care. The main argument of this thesis is that individual autonomy is a crucial element in securing privacy and a pre-requisite of a successful application of the AAL in the senior care. However, the legal norms, in particular, the ones that implement the right to data protection, are way too procedural to enable individual autonomy in the AAL application in senior care. And therefore, this research presented the set of ethical norms as essential in enabling individual autonomy. Moreover, the GDPR does “make room” for more use of the ethical norms and standards,<sup>191</sup> since the main drawback of the ethical norms is that they lack the “enforceability” aspect of the legal regulation.

AAL is very agile, and the contexts and norms under which it operates are very dynamic and constantly changing. Therefore, legal regulation needs to be augmented by a more flexible practice that is fit to meet the ever-changing landscape of the emerging technologies. Ethical technology design principles have a great potential to address the novelty of the AAL technology and the challenges that European data protection legislation is failing to address. Ethical guidelines are playing a crucial role in ensuring that individual autonomy is preserved and guaranteed. In AAL, privacy is a key component to ensure that seniors’ autonomy is preserved.

The relationship between ethical practice and the law is complex. Taking European data protection as an example, its regulation is “omnibus” and it does not have sector-specific rules and does not provide a clear guidance in complex specific cases.<sup>192</sup> Also, law may not be ethically correct – for example research practices in Nazi Germany may have been legal but were clearly immoral.<sup>193</sup> Ethics starts where the law ends.<sup>194</sup>

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<sup>190</sup> Nissenbaum - Barocas 2014, 33.

<sup>191</sup> GDPR, Article 40.

<sup>192</sup> Nissenbaum 2010.

<sup>193</sup> ‘European Textbook on Ethics in Research’.

<sup>194</sup> Groenewald - Dondé 2017.