From disability rights towards a rights-based approach to long-term care in Europe

Building an index of rights-based policies for older people

Working Paper I: Literature Review

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Executive Summary

Overview and main objectives

The need for better legal protection of older people's rights is currently a topic of debate at the international and European Union (EU) levels. Important questions being discussed include the role of the international community and national governments in upholding older people's rights, and the role that respective states' social welfare policies currently play and should play in the future. People in Europe are living longer than ever before and the share of older age groups in the population is increasing throughout Europe (Colombo et al., 2011). At the same time, near universal constraints on public sector funding are calling into question the sustainability of traditional social protection systems. Perhaps nowhere are these resource constraints felt more keenly than in care for older people, a vulnerable group whose members are exposed to age-based discrimination in all facets of life (Equinet, 2011; São José & Amado, 2017). Thinking about older persons' care through the lens of human rights offers one way forward, compelling us to view older people for what they are: a diverse group of individuals whose human rights must be upheld as they enter into contact with and exit the long-term care (LTC) system. Because of the unique overlaps in the long-term care needs of people with disabilities and older people, disability rights and its theoretical foundations offers an instructive entry point into the discussion on a rights-based approach to LTC for older people.

The following working paper summarises the results of a literature review carried out within the first phase of the project, "From disability rights towards a rights-based approach to long-term care in Europe: Building an index of rights-based policies for older people"; a two-year research project (2017-2019) funded by Sweden's Ministry for Health and Social Affairs. The main output of the project will be an index of LTC policies that takes a human rights approach, and which will offer the possibility of monitoring and comparing countries' progress in ensuring older people's rights as they relate to LTC.

The research questions guiding the literature review are:

1 Defining rights

a. How are the rights of people with disabilities characterised and/or defined?

b. How are the rights of older people characterised and/or defined?

2 Rights applied to LTC

a. What dimensions need to be considered in applying a rights approach to long-term care for older people?

Chapter 1 of this working paper provides the background for the themes discussed later on. *Chapter 2* delves into the key concepts forged over the course of the movement to secure the rights of people with disabilities, with a focus on the contexts of care and social inclusion. *Chapter 3* introduces the arguments for and against a specific focus on the human rights of older people in need of LTC. *Chapter 4* serves as a bridge between the two distinct discourses addressing the rights of people with disabilities and rights of older people, drawing from the former in order to better understand and develop the latter. *Chapter 5* distils the findings from the review in order to identify and describe the specific rights relevant for consideration in the context of care for older people. *Chapter 6* concludes the paper with a discussion of the most salient points raised by the review with a view to informing the next stage of the study.

Lessons from disability rights studies

Referring to people with impairments as 'disabled' has its origins in the medical model of health and disability, which views disability as a problem in need of fixing, and the person with the disability as the locus of the problem (Harpur, 2012; Jönson & Harnett, 2016; Kröger, 2009; Stein & Stein, 2007). Although certain aspects of the medical model are still considered important, disability activists and policymakers alike have come to favor the social model of disability (Harpur, 2012; WHO, 2011); Stein, 2007). The social model views the 'problem' of disability as socially constructed, whereby people with impairments are rendered disabled by barriers that society imposes on them. That said, an important criticism of the social model has been that it goes too far in its emphasis on societal barriers, ignoring the fact that even when all external barriers are removed, people with disabilities are nonetheless affected by their impairments and may need support in coping with them (Harpur, 2012, 2016; Shakespeare, 2006).

The fundamental link between people with disabilities and older people is the concept of impairment (AGE Platform Europe, 2014; Harpur, 2016). While not all older people experience impairments, for most, getting older comes with some reduction in functional abilities (Harpur, 2016). In a society that idealises physical and mental health and 'ableness', both people with disabilities and older people experience inequalities and discrimination as a result of their impairment. This common experience of discrimination in its many forms offers an opportunity for closer consideration of the conceptual linkages, as well as the potential development

of a common policy framework (Naue & Kroll, 2010; Jönson & Harnett, 2016; Oldman, 2002; Priestley & Rabiee, 2001).

Despite the commonalities between these two groups, there are a number of reasons why drawing on the experiences of people with disabilities is inadequate in formulating a rights-based framework for the situation of older people. First, older people with functional impairments generally do not themselves identify as 'disabled', nor do they necessarily want to be considered as such by others (Naue & Kroll, 2010). We as a society tend to view the impairments that develop as part of the ageing process as 'normal', and are not seen to "deviate from generational norms of old age" (Priestley & Rabiee, 2001: 10), unlike the norms that we associate with youth and adulthood. Similarly, disability activists have tended to hold the claims of older disabled people at arm's length in order to avoid the common ageist preconceptions that society wields against older members of society, namely that they are no longer productive members of society, and that they are "inflexible to change, having, or about to have, a reduction in their mental and physical abilities and focused on retirement" (Harpur, 2016: 1057). For these reasons, there is a need to more precisely delineate the rights of older people in the context of their care and support needs.

Rights of older people with care needs

A rights-based approach to LTC attempts to anchor all policies, action plans and programs in principles derived from international human rights treaties and declares progress towards the achievement of such rights as its ultimate objective (UNIRSD, 2016). Building on the European Network of National Human Rights Institutions' (ENNHRI) framework (2017a; 2017b) and synthesising the scholarship to date identified in the literature review, we identified 17 distinct rights of older people in the context of LTC, organised according to the point in the care trajectory at which each right is of *most* relevance.

Conclusions

A rights-based model for older people in need of long-term care must consider that older people in need of support do not experience discrimination due to their physical or mental impairment alone, but on the basis of discrimination because of their chronological age. The review revealed important divergences in the two discourses related to the concept of 'care' and 'dependence', with important

implications for the development of a rights-based framework for older people, given the traditional reliance on, and the values associated with family care in this context. There is considerable work being done at the international and European level to formulate a Human Rights-Based Approach (HRBA) for older people, and even a few initiatives focussing specifically on a HRBA to LTC for older people. In Chapter 5, we have attempted to summarise critically the specific rights most relevant in the context of older people and LTC, as well as the arguments put forth to support them (see Overview). While certain rights were often mentioned, including rights related to accessing care services, the right to choose and autonomy, the right to dignity, to palliative and to end-of-life care; other rights were less well covered in the literature, including rights related to the choice of care setting, particularly community care. In addition, discussion on the inclusion of the rights of carers—and what such rights might be—was scant. In the next phase of this project, we will be synthesising the findings from this review in order to develop a conceptual framework of a rights-based approach to LTC for older people.

Overview: The Rights of Older People in Need of LTC as Identified in the Literature

Before entry into LTC	Equal access to care services
	Affordability of care services
	Right to choose of LTC services
While in LTC	Right to life
	Right to freedom from torture, degrading or inhumane treatment
	Right to liberty, freedom of movement and restraint
	Right to choose, autonomy, legal capacity
	Right to dignity
	Right to privacy and family life
	Right to participation and social inclusion
	Right to freedom of expression
	Right to highest attainable standard of physical and mental health
	Right to an adequate standard of living
	Equality and non-discrimination
	Right to remedy and redress
End of life	Right to palliative and EoL care
Other	Rights of carers

1   Introduction

1.1   Situating the literature review within the larger research study

The need for better protection of the human rights of older people, as distinct from other vulnerable groups and from the general population, has been hotly debated at the international and EU level in recent years. An important element of this discussion revolves around the role of the international community and of national governments in upholding older people's rights, and specifically around the role that respective states' social welfare policies currently play and should play in the future. People are living longer than ever before—though as we well know, these later years are not necessarily lived in good health—and the share of older age groups in the population is increasing throughout Europe (Colombo et al., 2011). For many years, constraints on public sector funding, experienced more severely in some countries than in others but universally felt to some degree, are calling into question the sustainability of traditional social protection systems. Perhaps nowhere are these resource constraints felt more keenly than in the area of care for older people, a heterogeneous group whose members nonetheless almost uniformly experience age-based discrimination on myriad levels, from the superficial to the structural (Equinet, 2011; São José & Amado, 2017).

There is thus a need for a paradigm shift in the way older people are perceived and treated by society, and to narrow the focus, in the way that long-term care (LTC) benefits and services are designed and implemented. Considering LTC through the lens of human rights offers one possible way forward, forcing researchers and policymakers alike to perceive older persons as more than just care recipients, as more than just people in need, rather as a diverse group of individuals whose human rights must be upheld as they enter into contact with and eventually exit the LTC system. There is considerable precedent for taking a human rights approach to care for other distinct groups in international and regional legal instruments, notably in the case of women, people with disabilities, and migrants. Because of the unique overlaps in the long-term care needs of people with disabilities and older people— foremost the need for support to cope with impairment and reduced functional ability of some kind, and because many older people are themselves people with disabilities and vice versa—disability rights and its theoretical foundations offers an instructive entry point for dipping into the discussion on a rights-based approach to LTC for older people.

The following working paper serves to document and provide analysis of a literature review carried out within Work Package 1 of the project, "From disability rights towards a rights-based approach to long-term care in Europe: Building an index of rights-based policies for older people". This two-year research project (2017-2019) is funded by Sweden's Ministry for Health and Social Affairs and its main outcome will be the development of an index of long-term care (LTC) policies that takes a human rights approach. In adhering to a human rights perspective, the key question guiding the construction of the index is: how must LTC systems be designed, specifically what conditions and enablers should be in place, to ensure that older people's universal human rights as they relate to care and support are upheld? The index will aim to comprehensively capture a rights-based approach to LTC by populating relevant policy domains and indicators with available qualitative and quantitative data. The purpose of the index will be to compare, and ultimately to monitor over time, the countries of Europe in terms of the degree to which their respective LTC policies ensure the rights of older people in their access to care and support services, and in their participation and inclusion in society.

The literature review synthesised in the following pages is the first step towards the development of the index. Building on the outcomes of the review, the research team's next task will be to develop a conceptual framework for a rights-based approach to LTC. The conceptual framework will be validated by means of workshop with international experts and will then feed directly into the construction of the domains and indicators comprising the index. These domains and indicators will in turn be refined through a DELPHI survey, again with the participation of international experts. The index will then first be piloted with 4-6 EU countries and will then in a final stage be extended to include data for 12 EU countries. The selection of countries will strive to represent the diversity of LTC systems in the EU but will likely be restricted by the availability of data.

1.2 Objectives and research questions guiding the review

As the first stage in the development of an index of rights-based LTC for older people, our purpose in carrying out a literature review was to firmly ground subsequent stages of the research study in the human rights scholarship to date pertaining to care for both people with disabilities and for older people, albeit with the understanding that our focal point is older people's rights. The overarching objective of the review was to investigate the conceptual link between the disability rights and the older persons' rights discourses in order to begin to understand how to answer the following questions in a way that is both theoretically sound as well as feasible in

practice: *How can a rights-based approach to LTC be conceptualized, and how should this conceptualisation be reflected in policy and applied in practice?*

More concretely, the research questions guiding the review are presented in Table 1 below. They are divided into two major themes, the first on understanding which rights are particularly relevant for people with disabilities and older people in the context of care, and how these rights are defined and theoretically situated. The second theme addresses the application of a human rights approach specifically to the case of LTC for older people.

Table 1: Research Questions Guiding the Literature Review

RQ 1: Defining rights	How are the rights of people with disabilities characterised and/or defined?
	How are the rights of older people characterised and/or defined?
RQ 2: Rights applied to LTC	What dimensions need to be considered in applying a rights approach to long-term care for older people?

1.3 Methodology applied in the review

The *Methodological Annex* to this working paper provides a comprehensive description of the methods applied in carrying out the literature review and its results, including the keyword list employed, the stages of the review, and a tree diagram detailing the process of article selection for the peer-reviewed literature. In brief, the research team used a rapid review strategy to survey the peer-reviewed and grey literature. Rapid reviews are often used when the timeframe for the exercise is limited and are thus frequently employed in applied research contexts within the health and social sciences. They differ from systematic reviews in that they restrict one or more of the following parameters of the search: the number of years included in the search, geographic region, language, databases, and by the number of persons involved in the text review (Gannan et al., 2010; Tricco et al., 2016). In the case of this rapid review, articles and reports published only between 2005 and 2017 were included. The geographic region was not limited per se, but only articles and reports relevant for middle- and high-income contexts were included. For the review of the peer-reviewed literature, the database selected was Web of Science. For the grey literature segment of the review, the research team carried out searches in Google and targeted the websites of international and European governmental and non-governmental institutions to identify relevant publications. Lastly, only articles in

English were included. The majority of searches were carried out and documented by one member of the research team, under consultation with and validation by the other members of the team. The selection of articles and the extraction of information from selected articles was carried out mostly by two researchers, under consultation with and validation by the other members of the team in case of disagreements. In total, 85 peer-reviewed and 33 grey literature articles/reports were selected to be included in the review, including a small number of papers sourced through snowballing, i.e. the scanning of selected articles' reference lists.

1.4 Structure of the working paper

This working paper loosely follows the research questions guiding the review in that it moves from discussing more abstract concepts emerging from the review, to a more focused discussion of the specific rights that should be considered in a rights-based approach to LTC for older people. *Section 2* delves into the key concepts forged over the course of the movement to secure the rights of people with disabilities, with a focus on the contexts of care and social inclusion. *Section 3* introduces the arguments for and against a specific focus on the human rights of older people in need of LTC. *Section 4* serves as a bridge between the two distinct discourses addressing the rights of people with disabilities and rights of older people, drawing from the former in order to better understand and develop the latter. *Section 5* distils the findings from the review in order to identify and describe the specific rights relevant for consideration in the context of care for older people. *Chapter 6* concludes the paper with a discussion of the most salient points raised by the review with a view to informing the next stage of the study, namely the development of a conceptual framework for a rights-based approach to LTC.

2 The disability rights model

2.1 Key milestones in the protection of people with disabilities' rights

The crimes against humanity wrought over the course of the Second World War served as a catalyst for the establishment of international human rights protection mechanisms both for specific vulnerable groups and for all human beings generally in the second half of the 20th century. In theory, the rights of people with disabilities have been protected by a series of international human rights declarations, resolutions and recommendations since the passage of the United Nations' (UN) Universal Declaration of Human Rights (UDHR) in 1948 (UN, 1948a). The UDHR declared that every person is entitled to certain inalienable human rights and freedoms, "…without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status" (UN, 1948a: Article 2). What was initially intended as a legally binding instrument only managed to pass as a non-binding resolution, and did not go far in guaranteeing the rights of people with disabilities. Aside from its non-binding nature, the ineffectuality of the UDHR—and of subsequent instruments until recently —in the case of people with disabilities was due to the 'invisibility' of this group in the all-encompassing provisions proffered by the Declaration (Schulze, 2009; Quinn et al., 2002).

> **Box 1: Human Rights Defined**
>
> *Human rights are universal freedoms and entitlements of individuals and groups that are protected by law. They include civil and political rights, such as the right to life, as well as social, economic and cultural rights, which include health, social security, and housing. All human rights are interrelated, interdependent, and inalienable.*
>
> *(Baer et al., 2016: S207)*

In the 1960s, two further instruments, the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR) were passed by UN Member States. These two covenants,

together with the UDHR, constitute the International Bill of Human Rights (Schulze, 2009). Human rights scholars maintain that the decision to treat civil and political rights on the one hand, and economic, social and cultural rights on the other as distinct, has been severely detrimental to the realisation of human rights for all groups, including for people with disabilities because, as Schulze states, the split between these two 'types' of rights goes against the "universal, indivisible, interrelated and interdependent nature of all human rights" (2009: 10).

The worldwide social movements of the 1960s and 1970s also saw the mobilisation of disability rights activists and advancements in the area of disability rights. Beginning in the 1970s, there was a slow progression towards both soft and hard law internationally as well as at the national level in certain countries, focussing specifically on people with disabilities (Schulze, 2009). Signs of progress included the UN announcing 1981 as the International Year of the Disabled, and declaring 1983–1992 as the International Decade of Disabled Persons. Significantly, in 1982 the UN General Assembly adopted the World Programme of Action concerning Disabled Persons to encourage states to develop national programmes promoting equality for persons with disabilities. The 1980s also marked the emergence of the Independent Living Movement internationally, in which people with disabilities and their advocates demanded that governments provide the resources to support people with disabilities to live at home, to take part in community life, rather than be segregated and isolated in residential facilities (Brisenden, 1986).

The international community returned to the issue of human rights after the end of the Cold War with the Vienna Declaration and Programme of Action on Human Rights in 1993. Among other things, the signatories of the Vienna Declaration recognised the failure of previous mechanisms to affect change on the ground in terms of the realisation of human rights. Article 24 of the Declaration states: "Great importance must be given to the promotion and protection of the human rights of persons belonging to groups which have been rendered vulnerable [...] the elimination of all forms of discrimination against them, and the strengthening and more effective implementation of existing human rights instruments" (UN, 1993: Art. 24).

At around the same time in the United States, the Americans with Disabilities Act (ADA) was passed, prohibiting disability-based discrimination in the US (Stein & Stein, 2007). In subsequent years, many other countries adapted the statutes outlined in the ADA in order to formulate their own legislation. The ADA was an important step in firmly establishing the social model of disability over the previously dominant medical model (see Section 2.2). That said, its efficacy was limited because of its narrow focus on the *civil* aspects of disability law (Stein & Stein, 2007), which, as pointed out above in the case of the ICCPR and ICESCR, did not take into account and protect against the social determinants of inequality faced by people with disabilities. An important test of the ADA came in 1999 with the US Supreme Court ruling that people with disabilities have a (qualified) right to receive state funding to support

their living in the community rather than in residential facilities – a ruling that came to be known as the Olmstead Decision (Williams, 2000), and which registered an important victory for the Independent Living Movement.

The first legally binding international human rights instrument for people with disabilities was advanced by the UN in 2006 and received enough signatures for ratification in 2008. This instrument is the UN Convention on the Rights of Persons with Disabilities (CRPD), and at the time of its adoption was the culmination of many years of fierce international campaigning and advocacy (Sciubba, 2016), simultaneously marking a new era in the fight for the rights of people with disabilities. Disability rights scholars like Harpur (2012) and Stein and Stein (2007) provide three key reasons to explain why the CRPD has been such an important vehicle for change in the actualisation of the rights of people with disabilities. First, because it names not only universal rights (Articles 3-10) but also incidental or substantive rights (Articles 11-30), rights which serve to elaborate on and to provide guidelines for the implementation of universal rights, thereby essentially serving to ensure that universal rights are achievable (Harpur, 2012; UN, 2006). As an example, one of the universal rights enshrined in the CRPD is the right to equality and non-discrimination. The substantive rights named to support the former include the right to access buildings, schools, programs, public transport; the right to live independently; the right to be included in the community; the right to personal mobility; the right to access information; the right to privacy; the right to participate in cultural life, recreation, sport and leisure; and so on. By conceptualising substantive rights as acting, so to speak, in the service of other more expansive, universal rights, the drafters of the CRPD had the foresight to recognise that the declaration of rights such as the right to equality and non-discrimination is insufficiently precise, leaving too much room for interpretation or worse, neglect (Harpur, 2012).

Second, in addition to the first two sections which together list all of the rights to be protected, the Convention also includes sections on implementation and monitoring schemes (Articles 31-40) and rules governing its operation (Articles 41-50), respectively. It is within the series of articles pertaining to implementation and monitoring that that people with disabilities and national disability rights advocacy groups are endowed with an official role in national monitoring and reporting processes. Article 33, § 3 states, "Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process" (UN, 2006: 24). It is the central, formal role of persons with disabilities and of disability rights advocacy groups in its monitoring mechanism that makes the Convention such a paradigm shifting instrument (Harpur, 2012). The result is that people with disabilities are empowered to advocate and make decisions on their own behalf, perhaps *the* central tenet of the disability rights movement.

Writing just after its adoption but before its ratification and subsequent implementation, Stein and Stein (2007) pointed to a third reason why the passage of

the CRPD was a watershed moment in the disability rights movement. They argued that by combining civil and political rights (known as negative or first-generation rights; and the focus of antidiscrimination legislation up until that point) with social, cultural, and economic rights (known as positive or second-generation rights), the CRPD was advancing a more holistic human rights approach, ushering in a new paradigm for disability rights (Stein & Stein, 2007).

2.2 Key conceptual underpinnings of disability rights models

Referring to people with impairments as 'disabled' has its origins in the medical model of health and disability that dominated theory, policy and practice until at least the second half of the twentieth century. The medical model views disability as a problem, a deviation from the physical norm and ideal; essentially, as an abnormality in need of treatment, of fixing, and the person with the disability as the locus of the problem (Harpur, 2012; Jönson & Harnett, 2016; Kröger, 2009; Stein & Stein, 2007). The medical model was emblematic of the prevailing conceptions linking personhood, self-determination and citizenship with functional autonomy and physical independence, which may well explain why the disability advocacy discourse has long highlighted the distinction between being able to perform activities for oneself independently and *exercising control* over what those activities are,[1] and why it focussed early on the obtainment of basic civil rights (Fine & Glendinning, 2005; Boyle, 2008; Kröger, 2009). Writing in 1986, Simon Brisenden, a disability rights activist and the founder of one of the first Centres for Independent Living in the UK, summed up the inadequacy and indeed the harm of viewing people with disabilities solely through a medical lens: "The problem, from our point of view, is that medical people tend to see all difficulties solely from the perspective of proposed treatments for a 'patient', without recognising that the individual has to weigh up whether this treatment fits into the overall economy of their life" (Brisenden, 1986: 176).

Brisenden goes on to argue why an alternative to the medical model is needed; a model in which physical and mental impairment is recognised as one more

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[1] Collopy (1995) would later make this same distinction in the context of older people with functional impairments, using the terms 'decisional autonomy' and 'executional autonomy', where decisional autonomy is defined as having the capacity to make decisions and choices based on personal values, regardless of being able to carry them out independently (the definition of executional autonomy).

manifestation of humankind's diversity, in which disability is not an individual problem but a societal construct, in which people with disabilities are active rather than passive actors in every facet of decision-making concerning their own lives, and in which life holds the same promise and offers the same opportunities as it does for people without impairments (Brisenden, 1986). In his comments, Brisenden was outlining the core features of the social model of disability, a theory developed by disability activists with the Union of Physically Impaired Against Segregation in the UK in the 1970s and 80s (Kröger, 2009). The social model makes a sharp distinction between impairment and disability, whereby an individual's impairment is not the cause of his/her disability (Harpur, 2012; Kröger, 2009). Rather, it is the way in which society is structured, the way buildings are built, transportation systems planned, and the education system organised, taking little account of people with disabilities, that is disabling.

Although certain aspects of the medical model are still considered important (e.g. in supporting the need to allocate resources to fund clinical research into impairment-causing diseases and conditions), disability activists, scholars, and policymakers concerned with the human rights of people with disabilities have come to favor the social model and to use it as the basis for the development of alternative models of disability (Harpur, 2012; WHO, 2011; Stein, 2007). The premium it places on the fundamental equality of people with disabilities, and its situating the 'problem' of disability—and therefore its 'solution' as well—within society and its institutions, renders the social model a powerful tool in the fulfillment of both negative and positive rights of people with disabilities. That said, an important criticism of the social model has been that it goes too far in its emphasis on societal barriers, ignoring the fact that even when all external barriers are removed, people with disabilities are nonetheless affected by their impairments and may need support in coping with them (Harpur, 2012; 2016; Shakespeare, 2006). Harpur (2012) also points out that achieving equality, or having the same opportunities as people without disabilities, does not mean that people with impairments are the same as people without. It is important to consider that as the social model emerged from the civil rights activism and counterculture movement of the 1960s and 1970s, it has its roots in Marxists concepts and an anti-capitalist ideology (Harpur, 2012). This ideology deemed the prevailing liberal economic system and its welfare policies, which treated people with disabilities as non-productive members of society and a burden on state resources, as main drivers of the exclusion and marginalisation of people with disabilities from economic and social life (Harpur, 2012).

Indeed, while the social model lies at the heart of the CRPD and its foundational principles of equality, dignity, autonomy, and of social inclusion, mentioned first in its preamble and reinforced throughout by the provisions outlined in its articles (UN, 2006), some scholars argue that the approach espoused by the CRPD constitutes a new model for disability rights. Harpur calls this model the disability rights paradigm,

describing it as the 'non-radical' version of the social model in that it does not explicitly address the economic elements of the original social model, and as placing greater emphasis on the *interaction* between individuals' impairments and socially constructed barriers with the aim of supporting people with disabilities to actualise their full human rights (Harpur, 2012; 2016). In a similar vein, Stein and Stein (2007) develop the disability human rights paradigm, which builds on key aspects of the social model of disability, the human right to development model, and Sen and Nussbaum's capabilities approach to conceive of a more comprehensive rights-based theory in which societies have a moral obligation to nurture the potential of every individual (Stein & Stein, 2007: 1221). Summing up the core of their theory, Stein and Stein write, "An integrated human rights approach that values each individual for his or her own worth asks what qualities an individual has and in what ways developing her talents can benefit both that individual as well as society" (2007: 1223).

The strong emphasis within the disability rights discourse on self-determination, autonomy and independence has made for an uneasy relationship with concepts of 'care' and 'care-giving' because of the connotations with dependency and a lack of control on the part of the person receiving assistance (Fine & Glendinning, 2005; Chapter 4). This is most evident of course in the development of the 'personal assistance' model of support services for people with disabilities. The latter is perhaps one of the most significant policy changes brought about by wider acceptance of the social model and its successors, together with deinstitutionalisation and the integration of people with disabilities in the community.

3 Building towards a human rights model for older people

3.1 Key milestones in the protection of older people's rights

In 1948, the same year the UDHR was ratified, the Argentinian delegation to the UN General Assembly proposed a draft for a new declaration specifically protecting the rights of older people. The resolution, called *The Draft Resolution on a Declaration of Old Age Rights*, did not ultimately pass, but it serves as an early example of the aspirations for and expectations of the new welfare states and social protection systems being established at the time, and the newfound interest in social justice and

social rights. The first article of the draft resolution addressed the right to assistance and made it clear that family members held primary responsibility by stating, "Every aged person has the right to full protection by his family. In the case of destitute persons, it is the duty of the State to provide such protection, either directly or by means of institutions or foundations created for the purpose or already existing" (UN, 1948b: 1). Theories surrounding the roles of the public sector versus the family in the provision of LTC have since evolved, but it is worth noting that the underlying tension between these two sets of actors is still at the heart of the debate on who bears responsibility for ensuring that people's right to care and support in old age is fulfilled.

As there would be no special legal instrument for older people signed in 1948—nor is there to this day—the rights of this group are nonetheless currently protected by a number of conventions, declarations and covenants at the international and regional (European) levels (see Figure 1 below). From within the United Nations legal framework, these include fairly early on the UDHR, the ICESCR, and the ICCPR protecting the fundamental human rights of all persons to the inclusion of older people. More recently, the CEDAW and the CRPD were passed to protect the rights specifically of women and people with disabilities, respectively, inclusive of older members of both of these groups. The CRPD, in protecting the rights of all people with functional impairments, irrespective of whether one ages *with impairments* or *into impairments*, comes closest on paper to ensuring that the rights of older people in need of LTC are explicitly addressed. In addition to the UN instruments, one convention of the International Labour Organization (ILO) has particular relevance for older people's rights within the context of employment and participation in the labour market: the 1955 Convention C102 on Social Security Minimum Standards. This convention lays the foundation for the establishment of nine branches of social security, including old-age benefits. Notably, the primary ILO Convention against discrimination in the workplace, the 1958 Convention C111, does not feature discrimination on the basis of age, though subsequent ILO recommendations (non-binding instruments) have sought to address this gap (Martin et al., 2015; Harpur, 2016). Though non-binding, the Committee on the Economic, Social, and Cultural Rights (the body responsible for implementation and oversight of the ICESCR) has developed their series of 'General Comments', a unique, quasi-judicial feature enabling members of the Committee to engage with and react to states' reporting, and which have been heavily referenced in international case law (Harpur, 2016). In 1995, General Comment No. 6 to the ICESCR on the economic, social, and cultural rights of older persons was drafted, drawing attention to the need for special protection of the economic, social and cultural rights of this group (UN CESCR, 1995). At the European level, the Council of Europe European Social Charter of 1996 and the 2000 European Union Charter of Fundamental Rights both make explicit mention of older people's rights; the latter to the right of older people to social protection, and

the former to the "rights of the elderly to lead a life of dignity and independence and to participate in social and cultural life" (EU, 2000: Art. 25).

In parallel with the legally binding instruments detailed above, so-called 'soft law' or non-binding agreements, recommendations, and policy documents drafted at the international and European level by both governmental and non-governmental organisations promoting older people's rights has burgeoned in the past three decades. The earliest among these is the Vienna International Plan of Action on Ageing (VIPAA), adopted in 1982 by the UN General Assembly at the close of the First World Assembly on Ageing. VIPAA makes recommendations across 7 'areas of concern to aging individuals': a) Health and nutrition; b) Protection of elderly consumers; c) Housing and environment; d) Family; e) Social welfare; f) Income security and employment; and g) education (UN, 1982). The VIPAA was followed up in 2002 by the Madrid International Plan of Action on Ageing (MIPAA), the outcome of the Second World Assembly on Ageing. The MIPAA expanded on the previous Plan of Action and had as its main mission the mainstreaming of ageing—both its challenges and opportunities—into national policies (UN, 2002; Harpur, 2016; Martin et al., 2015). The impetus for development of the VIPAA and its successor the MIPAA came from an emerging, broad consensus that the issue of ageing could no longer be ignored in the context of national, regional and global economic and social development. The WHO's Active Ageing Framework, released in the same year as the MIPAA and taking the same general conceptual approach, contributed to a shift in the way policymakers approached the topics of ageing and care and support for older people (WHO, 2002).

Figure 1: Milestones in the legal protection framework & in policies addressing the human rights of older people in Europe
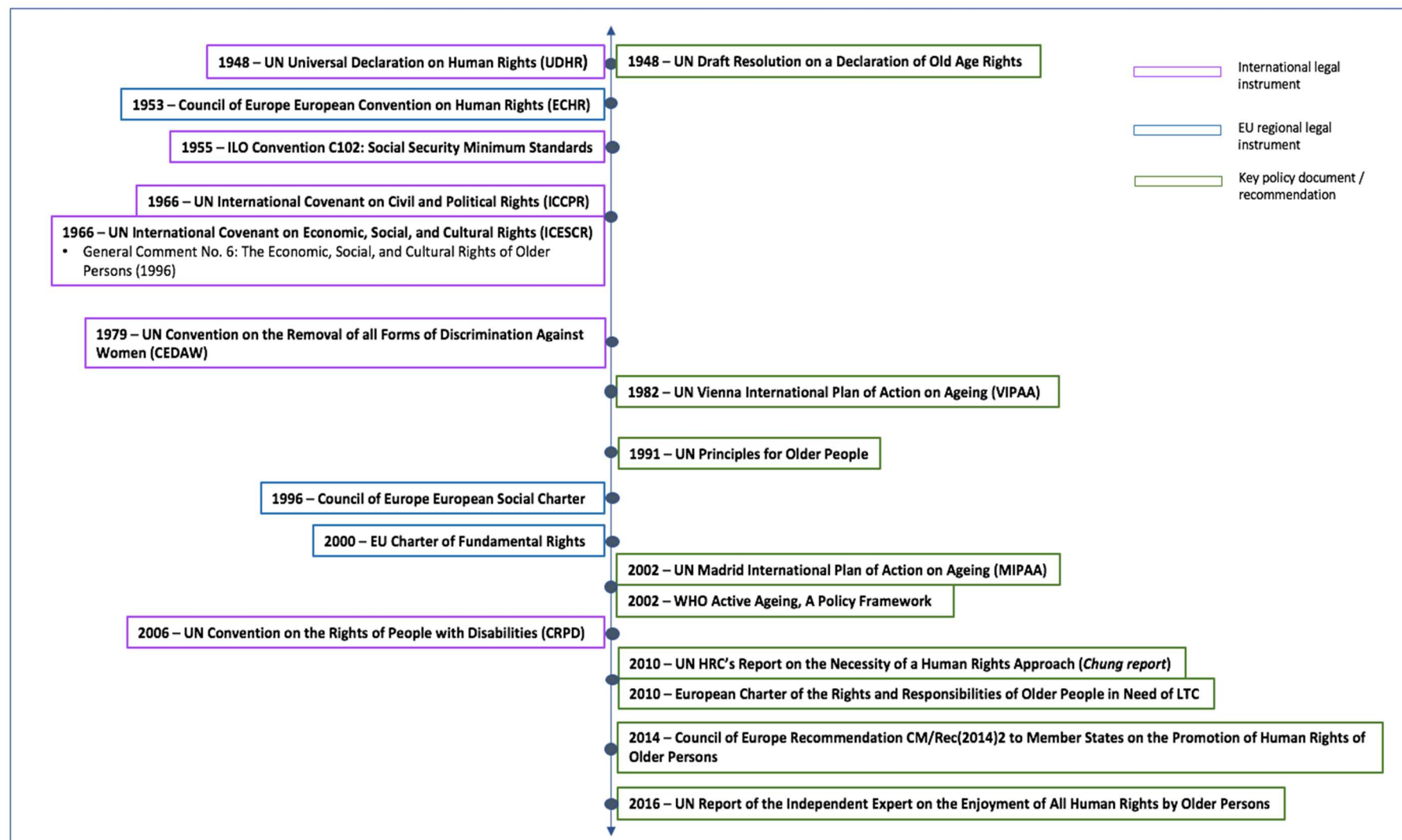
Sources: UN (2011); ENNHRI (2017a); De Hert & Mantovani (2011); Harpur (2016); Martin et al. (2015); AGE Platform Europe (2010); WHO (2002)

The MIPAA in particular has spurred a great deal of research, cooperation and consultations with a broad range of experts and advocacy groups on the topic of older people's human rights (Harpur, 2016). In between the two plans of action, the UN Principles for Older Persons was published in 1991, outlining a series of recommendations around five ethical principles: a) dignity; b) independence; c) participation; d) care; and e) self-fulfilment, with the stated purpose of encouraging states to incorporate said principles into their national programmes where possible (UN, 1991). One of the documents to come out of this increase in attention on the rights of older people is the 2010 report of the UN Human Rights Council's Advisory Committee on "The necessity of a human rights approach and effective United Nations mechanism for the human rights of the older person" (UN, 2010). Also known as the "*Chung report*" after its author, the report first set about recording global human rights violations of older persons in a broad set of domains, including health care, social security, and susceptibility to poverty among others (UN, 2010). The *Chung report* then discussed the need for improved legal protections for older people in the form of a new human rights treaty, and proposed a list of the human rights of older people (UN, 2010). Rosa Kornfeld-Matte, the "Independent Expert on the enjoyment of all human rights by older persons" appointed by the Human Rights Council in 2013, has taken the findings and proposals of the *Chung Report* and the MIPAA recommendations forward in her mandate to investigate the status quo concerning the realisation of older people's human rights across UN Member States (Kornfeld-Matte, 2015; 2016).

In addition, two important policy documents at the European level have been developed in recent years. The first is the Council of Europe's "Recommendation of the Committee of Ministers to member States on the promotion of human rights of older persons", adopted in 2014 (Council of Europe, 2014). The recommendation is notable for being the first to explicitly and self-consciously apply a human rights-based approach to the situation of all older persons, including in accessing and receiving care. At its core, the recommendation seeks to promote the autonomy of older people while at the same time ensuring that they are provided with the care and support necessary in a way that respects their fundamental human rights (Council of Europe, 2014).

The second key document at the European level is the European Charter of the Rights and Responsibilities of Older People in Need of Long-term Care (AGE Platform et al., 2010). The Charter was developed by an EU funded consortium of international and national partners led by AGE Platform Europe and aimed to "launch a discussion within the EU Member States on how best to recognise and affirm the rights of the most vulnerable older people" (AGE Platform et al., 2010: 4). The Charter includes nine groups of rights of older people in need of care, and one brief section on the responsibilities that older people themselves bear, notably to respect the rights of one's carers (AGE Platform et al., 2010). It is perhaps the first such policy document

to focus specifically on the rights of older people *in need of care* rather than on the rights of older people more generally. A project by the European Network of National Human Rights Institutions (ENNHRI), "The Human Rights of Older Persons and Long-term Care", has recently taken this focus a step further, elaborating a more comprehensive list of older people's rights before entry into LTC, while in LTC, and at the end of life, mostly in the context of residential care (ENNHRI, 2017a; 2017b).

Since its establishment in 2012, the UN Open-Ended Working Group on Ageing (OEWGA) has been tasked with investigating the need for and political will among Member States for a new UN convention on the rights of older people. For the time being, there is considerable disagreement among different factions concerning the necessity and feasibility of such a convention (Poffé, 2015).

3.2 The debate surrounding the need for greater human rights protections for older people

The developments outlined in the previous section demonstrate a clear increase in the perceived need for and interest among academics and policymakers in the development of a distinct human rights framework—in a human rights-based approach (HRBA)—for older people. Within this general framework, a HRBA is particularly relevant in LTC contexts where many frail and vulnerable individuals are faced with systematic breaches to their rights (Kornfeld-Matte, 2015; UN, 2012).

It has been pointed out by a number of authors that human rights can only be achieved where states are legally bound to uphold them, and where the monitoring mechanisms are thoughtfully operationalised, as "the difference between *de jure* and *de facto* status of State obligations to older persons is sometimes very great" (Martin et al., 2015: 25) and pressure needs to be exerted on governments and public institutions to ensure that they uphold their obligations (ENNHRI, 2017a). As a result, a good deal of the debate surrounding a rights-based approach to address the increasingly vulnerable situation of older people as a group has revolved around the need for a distinct human rights instrument addressing the rights of older persons, in the same vein as the conventions on the rights of children, women, and people with

disabilities.[2] Academics from within the research community and advocacy groups for older people and for human rights cite several reasons why a new legal mechanism specifically focussed on the rights of older people would be a positive development. These reasons include gaps in the existing human rights framework specific to the case of older people (Doron & Apter, 2010; Poffé, 2015; Harpur, 2016); the need for a legally binding instrument that specifically addresses the discrimination faced by older persons and that upholds their rights (Townsend, 2006; Stuckelberger et al., 2012; Harpur, 2016); the need to implement an international monitoring mechanism with which to hold states accountable (Poffé, 2015); and the need for increased visibility and increased awareness of the challenges facing older people in society (Tang, 2008; HelpAGE 2013; 2015; De Hert & Mantovani, 2011), a group that constitutes an ever-growing share of the population.

According to Townsend, "human rights offer a framework of rigorous analysis and anti-discriminatory work" with which to investigate and counteract the phenomenon of 'structured dependency' that people are subjected to in older age (Townsend, 2006: 177). He argues that beginning in the 1960s and 1970s, older people have been placed in a 'box of structured dependency' by the very measures taken by welfare states to lessen the negative effects of the frailty, vulnerability and dependency that often accompanies old age. Among the measures he references are a fixed age for pensions, the admission in great numbers of older people to residential care who did not necessarily require intensive care, and the 'enforced dependence' of older residents during their stays in hospitals and nursing homes (Townsend, 2006).

Stuckelberger and colleagues (2012) maintain that a human rights approach has the potential to reduce the social exclusion and marginalisation experienced by older people as a result of institutionalised and daily instances of ageism and age-based discrimination. Harpur points out that the CRPD—the only legally binding human rights instrument to specifically address older people with functional limitations— while it goes some way to protect the rights of frail older people, in order to be entitled to the rights enshrined in the CRPD, "older persons would need to be categorized as disabled" (Harpur, 2016: 1044), a designation that does not sit well with many older people themselves, their advocates, or with scholars of disability and ageing. It precludes those older people who may not have physical (or mental) impairments, yet who still may need support in order to live independently and participate fully in society. Harpur (2016) emphasises that while the CRPD has the

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2 Respectively, the UN Convention on the Rights of the Child (CRC, 1990), the UN Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW, 1979), and the UN Convention on the Rights of People with Disabilities (CRPD, 2006).

potential to protect older people exposed to discrimination based on their medical conditions, it does not protect against disadvantages experienced in old age caused by structural age-based discrimination, constituting a considerable gap in the protection of older people's rights.

In order to engender societies that serve the needs and wishes of all people, Stuckelberger and colleagues state that the "promotion of social inclusion—with a sustainable governance system—through the allocation of equal rights to people of all ages" is a necessary step (2012: 125). Despite being built on the principles of equality and non-discrimination, the existing human rights framework is furthermore inadequate in protecting older people because it does not take into account the unique form of discrimination they face (Harpur, 2016; Stuckelberger et al., 2012). The uniqueness of age-based discrimination stems from the embeddedness of ageing and old age in the life course. This means both that ageing (and the functional dependency that often accompanies it) is perceived as a 'normal', near-universal and expected process, and that age-based discrimination often intersects with other forms of discrimination experienced over individuals' lifetimes (Stuckelberger et al., 2012). As a result, it also means that age-based discrimination is the only form of discrimination that is officially sanctioned by states through the very organisation of their education, labour market, health and long-term care, and pension systems, which effectively treat people in later stages of life as unproductive members of society.

HelpAGE International, the advocacy group that has perhaps been most vocal in its call for a new legal instrument addressing the rights of older people states that such an instrument would serve to "establish norms and standards promoting dignity, equality, autonomy and self-fulfilment in older age to replace the deeply stigmatising and dehumanising ageist attitudes and behaviour that currently dominate the way we at every level in society respond to older age and older people" (HelpAge, 2015: 1). Improving the understanding and the adoption of a HRBA to address the situation of older people is a much-needed development in light of the systematic infringement on and overlooking of the rights of older people (Tang, 2006; 2008; WHO, 2015b; ENNHRI, 2017a) that has prevailed under needs-based or welfare-based approaches (Townsend, 2006; Martin, 2015). Adequate protection of human rights can only be achieved by "empowering people themselves […]—especially the most marginalized—to participate in policy formulation and hold accountable those who have a duty to act" (UNIRSD, 2016: 1).

Arguments against the promotion of a rights-based approach to address the situation of older people as such did not appear in the literature captured by this review. On the other hand, concerns and objections to the establishment of an international legal instrument specifically focussed on the rights of older people have been raised (Harpur, 2016; Poffé, 2015). Firstly, those voicing objections point to the fact that protections for older people do exist within the current international legal framework

on human rights, in particular as covered by the UDHR, the ICCPR, the ICESCR, and the CRPD; and, while not binding, the recommendations contained within the MIPAA (Poffé, 2015). According to this line of argumentation, the well-documented violations of older people's rights in Europe and elsewhere around the world (HelpAge, 2012; UN, 2010; Phelan, 2008; AGE Platform Europe, 2016a) is due rather to a failure of appropriate implementation and monitoring of the aforementioned legal instruments, than to a normative gap.[3] To counter that argument, many of those same authors advancing a new international legal instrument argue that the lack of 'legal certainty' of the rights of older people (i.e. stipulations that directly address circumstances and situations specific to older people) contained within the existing human rights legal framework, is the more fundamental problem (HelpAge, 2012; Townsend, 2006; Stuckelberger et al., 2012; Harpur, 2016). Secondly, policymakers and legal scholars alike have expressed trepidation about how to define 'older persons' in the context of a legal instrument. Lastly, and perhaps most crucially, national policymakers have expressed concerns that enshrining the rights of older people in a distinct legal document could bring significant financial obligations to bear on signatory states; financial obligations in the form of additional administrative costs, and fundamentally, in the form of additional services to adequately and appropriately support the growing number of older people (Poffé, 2015). In light of increasing constraints on public budgets, especially on funds directed towards health, social and long-term care sectors in most EU countries, this last point cuts to the heart of the tension between the need for better mechanisms to protect older people's human rights to begin with, and the feasibility of implementing such mechanisms in practice.

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3 HelpAge International defines normative gap as a "lack of protection against a particular practice that violates human rights" (HelpAge, 2011: 4).

4 Conceptual links between disability rights and rights of older people

4.1 Common points of reference and opportunities for transferability

4.1.1 Key links between people with disabilities and older people in the context of rights

The disability and ageing discourses grew out of distinctly separate advocacy movements and scholarship, and it has proven rare that academics working within the field of disability venture into discussions related to the concepts of ageing, and vice versa (Oldman, 2002). This has changed somewhat in recent years, particularly as scholars interested in topics related to ageing and care and the rights of older people recognise that there are important lessons to learn and to build on from the field of disability rights. According to Kröger, "The most significant lesson that care research can learn from the conceptual perspectives of disability studies might be to start to understand that access to adequate care is a civil and human rights issue" (2009: 413). Another compelling reason for the growing interest in linking the two fields is that, thanks to medical and social advancements, people with disabilities are also living longer, a phenomenon which has led the share of people *ageing with disabilities* to increase alongside that of people without disabilities (Naue & Kroll, 2010).

The obvious, fundamental link between people with disabilities and older people is the concept of impairment (AGE Platform Europe, 2014; Harpur, 2016). Recalling the social model of disability described previously (see Chapter 2), people with disabilities are persons with physical or mental impairments, who, through the interaction between individual impairment and social structures, experience disability (CRPD, 2006: Art. 1). And while not all older people develop impairments, for most, getting older comes with some form of impairment or a reduction in functional abilities (Harpur, 2016). In a society that idealises physical and mental health and 'ableness', both people with disabilities and older people experience inequalities and discrimination as a result of their impairment. For Naue and Kroll, both disability and ageing policies are "built upon the negative perception of the groups of disabled and elderly persons held by large parts of society. Discrimination, prejudice, stigmatisation, medicalisation, a focus on incapacitation and institutionalisation

underpin views of disability and old age and thus form or socially construct a uniform and homogeneous group" (2010: 4). In the context of ensuring the rights of both of these groups, then, this common experience of discrimination in its many forms offers an opportunity for closer consideration of the conceptual linkages, as well as the potential development of a common policy framework (Naue & Kroll, 2010; Jönson & Harnett, 2016; Oldman, 2002; Priestley & Rabiee, 2001).

If the common experience of impairment and its socially constructed consequences is the key conceptual link between people with disabilities and older people, then the perceived loss of autonomy and independence that accompanies it, and the need for assistance, care and support is an important secondary link (Priestley & Rabiee, 2001). Both discourses have sought to combat the perceived loss of autonomy that accompanies impairment by pointing out the important distinction between need for support on the one hand, and no longer being independent on the other. For advocates of the rights of both older people and people with disabilities, autonomy and independence are core principles around which services should be designed, and dependency is a condition to be avoided (Rummery & Fine, 2012; Kröger, 2009). While disability scholars have historically tended to equate the concept of 'care' itself with dependence and promoted the 'personal assistance model' of support, some care theorists have taken a more nuanced view, highlighting the often *inter*-dependent relationship between care user and care-giver (Rummery & Fine, 2012; Fine & Glendinning, 2005) (see Chapter 4.2.2 for more on this topic).

Kröger (2009) and others (Rummery & Fine, 2012) contend that recent theorists in both fields have moderated their approach to the concept of care and that the two perspectives have moved closer together, with care researchers placing greater emphasis on supporting the independence of older care users, and with disability researchers increasingly recognising the relational, inter-dependent and emotional aspects of assistance for people with disabilities.

4.1.2   A focus on autonomy, independent living and social participation

The autonomy of every individual human being is a central tenet of the human rights framework and is considered an essential component in the realisation of equality (Boyle, 2008). As such, it has featured prominently in both the disability and ageing and care discourses. The World Health Organisation defines autonomy in the context of care as the ability to make personal decisions about how to live one's life on a day-to-day basis, according to one's own values and preferences (WHO, 2002; AGE Platform Europe, 2014). Furthermore, autonomy encompasses the principles of dignity, self-determination and legal capacity, and entails the holding of both rights *and* responsibilities (AGE Platform, 2014).

Autonomy is often conflated with the concept of independence—where independence is the "capacity of living independently in the community with no and/or little help from others" (AGE Platform Europe, 2014: 10). Yet the two are distinct terms, with autonomy being a prerequisite for independence, while the converse does not hold true. As previously noted, Collopy's differentiation between 'executional autonomy' and 'decisional autonomy' implies that an individual maintains his/her autonomy even if he/she is not able to carry out tasks independently, as long as he/she has a voice in the decisions leading to the execution of those tasks (Collopy, 1995; Boyle, 2008).

In the provisions outlined in the CRPD, the rights of people with disabilities to autonomy and independence are closely interrelated with the right to participate fully in society. Article 19 of the CRPD, the article perhaps most often cited for its relevance to the case of older people with impairments in need of support, states that governments must "recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community" (CRPD, 2006: Art. 19). Townsley and colleagues maintain that enabling people with disabilities to live independently is crucial to the ultimate goal of full participation in society: "they should have choice and control over the decisions, equipment and assistance that they need to go about their daily lives, so that they can participate in society on the same basis as other people" (2007: 8).

The same can be—and indeed has been—applied to older people with functional impairments. The push for the deinstitutionalisation of support services for people with disabilities within the disability rights movements finds a parallel in the promotion of greater user choice of services, and in increased investment in home- and community-based care and 'Ageing in place' policies from within the LTC sector (Walker, 2008; WHO, 2002). In the case of older people in need of care, where residential care is still common, the right to autonomy and independence is highly relevant in the context of forced institutionalisation, which often implies a loss of the right to make decisions, to participate in public life (outside of the institution), to choose daily activities for oneself, and to maintain one's family life and create new personal relationships.

As some authors have pointed out, from a rights perspective, the concept of autonomy can be problematic in the case of people with cognitive impairments (both people *ageing with* such disabilities, and people *ageing into* disabilities, e.g. dementia) (Boyle, 2008). According to Doyal and Gough's (1991) designation of a 'minimally autonomous' threshold —essentially, the capacity to make informed choices and decision on one's own behalf—excludes many people from being able to realise their right to autonomy, with significant practical and legal implications for support and care services and carers.

4.2 The limits of and alternatives to a disability rights approach

4.2.1 The limitations of applying the concept of impairment to the case of older people

There are a number of reasons why drawing on the shared experience of impairment between people with disabilities and older people is inadequate in formulating a rights-based framework for the situation of older people in need of care and support. First, older people with functional impairments generally do not themselves identify as 'disabled', nor do they necessarily want to be considered as such by others, and society reinforces this distinction: "elderly persons have already one form of stigma, namely age, and they do not want to be labelled with another stigma, namely impairment and disability, which is often understood as a lifelong condition" (Naue & Kroll, 2010: 3). We as a society tend to view the impairments that develop as part of the ageing process as 'normal', and are not seen to "deviate from generational norms of old age" (Priestley & Rabiee, 2001: 10), unlike the norms that we associate with youth and adulthood. Similarly, disability activists have tended to hold the claims of older disabled people at arm's length in order to avoid the common ageist preconceptions that society wields against older members of society, namely that they are no longer productive members of society, and that they are "inflexible to change, having, or about to have, a reduction in their mental and physical abilities and focused on retirement" (Harpur, 2016: 1057).

Priestley and Rabiee (2001), in one of the earliest investigations into the potential overlaps between ageing studies and critical disability theory, surveyed local organisations representing the claims of older people in northern England. They found that while some respondents conceived of older people with age-related impairments as being no different from people *ageing with disabilities*, just as many made a strong distinction. One respondent expressed this view in the following terms: "I would not necessarily say an older person had a disability if they have got age related hearing loss. I would say well that's something that happens with age. It is like your hair going grey" (Priestley & Rabiee, 2001: 10). This crucial difference in the internalised and externalised perceptions of the identity of people with disabilities and older people helps to explain why there has been little overlap or collaboration in the advocacy movements promoting the rights of both of these groups to date.

A second, fundamental limitation to the linking of disability theory with ageing theory in the context of older people's rights is that not all older people have impairments. There has been significant discussion about the extent to which existing international human rights instruments protect the rights of older people, with many scholars and

policymakers alike citing the CRPD as the legally binding instrument (as distinct from 'soft law' resolutions and recommendations, e.g. MIPAA) that most explicitly addresses the situation of older people. Yet the CRPD, while it may, in technical terms, cover the rights of older people with disabilities (both those *ageing with* and *ageing into* disability), it does not address the rights of older people without explicit (or diagnosed) physical or cognitive impairments, who nonetheless may have needs for LTC in the form of support from family members or formal services, and who experience inequalities in accessing services as a result of age-specific or age-based discrimination and structural ageism (Harpur, 2016). According to the definition of LTC that we align ourselves with in this project (see Box 2 for further details), LTC services include, "services, facilities, knowledge and support aimed at increasing the individual's physical, mental and social well-being" (Kornfeld-Matte, 2015: 13).

This broader conceptualisation of what older people's long-term care needs are and what services should be made available to them goes beyond the provision of care to support older people with impairments, and renders the concept of impairment as defined within disability scholarship only a partially viable model. Investigating the extent to which the social model of disability and the CRPD can be applied to the case of older people, Oldman (2002) and Harpur (2016) both maintain that while the social model can be adjusted to accommodate the particular situation of older people *with impairments*, it is inadequate in addressing the inequalities and breaching of the rights of older people without impairments. According to Harpur, the key challenge of applying the same model of disability as set forth in the CRPD to the case of older people is that, "ageism is not strictly disablism. While ageism can be based upon generalized assumptions made about ability based upon age, ageism does not discriminate based upon different abilities but upon age...some manifestations of ageism are not based upon abilities but how society is structured more broadly" (2016: 27-28).

Another important consideration that has distinguished the disability rights movement from the discourse on ageing, and which stems in large part from the fact that old age is not only characterised by impairment, is pointed to by Jönson and Harnett (2016). Proposing an equal rights framework for residential care for older people, the authors cite Goffman's (1963) reference group theory to argue that a major challenge in thinking about rights in the case of older people is that there is no natural comparison group, where "comparative reference groups serve as a basis for claims that individuals or groups are treated unjustly relative to others" (Jönson & Harnett, 2016: 801). The identification of comparative reference groups has been used successfully in the case of people with disabilities, where persons without disabilities in the same stage of life were used as the reference group to claim equal rights. In the following sections, we discuss two areas where the discourse on rights for older people and rights for people with disabilities diverges with important

implications: the concept of 'care' itself and the ethics of care, and end-of-life care and decision-making.

Box 2: A Working Definition of Long-term Care

One of the most commonly cited definitions of LTC was proposed by the OECD in its seminal report on LTC, published in 2011:

> *"[... long-term care refers to] a range of services required by persons with a reduced degree of functional capacity, physical or cognitive, and who are consequently dependent for an extended period of time on help with basic activities of daily living (ADL). This "personal care" component is frequently provided in combination with help with basic medical services such as "nursing care" (help with wound dressing, pain management, medication, health monitoring), as well as prevention, rehabilitation or services of palliative care. Long-term care services can also be combined with lower-level care related to "domestic help" or help with instrumental activities of daily living (IADL)" (OECD, 2011: 11).*

In a recent report on care and autonomy, the UN Independent Expert on the Enjoyment of all Human Rights by Older Persons highlighted the importance of the social component of care, often neglected in definitions with a more clinical focus. The Independent Expert proposed that care for older people:

> *"... comprises a range of services, facilities, knowledge and support aimed at increasing the individual's physical, mental and social well-being, provided either by formal or informal carers, and through the public or the private sector" (Kornfeld-Matte, 2015: 13).*

In this working paper, we subscribe to a broader, more holistic interpretation of long-term care for older people, in line with the one proposed by the UN Independent Expert.

4.2.2 Views of care from a feminist ethics of care perspective: care-giving and collective rights

Arguably one of the streams of literature that has focussed the most on the phenomenon of LTC for older people has been the feminist scholarship. This body of literature can be traced back to the feminist critique of the male-centeredness of

welfare policy that rendered caregiving, often provided within the confines of people's own homes, invisible (Fine & Glendinning, 2005). Given that most of this care was and still is carried out by women, this invisibility resulted in deeply gendered-biased practices and policies regarding LTC.[4] As a first step to address this bias, feminist scholars emphasised the unequal opportunities resulting from caring responsibilities and the costs arising from it (e.g. in terms of forgone employment and mental burnout); often depicting care as 'burdensome' and those in need of care as 'charges' and dependents (Ungerson, 1990; Daly, 2002). Against this backdrop, the feminist literature therefore focussed to a substantial extent on carers, particularly informal or family carers, and on caregiving (Rummery & Fine, 2012). The latter concept is a central tenet of the feminist critique with several authors (Graham, 1983; Hochschild, 1983) stressing the relational component of caregiving. This relational dimension revolves around the distinction between the concepts of *caring about* – nurturing a feeling of concern for those cared for – and *caring for* – the actual delivery of care – from which the depiction of care as 'emotional labour' (Hochschild, 1983) or a 'labour of love' (Folbre & Nelson, 2000) has emerged. Another related stream of feminist scholarship has instead elected to emphasise the moral principles associated with providing and receiving care in contexts of vulnerability and concerns for human relationships (Gilligan, 1982; Tronto, 1993; Sevenhuijsen, 1998), in what came to be coined the 'ethics of care'. These authors defended the notion that care is an integral part of one's condition – throughout the life course everyone is dependent on someone – and that it has intrinsic and ethical value (i.e. not only as predisposition of some groups in society or as a response to needs) and should thus be seen as a citizenship right.

The several strands of the feminist literature can be seen as providing alternative (sometimes even opposing) contributions or formulations to the discussion around the rights of older people. The two main alternative formulations emerging from the literature surveyed concern the inclusion of carers as holders of rights (particularly informal or family carers) and the conceptualisation of rights as collective (i.e. pertaining jointly to a group) rather than individual rights (i.e. pertaining to members of a group individually). Concerning carers, the feminist literature brings to the forefront the central role played by informal or family carers, not only as providers of care, but also as actors whose wellbeing is often interconnected with that of the person receiving care (i.e. with older people themselves) (Boyle, 2008; Kirk, 2011).

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4 While informal care provided within the realm of private households by female carers was the initial leitmotiv of much of the feminist critique, the gendered issue of care-provision goes beyond informal care to include also professional care, which is in itself as markedly gendered and affected be similar issues around low pay and recognition (Szehebehely, 2005).

Not only are choices and values imbedded within relationships, but older people's wellbeing is deeply affected by, and in turn affects, the wellbeing of their carers – a point to be further developed below.

The relevance of carers and caring relationships suggests an alternative way to conceptualise the rights of older people that builds on the notion of relational rights, i.e. rights that arise from and recognise the interdependency that characterises caring relationships (Fine & Glendinning, 2005; Kröger, 2009). Within this formulation, rights are conceptualised as collective, a deviation from the individualistic approach to rights that has characterised the disability rights movement and indeed most of the right-to-health care discourse in the Western tradition (Boyle, 2008). This collective approach to rights can be traced directly to recent developments in the ethics of care scholarship (Tronto, 2013) with its focus on solidarity as opposed to the individualistic paradigm interwoven with neoliberalism. It is an approach that directly confronts the trade-offs that often arise, not only between public officials and older people as to the assessment of needs – a topic that is also central to the disability rights movement – but also between older people receiving care and their carers (Brannelly, 2016).

In this sense, the view of the right to receive and provide care as a collective right has closer ties to the 'family-centred model' discussed in the context of the right to palliative care (Kirk, 2011), for example, or to recent views that defend the collective right to public health as a way to address inequalities and structural determinants of health (Meier, 2007). Meier (2007) in particular makes the case that if one subscribes to an 'ecological model' of the determinants of health – the underlying rationale of which has a good deal in common with the social model of disability – we should define rights at the level where the determinants of health (or dependency) are situated: at the societal rather than individual level.

This relational or collective conceptualisation of rights is not without its critiques, however, as autonomy has been conceptualised as the domain of individuals rather than of groups or societies (Besirevic, 2010). While Boyle (2008) welcomes the need to recognise the rights of both cares and those in need of care, she voices the concerns of certain disability rights scholars (Shakespeare, 2000) when she posits that interdependency may erode decisional autonomy of older people; while at the same time failing to recognise that achieving decisional autonomy is in itself a need that must be addressed in long-term care (an issue that is nowhere more relevant than in the case of people with dementia).

Despite the well-documented differences, and quite often controversies, between the disability and feminist scholarships (Kröger, 2009; Weicht, 2015), there are issues where both bodies of literature converge regarding the conceptualisation of rights for older people. In fact, a number of authors have attempted, or at least pointed to the possibility of harmonising the two (Fine & Glendinning, 2005; Kröger, 2009; Rummery & Fine, 2012; Weicht, 2015). Both the ethics of care and disability rights literature have strongly contested the notion of citizenship and personhood built

around norms of functional autonomy and independence, which often have the effect of marginalising disabled but also older and frail people. Fine & Glendinnig (2005), Kröger (2009) and Rummery and Fine (2012), all place the emphasis on the concept of autonomy and self-determination, building on Collopy's (1995) distinction between "decisional" and "executional autonomy", as a possible common ground on which to define needs and rights for older people.

Both ethics of care and disability scholars have emphasised that the underlying principle of rights is equality:[5] equality before the law, but also equality of opportunities and outcomes (Kröger, 2009). In its original conception, the ethics of care emphasised the moral duty that is attached to caring for someone. However, both care needs and the duty to provide care are not equally distributed among members of society, a fact that was not lost on scholars in the field (Brannelly, 2016), and which implies that care may generate inequalities that lead to marginalisation of certain individuals. Among other groups, these inequalities are likely to be most felt by women, as both care needs and the 'duty to care' are disproportionately concentrated on women. Likewise, the discrimination (i.e. inequalities) faced by people with disabilities was key in the debate surrounding the need for the CRPD (Harpur, 2016). Thus, addressing the rights of older people by creating the necessary conditions for equality, namely by providing them with sufficient resources is a point where both disability and ethics of care can come together (Rummery & Fine, 2012).

4.2.3   Balancing perspectives and shifting identities: rights of older people and of carers

As mentioned in the previous section, one of the main additions of the feminist literature to the discussion of the rights of older people is the need to recognise the rights of carers. In this respect, one of the more powerful arguments is that the wellbeing of both older people and their carers are intrinsically connected (Kirk, 2011). There is, however, at least one other equally strong argument in favour of considering the rights of carers when debating the rights of older people. This is the fact that older people themselves often care for others (either children or adults, e.g. spouses) (Fine & Glendinning, 2005). A discussion of rights that ignores or negates

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5 Initially the ethics of care was built on the distinction between the ethical and subjective concept of "care" as opposed to the universal and objective concept of "justice", but more recent authors have bridged both concepts by highlighting the need to give political recognition to care and stressing that care is in itself an issue of justice, e.g. equal access and right to provide and receive care (Kröger, 2009).

older people in the role of carers and their contributions to society, further risks depicting them as 'dependent' and 'burdensome' and liable to be exploited in their role as carers; not least by the State itself in the context of retrenchment of care policies (Rummery & Fine, 2012).

This dual role of older people as receivers and providers of care is not without its challenges in terms of the definition or operationalisation of rights. Beyond the possible implications for autonomy of considering care as a collective right (Boyle, 2008) discussed above, Brannelly (2016) points to the trade-offs that can easily arise between the condition of carer and recipient of care, although she provides little guidance about how to address these trade-offs. One could foresee situations, for example, where not moving into a care home or receiving care at unusual hours could be in the best interest of recipients of care, but not of carers. With such trade-offs, and the often dual condition of older people as carers and recipients of care in mind, Rummery and Fine (2012) propose that both the right to receive and give care be recognised as part of the broader goal of ensuring older people's self-determination and participation in society. In this sense, care can be conceptualised as another resource that enables social participation in society in the tradition of Sen's (1992) broader conceptualisation of resources. There is of course the danger that the right to receive and provide care could, on the one hand, lead to the exploitation of carers, and on the other, to a disempowering 'burden of gratitude' on the part of care recipients. The key to the prevention of both rests in the voluntary nature of receiving and providing care, rendering choice a fundamental aspect of the right to care (Rummery & Fine, 2012). In turn, choice is only possible with sufficient resources, which brings us back to justice and equality as underlying principles on which rights are based. Increasingly, due to competing obligations, family members who want to provide care can only afford to do so if support services are in place that enable the sharing of the care 'burden'. This means that, in practice, upholding the right to care often presupposes the sharing of care tasks between family members and formal caregivers. In Section 5.4.1 below, we discuss in greater detail the ways in which resource constraints constitute barriers to the realisation of the rights of older people and their carers.

4.2.4 End-of-life care and decision-making

End-of-life (EoL) care has not been one of the focal issues in the disability rights discourse and, with the noteworthy exception of care for individuals with intellectual and learning disabilities (Tuffrey-Wijne et al., 2007; Dunkley & Sales, 2014), the complexities of EoL care have not occupied a prominent place in the specialised literature on disability rights. By contrast, in the discussions surrounding the rights of older people in need of care, the eventuality and proximity of death has meant that

discussions about the right to EoL care has received considerable attention in both policy and research circles. Ideas around dignity in death and quality of life at the end of life first gained prominence in the public sphere in the 1970s in the United States after the landmark case of Karen Ann Quinlan, a young woman reduced to a persistent vegetative state following a traumatic brain injury. While her parents wanted to remove her from life-support, her doctors refused, citing legal obstacles. The courts ultimately ruled in Quinlan's parents' favour, significantly widening the scope for patient's rights in the context of (withholding) medical treatment and of suspending life-sustaining treatment (Horn, 2013; Wolf et al., 2015). More than a decade later, in the case of Nancy Curzan, the US Supreme Court upheld the right to refuse life-sustaining treatment and recognised the authority of surrogates (medical proxies) to make end-of-life choices for patients lacking capacity (Wolf et al., 2015). The debate quickly extended to other developed countries and gained increasing attention in many Western European countries beginning in the 1990s. In the academic literature, our review uncovered three main recurring themes related to the discussion of EoL care as a right: 1) dignity in dying; 2) euthanasia (and palliative care); and 3) advanced directives and surrogate decision-making. We shortly describe each in turn. It should be noted that while certain authors have chosen to present the latter two themes as sub-aspects of (the right to) dignity in death rather than as independent issues (Horn, 2013; van Beek et al., 2013; HelpAge, 2015), we treat them as distinct themes in order to highlight the significance of each.

Much of the EoL care discourse stems from the notion that an individual's right to dignity in life is inclusive of his/her right to a dignified death. In most cultures, the last moments of life and the manner of one's death are value laden (Hemati et al., 2016). Dignity in death also features prominently in the clinical ethics discourse where the need to address the physical and mental distress faced by many at the end-of-life is a focal point (Abiven, 1991; Baumann et al., 2009). In addition, dignity at the end-of-life has emerged as an increasingly prominent ethical issue in the long-term care literature (Prud'homm et al., 2017; Schulmann et al., 2017). While dignity in death or dying with dignity remain vaguely defined concepts, a review of the literature by Guo and Jacelon (2014) found that patients, care professionals and families define dignity at the EoL in the following terms: autonomy and independence, relieved symptom distress, respect, meaningful relationships, dignified treatment and care. Patients and families also associated the meaning of dignity in death with human rights, with existential and spiritual satisfaction and with privacy (Guo & Jacelon, 2014). In a more recent review and concept analysis, Hemati and colleagues (2016) identified among the attributes of dignity "...the right to participate in decision making, privacy (varies in different cultures), lack of dependence on mechanical devices and aids for survival or devices which decrease the independency and quality of life of the patient, being respected, and moral comfort and spiritual needs fulfilment with particular attention to the patient's beliefs" (Hemati et al., 2016: 1225).

While the principle that no medical care (life-saving or otherwise) should be imposed on an individual without his/her consent is a cornerstone of biomedical ethics (UNESCO, 2005), considerable controversy still surrounds the issue of individuals determining the precise circumstances of their death – variously termed (passive or active) euthanasia, assistance to die or physician-assisted suicide. Within Europe, Belgium, the Netherlands and Luxembourg have passed laws allowing medical professionals to play an active role in assisting patients to end their own lives, while in Switzerland the practice of physician-assisted suicide (for both citizens and non-nationals) is tolerated and not prosecuted (Schulmann et al., 2017). The debate on euthanasia revolves around recognition of the right of the individual to choose the time and place of his/her death and to do so in a way that preserves their dignity. In practice, however, public attitudes towards care, the practice of care and the power dynamics that dictate the nature of the care relationship between care recipient and carer(s) are shaped by strongly embedded cultural values (Horn, 2013; Baumann, et al., 2009).

A similar discourse can be extended to the issue of EoL decision-making: despite growing consensus from ethics scholars regarding the utility of advanced directives for EoL care, the discussion is strongly influenced by cultural and religious values. In fact, some authors point out that autonomy in care decision-making and even the mere concept of dignity at the end of life are Western values that are in conflict with values in other parts of the world (Besirevic, 2010; Hemati et al., 2016). Despite such tensions, the promotion of tools for advanced decision-making is seen as a powerful promoter of individual autonomy and is protected under the Oviedo Convention on Human Rights and Biomedicine, Art. 9: "The previously expressed wishes relating to a medical intervention by a patient who is not, at the time of the intervention, in a state to express his or her wishes shall be taken into account" (Council of Europe, 1997).

5 Applying a human rights-based approach to long-term care

5.1 A human rights-based approach to care

5.1.1 Defining a human rights-based approach to long-term care

A human rights-based approach (HRBA) is a conceptual and normative framework grounded in international human rights standards, one that is directed towards the protection and promotion of these rights (UNIRSD, 2016). A HRBA builds on the existing system of rights and obligations as it emerges from international law, with the professed aim of identifying and tackling inequalities, discrimination against vulnerable groups, and unfair distributions of power and resources, all of which may hinder the realisation of human rights. Understood in this way, a HRBA can be applied to a range of policy areas. Indeed, it has gained considerable attention within the international development (Berman, 2008), social protection (Sepúlveda & Nyst, 2013), education (UNICEF & UNESCO, 2007) and health (WHO, 2015a & 2015b) sectors. Within this general context, a **HRBA to long-term care** is the application of a rights-based approach to the field of LTC (see Box 2 for a definition of LTC), as distinct from other sectors falling under the umbrella of social welfare systems, including most notably healthcare. However, as there are considerable overlaps between the health and LTC sectors, our review draws numerous insights from the substantial literature available on a HRBA to healthcare. That said, we make every effort to distil from the body of research on a HRBA to healthcare those aspects that are of particular relevance to the context of LTC for older people.

A HRBA to LTC may be interpreted as supporting the explicit legal recognition of the right to LTC for all older, dependent individuals (currently covered only implicitly in the international protection regime), but it also goes well beyond it. Building on the approach taken by ENNHRI (2017a; 2017b), we subscribe to an interpretation of the right to LTC as only one of the key elements of a rights-based approach to long-term care which should comprehensively strive to uphold *all* human rights of individuals in need of LTC. In practice, a rights-based approach to LTC attempts to anchor all policies, action plans and programs in principles derived from international human rights treaties, and declares progress towards the achievement of such rights as its ultimate objective (UNIRSD, 2016). This stands in stark contrast with a needs-based approach, which recognises care needs assessed by a competent authority (not by

the recipients themselves) as valid claims to support and strives to respond directly to them, without emphasising the improvement of the individual's general status or well-being. From this counter-position, we identify two distinctive characteristics of a HRBA to LTC: a focus on the empowerment of beneficiaries; and being encompassing and cross-sectoral in nature.

The empowerment of users as espoused by a HRBA represents a paradigm shift in social policy discourse, seeing beneficiaries not as needy, dependent and burdensome (the more traditional stance adopted by social protection systems) but rather as empowered, equal citizens (rights-holders), whose rights states and public institutions have the obligation to protect (Kornfeld-Matte, 2016; Sepúlveda Carmona, 2014). What is more, user empowerment calls for individuals to retain control over their care and be actively involved in the fulfilment of their rights. In this spirit, when identifying the key elements of a HRBA approach to LTC, ENNHRI (2017b: 7) lists as the first goal that, "all key stakeholders are empowered and can participate in achieving the realisation of rights".

The second notable characteristic of a HRBA, that of being encompassing and of cutting across sectors, stems from the very nature of human rights, which are enshrined in international law as indivisible, interdependent and interrelated (i.e. the fulfilment of one right often depends, in part or entirely, on the fulfilment of other rights). As summarized by Baer and colleagues (2016) in a review of the literature on the right to health of older people: "Given the interrelatedness of human rights, a rights-based approach promotes a broad, whole-of-system, -government, and -society approach to the health and well-being of older people, deliberately going beyond, for example, the narrow focus on the costs of care due to population ageing, which is often the issue most highlighted in the media". In fact, rights-based approaches necessarily spill over from any one policy area as they require a wide range of policies and actions to tackle upstream causes and determinants. In its 2015 World Health Report, the WHO described a HRBA to health as "[embracing] a wide range of socioeconomic factors that promote conditions in which people can lead a healthy life, and extends to the underlying determinants of health, such as food and nutrition, housing, access to safe and potable water and adequate sanitation, safe and healthy working conditions, and a healthy environment" (WHO, 2015a: 14). This belief that the realisation of human rights cannot be achieved in a silo-like, right-by-right manner and that social policies should take a more comprehensive perspective is often echoed in the literature on LTC, palliative care and EoL care (ENNHRI, 2017a; 2017b; Morrissey et al., 2015; Brennan, 2007).

5.1.2   Principles underpinning a HRBA to care

The description of a rights-based approach above already provides a glimpse into its grounding principles, although no absolute consensus exists in the literature on a common set of principles underpinning a rights-based approach. This is largely because different authors have tended to focus their attention on different aspects of human rights as they relate to care and older people that they identify as most relevant. It does not seem to be a reflection of conflict or disagreement over which principles should be recognised as most valid. Indeed, there is considerable agreement on specific foundational tenets of a HRBA. Reflecting its grounding in the human rights tradition, the principle of **non-discrimination** (or *equality* as described in the CRPD) is often cited among the core underpinnings of a HRBA to care (HelpAge International, 2015; Council of Europe, 2014; Chesterman, 2014; Gallagher et al., 2012). Combating inequalities and discrimination is a key characteristic of a rights-based approach and in the field of care, this is particularly relevant for defending and promoting the interests of the most vulnerable groups, including people with dementia, older women, individuals with limited capacity or at the end of life, older LGBTQ individuals, and older people living in poverty (ENNHRI, 2017b; WHO, 2015b; Gilmour & Brannelly, 2010; Choi et al., 2017; Kornfeld-Matte, 2015). The Independent Expert appointed by the UN to investigate the human rights of older people explicitly states, "Gender, disability and cultural sensitivities should be promoted in care settings to allow older persons from different backgrounds to be informed effectively and to be able to make decisions" (Kornfeld-Matte, 2015: 16). The Independent Expert also highlights the importance of integrated social and health care services for people with dementia and other neuro-degenerative diseases.

Similarly, the principles of human **dignity** and **autonomy** (independence) are often included separately or in conjunction with one another in attempts to theoretically ground rights-based approaches to care (HelpAge, 2015). The preamble of The European Charter on the Rights and Responsibilities of Older People in Need of Long-term Care, which draws heavily on Article 25 of the EU Charter of Fundamental Rights, begins by stating that, "The European Union recognises and respects the rights of older people who are more likely to come to depend on others for care, to lead a life of *dignity* and *independence* [...]" (AGE Platform Europe et al., 2010: 3). In a report prepared for the 30th Session of the Human Rights Council, the UN Independent Expert on the Enjoyment of Human Rights for Older People grounds her discussion of rights in the context of care in the principle of *autonomy*, as defined in the CRPD (art. 3 & 25) and corresponding to the principle of *independence* included in the UN Principles for Older People (UN, 1991). Likewise, in the academic literature on care, autonomy and dignity are frequently cited principles anchoring arguments surrounding the right to health (Baer et al., 2016; Robinson et al., 2007; Jacobson, 2007); community-based care and social participation (Häggström et al., 2007; Brownie & Horstmanshof, 2012); dementia care (Boyle, 2010; Charras et al., 2016;

Agich, 2012); residential care (Brownie & Horstmanshof, 2012; Welford et al., 2010); EoL care and decision-making (Baumann et al., 2009; Horn, 2013; Hemati, 2016; Guo & Jacelon, 2014; Besirevic, 2010) and others. Some authors, however, question the interpretation of these principles within the field of medical ethics and express doubts about whether they are sufficient for guiding practical choices in care (Freeman, 2010; Agich, 2012).

In 2009, the Scottish Human Rights Commission proposed the PANEL principles[6] as a framework for synthesising the fundamental principles for a HRBA to LTC (SHRC, 2009; SHRC, 2012), which can be shortly summarized as:

- **P**articipation – "Everyone has the right to participate in decisions which affect their human rights. Participation must be active, free, meaningful and give attention to issues of accessibility […]"

- **A**ccountability – "Accountability requires effective monitoring of human rights standards as well as effective remedies for human rights breaches"

- **N**on-discrimination and equality – "[…] all forms of discrimination in the realisation of rights must be prohibited, prevented and eliminated […]"

- **E**mpowerment – "[…] individuals and communities should know their rights [and …] should be fully supported to participate in the development of policy and practices which affect their lives and to claim rights where necessary"

- **L**egality – "A human rights-based approach requires the recognition of rights as legally enforceable entitlements and is linked in to national and international human rights law".

The PANEL principles have been endorsed by the WHO and proposed as the foundation for a rights-based approach to dementia care (WHO, 2015b). The framework has also been adopted by ENNHRI (2017b) in their work to promote a HRBA to LTC.

Building on the PANEL principles, the Scottish Human Rights Commission (2012: 14) developed the FAIR approach, which provides a roadmap specifically for decision-making within a HRBA to LTC. The four steps are:

- **F**acts: What is the experience of the individuals involved and what are the important facts to understand?

………

6 The PANEL principles have been developed within the UN system (see Mokhiber, 2001) for an early mention) for rights-based approaches in general and ground their application in varied contexts outside care – e.g. UNESCO has proposed the PANEL principles for a rights-based approach to development cooperation (Berman, 2008).

- **A**nalyse rights: Develop an analysis of the human rights at stake;

- **I**dentify responsibilities: Identify what needs to be done and who is responsible for doing it;

- **R**eview actions: Make recommendations for action and later recall and evaluate what has happened as a result.

The FAIR approach is intended to be used directly by care workers to orient them through difficult practical decisions that have the potential to infringe on the rights of individual care users (SHRC, 2012; ENNHRI, 2017a).

5.1.3   Why do we need a HRBA to long-term care?

As has already been touched on above (see Section 3.2), gaps in the legal protection of older people's rights and the documentation of widespread infringement of these fundamental rights, including but by no means limited to the right to health and to a broad spectrum of care services that support its attainment, are in itself a strong argument in favour of a human rights approach (WHO, 2015b; ENNHRI, 2017a; Tang, 2008; Harpur, 2016). While its core values are underpinned by moral and ethical arguments, it is also possible to make an economic case for a HRBA to LTC. Although much of the currently available evidence is based on small or local samples and primarily qualitative results, there is reason to be optimistic about the economic impact of rights-based approaches. Care providers who have implemented a HRBA found that it contributed to improved care quality as perceived by both care recipients and staff, and that user satisfaction and involvement also increased (ENNHRI, 2017b; SHRC, 2009; Donald, 2012). A review of the impact of HRBA on mental health services found that therapeutic outcomes improved at relatively low costs in all reported studies, although methodological rigour was limited in many cases (Porsdam Mann et al., 2016). Similarly, improved outcomes at lower or comparable costs have been reported in the context of long-term care by providers implementing patient-centred and rights-based care models (Brownie & Horstmanshof, 2012; SHRC, 2009).

One study highlights that the organisational processes of care providing organisations have also benefitted from the implementation of a HRBA to LTC, with care managers reporting that the new approach was instrumental in formulating balanced solutions to the highly complex problems arising in the process of care and that it provided a useful tool for improved risk management (Donald, 2012). Organisational culture, staff relations, turnover and absenteeism may also improve following the adoption of a HRBA to care, leading to improvements in the reputation of organisations (ENNHRI, 2017b; Donald, 2012). On the whole, there is evidence that a HRBA to LTC

can lead to better outcomes, higher satisfaction and a more positive atmosphere for all those involved in the process of care (SHRC, 2012).

5.2 What are the rights of older people in need of long-term care?

Our review uncovered no contributions in the peer-reviewed literature that provide an overview or a summative discussion of the rights of older people in need of or receiving LTC. In the grey literature, however, a number of organisations have published reports, toolkits and information packs that address the most relevant human rights in the context of care for older individuals. Without attempting to present an exhaustive list, we take note below of what we assess to be the most important among them.

The European Charter on the Rights and Responsibilities of Older People in Need of Long-term Care was published in 2010 as part of the DAPHNE III project, with input from a network of academics and NGOs in the field of ageing and LTC. The Charter recognizes 9 rights of older people in the context of LTC, each corresponding to one article of the Charter:

Art. 1   Right to dignity, physical and mental well-being, freedom and security;

Art. 2   Right to self-determination;

Art. 3   Right to privacy;

Art. 4   Right to high quality and tailored care;

Art. 5   Right to personalised information, advice and informed consent;

Art. 6   Right to continued communication, participation in society and cultural activity;

Art. 7   Right to freedom of expression and freedom of thought/conscience; beliefs, culture and religion;

Art. 8   Right to palliative care and support, and respect and dignity in dying and in death;

Art. 9   Right to redress.

The Charter closes with Article 10, detailing the responsibilities of older individuals in need of long-term care (AGE Platform Europe et al., 2010).

In her **Report to the 30th session of the Human Rights Council in 2015,** the UN Independent Expert on the Enjoyment of all Human Rights by Older Persons, singled out "the right to autonomy and care, which she considered to be priority areas"

(Kornfeld-Matte, 2015: 1). In the broader context of her mandate to reflect on all human rights of older persons (i.e. going beyond the context of LTC), the Independent Expert makes references the right to equal recognition before the law, the right to adequate standard of living and social protection, the right to work, the right to adequate housing and accessibility, the right to participation and social inclusion, the right to education and lifelong training, the right to health, the right to palliative care, the need to protect and support care workers and family care givers.

In 2016, AGE Platform Europe published the **Dignity and wellbeing of older persons in need of care: Toolkit for policymakers and practitioners** (Age Platform Europe, 2016a). The publication includes an overview of historical and current developments within the UN, Council of Europe and European Union frameworks that are relevant for the rights of older people in need of care. This includes not only legislation but also on-going processes and policy action plans that can be expected to have an impact on the dignity of older people in care.

The most comprehensive overview of the rights of older people in need or in receipt of LTC (including references to corresponding provisions in the international protection regime) can be found in ENNHRI's **Human Rights of Older Persons and Long-Term Care Project: The Application of International Human Rights Standards to Older Persons in Long-Term** report (2017a). The report includes an overview of the most important documents in the international human rights framework and a detailed description of the human rights of older people organised according to the older person's position vis-à-vis the care trajectory: before entering care, once in care, and at the end of life. In addition, a short discussion of the rights of carers (formal care professionals) is provided (ENNHRI, 2017a). In the remaining sections of this chapter, we adhere to ENNHRI's categorisation of rights along the care trajectory in order to document the rights emerging from the peer-reviewed and grey literature relevant for LTC. Table 2 below presents an overview of the rights detailed in the subsequent sections.

It is important to note here also that neither the international nor the regional (European) human rights framework recognises the right of older people to long-term care explicitly (ENNHRI, 2017a). However, as we will highlight in the following, some key aspects of a right to care can be considered to be implicitly covered by the existing international protection regime.

Table 2: The Rights of Older People in Need of LTC as Identified in the Literature

Before entry into LTC	Equal access to care services
	Affordability of care services
	Right to choose of LTC services
While in LTC	Right to life
	Right to freedom from torture, degrading or inhumane treatment
	Right to liberty, freedom of movement and restraint
	Right to choose, autonomy, legal capacity
	Right to dignity
	Right to privacy and family life
	Right to participation and social inclusion
	Right to freedom of expression
	Right to highest attainable standard of physical and mental health
	Right to an adequate standard of living
	Equality and non-discrimination
	Right to remedy and redress
End of life	Right to palliative and EoL care
Other	Rights of carers

5.2.1 The rights of older people before entering long-term care

The **right to equal access to health services** for all persons, including older people, is guaranteed in all states that are signatories to the International Covenant on Economic, Social and Cultural Rights (ICESCR). Furthermore, the right to equal access recognises that states should take specific measures to provide for groups with specific needs and vulnerabilities, arguably applicable to the case of older people in need of LTC. Equality in access (accessibility) is also highlighted in the peer-reviewed literature as a core element of the right to health (Baer et al., 2016; Jönson & Harnett, 2016; Randall et al., 2013) and dignity (Jacobson, 2007) and is identified as a right that should be reinforced in the international protection regime for the specific case of older people (Doron & Apter, 2010).

The **affordability of (health)care services**, as covered by multiple legal instruments, attempts to guarantee that despite financial constraints and if necessary, with

support from dedicated social protection mechanisms, all individuals can access care services (Baer et al., 2016; Amano et al., 2016). However, the literature highlights that, in practice, service affordability remains a substantial concern (Giordano, 2005; Boyle, 2008; Chesterman, 2014), especially for certain services like palliative care (Brennan, 2007; Brannelly, 2016).

The **right to choose of LTC services** is currently not explicitly protected by the international human rights protection regime. However, the argument can be made that older people do currently have the right to choose the care they receive protected as a derivation of their legally enshrined right to health, specifically its *acceptability of services* component (Baer et al., 2016; Baumann et al., 2009), their right to autonomy and participation (Boyle, 2008; Kroger, 2009; Rummery & Fine, 2012; Palm, 2014) and their right to be protected from the deprivation of liberty (Boyle, 2010) – see below for more detailed discussion of each of these rights.

5.2.2   The rights of older people receiving long-term care

The **right to life** (including the obligation to not take life and the obligation to protect life) as enshrined in the Universal Declaration of Human Rights and the European Convention on Human Rights, is mostly overlooked in the literature captured by our review. A notable exception is its inclusion by HelpAge International among the rights of older people that should be covered by future developments in the international protection regime (2015). Similarly, in the academic literature reviewed, only one contribution includes a discussion of the right to life as it connects with dignity in bioethics (Jacobson, 2007).

The **right to be free from torture and cruel and degrading treatment**, recognised by the European Convention on Human Rights and other international treaties, is often discussed in the literature in connection with the widely documented phenomenon of elder abuse (Age Platform Europe et al., 2010; WHO, 2015; Kornfeld-Matte, 2016; Harur, 2016; Brennan, 2007; Choi et al., 2017; Crome et al., 2014; Randall et al., 2013; Amano et al., 2016). This right is also frequently mentioned in association with the management of pain and palliative care - see below for a more detailed discussion (Brennan, 2007; Lohman et al., 2010; Radbruch et al., 2013; van Beek et al., 2013) and dignity, especially at the end of life (Jacobson,2007; Kountouros & Rees, 2016).

The **right to liberty, freedom of movement and restraint**, recognised by the European Convention on Human Rights and the International Covenant on Civil and Political Rights, is protected for all individuals, including older persons, but it is not an absolute right, i.e. in cases deemed appropriate, restrictions may legally be placed on this right. Exceptions for those of "unsound mind", for public safety or for the protection of the individual him-/herself are provided for. Within the body of

literature on older people's rights in LTC, the right to liberty and freedom is mostly discussed in connection with infringements on individual autonomy linked to institutionalisation (residential care) and monitoring (Boyle, 2008; Palm, 2014; Grubman, 2016; Age Platform Europe, 2014; HelpAge, 2015; Kornfeld-Matte, 2015). Alternatively, some authors link it directly to the use of restraints and seclusion (Randall et al., 2013).

The **right to choose, autonomy, legal capacity and equality before the law**, while not explicitly provided for in the major human rights conventions – with the notable exception of the CRPD, is reaffirmed by a considerable body of case law (ENNHRI, 2017b) and is widely recognised as both fundamental to the rights discourse and as a guiding principle of the human rights framework (Chung, 2010; Council of Europe, 2014; Kornfeld-Matte, 2015; Age Platform Europe et al., 2010). The right to choose and autonomy are linked in the reviewed literature on LTC with discussions surrounding decision-making at the end of life (Besirevic, 2010), palliative care (Brennan, 2007), care rationing and access to care services (Giordano, 2005).

The **right to dignity** is also not explicitly protected by the majority of human rights conventions, although it constitutes the first article of the EU Charter of Fundamental Rights: "Human dignity is inviolable. It must be respected and protected". As already discussed in this report, the concept of dignity is intimately related to the protection of human rights for older individuals generally speaking and is likewise prominent in the discourse related specifically to a rights-based approach to LTC (see Section 5.1.2). In addition, in the peer-reviewed literature attention has been paid to unpacking the meaning and complexities of the concept (Hemati et al., 2016; Jacobson, 2007; Guo & Jacelon, 2014), its relation to the ethics of care and caring professions (Berridge, 2012; Phelan, 2008; Meenan et al., 2016; Gallagher et al., 2012; Horn, 2013) and with care-related decision-making (Besirevic, 2010; Baumann et al., 2009).

The **right to privacy and family life**, covered by numerous human rights international instruments, is less well covered in the academic literature included in our review than other rights, and is mainly mentioned in the context of older people's right to sexual intimacy (Spring, 2015; Aboderin, 2014; Everett, 2007), an important and contentious issue that Aboderin (2014) characterises as a 'policy blind spot'. However, as the right to privacy is often not upheld for older people who receive care in residential institutions, Randall and colleagues (2013) include it as a key item in their monitoring tool of the protection of human rights in psychiatric and LTC institutions. Additionally, Jönson and Harnett (2016) reflect on the importance of the right to family life in LTC by referencing a recent policy enacted in Sweden to protect the right of older people moving into residential care to move together with their partner/spouse (irrespective of whether the spouse is him-/herself in need of LTC).

The **right to participation and social inclusion**, a cornerstone of the CRPD (Kröger, 2009; ENNHRI, 2017a), has broad applicability in the case of older people in need of

LTC. It encompasses the right to participation in certain specific sectors such as education, employment, health and social service systems, as well as transportation and technology and, importantly, "society generally" (ENNHRI, 2017a: 22). The right to participation in society for older individuals in LTC is often discussed in relation to the principle of autonomy (Council of Europe, 2014; Welford et al., 2010; Baer et al., 2016; Rummery & Fine, 2012) and in arguing for the promotion of community-based solutions in care as well as the prevention of social isolation in the case of persons living in residential LTC facilities (Boyle, 2010; Kornfeld-Matte, 2015; Brannelly, 2016; Jönson & Harnett, 2016). Unfortunately, many authors recognise that persistent ageist attitudes and discrimination pose significant barriers to the realisation of the right to social participation and inclusion (Phelan, 2008; Stuckelberger et al., 2012; Townsend, 2006; Harpur, 2016). Consequently, a number of authors identify it as among the most important gaps in the current protection regime for older people (Kornfeld-Matte, 2016; UN, 2012; Doron & Apter, 2010).

The **right to freedom of expression, freedom of thought, conscience, beliefs, culture and religion**, a group of civil and political rights recognised by multiple international human rights instruments, is often included in sources from the grey literature among the rights of older people that should be upheld in the context of LTC (HelpAge, 2015; Age Platform Europe et al., 2010; SHRC, 2012). However, our review of the academic literature revealed no explicit mention of this right, although respect for individual's culture and religious beliefs was identified by some authors as a key dimension of the concept of dignity (Hemati et al., 2016; Guo & Jacelon, 2014).

The **right to highest attainable standard of physical and mental health** or the **right to health** is protected by numerous human rights treaties, foremost by the Universal Declaration of Human Rights and the International Covenant on Economic, Social and Cultural Rights. Because the right to health is broadly defined to cover preventative, curative and palliative elements of care, it can also be interpreted to cover most of the services provided in LTC settings and is therefore highlighted as a crucial right in the context of care by several authors and organisations (Kornfeld-Matte, 2015; Age Platform Europe, 2016a; Age Platform Europe, 2014). Furthermore, in its General Comment No. 14, the United Nations Committee on Economic, Social and Cultural Rights recognises four key components of the right to health as: 1) *availability* (i.e. sufficient quantity of services to meet the needs of older people in need of care); 2) *accessibility* – itself comprising the dimensions of non-discrimination, physical accessibility of services, economic accessibility (or affordability), and information accessibility; 3) *acceptability* (i.e. care services should uphold ethical and cultural standards; and 4) *adequacy* or *quality of care*. These core components of the right to health of older people are highly relevant for and should also be considered in the context of LTC. An important branch of the literature refers to the right to health of older people when calling for the recognition and promotion of specific care types,

including palliative care and pain management (Brennan, 2007; van Beek et al., 2013; Pesut et al., 2012; Gwyther et al., 2009).

In the reviewed literature, safeguarding the right to health is frequently linked to the protection of other, inter-connected human rights, and therefore cross-sectoral action and policies are called for (Baer et al., 2016; Morrissey et al., 2015; Brennan, 2007). The **right to an adequate standard of living** is one such related right, and is featured in the reviewed literature on the rights of older people in need of LTC almost exclusively in relation to the achievement of the right to health or the right to social protection (Townsend, 2006; Kornfeld-Matte, 2015).

The **right to equality and non-discrimination** of all older people is not currently explicitly protected by the major instruments in the international protection regime, and even in the EU protection framework it is directly addressed only within the context of employment, in the context specifically of older women, and older people ageing with disabilities (AGE Platform Europe, 2014; ENNHRI, 2017a). Some scholars argue, however, that older people are indirectly protected against discrimination in key human rights instruments (e.g. UDHR, ICCPR, ICESCR) because 'age' is subsumed under 'other status' in provisions detailing the groups to be protected (AGE Platform Europe, 2012). In the literature on the rights of older people in LTC, some authors have reflected on equality and non-discrimination as a core principle of a HRBA to LTC and as a core theme related to dignity and autonomy. At the same time, most references to equality and non-discrimination are made from a negative perspective. That is, the focus tends to be on barriers to the achievement of equality and on documenting breaches of this right (Phelan, 2008; Freeman et al., 2013; Baer et al., 2016) and documenting policies that have failed to protect the right to equality of older people in the context of care (Giordano, 2005; Townsend, 2006).

The **right to an effective remedy or redress** (access to justice in Article 13 of the CRPD) is upheld by the International Covenant on Civil and Political Rights (ICCPR) (Article 3), the European Union Charter of Fundamental Rights and the European Convention on Human Rights. It aims to provide opportunities for remedy and reparation (at the very least, a fair trial) for individuals whose rights have been infringed upon (ENNHRI, 2017b). The right to redress for older individuals in LTC contexts specifically is highlighted in the European Charter on the Rights and Responsibilities of Older People in Need of Long-term Care and in the Recommendation CM/Rec (2014)2 and explanatory memorandum on the Promotion of Human Rights of Older Persons (Council of Europe, 2014). Despite this recognition, the abuse and mistreatment of older people in LTC remains severely under-reported (Phelan, 2008; Townsend, 2006; Choi et al., 2017; Crome et al., 2014) as mechanisms for filing and processing of complaints and monitoring are routinely lacking or ineffective across care settings (Mulley, 2013; Crome et al., 2014; Randall et al., 2013; Amano et al., 2016). As a result, protecting and upholding the right to redress is identified as a key priority in the protection of the rights of older individuals in LTC

(HelpAge, 2012; UN, 2012; Kornfeld-Matte, 2016; Sethi et al., 2011). Several authors suggest that improving access to information and rights awareness among older people and their carers could contribute to significant improvements in this area (Doron & Werner, 2008; Welford et al., 2010; Phelan, 2008; Sethi et al., 2011).

5.2.3 The rights of older people to palliative and end-of-life care

Many have argued that a right to palliative care is already recognised and protected within the international human rights framework under the general umbrella of the right to health—detailed in the International Covenant on Economic, Social and Cultural Rights (ICESCR) and further qualified in General Comment 14 of the United Nations Committee on Economic, Social and Cultural Rights (Gwyther et al., 2009; Morrisey et al., 2015; Pesut et al., 2012; Brennan, 2007). Others, focusing on the aspects of minimising pain and suffering propose situating the right to palliative care and pain management within the broader right to freedom from torture and inhuman treatment (Radbruch et al., 2013; Lohman et al., 2010). Still others link the right to palliative care directly with the principle of dignity, or more specifically dying with dignity (see Section 4.2.3). Finally, a few dissenting voices level criticism against the representation of palliative care as an individual right on the grounds that this approach disregards the key *relational* component of care in the last stages of life and which could be better dealt with within a collective rights and relational liberty framework (Kirk, 2011). 'Relational' care used here means that the care user is considered to be "deeply and inseparably linked to others in their development and expression of self" (Kirk, 2011: 88).

Despite the lack of explicit recognition in the international protection regime, many (Western) countries have introduced legislation recognising a right to palliative care (van Beek et al., 2013; Pesut et al., 2012, Baumann et al., 2009), and there is already a large and growing advocacy movement for the formal global recognition of palliative care as a right, spearheaded by international associations and organisations (Morrissey et al., 2015). Two interesting examples from within this movement are the Declaration of Montréal and the Lisbon Challenge. The Declaration of Montréal put forth by the International Association for the Study of Pain in 2010, with signatory organisations from over 60 countries, declares that access to pain management is a fundamental human right (IASP, 2010). The Lisbon Challenge, drafted by the European Association for Palliative Care, the International Association for Hospice and Palliative Care and Human Rights Watch in 2011, acknowledges palliative care as a human right (Radbruch et al., 2013). Following this growing momentum, powerful international actors are throwing their weight behind the movement to promote the explicit recognition of a right to palliative care by highlighting the severity of existing

gaps in service provision and identifying it as a priority for the promotion of human rights of older people (World Health Assembly, 2014; WHO, 2015; Kornfeld-Matte, 2015; Kornfeld-Matte, 2016; Council of Europe, 2014; UN, 2012).

5.2.4 The rights of carers

Aside from the discussion emanating from within the ethics of care discourse (see Section 4.2.2), the rights of carers (both care professionals and family caregivers) of older individuals are sparsely covered in the academic literature captured by our review. While carers' rights are not brought into focus in the reviewed grey literature either, several contributions acknowledge this topic to be highly relevant and instrumental to a HRBA to LTC. In their report on the rights of older people in residential care settings, ENNHRI recognises that "the rights of those employed in the long-term care sector themselves is also an important issue, both in its own right, and also because it impacts on their capacity to uphold the rights of those in their care" (ENNHRI, 2017a: 28).

The same perspective is echoed in the European Charter on the Rights and Responsibilities of Older People in Need of Long-term Care. The Charter expands the scope of the discussion on carers' rights by including the right of both care workers and informal carers to be treated with civility and respect and to not be subjected to abuse. Addressing the older person in need of care, Article 10.1 reads: "Respect the rights and needs of other people living and working within your environment and respect the general interests of the community in which you live; your rights and freedoms should be only limited by the need to respect similar rights of other members of the community" (AGE Platform Europe et al., 2010: 24) And Article 10.2 states: "Respect the rights of carers and staff to be treated with civility and work in an environment free from harassment and abuse" (AGE Platform Europe et al., 2010: 24).

In her report on the priority areas of autonomy and care, the UN Independent Expert on the Enjoyment of all Human Rights by Older Persons draws specific attention to the support needs of family caregivers and the responsibility of states to provide these parallel support services, e.g. respite care, needs assessment, counselling and advice, training (Kornfeld-Matte, 2015: 13). This right is also recognised by the Council of Europe: "Caregivers should receive sufficient training and support to adequately ensure the quality of the services provided. Where older persons are being cared for at home by informal carers, the latter should likewise receive sufficient training and support to ensure that they are able to deliver the care needed" (Council of Europe, 2014: 19). Furthermore, the UN Independent Expert clearly states that the contributions of families and communities to the care and the fulfilment of human rights for older persons in no way detracts from the

responsibility that states have for their older citizens: "the assistance provided by family members and communities cannot substitute for States' obligations to promote and protect all human rights of older persons" (Kornfeld-Matte, 2015: 13).

5.3 Upholding the human rights of older people in need of long-term care

5.3.1 The duty-bearers of rights

While much has been written on which rights and whose rights are currently and should in the future be recognised in the international human rights protection regime, considerably less attention has been paid to the so-called "supply-side" of human rights – i.e. every legal right generates a corresponding obligation to protect and promote it, therefore it is essential to understand to whom this duty can be ascribed. In the literature surveyed, very little attention is given to who the "duty-bearers" of human rights are, despite numerous references to their obligations by authors of both grey and academic literature (SHRC, 2015; Martin et al., 2015; Donald, 2012; Baer et al., 2016, Nedlund & Larsson, 2016).

It seems clear, and is implicit in many of the references identified in the literature, that states, as signatories to human rights treaties and convention, bear the duty to protect human rights (Besson, 2015; ENNHRI, 2017b). Furthermore, national governments have the authority to legislate and enforce that legislation within their territory, a crucial instrument in the promotion and protection of human rights. What the rather abstract term "state" actually entails in practice remains somewhat unclear, however. Some authors include within the definition of duty-bearers the government of a state and all public institutions acting on its behalf. In its report on the rights of older people in LTC, ENNHRI proposes that a duty-bearer of human rights is "any organisation providing services on behalf of the state, including a residential care setting providing long-term care services for older persons" (ENNHRI, 2017b: 4). The Scottish Human Rights Commission also identifies the "state / public authorities" as bearing the duty of human rights protection and goes a step further in explicitly extending this obligation to all policymakers who work on behalf of the state: "As policy makers, commissioners of care and regulators of care you are 'duty bearers' in the legal sense to respect, protect and fulfil the human rights obligations owed to rights-holders" (SHRC, 2012:81).

In her article on human rights duty-bearers, Besson (2015) proposes that a clear distinction be made between human rights *duty-bearers* and *bearers of responsibilities* for human rights. She builds the argument that only institutions that

are in a relationship of jurisdiction with the right-holders and that are democratically elected to represent their rights can be considered to be primary duty-bearers. Under the provision of international law, these are primarily states but certain international organisations fulfilling the above-mentioned criteria can also qualify (In Europe, according to these criteria, only the European Union qualifies). The bearers of responsibilities for human rights, however, constitute a more diverse class of actors including, "other individuals, states and international institutions" (Besson, 2015: 261). Responsibilities for human rights "are related to and coexist with human rights duties to the extent that they help prevent human rights violations by human rights duty-bearers or remedy those violations when human rights duty-bearers are unable or unwilling to fulfil their duties" (Besson, 2015: 262). Such responsibilities can include instituting mechanisms for accountability (e.g. ensuring monitoring and compliance), providing aid and assistance (mostly through cooperation) in promoting human rights and establishing mechanisms for direct intervention, as a last resort.

5.3.2   Monitoring and enforcement

Formal recognition in international and national legislation is a necessary but insufficient step in upholding the human rights of older people in need of LTC. In fact, legal protections are often not fully upheld and enforced in practice and considerable differences persist between *de jure* and *de facto* protections across signatory states (Martin et al., 2015; Hunt, 2005). This lack of enforcement and practical action is termed the *implementation gap* (Chung, 2010; SHRC, 2009). Doron and Apter, reflecting on the potential of extending the international protection regime to account specifically for the human rights of older people, conclude: "Accountability systems to monitor human rights compliance are weak and overburdened especially at the international level, with no accompanying effective sanctions attached to them, which can be dangerous" (2010: 589). The Council of Europe echoed the same sentiment in their Recommendation and explanatory memorandum on the Promotion of human rights of older persons but allowed that "additional efforts should be made to assess the protection gaps that arise from insufficient implementation of, information about and monitoring of existing law as regards older persons" (Council of Europe, 2014: 6).

Against this backdrop, it is evident that improving the accountability of duty-bearers of the rights of older persons in need of care will be crucial. According to the Scottish Human Rights Commission (2009), this requires effective monitoring through the collection of data and inspections; effective remedies including mechanisms for filing complaints and accessing courts of justice; and effective corrective action. In the following, we provide an overview of the coverage in the literature of the former two.

Monitoring procedures

As Baer and colleagues (2016) note in their work on the right to health of older people, extensive human rights monitoring mechanisms have been set up at the international, and importantly, at the national and regional level as well in order to track progress and promote accountability. However, several authors cite substantial limitations to the existing monitoring infrastructure (INPEA et al., 2010; UN, 2012; Doron & Apter, 2010; Council of Europe, 2014; Randall et al., 2013; Poffé, 2015). In fact, some question the extent to which such procedures have been at all effective in protecting the rights of older people given that from over 120 country monitoring reports received by the United Nations Human Rights Committee between 2000 and 2008, only three addressed the issue of age-related discrimination and only one reflected on the situation of older people receiving LTC in residential care settings (Chung, 2010). In addition, some of the international instruments that aim to protect the rights of older people do not include any monitoring or enforcement mechanism at all. This is, for example, the case with the 2002 Madrid International Plan of Action on Ageing (MIPAA), which despite its value in promoting a strong policy agenda on ageing, is not considered a powerful tool for the protection of human rights of older people in large part because it lacks a mandatory reporting regime, nor does it provide recourse to complaints (Harpur, 2016).

Given this status quo it is perhaps not surprising that numerous UN Experts (Hunt, 2005; Chung, 2010; Kornfeld-Matte, 2015), NGO's (ENNHRI, 2017a; 2017b; HelpAge, 2013; INFEA et al., 2010) and academics (Poffé, 2015; Tang, 2008; Doron & Apter, 2010; Chesterman, 2014) unequivocally call for improving and extending the scope of current monitoring procedures to better cover the rights of older people (in need of LTC). Some developments in the international scholarship do give cause for optimism. The development of a dedicated tool for human rights monitoring in psychiatric and social care institutions, called the ITHACA toolkit, is one such response (Randall et al., 2013). The ITHACA instrument is a comprehensive (covering 30 dimensions) yet flexible instrument that has been validated in the course of 78 site visits across 15 European countries and can be used for longitudinal monitoring. Through its large-scale adoption and systematic application, much could be achieved in human rights monitoring in social care institutions in Europe. Similarly, ENNHRI's monitoring efforts in six of their member countries (Belgium, Croatia, Germany, Hungary, Romania, Lithuania) has produced crucial insights into the normative and implementation aspects related to the human rights of older people in need of LTC in Europe (ENNHRI, 2017b). Furthermore, such efforts could contribute decisively to increasing the evidence base and building the case for extending HRBA to LTC in Europe.

Complaints

Another aspect crucial to a working accountability system is an effective mechanism for remedy and complaints: "The right to complain is seen as a key right of patients […] Complaints are thereby expected to act as a form of social regulation and as instruments for improving the quality of care" (Bomhoff & Friele, 2017:75). Unfortunately, existing mechanisms for individual complaint leave much to be desired in most LTC settings as older people tend to lodge few complains despite their documented lack of satisfaction with care received. In their study of complaints in LTC facilities in the Netherlands, Bomhoff and Friele (2017) find that residents avoid complaining mainly because they have strong negative associations with being labelled "a complainer". They often found it difficult to complain because they did not wish to offend the care staff or to attract their scorn: "[the older persons] may experience a sense of gratitude, but also of insecurity and fear and these emotions may prevent them from voicing possible dissatisfactions" (Bomhoff & Friele, 2017: 78).

A similar study aiming to assess how care users and care professionals in Israel reflect on the right to health in old age found that older people are often not aware of their rights and the possibility to complain, and even when they are aware, they refrain from complaining out of a conviction that taking such action is futile; a phenomenon that Bershtling and colleagues term the "*deafness* of the system" (Bershtling et al., 2016: 475). The issues of rights awareness and of manageable complexity as necessary preconditions for building a working culture of accountability and effective remedy and complaint mechanisms feature frequently in the literature, with many calling for improvements to policy in this area (Chesterman, 2014; Donald, 2012; Doron & Apter, 2010; Field, 2016).

In her report to the 33rd session of the Human Rights Council in 2016, the UN Independent Expert on the Enjoyment of all Human Rights by Older Persons proposed the following strategies to achieving quality monitoring and effective accountability mechanisms: "clearly defined accreditation requirements and procedures, the development of benchmarks and quality standards, as well as reporting and monitoring guidelines to assess the quality of care by sufficient and well-trained staff, taking into account the evaluations of older persons themselves" (Kornfeld-Matte, 2016: 9). In the same report, the Independent Expert cites the creation of an independent inspectorate providing oversight for care provided in residential facilities as one example of good practice (Kornfeld-Matte, 2016).

5.4 Practical and political limitations of applying a HRBA to long-term care

5.4.1 Resource constraints and progressive realisation

Because many of the rights that are most relevant for older people in need of LTC (e.g. the right to health) are economic, social and cultural rights, they can only be achieved as part of a large and complex social agenda that might not be within the immediate grasp of all states. For many duty-bearers, the inadequacy of available resources can render the achievement of all or some economic, social and cultural rights of their citizens seemingly impossible (Brennan et al., 2007; Gwyther et al., 2009). In recognition of the considerable limitations states face in upholding their obligations, the United Nations Committee on Economic, Social and Cultural Rights has introduced the principle of *progressive realisation*. Progressive realisation takes into account that newly enshrined rights cannot be achieved overnight, but rather commits states to a continuing obligation to realise the rights of older people in question as rapidly and as effectively as possible (CESCR, 2000).

Unfortunately, the principle of progressive realisation has sometimes been used as an argument for the interpretation of the human rights of older persons as merely aspirational and as a justification for insufficient state responses to human rights issues (Martin et al., 2015; Gwyther et al., 2009). This, however, is a grave misinterpretation of the spirit and indeed the letter of international human rights law. Excluding situations where a state's lack of resources is so dire as to render even the most minimal standards unattainable, under the ICESCR, all signatory states have the obligation to "take deliberate, tangible and targeted steps toward progress on the right to health, within available resources" and to meet core obligations (among them, to ensure the right of access to health facilities, goods and services on a non-discriminatory basis, especially for vulnerable or marginalized groups; to provide essential medicines; to adopt and implement a national public health strategy). Furthermore, General Comment 14 to the ICESCR places the burden of demonstrating that every effort and every available resource has been used in an attempt to achieve core obligations on non-achieving governments (Gwyther et al., 2009).

Issues related to resource constraints and limited fulfilment of the right to health of older people are pressing not only in low-resource environments but in many developed countries as well. Writing about the situation in Europe, with special attention on the UK and Ireland, Phelan (2008) identifies the lack of community-based care and support services and the covert discrimination and cultural devaluation of older people as key contributors to the breaching (for example in the case of elder abuse) and lack of fulfilment of their human rights. A similar argument

is presented by Boyle (2010) who contends that older people's rights to autonomy and to participation are limited by a lack in availability of social support services, particularly home-based and community-based support and direct payments. In the author's words: "It is important to emphasise that the provision of social rights is necessary to ensure that older people's right to autonomy (executional and decisional) is facilitated. Such social rights relate to having access to high quality social care services, the provision of direct payments (or individual budgets) in order to directly purchase services and a fundamental right to independent living" (Boyle, 2008: 306). We also recall here the literature identifying the lack of palliative care and pain management as a significant breach of the rights of older people in need of LTC (see above).

5.4.2 Care rationing and the achievement of human rights

The practice of care rationing—loosely defined as the allocation of resources based on prioritisation—is common practice in developing and developed countries alike. It is also highly problematic from a rights-based perspective and is a substantial barrier to the actualisation of a HRBA to LTC (WHO, 2015; HelpAge, 2013 & 2015; Bershtling et al., 2016). While some authors have blamed the diffusion of such practices on the considerable pressure to reduce and defund welfare systems under the dominant neoliberal ideology (Tang, 2008), others ground it in a profound misunderstanding of the principle of equality and non-discrimination. In her argumentation against the different forms of age-based rationing that are currently being applied in Europe, Giordano (2005) proposes that the utilitarian interpretation of equality, i.e. that care systems should aim to ensure the largest quality and quantity of life (well-being) is shared among the largest possible number of people, is inherently flawed and at odds with a human rights framework. An interpretation of equality that is more in line with a rights-based approach calls for care systems to provide equal moral weight to an individual's preferences with respect to his/her care. Citing care rationing based on cost-utility approaches and quality-adjusted life years saved as approaches that are currently gaining increased popularity in European countries, Giordano writes: "The argument that healthcare distribution should be based on patients' quality and quantity of life and that elderly people have a lower entitlement to have their human rights respected is based on a misunderstanding of equality, one that leads to violation of the fundamental human rights and universal ethical principles stated in declarations, conventions, and charters of human rights" (Giordano, 2005: 88).

In a recent position paper on structural ageism, AGE Platform Europe raises the alarm concerning the increasingly vulnerable position of older people as the pressure on policymakers to ration care rises in austerity conscious European care systems (AGE

Platform Europe, 2016b). This increasing pressure is evident in the proliferation of means-tested entitlements and higher and higher co-payments for care provision in certain countries. "Older people constitute one of the largest groups of users of such services and are therefore particularly penalised by related reforms, which take place in addition to shrinking pension incomes. Moreover, there is a danger that prejudicial value judgements (or 'age-based rationing') may occur when assessing older people's health and long-term care needs, resulting in them not being allocated the appropriate resources to live independently and with dignity" (AGE Platform Europe, 2016b: 6). One may conclude that such policies constitute direct barriers to the achievement of the human rights of older people in general, but especially so for those who are in need of or dependent on care and support.

While both the grey and academic literature included in our review discussed care rationing almost exclusively from a critical and disproving perspective, some authors take a different view. In reflecting on the mounting costs of care in the US, Freeman (2010) proposes EoL care rationing as a potentially helpful solution. He questions whether autonomy and dignity are maintained under current EoL care practices and whether they should be, as a principle, upheld in certain end of life medical situations. He argues that, "decisions about end-of-life care, whether for the incompetent, the comatose, or the new-born should not be bound by autonomy of surrogate autonomy" (Freeman, 2010: 62).

6   Conclusions

Recent decades have witnessed increasing interest among policymakers, academics and advocacy groups in the application of a human rights framework to the case of older persons. As they age, people become more vulnerable, in part because of physical and mental frailty that often accompanies the ageing process, but also because of age-based discrimination that cuts across all facets of life. Such age-based discrimination is due not only to perceptions of older people as functionally impaired—not all older people experience impairment—rather it is tied also to institutionalised perceptions of older people as non-productive members of society and as burdens on the state and on family members. Violations of older people's human rights have been well-documented, including notably in their choice of, access to, and quality and adequacy of LTC services. As the share of older people increases across Europe, there is growing concern on the part of both those holding the proverbial purse strings, as well as on the part of older people and their advocates regarding the sustainability of existing LTC services and systems and on how to ensure that the fundamental rights of vulnerable older persons are upheld. While the human rights of every individual, including older persons, are legally enshrined within international human rights law, implementation of these legal instruments has been weak in the case of older people, a group with unique vulnerabilities and unique threats to their rights. Considerable 'soft law' does exists which addresses older people and their rights directly—first and foremost the MIPAA instrument—yet their non-binding nature means that older people's rights currently lack the necessary enforcement, and crucially, political and public visibility.

This working paper set out to investigate *what a human rights approach to LTC for older people means* and what it would *entail in practice*, with a focus on which 'substantive rights' should be specified in the case of older people in order to be able to fully realise their 'universal rights' (see Section 2.1 for definitions). The starting point for the review presented in the pages above has been to examine the link between the rights of people with disabilities and the rights of older persons, and the distinct discourses that have emerged around these two fields. There are obvious links between the experiences of people with disabilities and the experiences of older people with age-related functional impairments, a fact made even more relevant by increasing recognition of the large numbers of people *ageing with disabilities*. In fact, older people with impairments are, in theory, protected by the CRPD, the landmark human rights instrument that grew out of many years of advocacy and campaigning by disability activists. Many of the provisions contained within the CRPD are highly relevant to the situation of older people, including the focus on promoting the interrelated principles of autonomy, independence, and full participation in society. Indeed, the guiding theory behind the CRPD, a moderate version of the social model of disability (see Chapter 2), has important implications for older people's rights,

particularly as it relates to the provision of care and support services by the state. And yet, there was consensus among the authors included in this review that while disability rights serve as a useful lens through which to consider the rights of older people in need of LTC, there are areas where it is inadequate and inappropriate.

A rights-based model for older people in need of long-term care must take into account that older people in need of support do not experience discrimination due to their physical or mental impairment alone, but on the basis of discrimination simply to their chronological age, a form of discrimination that is aimed at physically healthy and able older persons as well. In addition, the review revealed important divergences in the two discourses related to the concept of 'care' and 'dependence', with important implications for the development of a rights-based framework for older people, given the traditional reliance on, and the values associated with family care in this context. There is considerable work being done at the international and European level (and though they were outside the scope of this review, at the national level as well) to formulate a HRBA for older people, and even a few initiatives focussing specifically on a HRBA to LTC for older people. In Chapter 5, we have attempted to summarise critically the specific rights most relevant in the context of older people and LTC, as well as the arguments put forth to support them (see Table 2 for an overview). While certain rights were often mentioned, including rights related to accessing care services, the right to choose and autonomy, the right to dignity, to palliative and to end-of-life care; other rights were less well covered in the literature, including rights related to the choice of care setting, particularly community care. In addition, discussion on the inclusion of the rights of carers—and what such rights might be—was scant. In the next phase of this project, we will be synthesising the findings from this review in order to develop a conceptual framework of a rights-based approach to LTC for older people.

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