

Developing a New Framework for Human Rights in Older Age: Exploration, Interpretation and Application

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Declaration Regarding the Work

I declare that this thesis has been composed solely by myself, that the work contained herein is my own, except where explicitly stated otherwise in the text or references, and that this work has not been submitted for any other degree in the National University of Ireland Galway, or elsewhere.

5 April 2020

Athina-Eleni Georgantzi

Abstract

While there is growing attention on the rights of older persons and the feasibility of a new treaty, the conceptual basis for a new United Nations (UN) convention has not yet been clearly articulated. This thesis addresses this gap by providing the first empirical study on this issue.

The thesis set out to discuss the value of a new UN convention by i) providing a theoretical understanding of older people's rights ii) discussing how the human rights of older persons should be interpreted in international standards and iii) suggesting how a new Convention should be framed to achieve better normative impact. The study carried out a comparative socio-legal analysis in Ireland, France and Greece and applied an interpretation of the constructivist grounded theory for the analysis of the data. Interviews were conducted with 24 participants involved in various organisations, which are active in advocacy or implementation of older people's rights in the three selected countries.

Discounting, which is defined as a form of systemic undermining of dignity of older persons, exists at societal level and in normative standards, as revealed in the current limited conception of human rights in older age. The thesis argues that a new convention could help detect human rights breaches against older persons (Recognizing); expand policy attention and State obligations to a wider range of issues (Enabling); and also help individuals and advocacy organisations raise their voice, claim their rights and seek remedy (Empowering).

Based on the findings, older people do not carry certain inevitable qualities that make discrimination inevitable, rather the denial of human rights is, more often than not, socially constructed. Therefore, discussions about a new treaty need to move away from restrictive and confining medical and welfare approaches that characterize current human rights discourse and practice. Instead, the thesis suggests that a new frame based on the promotion of '*human rights in older age*' would be much more enabling and inclusive.

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The Author

Nena Georgantzi graduated in 2008 from the Aristotle University of Thessaloniki with a Law Degree. She subsequently completed her Masters in Human Rights from the University of Strasbourg, in 2009. She then went on to study for a Masters in European Social Protection Law in Katholieken University in Leuven, which she received in 2010. On the same year she started work with AGE Platform Europe, the largest EU network of organisations of older persons, where she has been working ever since covering different positions in research project management and policy. Since 2014 she has been leading the organisation's policy and advocacy work in relation to non-discrimination and the human rights of older persons. In parallel she was awarded a fellowship by the National University of Ireland in Galway to complete this doctoral research. She has been personally involved in the UN Open-Ended Working Group on Ageing and participated in the Council of Europe drafting group, which finalised in 2013 a recommendation on older people's rights. Nena has also consulted the UN Office of the High Commissioner of Human Rights in the course of the mandate of the UN Independent Expert on the Enjoyment of all Human Rights by Older Persons and the UN Special Rapporteur on the Rights of Persons with Disabilities.

List of Abbreviations

AARP	American Association of Retired Persons
AGE	AGE Platform Europe
AGSSE	Highest General Confederation of Pensioners of Greece
APA	Allocation Personnalisée d'Autonomie (Personal Autonomy Allowance)
ARI	Active Retirement Ireland
CEDAW	Convention on the Elimination of all Forms of Discrimination Against Women
CESCR	Committee on Economic, Social and Cultural Rights
CNBD	Comité National pour la bienveillance et les droits des personnes âgées et les personnes handicapées (National Committee for the Well-treatment and the Rights of Older Persons and Persons with Disabilities)
CNCDH	Commission Nationale Consultative des Droits de l'Homme (National Consultative Commission on Human Rights)
CNRPA	Comité National des Retraités et des Personnes Agées (National Committee of Retirees and Older Persons)
CNVA	Conseil National de la Vie Associative (National Council of Associations)
CODERPA	Comité Départemental des Retraités et Personnes Agées (Departmental Committee of Retirees and Older Persons)
CoE	Council of Europe
CRC	Convention on the Rights of the Child
CRPD	Convention on the Rights of Persons with Disabilities
DPOs	Disabled People's Organisations
ECLAC	Economic Commission for Latin America and the Caribbean
ECOSOC	Economic and Social Council
EEDA	National Commission of Human Rights (Greece)
EOPYY	National Organism of Provision of Health Services (Greece)
ESR	Economic and Social Rights
EU	European Union
EURAG	European Federation for Older Persons
FERPA	European Federation of Retired and Elderly People
FIAPA	Fédération Internationale des Associations des Personnes Âgées
FNAPAEF	Fédération Nationale des Associations et Amis de Personnes Agées Et de leurs Familles (National Federation of Association and Friends of Older Persons and their Families)
FNAR	Fédération Nationale des Associations des Retraités (National Federation of Associations of Pensioners)
GA	General Assembly of the United Nations
GTM	Grounded Theory Methodologies
HRBA	Human Rights Based Approach
HRC	Human Rights Council
HSE	Health Service Executive
ICCL	Irish Council of Civil Liberties

ICESCR	International Covenant on Civil and Political Rights
IFA	International Federation on Ageing
ISCP	Irish Senior Citizens Parliament
KAPI	Centres of Open Protection for the Elderly
LTC	Long-term Care
MIPAA	Madrid International Plan of Action on Ageing
NCAOP	National Council on Ageing and Older People
NCHR	National Commission of Human Rights (Greece)
NGO	Non-Governmental Organisation
NHRI	National Human Rights Institution
NHRI	National Human Rights Institution
NHS	National Health System
NPAS	National Positive Ageing Strategy (Ireland)
OAS	Organisation of American States
OEWG	Open-Ended Working Group on Ageing
OHCHR	Office of the High Commissioner of Human Rights
PACE	Parliamentary Assembly of the Council of Europe
PAYG	Pay As You Go
PCH	Prestation Compensation Handicap (Allowance for Compensation of Disability)
RESC	Revised European Social Charter
UDHR	Universal Declaration of Human Rights
UN	United Nations
UNFPA	United Nations Populations Fund
UNRPA	Ensemble et Solidaires – Union Nationale des Retraités et Personnes Âgées (Together and in Solidarity, Former National Union of Retired and Older People)
UPR	Universal Periodic Review
VIPAA	Vienna International Plan of Action on Ageing
WHO	World Health Organisation

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[E]ach time we let in a new excluded group, [that] each time we listen to a new way of knowing, we learn more about the limits of our current way of seeing.

Carrie Menkel-Meadow¹

Chapter 1: Introduction

The United Nations (UN) has already adopted a number of thematic treaties, tailoring human rights standards to the specific lived experiences of certain groups, including women, children and persons with disabilities. The fragmentation of the human rights project suggests that there are often significant differences in the ways in which the rights of various groups should be treated.² Although it has been argued that the protection offered to the rights of older persons in existing international and regional human rights treaties is insufficient, there is currently no UN binding instrument expressly protecting the rights of older persons.³ An increasing number of civil society organizations, human rights experts and States are supporting the expansion of the human rights framework, with the elaboration of a new UN convention, in order to adequately address human rights breaches against older persons.⁴ Even though

¹ Carrie Menkel-Meadow, "Excluded Voices: New Voices in the Legal Profession Making New Voices in the Law," *U. Miami L. Rev.* 42 (1987).

² Frédéric Mégret, "The disabilities convention: towards a holistic concept of rights," *The International Journal of Human Rights* 12, no. 2 (2008); Frédéric Mégret, "The Human Rights of Older Persons: A Growing Challenge," *Human Rights Law Review* 11, no. 1 (2011).

³ Chinsung Chung, *The necessity of a human rights approach and effective United Nations mechanism for the human rights of the older person*, UN Human Rights Council, Advisory Committee (2010); Office of the High Commissioner for Human Rights, Normative standards in international human rights law in relation to older persons - Analytical Outcome Paper, (2012); UN Secretary General, Follow-up to the Second World Assembly on Ageing, A/64/127, (2009). Israel Doron, "From national to international elder law," *J. Int'l Aging L. & Pol'y* 1 (2005); Diego Rodriguez-Pinzón and Claudia Martin, "The International Human Rights Status of Elderly Persons" *American University International Law Review* 18, no. 4 (2003).

⁴ Helpage International, *Why it's time for a convention on the rights of older people* (2009); European Network of National Human Rights Institutions, *Human Rights of Older Persons and Long-Term Care Project: The Application of International Human Rights Standards to Older Persons in Long-Term Care* (2015); European Network of National Human Rights Institutions, *We have the same rights: The Human Rights of Older Persons in Long-Term Care in Europe* (2017), http://ennhri.org/wp-content/uploads/2019/10/ennhri_hr_op_web.pdf; AGE Platform Europe, *Human Rights Manifesto* (2016), <https://www.age-platform.eu/sites/default/files/AGE%20Human%20rights%20Manifesto%20Dec2016.pdf>.

the debate has been ongoing for several years, no international consensus has been reached yet regarding the need for such a new binding human rights treaty on older people.⁵

The increased interest on the subject of an international treaty for older persons, clearly coincides with demographic changes. It seems particularly important to consider the rights of older people at the moment, because they are often labelled as a problem and a burden to society.⁶ Issues around older age are attracting now significant policy attention, but mainly in terms of the costs of an ageing population. These concerns need to be counterbalanced with a consideration of the growing levels of inequality and rights violations against older people. The importance of the topic is not restricted to today's older generation, but it is a truly universal issue that will likely affect everyone who will live long enough to be considered old. Research in the field of human rights of older people is therefore timely not only because it contributes to emerging international human rights law, but also because it can provide insights into the causes of the human rights challenges faced by older people and lead to domestic policies and laws that systematically incorporate a consideration of individual rights in old age.

Discussions around the feasibility and added value of a new international convention on older people are primarily taking place in the UN Open-Ended Working Group on Ageing (OEWG). Established in 2010 by the UN General Assembly, the OEWG is equipped with the mandate to assess the existing framework and '*identify possible gaps and how best to address them*'.⁷ In 2012 the OEWG was also asked to '*consider proposals for an international legal instrument*',

⁵ Léon Poffé, "Towards a New United Nations Human Rights Convention for Older Persons?," *Human Rights Law Review* 15, no. 3 (2015); Annie Herro, "The human rights of older persons: the politics and substance of the UN Open-Ended Working Group on Ageing," *Australian Journal of Human Rights* 23, no. 1 (2017).

⁶ Kieran Walsh, Thomas Scharf, and Norah Keating, "Social exclusion of older persons: a scoping review and conceptual framework," *European Journal of Ageing* (2017); Liat Ayalon and Clemens Tesch-Römer, *Contemporary perspectives on ageism* (Springer International Publishing, 2018); Hon Prof John R. Beard and David E. Bloom, "Towards a comprehensive public health response to population ageing," *Lancet (London, England)* 385, no. 9968 (2015).

⁷ UN General Assembly, *Follow-up to the Second World Assembly on Ageing, Resolution adopted by the General Assembly, 21 December 2010, A/RES/65/182* (2010), <https://undocs.org/A/RES/65/182>.

which – despite failing to initiate a drafting process - led to an increasingly focused body of work around normative elements that could be integrated in a new instrument.⁸ In 2013 the Human Rights Council (HRC) appointed the first UN Independent Expert on the Enjoyment of All Human Rights by Older Persons, who since has been contributing to the OEWG deliberations and has argued in favour of a new treaty.⁹ Despite these developments, the conceptual basis for a new convention has not yet been clearly articulated.¹⁰ In order to show the utility of a new convention, the consolidation of a defining principle is necessary from a practical, legal and normative perspective.¹¹ It is this conceptual vacuum that this thesis seeks to address.

Research Focus and Rationale

The Need for an Empirical Approach

This thesis represents the culmination of my professional involvement in the OEWG discussions.¹² Since 2010 I have been working for AGE Platform Europe, a European network that brings together more than 100 national, local and regional organisations working for and with older people. Having had the privilege to witness the development of the global debate on the potential of a new treaty, I became conscious of its complexity and lack of focus. I also gained unique insight into the failure of the transnational network that is advocating in favour of a new convention to gain traction. As has been argued by others, civil

⁸ UN General Assembly, *Towards a comprehensive and integral international legal instrument to promote and protect the rights and dignity of older persons: resolution adopted by the General Assembly, 20 December 2012* (2012), <https://undocs.org/A/RES/67/139>; UN General Assembly, *Towards a comprehensive and integral international legal instrument to promote and protect the rights and dignity of older persons: resolution adopted by the General Assembly, 20 December 2012, A/RES/65/182* (2012), <https://undocs.org/A/RES/67/139>. More information about progress in the OEWG can be found in the following chapter

⁹ UN Human Rights Council, *The human rights of older persons, Resolution adopted by the Human Rights Council, A/HRC/RES/24/20* (2013), <https://undocs.org/A/HRC/RES/24/20>; UN Human Rights Council, *Report of the UN Independent Expert on the enjoyment of all human rights by older persons, A/HRC/33/44* (2016), <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G16/147/83/PDF/G1614783.pdf?OpenElement>.

¹⁰ Mégret, "The Human Rights of Older Persons: A Growing Challenge." Alison Kesby, "Narratives of aging and the human rights of older persons," *Human Rights Review* 18, no. 4 (2017).

¹¹ Robin Allen, *Discussion papers: Legal issues for strengthening international legislation on the rights of older persons*.

¹² For more information on the researcher's positionality see Chapter 3

society that participates in the OEWG has not yet agreed on a shared advocacy frame.¹³

In addition, I realized the extent to which the OEWG was missing direct input by older persons' organisations¹⁴, in particular from a domestic perspective. As part of the movement that is trying to build support a new UN convention, I also witnessed first-hand the lack of domestic debate on the need and feasibility of a new international treaty. This knowledge encouraged me to undertake this research adopting a bottom-up approach that is able to capture the *unheard voices* of representative organisations of older people working at the national level.

With this study, I aimed to contribute to the theoretical and political debate around the need for a new UN convention, but also to help domestic NGOs become norm entrepreneurs, to improve advocacy around a new UN convention and ultimately to ensure that, in case of adoption, a new treaty can be grounded on the views and experiences of older persons as these are expressed by representative advocacy groups.

The true strength of this thesis lies in its methodological approach. Unlike existing scholarship on the added value of a new convention, which is either bibliographical or doctrinal, this thesis provides an empirical comparative perspective based on the views of older people's advocacy groups. Whereas it has been argued that the lived rights experience of older people can help define the distinct rights issues associated with older age¹⁵, the emerging field of human rights of older persons is not empirically based.¹⁶ Studying why older people are

¹³ Jennifer Sciubba, "Framing and Power in Aging Advocacy," *Social Movement Studies: Journal of Social, Cultural and Political Protest* 13, no. 4 (2014); Mégret, "The Human Rights of Older Persons: A Growing Challenge."

¹⁴ On this see also Jennifer Sciubba, "Explaining campaign timing and support for a UN Convention on the Rights of Older People," *The International Journal of Human Rights* 18, no. 4-5 (2014); Jennifer Dabbs Sciubba, "Securing rights in the twenty-first century: A comparison of the disability and older persons' rights conventions," *Journal of Human Rights* 15, no. 4 (2016).

¹⁵ Mégret, "The Human Rights of Older Persons: A Growing Challenge."

¹⁶ Israel Doron and Itai Apter, "International Rights of Older Persons: What Difference Would a New Convention Make to Lives of Older People?," *Marquette Elder's Advisor* 11, no. 2 (2010); Israel Issi Doron et al., "Ageism and anti-ageism in the legal system: A review of key themes," in

less advantaged, less well situated or less empowered is considered complementary to the legal positivistic approach.¹⁷ Scholarship on old age differs from that on disability and gender as it is largely written from the outside; it is about older people and not by or with older people.¹⁸ Collective old age advocacy at national level plays a prime role in the study because previous research on older people's rights focused mainly on transnational networks already active in the OEWG¹⁹.

On the one hand, seeking an organic understanding and expression of human rights as articulated by representatives from older people's organisations across three different European countries, the study brings forward a poorly understood perspective on the rights of older people. To attain its aim, the research gives prime positioning to organisations *directly* representing older people (i.e. those whose membership is comprised by a majority of older persons and are governed, led and directed by older people).²⁰

On the other hand, the decision to interview representatives of organisations of older persons means that the views and realities of those individuals that are not affiliated with any organisation are not reflected in the study. However, this choice is justified on the grounds that the thesis is primarily interested in capturing the views and capacity of older persons as a collective to motivate action on human rights. Participants are seen as experts on older people's issues as opposed to experts on their own lives. The thesis aims to highlight the structural issues that create disadvantage, as opposed to gathering personal

Contemporary perspectives on ageism, ed. Liat Ayalon and Clemens Tesch-Römer (Springer, Cham, 2018).

¹⁷ Paul De Hert and Eugenio Mantovani, "Specific Human Rights for Older Persons? The inevitable colouring of Human Rights Law," *European Human Rights Law Review* 4, no. 4 (2011).

¹⁸ Toni Calasanti, Kathleen F. Slevin, and Neal King, "Ageism and Feminism: From "Et Cetera" to Center," *NWSA Journal* 18, no. 1 (2006).

¹⁹ Herro, "The human rights of older persons: the politics and substance of the UN Open-Ended Working Group on Ageing."; Sciubba, "Framing and Power in Aging Advocacy."; Sciubba, "Securing rights in the twenty-first century: A comparison of the disability and older persons' rights conventions."

²⁰ For more information on sampling see Chapter 4

testimonies. This is why it aims to uncover general and shared -instead of individual- attitudes to human rights.²¹

The Importance of a European Perspective

The European perspective of this thesis is relevant and timely for manifold reasons. First, despite increased attention of the international community to the human rights of older persons, most European States have remained unconvinced about the added value of a new UN treaty.²² European scepticism in the frame of the OEWG has been attributed to concerns about the correlation of a rights framework with increased public expenditure.²³ However, a gradual openness to a human rights-based approach and to a norm-setting process has been noted among some European countries since 2016, partly due to the publication of the Independent Expert report that called on States to consider the elaboration of an international instrument.

Notwithstanding the existence of binding provisions on ‘the rights of the elderly’ in the European Union Charter of Fundamental Rights and the Revised European Social Charter²⁴, compared with other groups at risk of discrimination, older persons’ rights still lack a systematic and comprehensive consideration at European level.²⁵ Whereas both the Organisation of American States and the African Union have adopted binding instruments enshrining the rights of older

²¹ Some further limitations of the empirical approach and the focus of the study are discussed in Chapter 11, taking into account the sample and the findings.

²² Sciubba, "Explaining campaign timing and support for a UN Convention on the Rights of Older People."; Marijke de Pauw, "Global Population Aging from a Human Rights Perspective: The Need for a UN Convention on the Rights of Older Persons," *Global Europe–Basel Papers on Europe in a Global Perspective*, no. 114 (2017). Helpage International (2013) *Strengthening the Rights of Older People Worldwide: Building Greater European Support*, Report from Conference held 5-7 December 2012 in Osnabruck.

²³ Poffé, "Towards a New United Nations Human Rights Convention for Older Persons?."

²⁴ Article 25 of EU Charter of Fundamental Rights and Article 23 of Revised European Social Charter

²⁵ Anne-Sophie Parent, "The Impact of the European Year 2012 on Active Ageing and Solidarity Between Generations: A Critical Assessment," *Geron* 1 (2015). <https://mijn.bsl.nl/the-impact-of-the-european-year-2012-on-active-ageing-and-solidarity/6648962?fulltextview=true>; Nena Georgantzi, "The European union's approach towards ageism," in *Contemporary perspectives on ageism* (Springer, Cham, 2018).

people²⁶, the European region has not followed this example. Recently however, two Council of Europe (CoE) bodies adopted recommendations relating to the rights of older people, with the latest one also suggesting the elaboration of a new binding instrument.²⁷ A European contribution is therefore highly pertinent.

Additionally, such an analysis is particularly useful because European countries have been identified as influential actors in treaty negotiations and adoption.²⁸ This focus was also deemed appropriate because Hathaway, who despite being sceptical about whether human rights treaties improve countries' human rights practices, believes that they can improve the practices of democratic States.²⁹ Hence, limiting comparison to EU Member States appeared to be an interesting and useful contribution to the ongoing discussions around a UN treaty.

On this basis, three EU member countries were selected for the study. This selection was made taking into account the widest possible geographic, legal culture and welfare classification coverage; the potential of comparable and interesting findings bearing in mind the extent of involvement to the OEWG and the focus and maturity of the domestic framework on ageing; and ease of access to the national jurisdictions, in particular thanks to linguistic skills, knowledge of legal and policy systems and local contacts. Based on this analysis, the decision to compare Ireland, France and Greece was made.

Research Aim and Objectives

The study at hand aims at developing an understanding of human rights grounded in the advocacy of older people's organisations in Ireland, France and

²⁶ African Union, "Protocol to the African Charter on Human and Peoples' Rights on the Rights of Older Persons in Africa," (2016); Organisation of American States, "Inter-American Convention on Protecting the Human Rights of Older Persons (A-70)," (2015).

²⁷ Council of Europe, "Recommendation CM/Rec(2014)2 of the Committee of Ministers to member States on the promotion of the human rights of older persons," (2014); Parliamentary Assembly of the Council of Europe, "Recommendation 2104 (2017) Human Rights of Older Persons and their Comprehensive Care," (2017).

²⁸ Sciubba, "Securing rights in the twenty-first century: A comparison of the disability and older persons' rights conventions."; Sciubba, "Explaining campaign timing and support for a UN Convention on the Rights of Older People."

²⁹ Oona Hathaway, "Do Human Rights Treaties Make a Difference?," *Yale Law Journal* 111, no. 8 (2002).

Greece that can be incorporated in international human rights law and practice. From an international human rights law perspective considering something as a human rights issue means recognizing that individuals have legitimate claims vis-à-vis their governments and that States can be held accountable by the international community regarding their acts or omissions³⁰. In discussing the ways that the human rights of older people may be undermined, the research therefore explores the ability and scope of State obligations to support the realisation of human rights for this group in a domestic context. Addressing what constitutes a human rights violation in the context of older age, this research considers how the idea and content of human rights can be expanded to adequately integrate experiences of ageing and of older age. In doing so, the thesis responds to the UN Secretary General's call for '*an older persons' perspective on human rights*'.³¹

The study then serves the threefold objective of:

- Exploring the meaning given to human rights by national organisations of older persons in order to develop a substantive theory that could become the conceptual basis of a new treaty;
- Discussing whether existing norms reflect the scope of State obligations emerging from this theoretical understanding and identify gaps that could become the normative content of a new treaty;
- Suggesting how a new treaty could be framed to reflect the empirical understanding of human rights in older age and resolve some of the existing ambiguities and tensions.

Constructivist grounded theory was selected as the strategy for the inquiry.³²

This allows a conceptualisation of human rights in older age that draws from the

³⁰ Magdalena Sepulveda Carmona, Carly Nyst, and Heidi Hautala, "The human rights approach to social protection," *Ministry of Foreign Affairs of Finland* (2012).

³¹ UN Secretary General, Follow-up to the Second World Assembly on Ageing, A/64/127, para 66; UN Secretary General, *Follow-up to the Second World Assembly on Ageing, Report of the Secretary General, A/64/127* (2009),

<http://www.un.org/esa/socdev/documents/reports/Ageing.pdf>.

³² Kathy Charmaz, *Constructing Grounded Theory*, 2nd ed., Introducing Qualitative Methods series, (SAGE, 2014).

views of study participants (i.e. Exploration). The researcher co-constructs the theory by interacting with and interpreting the data (i.e. Interpretation). In this sense, the experiences and views of older people's advocacy groups are distilled - based on my own interpretations - to create a framework for the development of a new rights-based model for older age that may help to influence future iterations towards a new convention (i.e. Application).

Research Questions

The effect of a new treaty will ultimately depend on unpredictable factors such as its content, level of ratification by States, enforcement mechanisms, integration of norms in national law or judicial interpretation, economic constraints, State willingness to translate norms into practice, etc. The study could not of course take into account all these variables, since at the time of writing the United Nations has not yet started drafting such a treaty. This is why I decided to address this issue from the perspective of theoretical and normative innovation and potential impacts of a new treaty when compared with the current situation, by addressing the following question:

In which ways can a new UN treaty make a difference in law, policy and advocacy in order to address the barriers faced by older persons, as these are expressed by representative advocacy groups?

The study is interested in how a new theoretical frame based on human rights could push boundaries in law, policy and advocacy regardless of whether a new treaty would have the 'teeth', political support and enforcement mechanisms to guide and constrain government behaviour. In other words, while the study could not evaluate the actual influence that a new convention would have on the realisation of the norms it espouses, it is geared towards exploring the *potential* for international and domestic change, i.e. the ways in which it is likely to make a difference, provided it is followed up by treaty compliance. Therefore, it was less

interested in outcomes (i.e. implementation) than in new or '*neglected dimensions of rights*' in the context of older age.³³

The following figure illustrates the threefold approach – covering exploration, interpretation and application - that I followed in order to tackle my research question.

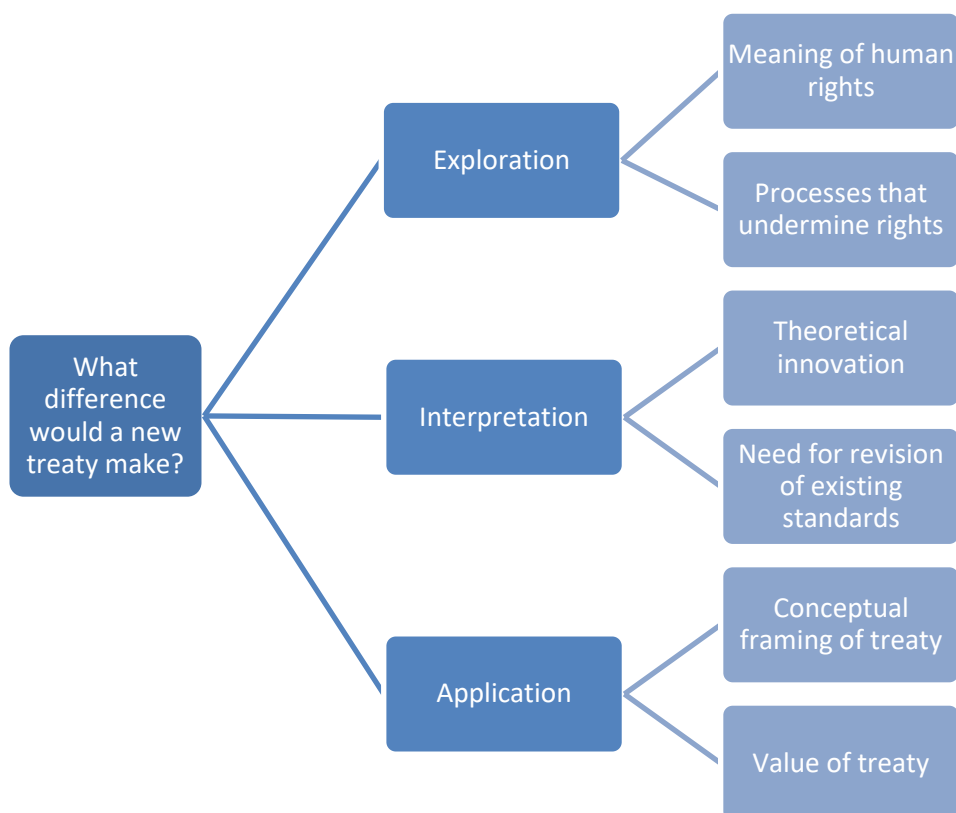


Figure 1: Threefold Approach of the Thesis

The first part of the thesis aims to explore the conceptual innovation that could be included in a new treaty, by addressing the following sub-question:

1. How do older people's groups understand human rights and States' role and responsibilities to realise them?

In order to elicit what specific to old age human rights law would protect, the research discussed older persons' own conception of their rights and how they

³³ Lung-chu Chen, Philip Alston, and Martin L. Levine, "Aging: A New Human Rights Concern—A Policy-Oriented Perspective" (1987), p.176.

advocate for State action to support them. In doing so, it focused on defining human rights, what drives rights violations and how rights can be enabled. (Chapters 6, 7, 8 and 9).

The following questions framed the answer to this research problem:

1.1 How are the human rights of older persons characterized and/or defined?

1.2 What is the process through which human rights violations in old age take place?

Answering these questions laid the foundations for the emerging theory and provided the backbone for the second sub-research question, which aims to discuss how existing legal standards need to be revised:

2. How can the emergent understanding of human rights of older persons be integrated into human rights law?

Focusing on the gap between older people's expectations and understandings - as defined by research participants - and existing human rights commitments, answering this question allows the thesis to identify protection gaps and how a new treaty could help address them (Chapter 10).

Concretely, to discuss the normative innovation of new treaty these issues were tackled:

2.1 How far do existing standards reflect participants' conceptions of human rights and the perceived barriers?

2.2 In which ways should existing norms be revised or expanded to better reflect experiences of human rights breaches against older persons?

The final part of the thesis discusses how the findings can be applied in practice and what the added value of a new treaty for law, policy and advocacy could be (Chapter 11).

3. How could a new treaty be framed to integrate the meaning of human rights advocated by older age groups and better reflect real experiences of violations?

The following sub-questions guided the discussion of how a new treaty should be framed to be more likely to positively influence the lived realities of older persons in the selected countries.

- 3.1 What should be the defining aim(s) and principle(s) of a human rights-based approach to older age?*
- 3.2 Are there advantages in the adoption of a new UN treaty in supporting the lived experiences of rights of older persons, when compared with the existing legal norms, policy paradigms and collective advocacy on old age in Europe?*

Structure of the Thesis

Chapter 2 sets the stage for the research exposing current conceptions of the rights of older persons, existing normative standards and the complexity of the political debate at the OEWG. This chapter also explains the added value of an empirical approach focusing on old age advocacy within the European Union (EU) context. Chapters 3 and 4 detail the selection and application of the methodology of the thesis, which is underpinned by constructivist grounded theory. Chapter 5 gives a brief overview of the state of the art in terms of policy, law, discourse and movement on older people's rights in the three compared countries. Chapters 6 to 9 reply to the first research question. Chapters 6 and 7 present the empirical findings of the interviews, in terms of a general understanding of human rights and the structural cause of human rights abuses (i.e. discounting). Chapter 8 presents the emerging theory of 'overlooking the injustice', which is based on the researcher's interpretation of the findings. Chapter 9 further presents conceptions of human rights that are based on participants' views, highlighting the framing and dimensions of rights that could be integrated in a new treaty. Together these four Chapters provide the backbone for the analysis that is done in subsequent Chapters of the thesis. Chapter 10 addresses the second research question by critically analysing existing human rights standards and identifying

inconsistencies and gaps that undermine the protection of the human rights of older persons. Compliant with the constructivist grounded theory methodology, the empirical data are not analysed considering existing theory, research, law and policy, until the final Chapter 11. This chapter presents arguments in favour of a new treaty, as well as some possible frames that could facilitate support for its adoption and in doing so provides an answer to the final research question.

Chapter 2: Research Context

According to Mégret, to argue for the need for a convention on the rights of older persons, we need to prove three things.³⁴ First, to demarcate older people as a distinctly definable group, second, to determine the extent to which international law fails to protect older people's rights and third, to discuss the distinct human rights challenges that justify a targeted approach to older age. This chapter addresses these issues by turning to extant human rights law, legal scholarship, the political debate in the OEWG and gerontological literature:³⁵ It begins with an overview of how the discourse on ageing has gradually moved from welfare to rights. It also reveals the limited involvement of older people's organisations in this development. Then it explores gaps and tensions in the conceptualisation of older people's rights that this thesis aims to address. Ultimately this chapter illustrates that, notwithstanding growing attention to the human rights of older persons, diverse frames and conceptualisations co-exist.

From Welfare to Rights: A Historical Outlook

Although it is not philosophically contested that older people are rights holders, older people have been traditionally seen as subjects of welfare; therefore, a needs-based instead of rights-based approach has prevailed in the ageing sector:³⁶ When older persons are seen as beneficiaries of welfare, they are

³⁴ Mégret, "The Human Rights of Older Persons: A Growing Challenge."

³⁵ Bearing in mind the emphasis of this thesis on how institutions and policies shape experiences of rights violations, this part primarily draws on the political economy of ageing. As a strand of critical gerontology, political economy focuses on the State structures and how they produce what Townsend called 'structured dependency' meaning, how they force older people's exclusion, passivity and poverty. Peter Townsend, "The Structured Dependency of the Elderly: A Creation of Social Policy in the Twentieth Century" *Ageing and Society* 1, no. 1 (1981); Peter Townsend, "Policies for the aged in the 21st century: more 'structured dependency' or the realization of human rights ?," *Ageing and Society* 26, no. 2 (2006).

³⁶ Economic Commission for Latin America and the Caribbean (ECLAC), "Challenges to the autonomy and interdependent rights of older persons," (2017); Nevena Petrušić, Nataša Tođorović, and Milutin Vračević, *INTRODUCTION TO AGEING AND HUMAN RIGHTS OF OLDER PEOPLE -PILOT RESEARCH STUDY ON FINANCIAL ABUSE OF OLDER PEOPLE* (Red Cross of Serbia, 2015); Office of the High Commissioner for Human Rights, Normative standards in international human rights law in relation to older persons - Analytical Outcome Paper; Chung, *The necessity of a human rights approach and effective United Nations mechanism for the human rights of the older person*; UN Secretary General, *Follow-up to the Second World Assembly on Ageing, Report of the Secretary General, A/64/127*.

defined based on their deficits and needs.³⁷ This approach reflects a biomedical model, whereby ageing is seen as a process of 'decline and decay'.³⁸ Ageing is constructed primarily as medical problem, which merits medical intervention.³⁹ Cognitive and physical limitations are considered inevitable and a problem of the individual, who carries the burden of adjusting to growing older.⁴⁰ Under the biomedical paradigm exclusion can be seen as natural.⁴¹ The State primarily has the responsibility to compensate for loss, in terms of income, autonomy and roles.⁴² The failure to meet needs and address disadvantage does not create a legitimate claim for reparation.

On the contrary, according to the social model, inequality and exclusion are products of society. Older people are not made vulnerable and dependent on assistance because of age, illness, incapacity or disability – but because of the diminishing opportunities and life chances that the State and other actors impose on them.⁴³ Formal retirement excludes older people from the labour market but also unrobes them of their social role and may lead to exclusion and poverty.⁴⁴ Capitalism contributes to an unequal distribution of resources and consequently power and renders many older people economically dependent on social security.⁴⁵ Dependency is further enhanced through the inadequacy of old age income and the provision of care, which treats older people as passive recipients

³⁷ Sandra Huenchuan and Luis Rodríguez-Piñero, *Ageing and the protection of human rights: current situation and outlook* (Santiago, Chile: Economic Commission for Latin America and the Caribbean (ECLAC), United Nations, 2011); European Union Agency for Fundamental Rights, *Shifting perceptions: Towards a rights-based approach to ageing* (2018), https://www.age-platform.eu/sites/default/files/fra-2018-fundamental-rights-report-2018-focus_en.pdf.

³⁸ Chris Phillipson, *Ageing* (Cambridge, UK: Polity Press, 2013), p.132.

³⁹ Phillipson, *Ageing*, p.133.

⁴⁰ Elaine Cumming and William Earl Henry, *Growing old, the process of disengagement* (Basic books, 1961).

⁴¹ Gerard Quinn and Eilionóir Flynn, "Transatlantic borrowings: the past and future of EU non-discrimination law and policy on the ground of disability," *The American Journal of Comparative Law* 60, no. 1 (2012).

⁴² Huenchuan and Rodríguez-Piñero, *Ageing and the protection of human rights: current situation and outlook*; Quinn and Flynn, "Transatlantic borrowings: the past and future of EU non-discrimination law and policy on the ground of disability."

⁴³ Carroll L. and Associates Estes, *Social Policy and Aging - A Critical Perspective* (Thousand Oaks, CA: Sage Publications, 2001).

⁴⁴ Alan Walker, "Towards a political economy of old age," *Ageing and Society* 1, no. 1 (1981).

⁴⁵ Chris Phillipson, *Reconstructing Old Age* (London: Sage, 1998).

whether in institutions or in the community.⁴⁶ The role of the State then lies in eliminating these societal barriers.

Rights-based approaches essentially reflect a social model. They are interested in how States can tackle socially created obstacles in order to ensure full participation, equality and respect for the dignity of all individuals. Instead of looking at deficits and needs, they impose duties on States to strengthen the capacities of individuals.⁴⁷ The failure to respect rights entails a violation and an obligation for redress.

Older people's rights have not received emphasis in international law to the same extent that discrimination, suffering and deprivation on the basis of one's sex, race, sexual orientation or disability have. Even though gradually a human rights discourse on ageing has begun to emerge, there are still '*normative gaps, as well as fragmentation and a lack of coherence and specificity of standards as they relate to the experience of older persons*'.⁴⁸ Additionally, a human rights-based approach to ageing has mainly taken the form of soft law. Although it has been argued that there is an inadequacy of human rights protection for older people, there is currently no UN binding instrument expressly protecting the rights of this group.⁴⁹

Even though the shift from a welfare perspective to a human rights approach to ageing is sometimes considered as a recent development, in reality the idea that older persons may require targeted protection in a specific human rights

⁴⁶ Peter Townsend, "Ageism and social policy," in *Ageing and social policy*, ed. Chris Phillipson and Alan Walker (Aldershot, UK: Gower, 1986); Townsend, "Policies for the aged in the 21st century: more 'structured dependency' or the realization of human rights?"; Paul Harpur, "Old Age is not just Impairment: The CRPD and the Need for a Convention on Older Persons," *U. Pa. J. Int'l L.* 37 (2016).

⁴⁷ United Nations Development Group, *The Human Rights Based Approach to Development Cooperation Towards a Common Understanding among UN agencies* (2003), https://unsdg.un.org/sites/default/files/6959-The_Human_Rights_Based_Approach_to_Development_Cooperation_Towards_a_Common_Understanding_among_UN.pdf.

⁴⁸ Office of the High Commissioner for Human Rights, Normative standards in international human rights law in relation to older persons - Analytical Outcome Paper.

⁴⁹ Office of the High Commissioner for Human Rights, Normative standards in international human rights law in relation to older persons - Analytical Outcome Paper.

instrument is not novel. The first efforts to link old age with human rights go all the way back to the adoption of the Universal Declaration on Human Rights (UDHR) in 1948, when Argentina made a proposal to the UN for a 'Declaration of Old Age Rights'.⁵⁰ Since this suggestion was not followed through, the only reference to old age in the UDHR is limited to social protection. Article 25 mentions old age among other conditions, like unemployment, sickness, disability and widowhood that deserve state protection to ensure an adequate standard of living. But the remit of this provision is evidently limited.

The need to enshrine the rights of older persons was reiterated during the negotiations of the International Covenant on Economic, Social and Cultural Rights (ICESCR), one of the cornerstones of international human rights law. It was suggested that a specific reference to older age be included in the Covenant, but this was rejected on the basis that the UN might adopt a dedicated instrument on the rights of older people.⁵¹ Around the same time as the entry into force of the ICESCR, in 1976, McDougal, Laswell and Chen published an article on the 'human rights of the aged', problematizing older people's issues as human rights and pleading for making better use of existing standards to outlaw mandatory retirement and discrimination in the labour market.⁵²

Concerted efforts to increase international attention to the situation of older persons began at the first World Assembly in 1982, which resulted in the adoption of the Vienna International Action Plan on Ageing (VIPAA). Although the VIPAA mainly frames ageing as a humanitarian and development issue, it reiterated the full and undiminished application of the rights enshrined in the Universal Declaration of Human Rights to older persons.⁵³ But VIPAA sparked

⁵⁰ Israel Doron and Kate Mewhinney, "The rights of older persons," *Collection of International Documents. Jerusalem: JDC-ESCHEL* (2007).

⁵¹ De Hert and Mantovani, "Specific Human Rights for Older Persons? The inevitable colouring of Human Rights Law."

⁵² Myres S. McDougal, Harold D. Lasswell, and Lung-Chu Chen, "The Human Rights of the Aged: An Application of the General Norm of Nondiscrimination," *U. Fla. L. Rev.* 28 (1975).

⁵³ Preamble to the Vienna International Plan of Action on Ageing, adopted by the World Assembly on Aging held in Vienna, Austria from 26 July to 6 August 1982; Report of the World Assembly on Ageing, Vienna, 26 July - 6 August 1982, U.N. Sales No. E.82.1.16 (1982).

little interest among human rights bodies and national legislators in the plight of older people as human rights subjects.⁵⁴ One of its main weaknesses is that it did not impose any obligation on States to revise their own laws to better protect the human rights of older persons.⁵⁵

The VIPAA's 10th anniversary provided the impetus for further attention to the human rights of older persons. In 1991, the International Federation on Ageing (IFA) and the Dominican Republic put on the table the 'Declaration of the rights and responsibilities of older persons', which formed the basis of the United Nations Principles for Older Persons adopted by the UN General Assembly in the same year.⁵⁶ The UN Principles⁵⁷ are neither binding nor exhaustive; they do not proclaim the whole catalogue of human rights, but emphasize aspects of independence, participation, care, self-fulfilment and dignity. The text does not adopt rights language, which implies State obligations, but is framed in a series of 'shoulds'.⁵⁸ Even though they are generic and lack concrete standards for implementation, the UN principles still remain one of the main references with regard to the rights of older persons.⁵⁹ Since their adoption in 1991 they have influenced subsequent declarations, treaty body recommendations and other soft instruments.⁶⁰ The UN Committee on Economic, Social and Cultural Rights (CESCR) in particular has issued a number of General Comments containing

⁵⁴ Chen, Alston, and Levine, "Aging: A New Human Rights Concern—A Policy-Oriented Perspective".

⁵⁵ Arlene S. Kanter, "The United Nations Convention on the Rights of Persons with Disabilities and its implications for the rights of elderly people under international law," (2009); Chen, Alston, and Levine, "Aging: A New Human Rights Concern—A Policy-Oriented Perspective".

⁵⁶ Charlotte Nusberg, "UN takes action on Principles for Older Persons," *Ageing International* 18, no. 1 (1991).

⁵⁷ United Nations Principles on Older Persons, UNGA Resolution 46/91, "Implementation of the International Plan of Action and Related Activities", 16 December 1991, *UN Doc. A/RES/46/91*

⁵⁸ Nusberg, "UN takes action on Principles for Older Persons."

⁵⁹ Huenchuan and Rodríguez-Piñero, *Ageing and the protection of human rights: current situation and outlook*.

⁶⁰ Barbara Mikołajczyk, "International law and ageism," *Polish Yearbook of International Law*, no. 35 (2015). UN Committee on the Elimination of Discrimination Against Women (CEDAW), *General recommendation No. 27 on older women and protection of their human rights*, 16 December 2010, CEDAW/C/GC/27 (2010), United Nations, Political Declaration and Madrid International Plan of Action on Ageing, Second World Assembly on Ageing, Madrid, Spain (2002), UN Committee on Economic, Social and Cultural Rights (CESCR), *General Comment No. 6: The Economic, Social and Cultural Rights of Older Persons*, 8 December 1995, E/1996/2 (1995)

references to age or older persons.⁶¹ However, the UN principles do not reflect all the human rights challenges affecting the older population and they sometimes even contradict binding standards. The lack of prohibition of age discrimination and of institutionalisation are two such examples that will be further discussed in the thesis.

In 1995 the CESCR adopted a general comment focusing exclusively on the rights of older persons. Recognizing that older people are '*among the most vulnerable, marginal and unprotected groups*', General Comment 6 focuses on the rights to work, social security, protection of the family, adequate standard of living, physical and mental health, and education and culture.⁶² However, drawing heavily from the VIPAA and the UN Principles of 1991 it offers little original analysis of human rights in the context of older age.⁶³ For example, it failed to include a general prohibition of age discrimination covering the whole spectrum of rights enshrined in the International Covenant on Economic, Social and Cultural Rights (ICESCR).⁶⁴

On the occasion of the International Year of Older Persons in 1999, the Dominican Republic submitted to the Commission on Social Development a draft of a 'Declaration of Interdependency' and the American Association of Retired Persons (AARP) of the United States proposed the 'Charter for a society for all ages' for consideration by the UN. Both initiatives aimed at gathering support for a new international instrument but did not yield any follow-up action.⁶⁵

⁶¹ See among others UN Committee on Economic, Social and Cultural Rights (CESCR), *General Comment No. 4 The Right to adequate housing* (art.11 (1) of the Covenant) 13 December 1991, E/1992/23 (1991), UN Committee on Economic, Social and Cultural Rights (CESCR), *General Comment No.12 The right to adequate food*, 12 May 1999, E/C.12/1999/5 (1999); UN Committee on Economic, Social and Cultural Rights (CESCR), *General Comment No 14 The Right to the highest attainable standard of health*, 11 August 2000, E/C.12/2000/4 (2000)

⁶² UN Committee on Economic, Social and Cultural Rights (CESCR), "*General Comment No. 6: The Economic, Social and Cultural Rights of Older Persons*"

⁶³ Doron, "From national to international elder law," p. 59.

⁶⁴ See more about this in Chapter 10

⁶⁵ Sciubba, "Explaining campaign timing and support for a UN Convention on the Rights of Older People."

In the beginning of the 21st century attention to the human rights of older persons grew exponentially from the perspective of scholarship, global policy and human rights law. Experts from the field of gerontology and law advanced the case for a human rights narrative and a new UN convention targeting older persons.⁶⁶ Twenty years after the Vienna Assembly, a Second World Assembly injected an increased focus on human rights in the international agenda. With the adoption of the Madrid International Plan of Action on Ageing (MIPAA) in 2002, for the first time, States linked population ageing to human rights frameworks.⁶⁷ Divided into three policy directions: older persons and development; advancing health and well-being into old age; and ensuring enabling and supportive environments for older persons, the MIPAA emphasized the roles and contributions of older persons, departing therefore from their portrayal merely as beneficiaries of welfare.⁶⁸

Although it includes a few commitments to human rights, such as eliminating age discrimination, the MIPAA is not a human rights instrument since governments have no legal obligation to implement any of the recommendations within it.⁶⁹ Despite foreseeing a review every 5 years, it does not include an independent monitoring mechanism. As a result, it lacks sanctions and accountability for non-

⁶⁶ Russell E. Morgan and Sam David, "Human Rights: A New Language for Aging Advocacy" *The Gerontologist* 42, no. 4 (2002). Rodriguez-Pinzón and Martin, "The International Human Rights Status of Elderly Persons"; Doron, "From national to international elder law." Kwong-Leung Tang and Jik-Joen Lee, "Global Social Justice for Older People: The Case for an International Convention on the Rights of Older People," *British Journal of Social Work* 36 (2006).

⁶⁷ United Nations, Political Declaration and Madrid International Plan of Action on Ageing, Second World Assembly on Ageing, Madrid, Spain, 8-12 April 2002, Foreword by Kofi A. Anan. de Pauw, "Global Population Aging from a Human Rights Perspective: The Need for a UN Convention on the Rights of Older Persons." UN Human Rights Council. (2016). Report of the Independent Expert on the enjoyment of all human rights by older persons, A/HRC/33/44. Geneva: United Nations.

⁶⁸ Adrienne Komanovics, "Old-Age Discrimination: The Age-Blindness of International Human Rights Law," *Hungarian YB Int'l L. & Eur. L.* (2013).

⁶⁹ Office of the High Commissioner for Human Rights, Normative standards in international human rights law in relation to older persons - Analytical Outcome Paper; UN Human Rights Council, *Report of the UN Independent Expert on the enjoyment of all human rights by older persons, A/HRC/33/44*. In addition, the limited and sometimes non-existent awareness of MIPAA and its limited implementation was recognized by the UN General Assembly in 2011 in resolution 65/182. Indeed, it is demonstrative to note that only 40 States responded to the Secretary General's request for information on the implementation of the same resolution: <https://www.ohchr.org/EN/Issues/OlderPersons/Pages/Submissions.aspx>

adherence.⁷⁰ Additionally, national efforts to implement the MIPAA do not cover the full spectrum of the human rights of older persons.⁷¹ Important human rights issues such as forced or encouraged institutionalisation, guardianship, legal decision-making and freedom from cruel, inhuman and degrading treatment are not addressed in MIPAA. So, despite representing the widest consensus and most detailed commitment regarding political priorities on ageing, the Action Plan cannot provide specific and targeted guidance and support to governments in order to fulfil their human rights obligations. However, the MIPAA raised the profile of ageing at international level⁷², resulting in human rights mechanisms and other UN bodies addressing issues affecting older persons and elaborating on existing standards from the perspective of ageing.

A turning point for the development of a human rights- based approach on ageing was the adoption of the Brasilia declaration.⁷³ Issued in 2007 at a UN conference for Latin America and the Caribbean, this declaration called for the development of an international convention and for the designation of a special rapporteur with a specific mandate covering older persons.⁷⁴ Since then the human rights of older persons have figured firmly in the UN agenda. In 2009, the first expert group

⁷⁰ Michael Barnett and Robert Hayes, "Not seen and not heard: Protecting elder human rights in aged care," *UW Sydney L. Rev.* 14 (2010); Law Commission of Ontario, *The Law as it Affects Older Adults: A Draft Framework for an Anti-Ageist Approach to the Law* (2011).

⁷¹ UN Secretary General, Report on "Follow-up to the Second World Assembly on Ageing" in 2009 (A/64/127); UN Human Rights Council. (2016). Report of the Independent Expert on the enjoyment of all human rights by older persons, A/HRC/33/44. Geneva: United Nations.

⁷² Sciubba, "Explaining campaign timing and support for a UN Convention on the Rights of Older People," p. 11.

⁷³ Second Regional Intergovernmental Conference on Ageing in Latin America and the Caribbean: towards a society for all ages and rights-based social protection, Brasilia Declaration, 4-6 December 2007 (2007)

⁷⁴ However, this is not the first time the idea of an 'ageing treaty' comes to the UN. The first attempt dates back to 1948 when Argentina presented a "Declaration of the rights of older persons", which however did not succeed in starting up a norm-setting process. In 1991, the International Federation on Ageing and the Dominican Republic put on the table the "Declaration of the rights and responsibilities of older persons", which formed the basis of *the United Nations Principles for Older Persons* adopted by the UN General Assembly in the same year. Eight years later the Dominican Republic submitted to the Commission on Social Development a draft of a "Declaration of Interdependency" and the American Association of Retired Persons (AARP) of the United States proposed the "Charter for a society for all ages" for consideration by the UN. Both initiatives aimed at gathering support for a new international instrument but did not yield any follow-up action. To access these early documents see Doron and Mewhinney, "The rights of older persons."

meeting was convened in Bonn highlighting both normative and implementation gaps in the protection of older person's rights.⁷⁵ Based largely on the Bonn deliberations, the UN Secretary General issued a report enumerating gaps in human rights law and highlighting the invisibility of older persons within the existing human rights system. After laying down some of the key arguments for a new convention, he called on States to consider the added value of further instruments to improve the situation of older persons.⁷⁶ The same year, the Human Rights Council (HRC) Advisory Committee prepared a working paper on the necessity of a human rights approach for older persons, arguing that older people have specific needs that have not yet been legally recognized as human rights.⁷⁷ It also concluded that there is a need for a new convention in order to improve accountability and implementation.

Despite these developments, it has been increasingly argued that older persons continue to face particular challenges in the enjoyment of their human rights, which have not been adequately addressed in human rights law.⁷⁸ Existing norms that target older people are neither coherent nor provide specific obligations for States and are therefore unlikely to lead to changes in public policy.⁷⁹ Moreover,

⁷⁵UN Department of Economic and Social Affairs, Report of the Expert Group Meeting "Rights of Older Persons" Convened in preparation for the report of the Secretary-General to the 64th session of the General Assembly, 5-7 May 2009, Bonn, Germany

⁷⁶ UN Secretary General Follow up to the Second World Assembly on Ageing A/64/127 (2009) para 67e

⁷⁷ Chung, *The necessity of a human rights approach and effective United Nations mechanism for the human rights of the older person.*

⁷⁸UN Human Rights Council, *Report of the UN Independent Expert on the enjoyment of all human rights by older persons, A/HRC/33/44*; Chung, *The necessity of a human rights approach and effective United Nations mechanism for the human rights of the older person*; Office of the High Commissioner for Human Rights, Normative standards in international human rights law in relation to older persons - Analytical Outcome Paper. Mégret, "The Human Rights of Older Persons: A Growing Challenge.", Seanad Public Consultation Committee, *Report on the Rights of Older People* (2012), <http://www.oireachtas.ie/parliament/media/committees/seanadpublicconsultationcommittee/reports/FinalReport.pdf>; de Pauw, "Global Population Aging from a Human Rights Perspective: The Need for a UN Convention on the Rights of Older Persons.", Huenchuan and Rodríguez-Piñero, *Ageing and the protection of human rights: current situation and outlook*; Doron and Apter, "International Rights of Older Persons: What Difference Would a New Convention Make to Lives of Older People? ."

⁷⁹ Huenchuan and Rodríguez-Piñero, *Ageing and the protection of human rights: current situation and outlook.*, Office of the High Commissioner for Human Rights, Normative standards in international human rights law in relation to older persons - Analytical Outcome Paper.

human rights bodies have not analysed adequately the full range of challenges to the enjoyment of human rights by older persons and as a result normative gaps in the protection of the rights of older persons continue to exist.⁸⁰ For example, rights issues arising in the delivery of home, institutional or residential care services and rights at the end of life, including access to palliative care, have been almost completely overlooked by existing mechanisms.⁸¹ References to older people and age discrimination in national reports to human rights agencies are particularly scarce.⁸² Older people rarely appear in the Universal Periodic Review. Only 177 (0.3%) of the 57,686 recommendations made within the Human Rights Council's Universal Periodic Review to October 2017 address the rights of older people.⁸³ Among UN agencies, only the regional commission of Latin America and the Caribbean (ECLAC) and the United Nations Population Fund (UNFPA), have effectively championed and advanced older people's rights.⁸⁴ Overall - compared with other groups - older people's rights have only attracted residual attention in international law and policy.⁸⁵

Among the existing UN treaties, the UN Convention on the Rights of Persons with Disabilities (CRPD) includes increased consciousness of the impact of ageing to human rights and has been described as one of the key instruments that can offer human rights protection in older age.⁸⁶ Unlike pre-existing treaties, the CRPD

⁸⁰ Office of the High Commissioner for Human Rights, Normative standards in international human rights law in relation to older persons - Analytical Outcome Paper.

⁸¹ Office of the High Commissioner for Human Rights, Normative standards in international human rights law in relation to older persons - Analytical Outcome Paper.

⁸² UN Secretary General, Follow-up to the Second World Assembly on Ageing, A/64/127.

⁸³ UN Human Rights Council (2018). Report of the Independent Expert on the enjoyment of all human rights by older persons. A/HRC/39/50

⁸⁴ Claudia Martin, Diego Rodríguez-Pinzón, and Bethany Brown, *Human Rights of Older People-Universal and Regional Perspectives*, vol. 45, *Ius Gentium: Comparative Perspectives on Law and Justice*, (Springer, 2015).

⁸⁵ Martin, Rodríguez-Pinzón, and Brown, *Human Rights of Older People-Universal and Regional Perspectives*; Rodríguez-Pinzón and Martin, "The International Human Rights Status of Elderly Persons "; Doron, "From national to international elder law."; Mégret, "The Human Rights of Older Persons: A Growing Challenge."; UN Secretary General, Follow-up to the Second World Assembly on Ageing, A/64/127.

⁸⁶ Kanter, "The United Nations Convention on the Rights of Persons with Disabilities and its implications for the rights of elderly people under international law.", Paul Harpur, "Old Age is not just Impairment: The CRPD and the Need for a Convention on Older Persons," *U. Pa. J. Int'l L.* 37 (2015)., Office of the High Commissioner for Human Rights, Normative standards in international human rights law in relation to older persons - Analytical Outcome Paper; Marijke

includes several references to age and older persons. In its preamble the disability convention recognizes the difficult conditions due to the multiple or intersectional discrimination on the basis of disability and – among others – age.⁸⁷ In article 8 it also sets out an obligation to combat stereotypes, including on the basis of age. Moreover, article 13 refers to age-appropriate accommodations for access to justice, article 16 on age-sensitive assistance to prevent abuse, article 25 on health services to minimize and prevent further disabilities, including among older persons and article 28 aims to ensure access by older persons with disabilities, to social protection programmes and poverty reduction programmes. However, it is believed that in principle the consideration of age in the CRPD, mainly targets the needs of children and not those of older persons.⁸⁸ Unfortunately, unlike women and children for whom the Convention includes specific provisions, the CRPD does not single out older people as meriting special protection due to the challenges at the intersection of ageing and disability.

Older people who encounter barriers in their equal participation in society due to the existence of an impairment or because they are considered as persons with disabilities can seek bona fide protection under the CRPD, regardless of whether they have a pre-existing disability or they acquire one in later life. However, challenges that older people face and are either unrelated, or perceived as unrelated to disability, such as differential treatment solely on the basis of age, are not covered by this Convention.⁸⁹ Another challenge in the application of the CRPD is that older people need to be categorized as disabled to utilize the convention.⁹⁰ From a policy perspective sometimes, older people are seen as simply aged and not as disabled, and under national legislation specific benefits

De Pauw et al., "Ageism and Age Discrimination in international human rights law," in *Ageing, ageism and the law*, ed. Issi Doron and Nena Georgantzi (Edward Elgar, 2018).

⁸⁷ See under recital (p) of CRPD preamble

⁸⁸ De Pauw et al., "Ageism and Age Discrimination in international human rights law."

⁸⁹ Office of the High Commissioner for Human Rights, Normative standards in international human rights law in relation to older persons - Analytical Outcome Paper.; Harpur, "Old Age is not just Impairment: The CRPD and the Need for a Convention on Older Persons.;" HelpAge International (2012) International human rights law and older people: Gaps, fragments and loopholes

⁹⁰ Harpur, "Old Age is not just Impairment: The CRPD and the Need for a Convention on Older Persons."

are reserved for particular disabilities. For example, the European Network of National Human Rights Institutions concluded that:

*LTC (i.e. long-term care) services are often not defined as disability services by the policy makers or service providers, even though many older persons in receipt of LTC have a disability. This may result in the CRPD not being applied to older persons in LTC in practice, which in turn could impact on the design and delivery of services, as well as the reporting on the State's implementation of the obligations set out in CRPD.*⁹¹

Moreover, as argued by the OHCHR,

*the CRPD standards do not apply in toto to the situation of all older persons, nor are they sufficiently tailored to the situation of older persons. Furthermore, the situation of older disabled people is not necessarily given sufficient attention in the application and implementation of the CRPD standards. In sum, not all older persons are disabled, and not all age-specific standards are contained in the CRPD.*⁹²

Against the realisation that the attention of the human rights community to older age remains disproportionately low and unsystematic, the UN Open-Ended Working Group on Ageing (OEWG) was established in 2010 with a mandate to consider the existing international framework of the human rights of older persons and to identify possible gaps and how best to address them, including by considering the feasibility of further instruments and measures⁹³. Since then the OEWG has been discussing the current frameworks for the protection of the human rights of older persons around the world, including normative issues that may need to be further developed in any new instrument.

⁹¹ European Network of National Human Rights Institutions, *We have the same rights: The Human Rights of Older Persons in Long-Term Care in Europe*.

⁹² Office of the High Commissioner for Human Rights, Normative standards in international human rights law in relation to older persons - Analytical Outcome Paper, p. 4.

⁹³ UN General Assembly, *Follow-up to the Second World Assembly on Ageing, Resolution adopted by the General Assembly, 21 December 2010, A/RES/65/182*, para 28..

In 2012 a new General Assembly (GA) resolution updated the mandate of the OEWG requesting it to '*consider proposals for an international legal instrument to promote and protect the rights and dignity of older persons*'.⁹⁴ Although adopted with a high number of abstentions, this GA resolution reconfirmed the increased international attention to the need for a human rights treaty for older persons. Overall, and after ten sessions of the OEWG, while there is general agreement that there are significant gaps in the protection afforded to the human rights of older persons, there is no consensus on whether these should be addressed through a new legally binding international instrument. States are divided between those supporting a new convention in order to deal with the normative gaps and the fragmentation of existing mechanisms and those that argue that improved protection is merely an issue of better implementation of universal standards.⁹⁵ However, an increasing number of civil society organisations, experts and States continue to support the expansion of the human rights framework in order to adequately address human rights breaches against older persons.

In consolidating a human rights-based approach to older age, one more key milestone must be noted. In 2014 the UN Human Rights Council appointed Ms. Rosa Kornfeld Matte as the first Independent Expert on the enjoyment of all human rights by older persons.⁹⁶ Ms Matte's mandate signals that the rights of older people are gaining recognition within the UN human rights deliberative structures and among member States as the resolution that created this position was adopted by consensus. The Independent Expert's analysis of the current framework and her recommendation regarding the adoption of a new

⁹⁴ UN General Assembly, *Towards a comprehensive and integral international legal instrument to promote and protect the rights and dignity of older persons: resolution adopted by the General Assembly, 20 December 2012, A/RES/65/182*. General Assembly resolution A/RES/67/139

⁹⁵ UN Open-Ended Working Group on Ageing, *Chair's Summary First working session, 18-21 April 2011* (2011); UN Open-Ended Working Group on Ageing, *Chair's Summary Second working session, New York, 1-4 August 2011* (2011); UN Open-Ended Working Group on Ageing, *Chair's Summary Fourth Working Session New York, 12-15 August 2013* (2013).

⁹⁶ UN Human Rights Council, *The human rights of older persons, Resolution adopted by the Human Rights Council, A/HRC/RES/24/20*. Human Rights Council (2013).

convention⁹⁷, have served as a catalyst for moving the OEWG discussions towards normative elements that may yet become the object of a new treaty.

Despite the fact that older people are relatively invisible within the UN human rights system, many countries have worked together at regional levels to promote their rights. The Revised European Social Charter (RESC) of 1996 provides for the rights of the elderly in terms of social protection. Article 23 is the first legal provision focusing on the human rights of this group. It aims to ensure older people's participation in society, to allow them to lead independent lives in the community for as long as possible and to guarantee support for those living in institutions.⁹⁸ Drawing from this provision the EU Charter of Fundamental Rights includes a commitment to protect older people's rights to dignity, independence and participation to all aspects of society.⁹⁹ Unlike previous instruments that problematized older people as subjects of social security and economic and social rights, article 25 frames older people's rights as an equality issue and represents a remarkable legal innovation.¹⁰⁰ Despite not creating a directly enforceable right, this provision requires the EU to pay particular attention to the rights of older persons.¹⁰¹ The 1988 Protocol of San Salvador recognizes in article 17 older people as a vulnerable group in need of special protection. It calls for the adoption of targeted measures covering issues of care, work but also to support their participation civil society. Article 18(4) of the 1981 African Charter on Human and Peoples' Rights stipulates that the '*aged and the disabled shall . . . have the right to special measures of protection in keeping with their physical or moral needs.*'

⁹⁷ UN Human Rights Council, *Report of the UN Independent Expert on the enjoyment of all human rights by older persons, A/HRC/33/44.*

⁹⁸ Article 23 Council of Europe, "European Social Charter (Revised)," (1996).
<http://www.coe.int/en/web/conventions/full-list/-/conventions/rms/090000168007cf93>.

⁹⁹ Article 25 European Union, Charter of Fundamental Rights of the European Union, 2016/C 202/02 (2016).

¹⁰⁰ EU Network of Independent Experts on Fundamental Rights, Commentary of the Charter of Fundamental Rights of the European Union - Article 25. *Droits des personnes âgées*, (2006); Colm O'Conneide, "Article 25–The Rights of the Elderly," in *The EU Charter for Fundamental Rights - A Commentary*, ed. Steve Peers et al. (2014: Hart Publishing).

¹⁰¹ O'Conneide, "Article 25–The Rights of the Elderly."

More recently, the African, Latin American and European regions undertook specific initiatives echoing the need to develop tailored normative standards for older people. The African Commission on Human and Peoples' rights established in 2007 a Focal Point mandated to draft a protocol to the African Charter on the rights of older persons in Africa.¹⁰² The Organisation of American States (OAS) followed in 2012, initiating a process for the elaboration of an Inter-American convention. These initiatives resulted in the adoption of two regional binding instruments aiming to enhance protection of the rights of older persons.¹⁰³ Additionally, in 2012 the Latin American and Caribbean States adopted the San José Charter on the Rights of Older Persons. Even if this Charter is not binding, it includes a set of measures that the States of the region should follow to enhance protection of this group. Almost in parallel the Council of Europe began drafting a *Recommendation on the promotion of rights of older persons*, which was adopted by its Committee of Ministers early in 2014. Despite its non-binding nature, this is the first European legal instrument that addresses old age issues from a human rights perspective. In 2017 the Parliamentary Assembly of the Council of Europe (PACE) adopted another recommendation on older people's right to comprehensive care recommending, inter alia, the adoption of a new binding instrument. These regional developments showcase that the debate on older people's rights and the value of a targeted normative approach is no longer merely a UN issue. However, they differ in content and scope and they do not represent a comprehensive legal framework.¹⁰⁴

Overall, some progress has been made and increasingly a human rights discourse is evident in deliberations related to ageing.¹⁰⁵ The main reasons for this shift are

¹⁰² Martin, Rodríguez-Pinzón, and Brown, *Human Rights of Older People-Universal and Regional Perspectives*.

¹⁰³ African Union, "Protocol to the African Charter on Human and Peoples' Rights on the Rights of Older Persons in Africa."; Organisation of American States, "Inter-american Convention on Protecting the Human Rights of Older Persons (A-70)."

¹⁰⁴ Office of the High Commissioner for Human Rights, Normative standards in international human rights law in relation to older persons - Analytical Outcome Paper.

¹⁰⁵ European Union Agency for Fundamental Rights, *Shifting perceptions: Towards a rights-based approach to ageing*. Huenchuan and Rodríguez-Piñero, *Ageing and the protection of human rights: current situation and outlook*. de Pauw, "Global Population Aging from a Human Rights Perspective: The Need for a UN Convention on the Rights of Older Persons."

twofold. First, against the background of demographic ageing, governments and societies have become much more aware of the challenges associated with ageing. Family can no longer remain the main provider of assistance to the older population, due to increased levels of mobility, changing family structures and the trend of living alone, among other reasons.¹⁰⁶ This shifting demographic context has also enhanced recognition among human rights bodies about the need to offer better protection to the rights of this group.¹⁰⁷ Additionally, ageing is increasingly seen as a global policy issue that can be tackled through enhanced cooperation and multilateral agreements.¹⁰⁸

The development of international human rights standards and their incorporation in national law after World War II increased consciousness of the rights that everyone should enjoy by virtue of being human.¹⁰⁹ With an improved awareness that ageing demands global solutions, it was only a matter of time before international human rights principles diffused into older age.¹¹⁰ In that regard, the adoption of the CRPD, as the most recent group-specific UN treaty in the history of human rights, also incorporating interactions between ageing and disability, was one of the key dynamics that led to campaigning about older people's rights and a new convention.¹¹¹

But while human rights issues as they pertain to older age are receiving growing attention, they are far from being mainstreamed to the human rights machinery.¹¹² Diverging conceptualisations of older persons and older age and a

¹⁰⁶ Tim Blackman, "Defining responsibility for care: approaches to the care of older people in six European countries," *International journal of social welfare* 9, no. 3 (2000).

¹⁰⁷ Sciubba, "Explaining campaign timing and support for a UN Convention on the Rights of Older People."; Committee on Economic Social and Cultural Rights (CESCR), "General Comment No.6: The economic, social and cultural rights of older persons," (United Nations, 1995). <http://www.refworld.org/docid/4538838f11.html>. De Pauw et al., "Ageism and Age Discrimination in international human rights law."

¹⁰⁸ Doron, "From national to international elder law."; Phillipson, *Ageing*.

¹⁰⁹ Tang and Lee, "Global Social Justice for Older People: The Case for an International Convention on the Rights of Older People."

¹¹⁰ Doron, "From national to international elder law."

¹¹¹ Sciubba, "Explaining campaign timing and support for a UN Convention on the Rights of Older People."

¹¹² Economic Commission for Latin America and the Caribbean (ECLAC), *Challenges to the autonomy and interdependent rights of older persons*, ECLAC (2017); Petrušić, To dorović, and

lack of consensus about the need for a new treaty contribute to this stalemate. This overview already highlighted some of the existing gaps that illustrate the lack of a systematic and consistent consideration of older age in human rights mechanisms, which will be further explored in following parts of the thesis.

Year	Milestones on rights of older persons
1948	- Argentinian proposal to UN GA for Declaration on Old Age Rights
1960s	- ICESCR negotiations including suggestion for UN instrument on rights of older people
1982	- World Assembly on Ageing - Adoption of VIPAA
1991	- Submission of 'Declaration of the rights and responsibilities of older persons' by IFA and Dominican Republic - Adoption of UN principles on older persons
1995	- General Comment 6 of ICESCR on economic, social and cultural rights of older persons
1999	- International Year of Older Persons - Dominican Republic submits a 'Declaration of Interdependency' and the American Association of Retired Persons (AARP) proposed the 'Charter for a society for all ages' for consideration by the UN
2002	- 2nd World Assembly on Ageing and adoption of MIPAA
2007	- Adoption of Brasilia declaration including a call for a new UN convention
2008	- GA resolution requesting UN Secretary General to prepare report on rights of older persons
2009	- 1 st UN Expert Group meeting (Bonn) and Secretary General report on rights of older persons - Ms Chung prepares working paper on 'The necessity of a human rights approach and effective United Nations mechanism for the human rights of the older person' upon request of the Human Rights Council
2010	- Establishment of UN OEWG by GA resolution 65/182

Vračević, *INTRODUCTION TO AGEING AND HUMAN RIGHTS OF OLDER PEOPLE -PILOT RESEARCH STUDY ON FINANCIAL ABUSE OF OLDER PEOPLE.*; Office of the High Commissioner for Human Rights, Normative standards in international human rights law in relation to older persons - Analytical Outcome Paper; Law Commission of Ontario, *The Law as it Affects Older Adults: A Draft Framework for an Anti-Ageist Approach to the Law*; Chung, *The necessity of a human rights approach and effective United Nations mechanism for the human rights of the older person*; UN Secretary General, *Follow-up to the Second World Assembly on Ageing, Report of the Secretary General, A/64/127.*

2011	- 1st and 2nd session of OEWG
2012	- 3rd session of OEWG - GA Resolution 67/139 Towards a Comprehensive and Integral International Legal Instrument to Promote and Protect the Rights and Dignity of Older Persons
2013	- 4th session of OEWG
2014	- Establishment of mandate of UN Independent Expert on the enjoyment of all human rights of older persons by Human Rights Council - Adoption of CoE recommendation on the promotion of human rights of older persons by the Committee of Ministers - 5th session of OEWG
2015	- Adoption of Interamerican Convention on Rights of Older Persons - 6th session of OEWG
2016	- Adoption of Protocol to the African Charter on the Rights of Older Persons - 7th session of OEWG
2017	- Adoption of CoE PACE recommendation on human rights of older persons and their comprehensive care - 8th session of OEWG
2018	- 9 th session of OEWG
2019	- 10 th session of OEWG

Table 1 : Chronology of Key Initiatives on the Rights of Older Persons

Competing Understandings of the Rights of Older Persons

Whether and, if so, why older people may need targeted legal remains controversial. For some, law that is solely designed for older people can reinforce stereotypes of older people as different instead of enhancing equal opportunities.¹¹³ For others, a targeted approach is necessary in order to address existing disadvantages.¹¹⁴ This tension illustrates the highly complex and contentious space in which discussions about a new treaty are taking place.

Ten years after the establishment of the OEWG, States participating in the OEWG remain split between those who are in favour of a new treaty and those who

¹¹³ Sue Westwood, "I May Be Older, but I Ain't No Elder: A Critique of Elder Law," *Temp. Pol. & Civ. Rts. L. Rev.* 21 (2011); John Williams, "When I'm Sisty Four: Lawyers, Law and Old Age," *Cambrian L. Rev.* 34 (2003).

¹¹⁴ Rodriguez-Pinzón and Martin, "The International Human Rights Status of Elderly Persons "; Doron, "From national to international elder law."

remain unconvinced. On the one hand, support has been steadily increasing; 37 State representatives (i.e. about 1/5 of UN States) have openly declared their support for a new UN instrument.¹¹⁵ On the other hand, States, NGOs and other stakeholders participating in the discussions around a convention on older people have failed to coalesce around a common understanding of the adequacy of the existing framework, the value of dedicated provisions and enforcement mechanisms as well as on the definition of older people as rights holders. The majority of European States do not support the idea of a new convention.¹¹⁶ This is –at least partly – due to the absence of consensus among States about the added value of a new treaty and the defining elements of a human rights-based approach to ageing, the issue of definition of older persons and the cost implications of elaborating and applying an older persons' convention. The main factors that create division between those in favour and those against a new treaty are discussed in the following sections.

Are Existing Norms Adequate?

Proponents of a new treaty stress that the experience of older age has not been adequately reflected in the extant human rights framework. A study undertaken by the OHCHR in 2012 has been instrumental in highlighting key gaps in the protection of the human rights of older persons.¹¹⁷ According to this analysis only very few provisions of human rights treaties address specifically the rights of older persons. These cover just a couple of areas of older people's lives, in particular those of women, people with disabilities and migrants. There is no explicit prohibition of discrimination on the basis of age in UN instruments. This failure has led to very little attention to forms of age discrimination within the UN system. Moreover, some areas of older people's lives, like health, housing and

¹¹⁵ Based on records kept by Helpage International on the eight sessions of the OEWG and related sessions of the Human Rights Council.

¹¹⁶ Poffé, "Towards a New United Nations Human Rights Convention for Older Persons?."; Sciubba, "Explaining campaign timing and support for a UN Convention on the Rights of Older People."; Sciubba, "Securing rights in the twenty-first century: A comparison of the disability and older persons' rights conventions."

¹¹⁷ Office of the High Commissioner for Human Rights, Normative standards in international human rights law in relation to older persons - Analytical Outcome Paper.

social protection are broadly protected but lack in specificity. Whereas a few attempts to specifically address human rights concerns for this group were made by specific treaty bodies covering in particular older women and economic, social and cultural rights, these are ad hoc initiatives that do not constitute neither a comprehensive nor a binding framework. Finally, the analysis demonstrated that some experiences of older persons '*were all but completely overlooked by the human rights system*', including – inter alia - quality of and access to long-term care, palliative care, elder abuse, and autonomy.¹¹⁸

As a result of the absence, lack of specificity and fragmentation of standards, for instance, abuse of older people by non-State actors (i.e. family members and care professionals) is not currently clearly defined as a human rights breach that could be prevented through State intervention. Moreover, depending on national legislation - States may afford more or less protection to older victims depending on whether the abuse occurs at home instead of an institution, whether the abuse is financial or physical and whether the perpetrator is the partner of the older person. For those advocating for a new treaty, these cases are examples of normative gaps. Normative gaps exist when laws fail to provide specific guidance about how to address practices that breach human rights.¹¹⁹ Such discrepancies could be remedied through a universal definition of elder abuse, a clear prohibition of age discrimination and a list of necessary measures to prevent and address human rights breaches in old age integrated in a new treaty.

Another key issue for advocates of a new convention is that existing standards are dispersed in a large number of binding and soft instruments. In order to understand how human rights apply in the context of older persons, individuals, advocacy organisations, States and other actors would have to read together treaties like the CRPD and CEDAW and the General Recommendations issued by their Committees, but also important policy instruments, like MIPAA. This is a

¹¹⁸ Office of the High Commissioner for Human Rights, Normative standards in international human rights law in relation to older persons - Analytical Outcome Paper.

¹¹⁹ UN Secretary General, Follow-up to the Second World Assembly on Ageing, A/64/127; UN Secretary General, *Follow-up to the Second World Assembly on Ageing, Report of the Secretary General, A/64/127*.

complex and daunting task that leaves a wide margin for ambiguities. A single instrument would clearly articulate State obligations, would help older people claim their rights, would improve reporting by States and would facilitate reporting by NGO actors.

On the other hand, several delegations have repeatedly stressed that universal human rights instruments apply by definition to everyone. They consider that older people's challenges are the result, of implementation gaps, meaning a failure to take necessary action at domestic level, despite the existence of an adequate framework.¹²⁰ Consequently, according to this view, a new specific instrument is considered unnecessary. Similar points were raised when the CRPD and the CRC were being negotiated, but these did not impede their drafting process¹²¹ However, the distinction between so-called *normative* and *implementation* gaps has been particularly salient in the discussions on the rights of older people, to the extent that it has distorted the real issue, which is about how rights can be made real.¹²² It is noteworthy that when the Council of Europe was finalizing its recommendation on the rights of older persons, an introductory clause making the distinction between normative and implementation gaps was added at the last minute. Underlining that '*existing international human rights standards ... form an adequate normative framework*' was a deliberate attempt by delegates to affirm a European consensus about the absence of need for additional standards.¹²³

¹²⁰ UN Secretary General, Follow-up to the Second World Assembly on Ageing, A/64/127; UN Secretary General, *Follow-up to the Second World Assembly on Ageing, Report of the Secretary General, A/64/127*.

¹²¹ Sharon Detrick, Jakob Egbert Doek, and Nigel Cantwell, *The United Nations Convention on the Rights of the Child: a guide to the "travaux preparatoires"* (Martinus Nijhoff Publishers, 1992); Sciubba, "Securing rights in the twenty-first century: A comparison of the disability and older persons' rights conventions." Seanad Public Consultation Committee, *Report on the Rights of Older People*.

¹²² Seanad Public Consultation Committee, *Report on the Rights of Older People*.

¹²³ Council of Europe, "Recommendation CM/Rec(2014)2 of the Committee of Ministers to member States on the promotion of the human rights of older persons," p.6. The text reads as follows: "*Recognising that while existing international human rights standards apply to persons at all stages of life and form an adequate normative framework for the protection of the human rights of older persons, 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;*"

Although the UN Secretary General, the OHCHR, NGOs and scholars have reiterated several legal lacunas¹²⁴, a number of member States have recurrently argued that a strengthened protection of older people's rights can be achieved through an improved application of existing human rights norms, thus rejecting the view that gaps are of a normative nature.¹²⁵ For example, the 2002 Madrid International Plan of Action on Ageing (MIPAA), has been used as one of the main reasons why a new convention appears to be redundant. In spite of several reports and interventions that have exemplified the limitations of the Madrid Plan¹²⁶ – both in terms of substantive aspects and monitoring process – Member States have on several occasions stressed that the MIPAA has not lost its validity and that regional UN commissions are well equipped to guide its implementation.¹²⁷ Therefore, one of the chief reasons for the lack of consensus is a disagreement about the type of protections gaps facing older persons, with

¹²⁴ See among others UN Secretary General, *Follow-up to the Second World Assembly on Ageing, Report of the Secretary General, A/64/127*; UN Secretary General, *Follow-up to the Second World Assembly on Ageing, A/66/173* (2011); Office of the High Commissioner for Human Rights, Normative standards in international human rights law in relation to older persons - Analytical Outcome Paper; Rodriguez-Pinzón and Martin, "The International Human Rights Status of Elderly Persons "; Helpage International, *Why it's time for a convention on the rights of older people*.

¹²⁵ European Union, "Open Ended Working Group on Ageing for the purpose of strengthening the protection of the human rights of older persons, 4th Working Session, 12-15 August 2013, Opening Statement by the European Union <p align="center" class="MsoNormal" style="text-align:center;line-height:15.0pt;mso-pagination:none;mso-layout-grid-align:none;text-autospace:none">," (2013); European Union, "Open Ended Working Group on Ageing for the purpose of strengthening the protection of the human rights of older persons, 4th Working Session, 12-15 August 2013, Opening Statement by the European Union," (2013); European Union, "Open Ended Working Group on Ageing for the purpose of strengthening the protection of the human rights of older persons, 5th Working Session, 30 July - 1 August 2014, Opening Statement by the European Union, Delivered by Pit Koehler," (2014). Note however that in 2015 the EU delegation from stating that existing gaps are not of a normative nature in its 2013 and 2014 statements, stated that '*it remains sceptical that they are of a normative nature*', see European Union, "General Assembly, Open Ended Working Group on Ageing, 14 July 2015, Item 4: Existing International Framework on the Human Rights of Older Persons and identification of existing gaps at the international level, Statement delivered by Johan Ten Geuzendam, Directorate of Equality, DG Justice and Consumers, European Commission," (2015).

¹²⁶ See among others UN Human Rights Council, *Report of the UN Independent Expert on the enjoyment of all human rights by older persons, A/HRC/33/44*.

¹²⁷ See for example, European Union, "Open Ended Working Group on Ageing for the purpose of strengthening the protection of the human rights of older persons, 4th Working Session, 12-15 August 2013, Opening Statement by the European Union."; People's Republic of China Mission to the United Nations, "Statement by Councillor Yao Shaojun of the Chinese Delegation to the United Nations at the General Debate of the Sixth Session of the GA Open-Ended Working Group on Ageing, 14 July 2015," (2015).

the assumption that a treaty would be needed only if a consensus was to emerge that the existing framework is insufficient to address human rights breaches against older persons.

Who is Old?

The definition of older people as rights holders presents a key normative challenge and constitutes one of the main concerns for those opposing the idea of a new treaty.¹²⁸ Policies and laws frequently use a chronological definition for older persons. Several UN instruments draw on standard UN statistical practice, which considers older people as those aged 60 and above.¹²⁹ The African Union and the Organisation of American States also delineate older people purely in reference to chronological age.¹³⁰ Despite providing practical and legal certainty, such definitions are arbitrary since they do not necessarily reflect the demographic diversities across the world and they cannot be responsive to changing realities, such as raising pensionable age and increased life expectancy.¹³¹ They also fail to reflect socially constructed dimensions of older age, in particular how structural ageism, which is inherent in legal, social, and economic institutions, diminishes older people's life chances.¹³²

Defining certain elements that are shared by the older population entails a number of difficulties. First, older people rarely speak of old age as a distinct period of life.¹³³ Second, old age is not a binary characteristic and lacks a clear

¹²⁸ Poffé, "Towards a New United Nations Human Rights Convention for Older Persons?." e

¹²⁹ United Nations, "Political Declaration and Madrid International Plan of Action on Ageing," (2002); Committee on Economic Social and Cultural Rights (CESCR), "General Comment No.6:The economic, social and cultural rights of older persons."

¹³⁰ Organisation of American States, "Inter-american Convention on Protecting the Human Rights of Older Persons (A-70)," art 2; African Union, "Protocol to the African Charter on Human and Peoples' Rights on the Rights of Older Persons in Africa." art 1

¹³¹ Allen, *Discussion papers: Legal issues for strengthening international legislation on the rights of older persons*.

¹³² Scrutton, 1990, p.21 as cited in Colin Duncan, "The dangers and limitations of equality agendas as means for tackling old-age prejudice " *Ageing and Society* 28, no. 8 (2008); John Macnicol, *Age Discrimination, An Historical and Contemporary Analysis* (New York Cambridge University Press, 2006); Steve Scrutton, "Ageism," in *Age: The Unrecognised Discrimination*, ed. E. McEwen (London: Age Concern England, 1990)., Mégret, "The Human Rights of Older Persons: A Growing Challenge."

¹³³ Sharon Kaufman, *The Ageless Self: Sources of Meaning in Late Life* (New York: Meridian, 1986).

threshold based on which one is considered as old or not.¹³⁴ Despite the frequent employment of chronological cut-offs in a number of laws and policies, whether an individual qualifies as old depends as much – if not more – on the context, culture and generation they belong to. For example, at the age of 60 one may qualify for old age pension in one country but not in another. Individuals may be expected to work until the age of 65 or 70, but still be considered relatively old for a certain medical intervention or for taking part in a sport activity. The onset of old age will also depend on life expectancy in a given context, but also on the demographic characteristics of a certain community.¹³⁵ Older age is therefore a relative and fluid concept.

Chronological definitions also assume that people above a certain age are a homogeneous group. But as Lloyd Sherlock mentions,

*'some older people have high levels of vulnerability and dependence; others may be making more social and economic contributions than at any previous time in their lives and the great majority are both dependent and depended upon.'*¹³⁶

Neither is chronological age the same as biological age, meaning that two 70-year olds are likely to be in two completely different situations in terms of health status and potential for contributions.¹³⁷ As a result, the shared identity of older people has become controversial. At the heart of these controversies lie divergent understandings of older people's disadvantage and whether they are vulnerable on account of their age or other factors.

Arguably, class, gender, race and disability create inequalities that when carried into old age are amplified. Nevertheless, drawing on various studies about older

¹³⁴ Sandra Fredman and Sarah Spencer, *Age as an equality issue* (Hart Publishing, 2003).

¹³⁵ Allen, *Discussion papers: Legal issues for strengthening international legislation on the rights of older persons*.

¹³⁶ Peter Lloyd-Sherlock, *Living longer: Ageing, development and social protection* (Zed books, 2004), p.6.

¹³⁷ Allen, *Discussion papers: Legal issues for strengthening international legislation on the rights of older persons*; Huenchuan and Rodríguez-Piñero, *Ageing and the protection of human rights: current situation and outlook*.

people's poverty and exclusion, Vincent has explained that older people's experiences are not the mere result of low income, gender discrimination, racism and ill health.¹³⁸ Older women are likely to be poorer than older men, just like middle- and upper-class pensioners are more privileged than low paid retirees. But inequalities tend to grow the older people get. In other words, middle-aged women, younger black people and working-age disabled persons are better off than their older peers. So even though not all older people are poor, they are likely to have fewer means and a lower status than when they were in the younger age group. What Vincent showcases is that old age is an additional layer of inequality that crosscuts the categories of class, gender, race and disability.¹³⁹ Consequently, there is some evidence of a distinct negative impact imposed by the old age variable. Yet, what remains to be established from a human rights perspective is what this age-specific disadvantage is and whether this outcome is the result of a natural and therefore inevitable process, the product of societal attitudes and treatment of the older population, or a combination of both factors.

Older persons are often included among the 'vulnerable groups' that may require specific attention and special measures including, inter alia, in housing, detention facilities, armed conflicts, care and prevention of elder abuse.¹⁴⁰ Rodriguez-Pinzon and Martin argue that just like children, older people are vulnerable and

¹³⁸ John A. Vincent, *Inequality and old age* (Routledge, 2003), p.24.

¹³⁹ Vincent, *Inequality and old age*, p.30-32.

¹⁴⁰ Marth Albertson Fineman, "Elderly as vulnerable: Rethinking the nature of individual and societal responsibility," *Elder LJ* 20 (2012); Doron, "From national to international elder law."; Tang and Lee, "Global Social Justice for Older People: The Case for an International Convention on the Rights of Older People."; John G. Love and Rory Lynch, "Enablement and positive ageing: a human rights-based approach to older people and changing demographics," *The International Journal of Human Rights* 22, no. 1 (2018); Williams, "When I'm Sixty Four: Lawyers, Law and Old Age."; Audrey R. Chapman and Benjamin Carbonetti, "Human rights protections for vulnerable and disadvantaged groups: The contributions of the UN Committee on Economic, Social and Cultural Rights," *Hum. Rts. Q.* 33 (2011); Mégret, "The Human Rights of Older Persons: A Growing Challenge."; Chung, *The necessity of a human rights approach and effective United Nations mechanism for the human rights of the older person*; Office of the High Commissioner for Human Rights, Normative standards in international human rights law in relation to older persons - Analytical Outcome Paper; UN Human Rights Council, *Thematic study on the realization of the right to health of older persons by the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, Anand Grover (2011); Chen, Alston, and Levine, "Aging: A New Human Rights Concern—A Policy-Oriented Perspective"; Committee on Economic Social and Cultural Rights (CESCR), "General Comment No.6: The economic, social and cultural rights of older persons."

need special measures of protection.¹⁴¹ International instruments have also referred to the need for 'age – sensitive' measures, implying therefore that older people have particular needs that need to be taken into account in the formulation of policies.¹⁴² There is therefore an assumption of a disadvantage that is either intrinsically associated with older people, or it is attributed to characteristics and situations indirectly linked with older age or to how old age is understood and treated by society.

Presumably the vulnerability approach builds - at least partly - on an idea of older age that is synonymous to the end of the lifecycle.¹⁴³ But it may also reflect a conception of old age as proxy for chronic illness, impairment and limited legal capacity.¹⁴⁴ Under the medical model, mental and physical decline are considered as experiences inherent in older age that compromise older people's ability to look after their interests.¹⁴⁵ But to the extent that older people's limited life chances and social roles are attributed to disability, it is far from clear what, then –if any- is the discrete old age attribute that creates the need for specific legal attention. Similarly, some texts overly stress the welfare model. By problematizing older people as recipients of social assistance, they echo an assumption that older people are unable to provide for themselves and face an increased risk of poverty.¹⁴⁶ Equating older age with decline, dependency and incapacity - be it in terms of cognitive, physical, financial or other resources- does

¹⁴¹ Rodriguez-Pinzón and Martin, "The International Human Rights Status of Elderly Persons ".

¹⁴² For example, see article 16 (2) of the CRPD stating that protection services should be, inter alia, 'age-sensitive'.

¹⁴³ Mégret, "The Human Rights of Older Persons: A Growing Challenge."; Allen, *Discussion papers: Legal issues for strengthening international legislation on the rights of older persons*.

¹⁴⁴ Organisation of American States, "Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights 'Protocol of San Salvador'," (1988), art. 9; Organisation of African Unity, "African (Banjul) Charter on Human and People's Rights," (1981); Office of the High Commissioner for Human Rights, Normative standards in international human rights law in relation to older persons - Analytical Outcome Paper.

¹⁴⁵ OHCHR 2012 Office of the High Commissioner for Human Rights, Normative standards in international human rights law in relation to older persons - Analytical Outcome Paper.

¹⁴⁶ Office of the High Commissioner for Human Rights, Normative standards in international human rights law in relation to older persons - Analytical Outcome Paper; Love and Lynch, "Enablement and positive ageing: a human rights-based approach to older people and changing demographics."

not reflect the diversity of older age experiences and links old age with a state of vulnerability.

Such needs-based approaches reflect early gerontological thinking, which focused on ageing as a problem that resides within the individual. Retirement, ill-health, poverty and isolation were considered facts of life to which the individual older person needed to adapt.¹⁴⁷ These theories did not only build on a paradigm of older people as intrinsically weak, impaired and vulnerable, but they moreover gave prime positioning to individual versus societal responsibility for these challenges. This conceptualisation of older age has been highly contested¹⁴⁸. The fiscal crisis of the 1970s and the growing neoliberalism, which questioned the continuation of public support to older people and enhanced images of the older population as a burden, pushed scholars into conceptualising old age as interlinked with the social institutions, capitalism and power relations in society.¹⁴⁹ This new gerontological stream led by Estes, Townsend, Walker and Phillipson, among others, echoed the increasing awareness that old age cannot be seen in isolation from the social, economic and political environment in which it takes place.¹⁵⁰ As Estes puts it:

*The major problems faced by the elderly in the United States are, in large measure, ones that are socially constructed as a result of our conceptions of aging and the aged. What is done for and about the elderly, as well as what we know about them, including knowledge gained from research, are products of our conceptions of aging. In an important sense, then, the major problems faced by the elderly are the ones we create for them.*¹⁵¹

¹⁴⁷ Cumming and Henry, *Growing old, the process of disengagement*.

¹⁴⁸ Simon Biggs, Carroll Estes, and Chris Phillipson, *Social Theory, Social Policy and Ageing: Critical Perspectives* (Open University Press, 2003); Alan Walker, "Active ageing in employment: Its meaning and potential," *Asia-Pacific Review* 13, no. 1 (2006); Jan Baars et al., *Ageing, globalization and inequality: The new critical gerontology* (Routledge, 2016).

¹⁴⁹ Chris Phillipson, "The political economy of old age," in *The Cambridge Handbook of Age and Ageing*, ed. Malcolm L. Johnson (Cambridge: Cambridge University Press, 2005).

¹⁵⁰ Biggs, Estes, and Phillipson, *Social Theory, Social Policy and Ageing: Critical Perspectives*; Phillipson, *Reconstructing Old Age*.

¹⁵¹ Carroll Estes, *The aging enterprise* (San Francisco: Jossey-Bass, 1979), p.1.

Under the social model policies can be segregating; social institutions dictate the role of older people in society and serve to exclude them; and structural inequalities determine the disadvantaged status of older people. This is what political economists call '*structured dependency*'.¹⁵² Older people are therefore victims of forced inequalities due to loss of power, income and workplace roles, marginalisation and cultural devaluation.¹⁵³

The interaction between the biological and the social is at the foreground of discussions on older people's rights. Human rights scholars are increasingly recognizing that the use of age as a proxy for loss, vulnerability and deficit can become a source of disadvantage.¹⁵⁴ They acknowledge the social dimension that limits older people's opportunities for participation creating unique challenges for the older population. We see therefore a shift towards a conception of older age as a social construct. Yet, these social restrictions intersect with the biology of ageing. For instance, frailty and dementia are risk factors for human rights breaches, in particular elder abuse.¹⁵⁵ Cognitive and physical change also shape experiences of ageism, insofar as they define attitudes against older people and influence their social status.¹⁵⁶ An exclusive focus on social dimensions may be considered by some as conceptually unsatisfying insofar as it ignores the biological markers of ageing.¹⁵⁷ Older people are indeed more likely to experience

¹⁵² Townsend, "The Structured Dependency of the Elderly: A Creation of Social Policy in the Twentieth Century "; Walker, "Towards a political economy of old age."

¹⁵³ Calasanti, Slevin, and King, "Ageism and Feminism: From "Et Cetera" to Center."

¹⁵⁴ Marthe Fredvang and Simon Biggs, "The rights of older persons - Protection and gaps under human rights law," (Brotherhood of St Laurence Centre for Public Policy, University of Melbourne 2012); Mégret, "The Human Rights of Older Persons: A Growing Challenge."; De Hert and Mantovani, "Specific Human Rights for Older Persons? The inevitable colouring of Human Rights Law."; de Pauw, "Global Population Aging from a Human Rights Perspective: The Need for a UN Convention on the Rights of Older Persons."; Huenchuan and Rodríguez-Piñero, *Ageing and the protection of human rights: current situation and outlook*.

¹⁵⁵ UN Department of Economic and Social Affairs, *Report of the Expert Group Meeting "Rights of Older Persons" Convened in Preparation of the Report of the Secretary General to the 64th session of the General Assembly, 5-7 May 2009, Bonn, Germany* (2009). Chung, *The necessity of a human rights approach and effective United Nations mechanism for the human rights of the older person*.

¹⁵⁶ Amanda Phelan, "Elder abuse, ageism, human rights and citizenship: implications for nursing discourse," *Nursing Inquiry* 15, no. 4 (2008); Vincent, *Inequality and old age*.

¹⁵⁷ See similar comment made about disability vs impairment in Mike Oliver, "Defining impairment and disability: issues at stake," in *Disability and Equality Law*, ed. Elizabeth F. Emens and Michael Ashley Stein (Farnham, England: Ashgate, 2013).

illness, functional limitation and death.¹⁵⁸ A discussion on older people's rights cannot completely ignore this reality. Finding an appropriate and coherent balance between social and natural aspects is one of the salient challenges for the conceptualisation of older people's rights.

But even if we were to accept that there is a large number of older people who are vulnerable and unprotected, we also need to recognize that an increasing portion of the older population is living in good health, is not requiring financial assistance, and is even supporting younger generations.¹⁵⁹ Mégret has referred to this problem as the '*power/vulnerability paradox*'.¹⁶⁰ Changing life patterns have led to the separation between third and fourth age and the development of distinct policies for each.¹⁶¹ When Bismarck first introduced old age pensions in Germany, as a way to cover the needs of those who were no longer able to work, life expectancy did not exceed pensionable age for more than a few years.¹⁶² Consequently, in the late 19th century old age came to be immediately and sometimes catastrophically synonymous with decline and need for support. In contrast, today life expectancy has greatly increased, with length of retirement in European countries spanning 30 or 40 years. Consequently, there is a wide range of lifestyles linked with older people, from the wealthy retiree living independently to the frail elderly living in institutions. Third age is now widely associated with individual choice, consumption and opportunities¹⁶³. The 'young old' are considered to be fit to work beyond retirement age; some may go back into education, part-time work, volunteering, thus remaining independent whilst

¹⁵⁸ Kanter, "The United Nations Convention on the Rights of Persons with Disabilities and its implications for the rights of elderly people under international law."

¹⁵⁹ Committee on Economic Social and Cultural Rights (CESCR), "General Comment No.6: The economic, social and cultural rights of older persons," para.17. Love and Lynch, "Enablement and positive ageing: a human rights-based approach to older people and changing demographics."

¹⁶⁰ Mégret, "The Human Rights of Older Persons: A Growing Challenge," p.45.

¹⁶¹ Peter Laslett, *A Fresh Map of Life: Emergence of the Third Age* (Palgrave Macmillan, 1996).

¹⁶² Phillipson, *Ageing*.

¹⁶³ Chris Gilleard and Paul Higgs, "Old people as users and consumers of healthcare: a third age rhetoric for a fourth age reality?," *Ageing & Society* 18, no. 2 (1998); Paul Higgs and Chris Gilleard, "Frailty, abjection and the 'othering' of the fourth age," *Health Sociology Review* 23, no. 1 (2014).

maintaining productive roles in society.¹⁶⁴ The traditional forces that characterized vulnerability in older age, in particular retirement, dependency and physical decline have been undermined.¹⁶⁵

Today policies tend to focus on 'active', 'positive' and 'successful' ageing. Such models have distorted the narrative of old age as inherently associated with frailty, poverty and inferior legal and social status. Still, the fourth age (i.e. encompassing the very old) remains associated with physical and cognitive decline, loss of autonomy and isolation.¹⁶⁶ The dominant meaning of old age as a period of impairment, dependency and loss has not been completely eclipsed;¹⁶⁷ it has just been pushed to the fourth age and end of life. Consequently, images of older people engaging in sports and learning new technologies, alongside notions of old age as intrinsic weakness continue to shape competing understandings of older people's rights.

For example, several European States – among others – have argued in the OEWG that old age is not per se a cause of vulnerability. In 2014 Denmark stressed that focusing on the rights of older people implies looking into older people's weaknesses, which ignores their strengths and by consequence widens the conflict between generations.¹⁶⁸ The Netherlands claimed that older people are a relatively privileged group thanks to their stable pension income and their participation to society as employees, volunteers and caregivers, implying therefore that they are not in need of special protection.¹⁶⁹ The European Court

¹⁶⁴ Committee on Economic Social and Cultural Rights (CESCR), "General Comment No.6: The economic, social and cultural rights of older persons," para.17; Alan Walker, "Commentary: The Emergence and Application of Active Aging in Europe," *Journal of Aging & Social Policy* 21, no. 1 (2009). Kim Boudiny, "'Active ageing': from empty rhetoric to effective policy tool," *Ageing & Society* 33, no. 6 (2013).

¹⁶⁵ Phillipson, *Reconstructing Old Age*.

¹⁶⁶ Higgs and Gilteard, "Frailty, abjection and the 'othering' of the fourth age."

¹⁶⁷ Jan Baars, "Philosophy of Aging, Time and Finitude," in *A guide to humanistic studies in aging: what does it mean to grow old?*, ed. Thomas R. Cole, Ruth E. Ray, and Robert Kastenbaum (2010).

¹⁶⁸ During the fifth OEWG session the Danish delegation mentioned that a convention would only focus on older people's weaknesses and not their strengths, widen the gap between generations, require too many resources, and dilute the universal nature of human rights.

¹⁶⁹ Statement of the Dutch delegation during the third OEWG session in 2012, stating that '[y]ou must know that in the Netherlands older people have a better income position than the average citizens. The health situation is also quite good when compared with a lot of other countries.'

of Human Rights held that age is a relevant factor in the assessment of a prison sentence¹⁷⁰. On the other hand, in a recent case the European Committee of Social Rights has concluded that age alone cannot define a state of particular vulnerability.¹⁷¹ These polarised views illustrate not only the difficulty of generating political support for a new convention, but importantly the lack of convergence about the specificity of the age variable in undermining rights, for example in labour market participation, access to health and social care, having a voice, etc.

Insofar as older people are perceived as privileged in terms of safeguards and positive rights, there will be less support for using resources to cater for their needs or singling them out for human rights protection. On the other hand, if older people are seen as relatively deprived, providing them with a level of security that is not available to the rest of society would appear as compliant with intergenerational fairness. Older people are therefore seen as deserving but in need, which has been described by Binstock as a form of '*compassionate ageism*'.¹⁷² In discussing the rights of older people we need to recognize this complexity. And we need to take into account the heterogeneity of older people without downplaying the similarities in experience that sometimes lead to the denial of basic rights.

How to Protect Older People's Rights?

Permeating the discourse around older people's rights, is another division that relates to a paradigm of protection versus that of autonomy. The Council of Europe has epitomized the tension between these two approaches in its

People don't feel vulnerable because of the simple fact that they are 40, 50, 60 or 70 years old, or what age you might chose as a definition of being old. What we observe is, that older people do not like the label of being old. They don't picture themselves as such. They don't want to see themselves as possible victims. They are just people with responsibilities, sometimes as employees, sometimes as volunteers, sometimes as informal cares, sometimes as people with a business of their own. They participate in society'.

¹⁷⁰ *Farbthus v Latvia* App no 4672/02 (Judgment of 2 December 2004) cited in O'Conneide, "Article 25–The Rights of the Elderly."

¹⁷¹ *International Federation of Associations of the Elderly (FIAPA) v. France*, No. Complaint No 145/2017 para 58 (European Committee of Social Rights 2019).

¹⁷² Robert H. Binstock, "From compassionate ageism to intergenerational conflict?," *The Gerontologist* 50, no. 5 (2010).

recommendation on the rights of older persons, which '*aims at finding the right balance between the autonomy and the protection of older persons*'.¹⁷³ Extant literature and normative standards provide evidence of diverging narratives, thus illustrating the lack of consensus about where the focus should be and how such a balance can be kept in practice. The selection of either approach is not merely symbolic but has multifaceted consequences, from a theoretical, normative and practical perspective.

States, NGOs and experts in favour of a convention advocate for a change in the perception of ageing and older people '*from the passive and in need to entitled and participatory*'.¹⁷⁴ Recognizing older people as holders of rights would mean abandoning the welfare approach to old age, while acknowledging the varied and numerous contributions older people make to the social, political, economic and cultural life of their countries. States would not have to provide for older people because they are vulnerable or because they have specific needs; they would have an obligation to do so because –just like everyone else - older people are entitled to equal opportunities for participation in society. Recognizing older people as full actors in society, a dedicated treaty would promote a more positive image of ageing and would challenge practices and attitudes that perpetuate the discrimination and marginalisation of older people.¹⁷⁵

A protectionist approach on the other hand, echoes the idea that safeguards in the form of State interventions are needed to keep individuals safe from harm. Protection rights can be found in several provisions of the Convention on the Rights of the Child (CRC), including- inter alia- protection from child labour, sexual exploitation, trafficking and drug abuse. Protective measures reflect a paradigm of vulnerability that is intrinsically associated with underage children

¹⁷³ See paragraph 2 of Explanatory Memorandum Council of Europe, "Recommendation CM/Rec(2014)2 of the Committee of Ministers to member States on the promotion of the human rights of older persons."

¹⁷⁴ Geraldine Van Bueren, "The protection of the human rights of older persons in Europe: a legal perspective" (2009).

¹⁷⁵ UN Department of Economic and Social Affairs, *Report of the Expert Group Meeting "Rights of Older Persons" Convened in Preparation of the Report of the Secretary General to the 64th session of the General Assembly, 5-7 May 2009, Bonn, Germany.*

who lack legal capacity and maturity to make choices and represent their own interests. This is why the CRC espouses the principle of *'best interest'* of the child instead of the respect of the child's will and preferences.¹⁷⁶ The CRC has however been infused with other principles, including autonomy and participation, that move away from a purely paternalistic standpoint. The principle of evolving capacities in particular, recognizes that as children grow they develop competencies that allow them to make choices and take responsibility for their actions; as a result they become more autonomous.¹⁷⁷ Still, it can be argued that overall children's rights maintain –to a large extent - a protectionist character that focuses on the welfare rather than the autonomy of the child.¹⁷⁸

On the other hand, the Convention on the Rights of Persons with Disabilities (CRPD) has prioritized claims of autonomy. The disability rights movement broke away from a culture of protectionism which was imprinted in policy documents and advocacy for several decades.¹⁷⁹ The CRPD recognized, as one of the Convention's general principles, the individual autonomy and independence of persons with disabilities, which includes the freedom to make their own choices.¹⁸⁰ The approach taken by the disability community concurs with the paradigm shift from the medical to the social model and has been embodied in the work of the Committee that monitors the treaty, in particular with regard to legal capacity.¹⁸¹ It is now generally accepted that persons with disabilities should be supported to express and realise their choices on an equal basis with others, instead of being replaced in decision-making by guardians or others on the basis of the principle of *'best interest'*. At the same time, the CRPD also

¹⁷⁶ See articles 2, 9, 18, 20, 21, 37, 40 of the CRC

¹⁷⁷ See articles 5 and 14 of the CRC

¹⁷⁸ David William Archard, "Children's Rights," in *The Stanford Encyclopedia of Philosophy*, ed. Edward N. Zalta (2018).

¹⁷⁹ Michael Ashley Stein, "Disability human rights," *Cal. L. Rev.* 95 (2007); Theresia Degener and Andrew Begg, "From invisible citizens to agents of change: A short history of the struggle for the recognition of the rights of persons with disabilities at the United Nations," in *The United Nations Convention on the Rights of Persons with Disabilities A Commentary*, ed. Valentina Della Fina, Rachele Cera, and Palmisano Giuseppe (Springer, 2017).

¹⁸⁰ Article 3a of the CRPD

¹⁸¹ Committee on the Rights of Persons with Disabilities (CRPD), *General Comment No 1: Article 12 Equal Recognition before the law* (2014), <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G14/031/20/PDF/G1403120.pdf?OpenElement>.

recognizes the need to protect against violence, exploitation and abuse. So, it is not necessary to choose between a protectionist and autonomy-based approach. Both viewpoints can be incorporated in a treaty as they relate to specific rights.

When it comes to older persons, several authors have invoked the CRC model as a basis for a new convention, which could be interpreted as a preference for a protectionist approach.¹⁸² Conversely, several instruments refer to older people's autonomy; most of these texts however leave ample discretion for forced treatment and protective interventions. The UN principles exemplify this controversy by referring in the same sentence to the enhancement of older people's autonomy and protection in the context of care.¹⁸³ Similarly, the UN principles also reflect the need to respect individuals' personal preferences and at the same time they say that older persons should be able to reside at home '*for as long as possible*'.¹⁸⁴ This approach could be interpreted as accepting that older people may be denied some level of autonomy on the premise of necessary safeguards to protect them or others from harm. It could also be used to rationalise older people's exclusion from political, social, economic and cultural life and to legitimize their discriminatory treatment. Therefore, despite an increasing narrative about older people's autonomy, especially in regard to the choice of care settings, how this concept applies to older populations still seems to be subject to caveats, compared with the 'non-old'. The term '*as far as possible*' has been reiterated subsequently in many international and regional texts, including in civil society charters, which illustrates the potency of the protectionist framework in the narrative around older people's rights.¹⁸⁵

¹⁸² Rodriguez-Pinzón and Martin, "The International Human Rights Status of Elderly Persons "; Doron, "From national to international elder law."; Kristina Miller, "The Making of Ageing Policy: Theory and Practice in Europe by Rune Ervik and Tord S. Lindén," *Canadian Journal on Aging/La Revue canadienne du vieillissement* 33, no. 3 (2014).

¹⁸³ See paragraph 12 under Care

¹⁸⁴ Paragraph 5 and 6 under Independence

¹⁸⁵ Council of Europe, "Recommendation CM/Rec(2014)2 of the Committee of Ministers to member States on the promotion of the human rights of older persons."; Organisation of American States, "Inter-american Convention on Protecting the Human Rights of Older Persons (A-70)."; AGE Platform Europe, *European Charter on the Rights and Responsibilities of Older Persons in Need of Care and Assistance* (2010).

Perhaps the greatest shortfall of the current discourse is the fact that it fails to give a clear indication of whether it should be autonomy or rather protection that prevails. Williams has argued that whereas in principle autonomy should be favoured, protective measures may be needed to prevent abuse, taking into account the level of risk, degree of vulnerability, and undue influence, among other factors.¹⁸⁶ In contrast, Fineman suggests that older people's reality is much more complex and nuanced than what the concept of autonomy can reflect. She therefore disagrees with prioritizing autonomy and further argues that a certain level of protection and security is the necessary pre-requisite for making free choices. This controversy illustrates the wide margin of discretion regarding how to interpret and apply older people's rights.

A conventional way to think of rights is to distinguish between those that enhance liberty and those which ensure welfare. Under the human rights framework this separation is reflected in the categorisation between civil and political rights on the one hand and economic, social and cultural rights, on the other. Autonomy as a theoretical conception of rights underlines freedom of choice and is therefore typically associated with civil and political rights, which favour liberty and agency. On the contrary, the notion of protection draws from the special needs and '*best interest*' paradigm and involves welfare rights. By extension these two distinct types of rights tend to be associated either with positive action (i.e. in the case of welfare rights) or the obligation not to restrict individual freedom (i.e. in the case of liberty rights). So far, the protectionist approach seems to have taken precedence in the OEWG, where economic and social rights dominate the discussions.¹⁸⁷ The choice between autonomy and protection will influence the understanding of the nature of older people's rights and the scope of State obligations. If the current narrow focus on economic and social rights were to be introduced in a new convention, older persons would probably continue to be

¹⁸⁶ Williams, "When I'm Sisty Four: Lawyers, Law and Old Age." Williams, 2003

¹⁸⁷ Herro, "The human rights of older persons: the politics and substance of the UN Open-Ended Working Group on Ageing."

seen as objects of welfare.¹⁸⁸ Consequently, the OEWG debate has so far been deficient in consolidating a clear and comprehensive vision of the rights of older people.

What is the Cost and Value of Treaties?

The campaign on a new treaty has epitomized the limitations of non-binding instruments, such as the Madrid International Plan of Action on Ageing and the UN Principles for Older Persons, to become a real driver for change. Due to the lack of binding obligations States continue to pay very limited attention to older persons in their reporting to human rights bodies and in the frame of the Universal Periodic Review (UPR), a process of the Human Rights Council that is measuring States' compliance with the UN human rights framework. Older people's rights are not consistently considered by the committees that are charged with supervising existing UN conventions. Similarly, whereas the Special Rapporteurs on the right to health and on poverty have addressed the situation of older people¹⁸⁹, other UN mechanisms are to a large extent age blind. As a result, there may be progress in one area, while others remain completely overlooked. It is then argued a UN treaty would provide binding provisions, which would improve mainstreaming old age issues in the existing framework and would ensure that countries can be held accountable if they fail to protect and promote the rights of older people.

If a new convention would be framed similarly to previous treaties, States would not only have to refrain from action that might harm older people but also to adopt measures so that their rights can actually be guaranteed and applied in practice. Such positive duties could include the development of policies, collecting data, developing indicators and dedicated monitoring and implementation tools. Typically, a convention is followed by an international

¹⁸⁸ Herro, "The human rights of older persons: the politics and substance of the UN Open-Ended Working Group on Ageing."

¹⁸⁹ UN Human Rights Council, *Thematic study on the realization of the right to health of older persons by the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Anand Grover*; UN Human Rights Council, *Report of the Independent Expert on the question of human rights and extreme poverty Magdalena Sepulveda Carmona, 31 March 2010, A/HRC/14/31 (2010)*.

enforcement mechanism, known as a treaty body, which entails the establishment of an independent committee of international experts charged with reviewing periodic State reports and receiving individual complaints. But it may also include a responsibility to set up a national independent body to monitor, promote and report on the application of the convention. States would also have to consult older people and consistently factor them in all policy decisions and budget allocation procedures.¹⁹⁰ A new convention would facilitate necessary structural changes and the assessment of State compliance with human rights standards.

On the contrary, opponents to a new treaty bring forward the imperfections and burden of binding instruments. They argue that a new treaty does not necessarily mean policy change, since it requires the ratification and subsequent support and goodwill of the State to comply with its obligations. Fear of proliferation of human rights instruments and treaty fatigue is another reason for States' reservations.¹⁹¹ During the vote of the 2012 resolution that aimed at changing the mandate of the OEWG, Cyprus on behalf of the EU member States explained that they abstained, because they were not convinced that a convention is the best way to advance older people's rights, especially since existing human rights bodies are already overburdened and underfunded.¹⁹² Canada has also suggested that due to an overloaded human rights reporting and monitoring system, a new convention would not bring about timely and concrete change.¹⁹³ This argument is part of a wider debate around the sustainability and efficacy of the UN human rights system, but it most probably also relates to concerns about additional duties that would be imposed on governments.

The financial implications of a new treaty in terms both of negotiation but also domestic implementation are key concerns of some countries. The US has

¹⁹⁰ See for example CRPD article 33

¹⁹¹ Mégret, "The Human Rights of Older Persons: A Growing Challenge."

¹⁹² Poffé, "Towards a New United Nations Human Rights Convention for Older Persons?."

¹⁹³ See statement of the delegation of Canada in 2015 saying that: '*[a] new convention would provide little by way of new protections, would add to an overloaded human rights reporting and monitoring system, and would not bring about timely and concrete change*'.

suggested that the human and monetary resources needed to negotiate a new legal instrument '*would inevitably divert resources from addressing the more immediate and concrete needs of older persons*'.¹⁹⁴ Presumably the economic costs of implementing a rights programme would also impact on governments, particularly in times of austerity.¹⁹⁵ The CRPD increased awareness among States about the means necessary to meet human rights obligations and made governments more cautious in assuming further responsibilities.¹⁹⁶ EU States in particular have been using the crisis as a reason not to expand the existing legal framework.¹⁹⁷ Hence, while stressing on the one hand the limitations of binding treaties, States are also reticent in adopting a new instrument, precisely because of '*the fear that a new human rights convention would entail legal obligations to financially support older persons*'.¹⁹⁸

In enumerating the main reservations of countries that are opposing the elaboration of a new treaty, it becomes evident that some of the factors that triggered attention to older people's rights are at the same time hindering progress on a convention. The expansion of the human rights system, in particular with the adoption of the CRPD, is one of those dynamics that have influenced both positively and negatively the debate around a new instrument.¹⁹⁹ Similarly, the need to provide more for older people has acted as an enabler to the recognition of older people's rights, but also as a barrier to garnering support for a convention out of fear about financial implications. In addition to normative issues around the adequacy of the existing standards and the definition of the

¹⁹⁴ The United States mission to the United Nations, "Input to the note verbale for the fourth session of the OEWG," (2013).

¹⁹⁵ Sciubba, "Explaining campaign timing and support for a UN Convention on the Rights of Older People."

¹⁹⁶ Sciubba, "Securing rights in the twenty-first century: A comparison of the disability and older persons' rights conventions."

¹⁹⁷ Sciubba, "Securing rights in the twenty-first century: A comparison of the disability and older persons' rights conventions."

¹⁹⁸ Poffé, "Towards a New United Nations Human Rights Convention for Older Persons?," p. 10.

¹⁹⁹ Sciubba, "Explaining campaign timing and support for a UN Convention on the Rights of Older People."; Sciubba, "Securing rights in the twenty-first century: A comparison of the disability and older persons' rights conventions."

target group, State support is delayed by practical questions around the implementation and regulatory mechanisms that would follow a new treaty.

Notwithstanding the growing attention of the international community on the rights of older people, this field is still characterised by the absence of a cohesive and holistic understanding of older persons as holders of rights and a contentious political space. As an emerging area of human rights law, older age deserves further analysis from a theoretical and normative perspective, which could feed into discussions about a new treaty.

The Lack of an ‘Older Persons’ Perspective’

In discussing the evolution of the rhetoric on older people’s rights, one cannot help but notice the very limited involvement of older people’s organisations. Early attempts to enshrine the rights of older people in 1991 and 1999 were launched by two NGOs but without wider support from civil society at international and grassroots levels.²⁰⁰ The latest phase on older people’s rights, which begun with the Brasilia declaration and in particular with the establishment of the UN OEWG, also showcases that this agenda was to a large extent initiated and still supported by a committed group of Latin American States and not by civil society.²⁰¹ Older people’s participation in the OEWG has increased but remains weak and lacks coordination.²⁰² In addition, influential NGOs, like Amnesty International and other rights movements, such as women’s groups, have played a very limited role in broadening the scope of attention to older people’s rights.²⁰³ It is however noteworthy that recently National Human Rights Institutions (NHRIs) have initiated projects and advocacy on the rights of

²⁰⁰ On the role played by IFA and AARP see previous Section: ‘From Welfare to Rights: A Historical Outlook’

²⁰¹ Sciubba, "Securing rights in the twenty-first century: A comparison of the disability and older persons' rights conventions."

²⁰² Sciubba, "Explaining campaign timing and support for a UN Convention on the Rights of Older People."; Sciubba, "Framing and Power in Aging Advocacy."; Sciubba, "Securing rights in the twenty-first century: A comparison of the disability and older persons' rights conventions."

²⁰³ Sciubba, "Explaining campaign timing and support for a UN Convention on the Rights of Older People."

older people.²⁰⁴ A couple of disability groups and scholars also grew an interest in the OEWG process, including among others the European Network for Independent Living and the Centre for the Human Rights of Users and Survivors of Psychiatry²⁰⁵. All in all however, civil society seems to be lagging behind in their understanding and application of human rights norms in the international and domestic arena.²⁰⁶

Older people's organisations are generally not well funded and largely rely on networks of volunteers for their work.²⁰⁷ They also lack the support and opportunities for participation in UN meetings, training and consultations at national and regional level. In contrast, disability groups had access to resources that enabled their involvement with the Ad Hoc Committee elaborating the CRPD.²⁰⁸ Organisations of people with disabilities were also involved in national delegations, something that has only happened exceptionally in the OEWG.²⁰⁹ However, this may change when the OEWG begins the drafting of a new convention, a process which is expected to increase NGO engagement with the Working Group.²¹⁰

Sciubba has explained that the ageing network is pulled in different directions and lacks a strong unified voice.²¹¹ The author believes that weak advocacy by the transnational network is one of the reasons for the lack of adoption of a new

²⁰⁴ UN General Assembly, *Draft Decision Submitted by the Chair on the basis of Informal Consultation - Modalities of Participation of National Human Rights Institutions in the Work of the Open Ended Working Group on Ageing, 1 December 2016, A/A.C278/2016/L.1* (2016); European Network of National Human Rights Institutions, *We have the same rights: The Human Rights of Older Persons in Long-Term Care in Europe*.

²⁰⁵ See in particular their contributions to the ninth session of the OEWG

²⁰⁶ Martin, Rodríguez-Pinzón, and Brown, *Human Rights of Older People-Universal and Regional Perspectives*.

²⁰⁷ Sciubba, "Securing rights in the twenty-first century: A comparison of the disability and older persons' rights conventions."

²⁰⁸ Sciubba, "Securing rights in the twenty-first century: A comparison of the disability and older persons' rights conventions."

²⁰⁹ To my knowledge only Slovenia and Germany have supported the participation of national NGOs to the OEWG

²¹⁰ Sciubba, "Securing rights in the twenty-first century: A comparison of the disability and older persons' rights conventions."

²¹¹ Sciubba, "Framing and Power in Aging Advocacy," 11; Sciubba, "Securing rights in the twenty-first century: A comparison of the disability and older persons' rights conventions."

convention. She however argued that the discussions about a new convention are gradually converging older people's organisations under the human rights frame. As the discussions shift towards '*substantive input*'²¹² and '*concrete proposals*'²¹³ for a new instrument, the nature of civil society's contribution will need to change too. It will have to move away from general positions on the need for a convention to fine-tuned messages, including a discussion on technical aspects based on human rights standards. Garnering State support for a convention requires effective coordination of NGOs' efforts at international level but also rallying support and advocacy at domestic level.²¹⁴ Previous research has shown that NGOs involved in the OEWG are unanimously supportive of a dedicated treaty on older persons' rights.²¹⁵ That said, only a small number of EU countries have expressed strong support for the idea of a treaty.²¹⁶ Limited campaigning and the weak influence of older people's organisations at domestic level may explain the absence of wide support for a dedicated instrument on older people's rights. This research set out to find out the extent of national NGOs engagement with human rights concepts and the debate around a new convention.

This study builds on the premise that NGOs are not just passive receivers of international norms, but instead they should have an opportunity to shape and influence emerging human rights law so that it is responsive and relevant to their concerns and needs. The study aims to help older people's organisations enhance their role and improve their efficiency as norm entrepreneurs. If the international framework is grounded on lived experiences and understandings of rights, a new

²¹² UN General Assembly, *Report of the Open Ended Working Group on Ageing on its Ninth Session, 24 August 2018, A/A.C. 278/2018/2* (2018).

²¹³ UN General Assembly, *Towards a comprehensive and integral international legal instrument to promote and protect the rights and dignity of older persons: resolution adopted by the General Assembly, 20 December 2012, A/RES/65/182*.

²¹⁴ Herro, "The human rights of older persons: the politics and substance of the UN Open-Ended Working Group on Ageing."; Sciubba, "Securing rights in the twenty-first century: A comparison of the disability and older persons' rights conventions."

²¹⁵ Herro, "The human rights of older persons: the politics and substance of the UN Open-Ended Working Group on Ageing."

²¹⁶ Annie Herro, "Advocating a UN Convention on the Rights of Older Persons in the United Kingdom: The Case for a Radical Flank," *Journal of Human Rights Practice* (2019); Annie Herro, "Domestic interest groups and rights mobilization: explaining the case of Slovenia's support for the proposed Convention on the Rights of Older Persons," *Global Networks* 18, no. 4 (2018).

treaty is more likely to be utilised and have wider impact at grassroots level. Collective advocacy is critical to keep governments accountable for their human rights promises and translate international norms to domestic policy change.²¹⁷

The empirical approach taken by this thesis aims to ensure that older people's views are entrenched in the human rights frame, so that legal - and by consequence social - change can be channelled back into positive outcomes for older people's lives. The ultimate goal of this research is to contribute to legal knowledge and ensure that - in case of adoption - a new treaty would be grounded on the real needs, experiences and expectations of the group it aims to serve, in this case older persons.

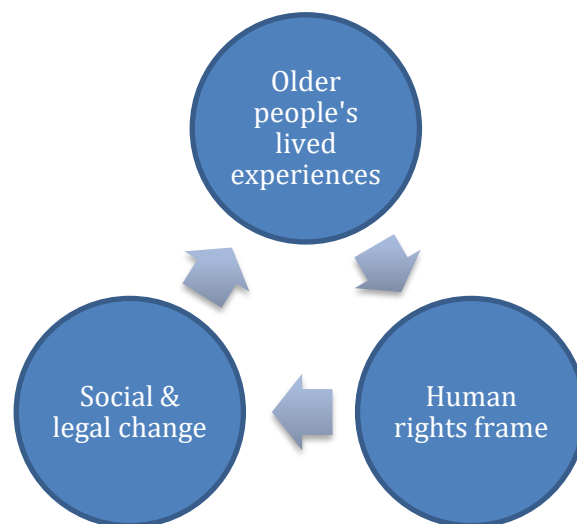


Figure 2: The Cycle of Change

Against the backdrop of limited consideration of empirical experiences and understanding of rights in old age, a study of the types of human rights violations older persons face, the conditions or processes on which these violations reside, and the reasons why they take place seems appropriate. A European perspective is important because of the influential role of European countries in the debate around a new treaty. EU countries have been recognized as key players, whose support for a convention could potentially move discussions to negotiating a new

²¹⁷ Beth A. Simmons, *Mobilizing for human rights: international law in domestic politics* (Cambridge University Press, 2009). Thomas Risse-Kappen et al., *The power of human rights: International norms and domestic change*, vol. 66 (Cambridge University Press, 1999).

instrument.²¹⁸ As the OEWG is moving towards a more substantive debate on elements that could be integrated in a treaty, an analysis of the added value of a targeted treaty from a European perspective seems, therefore, very timely.

²¹⁸ Sciubba, "Securing rights in the twenty-first century: A comparison of the disability and older persons' rights conventions."; Sciubba, "Explaining campaign timing and support for a UN Convention on the Rights of Older People."

Chapter 3: Research Framework: Paradigm and Design

This chapter explains the choice of my research strategy, which is dependent on my ontological and epistemological paradigm, presenting the reasons for applying a qualitative and comparative approach underpinned by constructivist grounded theory methodology. This approach was motivated by my intention to address the existing gap in studies on the human rights of older people, which are not empirically based.

The objective of the empirical perspective applied in this study was twofold. First, I wanted to develop a conceptual understanding of human rights grounded on the views of organisations campaigning around issues of older age. Second, as someone who is professionally involved in the ageing movement, with this study I ultimately aimed at encouraging organisations to engage with the human rights framework and at improving their capacity and efficiency to advocate for a new UN convention. The constructivist grounded theory used for this research, which does not require the researcher to be neutral but instead promotes researcher reflexivity and interaction with the data, allowed me to pursue both objectives through a systematic inquiry without compromising my findings.

A Qualitative Research Approach

This research is focused on developing a theoretical and normative understanding of human rights in older age based on the views and experiences of organisations of older persons. Qualitative research aims to '*study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them*'.²¹⁹ In contrast to quantitative research, which is geared towards objective measurements, qualitative research allows for capturing comprehensive insights and rich data of the phenomena under study. These assets are considered necessary for the study at hand, since

²¹⁹ Norman K. Denzin Yvonna S. Lincoln, *The Sage handbook of qualitative research* (Sage, 2005), p.3.

knowledge in this area is limited and cannot be easily standardized in a set of measurement tools.

Following a qualitative approach, I was able to focus on the meanings that older people's representatives give to human rights, to discuss processes of human rights violations but also to look into how different contexts affect the understanding of human rights as they are experienced by older persons. Attaining these three objectives would have been impossible through a quantitative approach, which would merely capture the statistical significance of this phenomenon. A qualitative research strategy therefore better responds to the goal of the study to surface and to interpret issues that have not necessarily been identified as human rights breaches by science, law or policy.

A Comparative Socio-Legal Analytical Framework

For the purposes of this study I adopted a comparative socio-legal approach, contrasting empirical views, policy and law in three European countries. Comparison is central in the process of shaping understanding.²²⁰ Analysing different conceptualisations of human rights and the socio-economic background in which these are realised or breached can help illuminate their content.

A comparative methodology is appropriate for this study because the '*human rights of older persons*' is a novel concept in legal doctrine, which is only now beginning to be utilized at national level; this concept therefore merits an examination in context. Socio-legal comparison can unfold how older people and domestic laws and policies understand this term, as well as how they define States' obligations to cater for older people. This approach can expose the theoretical and substantive plurality enshrined in law, policy and collective advocacy regarding the rights of older people in the countries under study.

Using a socio-legal methodology served a threefold objective. Firstly, to build on knowledge from social gerontology and human rights law to further understanding of the concepts discussed. Whereas human rights law is only

²²⁰ Vivian Grosswald Curran, "Dealing in Difference: Comparative Law's Potential for Broadening Legal Perspectives," *The American Journal of Comparative Law* 46, no. 4 (1998): p.658.

starting to grapple with concepts of ageing and older persons, social gerontology has developed a robust body of theories to understand older age. Bearing in mind the emphasis of this thesis on how institutions and policies shape experiences of rights violations, the thesis primarily draws on the political economy of ageing. As a strand of critical gerontology, political economy focuses on the State structures and how they force older people's exclusion, passivity and poverty.²²¹

Secondly, the study aimed at highlighting the experience of older persons and the societal barriers they face in enjoying their human rights. Instead of assuming that a new convention should be based on extant gerontological and legal interpretations of older age, I wanted to clarify the meaning of human rights for older persons as well as to identify the real problems that the law is expected to resolve in the countries under review. In this sense, the socio-legal approach served the purposes of the comparative legal methodology. Last, the employment of the socio-legal analysis allowed me to critically discuss the policy and legal solutions given to the identified problems.

Constructivist Grounded Theory as the Strategy for Inquiry

Originally coined by Glaser and Strauss in 1967, grounded theory offsets the former domination of grand theory and deductive approaches to social research, aiming to produce theory based on data collected by research.²²² Instead of using existing theories to explain certain phenomena, this approach is grounded on the experiences and views of research participants.

Grounded theory is very helpful when current theories about a phenomenon are either inadequate or non-existent.²²³ As explained in the second chapter, notwithstanding the leading and growing scholarship on social aspects of ageing within the academic field of social gerontology, the theoretical underpinnings of

²²¹ Townsend, "The Structured Dependency of the Elderly: A Creation of Social Policy in the Twentieth Century "; Walker, "Towards a political economy of old age."

²²² Barney G. Glaser and Anselm L. Strauss, *The discovery of grounded theory : strategies for qualitative research* (Hawthorne, N.Y.: Aldine de Gruyter, 1967).

²²³ John W. Creswell, *Educational research: Planning, conducting and evaluating quantitative and qualitative research*, 3rd ed. (Pearson, 2008); Uwe Flick, *An introduction to qualitative research*, Fifth edition. ed. (SAGE, 2014).

the human rights of older persons remains limited. The selected methodology therefore contributed to constructing a grounded theoretical understanding of human rights in old age.

Various versions of grounded theory have been applied in practice. There are three main versions of grounded theory.²²⁴ The *classic* one developed by Glaser, which aims at discovering a theory that pre-exists but emerges through the data. The *Straussian* version²²⁵ sees grounded theory as a method of verification²²⁶ and focuses on a number of prescriptive procedures for data analysis. And finally, *constructivist* grounded theory, which offers a more flexible application and advocates for an enhanced role for the researcher.²²⁷ More recently, Fassinger has identified a fourth type, the *feminist grounded theory*, applied mainly by feminist scholars in the field of nursing.²²⁸

Despite their differences, all grounded theory methodologies (GTM) share some common features, in particular their inductive approach, iterative process, comparative methods and their aim to develop theory.²²⁹ In an attempt to end the epistemological conflict among the supporters of the different types of grounded theory, Bryant argued:

'The epistemological issues that separate different strands, or branches of the GTM family, can then be set to one side provided that people's research writings do not seek to make strong epistemological claims: the ultimate criterion of good research should be that it makes a difference'.²³⁰

²²⁴ Andrew Hunter et al., "Navigating the grounded theory terrain. Part 1," *Nurse Researcher* 18, no. 4 (2011); Andrew Hunter et al., "Navigating the grounded theory terrain. Part 2," *Nurse Researcher* 19, no. 1 (2011).

²²⁵ Anselm L. Strauss and Juliet M. Corbin, *Basics of qualitative research : grounded theory procedures and techniques* (Newbury Park, Calif.: Sage Publications, 1990).

²²⁶ Charmaz, *Constructing Grounded Theory*.

²²⁷ Charmaz, *Constructing Grounded Theory*.

²²⁸ Ruth E. Fassinger, "Paradigms, Praxis, Problems and Promise: Grounded Theory in Counseling Psychology Research " *Journal of Counseling Psychology* 52, no. 2 (2005).

²²⁹ Charmaz, *Constructing Grounded Theory*, p.15.

²³⁰ Antony Bryant, "Grounded theory and pragmatism: The curious case of Anselm Strauss" (2009). cited in Gary L Evans, "A Novice Researcher's First Walk through the Maze of Grounded Theory: rationalisation for classical grounded theory," *Grounded Theory Review - An international Journal* 12, no. 1 (2013), p. 32, <http://groundedtheoryreview.com/2013/06/22/a->

I do not intend to enter this debate, nor analyse in detail the pros and cons of each approach, as I tend to agree with the above statement. I am however conscious that the selection of my methodology should be a choice informed by my own philosophy, as well as by the objective of my research.²³¹ Charmaz admits that grounded theory strategies can be used in various epistemological and ontological gulfs, although their application presupposes certain epistemological and ontological positions.²³² For this reason, I spent part of the preliminary research phase trying to grasp the ontological and epistemological grounds of the various types of grounded theory and to understand the practical implications of their application, in order to determine which version of grounded theory would best meet the requirements of this research and my own philosophical paradigm. Both the classic and the Straussian grounded theory originated from a positivist tradition with assumptions about an objective external reality.²³³ Looking for a single truth, positivism rejects the idea that there may be different interpretations of the studied phenomenon. The constructivist approach on the other hand, seeks to understand what is happening in a specific context.²³⁴ Constructivists are tasked with presenting the views of participants in order to construct and understand reality.

Charmaz's constructivist grounded theory rejects the claim of an objective external world; instead she accepts multiple realities and acknowledges the influence of the researcher in the construction and interpretation of the data. For Charmaz, the researcher and the participant *co-construct* the theory:

The constructivist approach perspective shreds notions of a neutral observer and value-free expert. Not only does that mean that researchers must examine rather than erase how their privileges and preconceptions may

novice-researchers-first-walk-through-the-maze-of-grounded-theory-rationalization-for-classical-grounded-theory/.

²³¹ Evans, "A Novice Researcher's First Walk through the Maze of Grounded Theory: rationalisation for classical grounded theory."

²³² Charmaz, *Constructing Grounded Theory*, p.12.

²³³ Glaser and Strauss, *The discovery of grounded theory : strategies for qualitative research*.

²³⁴ Creswell, *Educational research: Planning, conducting and evaluating quantitative and qualitative research*.

*shape the analysis, but it also means that their values shape the very facts that they can identify.*²³⁵

Instead of focusing on rigid processes, Charmaz encourages reflexivity and views data collection as a dynamic process where standpoints and decisions are constantly changing and evolving based on the interaction between participants and researchers. Researchers use their own experience and understanding to interpret the data.

Constructivist grounded theory has been criticized as departing from the premises of its original form to the extent that it ceases to be grounded theory.²³⁶ It is believed to be biased and leading to an 'unwarranted intrusion of the researcher'.²³⁷ Charmaz on the other hand argues that the quest for objective facts fails to acknowledge the presumptions that researchers bring into their study.²³⁸ I agree with Charmaz that our interests, biographies and context of the research influence how data is interpreted. In my understanding grounded theory merely provides tools and guidance for systematic inquiry, but essentially theory-making is not immune to the researcher's position.

This method fits with my research attitude, which does not build on a *tabula rasa*. I have in fact been following the discussion around a new UN convention in a professional capacity since 2012. I was familiar with the relevant scholarship, political debate, stakeholders' views before the beginning of my research and I have developed my own opinion about the subject matter, which is exposed in the following section about researcher positionality. I am moreover part of the studied phenomenon in that I actively participate in shaping the discussions around the value and content of a new treaty. The liberty offered by the constructivist grounded theory and the fact that it denies objectivity, is in line with a practitioner's approach and constitutes one of the main reasons for the selection of this methodology. It also allows me to take into account my

²³⁵ Charmaz, *Constructing Grounded Theory*, p. 13.

²³⁶ Barney G. Glaser, "Constructivist grounded theory?," 3 (2002).

²³⁷ Glaser, "Constructivist grounded theory?," para 8.

²³⁸ Kathy Charmaz, "Grounded theory methods in social justice research," *The Sage handbook of qualitative research* 4 (2011).

professional insights, which – as will be exposed in different parts of this thesis - I consider being of real added value to the research.

Constructivist grounded theory has been found to be particularly useful in social justice inquiries²³⁹, which are understood as studies looking into how social structures affect individual and collective action and pay attention to rights, equality and societal barriers.²⁴⁰ Unlike, other grounded theory approaches, which preclude social conditions and focus only on experiences, the constructivist turn, is also interested in the setting that shapes behaviours and outcomes. It therefore allows to make connections between individual experiences and macro structures and to enhance understanding about how systems of power, oppression and inequity affect individuals or categories of people.²⁴¹ The thesis' emphasis on lived experiences of rights and on State action or inaction, necessitates a methodology that permits a thorough understanding of older people's realities and how these are constructed. By looking into the conditions and processes that shape inequality, the constructivist grounded theory is an appropriate strategy for investigating the meaning of human rights in context. Moreover, such analysis can influence the law and policy that research aims to change.²⁴²

My study was geared towards capturing the multiple views and experiences of older people. Rather than beginning with a set of predefined concepts, I wanted to develop a meaning of human rights in older age based on collection of original data from interviews. I do not believe there is a single way to experience older age and to understand one's rights as an older person. I do consider however that certain structures or processes influence the experience of older age and give rise to meanings and actions. It is by unravelling the conditions that generate human

²³⁹ Elaine Keane, "Considering the practical implementation of constructivist grounded theory in a study of widening participation in Irish higher education," *International Journal of Social Research Methodology* 18, no. 4 (2015); Kathy Charmaz, Robert Thornberg, and Elaine Keane, "Evolving grounded theory and social justice inquiry," (2016); Charmaz, *Constructing Grounded Theory*.

²⁴⁰ Charmaz, "Grounded theory methods in social justice research."

²⁴¹ Charmaz, "Grounded theory methods in social justice research."

²⁴² Charmaz, Thornberg, and Keane, "Evolving grounded theory and social justice inquiry," p.2.

rights breaches in older age that I wish to construct an interpretation of human rights in the context of the three countries under study. I subscribe to the basic premises of social constructionism and symbolic interactionism, which assume that reality is constructed through individual and collective action based on meanings we develop through interaction with others.²⁴³ These considerations that guided my decision to work with the constructivist grounded theory are captured in Table 2 below.

Consideration	Motivation for Constructivist Grounded Theory
Ontological assumptions	<ul style="list-style-type: none"> • Relativist, Subjective and Symbolic Interactionist perspective • Multiple realities • World is constructed through human participation and interpretation
Knowledge	<ul style="list-style-type: none"> • Absence of pre-defined concepts • Social phenomena are contextualised • Theory grounded in the data
Role of researcher	<ul style="list-style-type: none"> • Co-constructs theory • Acknowledges own assumptions and expectations
Methods	<ul style="list-style-type: none"> • Flexible • In line with practitioner’s approach

Table 2: Motivation for Using Constructivist Grounded Theory

Selection of Countries

The thesis develops a theoretical understanding of older people’s rights in a European context. As already explained in the introduction a number of factors were taken into account for the selection of the three countries. Based on preliminary research I mapped out all EU Member States on the basis of criteria such as: geographic coverage, legal culture, extent of ratification of human rights

²⁴³ Charmaz, *Constructing Grounded Theory*.

treaties, involvement in the debate regarding a dedicated UN convention and other related processes, dominant ideology in legislation and policies on ageing, support of civil society for new UN treaty, as well as GDP per capita and welfare classification.

The selected States represent diverse welfare regimes and legal theories as well as other characteristics that were likely to improve the breadth and validity of the findings. Based on the Esping-Andersen typology and its later evolution, France is conservative, which means that welfare is based on compulsory social insurance. Ireland as a liberal country, mainly focuses on social assistance, whereas in Greece family plays a key role in providing support, which is why it is categorized under the Southern-European/Mediterranean welfare category.²⁴⁴ This means that countries that present different nuances of the role of the State were considered. In addition, whereas France has its own civil code and Ireland follows a common law system, Greece builds both on the German and the Roman codes. The combination of the three States therefore permitted to discuss the human rights of older persons across different – albeit not completely distinct – legal traditions. The three countries also constitute interesting case studies in terms of their relationship with international human rights standards. Unlike the other two, Ireland is a dualist State, which means that international treaties must be explicitly incorporated in national law in order to gain effect. On the contrary, for France and Greece the mere ratification of a UN treaty means it becomes part of the national law and therefore can be invoked by citizens and applied by domestic courts.

Besides these initial categorisations, the selection was motivated in particular by a number of interesting factors that relate to the research focus. Firstly, as will be explained in a following chapter, the three countries are at different levels of preoccupation about ageing and the rights of older persons and public views around the question of a convention showed diverging opinions. France has put in place a specific legislation on the adaptation of society to ageing, which aims to

²⁴⁴ Noemi Lendvai, "Variety of Post-communist welfare: Europeanisation and emerging welfare regimes in the New EU Member States" (RC-19, Montreal, 2009).

improve the level of support for older people in situations or at risk of dependency.²⁴⁵ Ireland has adopted in 2013 a policy framework, called the National Positive Ageing Strategy, covering multiple areas of government action relevant to older persons.²⁴⁶ On the other hand, Greece has no dedicated policy or legal framework targeting older persons. Moreover, institutional differences can be found, with equality bodies in France and Ireland working on age discrimination in all areas of life, whereas in Greece only discrimination in employment and occupation is covered. Some discrepancy in terms of applicable standards can also be found, in that unlike the other two countries, Greece is not bound by article 23 of the revised European Social Charter, one of the few legally binding provisions on the rights of the elderly. There are also diverse types of organisations, varied levels of mobilization of older people and different forms of consultation of civil society at national level.

In terms of practical advantages, having worked and/or studied in each of the selected States I already had in the beginning of my research a relatively good experiential knowledge of the three countries. Contacts on the ground and good command of the national language also facilitated the qualitative phase of work. Whereas these were the initial considerations that informed the selection of the objects of comparison, consistent with the constructivist grounded theory methodology followed in this research, further points of comparison emerged from the data. Chapter 5 exposes more in details the relevant characteristics of the three countries discussing similarities and divergences that form the context of the research and the comparison.

Researcher Positionality

The previous section explained that the constructivist grounded theory acknowledges that researchers bring their own standpoints and background in their studies in the construction of theory. *'Being explicit about the researcher's prior ideas, conceptions, and experiences is particularly important in a social*

²⁴⁵ "Loi No 2015 - 1776 du 28 décembre 2015 relative à la adaptation de la société au vieillissement," ed. Assemblée Nationale and Sénat (2015).

²⁴⁶ *National Positive Ageing Strategy*, Department of Health (2013).

justice-oriented grounded theory study'.²⁴⁷ Consistent with the constructivist grounded theory approach, I engaged in reflexivity from the outset and throughout the research process. As a means to understand how my position intersected with the opinions of participants, I started by identifying my own values, preconceptions and attitudes but also my relation with the field of study. Encouraged by Keane, who kept detailed notes exploring and exposing her own experiences and how these shaped her research²⁴⁸, I decided to give visibility to the history, motivation, privileges and weaknesses that I brought into my research.

My background converges with my interest and take on this topic. The aim for this research to give an 'older persons' perspective' reflects my personal values and is informed by my professional experience. I have been working since 2010 for AGE Platform Europe (AGE), the largest EU-wide network of organisations of and for older people. My involvement within the organisation gave me a ground-based understanding of what are some of the challenges of old age and how representative organisations of older people understand old age. One of my main duties during my employment with AGE is to bridge the gap between older people's experiences and policy. But even before joining AGE, I was asked during a short traineeship with the European Youth Forum to gather the experiences of young people around Europe as a first step to making the case for a new Council of Europe treaty.

Following such bottom-up consultation mechanisms in my daily work, I became entrenched with the idea that older persons through their representative organisations should be consulted at all stages of policy and lawmaking processes. One of the times I was required to put this approach in practice was during the negotiation of a non-binding instrument on the rights of older persons by the Council of Europe. This experience reinforced my view about the

²⁴⁷ Kathy Charmaz, Robert Thornberg, and Elaine Keane, "Evolving grounded theory and social justice inquiry," in *Lincoln, Yvonna*, ed. Norman Denzin (SAGE Publications, 2017), p. 422.

²⁴⁸ Keane, "Considering the practical implementation of constructivist grounded theory in a study of widening participation in Irish higher education."

importance of a 'grounded' approach, as I discovered inconsistencies between how State delegates and older people's groups perceived older age, where they put emphasis and what they left out of their deliberations. By including the views of older people's organisations, I witnessed how earlier drafts that were largely reflecting situations of vulnerability and dependency become embedded with positive aspirations around older age, including aspects of employment, autonomy and participation.

In reflecting on my perspective, some of the underlying assumptions and bias that I brought to this work need to be recognized. Since 2012 I have been the main AGE representative in the discussions around the potential of a new UN treaty. This means that I have a high level of familiarity with the political process, the stakeholders involved and the substantive discussions in the UN Open-Ended Working Group on Ageing. This level of familiarity presents the risk of taking for granted certain arguments but also stumbling blocks in the debate around the added value of a new convention.

The constructivist grounded theory does not require researchers to be detached from the field of study but rather invites them to participate in the construction of theory. This is why instead of completely overlooking the knowledge I had gained as Human Rights Officer with AGE I decided to use it for the benefit of my inquiry. I was very conscious for instance before the beginning of the research that despite an overall support for new treaty, a human rights approach was not consistently used by NGOs in the ageing arena. This knowledge stimulated my interest in exploring advocacy frames across three countries and why human rights failed in the first place. This perspective, which focuses on domestic organisations, extends beyond existing literature and makes a unique contribution to scholarship.

The selection of countries for comparison also echoes my intention to mirror diverging perspectives. As will be explained in a following chapter, older people's organisations in the three countries showed different levels of familiarity, support and engagement with human rights language and instruments.

Acknowledging these inevitable biases and assumptions allowed me to contrast my emerging data against this professional background and critically assess whether my interpretation was influenced by opinions I had come across or adopted outside the scope of my study.

As an advocate for older persons' rights I am not a neutral observer; instead, I have a rather obvious interest in promoting the idea of a new legally binding instrument. In fact, in my professional life I have witnessed the positive impact that the UN Convention on the Rights of Persons with Disabilities had for disability advocates and I had often been frustrated by the absence of a similar legal framework for older persons, which I considered as a significant impetus for law and policy development. Despite my interest in the practical value of a binding instrument for advocacy organisations, at the beginning of my research I did not have a strong personal opinion about its theoretical innovation. It is precisely because I noticed with concern that as advocates of older people's rights, we had not yet clearly articulated their underlying conceptual basis that I decided to undertake this research in the first place. I realised that sometimes discussions on a new treaty were perceived by advocacy groups as exogenous or even conflicting with their campaigning frames and priorities. My motivation therefore was to attempt to develop an understanding of human rights exploring the domestic processes and conditions that shape these conceptualisations. I was hoping that by doing so I would be able to engage in meaningful advocacy and at the same time to encourage older persons' organisations to take ownership and be involved in the debate around a new UN treaty.

The constructivist approach does not require researchers to ignore their preconceptions, but to acknowledge them and bring them into their analysis.²⁴⁹ Recognizing my bias, I considered necessary to involve in the study people with different views around the idea of a new convention, but also decided to expand my sample to professionals from national human rights institutions and ombudspersons to get their perspective about the influence of UN treaties at

²⁴⁹ Charmaz, *Constructing Grounded Theory*, p. 13.

domestic level. Whilst – compliant with constructivist grounded theory - my findings are not objective, I paid attention not to force a certain interpretation to my data. Comparing between my own and participants' positionality in a reflective journal was particularly helpful in terms of transparency. This level of reflexivity moreover strengthened my analysis as I was encouraged to look deeper into my data, distance myself from the participants and reflect on their assumptions, their background and whom they represent. This was particularly important as I already had working relations with some of the participants or their organisations. For example, although the majority of participants can be considered as older persons, I quickly became aware that they all came from a position of privilege, as they are educated, they come from majority populations, have a certain status as elected or employed representatives of organisations, reflect an above average socio-economic background and are not particularly physically or cognitively challenged. The more I reflected on my own predispositions, the more I gained consciousness of the participants' biases, which allowed me to look deeper into my data, asking for instance whose interests do the participants actually represent.

Interviewing people who I already knew was not intentional, but unavoidable since the ageing sector is not large enough to allow me to choose between organisations I had worked with and others I hadn't. Even in countries like France, which has a relatively larger civil society sector than Ireland and Greece, I decided that the study would benefit more from including the most influential and representative organisations, rather than smaller associations solely on the basis that I had no previous collaboration with them.

Overall, familiarity with the setting and research participants was beneficial to the study. For example, my acquaintance with organizational structures of NGOs allowed me to select a sample that made both methodological and practical sense, despite the quite diverse situation of civil society in the three countries. Knowing a little bit about other organisations in the field, I was also able to efficiently address the niche that each entity represents. Additionally, on a practical level, the qualitative phase was facilitated thanks to my easy access to representative

organisations of older persons at European and national level. In return, my study contributed significantly in my work and advocacy, as will be further explained in the concluding chapters of this thesis.

Chapter 4: Research Methods: Data Collection and Analysis

Charmaz provides a set of flexible guidelines for undertaking constructivist grounded theory data collection and analysis, allowing the researcher to choose the methods that best suit their research project.²⁵⁰ Motivated by this approach I have applied an *interpretation* of the methodology for my thesis. To do so, I have engaged in the main actions proposed by grounded theorists, involving coding, constant comparison, memo writing, theoretical sampling and theorizing, but also made some necessary adaptations in order to better fit my study's purpose. Data was collected through interviews and document review and took place simultaneously with data analysis to comply with the grounded theory method. Findings of this study were co-constructed through shared understandings, interaction and discourses on human rights of older people between myself, participants and other data sources, including law, policy, academic scholarship and NGO documentation.

Stages and Sources of Data Collection

Grounded theory is in principle a method of data analysis, which foresees little about data collection.²⁵¹ The appropriate method of data collection flows from the research problem.²⁵² Although the pursued data collection methods were not completely predefined at the beginning of my study, I began by using interviews, which is a method employed by many grounded theorists as their primary method of data collection.²⁵³ Interview data were complemented by a mixed method approach, involving document analysis. A mixed method approach may

'advance social justice inquiry by providing a fuller understanding of complex problems, placing actions in context, demonstrating how people

²⁵⁰ Charmaz, *Constructing Grounded Theory*.

²⁵¹ Kathy Charmaz, "Grounded Theory: Objectivist and Constructivist Methods", ed. Norman K. Denzin and Yvonna S. Lincoln (Thousand Oaks: SAGE, 2000).

²⁵² Charmaz, *Constructing Grounded Theory*.

²⁵³ Fassinger, "Paradigms, Praxis, Problems and Promise: Grounded Theory in Counseling Psychology Research".

experience or impose inequities, involving stakeholders in the research, and explicating connections between actions and events'.²⁵⁴

The extent of engagement with documents and literature was dictated by my research question and the emerging data from the interviews.

Comparing expert understanding of human rights in older age in different organisations in the three countries, interviews generated theoretical categories that were compared to the paradigms enshrined in law, policy and literature, gathered mainly through document analysis. The different phases of the data collection process, operationalized through constant comparison, theoretical sampling and memo-writing are summarized in the diagram below and explained in more detail in the following sections of this chapter.

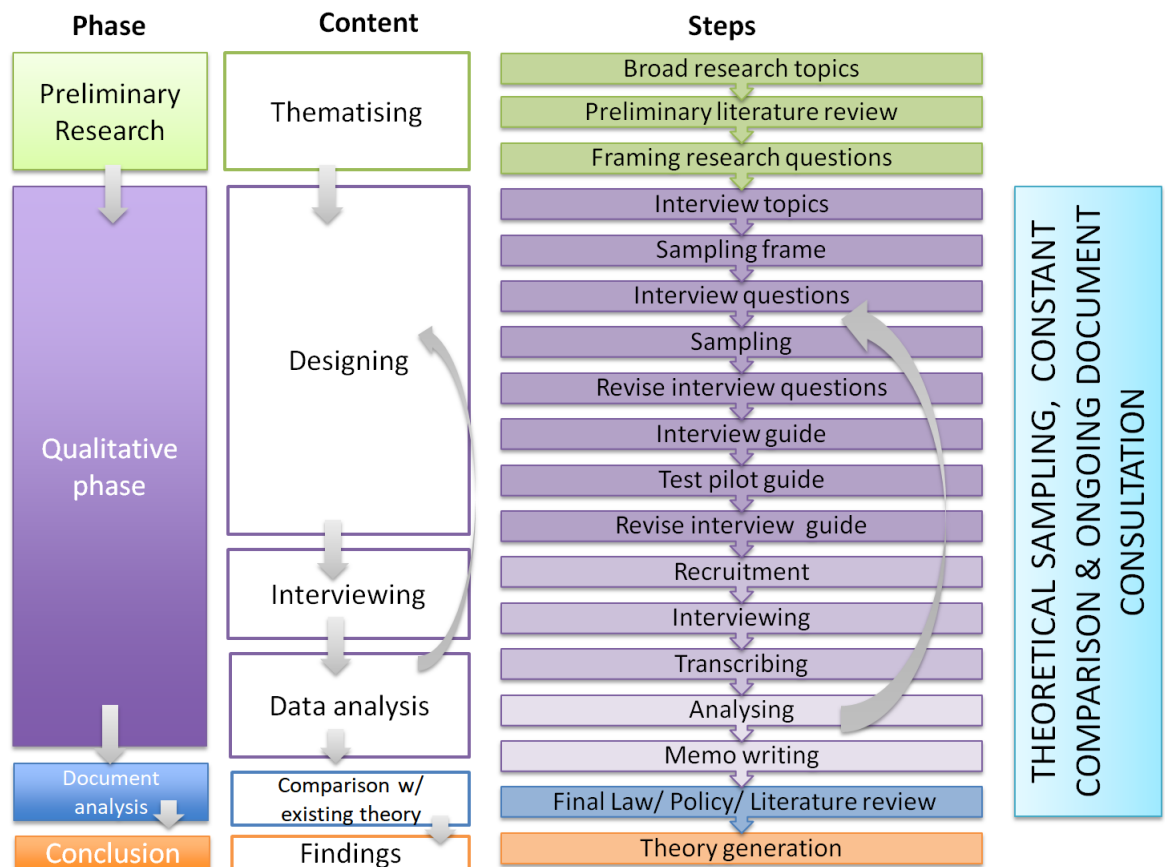


Figure 3: Stages of Data Collection

²⁵⁴ Charmaz, Thornberg, and Keane, "Evolving grounded theory and social justice inquiry," p. 433.

Overview

In the beginning of my study I did preliminary research. During this stage I mostly undertook a desk-based review of key documents and literature, but I also completed a small number of informal interviews with key informants in the three countries in order to gain a better understanding of the context in which the research participants operate. I also did three pilot interviews, which allowed me to gain insights about the interview process, gain some experience as an interviewer and also to revise the interview guide in a way that was better understood by participants. Then I proceeded with the qualitative phase, which involved two rounds of interviews. The first stage targeted NGO representatives from organisations directly representing older persons. The second stage expanded the NGO sample with organisations that work with and for older persons and also included professionals working in equality and human rights bodies. In each of these rounds I had to choose the interview topics, decide on my sample, draft the interview guide, recruit participants, undertake the interviews, transcribe and analyse them. Towards the end of the research, primary data was contrasted with information from other sources, including law, policy, advocacy and scholarship. This last step permitted making connections between my ideas and other relevant work, supporting my claims and situating the emerging theory in the field of study.

This snapshot illustration of the process however cannot fully capture the iterative progression, complex decision-making and conceptual analysis involved in this work. In reality the research did not advance in a linear way. The iterative nature of grounded theory requires data collection and analysis to run in parallel constantly informing each other. Data collection and conceptual analysis continue until theory is developed, through a method that grounded theorists call constant comparison. Comparing different sets of data, data with emerging codes, codes with codes, codes with categories, categories with categories and categories with concepts helps researchers to surface relationships and become more analytic.²⁵⁵

²⁵⁵ Kathy Charmaz, *Constructing grounded theory : a practical guide through qualitative analysis* (London: SAGE, 2006).

This is accomplished through writing memos where these comparisons are captured.

Use of Documents

This complex research practice is best illustrated in the way in which I treated documents throughout my study. Unlike classic grounded theorists, Charmaz encourages researchers to engage with scholarship early on in their inquiry.²⁵⁶ Following her advice, I familiarized myself with the most pertinent ageing theories and other relevant material in the beginning of my study. In the beginning of my study I developed a list of sensitizing concepts based on existing literature and my own understanding of the topics. In addition, as theoretical categories emerged from the data, I explored some substantive areas in order to be able to deepen my analysis and critically assess my interpretation. For example, I looked into literature on care in comparison with disability scholarship around support. In applying theoretical sampling, I did not only look for data from interviews but also from academic and grey literature in order to elucidate the properties of the emerging concepts. To ensure that this interaction between existing and emerging theory did not impose a certain perspective in my analysis, I kept a reflective journal where I captured decisions about ideas to explore further and how literature informed the analysis as part of the iterative process.

Nevertheless, it must be noted that, although document analysis was an integral part of the development of a theoretical understanding of human rights of older persons, documents - unlike interviews - were not coded. This decision is not only in line with Charmaz's flexible approach to the research process, but it is also justified by my objective to give priority to primary over secondary data during the analysis. This entailed making comparisons in memos between the views of older persons' representatives, other stakeholders and published material. This process elucidated whether there was a common narrative and helped identify diverging nuances between advocates and decision-makers. Textual analysis did not just serve triangulation purposes but genuinely enriched the analytic

²⁵⁶ Charmaz, *Constructing Grounded Theory*.

experience as it allowed me to interpret in different ways what I was seeing in the data.

My study does not stop at the development of a theory of human rights of older persons, but it also aims to discuss the normative content of rights and the practical value of a new treaty. Answering the second and third research questions involves analysis of existing international human rights standards, critical assessment of the implementation of other treaties, and description of the policy and legal measures that currently protect older persons in the selected jurisdictions. Document analysis was the main source of data to achieve these aims (Chapters 10 and 11). Law, policy and scholarship were used to identify the existing norms on older people's rights and the State of their protection at national level (Chapter 5). Theoretical sampling, which is a key element of the grounded theory, was also applied in this stage of the inquiry. For example, instead of an arbitrary selection of international standards and national measures, sampling texts for this phase was based on the topics and instruments emerging from the interviews. Tentative categories that originated from the interviews were moreover used to inform the discussion around the added value of UN treaties, the efficacy of existing law and policy and eventual protection gaps. In sum, although in interpreting and applying the empirical findings I gave more weight to secondary data, data collection was guided by the main methodological tools of grounded theory, i.e. theoretical sampling and constant comparison.

Qualitative Phase

During the qualitative phase I engaged in intensive interviewing, which is both open-ended and focused and therefore fits particularly well the purpose of the grounded theory analysis.²⁵⁷ The objective of the qualitative analysis was to expose commonalities in the advocacy frame of organisations working at the national level through unearthing unique ways in which inequalities are experienced by older people as a group. In this sense, I was not interested in individual cases of rights abuses. This is why my initial sample included

²⁵⁷ Charmaz, *Constructing Grounded Theory*, p. 85.

organisations that provide platforms for the *direct* engagement and consultation of older persons. This allowed the study to achieve an improved breadth of the findings, compared to studying a small number of individual cases. Since domestic civil society actors have had so far limited engagement in discussions on the value of a new international convention, I was interested in exploring the shared views and expectations of organisations representing older people with regard to human rights.

This perspective is innovative in the sense that – as explained earlier - previous literature on this topic has not directly engaged with the representatives of national organisations of older citizens and therefore provides a fresh contribution to the ongoing debate. Consequently, data collection involves individuals in their capacity as key stakeholders or experts in their institutions or respective field. Flick defines *expert interviews* as follows:

'In contrast to biographical interviews, here the interviewees are of less interest as a (whole) persons than their capacities as experts for a certain field of activity. They are integrated in the study not as a single case but as representing a group'.²⁵⁸

For the purposes of the study, 'experts' were understood as individuals who thanks to their professional or voluntary activity in organisations of older persons or other entities had gathered considerable experiential knowledge that is relevant to the research questions. Information gathered by experts helped describe the context, i.e. the social situation of older persons (key challenges, positive or negative influence of existing policy and law) and discuss the concept of human rights and its meaning. Experts were asked to contribute with *technical, process and interpretive knowledge*.²⁵⁹ *Technical knowledge* refers to information on the existing legal and policy framework, administrative processes as well as practices in their country. *Interpretive knowledge* refers to subjective opinions, for example regarding the efficacy of law in addressing the realities of older

²⁵⁸ Flick, *An introduction to qualitative research*, p. 227.

²⁵⁹ Flick, *An introduction to qualitative research*.

people, which may be informed by the views of individual members or reflect purely personal ideas. *Process knowledge*, i.e. information about how organisational decisions are made and the extent to which older people are involved in these instances, allowed me to have a better idea about whether organisational opinions were informed by the positions of members and to differentiate between personal and organisational views.

As expected, self-advocacy organisations, which were included in the initial sample had clearer and more defined consultation mechanisms than charities, service providers and other organisations not directly representing older people. They were therefore given priority in the collection and analysis of data since they are more likely to reflect the views of the group they directly represent. As an additional method of triangulation, I looked into the organisations' websites and selected published material after each interview in order to critically assess whether the collected data was consistent with the organisation's narrative. My assessment, which was documented in a reflective journal, did not reveal an important difference between what I was seeing in the data and what I was reading in other sources.

Organisations that work with and on behalf of older persons, as well as human rights professionals in the three countries were only involved at the second stage, in order to close data gaps and achieve better theoretical understanding.²⁶⁰ In total I conducted 21 interviews with 24 participants between June 2016 and June 2017.²⁶¹ 19 actors from NGOs representing and working with older persons and human rights organisations were involved in the sample. In two cases, I interviewed separately two individuals from the same organisation that had complementary experience and expertise. Three interviews were conducted with the simultaneous participation of two individuals from the same organisation. As shown in the below table, the overall sample included eight organisations representing directly older persons, six organisations working with or on behalf

²⁶⁰ The process of theoretical sampling followed to achieve this is further explained in a following section of this Chapter.

²⁶¹ Three organisations wanted to involve more than one person in the interview

of older persons and six human rights professionals. One NGO fulfilled the criteria both as self-advocacy organisation and organisation that works with older people, as its membership includes both users of care services and their families. A more detailed breakdown of the participants can be found in Appendix 1.

COUNTRY	SELF ADVOCACY ORGANISATIONS	OTHER NGOS	HUMAN RIGHTS ACTORS
FRANCE	4	2	2
IRELAND	2	4	2
GREECE	2	0	2
TOTAL	8	6	6

Table 3 Summarized List of Participants per Type of Organisation

The Design of Semi-Structured Interviews

Semi-structured interviews allow for both focused and open exploration, unlike *'rigidly structured interviews or surveys, which predetermine the agenda'*.²⁶² As such, they are in compliance with the openness to new data, which is characteristic of the grounded theory. This is why semi-structured interviews provided the bulk of data for this study.

The majority of interviews were done face-to-face at a setting chosen by participants. In most cases the interviews took place at the organisation's office, but a small number of interviews took place in cafes or hotel lobbies. Four interviews took place over the phone or skype, either because it was the participant's preferred method, or because it was impossible to schedule a face-to-face meeting. In all four cases the chosen medium did not seem to compromise the quality of the interview. Skype and phone interaction is now quite commonly used by people in the sector, who have a considerable experience using such means in their daily work. Therefore, this form of communication seemed quite natural to people involved in the study. I did however take extra care in establishing a relationship and sharing information in advance of the interview. The length of each interview ranged from 35 to 105 minutes, the average being a bit over an hour.

²⁶² Paul Hodkinson, "Grounded Theory and Inductive Research," in *Researching Social Life*, ed. Nigel Gilbert (London: SAGE, 2008), p. 85.

The interview guide I used for the first round of interviews included specific topics but remained flexible. It was translated in the three languages (English, French and Greek) and I paid attention to use - as far as possible - similar wording and tone with all participants. However, I did not follow a script or address the questions in a specific order. Instead, I gave priority in not disrupting the flow of the interview process and therefore each interview was quite distinct from the rest.

In parallel, as co-creator of the research, I took several decisions aiming to demarcate the field of study and ensuring the generation of data that was relevant for the construction of theory. Inquiring about underlying context, ideas and bias allowed participants to expand about their views of older age and rights and to discuss abstract notions, instead of their formal application in law and policy. I also asked them specific questions about the shared responsibility between States, individuals and the private sector. Relating these questions to the national context I was better placed to gather answers on meanings of rights, based on the obligations they generate.

The interview guide (see in Appendix 2) was improved constantly after the first interview, according to the grounded theory approach, which requires revisiting the questions in view of emerging data. For example, after the first couple of interviews it became evident that participants were struggling to define older persons. This lack of clarity encouraged me to ask more questions about their understanding of this notion, although it was not initially foreseen in my interview guide. Recognizing that their perceptions of themselves, the older population and of ageing impacted their understanding of human rights, I decided to explore this further and adapted my research questions in order to focus on older age instead of older persons.

The second round of interviews with non-NGO stakeholders included a couple of new questions aiming to delineate better the concepts of human rights and equality and to discuss how advocacy on behalf of older persons was perceived by these actors. Some of the wording and structure of interviews was also

changed based on the experience of the first round. Interviews with human rights stakeholders were also framed in slightly different terms, to be more easily answered by human rights and equality bodies as opposed to NGOs. (See interview guide in Appendix 2)

Initial Sampling of Study Participants

For the initial data collection, purposeful sampling was followed. I targeted *representative organisations of older persons*, believing that they can provide rich understandings of human rights in older age based on their experiences and insights from their members. Representative organisations are considered associations:

- that have as members a majority of older and/or retired people, either individually or via member organisations;
- whose main decision-making body is composed of a majority of members who are over 55 years old;
- where there is a direct, constitutional link between the older members and the main decision-making body;
- if the organisation provides services to older people, there are mechanisms to ensure that service users are enabled to express their views on service delivery.

This definition of representative organisations of older persons, which can be found in the statutes of AGE Platform Europe²⁶³, the largest European network bringing together organisations active on older people's issues, is congruent with that of disabled persons' organisations (DPOs) as understood by the CRPD Committee. According to the CRPD Committee DPOs are *'those comprised by a majority of persons with disabilities -at least half of its membership-, governed, led and directed by persons with disabilities'*.²⁶⁴

²⁶³ AGE Platform Europe, "Revised Statutes adopted at AGE General Assembly 17 November 2016," (2016), art. 13. <https://www.age-platform.eu/statutes>.

²⁶⁴ UN CRPD Committee, "Guidelines on the Participation of Disabled Persons Organizations (DPOs) and Civil Society Organizations in the work of the Committee.," (2014), para 3.

I compiled an extensive list of organisations of and for older people working at national level, which served as a sampling frame. I started by listing the organisations I already had heard of thanks to my professional experience. I continued by looking into the websites and archives of relevant European and international networks, including AGE Platform Europe, EURAG, FIAPA, Helpage International and FERPA looking for their members in Ireland, France and Greece. In addition, I had a look at the lists of NGOs who are accredited with the UN ECOSOC and with the Council of Europe Conference of INGOs. Moreover, I searched the database of a European project, which had developed national coalitions promoting the rights of older people (WeDO project). I also looked into the websites of the identified organisations to find mentions of other relevant entities. Finally, I did a Google search with key words in the three languages and also examined relevant NGO databases where those exist.²⁶⁵ I also asked the views of key informants (see previous section about preliminary research) in order to fill in gaps in the sampling frame. During this mapping exercise the following criteria were taken into account:²⁶⁶

- *Self-representation* (i.e. whether organisations fulfil the above-mentioned criteria of representative organisations of older people)
- *Target group* (whether organisations aim to represent a specific age, gender or interest group, ex. Older workers, older women, older victims of abuse or a group larger than the target group of the study, ex. Men, which includes older men)
- *Membership structure* (whether they are a single organisation, an umbrella organisation, or part of a network)

²⁶⁵ In France these included the database about Law 1901 on associations: <http://www.associations.gouv.fr/626-la-loi-du-1er-juillet-1901-et-la.html> and the official journal <http://www.journal-officiel.gouv.fr/association/> as well as the list of members of two representative bodies of older people at government level, the 'Comité Nationale des Retraités et Personnes Âgées' (CNRPA) and the 'Comité National pour la bienveillance et les droits des personnes âgées et les personnes handicapées' (CNBD)

²⁶⁶ Adapted from Anne Waldschmidt et al., "Working Paper: A Comparative Analysis of Disability Rights Activism – with reference to the concept of Active Citizenship " (DISCIT project, 2014).

- *Activities* (whether they work at regional, national, local, European, international level and if they are involved in policy-oriented activities or just programmes/service provision)

In order to ensure that participants' views were primarily guided by the position of older people in the three countries, relevant for the development of theory and as representative as possible of civil society in the three countries, the following inclusion/exclusion criteria were identified. See table 3 below.

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"> ▪ Fall under the category of representative organisations of older persons ▪ Include in their mission specifically older and/or retired people ▪ Be involved in policy-oriented activities ▪ Have a broad remit (i.e. not focusing on a specific area of older people's lives, such as work, care, Alzheimer or elder abuse) 	<ul style="list-style-type: none"> ▪ Represent the same members/views as another organisation in the sample (in case of networks or umbrella organisations) ▪ Be a public/governmental body

Table 4: Inclusion and Exclusion Criteria

In selecting NGOs, I prioritized organisations that work specifically with older persons, are active at national level, are involved in policy activities (i.e. not just offering services and social activities) and cover several aspects of older people's rights. When possible, networks were preferred to individual organisations in order to cover civil society as widely as possible.

In total, I undertook 21 interviews with 24 individuals representing 19 different entities (Appendix 1). Among these, six interviews were with professionals in Equality Bodies, Offices of the Ombudspersons and National Human Rights Institutions and the remaining with NGOs. Eight interviews targeted stakeholders in Ireland, seven French actors and six from Greece. In Greece I undertook separate interviews with two different actors from two of the targeted organisations because the initial sample did not cover fully the interview questions and participants themselves suggested that I contact other persons in their NGOs to access additional expertise. Eight of the involved actors came from representative organisations of older persons, five from organisations working for and with older persons and six were stakeholders involved in National Human Rights Institutions, Equality Bodies and Ombudspersons in the three countries. Since interviewees spoke in their capacity as experts, I did not collect demographic information from this group. I was more interested in achieving a wide representation of civil society, rather than a demographic balance.

To select organisations for the initial sample I took into account the context in the three countries aiming to find organisations that did not merely technically fulfil the above criteria but were interesting and important. Initially I identified two NGOs in each country that would provide the data for the first round of interviews. An analysis of the organisation of civil society on ageing in the compared countries is given in Chapter 5. The following section describes the process of selection of participants for the second round of interviews, which was based on theoretical sampling. This part briefly refers to the stakeholders involved in the initial stage of data collection.

In France, the initial sample included the Fédération Nationale des Associations des Retraités (FNAR) and Ensemble et Solidaires, formerly known as Union Nationale des Retraités et Personnes Âgées (UNRPA). FNAR, which stands for National Federation of Associations of Retired People brings together national and regional clubs of older people and organisations of retired workers of enterprises in France. FNAR is apolitical without affiliation to trade unions. Their

mission is to defend retirees and make sure their voice is heard, in particular around pensions, purchasing power, health (i.e. complementary insurance), autonomy, representation and recognition of the role of pensioners and non-discrimination. FNAR is very well represented in a number of national and regional consultative bodies and is one of the founding members of the Confederation Française des Retraités (CFR), which brings together the 5 largest federations of associations of pensioners that represent together about 1.5 million older members in France.

UNRPA, i.e. National Union of Pensioners and Older People is one of the oldest organisations representing older people in France. Established in 1945, the same year that France launched its social security system, the history, mandate, discourse and the demands of the association are heavily influenced by the principles and foundations of social security. Despite being apolitical, the association has strong historical ties with the French communist movement. According to their statutes they work for social justice and to defend the rights and interests of pre-retired people, pensioners, older people losing their autonomy and older persons with disabilities. Like FNAR, they are represented in the main governmental consultative bodies, as well as within a committee on health of the French Ombudsman (Defenseur des Droits).

In Greece I conducted interviews with 50+ Hellas and the Highest General Confederation of Pensioners of Greece (AGSSE). 50+ Hellas aims to improve the quality of life of those over 50 years of age in Greece, through actions and activities affecting all aspects of life. It supports and promotes the rights of older people to equal treatment in society, particularly in employment, in health and medical care, in their independence and decent living standards, in their right to participate as full citizens in decision making as well as in the development of policies affecting them. While 50+ Hellas typically fulfils the inclusion criteria of a representative organisation explained above, they lack a large membership basis and offer limited opportunities to involve older people in their advocacy work, outside EU-funded projects and training opportunities that they offer. Even

if the limited membership of 50+ cannot be representative of the older population in Greece, it is the only NGO focusing its activities on this population and has made remarkable efforts to give visibility to their concerns vis-a-vis Greek and European public bodies. Their experience and testimony are therefore particularly relevant to the study.

AGSSE is an umbrella organisation bringing together PanHellenic federations of pensioners from the private sector. Their current membership includes 9 national federations, but they also collaborate with federations that are not officially AGSSE members yet. In total through their membership and collaborating entities they represent about 180.000 individuals. Their aspiration is to grow in order to represent the majority of pensioners in Greece. Their objectives are to promote at the highest level (governmental and civil society) the interests of retired people in Greece; to promote the need for social benefits and rights; to ensure the rights of retired people are respected; to ensure better living standards by providing supporting means and measures; and to pressure authorities to provide financial and/or legislative measures for better living conditions of pensioners.

In Ireland I initially involved Active Retirement Ireland (ARI) and the Irish Senior Citizens Parliament (ISCP). The first Active Retirement Association was formed in 1978 as a means to enhance social networks and provide opportunities for participation, volunteering and other activities targeting older people. Now there are more than 570 local associations representing more than 24,500 individual members. ARI is the national umbrella that brings together these local associations. Although ARI's members are targeted towards offering social activities, aiming to ensure older people's engagement in education, culture, sports, social life and their communities, more recently ARI's strategic orientation includes also advocacy and policy-oriented action at a national level. It is in this capacity that I was interested in including ARI's views in the research.

ISCP is a network of about 400 affiliated local organisations, run by older volunteers. Through their membership it is estimated that they represent a total

of around 100.000 people. The ISCP originated from the trade unions movement and has a strong advocacy mandate. ISCP aims to represent older people's issues at government, to improve the quality of life of older people and to promote intergenerational solidarity. In the past they have been recognized as social partners, which gave them privileged access to decision-making at the highest level, but social partnership no longer exists in this form, which has weakened the organisation's influence at policy level.

Theoretical Sampling

Theoretical sampling '*distinguishes grounded theory from other types of qualitative inquiry*'.²⁶⁷ It involves collecting more data to close gaps and achieve greater understanding of the tentative theoretical categories. At this stage - unlike my initial sampling, which was purposeful and aimed at including the genuine voice of older persons through their representative organisations - I sought data to answer questions that were raised through my preliminary analytical findings. I relied heavily on memos where I had identified issues, areas and ideas that needed further exploration for the development of my emerging theory. Theoretical sampling requires taking decisions about where and how to access necessary data to fill incomplete categories.²⁶⁸ Consequently, the logic of theoretical sampling guided both my choices about the second phase of interviews and the use of documents. This part explains how further study participants were selected.

After the first round of interviews some patterns in my data started to emerge, which I could not have anticipated in the beginning of my research. Despite being aware of issues pertaining to the difficulty to legally define the target group, I had not imagined that '*struggling to define older persons*' would be a key code affecting the understanding of older people's rights by self-advocates. Despite being a common narrative among interviewed organisations, I could not help but wonder whether other actors in the field, in particular organisations working with and for older people would be able to give better insights about what distinguishes older

²⁶⁷ Charmaz, *Constructing Grounded Theory*, p. 192.

²⁶⁸ Charmaz, *Constructing Grounded Theory*, p. 199.

people as a group. This is why I considered that during the second round of interviews it was particularly important to enlarge the sample to include charities and other civil society organisations who do not necessarily fulfil the criteria of organisations of older persons, but nevertheless are doing influential advocacy work on behalf of older people at a national level. In addition, I wanted to include the views of stakeholders who are involved in human rights advocacy to understand how they have defined older persons for the purposes of their work.

I also wanted to approach organisations, which are offering opportunities for older people to live their full potential and are aiming to empower them to benefit from their next phase of life. Many of the respondents in the first round were focused on voicing older people's interests and concerns and - despite aiming to make their ongoing contributions known and recognized - did not necessarily adequately reflect on all aspects of participation. In order to better understand the challenges and also complete the vision of what participation in older age (especially for the oldest old and those who are frail or disabled) might look like, I looked for organisations which were focusing on transitions relating to later life, volunteering, lifelong learning and active citizenship.

As the intersections between ageing and disability were underlined by participants, I was encouraged to explore these notions further by engaging organisations that represent users of care services. I also needed to speak to human rights practitioners regarding the extent to which they see older people's issues through a disability rights perspective and to discuss whether there are unique forms of human rights violations in older age. Contrasting the views of civil society and human rights professionals, I was interested in exploring whether practice was informed by or departed from the narrative of older people about experiences of disability. Additionally, I felt that my engagement with human rights bodies would allow me to test whether they mirrored a wide range of human rights issues raised by older people's representatives or rather adopted a narrow perspective, primarily focusing on issues around old age disabilities.

Equal treatment also emerged as a less controversial term than the rights of older people and I wanted to gain further insights into the concepts of equality and non-discrimination. In addition to adapting my interview guide, I decided to approach equality bodies to better reflect these nuances.

My initial sample was -intentionally- not guided by criteria regarding organisational positions on a new UN convention. As a result, many of the involved organisations had only marginally reflected on the idea, which was not unsurprising. For the last stage of the inquiry, therefore, I wanted to include some respondents, who had publicly positioned themselves either positively or negatively regarding the adoption of a new treaty, or at least had initiated an internal discussion. The following organisations were involved in the second and final round of interviews.

Old Up is a French NGO focusing their activities on older people in – what they call – the second stage of retirement . They work to reimagine and make known the role and contributions of this generation (i.e. 75+). According to their motto the organisation strives to *'give meaning and utility to the lengthening of life'* and to establish a paradigm of ageing that is sustainable and creative. It has both individual and associations as members. Despite being a national association, it maintains important links with older people at the grassroots level, especially in the wider Paris region. It was precisely because of their focus on the oldest old that I decided to include Old Up in my sample.

FNAPAEF (Fédération nationale des associations et des amis de personnes âgées et de leurs familles) is a non-profit network that brings together associations of service users, individual members (including family caregivers), experts, and volunteers. Their main mission is to listen to the experiences and expectations of older people who need support, whether they are at home or in institutions, and their loved ones, and to represent their concerns in public consultations. FNAPAEF is also committed to improving the quality of care and to preventing elder abuse, by raising awareness of older people's rights and providing

information and training. The organisation has been very active in proposing amendments to legislative proposals regarding long-term care schemes.

FIAPA, the *Fédération Internationale des Associations des Personnes Âgées*, brings together 41 associations or federations in 15 countries. Despite formally being an international organisation with affiliates outside of France, I decided to include FIAPA in the sample due to the instrumental role they have played in national discussions around a new UN convention. FIAPA endorsed and promoted a shadow convention on the rights of older people, which was elaborated by several NGOs in the margins of the informal consultations of the French ministry around the added value of a new UN convention. Consequently, although their remit goes well beyond the domestic level, I was interested in their positioning around a convention (which differs from other civil society organisations in France).

CNCDH, the *Comité Nationale Consultative des Droits de l'Homme*, is the French National Human Rights Institution (NHRI), a body mandated by the State to monitor the situation of human rights but is independent from government. I was interested in involving NHRIs in the three countries because they act as bridges between civil society and state as well as national and international authorities ensuring the compliance of the domestic framework with international norms. I was moreover interested in CNCDH because they had been mandated by the French government before the beginning of the study to hold a stakeholder consultation and issue an opinion on the rights of older persons and the added value of a new UN convention.

The *Defenseur des Droits* is at the same time the French Ombudsperson and the national Equality Authority, since the the former institutions merged in 2011. As such it has a wide mandate, which includes responsibility to undertake own investigations but also to receive complaints on matters of discrimination and misconduct of public authorities and services. In addition, the *Defenseur* organises debates and publishes opinions on a range of issues related to human rights, as well as studies and inquiries that aim to raise public awareness.

Age Action Ireland is a charity advocating on behalf of older people and calling for better services, pensions, engagement opportunities and recognition of their rights. It is a well-respected organisation for its advocacy efforts, which focuses on changing policies, in particular for those who are most vulnerable and disadvantaged²⁶⁹. In addition, they deliver a number of services, programmes and trainings, as well as information, including support for victims of elder abuse. They engage older people in some of their work, but they are not a self-advocacy organisation.

SAGE was established by Third Age, an Irish voluntary organisation dedicated to promoting the value and contribution of older people through its volunteer-led programmes and services. SAGE provides personal support and advocacy services for older people primarily in care settings, but also in family conflicts, transition from hospital to a care service and more generally all issues affecting older people's rights. SAGE was interesting for my sample because they employ a rights-based approach in their work drawing primarily from the CRPD.

Age & Opportunity is another of the main Irish NGOs active in the field of ageing. It was established following the outcomes of a national survey that illustrated negative attitudes to older people. Aiming to change the image of ageing, Age and Opportunity is dedicated to offering practical programmes about older people's active involvement in arts and cultural activities; sport and physical activity; learning, active citizenship, capacity building and ageism awareness.

Active Ageing Partnership, is not a distinct organisation, but the most recent civil society collaboration which brought together Age and Opportunity, Active Retirement Ireland and Third Age. This collaboration was an attempt to better realign the work of the three organisations and support the implementation of ageing policies in Ireland. The co-ordinator of Active Ageing in Partnership is also chairing an informal NGO working group on the rights of older persons, so I was

²⁶⁹ Eoin O'Dell, *Older People in Modern Ireland: Essays on Law and Policy* (Dublin: First Law, 2006).

hoping to further explore key challenges in the enjoyment of human rights and get their views on the topic of a new convention.

The Irish Human Rights and Equality Commission brings together under a single body the Irish NHRI and Equality authority. They aim both to influence law and policy and to monitor the situation of human rights on the ground. They are also tasked with providing legal support in cases around equality and rights.

The Office of the Ombudsman, similar to the French *Defenseur*, is in charge of examining complaints regarding unfair treatment by public bodies. What is particularly interesting about their mandate is that since 2012 they can also receive complaints regarding private nursing homes on the basis that they are partly or fully funded by the public purse. This means that they currently have jurisdiction over the vast majority of nursing homes in the country, both private and public.

The Greek Ombudsman (*Synigoros*) acts also as the national equality body, therefore having similar functions to the Irish Ombudsman and the French *Defenseur*. In order to cover the wide scope of their mandate, which includes age discrimination in employment and issues around the provision of social protection, I was advised to interview two people from the organisation. In this way I was able to cover both issues around the legality of age-based distinctions and about care provisions, both of which were key aspects of my preliminary findings.

The National Commission for Human Rights (NCHR) is Greece's NHRI. In 2014 they addressed for the first time the rights of older people, noting the invisibility of their rights at national level and supporting the idea of a UN Convention. NCHR has also been involved in the development of an EU-funded project on the human rights of older people in long-term care.

Due to the absence of other organisations from Greece, I decided to include in my sample another representative of 50+ Hellas hoping to capture a different or complementary perspective. I asked to interview someone with more specialist

knowledge, who could complement the views of the expert who was interviewed during the first stage.

Theoretical Saturation

In grounded theory, theoretical sampling is pursued until no new properties emerge.²⁷⁰ This process, which is known as saturation or sufficiency, dictates when data collection stops. In other words, the adequacy of data is not defined by exogenous factors, such as timeframe and resources, but is rather imposed by the quest for rich and theoretically relevant data. Grounded theorists are less interested in collecting huge amounts of data and ensuring a representative sample than they are in gaining insights that can illuminate the studied phenomenon.

After the second round of interviews, I felt that I had gained enough information to describe the process of human rights violations in older age. My carefully selected sample and the adaptation of my research inquiry put me in a position where I could visualize the connections between the different categories and develop abstract conceptualisations. Although my study could have benefited from more examples and stories, I did not feel that further data would deepen my understanding of the emerging categories.

This brief section has given some information about how data was produced and analysed and how these processes connect to the research objectives and questions. But it cannot fully capture in detail the application of the research method. In the appendices some additional details are shared with a view to providing further insights to the research process.

Ethical Issues

Interview questions referred to experts' opinion and knowledge, without aiming to uncover personal stories about experience or feelings.²⁷¹ In this sense, participants were less vulnerable during the interview process, as they were

²⁷⁰ Charmaz, *Constructing Grounded Theory*.

²⁷¹ For this distinction see M.Q. Patton, *Qualitative research and evaluation methods* (London: SAGE, 2002).

asked to discuss aspects relevant to their work and/or public role, most of which had already been expressed publicly elsewhere. Moreover, I did not gather sensitive data; the questions were broadly defined and were not designed to cause, nor did they, discomfort or distress to participants.

Based on these considerations, the opinion of the supervisors and the Graduate Research Committee members was sought as to whether ethical approval was necessary for the study. After consultation, there was agreement that for this research ethical approval from the competent university authority was not obligatory, since the research aimed at gathering expert opinion where ethical risks were practically non-existent.

Despite the absence of formal ethical approval, ethical considerations were duly integrated in all aspects of the research. During the initial contact for the interviews, potential participants were handed an information package outlining the purpose of the research, the aim of the interviews (including the main questions), the participants' rights, information about data management and resources for further clarifications (See Annex 4). Prior to the interview, I asked participants permission to record the interview, in order to allow for a detailed transcription and a better analysis. I explained that the transcription and audio file would only be accessible by myself and the academic supervisors. I also clarified that the interviews would not disclose personal or private information (i.e. the name of interviewee and role in the organisation) and that material gathered from the interviews would remain anonymous, private and unpublished.

Nevertheless it needs to be noted that even if not directly asked about their biographies (with the exception of their position and involvement in the organisation, in order to contextualize the given information), some of the experts, especially those who are older persons themselves, have on some occasions referred to their own lived experiences or to those of people that they personally know. While this was inevitable, participants were not encouraged to go down this route. In such cases when experts willingly shared personal stories,

these were documented for the purposes of the research, insofar as they provided new data and/or helped distinguish between personal and organisational views.

In order to ensure that no one would be able to link the data they provided to the identifying information (i.e., name, position), the notes, final PhD thesis and subsequent publications will not include the names of individuals, but will refer to the organisations participating in the research based on the approval of the participating entities. Where single statements (i.e. quotations) are used within this thesis and for academic purposes (such as publications in journals, conferences, etc), I made contact with the individuals in advance to get their approval to use the material. Quotations remained anonymous. Findings are presented in a way that cannot be linked to an individual or a single organisation.

Only upon the permission of participants did I undertake and record the interview. Participants were reminded once more about these ethical issues upon completion of the interview and were asked to sign the informed consent sheet, indicating their agreement on these aspects one by one, by adding their initials to each corresponding statement. I felt that formally asking for participants' consent once they had given their input, was a far better way to respect their autonomy, since at the end of the interview they actually knew what had been discussed and were able to raise any doubts, if need be.

Only in one interview one participant raised concerns about the recording and the use of the data prior to the interview. The interviewee was concerned that their opinions would be interpreted as reflecting the views of the executive body they represent. The concerned staff wanted to make it clear that their opinion does not necessarily reflect the diversity of the stakeholders involved in the organisation. I took note of this concern and confirmed that I would consult them in advance of using statements from the interview and I would make sure that these did not give the impression of broad consensual positions of the organisation in question. It was also reassuring that the second participant from this organisation did not share these concerns and understood that they were

been contacted as experts. Following my clarifications, both were happy to proceed with the interview and signed the informed consent sheet.

In order to ensure that participants can benefit from the outcomes of the research, I asked them whether they would be interested in receiving a summary of the findings and other published material upon completion. All participants gladly agreed to being informed about the outcomes of my research. In addition to sharing a summary, I also updated some of the participants informally and upon their request on the occasion of professional contacts.

As mentioned earlier, professional contacts allowed me to have easy access to entities and individuals for interviews. Despite the indisputable value of these contacts, I wanted to make sure that people did not feel pressured to participate in the study. In order to do so, I made sure that I did not refer to any issues unrelated to my academic inquiry in my electronic message and stressed my research capacity at the head of the email. I moreover made it clear that targeted organisations and individuals were free to opt out from the research without having to explain the reasons for this. In addition – to the extent possible – I addressed the communication to more than one individual from the same organisation and to a general contact address, so that organisations were able to retain control over who should participate in the research in case they decided to do so. I found that in general people were both eager to participate and enthusiastic about the research and its potential added value. In the case of conflicting commitments participants proposed alternative dates for an interview, which illustrated their willingness to be included in the study. A couple of organisations did not reply to the request and one organisation declined. These examples showcase that the risk of undue pressure was mitigated, since targeted organisations and individuals were free to decide about their participation to the study.

In order to respect the ethical principle of non-discrimination I took care not to privilege stakeholders I already knew over others. As mentioned previously, I made a comprehensive sampling frame, based not only on my knowledge and

professional network, but also based on desk research and insights gained through informal interviews. Although I was not always in control of the sample, since I allowed organisations flexibility over who would participate in the research, I did manage to achieve gender balance in my sample; out of the 24 individuals involved in the research 12 were women and 12 were men.

Data Analysis

Data analysis in grounded theory is continuous and concurrent with data collection and conceptualisation until theory is developed. This section gives an account of how the analysis of the data took place. Sources of data for the analysis included the transcribed interviews. As explained above, my own observations, as captured in memos, relevant literature and other documents also informed the analysis but were not coded. Analysis of the collected data began after the first interview and included: initial, revised and focused coding, constant comparison of coded data and conceptual categories and memo writing to explore emerging ideas.

I decided to transcribe entire interviews by myself. Although time consuming, I found that the detailed transcriptions allowed me both to relive the interviews and not to risk losing important cues for the analysis. As I transcribed, I became deeply familiar with the participants' words and tone and was able to better interpret their meanings.

Encouraged by other grounded theorists, I initially opted for the Nvivo software to manage the codes of my data. I transcribed and coded my first interview in Nvivo. As I went forward, I realised that the mechanical operations did not allow me to have an overview of the data that would facilitate the iterative process. I found myself using more and more manual notes to make comparisons. After spending more than a week with the software, I tried using excel spreadsheets for the analysis. I found that although it was more difficult to search, classify and sort the codes in the excel sheets than in Nvivo, I was closer to my data using excel, as I was able to return to the codes and interview data and to integrate my own questions and comments in the excerpts, which facilitated the interpretation. I

therefore gradually used Nvivo less and less and moved all my data to excel. As the analysis proceeded, I also used handwritten notes and word documents to complete the detailed coding work. Overall, using excel allowed me to better visualize my data and make linkages between codes and conceptual categories more explicit.

Coding

While coding I followed Charmaz's advice about coding for actions, instead of themes, using gerunds (see Appendix 3). Although Charmaz encourages researchers to undertake initial and focused coding, I undertook at least a three-stage analysis, including initial, revised and focused coding. I found the intermediate step of revised coding necessary since my initial coding involved a quick attribution of codes as close as possible to data and language used by participants, without too much effort and thought about how I understood them. Many of the initial codes started with words like claiming, critiquing, arguing etc, thus describing the interview process, i.e. actions or statements of the participant. An example of how the coding evolved can be found in Appendix 3.

During the initial coding I was particularly cautious about finding deviations and variations in language and emerging categories. Since there is no previous empirical study on this topic, I was interested in echoing the manifold ways that rights in old age are expressed, understood, enhanced, diminished and promoted.

My focus was on:

- What is happening here?
- From whose point of view?

The codes were quite long and distinct from each other but allowed me to get acquainted with my data. I coded line-by-line, incident-by-incident, or word-by-word depending on the context. Some passages were coded more than one time, for example once for the overall incident, once for the language used and once for comparing with other ideas. I found this way of coding a good learning experience in terms of what had to be coded.

After having completed a round of coding and memos I undertook revised coding where I wanted to be more critical in respect of the data, leaving out the process statements and answering the questions:

- What are the data telling me?
- What are they leaving out?
- What is the conceptual understanding of what people are saying?
- What process(es) is/are at issue?

This is the stage where I began applying the method of 'constant comparison' based on early codes, my own notes and emerging ideas in order to inform future data collection and analysis. Interlinked with this process was memo writing, where I interpreted what I was seeing in the data and what was missing, I unravelled some of my own and participants' preconceptions and explored similarities and differences in order to build categories and theoretical concepts.

During this stage the importance of the context became apparent and I attempted to capture relevant linkages and reflections in memos after gathering relevant information about the country (i.e. older people's movement, socio-political-economical-cultural framework and welfare State, human rights understanding, position on convention, demographics, key law and policy, role in OEWG, ratification of UN treaties and key influencers); the organisation (origins, membership, mandate, where they get rights-based understanding from, strategic alliances, representation, transitions and critical moments in evolution of thinking, position on convention, important issues, discourse and agenda that drives organisation, i.e. exogenous versus endogenous factors); and the participant (gender, age group, role, background). This process allowed me to contextualise the data and be more critical with my codes.

As many of the interviewees are also experts in the field, their own views were likely to have been influenced by current theories and practice on ageing. Hence, situating their perspective in the wider theoretical context allowed me to examine any preconceptions. French participants for instance converged over a

particular understanding of older age, which seems to relate to an early national policy document, which influenced thinking in this area.²⁷² Looking this reference up before the end of the study, I was able to analyse my data more critically and to better prompt participants regarding their position.

The final round of the analysis was focused coding, which involved revision and critical assessment of my codes and emerging concepts based on reflections and comparisons in memos. At this stage, I revisited my codes, made extensive comparisons between them and selected those that made more '*analytical sense*'²⁷³ answering the following questions:

- What patterns do my codes reveal?
- Where does the comparison between my codes point to?
- Which of the codes best capture the data?

This entailed looking into the sources of data for each of the main codes and refining their content in memos, before developing them into conceptual categories.

Memo-Writing

Memos reflected comparisons, patterns, repetitions, overlapping and complementarity of codes feeding into the establishment of conceptual categories. They were spontaneous and temporary accounts of my ideas that have been revised several times in the course of theory building. I began writing memos from the first interview exploring some of the early codes in order to clarify their properties, make direct links with the data and test for biases as well as to see how they fit with other data and codes. Some of these tentative linkages were also captured manually, in scribbled notes and diagrams.

Memos became increasingly detailed and analytic while I was undertaking focused coding. This phase revealed both processes through which human rights breaches take place but also processes that guarantee human rights. In addition,

²⁷² More information about this can be found in Chapter 5

²⁷³ Charmaz, *Constructing Grounded Theory*, p. 138.

as explained in previous sections, I kept a reflective journal throughout the data collection and analysis where I recorded and reflected on my methodological decisions, directions and dilemmas.²⁷⁴ This journal primarily served the purpose of assessing preconceptions and avoid bringing my own assumptions into the data. In addition however, they also provided an opportunity to raise substantive questions and analytical directions even before coding the data. Capturing early impressions from the interviews, I was able to critically assess my approach and positioning as a researcher and also to record suggestions about next steps of the data collection and the analysis.

²⁷⁴ Charmaz, *Constructing Grounded Theory*, p. 165.

Chapter 5: Context and Comparison: France, Ireland and Greece

Population ageing is transforming European societies. Longer life expectancies and low fertility rates have been gradually translated into larger numbers of older people in all EU Member States. Even more dramatic changes are expected in the future. From 101 million older people in 2018, the EU population is expected to reach 149 million individuals aged 65+ by 2050.²⁷⁵ A remarkable transition is the number of the 'oldest old', i.e. the share of people 85+, which will more than double, with the number of people 100+ in the EU expected to exceed half a million by 2050. This demographic change puts pressure on policymakers to build sustainable pension, health and long-term care systems and to encourage older people to remain in the labour market for longer in order to alleviate some of the economic implications of the increasing numbers of inactive older people. Whereas demographic, economic and budgetary projections reign over public discourse on ageing at EU level,²⁷⁶ it is less clear whether a human rights narrative is used – and if so, to which extent - at domestic level. This Chapter sets the scene for the comparison, describing the main policy concerns in the context of an ageing population, the degree to which human rights are part of the public debate and the focus, capacities and organisation of older people's advocacy groups in Ireland, France and Greece. But first it explores some key distinctions between the three countries from a demography and welfare state classification perspective.

The selected countries represent three quite diverse situations in terms of demography, which are likely to create distinct challenges for the older population and for public policies. To begin with France is, of course, a much bigger country compared to Ireland and Greece. According to World Bank Data, in 2018 France had a total population of almost 67 million, while Greece has just

²⁷⁵ Data for this chapter are taken from Eurostat, "Ageing Europe - Looking at the lives of older people in the EU," (2019).

²⁷⁶ Georgantzi, "The European union's approach towards ageism."

under 11 million people and Ireland slightly over 4.8 million.²⁷⁷ It's also worth noting that Greece's population has shown a steady decline since 2011 mainly due to low birth rates since the 1970s but also to Greek post-crisis emigration.²⁷⁸ Moreover, Greece is one of the 'oldest' EU countries - coming second after Italy - with 21.8% share of its population being 65+ in 2018.²⁷⁹ At the same time Ireland is the 'youngest' EU country with only 13.8% older persons, whereas France is at the EU average with older people making up 19.7 % of the total population. It is noteworthy, that although a decade ago life expectancy at 65 in Ireland was quite low compared with other EU countries²⁸⁰, in 2013 *life expectancy at the age of 65 is rising faster here than anywhere else in the EU.*²⁸¹ So Ireland is steadily catching up with EU's ageing populations and will likely experience more demographic pressure in the future. However, older people in Ireland are expected to live more years in good health after the age of 65 than their peers in France and Greece.²⁸² In 2017 healthy life years expectancy²⁸³ at the age of 65 reached 13.4 years for women and 12.5 for men in Ireland, a score well above the 10 years at EU average. France follows with 10.8 for women and 9.3 for men, while Greece comes third among the countries in comparison with only 7.8 healthy life years for women and 8.1 for men. In summary, French and Greek seniors spend more years in poor health. This means that there is additional pressure for the welfare systems of these countries. However, the poverty rate²⁸⁴ for people over the age of 66 is

²⁷⁷ World Bank, "World Development Indicators Database,," (2019).

<https://databank.worldbank.org/data/download/POP.pdf>.

²⁷⁸ Kostas Mavraganis, "Διανέοσις Δραματικό το δημογραφικό στην Ελλάδα. Μείωση πληθυσμού ως και 2,5 εκατ ως το 2050," *Huffington Post Greece* 2016, http://www.huffingtonpost.gr/2016/09/18/dhmografiko-ellada_n_12069054.html.

²⁷⁹ For the purposes of comparison the age of 65 is taken as the cut-off point for the older population. This is done for facility, since this is the basis of EU-wide statistics: Eurostat, "Ageing Europe - Looking at the lives of older people in the EU."

²⁸⁰ Eamon O'Shea, "Developing a healthy ageing policy for Ireland: The view from below," *Health policy* 76, no. 1 (2006).

²⁸¹ *National Positive Ageing Strategy*, p.7.

²⁸² Eurostat, "European Core Health Indicators (ECHI) Data tool - Health Expectancy: Healthy Life Years (HLY) from 2004 onwards," (2019).

<http://ec.europa.eu/health/dyna/echi/datatool/index.cfm?indlist=40a>.

²⁸³ Healthy life years, abbreviated as HLY and also called disability-free life expectancy (DFLE), is defined as the number of years that a person is expected to continue to live in a healthy condition.

²⁸⁴ The poverty rate is the ratio of the number of people (in a given age group) whose income falls below the poverty line; taken as half the median household income of the total population.

higher in Ireland than in France and Greece, compared with the status of the rest of the population age groups.²⁸⁵ Presumably therefore, adequate income in old age must appear more prominently in Irish public discourse on ageing, whereas health and long-term care should be main priorities in France and Greece.

The three countries also present different nuances of the role of the State. To illustrate such diversities the original Esping-Andersen typology and its later evolution continue to be highly influential. Although the validity and utility of this classification for modern welfare states is regularly put into question, from a comparative perspective it is interesting to - at least initially - categorise the selected countries on the basis of some common and discrete characteristics of social welfare. France is conservative, Ireland presents elements of a liberal system, while Greece draws from the conservative type but is characterized by much more fragmented social insurance and high reliance on family for social protection and is therefore often clustered under the Southern-European/Mediterranean category.²⁸⁶

The conservative model, which is typical of continental European countries, aims to provide security and compensation in case of social risks mainly through a redistributive system of social insurance. It maintains traditional values and classes with the State playing a paternalistic role. In compliance with this regime, from its origins, the French system aspired to provide benefits for the working population. Hence in principle it is not a universal scheme. However, some of its aspects have gradually become more universal, in particular family benefits and medical coverage. Social insurance is managed by trade unions and employers' representatives with a certain level of State supervision but limited financial contribution by the State. Social assistance is governed and funded by the State and is not officially part of the social security regime, which has been described

However, two countries with the same poverty rates may differ in terms of the relative income-level of the poor.

²⁸⁵ OECD, "Poverty Rate (indicator)," (2020). <https://data.oecd.org/inequality/poverty-rate.htm>.

²⁸⁶ Lendvai, "Variety of Post-communist welfare: Europeanisation and emerging welfare regimes in the New EU Member States".

as a *'residual model of welfare'* that can be stigmatizing for those in need.²⁸⁷ Several public assistance services, including those targeting older people, are decentralized and run by the *départements*. Collective labour agreements also play an important complementary role in the French scheme. Pensions are based on intergenerational solidarity, but due to the difficulties of the Pay As You Go (PAYG) system, private pension funds are also flourishing. Under economic and demographic pressure, the system has increasingly become means-tested, compromising for instance the universality of family benefits.²⁸⁸

Greece mirrors the Mediterranean cluster of countries, with low social transfers by the State and heavy reliance on family, in particular for income security and care.²⁸⁹ As in France, entitlements are related to employment, *'but the system is much more fragmented and particularistic'*.²⁹⁰ Welfare institutions are less well developed, social services are limited and a culture of clientelism prevails. In Greece the redistribution of resources based on *'favourable and discriminatory'* State policies has created important discrepancies between socio-professional groups.²⁹¹ Likewise, the country's National Health System (NHS) is not universal in practice: largely based on health insurance contributions, it provides differential services depending on the insurance scheme and does not sufficiently cater for those with undeclared employment, which is a quite common form of labour in Greece. In addition, there are important gaps in the protection of the most vulnerable groups.²⁹² The Greek pension system is based on a PAYG model financed by the State, employers and employees. Since the financial crisis in 2010

²⁸⁷ Denis Bouget and Gérard Brovelli, "Citizenship, Social Welfare System and Social Policies in France," *European Societies* 4, no. 2 (2002).

²⁸⁸ Jacqueline Fraysse, "Une des plus grandes inventions du XXe siècle," in *Supplément au magazine Ensemble et Solidaires No 23 - 70 ans UNRPA*, ed. Francisco Garcia (Union nationale des retraités et des personnes âgées (UNRPA), 2015).

²⁸⁹ Luis Moreno and Pau Mari-Klose, "Youth, family change and welfare arrangements: is the South still so different?," *European societies* 15, no. 4 (2013). 2013_Youth, family change and welfare arrangements. Maurizio Ferrera, "The 'Southern model' of welfare in social Europe," *Journal of European social policy* 6, no. 1 (1996).

²⁹⁰ Stella Zambarloukou, "Greece After the Crisis: Still a south European welfare model?," *European Societies* 17, no. 5 (2015).

²⁹¹ Theodoros Papadopoulos and Antonios Roumpakis, "Familistic welfare capitalism in crisis: social reproduction and anti-social policy in Greece," *Journal of International and Comparative Social Policy* 29, no. 3 (2013): p. 209.

²⁹² Zambarloukou, "Greece After the Crisis: Still a south European welfare model?."

however, government funding has ceased, employers' payments have been lowered and employees' contributions reduced due to high levels of unemployment.²⁹³ The current situation has put even more pressure on the family to redistribute resources and provide services, while its capacity to do so has declined; this was described by Papadopoulos and Roumpakis as '*a political economy of generalised insecurity*'.²⁹⁴

Ireland on the other hand is typical of a liberal regime, which puts emphasis on free market and individual responsibility, concentrating on poverty alleviation. Although there is compulsory social insurance, '*the principle of adequacy of payments was not formally enshrined in the Irish social security system*' and provisions tend to remain at low flat rate levels.²⁹⁵ Yet, pursuant to the British/Beveridgean welfare model, means-tested social assistance remains the main pillar of the social security. Although the Irish system does not offer universal coverage, old age pension is available to everyone above a certain age, while the concept of equality is prevalent in social policy. According to Daly and Yeates '*[t]his is significant because development in Ireland has historically been framed in economic terms, crowding out discussion of the relations between the economy and society and the role of social policy in that process*'.²⁹⁶ Ireland shares some common characteristic with Greece, where welfare is largely seen as a private affair, through the strong role played by families in the welfare State, particularly in regard to the provision of social care. Historically, the Catholic Church played a prominent role in Ireland, promoting voluntarism and charity as a welfare model instead of, or in parallel to, State intervention.²⁹⁷

²⁹³ Papadopoulos and Roumpakis, "Familistic welfare capitalism in crisis: social reproduction and anti-social policy in Greece."

²⁹⁴ Papadopoulos and Roumpakis, "Familistic welfare capitalism in crisis: social reproduction and anti-social policy in Greece."

²⁹⁵ Mary Daly and Nicola Yeates, "Common origins, different paths: adaptation and change in social security in Britain and Ireland," *Policy & Politics* 31, no. 1 (2003).

²⁹⁶ Daly and Yeates, "Common origins, different paths: adaptation and change in social security in Britain and Ireland," p.91.

²⁹⁷ Michel Peillon, *Welfare in Ireland: Actors, resources, and strategies* (Praeger Publishers, 2001). Cited in Daly and Yeates, "Common origins, different paths: adaptation and change in social security in Britain and Ireland."

Despite these useful categorisations, '[i]n reality, however, all EU countries have parts of all three welfare models to varying degrees'.²⁹⁸ For instance, the lack of formal service provisions in Greece, which is characteristic of the southern model, certainly shapes some of the distinct challenges of old age in that country. But family also plays a key role in the provision of care both in Ireland and France.²⁹⁹ For example, older people's involvement in care for children and grandchildren in Ireland rose sharply between 2010 and 2014, according to the Active Ageing Index, reaching 39%. Moreover while intergenerational households are likely to be found more frequently in Greece, the housing crisis in Ireland has also led to an increase in the number of older adult children continuing to live in the family home with their parents. In general, following the crisis of 2008, structural reforms are reshaping national social protection systems:³⁰⁰ the imposition of more means tested benefits and/or stricter conditions to access them are more common alongside decreased social spending in all three countries.

Although there are obvious intersections in the welfare models that the selected countries represent, it is interesting to explore how far their political and economic foundations are mirrored in NGOs' advocacy and their understanding of human rights, or whether, on the contrary, human rights are seen as contradicting with or complementing the welfare regime in each country. Moreover, welfare culture impacts public perceptions and expectations in terms of social protection and services for old age. The comparison can therefore reveal how far the welfare culture in each of the countries under review has influenced the political commitments and public discourse on human rights and ageing. To highlight differences and similarities it's worthwhile looking separately at each country's legal and political framework and civil society landscape, in an effort to present the current narrative of old age.

²⁹⁸ Jon Kvist, "The post-crisis European social model: developing or dismantling social investments?," *Journal of International and Comparative Social Policy* 29, no. 1 (2013): p.93.

²⁹⁹ *National Positive Ageing Strategy*; Bernard Ennuyer, "La dépendance en France, état des lieux et prospective: vers un nouveau contrat social," *Regards sur l'actualité* 363 (2010).

³⁰⁰ Zambarloukou, "Greece After the Crisis: Still a south European welfare model?."; Maria Petmesidou, "Is social protection in Greece at a crossroads?," *European Societies* 15, no. 4 (2013).

France

Legal Commitments

The French Constitution – unlike on the grounds of origin, race and religion – does not explicitly prohibit age discrimination. In 2017 the Court of Cassation decided that non-discrimination on the ground of age did not constitute a fundamental right and freedom protected by the French Constitution.³⁰¹ By treating age differently than other grounds of discrimination, the Court effectively established a hierarchy of grounds, whereby age is seen as less important.³⁰² It remains to be seen whether this approach will be followed by the French Conseil d'État and the Constitutional Court. Despite this restrictive interpretation, under the French Penal Code protection from age discrimination spans beyond the field of employment. However, the extent to which the penal provisions constitute a sufficient framework in practice need to be further established.³⁰³ On a positive note, French Defender of Rights (i.e. Ombudsman) has extended responsibilities to incorporate age discrimination in employment, housing, education and access to goods and services.³⁰⁴

In addition, the French constitution enshrines social protection in old age. Its preamble also declares that the nation guarantees to all - notably to children, mothers and older workers - the protection of their health, material security, rest and leisure. And that every human being, who by reason of their age, physical or mental status, economic situation is incapable of working, has the right to receive adequate means for their existence. These constitutional provisions reconfirm the employment-related rights of the French welfare system, but also the responsibility of the State to provide for those who do not work. The primary law

³⁰¹ , No. 16-14.281 (Cour de Cassation, Social Chamber 2017). Cited in Sophie Latraverse, *Country Report Non-Discrimination France* (2019), <https://www.equalitylaw.eu/downloads/5000-france-country-report-non-discrimination-2019-pdf-1-94-mb>. This position has not been confirmed by the Conseil d'État or the Constitutional Council.

³⁰² Latraverse, *Country Report Non-Discrimination France*.

³⁰³ European Committee on Social Rights, *Conclusions on Article 23 The right of the elderly to social protection* (2013).

³⁰⁴ Law no 2008-496 of 27 May 2008 relating to the adaptation of National Law to Community Law in matters of discrimination

of the nation problematizes old age as a period of inactivity, which merits the protection of the State, in particular in terms of economic security.

Ageing Policies

The notion of citizenship is central in French politics and everyday language. When Pierre Laroque prepared in 1962 the report that is largely considered as the cornerstone of ageing policies in the country, he framed ageing in the context of citizenship, adopting a comprehensive vision of older people not in the margins, but within society.³⁰⁵ This is noteworthy because although Laroque is known as the ‘father of social security’ in the country, he tackled ageing looking beyond how to address old age poverty through the pensions system. According to Laroque, the main challenge of ageing does not lie in the lack of adequate resources, but in the structural marginalization that impedes older people from living independently and maintaining their position in society.³⁰⁶ The report discusses seniors’ employment, pensions, housing, health and social care and social integration. Old age is not seen through the spectrum of economic deprivation, but as a stage of life when one remains a full citizen continuing to contribute to society. This perspective disentangled ageing from a mere right to a pension and inaugurated public policy for ‘living in old age’ (‘mode de vie’).³⁰⁷ As a result, the life course is seen as a continuum and ageing is not considered meriting specific policies; on the contrary Laroque calls for policies aiming to absorb the existing social inequalities.³⁰⁸ This focus on social integration and citizenship established a common understanding and language to be used by professionals, policymakers, advocates and policy experts for the decades to come. Indeed, although drafted more than 50 years ago, this report is still

³⁰⁵ Pierre Laroque, *Rapport Laroque: Commission d'étude des problèmes de la vieillesse du Haut comité consultatif de la population et de la famille* (Editions L'Harmattan, 2014).

³⁰⁶ Anne-Marie Guillemard, Préface in Laroque, *Rapport Laroque: Commission d'étude des problèmes de la vieillesse du Haut comité consultatif de la population et de la famille*, p.9.

³⁰⁷ Anne-Marie Guillemard and Jean-Philippe Viriot-Durandal, "Âge, citoyenneté et politiques du vieillissement," in *Droits de vieillir et citoyenneté des aînés. Pour une perspective internationale*, ed. Jean Philippe Viriot-Durandal et al. (Québec: Presses de l'Université de Québec, 2015). D

³⁰⁸ Bernard Ennuyer, "L'actualité du rapport Laroque," in *Supplément au magazine Ensemble et Solidaires No 23 - 70 ans UNRPA*, ed. Francisco Garcia (Union nationale des retraités et des personnes âgées (UNRPA), 2015).

considered as the 'bible' of the ageing sector as evident in its relevance and influence in the recent reforms and public discourse.³⁰⁹

But French policy has not lived up to the standards of Laroque. The years following the adoption of his report, pension reforms improved the economic situation of older persons, resulting in France still having today one of the lowest rates for risk of poverty of seniors among EU countries.³¹⁰ Older people are regularly targeted in national action plans, sometimes even being their primary focus.³¹¹ Most notably, France was the first European country adopting a national action plan on Alzheimer in 2001. However, progress in the long-term care sector has been much slower.³¹² This issue gained increased public attention in modern politics when a heat wave hit France in 2003, which caused about 15.000 deaths, among which the vast majority were older people living alone.³¹³ This led to the publication of another policy document³¹⁴, which discussed ways to support older people to stay at home and suggested the creation of new branch of social security for those with long-term care needs.³¹⁵

Since then contemporary French old age policy is centred around what is called 'loss of autonomy' (*perte d'autonomie*) or 'dependency' (*dépendance*). Under

³⁰⁹ Anne-Marie Guillemard, Préface in Laroque, *Rapport Laroque: Commission d'étude des problèmes de la vieillesse du Haut comité consultatif de la population et de la famille*.

³¹⁰ OECD, "Poverty Rate (indicator)." Daniel Schraad-Tischler and Christof Schiller, *Social Justice in the EU - Index Report 2016* (2016), https://www.bertelsmann-stiftung.de/fileadmin/files/BSt/Publikationen/GrauePublikationen/Studie_NW_Social-Justice-Index_2016.pdf.

³¹¹ See for instance, among others, le Programme de lutte contre la douleur 2006-2010 ; le Plan qualité de vie des personnes atteintes de maladies chroniques (2007-2011) ; le Plan de développement de la bientraitance et du renforcement de la lutte contre la maltraitance 2007/2011 ; le Plan de développement des soins palliatifs 2008 ; le deuxième Plan santé au travail (2010-2014) ; Le Programme national pour l'alimentation ; le Programme National de Réforme de la France 2011 ; la stratégie nationale de développement durable 2009-2013 ; Le Plan solidarité grand âge 2007-2012 ; le Plan Alzheimer 2008-2012 ; le Plan Bien vieillir 2007-2009 ; Plan national d'action concerté pour l'emploi des seniors sur la période 2006-2010

³¹² Until 1994 there was no specific policy planned in the French territory. The first attempt to address the risk of dependency in old age was adopting pilot schemes at the local level

³¹³ Bernard Ennuyer, "Politique de la France concernant les personnes âgées dites 'dépendantes'," in *Droits de vieillir et citoyenneté des aînés. Pour une perspective internationale*, ed. Jean Philippe Viriot-Durandal et al. (Québec: Presses de l'Université de Québec, 2015).

³¹⁴ Jean-Marie Palach, *Vieillesse et Solidarités* (2003).

³¹⁵ The four traditional risks recognized under the French social security system are: sickness, family, work accidents and old age (pensions)

French law and public discourse, until the age of 60 someone who has a disability and needs support is considered 'handicapped' (personne handicapée), whereas after the age of 60 an individual who needs care in daily living activities is considered dependent.³¹⁶ This absurdity of the French system demonstrates that functional decline is typically considered as inherent in older age.

A particularity of the French public provision for long-term care needs is the division of health and social services. Based on the French system '*[a]ccess to a home-helper and other domiciliary services (nursing excluded) is not a legal right; access to medical treatment and APA (i.e. universal benefit for social care) is*'.³¹⁷ On the one hand, the health insurance scheme covers the cost of health care provided in an institutional setting to the dependent older or disabled patients, but also finances long-term care units in hospitals and nursing care at home.³¹⁸ On the other hand, two separate schemes, essentially financed by the State and by local authorities, provide social benefits to the old and to the disabled to help them meet some of the cost of care that is not covered by health insurance, whether that care is provided in institutions or in a domiciliary setting. This system includes a disparity between people 60+ who receive the '*Allocation Personnalisée d'Autonomie*' (APA) and younger people with disabilities, since the scheme targeting older people is a lot less generous and comprehensive than the one targeting people with disabilities, known as '*Prestation Compensation Handicap*' (PCH). The inadequacy of the APA benefit to cover for the costs of institutional and domiciliary care is central in public debate, as users are asked to pay large amounts out of their pocket.³¹⁹

³¹⁶ Ennuyer, "Politique de la France concernant les personnes âgées dites 'dépendantes'."

³¹⁷ Hannelore Jani-Le Bris, *EUROFAMCARE National Background Report for France* (2004).

³¹⁸ Social Protection Committee and European Commission, *Adequate Social Protection for Long-Term Care Needs in an Ageing Society* (European Union, 2014).

³¹⁹ According to the report Social Protection Committee and Commission, *Adequate Social Protection for Long-Term Care Needs in an Ageing Society*, p. 146. '*the remaining cost that users have to meet themselves remains high – between 2200 and 2900 euros a month for institutional care, and 1400 euros on average for domiciliary care*'.

Contemporary Discourse on Ageing

A law on the adaptation of society to ageing was adopted at the end of 2015 to address some of the deficits of the French long-term care provision.³²⁰ The framing of the law is interesting as it suggests that it is society that needs to adjust to population ageing, rather than leave the burden to older persons to make necessary changes to cope with ageing. However, there has been some critique of this law in that it went against Laroque's vision, by categorizing older people as in need of special protection and imposing a thinking of old age as deficit, cost and burden.³²¹ Indeed, despite its name, the law targets the most vulnerable part of the older population, who need care and assistance. Even though the 2015 law was supposed to equalize the benefits offered to handicapped and dependent people, it has maintained the separation. Nevertheless, it improved some of the conditions for APA beneficiaries and introduced some support for caregivers.³²²

This separation of the French system and the legacy of Laroque who stressed integration, full citizenship and equality that ought to be achieved in the frame of mainstream policies, renders French commentators and civil society quite sceptical to the idea of specific policies, laws and human rights for older persons.³²³ Their view may also relate to a narrow understanding of rights. For example, Guillemard and Viriot-Durandal, two prominent French scholars in the field of ageing and citizenship, have argued that ageing does not challenge civil and political rights but only social rights.³²⁴ In addition, one can come across a dichotomy between social rights and human rights, viewing the latter as

³²⁰ "Loi No 2015 - 1776 du 28 décembre 2015 relative à la adaptation de la société au vieillissement."

³²¹ Guillemard and Viriot-Durandal, "Âge, citoyenneté et politiques du vieillissement."

³²² "Loi No 2015 - 1776 du 28 décembre 2015 relative à la adaptation de la société au vieillissement." However, very recently in March 2020 the age barrier separating those with care needs under and above the age of 60 has been abolished by "Loi No 2020-220 du 6 mars 2020 visant à améliorer l'accès à la prestation de compensation du handicap (1)," ed. Assemblée Nationale and Sénat (2020).

³²³ See for example, Ennuyer, "Politique de la France concernant les personnes âgées dites 'dépendantes.'"; Ennuyer, "L'actualité du rapport Laroque."; Société Française de Gériatrie et de Gérontologie *Droits Fondamentaux - Déclaration de la SFGG sur l'avancée en âge l'accès aux droits et l'exercice des droits par le citoyen âgé* (2018); Fédération Internationale des Associations des Personnes Âgées (FIAPA), "Convention relative aux droits des adultes âgées et Protocole facultatif (Version 6)," (2012).

³²⁴ Guillemard and Viriot-Durandal, "Âge, citoyenneté et politiques du vieillissement," p.14.

individualistic entitlements based on freedom, unlike the former notion which integrates an objective of pursuing social solidarity.³²⁵ This controversy appears to be more common in France than in the other countries. As a result, it needs to be taken into account in a comparative context.

Despite this scepticism around human rights, there is some rights language increasingly used in national policy making and advocacy in France. Most notably, the 2015 law refers explicitly to the rights and liberties of older people, albeit with a limited scope aiming to provide safeguards for those in residential care, in particular extending them a right to designate an advocate, improving conditions for informed consent and opening the possibility to give advance directives. Although the focus on rights is encouraging, the restricted nature of these provisions enshrines an understanding of human rights in old age as synonymous to alleviating dependency and incapacity. More recently, French policy demonstrated a turn away from loss of autonomy as the norm, with the development of an action plan for its prevention.³²⁶ Additionally, a proposal to ban the use of the term 'dependency' and 'dependent older persons' has been made by the civil society council on ageing.³²⁷ There is therefore increasing consciousness in French society that the conflation of ageing with decline and loss of capacity and independence is stigmatizing and may lead to discrimination and exclusion. Moreover, until recently, the largely institution-based model of elder care in the French territory and the conditions of access and poor standards of care of these facilities remained largely unquestioned. Yet, in 2018 a movement largely organised by care professionals was mobilised in France aiming to allocate more public resources to improve the conditions of care both for workers and older persons and to change the image of ageing.³²⁸ The transition towards a

³²⁵ Guillemard and Viriot-Durandal, "Âge, citoyenneté et politiques du vieillissement."; Bouget and Brovelli, "Citizenship, Social Welfare System and Social Policies in France."

³²⁶ Ministère des Solidarités et de la Santé, *Vieillir en bonne santé - Une stratégie globale pour prévenir la perte d'autonomie 2020-2022 Dossier de Presse* (2020); Dominique Libault, *Concertation Grand Âge et Autonomie* (2019).

³²⁷ Le Conseil de l'Âge, *Avis du Conseil de l'Âge sur la Terminologie du Grand Âge* (2019), http://www.hcfea.fr/IMG/pdf/hcfea_-_conseil_de_l_age_-_avis_terminologie_grand_age_vf.pdf. 9

³²⁸ Anne-Christine Poujoulat, "Mobilisation pour les personnes âgées: Début de rassemblement à Paris," *CNEWS* 2018, <https://www.cnews.fr/france/2018-01-30/mobilisation-pour-les->

more inclusive and positive approach based on dignity, equality and maintenance of autonomy is illustrative of a transition to a more rights-based thinking that better reflects Laroque's vision. But these developments are rather sporadic instances than part of a coherent and systematic paradigm shift.

French society has been at least partially concerned with the idea of a new UN convention. In 2012 the past deputy Minister for Older People, Mme Delaunay, declared her support for a UN convention on the rights of older people but did not get traction or support within the government. Mme Delaunay asked the opinion of the CNCDH (national human rights body), which organized a public hearing and published a report on the subject. The human rights institution, in its report, did not consider older people as a particularly disadvantaged fragment of the French population.³²⁹ It noted with concern the age barrier distinguishing people with disabilities on the basis of their age instead of their need but endorsed a quite soft language in their recommendations. In the same report, the human rights institution identified a lack of awareness among older people of their legal entitlements, but argued that *'the rights of older people are neither disputed, nor ignored'*.³³⁰ While acknowledging the persisting barriers in the effective exercise of their rights, the Committee discouraged the French government from embarking in a new treaty, which would pose practical and legal difficulties.³³¹ Still, despite mirroring the integrated approach promoted by Laroque, the French NHRI was heavily preoccupied with people in care or dependency contexts, failing to equally address the full spectrum of civil, political, economic, social and cultural rights.

The ex-Deputy Minister also formed a group of NGOs that elaborated a shadow convention on the rights of older people aiming to inform the international

personnes-agees-debut-du-rassemblement-paris-773850. Pascal Champvert and Marie de Hennezel, "Contre l'impératif jeuniste! Changeons le regard sur la vieillesse!," *Le Figaro* 2018, https://ageing-equal.org/wp-content/uploads/2015/12/Tribune_Contre-imperatif-jeuniste_PC-et-MdH.pdf.

³²⁹ Commission Nationale Consultative des Droits de l'Homme, *Avis sur l'effectivité des droits des personnes âgées* (2013).

³³⁰ Ibid Para 54

³³¹ Ibid Para 53

debate. As government support was lacking, the group of NGOs continued to work outside the auspices of the Minister and published a draft Convention with the endorsement of FIAPA, the International Federation of Associations of Older People based in Paris.³³² The group stressed that there are no new rights specific to older people and underlined the fact that such an approach might be stigmatising for older people. This is why they framed issues in terms of *access* to (existing) rights.³³³ They put huge emphasis on loss of autonomy and the human rights challenges it entails, drawing a lot from the CRPD but also enshrining a right to 'dependency'.³³⁴ Once again, a very restricted approach to human rights in old age is noticeable.

Overall, it is interesting to note that although the role of the State is important in French politics and issues are often framed as rights and duties of citizens, an overarching and consistent human rights-based approach to old age, covering all aspects of old age from work and participation to end of life, is missing. Issues around elder care and fourth age have practically monopolized public discourse on the rights of older persons and - according to Guillemard and Viriot-Durandal - generally the more recent phase of public policy in France, thus failing to reflect Laroque's comprehensive vision. This entails an understanding of human rights limited to situations of disability or vulnerability. Therefore, it is not surprising that old age advocates are not convinced about the need for a new convention taking into account that the CRPD - at least in principle - covers these situations.

Civil Society Landscape

Turning now to advocacy organisations, the two main pillars of civil society for older people in France are the trade unions, which are mainly active on social welfare, and the voluntary non-profit associations. Walker and Naegele demonstrate that the voluntary branch, which focuses on the active participation

³³² (FIAPA), "Convention relative aux droits des adultes âgées et Protocole facultatif (Version 6)."

³³³ Same approach taken by *Commission Nationale Consultative des Droits de l'Homme, Avis sur l'effectivité des droits des personnes âgées.*

³³⁴ On the right to dependency from others see also Robert Moulias, "Plaidoyer pour 'un droit à la dépendance'," *Gérontologie*, no. 164 (2012).

of older people was largely developed by the socialist government in the 1960s as part of the social economy and includes about 20,000 associations made up by or intended especially for senior citizens, including local clubs for care and leisure³³⁵. Some organisations - although not union-affiliated - have formulated their objectives as demands in a similar way as trade unions.³³⁶ There is also a large number of organisations of past employees of the same company, which are primarily active in offering leisure activities.

Several ageing organisations are consulted and actively involved in policymaking. In 1980s the 'Comité Nationale des Retraités et Personnes Agées' (CNRPA) was created by law as an advisory body of the ministry in charge of older people, including delegates from 16 organisations - including trade unions- that are the most representative of pensioners and older people, alongside experts and elected officials. Similar committees also exist at local level, in the 90 departments (CODERPA), which concentrate on social care infrastructure. In 2013 the 'Comité National pour la bientraitance et les droits des personnes âgées et les personnes handicapées' (CNBD), was established as a body of exchange between the representative groups, professionals, administration and ministries in charge to discuss issues of prevention of suicides at home, right to liberty, and prevention, detection and intervention in cases of abuse at home or in institutions. Thanks to the 2015 law on adaptation of society to ageing, the CNRPA and CNBD were replaced by the 'Haut Conseil de la famille, de l'enfance et de l'âge'. This new body, formally established in the end of 2016, brings together the representative organisations and public institutions on family, ageing and children policies. They meet once a year in plenary and at least four times annually in formations representing the three sub-groups. According to its mission, the High Council is supposed to make recommendations on how to guarantee the respect of rights and the well-treatment of vulnerable people at all ages and to be consulted in all related legislative proposals. Furthermore, the law on the adaptation of society

³³⁵ Alan Walker and Gerhard Naegele, *The politics of old age in Europe*, Rethinking ageing series, (Buckingham England ; Philadelphia: Open University Press, 1999).

³³⁶ See for example, Union Nationale des Retraités et Personnes âgées ; Union Française des Retraités

to ageing specifies that the old age sub-group will focus on questions of dependency, making the necessary links with the disability sector.³³⁷ Hence, the new consultative body of the French government - although equipped with an enlarged membership - continues to concentrate on situations of care, failing to encompass a wider analysis of old age challenges.

In addition, the National Association Council (CNVA) includes representatives of pensioners and seniors' organisations. Older people also take part in the boards of administration of the social insurance fund and the national council for social work. Since November 2015 FNAR, one of the oldest and largest organisations, is given by the Ministry for Social Affairs competence to receive complaints alongside the Ombudsman and another organisation representing families, as representative of users of nursing homes at national level. There are additional instances for complaints in the departments and residential facilities. These initiatives acknowledge and strengthen the role of civil society as watchdogs and (quasi) social partners in the design and implementation of ageing policies, albeit mainly limited to addressing the risk of loss of autonomy.

Ireland

Legal Commitments

Unlike for children, the Irish constitution does not include a specific section on older people. However, article 45 on the directive principles of social policy states that '*[t]he State pledges itself to safeguard with especial care the economic interests of the weaker sections of the community, and, where necessary, to contribute to the support of the infirm, the widow, the orphan, and the aged.*' Although this is not an enforceable part of the constitution, nor does it refer to a right than can be invoked, the principles therein are to be taken into account by the Oireachtas and national courts.³³⁸ According to this constitutional provision older people count

³³⁷ "Loi No 2015 - 1776 du 28 décembre 2015 relative à la adaptation de la société au vieillissement."

³³⁸ Ita Mangan, *The Human Rights Commission - Older People in Long Stay Care* (2002), https://www.ihrec.ie/app/uploads/download/pdf/research_elderly_in_institutions_200304.pdf

among the most vulnerable parts of the population, in particular in terms of economic insecurity.

Ireland is seen to be at the forefront of EU countries in terms of protection from discrimination, since both employment and access to goods and services are covered under equality law. The Equality and Human Rights Commission (formerly Equality Authority) and the Equality tribunal are also considered good examples of promoting equality and offering remedy.³³⁹ The Equality Authority also published in 2002 a report on how to implement the principle of equality for older people, making several recommendations for government, including the abolishment of upper age limits in law and policy.³⁴⁰ They also argued that there is a need to extend a statutory duty of positive action, based on the example of Northern Ireland, which promotes systematic monitoring and equality proofing, as this would '*embed equality as a core principle in public administration*'.³⁴¹ This report distinguishes Ireland from the other two countries, as older people's issues-at least in principle- are integrated in an equality agenda. Since then studies and advocacy tend to be more centred around equality and human rights. What is also interesting in this report is that even though it was drafted almost 20 years ago it included consciousness of ageism and the need to tackle stereotypes against older persons, whereas – as shown above- only in the past couple of years has public opinion and policy and France just started paying attention to ageism. After the 2002 report drew attention to ageism, a conference on Ageism and Age Equality was organised in 2005 by the Equality Authority, the Health Service Executive (HSE) and the National Council on Ageing and Older People (NCAOP). The same organisations have launched the 'Say no to ageism Week', aiming to tackle stereotypes of older people and promote age-friendly measures in several sectors. These initiatives can increase awareness of human rights in old age and as a result penetrate the advocacy and policy sphere.

³³⁹ Schraad-Tischler and Schiller, *Social Justice in the EU - Index Report 2016*.

³⁴⁰ The Equality Authority, *Implementing Equality for Older People* (2002).

³⁴¹ The Equality Authority, *Implementing Equality for Older People*.

The Employment Equality Act prohibits discrimination in the workplace, on several grounds, including on the basis of age. Originally this act included an explicit age limit at the age of 65. Provision 6 (3) read:

Where— (a) a person has attained the age of 65 years, or (b) a person has not attained the age of 18 years, then, subject to section 12(3), treating that person more favourably or less favourably than another (whatever that other person's age) shall not be regarded as discrimination on the age ground.

But this provision has been amended on a number of occasions, including in 2004 to get rid of the 65 cut off for discrimination claims. More recently the Equality (Miscellaneous Provisions) Act 2015, provides that it shall not constitute discrimination on the age ground to fix different ages for the retirement if it is objectively and reasonably justified by a legitimate aim, and the means of achieving that aim are appropriate and necessary. Thanks to these amendments people 65+ are now generally covered by the Act, but there are specific provisions about offering fixed terms contracts. There is however an issue about entitlement to old age pension. People need to be 66 to receive a State pension but based on employment contracts they may already be required to retire earlier, with 65 being the most common retirement age. This leaves older people dependent on social welfare payments in the interim, such as on jobseekers' allowance, since they are not eligible for the old age pension for a year or more. During this time that older people receive jobseekers' payment, whereas genuinely seeking work provisions, such as job training and other activations programmes are not enforced.³⁴²

The Equal Status Acts prohibit discrimination in the provision of goods and services, accommodation and educational establishments and cover among other grounds also age. The upper age limit of 65 does not apply under the Equal Status Act. There are however exceptions to age equality with regard to adoption, fostering but also insurance. Insurance companies can apply different charges if

³⁴² Irish Council for Civil Liberties, *Know your Rights - A Guide for Older People* (2016).

the differences are based on proper risk assessment, research and statistics. It also allows a reasonable preferential charge for people in a specific age group. Unfortunately, the Equal Status Act cannot challenge all age limits as it includes a general exemption for action required under statutory provisions or court orders; this is why the Equality Authority argued for eliminating upper age limits unless there is objective justification provided by the relevant body.³⁴³ However, the Committee on Social Rights in its 2013 conclusions on article 23 concluded that that Irish legislation provides adequate guarantees to protect older persons against discrimination outside employment, but requested more information on equality policies and the application of these acts.

Ageing Policies

From a policy perspective however, an equality and rights narrative is far from being consistently applied in Ireland. Even with a relatively low share of older people in comparative European terms, Irish policy had already begun to address the challenges of older age in 1968 - around the same time as the Laroque report in France - with the publication of the 'Care of the Aged' report.³⁴⁴ Just like its French counterpart, this report opened a public debate on ageing beyond income maintenance. However, it did not adopt the broad French approach but problematized old age as a care issue, focusing on '*vulnerability and neediness*' and saying little about older people's contributions to society.³⁴⁵ While putting the building blocks for the transition from institutional to community care, it established a charitable approach to ageing, failing to inspire more positive images of older people.

However, it is a report adopted 20 years later that is considered as the backbone of modern ageing policy in Ireland.³⁴⁶ The 'Years Ahead: A Policy for the Elderly'

³⁴³ The Equality Authority, *Implementing Equality for Older People*. 2

³⁴⁴ Government of Ireland, *The Care of the Aged - Report on an Inter-Departmental Committee on the Care of the Aged* (1968).

³⁴⁵ Carmel Gallagher, "Social policy and a good life in old age," in *Older People in Modern Ireland: Essays on Law and Policy*, ed. Eoin O'Dell (2006). p. 53-54

³⁴⁶ E. O'Shea, "Public policy for dependent older people in Ireland: Review and Reform," in *Older People in Modern Ireland: Essays on Law and Policy*, ed. Eoin O'Dell (Dublin: First Law, 2006). P.13.

was published in 1988 and adopted as public policy in 1993. This influential document aimed to:

'(a) to enable the elderly person to live at home, where possible, at an optimum level of health and independence, (b) to enable those who cannot live at home to receive treatment, rehabilitation and care in accommodation and in an environment as near as possible to home'.³⁴⁷

According to Gallagher, the 'Years Ahead' policy enshrined a positive vision of ageing valuing the *'accumulated wisdom, life and practical skills'* of older people and aiming to strengthen their participation.³⁴⁸ However, the report put emphasis on medical and social care. Moreover, subsequent resource allocation did not provide the choices promised in the report and public policy continued to support residential care over home care. Ageing continued to be interpreted in dependency terms.

From the 1990s an enhanced focus on 'healthy ageing' is noticeable, as health promotion becomes the priority of the 'Adding Years to Life and Life to Years' Strategy in 1998. The concept of 'healthy ageing' in the Irish framework is mainly about preventive measures and life choices aiming to improve healthy life expectancy. Nevertheless, apart from a falls prevention strategy published in 2008, *'there are no specific national policies or programmes for prevention and rehabilitation of older people'*. Moreover, healthy ageing strategies do not cover all areas falling under the ideal of 'active ageing', which promotes the active participation of older people in society.³⁴⁹

In 2013 the new National Positive Ageing Strategy (NPAS) replaced the 'Years Ahead' policy, as public framework focusing on older people. The new strategy aims to be broader in focus than the previous documents and takes the World Health Organisation (WHO) Active Ageing Framework as the theoretical underpinning for its development. According to the vision Statement:

³⁴⁷ *The Years Ahead: A policy for the elderly - Report of the Working Party on Services of the Elderly*, (1988). See Terms of Reference, p. xi

³⁴⁸ Gallagher, "Social policy and a good life in old age." p.57

³⁴⁹ O'Shea, "Developing a healthy ageing policy for Ireland: The view from below."

Ireland will be a society for all ages that celebrates and prepares properly for individual and population ageing. It will enable and support all ages and older people to enjoy physical and mental health and wellbeing to their full potential. It will promote and respect older people's engagement in economic, social, cultural, community and family life, and foster better solidarity between generations. It will be a society in which the equality, independence, participation, care, self-fulfilment and dignity of older people are pursued at all times.³⁵⁰

The four national goals and priority areas that the NPAS sets out are far-reaching, outlining action on healthy ageing; health and personal social services; carers; employment and retirement; education and lifelong learning; volunteering; cultural and social participation; transport; financial security; housing; the built environment; safety and security; and elder abuse. Therefore, we witness a broadened understanding of ageing and an approach that goes beyond undertaking some necessary reforms but acknowledges the need for addressing the root causes through an attitudinal shift towards older people.

It is noteworthy that the NPAS - although it does not make explicit reference to rights - aspires to fulfilling principles including equality, independence and dignity. Moreover, the UN Principles for Older Persons are supposed to be guiding the implementation of the strategy. Nevertheless, this does not go as far as implementing a human rights-based approach, nor does NPAS translate legally enforceable human rights standards. Additionally, it is not accompanied by an implementation budget. Besides - and despite aiming to involve several governmental departments in its implementation - the NPAS is mainly operationalized through the Department of Health and its related programmes, in particular with the Healthy Ireland Strategy. Although the Healthy Ireland Strategy takes a lifecycle approach and aspires to provide '*more opportunities for the involvement of older people in all aspects of cultural, economic and social life in*

³⁵⁰ *National Positive Ageing Strategy.*

*their communities*³⁵¹, its potential for a more comprehensive approach to older people - beyond health related issues - remains limited. This is why NGOs in 2016 campaigned against the government's lack of a comprehensive implementation of its own stated objectives.³⁵² There are also concerns about NPAS' lack of time bound goals and monitoring mechanisms, which would ensure the translation of the goals into tangible results.

There is also a valiant commitment of a trend of local authorities to become 'age-friendly'. This approach builds on the WHO framework, which aims to change how ageing services are planned and delivered in the community.³⁵³ In 2019 Ireland became the first age-friendly country in the world, meaning that all its local governments are members of the WHO age-friendly programme and have adopted strategies to include and support older persons. The age-friendly approach aims to put older people in the centre of decision-making and thanks to the requirement found in the NPAS has promoted the development of older people's councils in local communities. Therefore, as long as age-friendly initiatives are used to operationalize the NPAS, they have the potential to implement the human rights principle of empowerment and participation and promote several good practices on the ground.

Overall, despite a strong focus on care in the community among the policy commitments in Ireland, these aspirations have not yet materialised. Several reports by NGOs, the Equality Authority and the NCAOP illustrate that the Health (Nursing Homes) Acts and the so called 'Fair Deal Act' are counterproductive as they move resources from the community to institutions. There also appears to exist a level of mistrust from civil society, vis-à-vis the government for their failure to deliver care in the community despite consecutive political commitments. For example, in spite of extensive recommendations in respect of community care, most remain unfulfilled and additional funding for older people

³⁵¹ Department of Health, *Healthy Ireland A Framework for improved health and Wellbeing 2013-2015* (2013). p.25

³⁵² See in particular 2016 'Earn our vote' campaign

³⁵³ World Health Organisation, *Global Age-Friendly Cities: A guide* (2007).

living at home has not materialised, particularly at a scale that would recalibrate care from residential care to community-based alternatives. In addition, Ireland lacks a specific policy on independent living.³⁵⁴ The Seanad Report on the Rights of Older People points to the lack of statutory footing of the 'Home Care Package Scheme' as the reason for this stalemate, although this will likely be addressed in the coming years, as new legislation is currently being prepared by government to provide new rights for home care services and supports.³⁵⁵ Moreover, Broderick argues that often older people in need of care end up in hospital, as the State has the legal obligation to provide in-patient hospital services to all citizens.³⁵⁶ Others point to the lack of uniformity of home care services across the country, which creates disadvantages especially for those living in rural areas.³⁵⁷ In addition, there is no legal entitlement to respite care for carers.³⁵⁸

Contemporary Discourse on Ageing

In spite of strong equality provisions and far reaching policy commitments, human rights discourse is only marginally used at government level to refer to older people's issues. An exception is Seanad Éireann's Public Consultation Committee 2011 invitation to make submissions on the Rights of Older People. Following a public hearing they published a report stressing that '*future policies relating to older people must move away from the 'maintenance' model to the 'rights' model*'.³⁵⁹ They recommended giving older people's entitlements a statutory footing and also '*urge[d] the Government to advance the case for drafting*

³⁵⁴ Social Protection Committee and Commission, *Adequate Social Protection for Long-Term Care Needs in an Ageing Society*.

³⁵⁵ Seanad Public Consultation Committee, *Report on the Rights of Older People*; The Institute of Public Health in Ireland, *Improving Home Care Services in Ireland: An Overview of the Findings of the Department of Health's Public Consultation* (2018).

³⁵⁶ Andrea Broderick, *An analysis of the adequacy of Irish law and policy for older people with disabilities: A European and international perspective*, 2012, National University of Ireland Galway.

³⁵⁷ Mary McMahon and Brigid Barron, *EUROFAMCARE National Background Report for Ireland* (2004); Kieran Walsh, Eamon O'Shea, and Thomas Scharf, "Rural Old-Age Social Exclusion: a Conceptual Framework on Mediators of Exclusion across the Lifecourse," *Ageing & Society* (2019).

³⁵⁸ Virpi Timonen, Maria Doyle, and Ciara O'Dwyer, "Home care in Ireland " in *Living Independently at Home: Reforms in home Care in 9 European countries*, ed. Tine Rostgaard (The Danish National Centre for Social Research, 2011).

³⁵⁹ Seanad Public Consultation Committee, *Report on the Rights of Older People*. p.9

a new UN Treaty on the Rights of Older People'.³⁶⁰ Despite this endorsement of the human rights discourse and the call for a UN treaty by the Seanad, human rights largely remains an organizational approach of NGOs at this stage, lacking practical support at policy level and from public opinion, where older people are largely seen as vulnerable and sometimes as a 'burden'. As Ni Leime et al explain, this is '*evidenced by the fact that most of the resources devoted to healthy ageing in the community are spent on medical services provided by a range of professionals while a relatively small proportion is devoted to providing social, physical, cultural and educational programmes designed to promote and preserve health*'.³⁶¹ O'Connor and Dowds argue that the growing attention of policy measures to ageing are primarily related to demographic concerns about the funding of pensions but also increasing economic competitiveness through the increased participation of older people in the labour market.³⁶² They note however that the equality/human rights agenda is gaining traction.

Yet, Aoife Nolan argues that overall, Ireland lacks '*a societal awareness and absorption of rights as concepts that should direct and constrain State action, and that may ultimately operate as the bases of claims against the State in the case*'.³⁶³ For the author, the Irish government tends to refer to 'fairness' and 'progressiveness', instead of 'rights' and 'equality' concepts. Although this claim is not specific to the case of older people, it is setting the context in which more recent attempts to frame issues as rights take place. On the other hand, Nolan notes that throughout the crisis rights language was more and more used by civil society to challenge austerity measures and call for greater protection of economic and social rights (ESR) at domestic level and concludes that '*[p]erhaps*

³⁶⁰ Seanad Public Consultation Committee, *Report on the Rights of Older People*. p.7

³⁶¹ Áine Ní Léime and Aoife Callan, "Evaluating the impact of membership of Active Retirement Ireland on the lives of older people," (2012).

³⁶² Sile O' Connor and Lizanne Dowds, "Ageism and Attitudes to Older People in the Republic of Ireland: Report of ARK Survey 2003," in *From Ageism to Age Equality: Addressing the Challenges Conference Proceedings*, ed. Yvonne McGivern (National Council on Ageing and Older People, 2005).

³⁶³ Aoife Nolan, "Welfare Rights in Crisis in the Eurozone: Ireland," in *Social rights in times of crisis in the Eurozone: The role of fundamental rights' challenges*, ed. Claire Kilpatrick and Bruno De Witte, EUI Department of Law Research Paper (European University of Florence Department of Law, 2014), p.30.

the most important positive impact of the crisis in terms of ESR has been the galvanising of support for the inclusion of economic and social rights within the mandate of the ongoing Constitutional Convention'.³⁶⁴

On the other hand, a rights-based approach is gaining traction amongst NGOs. For example, a former coalition of organisations that successfully lobbied for the adoption of the National Positive Ageing Strategy called 'Older and Bolder' defined their objective as aiming '*to champion the rights of older people and to combat ageism*', they frequently framed their calls as rights claims and even called for a new UN treaty.³⁶⁵ In 2013 the Human Rights and Older People Working Group was established, bringing together the Alzheimer Society of Ireland; Irish Council for Civil Liberties (ICCL); Age and Opportunity; Third Age; Public Interest Law Alliance; Age Action Ireland; Active Ageing in Partnership and Active Retirement Ireland. The Alzheimer Society was the leader in this Group, building on their experience of advocacy for a rights-based approach for people with dementia. The ICCL was also instrumental in framing the discussions towards a rights-based approach and recently published a guide on older people's rights.³⁶⁶ According to the Working Group, ageism is a major barrier to the realization of older people's human rights, whereas other factors include: information, voice, access to redress, resources and choice.³⁶⁷ Asserting that there are basic human rights at any age, the Working Group examined existing legislation and policy in housing, community care, health and transport to find references to older people's entitlements and propose relevant amendments. However, the organisations involved in this initiative do not necessarily follow a rights-based approach consistently in their discourse. For example, their Earn Our Vote campaign, which brought together the main civil society organisations working on behalf and with older people to influence the 2016 General Election, did not frame their pledges as rights. On the other hand, Age Action Ireland has submitted

³⁶⁴ Nolan, "Welfare Rights in Crisis in the Eurozone: Ireland," p.40.

³⁶⁵ Joe Larragy, *A Bounty not a Burden! Submission on the National Positive Ageing Strategy* (Older and Bolder, 2009).

³⁶⁶ Irish Council for Civil Liberties, *Know your Rights - A Guide for Older People*.

³⁶⁷ The Alzheimer Society of Ireland, *Human Rights and Older People in Ireland Policy Paper December 2013* (2013).

written input to the UN OEWG and also contributed to civil society reports on Ireland's implementation of UN treaties.³⁶⁸

In sum, until a decade ago ageing retained a relatively low profile in public opinion in Ireland, which did not associate older people with a huge burden on the State budget.³⁶⁹ However, the issue is now firmly on the political agenda, due to an increasing realisation that the demography of ageing in Ireland is now rapidly catching up on the standard European experience. The implications of an ageing population for pensions, health care expenditure and the labour market in general are now much more appreciated.

Similarly to France there is overwhelming concern on aspects of care, but these are more and more seen by advocacy organisations as 'hard' entitlements. This may be linked to the fact that as a liberal welfare State, Ireland foresees less statutory entitlements for old age, but aims to provide for those most at need. On the other hand, France has already a quite developed - although defective - system around old age care. In Ireland there is also increasing concern among NGOs for income security, in particular safeguarding the protection of old age income which is compromised due to cutbacks in benefits and additional taxes.³⁷⁰ The framing of issues as rights - to a certain extent - may be easier in Ireland where the provision for old age has a more residual nature. Yet, just like in France we witness here an a-la-carte approach to ageing whereby some issues are better addressed than others, failing to view older people as rights holders in all areas of their lives.

Civil Society Landscape

When it comes to the organisation of civil society on ageing, Irish civil society mainly follows a 'charity model' and most organisations representing older

³⁶⁸ See dedicated webpage: "Human Rights and Older People," <https://www.ageaction.ie/how-we-can-help/campaigning-policy/human-rights-and-older-people>.

³⁶⁹ O'Shea, "Public policy for dependent older people in Ireland: Review and Reform." O'Shea (2006) in O'Dell p.8

³⁷⁰ See Earn our vote campaign and also Age Action Ireland, *Overview of the Human Rights of Older People in Ireland* (2014), https://www.ageaction.ie/sites/default/files/attachments/overview_of_the_human_rights_of_older_people_in_ireland_july_2014.pdf.

people are not self-advocacy organisations. The NGO landscape seems to be heavily influenced and supported by external funding, mainly from the Atlantic Philanthropies from around 2006 onwards. This possibility strengthened and helped the development of the 'movement' on older people in Ireland. It allowed the realization of important projects and the collaboration of stakeholders, which would not have been otherwise possible. However, it may also have entailed a risk of social engineering, as organisational activities had to comply with the priorities of the main funder in order to receive funding. With Atlantic Philanthropies ceasing their granting function in 2018, many organisations are facing problems and, lacking secured alternative funding, some have cut back their staff and/or activities.

Regardless of these constraints, there are a number of active organisations on older people's issues and interestingly they all seem to serve a slightly different niche. The organisations that represent directly older people are Active Retirement Ireland (ARI) and the Irish Senior Citizens Parliament (ISCP). As illustrated by its name ARI mainly engages with active retirement groups, which involve mainly people who are active and healthy. Their core action lies in offering a series of activities to their members across the country. The ISCP on the other hand originated from the trade unions movement and uses more instinctively a rights language in their advocacy. They have previously been recognised as social partners under the Community and Voluntary Pillar, their outreach has weakened in recent years due to the loss of the social partnership status.³⁷¹ Some of their members overlap with those of ARI. Although in the past the two organisations were clearly complementary with ARI serving the social aspects and ISCP advocating about rights, given the increasing involvement of ARI in policymaking the two are now playing in the same field.

³⁷¹ Eurofound, *Ireland: The role of government and social partners in keeping older workers in the labour market* (2013), <https://www.eurofound.europa.eu/publications/report/2013/ireland-the-role-of-government-and-social-partners-in-keeping-older-workers-in-the-labour-market>.

Age Action Ireland is an important charity advocating on behalf of older people. They focus on changing policies, in particular for those who are most vulnerable and disadvantaged. Like ISCP they were also in the past considered as social partners. Third Age is an organisation primarily dedicated to old age volunteering, but they also offer support services, in particular through the Senior Helpline and the advocacy program (SAGE). Age and Opportunity focuses on community development, undertaking programmes about the active participation of older people in arts and cultural activities; sport and physical activity; learning and active citizenship. Alone is a charity working with and offering services to the most disadvantaged older people, those who are socially isolated, homeless, living in poverty or crisis. The Alzheimer Society provides dementia specific services and supports and advocates for the rights and needs of all people living with dementia and their carers. They have established the Irish Dementia Working Group, which includes self-advocates.

As explained above, an increasing number of organisations working for and with older people championed a rights perspective under the umbrella of the Human Rights and Older People Working Group. In the past, a number of impactful coalitions were also funded for specific purposes but ceased after funding was over. In addition to 'Older and Bolder', which was established to influence the elaboration of the National Positive Ageing Strategy, the Ageing Well Network brought together heads of organizations and units from the ageing sector, across government departments and agencies, businesses, NGOS, and academia. Funded by Atlantic Philanthropies the network aimed to influence the agenda on ageing and develop innovative solutions for old age challenges but ceased operations in 2013. The Active Ageing in Partnership brought together Age and Opportunity, ARI and Third Age under a funding grant until the end of 2016. This collaboration was an attempt to better realign the work of the three organisations and support the implementation of NPAS and other relevant policies more generally. In addition, they did work on human rights and developed a 'laboratory' for the civic engagement of older people at local level in cooperation with NUI Galway university.

All these organisations focus their advocacy at national level, although some may have also local chapters. In addition, there are various structures for participation and consultation at local/regional level, for example, Public Participation Networks, Older People's Councils, and Age-Friendly Counties. The National Positive Ageing Strategy foresees the establishment of Older People Councils by local authorities, where local concerns can be raised in the frame of the implementation of the Strategy.

The NPAS foresees an important role for the voluntary sector and also plans a civil society forum every 4 years. Despite the continuous funding, part of which was dedicated to collaborations, to date no national umbrella network on older people has emerged. Advocacy for older people in Ireland continues to be fragmented and lacking in consistent and strategic focus. This may be one of the reasons why the movement is not very strong. In the absence of social partnership, older people are still consulted, but in a less formal way and not as part of an agreement, thus it is less consistent. Crucially, there are much less structured opportunities to influence government policy, compared to France. But regardless of these limitations, NGOs seem to have been fairly successful into pushing older people's issues in the political agenda. Additionally, even if the issue of a new treaty is far from being part of their advocacy priorities, NGOs in Ireland are more likely to engage in human rights discourse than in France.

Greece

Legal Commitments

Similar to France and Ireland, the Greek constitution does not include specific reference to age discrimination, in spite of enshrining a general principle of equality before the law. In accordance with article 21.3 of the Constitution, the State has the obligation to provide for the health of its citizens and to take special measures for the protection of - among others-old age. In addition, article 25 creates a State obligation to guarantee the exercise of fundamental rights by all citizens. Despite these constitutional guarantees, it has been argued that *'it is extremely difficult to derive specific enforceable rights from these general*

principles'.³⁷² Even though the Constitution further declares that the State has the obligation to design and implement demographic policies in article 21.5, Greece does not have a clearly stated law, action plan or strategy on ageing. Public focus on ageing is centred on issues of income and to a lesser extent access to health and care, which is jeopardised due to increasing out of pocket payments. Greece is far from applying a comprehensive approach to ageing and focuses on issues of social insurance while relying heavily on families to cover the gaps. This is perhaps not surprising since it is in line with the characteristics of a Mediterranean welfare State characterized by less developed welfare institutions.

The 'protectionist' approach of the Greek Constitution towards old age is also reflected in public administration. Pensions fall under the social insurance branch of the Ministry of Labour, whereas every other action for older people is part of the Ministry's responsibility on welfare or social solidarity. The relevant unit - clustered under 'Family affairs' - is called 'Department for the protection of older people'. The language used to describe the responsibilities of the Secretary General in charge brings evidence of the fact that the older population is problematized as vulnerable and in need of protection or social assistance.

Equality provisions are largely inadequate. Even though law N 3304/2005 transposed the EU equal treatment directive, no protection beyond employment exists. Unlike France, criminal law does not include any additional prohibition of age discrimination, since article 29 of Law 4356/2015 does not address discrimination ('contempt' in the original Greek text) based on age as a criminal act.³⁷³

Greek law has established three equality bodies. First, the Greek Ombudsman is mandated to implement the principle of equal treatment in public services. As such their activities extend beyond the field of occupation and employment, covering for instance social protection and education. However, the Ombudsman

³⁷² Athanasios Theodoridis, *Country Report Non-Discrimination Greece 2016* (2016). 6

³⁷³ See article 361 B of Penal Code

does not have a wide remit encompassing for instance discrimination in access to goods and services.³⁷⁴ Second, the Equal Treatment Committee is supervised by the Minister of Justice and aims to address discrimination in private relations, with the exception of employment and occupation. Third, the Labour Inspectorate is a government body acting as mediator between employer and employee in cases of violation of the principle of equal treatment. All three equality bodies cover age discrimination with distinct remits, but only the Ombudsman is an independent body, which can intervene between the public and the citizen and also publish reports on human rights issues in the Greek territory. In 2010 the National Commission of Human Rights (EEDA) made several suggestions for the improvement of the equality legislation and its implementation, among which the recommendation to assign only one body (i.e. the Ombudsman) with the monitoring of the equal treatment act and extend the Ombudsman's mandate in this field.³⁷⁵

The Economic and Social Council is entrusted with annual reporting on the application of the principle of equal treatment and encouraging dialogue with NGOs and representative unions. It is nevertheless noteworthy that representative organisations of older people are not included in the structure of the Economic and Social Council. The same entity however has been funded by the EU to establish an observatory on active ageing (2006) as well as to analyse the Greek situation, gather good practices and provide recommendations to promote active ageing (2012). Both actions have merely focused on the labour market, failing to inspire a more positive view of old age beyond employment. According to the available information, none of these projects have involved representative organisations of older people.

³⁷⁴ The Ombudsman on consumers could be seized for related questions.

³⁷⁵ Athanasios Theodoridis, *Country Report Non-Discrimination Greece* (2016).

Ageing Policies

In spite of the general lack of policies on ageing, the 2014 National Action Plan on Human Rights includes a chapter on older people as a vulnerable population.³⁷⁶ This refers to issues of: discrimination, abuse, care, housing, adequate income and calls for the establishment of an action plan for older people, the creation of a National Council for Older People, for using the momentum of the International Day of Older Persons to discuss relevant issues among political leaders, stressing the need to provide a minimum guaranteed income to older people at risk of survival. The Action Plan moreover promotes the right of older workers 55-64 to access employment and refers to older people in terms of equal access to technologies. It also addresses some aspects of multiple discrimination against older migrants. However, there was no follow-up action to implement these commitments.

On a positive note the law 2500/2006 on intra-familial violence explicitly protects older persons from abuse. Furthermore, in 2014 a National Observatory on Dementia was established and in 2016 the committee on social affairs of the Greek Parliament adopted the National Action Plan on Dementia and Alzheimer, which should be monitored by the dedicated observatory.³⁷⁷ Although it is not directly targeting older people, if applied, this Action Plan can improve the situation of those with dementia and their caregivers, who are often older people.

On the other hand, like in Ireland and France, there is no universal statutory right to access long-term care and the bulk of care is provided by informal caregivers at home. In Greece however, State-funded long-term care services are more absent than in the other countries. The community-based program 'help at home', which is often portrayed as good practice³⁷⁸ as it aims to provide care at home to

³⁷⁶ Γενική Γραμματεία Διαφάνειας και Ανθρωπίνων Δικαιωμάτων, *Δικαιώματα του Ανθρώπου Εθνικό Σχέδιο Δράσης* (Εθνικό Τυπογραφείο, 2014).

³⁷⁷ Υπουργείο Υγείας, *Εθνικό Σχέδιο Δράσης για την Άνοια-Νόσο Alzheimer* (2016).

³⁷⁸ Council of Europe, "Recommendation CM/Rec(2014)2 of the Committee of Ministers to member States on the promotion of the human rights of older persons."; Permanent Mission of Greece in Geneva, *Submission received to the public consultation on the human rights of older persons* (2013), <https://www.ohchr.org/Documents/Issues/OlderPersons/PublicConsultation2013/Greece.pdf>.

older and disabled people, only covers a small part of the older population, due to strict means-testing as well as age and disability criteria. Moreover, it has been financed by EU funds and recently it has experienced several cuts, jeopardising its availability and sustainability. In addition, other related services are largely underdeveloped in Greece and do not cover existing demand. Moreover, some disability benefits are not available to pensioners, a situation which was deplored as discriminatory by the Ombudsman but not remedied by the Greek government.³⁷⁹ Despite this evident gap in public policy, long-term care issues rank very low in the State agenda.

Contemporary Discourse on Ageing

Overall, just like in Ireland, human rights discourse intensified in the context of the crisis and its impact on social rights, which is evidenced by a number of policy and research reports.³⁸⁰ The UN special rapporteur on foreign debt made a visit to assess the situation in Greece and paid particular attention to vulnerable groups, including older persons, making several recommendations regarding the reform of pensions.³⁸¹ Furthermore, the UN Committee on Economic, Social and Cultural rights found in 2015 a violation of article 9 of the Covenant because due to drastic cuts the availability of social security benefits is inadequate to secure decent living conditions for older persons and their families³⁸². Additionally, a couple of cases were brought to the European Committee of Social Rights regarding cuts in pensions, deploring the impact of austerity measures on pensioners.³⁸³ The National Commission of Human Rights (EEDA) noted with concern the disproportionate impact of financial reforms on older people but

³⁷⁹ Συνήγορος του Πολίτη, *Χορήγηση του επιδόματος απολύτου αναπηρίας σε συνταξιούχους γήρατος* (2008), <https://www.synigoros.gr/resources/docs/113878.pdf>.

³⁸⁰ See for example reports of the National Commission for Human Rights on financial crisis: <http://www.nchr.gr/index.php/2013-04-03-10-23-48/2013-04-03-10-41-02>

³⁸¹ Juan Pablo Bohoslavsky, "End of Mission statement of the IE on the effects of foreign debt and other related international financial obligations of States on the full enjoyment of all human rights, particularly economic, social and cultural rights," news release, 2015, <https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=16852&LangID=E>.

³⁸² UN Committee on Economic Social and Cultural Rights, *Concluding observations on the second periodic report of Greece, 27 October 2015, E/C/12/GRC/CO/2* (2015).

³⁸³ European Committee on Social Rights, Federation of employed pensioners of Greece (IKA-ETAM) v. Greece, complaint No. 76/2012, European Committee on Social Rights, Greek General Confederation of Labour (GSEE) v. Greece, complaint No. 111/2014

their unequal effect remains largely unchallenged.³⁸⁴ At the same time - even if substantially lower due to cuts imposed by austerity measures - pensions are often the cornerstone of family income with close to half of Greek households living merely on pensions.³⁸⁵ Even so, the older population is still sometimes seen as a burden for productivity, economy, social cohesion and the social security system.³⁸⁶ So the potential of intergenerational tension could impact discourse on ageing and human rights in Greece.

In 2014 the EEDA for the first time addressed the rights of older people, with the adoption of a recommendation. The human rights commission noted the invisibility of their rights at national level and supported the idea of a UN convention.³⁸⁷ Their position focuses on discrimination, autonomy and participation, informed consent, abuse and neglect, social security, employment, health and social care. The EEDA noted that the active ageing approach which is promoted by the EU is not sufficient for the safeguard of their rights, as it concentrates on the extension of working lives without paying attention to the reduced income and pensions and the disruption intergenerational solidarity. While this attention to the human rights of older persons is noteworthy, it appears to be a one-off initiative that did not have any follow up.

Thanks to EU funding some civil society organisations were involved in the elaboration of awareness raising material. The *European Charter on the Rights of Older Persons in Need of Long-Term Care and Assistance* was translated in Greek and the Greek partners of the project also participated in a follow-up action to address quality of care as a way to safeguard users' rights.³⁸⁸ In addition, in 2013 an EU-funded project on mental health developed a guide on the rights of older

³⁸⁴ Greek National Commission for Human Rights, *Protection of the rights of older persons* (2014).

³⁸⁵ Greek National Commission for Human Rights, *Protection of the rights of older persons; Greece 50+ Hellas, Submission to the Public Consultation on the Human Rights of Older Persons* (2013).

³⁸⁶ See for example, Thanasis Koukakis, "ΔΝΤ Το δημογραφικό πρόβλημα η αχίλλειος πτέρνα του ελληνικού χρέους," *CNN Greece* 2017, <https://www.cnn.gr/oikonomia/story/83638/dnt-to-dimografiko-provlima-i-axilleios-pterna-toy-ellinikoy-xreoys>.

³⁸⁷ Greek National Commission for Human Rights, *Protection of the rights of older persons*.

³⁸⁸ See EU projects EUSTaCEA and WeDO, coordinated by AGE Platform Europe. More information : <https://www.age-platform.eu/project/wedo-wellbeing-and-dignity-older-people>

people, which aimed to inform older people about the framework on the protection of their human rights, focusing on freedom from abuse and exploitation, right to private and family life and right to life.³⁸⁹ Just like in France, despite this growing attention on rights, NGO advocacy appears to be using the human rights framework to a limited extent and only for issues around care and abuse.

Civil Society Landscape

There are very few organisations working specifically for older people in Greece. Civil society includes two national organisations of trade unions including their retired members (one representing retired civil servants and the other retired employees in the private sector), 50+ Hellas, an organisation that began as a think tank and developed into a membership organisation and the Centres of open protection for the elderly (KAPI) which are open programs involving people over 60 with any socio-economic criteria and their goal is to integrate and socialise all members of community. The KAPI offer mainly social and leisure activities and are not involved in policymaking. They began their operation in 1978 and since 1994 the KAPI has been one of the responsibilities of the local government.

Some local authorities have councils of older people but there is no consistency across the country. According to the Greek report for MIPAA review in 2007,

'[o]ld persons actively participate in the Boards of Institutions and Organizations which implement policies for Elderly Persons. Also, they participate as partners in Councils that are planning policies for promoting the mainstreaming agenda. I name the <National Council of Families and Population>, the <Institute of Social Demography and Research>. Also many persons appointed by the Greek Government in the Decision Making Centres are above 65 years. ...They have been established two new Institutes as Governmental Agencies which promote policies for Aged people and encourage the Elderly to have a voice in many issues such as the Human

³⁸⁹ Δίκτυο Ψυχαργως, "Τα ανθρώπινα δικαιώματά σου": Ένας οδηγός για ηλικιωμένα άτομα (2013).

Rights of vulnerable persons and their encouragement for active social participation. Also, it has been established a Council of Third Age Persons in order their voice been heard and their opinion been respected.³⁹⁰

However, in my research and interviews with stakeholders I have found no evidence of these forms of participation. AGSSE, the pensioners' confederation, has called for a framework giving statutory footing to the involvement of older people (their members) in national policymaking. Thanks to their advocacy efforts, they managed to be consulted on an ad hoc basis by the EOPYY, national organism for the provision of health services. Yet, a structural requirement for the involvement of representatives of older people and pensioners is still missing. The previous government had announced in 2013-2014 the establishment of a National Council of Older Persons, which would have an advisory capacity and involve NGOs, but this has not seen the light of day. *In sum*, Greece is lagging behind compared to Ireland and France both in terms of policy framework and civil society engagement.

Rights and Advocacy in a Comparative Context

Compared to the other two countries, Greek policies on ageing are at an embryonic stage. Yet, all three countries also present some commonalities in particular insofar as they do not recognise older people as rights holders in all areas of their lives. In none of the selected countries has a comprehensive conceptual understanding of human rights in old age emerged. All three countries implement rights in old age selectively, focusing primarily on issues of long-term care, income and to a lesser extent access to health care. Frameworks on active participation and inclusion (beyond employment) are absent in all three countries.

All in all, we come across a fundamental discrepancy between the vision and rhetoric of the ageing agenda and its practical application in Ireland, France and

³⁹⁰ Ministry of Health and Social Solidarity, *Guidelines For Reporting on National Follow-up to the UNECE Regional Implementation Strategy(RIS) of the Madrid International Plan of Action on Ageing(MIPAA)* (2007).

Greece. In terms of political commitments, the Irish NPAS is more far-reaching than the existing dedicated frameworks in the other two countries, as it covers more substantive areas and aspires to an attitudinal shift towards older people. France, regardless of the Laroque legacy, has gradually moved towards a more restricted approach to old age, mainly addressing situations of dependency in age-specific legislation. Yet, at the same time France seems to have managed to mainstream older people's issues better in general laws and policies. In Greece on the other hand, ageing policies are yet to be developed. Hence, the countries under comparison are at different points in their development of political interest in older people. Likewise, equality bodies have diverse mandates and have addressed to varying degrees issues around old age. Consequently, the diversity of legal norms, policies and extent of protection in the countries under study allow for an interesting comparison as to how a new convention might function at the domestic level.

The consideration of the political framework in the three countries unearths three interesting findings that showcase the added value of a rights-based approach in this thesis. First, access to long-term care services and supports across all care settings is not a universal right with a statutory footing in any of the three countries. Second, age limits persist in the selected countries and to a large extent remain unquestioned, in spite of the variable degrees of protection from age discrimination. Third, adequacy of old age income is more vividly debated in Greece but remains highly relevant also in the other two countries. In Ireland increases in pensions in the last decade have maintained a relatively stable poverty risk rate amongst older people, but *'it remains a concern that so many of this county's senior citizens are living on so little'*.³⁹¹ In France, approximately 10% of the older population live in poverty. While this is lower than the national average, it is at its highest level since 1996, particularly for older women.³⁹² However, the impact of austerity seems to have influenced the debate

³⁹¹ Social Justice Ireland, *Poverty Focus 2019* (2019), p.4, <https://www.socialjustice.ie/sites/default/files/attach/publication/5763/2019-04-15-sjipovertyfocus2019final.pdf?cs=true>.

³⁹² Schraad-Tischler and Schiller, *Social Justice in the EU - Index Report 2016*.

on human rights in Ireland and Greece more than in France, possibly due to the more profound and far-reaching measures of fiscal retrenchment applied in these two countries. The table below gives an overview of how a human rights narrative and public discourse on ageing play out in the three countries.

	France	Ireland	Greece
Constitution	Social protection in old age	Economic security of the aged (as guiding principle of social policy)	State responsibility for special measures to protect old age
Political framework	Mainstream and specific	Mainly specific	N/A
Equality legislation	Employment and access to goods and services (limited to criminal law)	Employment and access to goods and services (with exceptions)	Employment
Community understanding of human rights	Mixed/Complicated (<i>juxtaposition with citizenship, equality and solidarity</i>)	Advanced (<i>integration with equality, independence, participation, seen as hard entitlements</i>)	Limited (<i>mostly economic and social rights, access to income and evidence of intergenerational tension</i>)
Focus areas	Dependency (<i>loss of autonomy/care</i>)	Community care	Adequate Income

Table 5: Rights and Advocacy in Comparison

In terms of civil society movements, compared with the other two countries, France has a quite developed ageing sector counting many specialized associations, local seniors and pensioners clubs, several large national umbrella organisations and a couple of government consultative bodies. This is understandable given the fact that France is much bigger country in terms of

population and territory. There are fewer organisations in Ireland, but more evidence of strategic development, since the activities of the different NGOs complement to a large extent each other. In Greece there is hardly any evidence of an advocacy culture specifically addressing the needs of older people. There is only one NGO targeting older people, which was born out of a research group. This picture does not take into account trade unions, which are of course operating in all three countries. There are many more professional groups representing their retired members in France than in Ireland and Greece. Interestingly, although all three countries have Economic and Social Councils assuring engagement with civil society, only the French association *Petits Freres des Pauvres* represents older people in the stakeholder group.

In sum, the development of the old age movement runs at different speeds in the three countries. French civil society not only has a lot more organisations working on ageing, but also has more formal possibilities for consultation by public authorities. Irish organisations are voluntary in orientation and are often niche based, depending on accessible and sustainable funding for their survival. There is some collaboration, but the overall advocacy system is fragmented and less effective as a result. The Greek ageing movement is still at its infancy. As a result, there are diverse levels of mobilization of older people at domestic level, variable forms of consultation and different outcomes in terms of impact on the ground. These variations will be taken into account in the analysis that follows, beginning in Chapter 6 with how participants understand the human rights of older persons. As it will be shown, the empirical findings mirror to a great extent the narrative and approaches identified so far in the three countries.

Chapter 6: Perceptions of Human Rights and Older Persons in the Three Countries

Introduction to the Findings

The presentation of the findings includes excerpts from interviews, as well as my own interpretation and comparison with literature and key policy and legal documents. Chapters 6 and 7 present the meaning of human rights for participants and the distinct disadvantage that creates barriers in equally enjoying human rights in older age. These empirical findings are briefly discussed in context of existing literature and the policy, legal and civil society landscape introduced in Chapter 5 at the end of each of these two Chapters. However, it must be noted that - in compliance with the constructivist grounded theory - the more detailed discussion of my findings in terms of conclusions that could feed into negotiations of a new UN treaty only takes place in Chapter 11.

Chapter 8 moves on with developing the theoretical understanding of the processes that undermine the human rights of older persons. This Chapter draws directly from the empirical findings presented in Chapters 6 and 7, but relies on my own interpretation of the data as co-constructor of the theory. The theory introduced in Chapter 8, provides the basis for the critical analysis of the normative standards in Chapter 10, which is why it is presented here and not in the concluding Chapters of the thesis.

Chapter 9 introduces new empirical findings with regard to the content of key areas of rights based on participants' views. These empirical conceptualisations of the substance of rights are also used to critically assess the international framework in Chapter 10.

Albeit unconventional, the presentation of the findings in this non-linear way reflects the iterative nature of the constructivist grounded theory, whereby – as explained in Chapter 4 - data collection, analysis and interpretation run in parallel and inform each other.

Quotes from interviews that took place in Greek and French have been translated by me into English. Citations have been anonymized according to the ethical guidelines of this study, but numerical references to participants in the research are given in parentheses. In order to ensure an ‘older persons’ perspective’, NGOs’ opinions are presented first and given primacy over those of other actors that participated in the interviews, i.e. representatives of human rights institutions, equality bodies and ombudspersons. Where there is a substantial difference in the findings from the three countries, this is highlighted separately. Otherwise, the results of the analysis are presented as a whole.

The Lack of a Language of Rights

The interviews set out to discuss human rights but instead came across a gap in discourse. It became evident very early in the interviews that for the majority of participants the term ‘human rights’ seemed alienating and lacked relevance. Most of the NGO stakeholders did not use this concept instinctively, widely or on a continual basis in their advocacy.

Human rights, what’s that got to do with me?... People are surprised when we say your rights to x, y, z is your right as a human being (...) They wouldn’t come in and say my rights, they would come in and say I’m being kept prisoner here, can they do that? (Participant 8)

I also think that persons with disabilities for instance may well have had far greater need to come together and to engage in activism consciously to get quite basic rights in Ireland and indeed in other countries. Therefore the narrative (i.e. of human rights) I would say was possibly engaged with, has been engaged with for many many years, I don’t believe that that’s the case with older people at all .I don’t believe that older people see their issues in the context of a human rights agenda (...) In fact a human rights narrative is very rarely mentioned in this work, almost never mentioned by older people and I would say I practically never hear it from other people (Participant 9)

I think people don't see the need for a specific covenant for example for older people in the same way that we have covenants for women and children because they don't perceive or understand the way that older people can be left out in a way that they have come around to understanding how it applies to women and how it applies to children. (Participant 7)

Whereas some understood the ways in which government decisions breached the human rights of women, refugees and other disadvantaged groups, they did not necessarily share a common understanding of how policy action might adversely affect older people's human rights. Despite describing ways in which older people may be left out, lacking support or even be discriminated against, in many cases they did not problematize such harmful situations as human rights violations. Some were unable to associate this concept with everyday situations like access to health care and pensions, which they positioned in the realm of socio-economic policies. Participants from all countries also noted that older people and their representative organisations have limited knowledge of human rights and how to claim them.

Although the majority of the interviewees from older people's organisations did not employ human rights language, some utilised related concepts, such as dignity, freedom of choice, abuse, exclusion and discrimination. However, they did not link those with legal standards, State obligations and accountability mechanisms. For example, despite its relevance for many older people who face functional limitations, less than a handful of organisations referred to the UN Convention on the Rights of Persons with Disabilities (CRPD). But even those who did, were unsure about how they could use the convention in their work. With the exception of two Irish NGOs, none of the other NGOs considered how complaining to human rights bodies or using treaties' provisions might help improve the situation of older people and how they could hold their governments accountable based on their international obligations. NGOs seem rather unaware of the value

of human rights law and are not typically motivated by international norms.³⁹³ One of the reasons for this may be that older people have not been adequately exposed to the existing human rights standards, or to the theoretical models that drive human rights activism.³⁹⁴ Some shreds of human rights awareness seem to begin to appear possibly thanks to the implementation of the CRPD and the international debate around a new UN treaty. But NGOs remain slow in applying human rights standards to frame their demands across the whole spectrum of their advocacy action.

Furthermore, most organisations do not see the campaign around a new UN convention and the application of international human rights norms as part of their mandate. Only three out of 13 of the NGOs in the sample had addressed the question of a new UN treaty in their work. Another organisation admitted that this was an issue marginally addressed by staff, but not a concern for their members. Only three organisations, one from each country, had at the time of the interviews directly engaged with the UN human rights system, either by contributing to the OEWG or the work of UN treaty bodies and the Office of the High Commissioner for Human Rights. Among the rest of the organisations, none holds consultative status with ECOSOC, the UN body that facilitates civil society participation, neither are they accredited to the UN OEWG. The international debate around a new treaty and the legal protection of the human rights of older persons therefore appears to be exogenous and irrelevant to older people's advocacy in the three countries.

Human rights is not a language that policymakers use or necessarily understand, according to a couple of interviewees. In fact, depending on which part of the public administration ageing falls under, older people's issues are more routinely

³⁹³ Herro, "Domestic interest groups and rights mobilization: explaining the case of Slovenia's support for the proposed Convention on the Rights of Older Persons."

³⁹⁴ Doron, "From national to international elder law." See also Rosalyn B. Darling and D. Alex Heckert, "Orientations toward disability: Differences over the lifecourse," *International Journal of Disability, Development and Education* 57, no. 2 (2010). stating that compared with people with early onset of disability older persons are not as exposed to the social model of disability and AGE Platform Europe, AGE Platform Europe position on article 19 of the UNCRPD, (2016). mentioning that organisations of older persons lack familiarity with the CRPD.

seen through the spectrum of health or social welfare. As long as human rights language is met with resistance by the respective public officials, NGOs are more likely to frame issues in the context of the fight against poverty or measures for inclusion, especially insofar as the domestic landscape is equipped with relevant policy frameworks that they can call upon.

The empirical findings have therefore exemplified the lack of human rights awareness among NGOs in the sample. These findings from the national level therefore converge with extant literature that confirms a lack of awareness of human rights among older people and the underutilisation by representative NGOs of the international human rights framework.³⁹⁵ It has also been argued that the human rights lens is not regularly applied to older people.³⁹⁶ Indeed, representatives of equality and human rights entities involved in the study appeared to be lacking a significant and consistent body of work around older people's rights, unlike for other groups, such as women, children and persons with disabilities. As demonstrated also in the previous chapter, whereas some of the interviewed non-NGO stakeholders had opportunistically seized an occasion to do some targeted study, overall older people's rights did not count among their strategic priorities. The Greek NHRI (EEDA) adopted an opinion on older people's rights, including a recommendation for the adoption of a new UN treaty encouraged by relevant work at European level and by other NHRIs.³⁹⁷ Likewise, the French NHRI (CNCDH) was commissioned in 2013 by the French Ministry to do a hearing and a study on the same topic.³⁹⁸ The Irish Human Rights and Equality Commission contributed to the Citizens' Assembly around issues of old age and had also in the past done some work on age equality.³⁹⁹ But, with the

³⁹⁵ Morgan and David, "Human Rights: A New Language for Aging Advocacy ": 441; Love and Lynch, "Enablement and positive ageing: a human rights-based approach to older people and changing demographics."; Doron, "From national to international elder law."; Rodriguez-Pinzón and Martin, "The International Human Rights Status of Elderly Persons ".

³⁹⁶ Mégret, "The Human Rights of Older Persons: A Growing Challenge."

³⁹⁷ Greek National Commission for Human Rights, *Protection of the rights of older persons*.

³⁹⁸ Commission Nationale Consultative des Droits de l'Homme, *Avis sur l'effectivité des droits des personnes âgées*.

³⁹⁹ Emily Logan, *Irish Human Rights and Equality Commission Advance Briefing Paper to the Citizens' Assembly - Pensions, Income and Retirement: Human Rights and Equality Considerations*,

exception of these ad hoc initiatives, ageing does not appear as a potential focus for human rights institutions. Neither have human rights bodies addressed adequately the full spectrum of the human rights of older persons. So, older people's issues have not yet entered the mainstream of human rights practice at national level.

'Being the same': Rejecting an 'Older Person' Identity

This thesis is concerned about the unique disadvantage of older age –if any- that brings older people together in terms of human rights protection. Does this experience have to do with older age alone, or is it merely the accumulation of other lifetime disadvantages, such as low income and socio-economic status, gender inequalities and so on? Do older people share a common identity as a group? In discussing the meaning of human rights for this group answering these questions is crucial, especially since in discussions around the need for a new treaty, whether older age is a particular disadvantage that merits distinct human rights protection is contested.

The empirical findings concur with literature presented in Chapter 2 arguing that defining older people presents an important conceptual and normative challenge. The notion of older persons, despite being widely used, is according to most participants vague and open-ended.

Because there are certain sociologists that say that a two year old, is an older person compared to someone who was just born. So, 'older' what does it mean? It does not have a lot of sense. In life we all evolve and older persons are simply young people who are older than others (Participants 2)

A 100-year old and someone who becomes retired today for example, have a huge difference in their interests, their experiences and their needs (Participant 13)

Irish Human Rights and Equality Commission (The Citizens' Assembly, 2017); The Equality Authority, *Implementing Equality for Older People*.

Who is an older person will vary depending on the country, the context... In any case, the younger retirees do not find themselves in this notion (i.e. of older people). Talking about retirees, not everyone is retired, in some countries older people continue to work informally (Participant 19)

Most interviewees struggle to identify something specific in old age that renders it a separate stage of life. Neither can they describe a single moment when one becomes old. 'Are we talking about old people or about people of older age?' asked one of the participants. He explained that their organisation targets people above the age of 50, who are not necessarily reflected in the term 'old people'. This linguistic variation exposes a divergence in the understanding of what constitutes an old person. The latter concept of people of advanced age probably puts the focus more on a comparative aspect (i.e. people in older age than others), and on the normal progression of the life course rather than on reducing the group to certain characteristics stereotypically associated with later life. The emblematic example of the terminological difficulty of the notion of older people, according to the participant, is that it often fails to be associated with people who are still working. This population however may face discrimination on the basis of older age, despite not being considered – strictly speaking – as old. Other interviewees, including a couple of human rights actors, also mirror this complexity in conceptualising as old, those individuals who are still in the labour market.

In addition, several of the participants admit that themselves or some of the individuals that they represent or work with do not self-identify as being old.⁴⁰⁰

I knew somebody who in her 90s was very upset because she could no longer go – she had a fall - to the local nursing home to play cards with the people there, the old people, she did not consider herself old (Participant 5)

⁴⁰⁰ On this see also Jonathan Herring, *Older people in law and society* (Oxford University Press, 2009). p.18 citing Cathrine Degnen, "Minding the gap: The construction of old age and oldness amongst peers," *Journal of Aging Studies* 21, no. 1 (2007).

We are old when we need a walking stick, care, eyeglasses, hearing aid, then I am old; but when I am on the street, I am not older than a person of 50 years of age (Participant 1)

And everybody kind of puts off the older thing, that's the thing that I find, I think about that. 'Are you looking after my old age?' people say to me, these people are 70. And I said 'You should be looking after your old age'. What is your old age? When are you in it? You know? (Participant 5)

The above remarks illustrate that the term 'older persons' is not neutral; instead it remains heavily burdened with certain negative assumptions about what it means to be old. A couple of participants give examples of older people who do not want to install rails in their staircase or use hearing aids because that '*would make them into an old person*'. So even though old age advocates hold a nuanced view of older age that involves diverse experiences and attributes ranging from participation in the labour market to the need for care and support, they nevertheless sometimes consciously or unconsciously tend to differentiate themselves and the group they represent from the 'older people group'. To identify oneself with a group, one must hold positive attitudes towards the members of the group.⁴⁰¹ Insofar as older age has been associated with decline, end of life and stigma, it is perhaps unsurprising that old age advocates are against being associated with a specific older people identity.⁴⁰² Seeing older people as weak and frail leads - for participants - to a culture of paternalism and does not adequately reflect the diverse reality of the older population, who in their majority are healthy and active and are not in need of protection.⁴⁰³

⁴⁰¹ Francesca Polletta and James M. Jasper, "Collective identity and social movements," *Annual review of Sociology* 27, no. 1 (2001); Sagit Lev, Susanne Wurm, and Liat Ayalon, "Origins of Ageism at the Individual Level," in *Contemporary Perspectives on Ageism*, ed. Liat Ayalon and Clemens Tesch-Römer (Cham: Springer International Publishing, 2018)..

⁴⁰² Lev, Wurm, and Ayalon, "Origins of Ageism at the Individual Level."; Fineman, "Elderly as vulnerable: Rethinking the nature of individual and societal responsibility."

⁴⁰³ Stefanos Grammenos, *European Comparative Data on Europe 2020 & People with Disabilities* (2013),

<http://digitalcommons.ilr.cornell.edu/cgi/viewcontent.cgi?article=1569&context=gladnetcollect>.

As explained in the previous section, NGOs participating in the study do not accept that advocating for older people's rights is an essential expression of their mandate. One of the main reasons why human rights have not yet penetrated their work is because a majority of older people's organisations perceive the idea of 'human rights of older persons' as aiming to create a special system of protection for this group. Defending 'older people's rights' seems to participants like accepting that older people are different from other groups in society or that they have 'special needs'.

A convention on older people can be quite insulting to older people because a lot of them are perfectly capable and regard themselves as still full members of the human rights... is like admitting that older people are less human (Participant 8)

We want neither more nor fewer rights than citizens; we want equal rights. We want society's recognition... this is not something new, it is the application of what already exists (...) We want recognition of role. And we claim roles, we don't claim rights (Participant 3)

We have to balance that with the fact that part of our remit and part of our ethos and part of what we do is trying to say that people at this age, say 65-66 are no different from people at this age, 45-46. So, balancing that with oh, but we want a separate charter for the rights of the older adult, it can become difficult (Participant 6)

From the point we start creating categories in terms of rights we betray a bit the essence of human rights, which is about protecting each individual instead of offering protection per group (Participant 21)

Conversely, NGOs do not see older people as a separate group. They fear that the construction of older people as a distinct category reinforces stereotypes of older people as weak and vulnerable and acts as a licence to perpetuate paternalistic and discriminatory attitudes and practices. They believe it is seeing older people as different that nourishes the culture of division between 'us and them' and

provides the ground for exclusion on the basis of chronological age. The idea of 'human rights of older persons' is interpreted as an attempt to emphasize difference and by consequence as entailing the risk to widen their segregation as a distinct 'social class'. These concerns become quite clear when discussing the need and potential of a new convention, which is perceived by some as calling for the establishment of a specific set of rights attributed to the old.

We therefore see a conflation between a human rights-based approach and an idea that it entails different rights for older people. In other words, these participants fear that the narrative of older people's rights disconnects them from everybody else's human rights. They do not see it as an opportunity to explain how the universal rights that we all supposedly enjoy can become equally effective in the context of older age.

Moreover, participants believe that viewing older people as different can be used to justify their inferior treatment and maintain systems of subordination. For example, it is not the probability of sickness and disability that differentiates older people from other adults and creates an increased need for human rights protection; it is the fact that old age disability and illness are not treated on a par with similar conditions occurring in other stages of life. The categorisation of individuals as old creates binaries and boundaries, instead of ensuring universal access to entitlements and resources regardless of age or other status.⁴⁰⁴ So instead of attempting to determine specific aspects of older people's lives that distinguish them from other groups in society, participants are interested in how society defines fewer opportunities and support mechanisms for individuals in the old age group.

Using terms such as equal treatment from '*cradle to grave*' and '*go[ing] seamlessly*' from one stage to the next, participants seem to reject approaches that aim to

⁴⁰⁴ Fineman, "Elderly as vulnerable: Rethinking the nature of individual and societal responsibility."; Bill Bytheway, *Ageism* (Buckingham: Open University Press, 1995).

cater for the distinctive needs and interests of the old age group. This is why they stress the sameness and equality of older people with other citizens.

The life course is a continuum rather than a set of blocks ... what concerns older people more than anything else is what concerns everybody else...We push for how older people are portrayed and seen in wider society to be changed, that we no longer see retirement or the third stage of life as the end stage of life, but rather as another equally valid part and portion of a life course (...) We are just trying to point out the fact that older people are still doing everything they were doing in their working life (Participant 6)

I don't really see older people as changing as they get older as they move into things, you know. What I would like to see is older people continuing to be who they were and having a role in society but that is their choice (...) So what I would like to see is a situation in Ireland, if we are looking at a very high level goal where people can go seamlessly from one stage of their lives to another (Participant 5)

In sum, participants are against human rights protection on the basis that older people have unique characteristics that separate them from mainstream society. Based on the empirical findings, the development of a rights-based framework needs to favour universalism and equal treatment over specific rights based on difference or identity.

I need space to be able to create that opportunity to be who I am. I can do that through my citizenship but if there are fundamental ways in which I denied that I can't fully participate and that's inequality (Participant 10)

In terms of rights, we consider that we are citizens and therefore we enjoy the same rights with all the citizens of the nation. There should not be any difference. (Participant 2)

I think that it's not necessarily a good formulation to talk about 'the rights of older people' (,,) I think that older people are just adults who are older

than others. So, the Universal Declaration of Human Rights covers their rights and so do as well the other international conventions that derive from this declaration. On the contrary, because I am old I can have difficulties in accessing my fundamental rights or (...) I may experience on top of other discriminations, an additional discrimination related to age. (...) I think we should be talking about equality of rights rather than simply rights (Participant 19)

The argument that the conceptualisation of older people as holders of rights should not rely on an understanding of old age requiring special treatment is reflected in all three countries, but it is particularly prevalent and consistent in France.

Based on the analysis, it is plausible that this controversy –at least partly - originates from the fact that the French bodies have failed to disentangle challenges associated with older age with those arising from disability and to understand the distinct nature of structural inequality in old age.⁴⁰⁵ But as demonstrated in the previous chapter, this French particularity may also be due to reasons of political history and legal tradition, since from its inception ageing policy was not foreseen as affording special treatment to the old.⁴⁰⁶ But also more generally, for the French, the fragmentation of human rights for different groups is perceived as a breach of the indivisibility and the universality of human rights.⁴⁰⁷ Traditionally French thinking does not accept the need to recognize social groups as different, since such categorisation may enhance stereotypical identities.⁴⁰⁸ This may explain why both NGOs and human rights actors prefer

⁴⁰⁵ As explained above the French tend to conflate older people's rights with disability rights and argue that the CRPD is an adequate framing for older people's challenges.

⁴⁰⁶ See Chapter 5

⁴⁰⁷ Bouget and Brovelli, "Citizenship, Social Welfare System and Social Policies in France." A participant also explained that French constitutional tradition abolished any privileged treatment of interest groups, which involves not accepting human rights as collective challenges for groups.

⁴⁰⁸ Matthias Iser, "Recognition," in *The Stanford Encyclopedia of Philosophy*, ed. Edward Zalta (2019).

focusing on the effectiveness and equal access to universal norms, as opposed to a new treaty.

In the other two countries, some participants also believe that a new treaty signals that older people are intrinsically different or require special safeguards. They argue that human rights by definition include older persons. Others have explained that even if a new treaty can strengthen the protection of the human rights of older persons, it should not do so *'at the expense of an elitism'*, which implies that older people's rights have higher or different than others' rights.

In putting the emphasis on experiences of advanced age, as opposed to older people as a separate social group, participants locate disadvantage outside the individual. NGOs reject the idea that old age is a biologically bound predictor of capacities and behaviour. It is not a medical model that focuses on biological attributes or inevitable losses that defines older people's advocacy. Instead of focusing on a vulnerable status that is intrinsically associated with older individuals, they focus on situations that may create vulnerability. Participants therefore seem to imply that there are some structural barriers that are distinctly experienced in later stages of life.

Chapter 7: Evidence on Older People's Distinct Disadvantage: The Power of Discounting

Using terms such as *devaluing, diminishing, undermining, perceiving as worthless, ignoring or disrespecting*, participants consistently refer to an implicit - although automatic and systematic - subordination of older people, which leads to an absence of equal recognition, assistance and inclusion. Participants give varying examples where the views, knowledge, contributions, roles, experience, skills and life trajectory of older persons are devalued and where older people are systematically ignored in policy, law and practice in the three countries. They even refer to cases where older people are treated like objects.⁴⁰⁹

One participant talked about being treated differently as soon as you are perceived as old and based merely on your physical appearance, for example having white hair. Another participant explained that the chronological age of the person is sufficient for making guesses about their ability to take decisions despite the fact that the person is not suffering from a cognitive disability. Another one agreed that older people are *'kind of elbowed out of the way and pushed around'*, regardless of whether they are active or fragile. The assumption that older people are more likely to be poor or not likely to spend a lot also disregards their actual economic situation, which may be better than that of young people, commented another participant. Someone else stated that older people are treated *'like packages'*, as they are moved around without asking their opinion. One interviewee mentioned that inhumane treatment in care provision is not uncommon when older people are put in a situation where they are not able to communicate with caregivers or they are even at risk of neglect, violence and abuse. All these situations according to participants are not met with social disapproval.

⁴⁰⁹ See also Sue Thompson, *Age discrimination*, ed. Neil Thompson, Theory into practice, (Russell House Publishing, 2005), p.24.

Some participants explicitly refer to ageism and how it affects the unequal enjoyment of human rights in older age. Others, without naming an old age-specific disadvantage, or while acknowledging intersecting factors such as gender, socioeconomic status and disability, explain that there are some beliefs, structures and power imbalances based on age that are so institutionalised in society that they constitute a type of taken-for-granted social reality. Since not all interviewees use the term ageism to describe this process, *discounting* is preferred as a notion that is closer to participants' words, experiences and concerns and it allows us to delve deeper into its manifestations and effects avoiding any presumptions about its severity, expressions, causes or substance. Discounting relies on the successful stereotyping of older people, which includes implicit assumptions about older people as a group, ageing as a process and older age as part of the lifecycle.⁴¹⁰ It requires grouping older people together, whilst ignoring the vast heterogeneity of the group.⁴¹¹ It is about attributing certain (most often negative) characteristics to the group, such as decline, passivity and dependence. The problem with ageist stereotypes is that they tend to act as heuristic devices that we barely even notice when we employ them.⁴¹² It is the very fact that stereotyping is so entrenched in discourse, policy and practice that makes it difficult to observe and acknowledge the injustice against older people.

Forms of Discounting

Old age as decline

One of the key ways in which discounting operates is through associations of old age with loss of functional abilities.⁴¹³ Physical and cognitive decline are seen as the norm in later life. Equating older age with sickness according to participants entails the risk of considering pain and disease as normal. As a result, ill health is seen as a symptom of older age instead of as a medical condition that merits

⁴¹⁰ Liat Ayalon and Clemens Tesch-Römer, "Introduction to the section: Ageism—Concept and origins," in *Contemporary perspectives on ageism* (Springer, Cham, 2018).

⁴¹¹ Thompson, *Age discrimination*, p.4.

⁴¹² Ayalon and Tesch-Römer, "Introduction to the section: Ageism—Concept and origins."

⁴¹³ Erdman Palmore, "Guest editorial: Ageism in gerontological language," *The Gerontologist* 40, no. 6 (2000).

treatment.⁴¹⁴ One interviewee explained that health and long-term care professionals perpetuate biased views of older people as dependent because they work with older people who suffer from some chronic condition and need help. Therefore, they cannot conceptualise older age without disease and loss.⁴¹⁵ In addition, there is misapprehension that health care is ineffective in later life.⁴¹⁶ Consequently, sickness and disability in old age are not compensated and addressed in an equal manner as they would should they have arisen at a younger age. Participants gave examples of age limits in health preventive screening, among others.⁴¹⁷ One participant underlines that older people may even risk not receiving any care at all.

[W]e can't prove it but we think that some people don't get (i.e treatment), if you are over a certain age that you are not given the same as if you are under a certain age. You know, you certainly have a right to treatment but you haven't necessarily have a right for them to do everything that should be done for you...Like if you had the right to health services irrespective of age that would make a big difference...(Participant 5)

[I]n many cases, particularly in the medical sphere institutional ageism is huge and older people are being told that very real injuries and strains and pains are just wear and tear, old age and all those cliché things that you might hear (Participant 6)

Old age as nearing death

Discounting also encourages views of older age as a prelude to death. Whereas youth is typically associated with energy, potential, evolution and positive feelings, the belief that old age will be succeeded by death entails according

⁴¹⁴ Thompson, *Age discrimination*, p.22.

⁴¹⁵ Thompson, *Age discrimination*, p. 20.

⁴¹⁶ Sarah Spencer and Sandra Fredman, *Age Equality Comes of Age: Delivering Change for Older People* (Institute for Public Policy Research, 2003), p. 23.

⁴¹⁷ See also AGE Platform Europe, *AGE Platform Europe Position on Structural Ageism* (2016), http://age-platform.eu/images/stories/Publications/papers/AGE_IntergenerationalSolidarity_Position_on_Structural_Ageism.pdf.

participants a lower social status and valuation.⁴¹⁸ Based on such prejudices a person's age will play a role in determining whether or not assistance will be provided, whether a consultation will take place and whether an opinion or vote will be valued. According to some participants dying in old age is considered as normal and is therefore not avoided. In the context of rationalisation or shortage of resources, it is often argued that life-saving measures should prioritize young people.⁴¹⁹ All these attitudes are not only demeaning, but they also contradict the evidence on rising life expectancy, which means that people may live up to 30-40 years after retirement. Moreover, equalizing old age with end of life tends to serve as justification for the sacrifices or compromises that one has to make in later life. As a result, neglect, segregation and unfair treatment tend to be considered more acceptable just because they happen in later life.

It's not because you are old that we are not going to treat you. It's because you are frail that this treatment may not work for you. We may not offer the same treatment for cancer to a 50-year-old and 85-year-old. But the problem is that if the patient is 85 years old, they may [do nothing for them and] let them die (Participant 1)

One of the things I would also be concerned about is end of life issues because you think you are going to be protected because doctors are very 'do good and do no harm' but I recently I had experienced people assuming because you are 90 you want to die and it was furthest from the truth, so there is an ageism within the medical profession (Participant 10)

Old age as loss of productivity

Another stereotype that leads to discounting is the association of older people with passivity, unproductivity and burden.⁴²⁰ Social expectations of older people

⁴¹⁸ Herring, *Older people in law and society*.

⁴¹⁹ Paulo Antônio de Carvalho Fortes and Patricia Cristina Andrade Pereira, "Patient prioritization in medical emergencies: an ethical analysis," *Revista da Associação Médica Brasileira (English Edition)* 58, no. 3 (2012); Greta Privitera, "Italian doctors on coronavirus frontline face tough calls on whom to save," *Politico* 2020, <https://www.politico.eu/article/coronavirus-italy-doctors-tough-calls-survival/>.

⁴²⁰ Phillipson, *Ageing*; Fredvang and Biggs, "The rights of older persons - Protection and gaps under human rights law."

are often related to retirement and loss of productive roles.⁴²¹ Several participants mention that when people leave the active population, they are no longer recognized, respected and treated as equals. As long as retirement is seen as normal or inevitable, older people's right to continue working is not recognized and facilitated to the same extent as for other adults.

They may not mention it in the (i.e. job) advertisement because it is no longer legal, but when you go and you are over 55 they tell you 'thanks and goodbye' (...) that is, for someone who wants to work, it is practically impossible. This is why some of today's unemployed, the vast majority are obviously young and have not yet started, but there is also a large number of people who lost their job after 50 and cannot find anything. And they may also consider themselves that it is out of the question to find something (i.e. a job) again and wait until they reach a certain age to retire. There is great difficulty in this, which as we said – ok- it is contrary to the law, but it is happens and it is happens in many cases. (Participant 3)

Moreover, when inactivity is seen as natural, there are fewer opportunities for older people to learn and to contribute. For example, according to one interviewee there is far less investment for the training of older workers. Since they are routinely seen as passive, they are not necessarily encouraged to take political action, to volunteer and grow. Instead, as some participants underlined, they restrict themselves to roles associated with the family or with leisure. Stereotypes about older people's place in society seem to impact how policies, institutions and services are structured but also how individuals behave. Diminished roles also lead to a loss of social status in older age.⁴²²

⁴²¹ Diana K. Harris, "Age norms," in *Encyclopedia of ageism*, ed. Laurence Branch, Diana Harris, and Erdman Palmore (Haworth Pastoral Press, 2005); Diana Harris, "Role expectations," in *Encyclopedia of Ageism*, ed. Laurence Branch, Diana Harris, and Erdman Palmore (Haworth Pastoral Press, 2005).

⁴²² John Macnicol, "Ageism and age discrimination: Some analytical issues," *International Longevity Centre* (2010); Dominic Abrams and Hannah J. Swift, "Ageism doesn't work," *Public Policy and Aging Report* 22, no. 3 (2012).

Once we leave the production, we are considered just as 'worthless mouths to feed' (bouches inutiles). 'So, what do they want?' This is not good. (Participant 2)

So, the economic value of somebody to the State of not getting breast cancer up to retirement age is greater than no economic value to the State of somebody having cancer over the age of 65. Because they are now not paying tax, in fact they are dependent on the State, so I think it has to do with that as much as with the incidence of breast cancer, but they did increase the age, I think in some areas of the country I think now it's 70 and I don't know if they now realise that the risk factor is up to the age of 70 or because they think you are economically viable up until the age of 70, because you mind grandchildren etc, etc (Participant 8)

Older people are seen as having less economic value because they yield lower returns.⁴²³ This may become a reason why to deny prevention or treatment to people beyond a certain age. But such negative perceptions of older people as undeserving overlook their ongoing contributions as well as their underexplored potential to benefit their communities.⁴²⁴

Old age as privilege

Older people are sometimes considered undeserving for an opposite reason. In parallel to stereotypes of older people being frail and dependent, there exist also images of older people as being wealthy or privileged. According to a couple of participants, they are even perceived as '*fat cats*', who don't only have a lot of money but also do so at the expense of society. Especially in the context of the crisis, there is widespread belief that older people are doing better than others, in particular compared with the young unemployed, because pensioners have a relatively stable income.⁴²⁵ Such prejudices that nourish intergenerational

⁴²³ Macnicol, "Ageism and age discrimination: Some analytical issues."; Spencer and Fredman, *Age Equality Comes of Age: Delivering Change for Older People*.

⁴²⁴ Herring, *Older people in law and society*. p. 15-16

⁴²⁵ AGE Platform Europe, *Older people also suffer because of the crisis* (2012).

tension explain why it is difficult to talk about older people's rights in a period when young people's security is at stake.

A couple of participants argue that the social impulse to consider older people as wealthy and privileged considerably undermines the structural inequalities that many older people face. For example, some participants claim that portraying older people as active and wealthy, entails a risk of not catering for the needs of those who might require assistance and not facilitating their inclusion. Similarly, scholars have argued that the strategies of active and successful ageing that describe older people as retaining strength and social engagement may put an excessive burden on the individual to achieve those standards.⁴²⁶ So whereas in the past older people have been seen as 'deserving', this stereotype now turns older age into a period when individuals might not deserve assistance and support.⁴²⁷ But for participants, what scholars have described as '*compassionate ageism*'⁴²⁸ continues to exist in attitudes and policies that perceive older people as *deserving* of charity. These are also considered problematic in that they see older people as objects of care and not as agents. Overall, it is important to note that these stereotypes do not exist in a vacuum. They often intersect and complement each other. Several conflicting stereotypes can be simultaneously operating on perceptions of older people, such as being privileged and needy, deserving and undeserving, which may contribute to the complexity of conceptualising older people's grievances as human rights issues.⁴²⁹

The findings so far have demonstrated that undermining the worth of older persons acts as a structural power that shapes every interaction with and

⁴²⁶ Ayalon and Tesch-Römer, "Introduction to the section: Ageism—Concept and origins.;" Thibault Moulart and Simon Biggs, "International and European policy on work and retirement: Reinventing critical perspectives on active ageing and mature subjectivity," *Human Relations* 66, no. 1 (2012); Georgantzi, "The European union's approach towards ageism."

⁴²⁷ Robert Binstock, "Public Policy," in *Encyclopedia of Ageism*, ed. Laurence Branch, Diana Harris, and Erdman Palmore (Haworth Pastoral Press, 2005); Joan Harbison, "How ageism undermines older people's human rights and social inclusion: revisiting advocacy, agency and need in later life," in *Ageing, Wellbeing and Climate Change in the Arctic* (Routledge, 2015).

⁴²⁸ Binstock, "From compassionate ageism to intergenerational conflict?"; Thomas Nicolaj Iversen, Lars Larsen, and Per Erik Solem, "A conceptual analysis of ageism," *Nordic Psychology* 61, no. 3 (2009).

⁴²⁹ On this see also Mégret, "The Human Rights of Older Persons: A Growing Challenge."

measure targeting the old. It does not only affect individual behaviour but also policy and law. Discounting attitudes and beliefs affect social expectations about what is appropriate and fair for each age. They make it more acceptable and legitimate to marginalise, constrain and discriminate older people. Older people are not only disadvantaged; their disadvantages are considered as normal. They are not just neglected; they are not even pitied. People and society fail to see the human suffering in old age. When support and assistance is provided, they are given as charity instead of as a right to protect human dignity and to promote human flourishing. As a result, discounting is posited as a form of oppression that is deeply embedded in social structure, driving degrading attitudes, policies, practices and approaches towards older persons. It anchors all types of human rights violations in old age and serves to legitimize differential treatment, justify action or inaction, dictate priorities, create and enhance inequalities.

Even though several participants have difficulties in giving a name to the process of discounting, it clearly appears as a universal phenomenon that resonates with experiences in older age that emerge from the findings. Age-based discounting is real and pervasive and is the root cause of age-based differences and the denial of human rights. Yet it does not attract the same level of attention and social disapproval as inequalities associated with gender, race or disability⁴³⁰. Discounting is therefore posited as *systematically undermining human dignity in older age*. Its particularity lies in that it is pervasive, insidious and often remains unnoticed and unaddressed.

For interviewees, even if it does not always materialize, discounting as a form of vulnerability is dormant and shared among older persons, despite their heterogeneity. Discounting takes places irrespective of other factors such as illness, disability, social status or income. Simultaneously, the findings go against the idea that dependency is inevitable and argue that capacity, activity and contribution should be the presumption when it comes to providing human rights

⁴³⁰ Thompson, *Age discrimination*, p. 1.

protection.⁴³¹ Any attempt to provide human rights protection on the basis of vulnerability is unlikely to gain traction among older persons who have been trying to disentangle older age from inherent vulnerability.⁴³² This contradicts views of some of the human rights actors that often locate old age disadvantage primarily in the existence of an impairment.⁴³³

The Tension Between Advocacy and Public Discourse

The findings show that some national human rights bodies tend to conflate issues of disability and ageing and struggle to describe a unique and distinct disadvantage associated with old age. Overall, it is care in the context of old age that has quasi monopolised the attention of human rights bodies so far, especially in the case of France. The narrative adopted by French human rights bodies is centred around the loss of autonomy, i.e. the limited capacity of the individual to accomplish essential acts of everyday life. Moreover, French actors do not reflect on how older people are marginalised, excluded and disempowered due to perceptions of and attitudes to older age. Additionally, one of the French human rights actors admitted that they do not consult with older people's organisations on the assumption that their views are already covered by the disability organisations that they engage with. A French stakeholder also admitted not having considered whether decisions about deprivation of legal capacity could also be – partly – influenced by the age of the individual.

This French particularity may be due to the fact that, as shown earlier in this thesis, within the French context older age is often seen as synonymous with dependency and much of the policy attention and human rights discourse is geared towards the problems of those who need care and assistance. But also the Greek EEDA similarly suggests that people in the so-called 'fourth age' are in a more vulnerable position than others due to '*biological deterioration, illnesses and*

⁴³¹ Chen, Alston, and Levine, "Aging: A New Human Rights Concern—A Policy-Oriented Perspective".

⁴³² E. Dugarova, "Ageing, Older Persons And The 2030 Agenda For Sustainable Development," *United Nations Development Programme; New York* (2017).

⁴³³ Commission Nationale Consultative des Droits de l'Homme, *Avis sur l'effectivité des droits des personnes âgées*. Para 7; Greek National Commission for Human Rights, *Protection of the rights of older persons*. p.17 s

the increase in accidents'.⁴³⁴ It therefore seems to accept that physical and functional decline is an inevitable part of advanced old age. Consequently, in discussing substantive human rights issues, some human rights bodies struggle to move away from a paradigm of deficit and needs. Overall, aspects of participation have not attracted equal attention by human rights bodies in the three countries.

This finding illustrates a tension between old age advocates that want to dissociate older people from sickness and functional decline and the mainstream human rights approach to older age, which is based on disability. It is then plausible that the vulnerability and disability angle through which human rights bodies mainly see older people issues acts as a disincentive to engage with this framework. If human rights language and standards employed by human rights bodies covered aspects of older people's lives more widely, some of the NGOs stakeholders might engage in this type of work. In addition, the limited perspective of human rights actors in the three countries is also illustrative of the fact that several of the structural barriers faced by older people that have nothing to do with disability are less likely to be problematized as human rights issues. The extant conceptualisation and application of older people's rights by domestic human rights stakeholders contributes to the theory of overlooking the injustice, which as is explained in the following chapter, is about non acknowledging old age inequality and exclusion as human rights breaches.

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Chapter 8: Findings from the Constant Comparison of the Empirical Data: Developing the Theory of Overlooking the Injustice

This Chapter presents the theory of overlooking the injustice, which emerged from constant comparison and interpretation of the empirical data. This theory demonstrates that although, in principle, there is no formal denial that older people have the same human rights as everyone else, in practice their rights can be more easily undermined. This Chapter presents the processes through which the undermining of human rights is manifested. The inter-related processes of *non-recognizing*, *non-enabling* and *disempowering* derived from focused coding of the qualitative data. Select data is presented here to elucidate the three processes as they are defined and explained in following sections.

Discounting, which was presented in the previous Chapter, provides the backbone of the theory. Therefore, the data presented here are not disconnected from those presented in earlier Chapters but should be read together. Discounting creates distorted perceptions of inequalities that lead to systematic failures at personal, societal and normative level to elevate adverse old age experiences, like elder abuse, to human rights violations. This Chapter then merely offers some additional examples that in combination with data presented earlier are instrumental in understanding how the three processes operate in practice.

First, discounting leads to *non-recognizing* the wrongfulness of certain acts and behaviours and a failure to relate lived experiences of disadvantage to State obligations and human rights law. Second, insofar as such experiences fall out of the purview of human rights law, we also lack clarity about the specific changes that are necessary to prevent and address human rights abuses against older persons. This is described in the findings as *non-enabling* the equal realisation of the human rights of older persons. And finally, older persons are *disempowered* persons lack the knowledge and capacity to claim their rights and access remedy.

Through these three processes older persons are more likely to be denied their rights and less likely to access justice. Specific interventions to prevent and address violations are lacking.

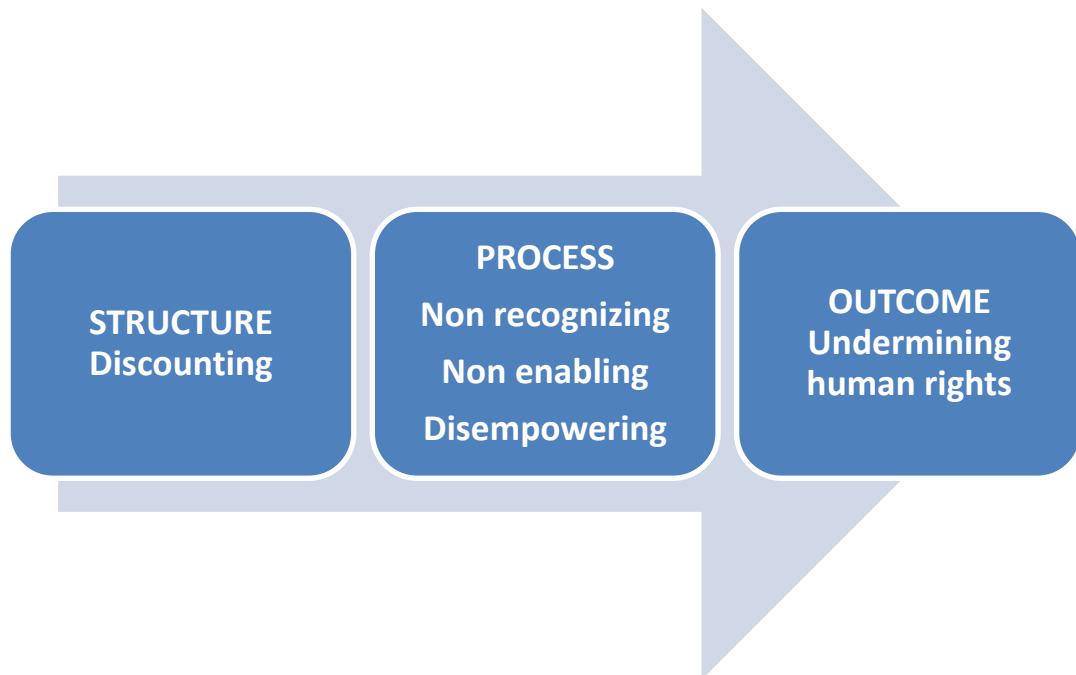


Figure 4: The Theory of Overlooking the Injustice

This theory has been inspired by the concept of hermeneutical injustice, which has been coined by Miranda Fricker to describe the process through which individuals cannot make sense of their experience of disadvantage, because there is a gap in individual and/or collective knowledge.⁴³⁵ Applied in the realm of feminism, hermeneutical injustice, for example, has been used to explain how women who were experiencing post-partum depression and sexual harassment were suffering injustice because they did not have the knowledge and language to describe their experiences; instead they felt embarrassed, guilty and did not speak out. As a result, they were isolated, vulnerable and lacked the resources and support to stop the harmful experience. For Fricker, at the core of systematic hermeneutical injustice lies a power lag that impedes a group or individual from taking part in the processes or professions that generate meanings that help

⁴³⁵ Miranda Fricker, *Epistemic injustice: Power and the ethics of knowing* (Oxford University Press, 2007).

make sense of the world. Most often people are excluded because of their identity. This hermeneutical marginalisation as she calls it, entails that interpretation of social experiences is biased since it is not adequately influenced by the powerless group. This is what makes the cognitive disadvantage truly unjust.

The theory of overlooking the injustice presented here bears some resemblance with the concept of hermeneutical injustice introduced by Fricker. They both describe an interpretative gap that obscures the awareness of, or trivialize, certain harmful or discriminatory experiences. Additionally, they both rely on a system of oppression. The impact that the non-recognition of rights has at individual level is where Fricker's theory and the one presented here bear more similarities. According to Fricker, women's cognitive disablement renders them confused, isolated and vulnerable to further abuse. Because their experiences of injustice are not widely intelligible, women are less likely to be perceived as credible and as a result of that may be subject to further stereotypes and marginalisation. The exclusion of older people from consultation mechanisms, human rights education and digital information could be compared to what Fricker describes as hermeneutical marginalisation.

However, the theory of overlooking the injustice primary aim is not to make sense of individual experiences, but rather to underline how discounting renders the injustice out of the sight of human rights law. It is used to describe how discounting ideas and practices affect the ways in which older people's experiences have not been reflected in mainstream human rights norms and practice and are therefore not linked to legal outcomes. Its objective is to render visible human rights violations against older people that currently are not recognized by the international community and to initiate a discussion about how older people's rights should be conceptualised and implemented. Overlooking the injustice is not about the lacuna of a name, but about a lack of acknowledgement of injustice in law. We may have the vocabulary to describe certain behaviours as discrimination or abuse, but in practice we witness a failure to associate these behaviours with structural and systematic prejudice against older people and a

failure to act against them. The theory of overlooking the injustice is therefore more than structural discrimination; it is the process through which old age disadvantages are normalised and prevented from becoming the object of human rights law. The remainder of this chapter explains the empirical categories of non-recognizing, non-enabling and disempowering and how they render human rights violations against older persons less visible and intelligible.

Non-Recognizing

Discounting creates firstly, a risk of *non-recognition* of rights. Due to discounting, experiences such as neglect in care settings, lack of support and the exclusion from preventive and rehabilitative treatment are disguised as malpractices, administrative anomalies, or inevitable losses. As a result, they are not recognized as human rights violations. In Greece for instance elder abuse, according to the NHRI, is most commonly seen as a social care issue, despite involving a fundamental violation of individual dignity and autonomy. Similarly, the French NHRI representative did not see social exclusion as a human rights issue but limited related questions to the realm of social policies. This means that the marginalisation of older people is potentially seen as a minor issue and is more likely to be attributed to individual circumstances rather than to structural issues, such as demeaning attitudes, spatial segregation, lack of accessibility of goods and services and absence of support, all of which are according to participants contributing factors to exclusion. And whereas lack of access to digital services is seen by some NGOs as a form of discrimination, for the representative of the French Ombudsperson it is merely a question of good service provision. But by describing these problems as failures, gaps or limits of policies, services or budgets we attribute to them less importance than if we were to describe them as violence, discrimination or exclusion. Non-recognition therefore primarily involves an asymmetry between the actual severity of certain acts and their valuation in discourse, law and practice.

Additionally, non-recognition is about a gap in collective consciousness that certain harmful practices are deeply rooted in structural prejudice (i.e.

discounting). Instead they are seen as random, exceptional or individualised acts. Failing to recognise the structural and systemic nature of existing inequalities, entails pushing them out of the realm of human rights law. If for example, elder abuse is seen as an act against a certain individual and is not understood as an illustration of institutionalised discounting, the State is divested of any legal responsibility for failure to prevent it. Legal protection is limited to individual redress. But instead, this thesis has argued that because discounting is so deeply embedded in culture and institutions, social transformation is crucial to respond to and address its harmful effect of discounting. Participants explain that because restraining practices have been used for a long time in elder care settings, they are not considered problematic. Similarly, they believe that mandatory retirement ages are socially and legally accepted as justified because they are ingrained in the social contract, despite violating individual freedom to choose whether they want to continue working. As a result, it is hard to identify them and challenge them as wrongful. Moreover, when frailty and disability in old age are seen as natural, it is difficult to transfer responsibility for disadvantage from the individual to society.⁴³⁶ Consequently, the individual and his family are more likely to be indicted with the burden of care and support, as opposed to having an entitlement through social protection.

So we would see a huge issue here of financial abuse but not calling it financial abuse, I mean to me if I see someone taking 20 euro out of their mother's pension is the equivalent of hitting someone over their head and taking their money, it's theft. (Participant 8)

Human rights is a legal term it's not a human term, it's not a term that other people go around using (...) I am not going to be an alibi for the EU and let them pretend they are doing something about it, talking about abuse, they are not. They are creating abuse, the creditors...So this is my very small protest, but I did talk about it to our board, I said I'm not going and I told

⁴³⁶ Arlene S Kanter, "The law: What's disability studies got to do with it or an introduction to disability legal studies," *Columbia Human Rights Law Review* 42, no. 2 (2011); Kesby, "Narratives of aging and the human rights of older persons."

them why and they said, 'we agree, don't go', So it's our public protest as a member to AGE platform and they should say that: that the Greeks refused (emphasis) to come since the structural abuse is so great that we have early deaths from this, and it's not correct. And you know everybody is quite happy talking about families abusing or institutions abusing older people, not realising that this is the result of people being under stress, not having any help, not having any services and that is structural. (Participant 4)

She was a woman in her early 70s and she went to the doctor and she had a problem with her left knee, so the doctor checked her left knee and checked her exercise and the reflexes and moved the knee and checked resistance and everything and eventually said to her 'to be honest with you, it's just old age' and she said 'but my right knee is the same age and there is no pain'. So he sent her for a scan and it turned out yes, she had some cartilage damage and there was a medical issue. But in many cases, particularly in the medical sphere, institutional ageism is huge and older people are being told that very real injuries and strains and pains are just wear and tear, old age and all those cliché things that you might hear. (Participant 6)

Non-recognizing is therefore about leaving undetected the pervasive and persistent forms of discounting and not labelling them as human rights violations. This process renders invisible the detrimental effect of discounting on human dignity. This is crucial because unless we name certain conducts -like age limits in health screening, exclusion from training or the lack of informed consent- as problematic, they will continue to be the norm. Due to the process of non-recognizing, injustice against older persons is not widely intelligible and in reality, is more common than we think.

Non-Enabling

The secondary implication of discounting - and a direct outcome of the process of non-recognition - is what is described in the findings as *non-enabling* the equal realisation of human rights in older age. Non-enabling impinges on attempts to accommodate older persons' needs and preferences and to eliminate discounting.

We tend to have a narrow understanding of rights in older age and we therefore limit the services, benefits and measures targeting older persons and fail to enable their equal participation in society.

We stereotype older people, we make fun of the idea of intimate sexual relationship in older age and in fact I think older women continue to experience sexism as well as ageism and I think there is an enormous amount of ageism in terms of our culture still, and that can limit our expectations of ourselves and of course limit other people's expectations for what is appropriate for elder persons (Participant 9)

I think that can be translated through a prevalence of ageism, through the way in which the State divides us, the way you know the economic opportunities for people as they get older are lessened, through some of the choices to travel are limited. One of the things I would also be concerned about is end of life issues because you think you are going to be protected because doctors are very 'do good and do no harm' but I recently I had experience of people assuming because you are 90 you want to die and it was furthest from the truth so there is an ageism within the medical profession (...) to me that's a bit worrying (Participant 10)

I think that part of the problem is a perception that once you reach the age of 65 you shut down, you are going into a nursing home, you are staying in your home watching your garden and you are waiting to die and that's not what being in your 60s is about any more, or in your 70s or 80s for example (...) I think we are not giving, because there is a perception that older people don't have anything to contribute, we don't put in place the structures to facilitate to make those contributions. So for example in Ireland you have a lifelong learning strategy, which is for people to pursue education once they have finished secondary school. The lifelong learning strategy in Ireland covers ages 18-65, why does it stop at 65? (...) there is a perception issue, but the perception issue shapes the fact that the support and facilitation isn't there. (Participant 7)

Because we lack the language and norms to describe certain acts against older people as breaches to human dignity, we may be unable to understand what is unique about human rights abuses in older age. The Irish human rights body admitted that because they '*don't have the language to describe older people's challenges as human rights*', they sometimes borrow language from disability rights. On the one hand, this approach can give greater weight to issues that, as mentioned above, are typically framed as socio-economic issues in the context of ageing, like health and long-term care. This perspective however may also fall short of tackling challenges that are unrelated to disability, such as those related to age discrimination and social isolation and fail to address the full range of human rights violations in older age. Language not only reflects what we perceive, it also helps us focus, notice and make distinctions. Unless we understand the specific ways in which older persons are disadvantaged compared to other groups in society, it is harder to define what specific changes are necessary to prevent and remedy abuses. Moreover, if we see older people's experiences through a general lens, it may be difficult to provide age-sensitive responses.

For example, to guarantee the right to work, we need to predefine those barriers that get in the way of its equal enjoyment and based on these, outline the changes that need to be made to society to remove those barriers. The findings reveal that old age-specific barriers include, among others, mandatory retirement ages, age limits in professional training, lack of necessary adaptations and stereotypical attitudes against older workers. But the lack of consistent language and standards to describe challenges associated with older age as human rights issues and their related solutions, involves a high risk of protection gaps and diverging interpretations. Precisely because mandatory retirement ages and age limits are ill understood and often justified, laws, policies and campaigns have limited scope and do not cover these aspects. Discounting not only impacts our ability to perceive certain behaviours and practices as wrongful, but it also impedes the

enforcement of rights in a way that takes into account the real experience of older people.⁴³⁷

Non-enabling is manifested in different ways. It may involve with lacking foresight about what is necessary to cater for older people's needs or the absence of monitoring of their situation in order to make necessary adjustments. It can range from missing the appropriate and adequate structures and resources to complete inaction. Failing to factor older people in policy decisions is not unusual, which demonstrates the absence of concern and accountability on behalf of States for this group. There is rarely an assessment of how a policy will affect the older population and how detrimental it will be for their rights. In fact, older people are sometimes overlooked in policy reforms, leading to important gaps.

[O]r the lack of availability of decision-makers to accept representatives of organizations or to raise issues and to discuss them... or when decisions are made about the way you live... and they do not consult you, that is why there is a lack of participation of the possibility of influencing decisions that concern you. This is another disadvantage that arises in addition to the physical aspects (Participant 3)

According to participants older people are deprioritized, neglected and undermined in several areas of public policies. Non-enabling in some cases is manifested as a complete lack of formal commitment. In Greece for example, unlike France and Ireland, there is no national strategy, law or other high-level goal on ageing. In Ireland, whereas there is in principle high-level aspiration to achieve certain goals, deliberate action to achieve these goals has not always materialised. Irish participants complained about the lack of funds, monitoring and implementation mechanisms to apply the National Positive Ageing Strategy. They felt that this gap illustrated that older people's issues are not taken seriously.

⁴³⁷ Based on this finding the following chapter 10 will try to surface the extent to which human rights law does or does not reflect these distinct experiences.

Importantly, domestic human rights practice has not paid widespread attention to the realisation of the human rights of older persons. Older people's rights rank very low in terms of priorities in the national human rights bodies. They do not have the expertise and the staff to do targeted work. Groups like women, children and persons with disabilities have received much more focused attention in the activities of those bodies. Not only have human rights organisations dealt with a narrow scope of older people's issues, in particular discrimination in employment and care, but more generally they have not yet played their role in documenting the problems that older persons face in their communities. There is no evidence that human rights bodies in the three countries are regularly monitoring the state of protection of the rights of older persons. Neither have they consistently used international accountability mechanisms to promote change in this field.

Disempowering

The third form in which overlooking the injustice is expressed relates to the personal level. Older persons can become disempowered because they are lacking awareness and confidence as rights holders. Participants explain that discounting - as it is manifested at various levels of society, policy, law and practice - prevents older persons from recognizing their experiences as human rights abuses. Older people tend to consider their grievances as trivial or normal and do not feel that their rights are restricted or taken away. Oftentimes it is because biases have become so internalised that older persons are unable to perceive the injustice. They lack a sense of entitlement and the necessary consciousness to claim their rights. Other times, whereas they feel that they are treated unfairly, they are willing to surrender their rights out of fear of becoming or being perceived as burden or because they believe that they have an obligation to do so for the sake of their family or younger generations. As a result, they are

more likely to remain silent, rather than to complain or speak out.⁴³⁸ This finding reflects a barrier in accessing justice.

One participant tells the story of an older lady who was unable to leave a nursing home without the consent of her family.⁴³⁹ *'I'm being kept prisoner here, can they do that?'*, she wondered. This person was unsure whether it was legitimate to force her to stay in the nursing home despite her will. As a result of this knowledge gap, she was in a disadvantaged position. She lacked the capacity to object their decisions. And because the care personnel believed that she had to comply with her family's wishes, she also lacked the capacity and support to seek help to change her situation. Disempowering is therefore not only caused by individual ignorance, but also by institutional attitudes and barriers that lead to coercion and tolerance of inequality and abuse.

I think with older people we have a level of education or a task of education that needs to be carried out before older people can themselves advocate, argue from a human rights-based approach. And part of this is educating them that these rights are there and then also how making them a reality can be very very difficult. One of the challenges I think, when you explain to somebody these are your human rights and they are written down in a legally binding international treaty to which Ireland is a participant and that person looks at those articles and says 'I don't have these, how come? Why don't I have these rights?' And you say 'Well, just because they are on paper you need to make them reality' and sometimes it can be quite disillusioning for people to go 'Hold on a minute the government signed up for these rights? But we don't have them' so I think that can undermine the value of the human rights framework sometimes to people, if they get very excited about the fact that they have these rights but then the

⁴³⁸ For underreporting of cases of abuse and discrimination see among others, Justyna Stypińska and Pirjo Nikander, "Ageism and age discrimination in the labour market: A macrostructural perspective," in *Contemporary perspectives on ageism*, ed. Liat Ayalon and Clemens Tesch-Römer (Springer, Cham, 2018). World Health Organization, *European report on preventing elder maltreatment*, Copenhagen: WHO Regional Office for Europe (WHO Regional Office for Europe, 2011).

⁴³⁹ The person in question was not put under formal guardianship or other form of substitute decision-making

loopholes and the exceptions and the ability of the government to not necessarily move forward as fast as they would like to, they would then create a certain level of cynicism about whether in fact these rights can be achieved (Participant 7)

Even the individuals are very often unaware of their rights so that they are in a position to claim them. Many times they will think 'ok, it's normal that they did not recruit me, since I am older (...) so how can you make them known, provide information, mobilise those who ignore the fact that they have rights (Participant 13).

The fact that you put age limits on things sends a signal to the rest of society and I think that is the cultural signal that it is sending out and is that culture that then makes the lady in the nursing home think that she has to do what her daughter is saying?(...) I think that it could be that the reason that rights might appear to get less as you get older is that your ability to stand up for them lessens (Participant 8)

Lack of awareness, information, education and support limit individuals' ability to advocate for their rights. None of the actors in the three countries has led educational initiatives in order to raise awareness about human rights and corresponding responsibilities and to build the capacity of rights holders and their representative organisations to claim their human rights and to create pressure using human rights standards. But *'until the general population is suitably informed, older people will continue to be denied their human rights and experience treatment in care that is neither respectful nor fair and may lead to neglect and abuse'*.⁴⁴⁰

Older persons do not have access to the processes that could allow them to increase their consciousness of injustice and to access the resources to claim their rights. Consequently, they are less likely to seek justice and redress to improve their personal situation and even less to become advocates and activists.

⁴⁴⁰ Love and Lynch, "Enablement and positive ageing: a human rights-based approach to older people and changing demographics." p. 93

Similarly, because NGOs lack the essential vocabulary to describe human rights abuses, they lack the capacity to protest and demand the fulfilment of State obligations. Therefore, the process of disempowering can also be observed at collective level. Additionally, the likelihood that others will stand up for the human rights of older persons is also limited as they are not understood as abuses or are not perceived as important. This is why for a couple of participants independent advocacy services are crucial.

However, certain aspects of rights seem to enjoy higher levels of consciousness among old age advocates who are prepared to take action to defend them. Adequate old age income is a characteristic example. This is perhaps unsurprising bearing in mind that pension rights have been traditionally the focus of the ageing community. Additionally, several of the actors that are now involved in older people's NGOs have been active in trade unions during their lifecourse, where they were mainly concerned with material interests. In particular those organisations that maintain links with pensioners' organisations and trade unions – as is the case in Greece - admit that issues like elder abuse are out of the scope of their activities. Besides, pension benefits and social security are statutory entitlements and earned rights, which is not the case – at least in the three countries under study – for care and education for instance.

Women's rights are another exceptional case where there seems to be more awareness of injustice. Participants seem prepared to discuss for instance the gender pension gap, possibly because it's the result of lifetime disadvantages due to lower pays and contributions, informal work and increased caring responsibilities.⁴⁴¹ One participant clearly says that those individuals that have been involved in the feminist movement and gay activism, are more prone to rights awareness in older age. But even if there is some variation in the capacity of individuals and organisations to advocate from a rights perspective, overall the findings clearly illustrate a limited ability to access justice and protest at least

⁴⁴¹ Prospect, *Report Tackling the Gender Pension Gap 2019* (2019), <https://library.prospect.org.uk/download/2019/01194>.

against some of the unique adverse experiences of older age. In sum, individuals, NGOs and human rights actors are not sufficiently aware of State obligations to respect, protect and fulfil the human rights of older persons.

The processes of non-recognizing, non-enabling and disempowering are not distinct; they intersect and reinforce each other. It is because the structural character of old age inequalities is not recognized that there is no State obligation to eliminate age limits. Older persons are disempowered not only because they lack knowledge of their rights but also because they lack the necessary information and support to stop the violation. The cognitive gap of older persons as rights holders not only limits their ability to claim and access rights, but it also nourishes non-recognition. As a result, the likelihood of legally enforcing the human rights of older people but also of developing policy responses and services that are necessary to fulfil those rights is limited in practice. Lacking the resources and assistance to challenge injustice, older people '*bow out*', '*give up*', '*feel insecure*' and become isolated. Remedy cannot be reached and violations continue. Human rights bodies contribute to an accountability gap through non-action in relation to ageing issues. This renders older people more vulnerable to further abuse, stigma, discrimination, exclusion and dependency, all of which feed into stereotypical views of older people as frail, dependent and inactive. Such stereotypes tend to consider deficit and weakness as intrinsic in older age and contribute to the medicalisation of ageing and the normalisation of discounting. This creates a vicious circle whereby under the current situation individuals are unable both to access remedy but also to disrupt the negative effect of discounting.

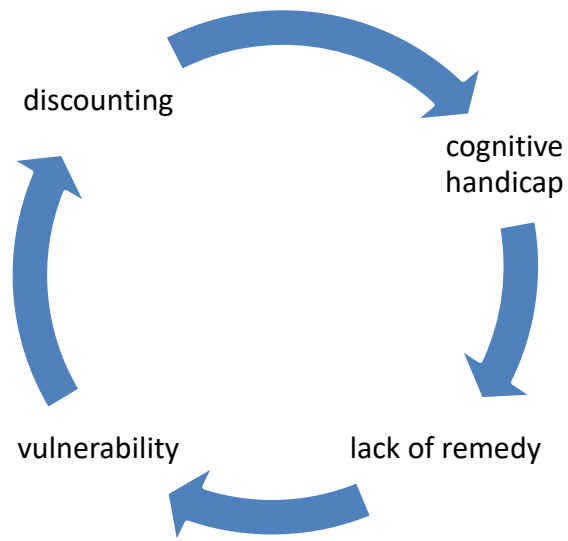


Figure 5: The Vicious Circle of Discounting

Chapter 9: The Paradigm Shift: From 'Protecting' to 'Living Full and Fulfilled Lives'

Although the findings so far have illustrated several of the reasons why older people's organisations have not yet engaged in a human rights narrative, there is also evidence of openness towards a more rights-based approach. Participants reject the current outlook on ageing. They explain that it is based on vulnerabilities and does not recognize abilities and contributions. They want to move away from the medical model of ageing that is equating old age with disease and disability. Similarly, participants do not accept that older people are always poor and in need of welfare protection. They criticise the charity approach that often underscores policy and practice around older age. Based on the findings, old age advocacy is not just about meeting needs; it is gradually focused on 'harnessing' or 'developing' older people's potential, 'seizing ageing', living a life 'worth living', 'being the person I am', and 'living full and fulfilled lives'. Policies and laws should enable older people to participate in society as full citizens and agents on an equal basis with others.

I think there should be right to have access to all the services in need to enable you to live a full and fulfilled life. I mean that's really what's important and you know a full and fulfilled life will change, will be different for different people. [it's] the ability to have enough money, you know all the poverty traps, to have the food that you want, I know they say to have a heavy coat and three meals with meat and all that, Bbut to have – within reason- what you require to enable you to live properly and that should touch on basic requirements, which include health, housing, heating, an element of culture...(Participant 5)

Ageing for me is genuinely an occasion of extraordinary gains and losses (...) It's not about avoiding ageing, it's about using it to do something, to seize, to tame older age (Participant 17)

We can lose our dignity and our individuality and that we end up being perceived in terms of the tasks that need to be performed to us, as opposed to some with a life to continue living (...) I think it (i.e. a human rights approach) should enshrine respect and dignity, it should enshrine valuing older people in terms of their experiences and also their right to plan for the future and their right to continue to contribute as - I think very often we box older people in a sense of they've got a past but they don't necessarily got a future, so I think it needs to be much more dynamic (Participant 9)

The findings therefore signal a transition from the protectionist or welfare paradigm that promotes material interests and has traditionally characterized collective action on behalf of pensioners⁴⁴² to an emancipatory model. Older people's organisations in the three countries are increasingly promoting a cultural change in the way ageing and older persons are perceived and addressed: from people in need of protection due to weakness and disease towards a paradigm that aims at recognizing them as full citizens and agents. So perhaps unconsciously, NGOs seem to be gradually adopting a human rights narrative, or are at least conscious that change is needed.

The following sections will explain the shift that according to participants needs to take place in the way older people and older age are regarded today. In general participants found it easier to talk about situations where they thought that dignity or equality were breached, rather than to describe what human rights meant and how exactly they could be applied in practice. For example, participants were more likely to discuss cases of undignified care or unfair policies than to define the content of dignity and human rights in various contexts. As a result, this part brings forward the vision of participants for change on the basis of barriers, restrictions and other forms of exclusion that emerged during the interviews. Although the action that is necessary to redress these situations and to achieve participants' call for independence, choice and

⁴⁴² Herro, "Domestic interest groups and rights mobilization: explaining the case of Slovenia's support for the proposed Convention on the Rights of Older Persons."

belonging in society, may not be sufficiently explicit, at least these three empirical categories that emerge from the findings provide some clarity with regard to the main principles or areas of rights that could provide the backbone of a human rights based approach to older age.

There is a certain overlapping and complementarity of these categories. This is for example the case for lack of support and skills to access digital services which for certain participants affects their sense of belonging and for others their ability for independence. Similarly, policies that include age limits, have been described by participants both as forms of exclusion but also as restricting their autonomy, since they entail fewer alternatives to choose from. But it appeared particularly important at this stage to stay as close as possible to participants' framing of issues, even if this entails that some of the challenges may appear in more than one category. Based on the analysis therefore the categories of belonging, having a choice and being independent are cross-cutting.

Since this Chapter presents the empirical findings, it uses the terms 'belonging', 'having a choice' and 'being independent', which have been used by study participants. This is done on purpose in order to stay as close as possible to participants' words, without imposing certain normative interpretations of the dimensions discussed. In the following Chapter, which involves a critical analysis of existing international legal standards, these three categories are translated into 'Participation', 'Autonomy' and 'Independence'. This interpretation by me as researcher who participates actively in the study is made in order to be more consistent with the normative language used within the human rights framework. Still, the concrete barriers, unique experiences of older age and narrative of change are best described in participants' own words, which is the reason for the different terminology used in this Chapter.

From 'Excluding' to 'Belonging'

Referring to '*excluding*', '*marginalising*', '*isolating*' and '*losing function*' participants capture the ways in which older people are '*pushed out of society*', they are '*elbowed out*', segregated and cut off from social, economic, civic and

political participation. They claim that older people are '*ghettoised into doing older people's things*', meaning that they are expected to be involved in stereotypical activities assigned to the old, such as playing cards, boules or golf, knitting, sewing and caring after others, which adversely impacts their opportunities to be involved in mainstream society. Exclusion is multidimensional and affects several aspects of later life.⁴⁴³

Risk of Isolation During Life Transitions

Life transitions including retirement, loss of spouse and declining health are important risks of isolation. First, the transition from work life to retirement, deprives older people of social status, essential networks, roles and support structures and adversely impacts their feelings of self-worth. According to participants older people are sometimes regarded as worthless just because they retire. Their contributions and achievements do not enjoy the same economic and social valuation as paid work in the labour market. For example, they play a paramount role in caregiving, which translates into real gains for society and for their children, who are able to continue working while grandparents take care of their grandchildren; they are important economic, social and political actors in their communities, they engage in volunteering but also in lucrative activities, sometimes even creating job opportunities for others. Nevertheless, all these roles remain largely invisible.

One out of two older people over the age 65 provide free childcare by looking after their grandchildren, which enables their own adult children to go to work, to receive education (Participant 7)

In every small town and village in Ireland it will be the older people who are running many things... [I]f people stopped doing this, these services would cease to exist (Participant 9)

⁴⁴³ Walsh, Scharf, and Keating, "Social exclusion of older persons: a scoping review and conceptual framework."

There is lots of roles that older people are involved in, I think that part of the problem is a perception that once you reach the age of 65 you shut down, you are going into a nursing home, you are staying in your home watching your garden and you are waiting to die and that's not what being in your 60s is about any more, or in your 70s or 80s for example. (Participant 7)

Someone who is providing care needs to have such care recognized by the State as a form of contribution, of work, to get certain benefits, he will not do it just for voluntary purposes...Older people are looking for roles they can play, they are open to such roles, but we need to trust and prepare them, which involves training, seminars...(Participant 13)

Pensioners are not very well known, and they are not in a situation of acceptance; neither are they perceived as linked with some action (Participant 3)

I still think older people are sometimes invisible or that they have been defined by the job that they had and now that they are no longer in that job, they are not considered... And I think a lot of the roles are family roles, so not obvious to anyone else and I think there are lot grandparents now who are looking after their grandchildren because the cost of childcare is so high etc etc, that kind support is never calculated really? The State would not know about that, that's within the family (Participant 8)

Loss of income due to retirement is another reason why older people may withdraw from public life as they feel less secure about their future and are less willing to undertake activities that require personal commitment or financial investment. One participant specifically mentioned the lack of support and planning for retirement as a reason for isolation and declining mental health.

For the transition from active to inactive life there is not much; meaning we lack elements of essential support so that someone can see himself in a new role (Participant 3)

[W]e feel there are a number of resources, initiatives that help people prepare financially but really very few focus on the emotional and psychological aspects of retirement (Participant 9)

Furthermore, personal changes, such as the death of a spouse or intimate friend triggers feelings of loneliness, loss of interest and insecurity among older people. For one participant, older age also makes individuals more aware of their mortality, which may result in emotional changes that they are not necessarily prepared to cope with.

I can distinctly remember my grandparents saying 'ah, she turned her face to the wall'... what it means is someone mainly say after the death of a spouse an older person gave up and it came from the old idea that the older person lived in the family home and they were in a room with a bed and they literally turned away towards the wall, given up, have had enough and I can remember being said about people (Participant 8)

For some people very bad experiences mean that they lose confidence, they lose their ability to interact, they go into themselves, they don't want to go out and other things that cause that can be things like the death of a spouse, or a partner or stuff like that and they don't acknowledge this (Participant 5)

Participants give different accounts of older people with very little social relations, especially when their health deteriorates or when family members live far away. Whereas traditionally older persons have been living with their children, overall there is a decline in intergenerational households, especially in Europe.⁴⁴⁴ Changing family patterns and mobility entail that many older people nowadays live alone without family.⁴⁴⁵

⁴⁴⁴ UN Department of Economic and Social Affairs, *Promoting Inclusion through Social Protection: Report on the World Social Situation 2018* (United Nations, 2018).

⁴⁴⁵ Blackman, "Defining responsibility for care: approaches to the care of older people in six European countries."

Interviewees also highlight that older persons who require care do not always have the choice to age in place and as a result may end up living in segregated institutional settings, without any ties to their neighbourhood, community and people in their close environment.⁴⁴⁶ Private homes can also become places of isolation, alienation and disempowerment, when people live alone without support.⁴⁴⁷

Discounting Underpinning Marginalisation

But according to the findings, individuals would be able to better cope with these transitions if societal structures and attitudes would change. Ageism is a key driver of exclusion, as perceptions of older people as frail, dependent and unproductive institutionalise and legitimize marginalisation.⁴⁴⁸ The interviews illustrate that as they move into old age, older people come across shrinking choices to contribute, grow and prosper. For example, they may be discouraged or not supported in order to participate in education or training.⁴⁴⁹ Age limits exclude older persons from work, health care, mortgages and insurance to name only a few.⁴⁵⁰ Most often, older people are expected to be engaged in leisure and caregiving, to be passive and to consume rather than to remain or become involved in active and productive roles. One participant explains that they may be regarded as nearing death and not having anything to contribute or expect. For

⁴⁴⁶ On how spatial exclusion impacts older people see Anna Urbaniak and Kieran Walsh, "The interrelationship between place and critical life transitions in later life social exclusion: A scoping review," *Health & place* 60 (2019).

⁴⁴⁷ Sarah Hillcoat-Nallétamby, "The meaning of "independence" for older people in different residential settings," *Journals of Gerontology Series B: Psychological Sciences and Social Sciences* 69, no. 3 (2014). UN Human Rights Council, *Report of the Independent Expert on the Enjoyment of all Human Rights by Older Persons*, A/HRC/39/50 (2018), para 80.

⁴⁴⁸ Astrid Stuckelberger, Dominic Abrams, and Philippe Chastonay, "Age discrimination as a source of exclusion in Europe: The need for a human rights plan for older persons," in *From Exclusion to Inclusion in Old Age: A Global Challenge*, ed. Norah Keating and Thomas Scharf (Bristol: Policy Press, 2012); Fredvang and Biggs, "The rights of older persons - Protection and gaps under human rights law."

⁴⁴⁹ UN General Assembly, *Substantive Inputs on the Focus Area Education, training, lifelong learning and capacity building*, Working Document submitted by the Department of Economic and Social Affairs (DESA) A/AC.278/2019/CRP.2 (2019), https://social.un.org/ageing-working-group/documents/tenth/A_AC.278_2019_CRP.2.pdf.

⁴⁵⁰ AGE Platform Europe, *AGE Platform Europe Position on Structural Ageism*. AGE Platform Europe, *Submission based on seminar with Europe-based experts on the Human Rights of Older Persons* (2018), https://social.un.org/ageing-working-group/documents/ninth/Inputs%20NGOs/AGE_Brussels_seminar_April2018_FINAL.pdf.

interviewees this '*limited playing field*' is unsatisfactory and not reflecting the full potential of older people.

The fact that an individual is retired does not mean that he is cut off completely from the political, social, economic and cultural life of a country (...) [We need] to move away from roles that have static characters, for example 'give something to the pensioners so that..., take some money to take an excursion, to have a reduced fare'. This is not the primary and substantive role that pensioners should have. A pensioner must have a concrete role... (Participant 3)

You know I was taken very aback by a public representative saying 'we probably should give to the older, the old folks, a few trips to the seaside' (...) patronising, you know? They should be enabled to get there themselves and to do stuff (Participant 5)

I think it's attitudes...I have not yet experienced it, it does not mean I won't, but for example a friend of mine, she's in her 80s and she was architect in a big organisation, hugely powerful lady and –well- good family, worked in volunteers and the girls guides and whole lot of stuff, she's a very modern woman in that sense. And she's like 'I can't believe that now that I am kind of elbowed out of the way and pushed around'. She said 'I didn't expect that (...) So they retreat back into this at the same level, and the men retreat back to the 'kafeneio'⁴⁵¹ and in a way it sort of stays traditional, but I think it's not enough... (Participant 4)

Lack of Inclusive Structures and Support

Older people need also to be trained and assisted in order to be able to contribute in a genuine and meaningful way and remain integrated in society. For example, because they lack the skills and support so that they are able to benefit from

⁴⁵¹ Traditional Greek cafeteria serving as social centres in small communities, mainly gathering older members people, typically older men.

digital services, they are either left behind or have to rely on others to do necessary transactions for them.

[W]e are supposed to switch all our government services and health services, everything, we're switching over to e-based services, banking everything! So we are not giving people training to actually deal with this, to me that's a scandal. That's a human right! (Participant 4)

I've also seen when people volunteer to come forward to represent the interests of older people in committee meetings or various meetings within a local authority, they are often not given grounding, they often don't understand the kind of unwritten rules, or indeed the written rules of engagement. They may not have experienced this whole sense of you know of creating agendas, of discussion, of minute taking, of decision-making and stuff and some of them may feel intimidated (...) so I think there is a real need for a proper orientation for older people when we invite them to engage (Participant 9)

There is no infrastructure to help them (i.e. long-term unemployed older workers). Existing structures do not offer at all good consulting services, they lack a network, they don't know their needs, they can't give any advice, they don't even help them write a CV (Participant 13)

Some participants further mentioned that city and community structures do not offer a lot of opportunities for interaction with others, especially in terms of intergenerational exchange. For participants the risk of isolation is particularly high for older persons residing in rural areas where they lack services and good public transport. It is also believed that those who are very old are more vulnerable.⁴⁵² Older people in southern familialistic countries, including Greece, tend to be more lonely than older persons in northern European countries who are more independent and can rely on more socially enabling institutions outside

⁴⁵² Pearl A. Dykstra, "Older adult loneliness: myths and realities," *European journal of ageing* 6, no. 2 (2009).

the family.⁴⁵³ Physical inaccessibility also reinforces spatial segregation to the extent that older people may not be able to leave their houses, move within their apartments or in their community due to environmental barriers, like stairs, broken pavements, inaccessible transport, poor lighting, etc.

[There are] collective spaces, even playhouses for the youngest, naturally schools, which are important meeting places, and then in the workplace we meet people, but then when we leave school, studentship and work and we move to retirement, there are no places of collective organisation (Participant 17)

And I think that the demise of shops, local shops and all that is dropping some of the interaction that people would have with their society, within their own area where they live, because more and more I see Tesco deliveries on the road (Participant 5)

Deficient Consultation of Advocacy Groups

Exclusionary practices affect both individuals and older people as a collective. Almost all participants refer to a right to be heard as a movement within the context of belonging. Nevertheless, they explain that in reality they have few opportunities to participate in decision-making and often consultation procedures are not meaningful and act merely as a tick-box exercise. Similarly, another interviewee in Greece argued that in order to give effect to the right to participation there is a need to create a framework that regulates the social and political action of pensioners, equally to the institutional possibilities that exist for the involvement of women and people with disabilities.

Our organisations are not invited (i.e. to contribute) more or less because there is this logic 'why should we care about them, they are finished' (...) One

⁴⁵³ Fredrica Nyqvist, Mikael Nygard, and Thomas Scharf, "Loneliness amongst older people in Europe: a comparative study of welfare regimes," *European Journal of Ageing* 16, no. 2 (2019); Dykstra, "Older adult loneliness: myths and realities."

of our politicians (...) said 'lock your grandmothers and grandfathers at home so that they do not vote' (Participant 3)

They (i.e. politicians) set the agenda too much (Participant 5)

We are consulted because they have to consult us, it's the law, but at the end (implies they are not listened to...we have been consulted because it's an obligation (...) the law foresees the consultation of older people when older people are affected (Participant 2)

In many cases these older people's councils and the role that they play in the decision-making process is lip service; that they are supposed to run decisions by these older people's councils but in many places the decisions have been taken, it's just a post decision, rubber stamp (Participant 6)

We are never represented in anything (Participant 1)

We have some consultative instances but the problem is are these instances really used, or are they sometimes just gadgets? (Participant 19)

The age-friendly programme in practice the way it happened was most local authorities had written their age-friendly strategies before they recruited people to older people councils. Now some of them may well have in some sense involved older people in terms of consultation and stuff but an awful lot of that can be very very tokenistic (Participant 9)

Expanding the Notion of Participation in Old Age

Despite high level policy commitments to active ageing, participants' descriptions illustrate that policy approaches and practice are still focusing on deficits and vulnerabilities, instead of encouraging and supporting the development of older people's potential. Participants aim at expanding opportunities for participation regardless of the state of health or care needs. They wish to overcome current images of older people as a burden and an economic drain and want to be seen as capable of contributions and deserving of empowerment and inclusion.

Interviewees stress that older people are equipped with knowledge, skills, judgement, memory and achievements that are useful to society and to future generations. Their lifelong experience makes them particularly fit for advisory roles especially in public bodies, but also in the private sector. Older people should be involved for the benefit of society as a whole and not only for a narrow scope of issues that are directly relevant to the older population, such as pensions. In addition, they can participate in knowledge sharing, mentoring and training younger generations. They are good at problem-solving and they can become innovators and entrepreneurs. They are particularly active in social, philanthropic, cultural, religious and sports organisations through volunteering, organising events and offering their expertise in different ways. They have a role in politics, not only as voters, but also as elected representatives of their communities. They participate in consultations voicing the interests and needs of service users, for example in health, transport and other domains of the public sectors. As an organised collective they can also better advocate and claim more equal access and opportunities, not just for the older population, but also for more vulnerable individuals and groups. Older persons also support economically and through caregiving their family members. And finally, they make multiple economic contributions as professionals, consumers, tourists, but also by creating jobs, for example for people in the care sector.

[Older people are] a reserve [of] accumulated professional, social, political, cultural experience and knowledge (...) Older people need to be at every table where decisions about society are made (Participant 3)

[B]ecause older people get disabling conditions that doesn't mean that they can't be active or participative (...) [A]s a citizen we have a right to participate, so if we don't do that in whatever age group or whatever socio-economic group that we find ourselves in if that is being denied it is a denial of human rights (Participant 10)

So that's what we seek to shine a spotlight on and sort of showcase the potential that older people have and what we do to empower older people to live an active and healthy retirement (Participant 6)

I think for instance in youth work there is a far greater recognition of the need to empower younger people so that they can participate in a more real way, and I just don't think we are doing the same with older people (Participant 8)

We need to think together how we can give sense and utility to the prolongation of life (...) we don't have the same position, but evidently we have a position, we are in, we participate (...) so the key question is (...) when we lose something, capacity, energy, should we spend our time to regret (i.e. our loss), to complain? I think this is where there is a real project to seize, to tame this new time, to discover it (Participant 17)

Overall, participants strive for 'belonging', which means ensuring continuity between pre-and post- retirement roles, being valued, retaining a status, enhancing their sense of purpose, self-worth and having opportunities to be involved at all levels, from individual to public life. The findings therefore demonstrate the need to expand the spectrum of roles and contributions we assign to older people, by including activities of high investment with a social orientation, such as volunteering and political participation.⁴⁵⁴ Achieving this change of paradigm is important because the economic, legal and medical approaches to ageing focus on deficits and problematize older people as individuals who need help.⁴⁵⁵

⁴⁵⁴ Rodrigo Serrat, Feliciano Villar, and Montserrat Celdrán, "Factors associated with Spanish older people's membership in political organizations: the role of active aging activities," *European Journal of Ageing* 12, no. 3 (2015): p. 243.

⁴⁵⁵ Gemma M. Carney and Mia Gray, "Unmasking the 'elderly mystique': Why it is time to make the personal political in ageing research," *Journal of aging studies* 35 (2015).

From 'Lacking Freedom' to 'Having a Choice'

Participants frequently refer to 'having a choice' as an integral part of respecting one's dignity or human rights. Moreover, they describe negative experiences of 'being forced', 'being made compliant', or 'lacking freedom'.

What I would like to see is older people continuing to be who they were and having a role in society but that is their choice (Participant 5)

(i.e. It has to be respected) even if the decision they choose to make is on the face of it unwise, or according to the family or according to the system, unwise (Participant 8)

So, we believe in retirement (...) but we firmly believe in personal choice, in personal circumstances and the personal context is what's important. If you don't want to retire, we as an organisation feel that being enforced to retire is every bit as bad as being forced to remain in employment if you want to retire (Participant 6)

And decision making in terms of capacity, definitely with or without disability, or conditions such as dementia or whatever, regardless of that I suppose, you know the capacity around decision-making more generally, around everything from where they will live to how they will handle their finance and what they will do with them and families ...(Participant 11)

Many things are decided because they think 'he is too old' (i.e. to decide for himself) (Participant 2)

Participants refer to several barriers that do not allow older people to have full control of their lives as individuals. These do not involve only legal impediments, such as restriction of legal capacity. They also include institutional but also attitudinal barriers, in particular stereotypes about the abilities, roles and contributions of older people that drive constraining practices. Firstly, participants describe several situations where older people are not allowed to decide for themselves despite being cognitively able to do so. Due to demeaning attitudes they are not asked for their opinions or their wishes and preferences

are routinely ignored by family or health and social care professionals, regarding in particular their daily routine and where and how care will be provided.⁴⁵⁶ They are expected to do what they are told and may be even considered disobedient or ungrateful for not agreeing. Older people are not always asked for their informed consent in aspects of medical treatment and end of life issues. Participants also discussed cases where older persons are de facto stripped off the ability to make any decisions in long-stay care settings, including handling their own finances. Some older people '*are not allowed to exercise their legal capacity without the consent of family members, even if there is no substitute decision-making regime in place*'.⁴⁵⁷ The informed consent of the older individual is not always a prerequisite for their admission in residential care.⁴⁵⁸

Secondly, participants refer to physical and other type of restraints that deprive older people of their personal liberty and autonomy. The findings bring evidence of practices including locking doors, overmedicalising, being put in chairs that older people cannot leave and detaining. Being physically bound or sedated is the ultimate expression of the denial of human rights.⁴⁵⁹

Choice for participants is not just about protection from interference, coercion and intrusion. It is also about giving support so that older people can make choices but also giving effect to those choices on a practical level. Due to the absence of adequate legal protections older people are more likely to lack the

⁴⁵⁶ Nena Georgantzi, "The right to autonomy, health and independent living" (United Nations Open-Ended Working Group on Ageing, Third Session, New York, 2012); European Network of National Human Rights Institutions, *We have the same rights: The Human Rights of Older Persons in Long-Term Care in Europe*.

⁴⁵⁷ On this see also UN Office of the High and Commissioner for Human Rights, *Summary Note Expert*

Group meeting Supporting Autonomy and Independence of Older Persons with Disabilities, 25-26 October 2017, UN Headquarters, New York (2017). UN Department of Economic and Social Affairs, *Analysis and overview of guiding questions on long-term care and palliative care received from Member States, "A" Status National Human Rights Institutions and accredited non-governmental organization (2018)*, https://social.un.org/ageing-working-group/documents/ninth/OEWGA9_Substantive_Report_LTC_Palliative-Care_DESA.pdf

⁴⁵⁸ European Network of National Human Rights Institutions, *We have the same rights: The Human Rights of Older Persons in Long-Term Care in Europe*.

⁴⁵⁹ On the use of chemical restraints in care institutions see also Human Rights Watch, *'Fading Away' How ageing facilities in Australia chemically restrain older people with dementia (2019)*.

freedom to exercise their rights.⁴⁶⁰ One participant for instance highlights the need for the development of independent advocacy services to help individuals take, defend and execute their decisions.

I mean we have a capacity to think and to make judgements and we have - in whatever way you find it - a spirituality that makes me the person that I am and I need space to be able to create that opportunity to be who I am (Participant 10)

[W]hat our new legislation does say is that it is no longer sufficient to stand at the mouth of the tunnel and shout at the person, hey you come here to me on my terms, it will be the duty, where it is under common law, but it will be the statutory duty, of any professional about a person taking a decision to go into the tunnel, find where they are, deal with them at their level and bear comprehension of language, pictures of whatever and enhance their capacity to its maximum (Participant 8)

Finally, participants stress the intersection between choice and participation.⁴⁶¹ They explain that older people are expected or forced to take certain roles. This relates both to passive and active roles. They cannot always choose whether they want to continue working or care for others. They feel compelled to assist their families or are expected to be active in order to be valued by others. It is not just attitudes that limit older people's choices but also structures and regulatory frameworks that may impact their ability to take charge of their lives, such as mandatory retirement or the absence of alternatives for care in the community. Several participants therefore underline that participation is a choice and not a norm and each individual should be able to decide how they lead their lives and how active they are in older age.

⁴⁶⁰ María Isolina Dabove, "Autonomy and capacity: about human rights of older persons in dependency situations," *Ageing International* 42, no. 3 (2017).

⁴⁶¹ On this see also Meredith Minkler and Martha B. Holstein, "From civil rights to... civic engagement? Concerns of two older critical gerontologists about a "new social movement" and what it portends," *Journal of Aging Studies* 22, no. 2 (2008).

[T]o be honest with you, it's very much a personal choice as to what activities you want to take part in at any stage in your life (...) and we start looking at so-called positive images of older people on Harley Davidson, or climbing cliffs or skydiving... no! if you have a choice and you are interested in so called traditional older people activities, like an escorted holiday or a cruise or knitting or playing cards, that's absolutely fine (Participant 6)

Now you can't turn people who never wanted to be involved in things to be participative when they get older. And we get phone calls from people and 'my father died' or 'my mother died and my father is sitting at home and he won't do anything, we want to get him involved and could you do something' and all this and you kind of say 'your father was he outgoing before that and whatever whatever' and I say 'it's very hard to change people's attitudes if they did not have it but you can try X, Y and Z'. But it's like older people should... (Participant 5)

They think older people should be into looking after other people as well and some of them don't give a damn and why should they? That's the way they always were! (Participant 5)

Overall, these findings illustrate that restrictions to one's ability for self-determination are not merely the result of functional limitations. They can be uniquely experienced in older age because of perceptions that older people are either unable to decide or unworthy of being consulted and because of the lack of options or assistance to enable the realisation of their choices. These are some of the reasons why autonomy has been identified as one of the key concerns regarding the human rights of older persons.⁴⁶²

⁴⁶² UN Office of the High and Commissioner for Human Rights, *Analysis and overview of guiding questions on autonomy and independence received from Member States, "A" Status National Human Rights Institutions and accredited non-governmental organization* (2018), https://social.un.org/ageing-working-group/documents/ninth/OEWGA9_Substantive_Report_Autonomy_Independence_OHCHR.pdf.

From 'Being Dependent' to 'Being Independent'

Independence appears to be important for participants because it contradicts extant discourse and policies on ageing that underline the risk for older people to need care and therefore become dependent on others. Instead of accepting that independence will naturally or inevitably be restricted in older age, participants acknowledge that older people are able to remain independent only to the extent that they are recognized as capable of living independently and are supported to do so. They reflect on attitudinal but also regulatory and institutional barriers that limit independence.

Interviewees accept that older age is likely to be experienced with certain physical and cognitive limitations that require a need for care and assistance. Nevertheless, they express a vision where older people are able to retain their physical and mental wellbeing. Independence is associated with not being a burden on others, in particular their close family. However, this concept also involves having the necessary support to continue living in the community, but also having financial security and access to essential services and information. So, although '*being independent*' is one of the codes that is repeated by several participants, the factors that enable it vary considerably.

[A]s an older person you want to be as independent as possible, you want to be able to not be dependent on anybody, I can imagine that's your first desire (Participant 11)

Older people will realise that in order to remain healthy, active, independent and engaged within the community they need a certain level of financial security (Participant 6)

Obviously transport is a key part of your independence, so public transport if you are a person who is not driving any more or maybe you never were a driver, public transport is key about how you are empowered, enabled to live your life, and information as well (Participant 11)

In terms of maintaining independence there is a certain overlap with disability, in that some of the issues discussed by participants involve older people who face functional limitations and may need assistance in their everyday living. The main issue is the lack of legal entitlement to long-term care.⁴⁶³ Especially in Greece, caring for older people is seen widely as a family responsibility instead of as a State duty. Greek participants explain that formal care for older persons in the community is a rare commodity.⁴⁶⁴ Informal care is routinely provided without any supportive services, training or financial assistance.⁴⁶⁵ This is why one of the Greek participants suggested that States duties should be about supporting families in their caregiving role, instead of organising and delivering formal assistance.

But also, in the other two countries, due to the lack of a legal right to long term care, older persons are more likely to be receiving informal care or have no alternative to institutional care. Participants in Ireland stress that home care is not a statutory entitlement and older people do not have an automatic right to choose a care setting.⁴⁶⁶ Additionally, necessary services or financial assistance for care sometimes only apply in residential settings. In France care in institutional settings is almost the norm for people in need of assistance. Older people are rarely provided with necessary assistance so that they are able to

⁴⁶³ Scheil Xenia Scheil-Adlung, *Long-term care protection for older persons: A review of coverage deficits in 46 countries*, ESS Working Paper No. 50 (International Labor Organization, 2015); UN Department of and Economic and Social Affairs, *Analysis and overview of guiding questions on long-term care and palliative care received from Member States, "A" Status National Human Rights Institutions and accredited non-governmental organization* (2018), https://social.un.org/ageing-working-group/documents/ninth/OEWGA9_Substantive_Report_LTC_Palliative-Care_DESA.pdf.

⁴⁶⁴ Phelan, "Elder abuse, ageism, human rights and citizenship: implications for nursing discourse."; Geraldine Boyle, "Autonomy in long-term care: a need, a right or a luxury?," *Disability & society* 23, no. 4 (2008).

⁴⁶⁵ UN Human Rights Council, *Thematic study on the realization of the right to health of older persons by the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, Anand Grover, para 47.; Department of and Economic and Social Affairs, *Analysis and overview of guiding questions on long-term care and palliative care received from Member States, "A" Status National Human Rights Institutions and accredited non-governmental organization*.

⁴⁶⁶ The Equality Authority, *Implementing Equality for Older People*. P. 50-51; Suzanne Cahill, Eamon O'Shea, and Maria Pierce, "Creating excellence in dementia care: A research review for Ireland's national dementia strategy," (2012). European Network of National Human Rights Institutions, *Human Rights of Older Persons and Long-Term Care Project: The Application of International Human Rights Standards to Older Persons in Long-Term Care*.

continue living in their own homes.⁴⁶⁷ According to participants, they are more likely to receive care in segregated institutional settings.

I think the other fundamental issue is that if you got a disability and you are under 65 you get out of these places (i.e. institutions), if you are over 65, we are getting you into these places (Participant 10)

We need formal trained caregivers; it should not be just the families caring for older people (Participant 18)

[A]nd then of course older people (...) end being placed in residential care because there comes a point when it's cheaper to be placed in residential care than to be given the support you need to continue living as independently as you can in the community (Participant 9)

I met somebody (...) who was talking about an older relative needing an injection everyday but can't access it in their own home because they won't pay for the district nurse to come in their home (...) and that person ended up living in an institutional setting and absolutely does not need to be there because this man needs an injection everyday (Participant 11)

Institutionalised ageism leads to age-based care rationing and other old-age related disadvantages in the provision of services, such as low quality, fewer services and limited coverage of needs.⁴⁶⁸ Supporting older people is rather seen as a burden and policies tend to focus on giving older people the minimum necessary instead of enabling them to remain active as full agents. People over a certain age may not be eligible for disability services or may lose certain

⁴⁶⁷ About increased risk of institutionalization see UN General Assembly, *Rights of persons with disabilities - Report of the Special Rapporteur on the rights of persons with disabilities - A/74/186* (2019).

⁴⁶⁸ Phelan, "Elder abuse, ageism, human rights and citizenship: implications for nursing discourse." Katharine Schulmann et al., *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 (2017); AGE Platform Europe, *AGE Platform Europe Position on Structural Ageism*. World Health Organization, *European report on preventing elder maltreatment*; Equality and Human Rights Commission, *Close to home: An inquiry into older people and human rights in home care* (2011).

entitlements or benefits.⁴⁶⁹ Care services in each of the three countries remain inherently medical in orientation. They often lack the capacity to support individual choices but are merely interested in keeping older people safe. For example, interviewees explain that while some support may be available, this rarely covers all aspects of older people's lives, including for instance the possibility to go out, meet with others and participate in the life of their communities. Older persons are rarely encouraged and assisted to do their own shopping or cooking, but they must depend on others to do such daily tasks. One participant mentions that it is rare that older people in nursing homes will have access to a hairdresser. There is therefore a very narrow perception of what an older person might want or need *'to live as an independent human being would'*.

If you get a stroke before the age of 59 you may receive the equivalent of up to 10.000 euros in services per month; after the age of 60 the maximum you get is 1300 and something. Why? Am I not a citizen? (Participant 18)

An example is somebody who has an acquired brain injury could be stroke, could be multicar accident could be anything and they are fine within the service until they reach 65 and then suddenly all of the rehabilitative support they had changes, 'no you are in another service now, you graduated and you have nothing!' that to me is not equal! (Participant 10)

It requires an attitude on the part of the carer to preserve the independence and the dignity of the older persons rather than say you know 'I've got 10 minutes to get you dressed and get your breakfast', you know these kind of things (Participant 9)

⁴⁶⁹ Scheil-Adlung, *Long-term care protection for older persons: A review of coverage deficits in 46 countries*, ESS Working Paper No. 50. UN Department of Economic and Social Affairs, *Promoting Inclusion through Social Protection: Report on the World Social Situation 2018*. European Network of Independent Living, *Ninth session of the UN Open-Ended Working Group on Ageing - Topic Autonomy and Independence - Submission by the European Network of Independent Living* (2018).

Additionally, older persons are more likely to be excluded from certain health treatments or services based on age limits in law or practice.⁴⁷⁰ Some health services including prevention or rehabilitation are not offered as part of social security for the older population.⁴⁷¹ A couple of interviewees also refer to the need to access assistive devices, including hearing aids but also mobility support in order to remain independent. But such technologies are not always readily available or affordable for older persons.⁴⁷²

Participants also argue that older persons are at high risk of abuse and neglect in the provision of care services.⁴⁷³ Low public funding coupled with shortage of care workers entails that often only the most rudimentary level of care is provided; in such cases the human rights of older persons who receive assistance are often neglected.⁴⁷⁴ The over reliance on family care, the prevalence of unqualified caregivers and the lack of standards and monitoring for formal care at home also entail an important risk of neglect and elder abuse.⁴⁷⁵

Supportive living environments and State support to adapt their houses are seen as key elements to allow older people to live independently in their own homes. But based on the findings older persons often experience discriminatory upper age limits when applying for mortgages and bank loans or can be subject to

⁴⁷⁰ Beverley Clough and Margaret Brazier, "Never too old for health and human rights?," *Medical law international* 14, no. 3 (2014).

⁴⁷¹ AGE Platform Europe, *AGE Platform Europe Position on Structural Ageism*.

⁴⁷² UN Human Rights Council, *Report of the UN Independent Expert on the Enjoyment of all Human Rights by Older Persons A/HRC/36/48* (2017).

⁴⁷³ World Health Organization, *European report on preventing elder maltreatment*. WHO (2011) *European report on preventing elder maltreatment*; Phelan, "Elder abuse, ageism, human rights and citizenship: implications for nursing discourse." Yongjie Yon et al., "Elder abuse prevalence in community settings: a systematic review and meta-analysis," *The Lancet Global Health* 5, no. 2 (2017); UN Human Rights Council, *Thematic study on the realization of the right to health of older persons by the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Anand Grover*; AGE Platform Europe, *Submission based on seminar with Europe-based experts on the Human Rights of Older Persons*; Equality and Human Rights Commission, *Close to home: An inquiry into older people and human rights in home care*.

⁴⁷⁴ Equality and Human Rights Commission, *Close to home: An inquiry into older people and human rights in home care*; World Health Organization, *European report on preventing elder maltreatment*.

⁴⁷⁵ Georgantzi, "The right to autonomy, health and independent living"; Equality and Human Rights Commission, *Close to home: An inquiry into older people and human rights in home care*; World Health Organization, *European report on preventing elder maltreatment*.

indirect discrimination when applying for a bank loan because they are perceived as lacking financial credibility.⁴⁷⁶ This creates barriers for older people to access credit for housing, including for necessary home adaptations to enable them to continue living in their community. States should ensure equal access to credit and financial assistance so that appropriate housing is affordable, and that older persons are able to make necessary adjustments to their homes.⁴⁷⁷

Another element of independence has to do with having access to essential goods and services. Transport, accessibility of housing and public infrastructure as well as online services are among those issues that are considered key in terms of determining the extent to which an individual can remain independent. Access to information is also considered essential, as in some cases some support may be available but older people are not adequately informed about available opportunities. These aspects are not problematic solely for those who are experiencing a physical or cognitive disability. For example, in Ireland access to transport is important for people in rural areas. The inability to easily access shops, medical services and maintain social relations considerably limits this population's ability to be independent. Whereas the lack of public transport may be an issue for other age groups living in remote areas, it appears as a particular form of exclusion for older people.⁴⁷⁸ Many older people live in such areas, but also many are not able to drive. They are therefore more likely to be affected by the lack of transport infrastructure. Lack of access to transport leads to exclusion from other essential services.⁴⁷⁹

Moreover, older people's independence is considerably limited when they lack adequate means. According to participants, many older people are not able to afford certain goods and services, they are '*at the whim of the government*', they are '*running on a shoestring*', and they are forced to make certain choices because

⁴⁷⁶ AGE Platform Europe, *AGE Platform Europe Position on Structural Ageism*.

⁴⁷⁷ UN Human Rights Council, *Report of the UN Independent Expert on the Enjoyment of all Human Rights by Older Persons, A/HRC/30/43* (2015). para 61, 62 and 109

⁴⁷⁸ Walsh, Scharf, and Keating, "Social exclusion of older persons: a scoping review and conceptual framework."

⁴⁷⁹ Walsh, Scharf, and Keating, "Social exclusion of older persons: a scoping review and conceptual framework."

'they lack necessities'. Although poverty and material deprivation are not necessarily experienced by all older individuals, older people are more likely to suffer from this type of disadvantage because their income is considerably reduced when they are no longer working. They also suffer the consequences of cuts in pensions and services. Since they rely primarily on State support pensioners have been an *'easy target'* in the context of austerity. According to some participants cuts in pensions are so severe that do not allow low income pensioners to cover their subsistence needs, such as rent or health care. According to one participant, they may even have to choose between buying food or going to the doctor.

In addition, opportunities for them to gain extra income are limited due to mandatory retirement ages or other regulations that do not allow them to earn a side income while receiving a pension. Age discrimination in the labour market also leads to long-term unemployment that drives the exclusion of older workers from the labour market and their inability to build an adequate old age income.⁴⁸⁰ Moreover, older people are often expected to support other family members who are unemployed or need care, which means that they have to share their earnings with other people or to reduce their working hours and by consequence their income. This is particularly true for older women who due to informal care duties have fewer opportunities to earn adequate pension rights.⁴⁸¹

Pensioners are faced with a very important problem, pensions that are very very low that do not allow us, but a life adapted to our needs 'at minimum', so this is a main issue, especially for women who have worked informally (Participant 18)

⁴⁸⁰ Social Justice Ireland, *A targeted approach to long-term unemployment may be required* (2019), <https://www.socialjustice.ie/content/policy-issues/targeted-approach-long-term-unemployment-may-be-required>; Organisation for Economic Co-operation and Development, *Ageing and Employment Policies Ireland* (2006).

⁴⁸¹ European Commission, *Pension Adequacy Report 2018. Current and future income adequacy in old age in the EU*, 2018. Prospect, *Report Tackling the Gender Pension Gap 2019*.

And what has happened more recently is that people have felt compelled to look after children, to collect them, to do stuff like that, they have felt compelled to go back on their spending ... (Participant 5)

The multidimensional understanding of independence is a key notion for advocacy in old age. This section has demonstrated some of the unique ways in which older persons' independence can be breached that need to be taken into account in the formulation of policies.

Whereas there remains a weak commitment to human rights as a tool for older people's advocacy, the findings presented in this chapter clearly demonstrate that representative groups both value and recognize the transformative potential of a focus on independence, autonomy and participation. These elements must be integrated into the human rights model that is under construction in order to resonate with the realities and concerns of older people and therefore increase the relevance and credibility of human rights for NGOs. In sum, even if NGOs still partly use language that is associated with needs and deficits, like 'dependency' and 'loss of autonomy' in France, claims for independence, autonomy and participation are becoming increasingly important.

Chapter 10: Towards Normative Change: A Critique of International Standards

The analysis has so far been interested in conceptions of rights and old age disadvantage that could underpin a human rights narrative and possibly a new legal framework. It has done this based on participants' views that stem mainly from exposure to national policies and older people's lived experiences. It is now time for the thesis to turn to international human rights standards. This chapter sets out to assess whether the theory of overlooking the injustice is also mirrored at the normative level.

The analysis takes place at three stages, mirroring the processes of non-recognizing, non-enabling and disempowering presented in Chapter 8. First, it explores whether international standards are conscious of how discounting harms human rights. If instead human rights law reproduces social constructions based on stereotypes, then it can be argued that it is biased and perpetuates the non-recognition of rights in older age. Second, this chapter evaluates the adequacy of human rights norms to respond to the real challenges faced by older persons, as articulated in Chapter 9. This part assesses whether the changes that need to be made to remove the barriers that older people experience are sufficiently explicit in existing standards. By critically examining the normative status quo, it identifies neglected areas of rights that exemplify the process of non-enabling. Finally, the last part of the normative analysis discusses whether the right to access justice, the right to be consulted and to advocate as part of a movement are articulated in a way that implementation can take into account later life challenges.

Evidently, the three processes are cross-cutting and inform each other. For example, stereotypes described in the section on non-recognizing, become the basis for incoherencies and gaps that are dealt with under the part on non-enabling. And vice versa the absence of explicit State obligations, for example around care, is also an illustration of non-recognition in that international norms

fail to conceptualise certain situations as human rights breaches. Additionally, the lack of explicit affirmation of older persons as holders of rights could impede individuals' sense of self-respect and confidence and therefore lead to disempowering. After describing the ways in which human rights law fails to efficiently protect the human rights of older persons, State obligations are tentatively presented as a starting point for reflection on the normative definition of human rights from an old age perspective.

Whereas the starting point of the analysis are the empirical findings, in order to provide a more comprehensive picture, this chapter also uses existing scholarship to discuss the main legal challenges from an old age perspective. Comparison with existing standards for persons with disabilities, is also selectively used to illustrate protection gaps, discrepancies and the undermining of dignity due to discounting. Complying with the constructivist grounded theory, the focus on disability as a comparative framework has been suggested by several participants who were consistently referring to differences of treatment between the two groups. The analysis pays particular attention to the language used to frame older people's rights so that these can be understood and implemented in practice. The main objective is to check how far the narrative of older people's rights that is integrated in existing instruments reflects the empirical findings of the thesis, or rather departs from it.

The normative analysis focuses on UN, CoE and EU human rights instruments, as well as the MIPAA. Despite not being - strictly speaking- a human rights mechanism, analysing the MIPAA is considered necessary, given its influence in the discourse on older people's rights and the development of ageing policies. The study does not involve a primary analysis of caselaw by European courts, treaty bodies and the European Committee of Social Rights as it pertains to the rights of older persons, since this has already been undertaken by other scholars⁴⁸². The

⁴⁸² Benny Spanier and Israel Issi Doron, "The European Social Charter and the rights of older persons," in *Ageing, Ageism and the Law* (Edward Elgar Publishing, 2018); Benny Spanier and Israel Doron, "In Course of Change: Soft Law, Elder Rights, and the European Court of Human Rights," *Law & Ineq.* 34 (2016); Benny Spanier, Israel Doron, and Faina Milman-Sivan, "Older persons' use of the European Court of Human Rights," *Journal of cross-cultural gerontology* 28,

analysis relies on secondary sources to discuss the appropriateness and adequacy of existing standards. The work of the most relevant Special Procedures until October 2019 has been included, in particular the mandate of the Independent Expert on the Enjoyment of all Human Rights by Older Persons, the Special Rapporteur on the Rights of Persons with Disabilities, the Special Rapporteur on the Right of everyone to the enjoyment Highest Attainable Standard of Physical and Mental Health and the Special Rapporteur on Extreme Poverty and Human Rights. Finally, whereas admittedly CRPD standards have potential of application in the context of older age, especially with regard to care settings, they are mainly considered here as a framework of comparison in order to illustrate discrepancies between ageing and disability standards.

Non-Recognizing

While on the face of it, international human rights law is age-neutral in that standards apply universally and therefore do not exclude older persons from their remit, it often reiterates stereotypical assumptions. The primary way in which human rights law institutionalises discounting is by perpetuating stereotyped and stigmatizing views of older age and older persons.⁴⁸³ This

no. 4 (2013); Eugenio Mantovani, Benny Spanier, and Israel Doron, "Ageism, Human Rights, and the European Court of Human Rights: A Critical Analysis of the *Carvalho v. Portugal* Case (2017)," *DePaul J. Soc. Just.* 11 (2018); Doron et al., "Ageism and anti-ageism in the legal system: A review of key themes."; Israel Issi Doron et al., "The legal appearances of dementia in court rulings: mapping the terrain," *International psychogeriatrics* 29, no. 5 (2017); Israel Doron, "Older Europeans and the European Court of Justice," *Age and Ageing* 42, no. 5 (2013); O'Conneide, "Article 25–The Rights of the Elderly."; De Hert and Mantovani, "Specific Human Rights for Older Persons? The inevitable colouring of Human Rights Law." Rodriguez-Pinzón and Martin, "The International Human Rights Status of Elderly Persons "; Martin, Rodríguez-Pinzón, and Brown, *Human Rights of Older People-Universal and Regional Perspectives*; De Pauw et al., "Ageism and Age Discrimination in international human rights law."; de Pauw, "Global Population Aging from a Human Rights Perspective: The Need for a UN Convention on the Rights of Older Persons."; Marijke De Pauw, "Interpreting the European Convention on Human Rights in Light of Emerging Human Rights Issues: An Older Person's Perspective," *Hum. Rts. & Int'l Legal Discourse* 8 (2014); Office of the High Commissioner for Human Rights, Normative standards in international human rights law in relation to older persons - Analytical Outcome Paper. European Network of National Human Rights Institutions, *Human Rights of Older Persons and Long-Term Care Project: The Application of International Human Rights Standards to Older Persons in Long-Term Care*.

⁴⁸³ There are some notable exceptions, such as the Preamble of the UN General Assembly, *United Nations Principles of Older Persons adopted by General Assembly resolution 46/91 of 16 December 1991* (1991), which suggest that decline is not inevitable and call on States to facilitate the participation and contribution of older persons

approach is exemplified in the General Comment 6 on the economic, social and cultural rights of older persons, which makes reference to the *problem* of demographic ageing⁴⁸⁴ and to the *detrimental* effects of ageing⁴⁸⁵. Older women are depicted as vulnerable and in need of protection; the language used limits older women's challenges to a single life experience, that of providing care within the family.⁴⁸⁶

Furthermore, international instruments widely use language that portrays older persons as passive recipients of care. The extensive use of the terms 'elderly', 'frail' and 'dependent'⁴⁸⁷, which are heavily associated with loss of capacities and declining health, across various instruments illustrates that human rights law endorses a narrative of decline and pathology.⁴⁸⁸ The 2014 CoE recommendation dedicates almost half of its provisions to aspects of health, long-term care and palliative care, giving therefore a disproportionate focus to declining health and function.⁴⁸⁹ General Comment 6 by referring to '*families who wish to keep elderly people at home*', adopts a paternalistic view of older persons as individuals that need to be taken care of.⁴⁹⁰ The UN principles encourage a protectionist approach to institutional care by stressing protection, rehabilitation and security, as opposed to participation, autonomy and independence.⁴⁹¹

⁴⁸⁴ Committee on Economic Social and Cultural Rights (CESCR), "General Comment No.6: The economic, social and cultural rights of older persons." para 11

⁴⁸⁵ Committee on Economic Social and Cultural Rights (CESCR), "General Comment No.6: The economic, social and cultural rights of older persons." para 24

⁴⁸⁶ Committee on Economic Social and Cultural Rights (CESCR), "General Comment No.6: The economic, social and cultural rights of older persons." para 20

⁴⁸⁷ See among others Art 25 European Union, Charter of Fundamental Rights of the European Union. Art 23 Council of Europe, "European Social Charter (Revised)." Preamble of UN General Assembly, *United Nations Principles of Older Persons adopted by General Assembly resolution 46/91 of 16 December 1991*.

⁴⁸⁸ Frameworks Institute, *Finding the Frame: An Empirical Approach to Reframing Aging and Ageism* (2017); European Union Agency for Fundamental Rights, *Shifting perceptions: Towards a rights-based approach to ageing*; Thompson, *Age discrimination*; Kesby, "Narratives of aging and the human rights of older persons."

⁴⁸⁹ Council of Europe, "Recommendation CM/Rec(2014)2 of the Committee of Ministers to member States on the promotion of the human rights of older persons."

⁴⁹⁰ Committee on Economic Social and Cultural Rights (CESCR), "General Comment No.6: The economic, social and cultural rights of older persons." para 31

⁴⁹¹ UN General Assembly, *United Nations Principles of Older Persons adopted by General Assembly resolution 46/91 of 16 December 1991*. Para 12-13.

The condition that certain rights should be enjoyed ‘*as far/as long as possible*’, which is included in many international and regional texts, illustrates the biased application of universal norms in the context of older age.⁴⁹² As briefly mentioned in Chapter 2, this wording leaves ample discretion for forced treatment, protective interventions and restrictions of rights to be considered as normal. It does not consider as human right breaches situations where older people are denied the right to decide where and with whom to live, to receive support at home and to be fully included in society, on account of limited resources or on the premise that limitations may be necessary to protect older people or others. It does not consider the adverse effect on older people’s mental health when they move to unfamiliar locations.⁴⁹³ For example, placement of older persons in institutional care against their will has not been interpreted as violating international human rights law.⁴⁹⁴ Whereas for persons with disabilities, care in institutions has been clearly labelled as a human rights abuse,⁴⁹⁵ restrictions to autonomy, independence and participation as result of segregation in institutions, have not been diagnosed as inappropriate⁴⁹⁶ and, as shown in previous chapters, continue to constitute the default response to older people’s need for formal care and assistance. Even though MIPAA clearly promotes ageing in place and community-based care, it seems to consider institutionalisation as

⁴⁹² UN General Assembly, *United Nations Principles of Older Persons adopted by General Assembly resolution 46/91 of 16 December 1991*. Para 5-6; Council of Europe, "European Social Charter (Revised)." Art. 23; Council of Europe, "Recommendation CM/Rec(2014)2 of the Committee of Ministers to member States on the promotion of the human rights of older persons." para 30, 38; United Nations, "Political Declaration and Madrid International Plan of Action on Ageing." Para 23, 28, 86 (c), 105 (i); Committee on Economic Social and Cultural Rights (CESCR), "General Comment No.6: The economic, social and cultural rights of older persons." para 33.

⁴⁹³ UN Secretary General, *Follow-up to the Second World Assembly on Ageing, Report of the Secretary General, A/64/127*, para 127. UN Secretary General, *Follow-up to the Second World Assembly on Ageing, A/67/188* (2012).

⁴⁹⁴ See European Network of National Human Rights Institutions, *We have the same rights: The Human Rights of Older Persons in Long-Term Care in Europe*. Citing the H.M. v. Switzerland (no. 39187/98), Watts v. the United Kingdom (no. 53586/09) cases of the European Court of Human Rights.

⁴⁹⁵ Committee on the Rights of Persons with Disabilities (CRPD), *General Comment No5: The right to independent living* (2017).

⁴⁹⁶ Several of the key normative standards on older persons refer to institutions, among which,

necessary to a certain extent.⁴⁹⁷ The CoE recommendation, while acknowledging that institutions are places where human rights violations may occur, instead of prohibiting institutionalisation it merely spells out ways to avoid and address elder abuse⁴⁹⁸. The current framework has therefore failed to extend to older persons the same safeguards to the human right to living in the community that everyone else in society has.

Perhaps the most flagrant example of non-recognizing in human rights law is the failure to enshrine a clear and comprehensive prohibition of age discrimination.⁴⁹⁹ Most UN human rights treaties do not include age as a ground of discrimination. Only the UN Convention on the Rights of Persons with Disabilities and the International Convention on the Protection of the Rights of all Migrant Workers and Members of their Families explicitly refer to age. Neither the VIPAA, nor the UN principles refer to age discrimination.⁵⁰⁰ The MIPAA refers to the elimination of age discrimination, but it primarily concentrates on work-related discrimination.⁵⁰¹ Existing human rights standards are also silent with regard to ageism. They lack an obligation for States to eliminate ageist practices and social norms and an obligation to take appropriate awareness-raising measures to counter stereotypes and prejudices towards older persons.

The majority of the regional instruments have also failed to prohibit age discrimination, or limit coverage on certain spheres of life, thus rendering protection against age discrimination less visible and comprehensive compared with other grounds. EU treaties explicitly recognise age as a ground suspect for

⁴⁹⁷ United Nations, "Political Declaration and Madrid International Plan of Action on Ageing." Despite aiming to prevent institutionalisation also accepts institutions as part of the spectrum of care, para 86, 98, 104, 105,107

⁴⁹⁸ Council of Europe, "Recommendation CM/Rec(2014)2 of the Committee of Ministers to member States on the promotion of the human rights of older persons.", in particular part C, Explanatory memorandum para. 66 and several of the good practices refer to institutional care

⁴⁹⁹ Mikołajczyk, "International law and ageism.", de Pauw, "Global Population Aging from a Human Rights Perspective: The Need for a UN Convention on the Rights of Older Persons."; Office of the High Commissioner for Human Rights, Normative standards in international human rights law in relation to older persons - Analytical Outcome Paper; De Pauw et al., "Ageism and Age Discrimination in international human rights law."

⁵⁰⁰ The VIPAA merely refers to rejecting stereotypes on the needs and capabilities of the elderly. The 1991 UN Principles state that older persons should be treated fairly.

⁵⁰¹ De Pauw et al., "Ageism and Age Discrimination in international human rights law."

discrimination⁵⁰². The EU Charter of Fundamental Rights prohibits in article 21 discrimination, including on the basis of age and dedicates a specific article to the rights of the elderly (article 25). However, secondary EU law only covers age discrimination in access to the labour market.⁵⁰³ In 2008, the European Commission prepared a proposal for a Council Directive that would complete the EU framework by affording to age – among other grounds - a similar level of protection as currently exists for race and gender under EU law.⁵⁰⁴ However, the directive is still stuck in negotiations, due to strong resistance from a few Member States. Due to this lack of coverage of other areas it has be argued that there exists a *'hierarchy of grounds'*, whereby EU law protects more comprehensively against discrimination on some grounds than on others.⁵⁰⁵

The European Convention on Human Rights and the European Social Charter do not include reference to age discrimination. The European Committee on Social Rights has however required States to adopt comprehensive age discrimination legislation as part of their obligations under article 23 of the Revised European Social Charter⁵⁰⁶. The 2014 CoE recommendation on the rights of older persons has suggested that States should make explicit reference to age in their national anti-discrimination laws.⁵⁰⁷ It has failed however to integrate a requirement for enacting laws where the national frameworks do not cover age discrimination in all areas of life.

⁵⁰² Article 13 of the Treaty of Amsterdam (now article 19 of the Treaty of the European Union)

⁵⁰³ Council of the European Union, "Council Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation," (2000). <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:32000L0078:en:HTML>.

⁵⁰⁴ European Commission, Proposal for a Council Directive on implementing the principle of equal treatment between persons irrespective of religion or belief, disability, age or sexual orientation, (2008); European Commission, Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions - Non-discrimination and equal opportunities: A renewed commitment (2008).

⁵⁰⁵ L. B. Waddington and M. Bell, "Reflecting on inequalities in European equality law," *European Law Review* 28 (2003).

⁵⁰⁶ O'Conneide, "Article 25–The Rights of the Elderly."

⁵⁰⁷ Para 7

Moreover, differential treatment on the basis of age is often considered permissible, even in instances where discrimination based on other grounds is not permitted.⁵⁰⁸ The Committee on Economic, Social and Cultural Rights failed to conclude that discrimination on the basis of age is comprehensively prohibited.⁵⁰⁹ In doing so the Committee basically acknowledged that the degree to which age discrimination can be tolerated is considerably higher compared to other forms of discrimination, like racism or sexism.⁵¹⁰ On the other hand, the UN Human Rights Committee, clarified that article 26 of the ICCPR, which concerns equality before the law, provides for protection against discrimination on the basis of age in law in any field regulated by public authorities.⁵¹¹ The discrepancy between the two UN bodies is symptomatic of the fact that age as an equally valid ground of protection remains highly disputable⁵¹².

For EU law age is the only ground for which direct discrimination can be justified. Article 6, provides that differences of treatment on the ground of age *'shall not constitute discrimination, if, within the context of national law, they are objectively and reasonably justified by a legitimate aim, including legitimate employment policy, labour market, and vocational training objectives, and if the means of achieving that aim are appropriate and necessary.'* Therefore, the extent of protection from age discrimination depends on the interpretation of this

⁵⁰⁸ Chung, *The necessity of a human rights approach and effective United Nations mechanism for the human rights of the older person*; AGE Platform Europe et al., *Equality and non-discrimination* (2017), https://social.un.org/ageing-working-group/documents/eighth/Inputs%20NGOs/Joint_Paper_Equality.pdf; Helen Meenan, "Reflecting on age discrimination and rights of the elderly in the European Union and the Council of Europe," *Maastricht Journal of European and Comparative Law* 14, no. 1 (2007).

⁵⁰⁹ Committee on Economic Social and Cultural Rights (CESCR), "General Comment No.6: The economic, social and cultural rights of older persons," para 12. Committee on Economic Social and Cultural Rights (CESCR), "General Comment No. 20: Non-discrimination in economic, social and cultural rights," (2009). para 29

⁵¹⁰ It is worth noticing that before the Committee issued this interpretation, it had already defined and prohibited discrimination based on disability in 1994 in General Comment 5, without setting out any limits to the prohibition

⁵¹¹ See for example, *Love et al. v. Australia*, Communication 983/2001, views of 25 March 2003, para. 8.2

⁵¹² Colm O'Cinneide, "Age discrimination and the European Court of Justice: EU equality law comes of age," *Revue des affaires europeennes*, no. 2 (2009); Pnina Alon-Shenker, "The Unequal Right to Age Equality: Towards a Dignified Lives Approach to Age Discrimination," *Canadian Journal of Law & Jurisprudence* 25, no. 2 (2012).

provision. This has been described as an *'inherent vulnerability, which 'means that a careful balance has to be struck in order to ensure that the prohibition is meaningful'*⁵¹³. This weaker and ambivalent protection of age discrimination is a reason why age discrimination has been the subject of several cases of the European Court of Justice. As explained by O'Cinneide, the European Court seems to have lightly applied the test of justification, accepting as legitimate any age-based distinctions that *'can be shown to be rationally linked to the achievements of a legitimate aim'*.⁵¹⁴

The emblematic example of the integration of age bias in human rights law are mandatory retirement ages, which are largely accepted as legitimate.⁵¹⁵ Forcing older people out of the labour market based on chronological criteria and regardless of their ability or willingness to continue working breaches their right to work and their right to take autonomous decisions about their life⁵¹⁶. It may also impact the enjoyment of other rights as, according to participants the exclusion from the labour market may lead to poverty, low self-esteem and social isolation. This infringement is serious especially bearing in mind that mandatory retirement is not temporary. But unlike other discrimination grounds where exclusion from the labour market is considered illegal, older people can under existing standards be legitimately prevented from working.

Additionally, even though the protection from discrimination in principle extends to aspects of social protection⁵¹⁷, discrimination in access to health care and disability benefits has not been explicitly considered illegitimate under current

⁵¹³ Declan O'Dempsey and Anna Beale, *Age and Employment*, European Network of Legal Experts in the non-discrimination field (Brussels: European Commission, 2011).p.5

⁵¹⁴ Colm O'Cinneide, "Constitutional and fundamental rights aspects of age discrimination," in *Age discrimination and labour law, Comparative and conceptual perspectives in the EU and beyond*, ed. Ann Numhauser-Henning and Mia Rönnmar (Kluwer, 2015).p.59

⁵¹⁵ Fineman, "Elderly as vulnerable: Rethinking the nature of individual and societal responsibility."; Doron et al., "Ageism and anti-ageism in the legal system: A review of key themes."

⁵¹⁶ Ontario Human Rights Commission, *Bill 211, Ending Mandatory Retirement Statute Law Amendment Act* (2005), <http://www.ohrc.on.ca/en/bill-211-ending-mandatory-retirement-statute-law-amendment-act>.

⁵¹⁷ *Love et al. v. Australia*, Communication 983/2001, views of 25 March 2003

norms and treaty bodies. As shown in the findings, some health services, including prevention, rehabilitation and access to mental health services are not equally offered to the older population.⁵¹⁸ The CRPD Committee has so far not challenged the existence of age limits in access to disability services and benefits.⁵¹⁹ These gaps perpetuate older people's exclusion and can lead to poverty and deprivation. They also adversely affect older people's right to financial independence. To fight these covert forms of discrimination, human rights standards need to acknowledge that all aspects of social protection, including health and long-term care need to be available to older persons on an equal basis as in other stages of the life course.⁵²⁰

These cases that emerge from the normative analysis illustrate that in its current form human rights law is conceptually ill-equipped to address human rights breaches against older persons. Binding human rights standards provide only weak and patchy safeguards from age discrimination and *'there is still little consensus on the meaning of equality in the context of age and how it can be achieved'*.⁵²¹ Age discrimination is not linked to historical oppression and is not considered to impact human dignity to the same degree with discrimination on the basis of gender or race⁵²². As argued by Ontario Human Rights Commission,

'[a]ge cases tend to be treated differently than other discrimination cases. (...) The most noticeable difference from a human rights perspective is the lack of a sense of moral opprobrium linked to age discrimination which in

⁵¹⁸ On this see also AGE Platform Europe, *AGE Platform Europe Position on Structural Ageism*; Annika Taghizadeh Larsson and Håkan Jönson, "Ageism and the Rights of Older People," in *Contemporary Perspectives on Ageism*, ed. Liat Ayalon and Clemens Tesch-Römer (Springer, Cham, 2018).

⁵¹⁹ Committee on the Rights of Persons with Disabilities, *General comment No. 6 (2018) on equality and non-discrimination*, 26 April 2018, CRPD /C/GC/6 (2018).

⁵²⁰ UN Human Rights Council, *Thematic study on the realization of the right to health of older persons by the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, Anand Grover, para 70

⁵²¹ Spencer and Fredman, *Age Equality Comes of Age: Delivering Change for Older People*. P.2

⁵²² O'Conneide, "Constitutional and fundamental rights aspects of age discrimination."; O'Conneide, "Age discrimination and the European Court of Justice: EU equality law comes of age."

*comparable circumstances would generate outrage if the ground of discrimination were, say, race, sex or disability.*⁵²³

Contesting inequalities presupposes being conscious of how certain practices or policies operate to the detriment of older persons and lead to human rights abuses. But by integrating false or limited conceptions about older people's capacities, potential and contributions, institutionalizing patronizing solutions to later life challenges and failing to diagnose and expose discriminatory practices as wrongful, human rights norms deny older people the same degree of agency and dignity as other human beings. To the extent that these biased modes of thinking are entrenched in norms, they will continue to be reproduced in caselaw and inform future human rights practice. In other words, the mere implementation of the existing framework does not recognize older persons as full agents with equal rights to others and risks perpetuating harmful and undignified practices.

Non-Enabling

This section explores whether the obligations to provide support and equal opportunities, to expand older people's sphere of choices for participation and to respect their desires and preferences that derive from participants' vision of belonging, having a voice and maintaining independence are adequately wide, specific, clear and coherent in the current framework. If this is not the case, then it could be argued that existing norms do not respond appropriately to the real challenges and needs of older persons. This would then provide evidence of the institutionalisation of non-enabling in human rights law.

This section does not attempt to cover the whole range of substantive rights. Neither does it offer an exhaustive list of gaps. The aim of this part is not to discuss how existing standards can be applied in the context of older age, but rather how

⁵²³ Ontario Human Rights Commission, *Discrimination and Age: Human Rights Issues Facing Older Persons in Ontario - Discussion Paper* (2000), http://www.ohrc.on.ca/sites/default/files/discussion%20paper_discrimination%20and%20age_human%20rights%20issues%20facing%20older%20persons%20in%20ontario.pdf.

the range of violations identified by participants can be held up against the international framework. The analysis suggests some ways in which international law could be expanded, if certain experiences of abuses, as they emerge from the findings, could be integrated in a new legal instrument. For the purposes of the normative analysis, the empirical categories of *belonging*, *having a choice* and *being independent*, have been translated into the headings of participation, autonomy and independence. This classification is merely practical: it refers to key areas of rights that have been empirically identified as forming the backbone of a human rights-based approach to older age. The choice of wording does not mirror single or specific rights as they have been enshrined in the extant framework. Participation, autonomy and independence ought to be seen as constellations of rights, which are inter-related and interdependent and are embedded in the ideas of dignity and equality, which are foundations of human rights. Several of the rights discussed, like access to work, social protection or protection from elder abuse have ramifications in all three areas of rights.

Before delving into the normative analysis of these aspects, a few general observations must be made. First, as noted in chapter 2, the vast majority of instruments that deal specifically with ageing and human rights are non-binding. By itself, the soft character of standards that apply in this field undermine the level of accountability in case of violation. Additionally, existing regulatory principles are fragmented across various soft instruments and often lack specificity. When looking into the international standards that apply to older age, in particular the UN Principles and the General Comment 6, it becomes evident that they lack explicit language and concrete recommendations. The UN principles are general; they do not include any reference on how to implement the objectives they aspire to. Likewise, the General Comment mainly reiterates the provisions of the Vienna International Plan of Action, as well as the Principles and shows little progress in defining rights and associated obligations in the context of older age. Although it could be assumed that this lack of specificity is due to the non-binding character of these instruments, the comparison with General Comment 5 on the economic, social and cultural rights of persons with

disabilities, which was adopted in 1994 illustrates that the Committee could have provided more clarity and original reflection to define rights and obligations in the context of older age. Additionally, both instruments are relatively old and the fact that they have not been revisited means that they are not conscious of issues that are more prevalent today than more than 20 years ago when these were drafted. Digitalisation, changing family patterns, migration and austerity, among others, form the background against which the human rights of older persons are understood and negotiated today, but they have barely been considered when earlier instruments were adopted.

Participation

Despite being – according to interviewees - pervasive, systemic and threatening several domains of older people’s lives, isolation and exclusion have not been widely described as human rights issues.⁵²⁴ The right of older persons to participate and be included in society is not explicitly recognized under international human rights law.⁵²⁵ As highlighted by Chung in her report for the Advisory Committee of the Human Rights Council, existing legislation focuses on aspects of protection and welfare of older persons and does not adequately reflect elements of participation in society.⁵²⁶ The Independent expert also explained that most national legal and policy frameworks refer to issues of age discrimination, care, elder abuse and social protection.⁵²⁷ It appears therefore that participation and inclusion are in principle relatively neglected aspects of human rights of older persons by international legal standards.

More recent soft instruments, as well as interpretation by treaty bodies and special procedures, have gradually recognised older people’s contributions and

⁵²⁴ For a notable exception see UN Human Rights Council, *Report of the Independent Expert on the Enjoyment of all Human Rights by Older Persons, A/HRC/39/50* ; Stuckelberger, Abrams, and Chastonay, "Age discrimination as a source of exclusion in Europe: The need for a human rights plan for older persons."

⁵²⁵ Office of the High Commissioner for Human Rights, Normative standards in international human rights law in relation to older persons - Analytical Outcome Paper.)

⁵²⁶ Chung, *The necessity of a human rights approach and effective United Nations mechanism for the human rights of the older person.*

⁵²⁷ UN Human Rights Council, *Report of the UN Independent Expert on the enjoyment of all human rights by older persons, A/HRC/33/44.* para 106 and 119

potential.⁵²⁸ However, even these mechanisms have not necessarily recognized older people as economic actors and by accepting mandatory retirement ages and other restrictions they fail to acknowledge older persons as truly equal citizens, fully entitled to participate in social, economic, cultural and civic life. For example, the EU Charter of Fundamental Rights does not recognize the right of older persons to participate in the labour market.⁵²⁹ Neither do international norms afford older persons a real choice to decide what roles they want to play and how they wish to contribute to society. For example, the MIPAA and its focus on active participation could be considered as limiting choice as it encourages older people to follow a certain lifestyle.⁵³⁰ This entails that if they fail to live up to this standard, they are likely to be stigmatized as unproductive, useless or a burden. Human rights standards need to be embedded with an idea of older age that is at the same time emancipatory but does not deprecate older persons who choose or are unable to have active roles, contribute and participate.

Under the Council of Europe Revised Charter of Social Rights, older people residing in institutions can enjoy their sociocultural rights only insofar as this is possible under institutional conditions.⁵³¹ In other words, as long as older people live in residential settings, they lose the right to access culture and develop social relations outside the walls of the institutions, as well as the right to contribute to the social, political, economic and cultural life of their communities. Similarly, UN Special procedures, the MIPAA and the UN principles have limited the right to participate in decision-making to issues related to care and personal wellbeing.⁵³²

⁵²⁸ United Nations, "Political Declaration and Madrid International Plan of Action on Ageing."; Council of Europe, "Recommendation CM/Rec(2014)2 of the Committee of Ministers to member States on the promotion of the human rights of older persons."; UN Human Rights Council, *Thematic study on the realization of the right to health of older persons by the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, Anand Grover.

⁵²⁹ O'Connell, "Article 25–The Rights of the Elderly."

⁵³⁰ Gail Wilson, "Conceptual frameworks and emancipatory research in social gerontology," *Ageing & Society* 21, no. 4 (2001).

⁵³¹ Mariya Riekkinen, "Participation of the elderly in sociocultural life: human rights and inclusive practices under residential care," *Journal of Public Affairs* 15, no. 3 (2015).

⁵³² UN Human Rights Council, *Thematic study on the realization of the right to health of older persons by the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, Anand Grover. para 12; UN Human Rights

Moreover, the Principles fail to encourage integration and participation by referring merely to '*social and mental stimulation*' as the objective of institutional care.⁵³³ These instruments effectively deny to those who live in care settings a set of rights that relate to continuing education, civic and social participation and access to culture, among others. So, the right to participation has been poorly articulated in the context of care.

Full and effective participation and inclusion in society is a key objective of human rights law, yet its application in the context of older age has a narrow scope. The very depiction of ageing as a problem, and older persons as in need of care elucidates how difficult it is to fully accept older age as an opportunity and participation as a right that should not be compromised in later life. Painting a portrait of older people in poor health or in conditions of poverty may cause sympathy but may undermine the view that they are also deserving of empowerment and inclusion.⁵³⁴ By prioritizing concepts of safety, care and needs over participation and empowerment, human rights law perpetuates a view of older people as passive and in need of protection,⁵³⁵ encouraging segregation and a failure to guarantee older people's participation in society on an equal basis with others. The rhetoric around older people's potential and inclusion needs to be coupled with specific obligations to prevent isolation and marginalisation and to enable *belonging* in the community. A more empowering framework is needed to tie human rights responsibilities with opportunities for growth and contribution to society.

According to the empirical findings such duties could, inter alia, include: the promotion of positive images of ageing and the recognition of older people's

Council, *Report of the UN Independent Expert on the Enjoyment of all Human Rights by Older Persons*, A/HRC/30/43. para 57; United Nations, "Political Declaration and Madrid International Plan of Action on Ageing." para 77; UN General Assembly, *United Nations Principles of Older Persons adopted by General Assembly resolution 46/91 of 16 December 1991*. para 14.

⁵³³ Para 13

⁵³⁴ Frameworks Institute, *Finding the Frame: An Empirical Approach to Reframing Aging and Ageism*. p. 14

⁵³⁵ Kanter, "The United Nations Convention on the Rights of Persons with Disabilities and its implications for the rights of elderly people under international law."

contributions among all sectors of government and society to change stereotypes that affect older people's full and effective participation, such as those that portray them as a burden to society and objects of care; the identification and gradual elimination of all the legislative, institutional, attitudinal and other barriers that impede older people's full participation in society, such as age limits and forced retirement; ensuring that all programmes, services and public spaces available for the general public in the community, including - among others- transport, education, cultural institutions, information and communication technologies, are accessible by older people and adapted to their needs, capacities and preferences;⁵³⁶ taking appropriate measures to ensure that older persons can take part on an equal basis with others in education, cultural life, recreation, leisure, sports and volunteering; and providing support, training and capacity-building in order for older people to make seamless transitions at different stages of their life, find their role and utility and increase their contributions.⁵³⁷

Autonomy

The adoption of the CRPD spearheaded a new paradigm regarding autonomy and legal capacity, whereby persons with disabilities should enjoy legal capacity on an equal basis with non-disabled people. This new standard has influenced discussions and policy developments on ageing, although its application in the context of older people may be limited due to the resistance to associate older age

⁵³⁶ Committee on Economic Social and Cultural Rights (CESCR), "General Comment No.6: The economic, social and cultural rights of older persons." Para 33, 40; United Nations, "Political Declaration and Madrid International Plan of Action on Ageing." para 95, 99, 100; UN Human Rights Council, *Report of the UN Independent Expert on the enjoyment of all human rights by older persons, A/HRC/33/44*. para 79-82; UN Human Rights Council, *Report of the UN Independent Expert on the Enjoyment of all Human Rights by Older Persons, A/HRC/30/43*. Para 58-60, 111-112; Council of Europe, "Recommendation CM/Rec(2014)2 of the Committee of Ministers to member States on the promotion of the human rights of older persons." para. 22

⁵³⁷ This issue is partly reflected in United Nations, "Political Declaration and Madrid International Plan of Action on Ageing." article 12, 14, para 12, 41, 48f, 89, 94. See also Committee on Economic Social and Cultural Rights (CESCR), "General Comment No.6: The economic, social and cultural rights of older persons." para 24, which refers to retirement preparation programmes aiming to help older workers cope with their new situation, provide information about their rights and obligations and about '*the opportunities and conditions for continuing an occupational activity or undertaking voluntary work; means of combating detrimental effects of ageing; facilities for adult education and cultural activities; and the use of leisure time*'.

with disability.⁵³⁸ References to ‘incapacity’, ‘guardianship’ and the ‘best interest’ of older persons, which appear prominently in ageing standards, mirror a custodian perspective to the protection of older persons’ rights and stand in stark contrast to the maintenance of full legal capacity propounded by the CRPD⁵³⁹.

It has been argued that international law does not cover adequately issues of autonomy from the perspective of older age.⁵⁴⁰ Within the ageing legal framework there has been little attention to aspects of legal capacity, beyond the exercise of informed consent in relation to medical and social care.⁵⁴¹ Legal capacity does not appear explicitly in any of the UN standards on ageing. Only the OAS convention and the non-binding CoE recommendation have included provisions affirming that older people enjoy legal capacity on an equal basis with others, although these also foresee restrictions for protection purposes.⁵⁴² For example, the 2014 CoE recommendation accepts that decisions may be taken without the consent of the older individual, such as in cases that *‘the person is becoming a danger to him/herself or third persons, is incapable of seeing to his or*

⁵³⁸ Eilionóir Flynn, "Disability and ageing: Bridging the divide? Social constructions and human rights," in *Routledge Handbook of Disability Law and Human Rights* (Routledge, 2016). UN Office of the High Commissioner for Human Rights, *Analysis and overview of guiding questions on autonomy and independence received from Member States, "A" Status National Human Rights Institutions and accredited non-governmental organization* (2018), [https://social.un.org/ageing-working-](https://social.un.org/ageing-working-group/documents/ninth/OEWGA9_Substantive_Report_Autonomy_Independence_OHCHR.pdf)

[group/documents/ninth/OEWGA9_Substantive_Report_Autonomy_Independence_OHCHR.pdf](https://social.un.org/ageing-working-group/documents/ninth/OEWGA9_Substantive_Report_Autonomy_Independence_OHCHR.pdf).

⁵³⁹ See in particular, UN Human Rights Council, *Report of the UN Independent Expert on the Enjoyment of all Human Rights by Older Persons, A/HRC/30/43*. African Union, "Protocol to the African Charter on Human and Peoples' Rights on the Rights of Older Persons in Africa."; Council of Europe, "Recommendation CM/Rec(2014)2 of the Committee of Ministers to member States on the promotion of the human rights of older persons."

⁵⁴⁰ UN Office of the High Commissioner for Human Rights, *Analysis and overview of guiding questions on autonomy and independence received from Member States, "A" Status National Human Rights Institutions and accredited non-governmental organization*. stating that: *‘Some respondents pointed to the fact that explicit standards on autonomy and independence of older persons in international human rights law were insufficient. Whereas a number of instruments recognized the right, those standards varied and were inconsistent across regions.’*

⁵⁴¹ The Independent Expert on the rights of older persons has also addressed marginally aspects of legal capacity, focusing on decisions regarding social and health care. See UN Human Rights Council, *Report of the UN Independent Expert on the Enjoyment of all Human Rights by Older Persons, A/HRC/30/43*. para 51

⁵⁴² Organisation of American States, "Inter-american Convention on Protecting the Human Rights of Older Persons (A-70)." Art. 30; Council of Europe, "Recommendation CM/Rec(2014)2 of the Committee of Ministers to member States on the promotion of the human rights of older persons." para 12-15

her basic personal needs or is becoming a threat to law and order'⁵⁴³. Overall, there is also lack of reference to supported decision-making for older persons within the human rights framework.⁵⁴⁴

Admittedly, there is potential in using the CRPD to provide much needed guidance with regard to the right to full legal capacity and supported decision-making in older age. However, the CRPD does not necessarily cover older persons to the extent that limitations to autonomy and legal capacity are due to ageism and not to the existence or perception of existence of a disability. As shown in the findings, very often, due to negative stereotypes, the views of older persons – regardless of their mental and cognitive capacities – are not taken seriously and their choices are not seen as equally worthy of support.⁵⁴⁵ Ageism also affects perceptions of older people's capacities by others and by themselves and therefore limits their ability to exercise autonomy.⁵⁴⁶ Dabove has also argued that other factors, including loss of income, negative preconceptions and family abandonment, in addition to physical and mental impairment can become grounds for the loss of capacity.⁵⁴⁷ Furthermore, older women face particular challenges in relation to their legal capacity. For example, they may not have the right to inherit and administer marital property on the death of their spouse or

⁵⁴³ Para 24 Explanatory Memorandum

⁵⁴⁴ One notable exception is the Council of Europe, "Recommendation CM/Rec(2014)2 of the Committee of Ministers to member States on the promotion of the human rights of older persons." Para 13.

⁵⁴⁵ See also Human Rights Council, *Report of the Independent Expert on the Enjoyment of All Human Rights by Older Persons*, Rosa Kornfeld-Matte, Human Rights Council (2015); UN Human Rights Council, *Report of the UN Independent Expert on the Enjoyment of all Human Rights by Older Persons*, A/HRC/30/43; Flynn, "Disability and ageing: Bridging the divide? Social constructions and human rights."; UN Office of the High Commissioner for Human Rights, *Analysis and overview of guiding questions on autonomy and independence received from Member States, "A" Status National Human Rights Institutions and accredited non-governmental organizations*; AGE Platform Europe, *Submission based on seminar with Europe-based experts on the Human Rights of Older Persons*; Georgantzi, "The right to autonomy, health and independent living". Helpage International, *Freedom to decide for ourselves, What older people say about their rights to autonomy and independence, long-term care and palliative care* (2018).

⁵⁴⁶ UN Human Rights Council, *Report of the UN Independent Expert on the Enjoyment of all Human Rights by Older Persons*, A/HRC/30/43; de Pauw, "Global Population Aging from a Human Rights Perspective: The Need for a UN Convention on the Rights of Older Persons."; Susan Sherwin and Meghan Winsby, "A relational perspective on autonomy for older adults residing in nursing homes," *Health Expectations* 14, no. 2 (2011). UN Human Rights Council. (2015).

⁵⁴⁷ Dabove, "Autonomy and capacity: about human rights of older persons in dependency situations."

their legal capacity is deferred to lawyers or family members without their consent.⁵⁴⁸ However, the existing framework lacks standards to challenge loss of decisional capacity, choice and control that is unrelated to disability.

Moreover, existing binding norms have not paid adequate attention to how the right to autonomy and legal capacity can be operationalised through advance directives.⁵⁴⁹ On the contrary, advance planning as a way to secure that individual wills and preferences are respected has received considerable attention in the ageing discourse and regional soft standards.⁵⁵⁰ The Independent Expert has highlighted that advance directives regarding care can prevent abuses in older age.⁵⁵¹ The Council of Europe stipulated that States should provide for legislation which allows older persons to regulate their affairs in the event that they are unable to express their instructions at a later stage.⁵⁵² The importance of advance directives has also been emphasized in the OEWG.⁵⁵³ Still, there is lack of clarity about how advance directives fit in with the paradigm of autonomy espoused by the CRPD.⁵⁵⁴

Moreover, there is a gap in understanding State obligations to respect autonomy and choice when care is provided through assisted technology. For example, in the current context of resource constraints and the growing numbers of people who will require support due to population ageing, it is likely that States will use their margin of discretion to introduce technological solutions in all care settings,

⁵⁴⁸ Robin Allen, *Discussion papers: Legal issues for strengthening international legislation on the rights of older persons*. Committee on the Elimination of Discrimination and against Women (CEDAW), *General recommendation No. 27 on older women and protection of their human rights* (2010).

⁵⁴⁹ Flynn, "Disability and ageing: Bridging the divide? Social constructions and human rights."

⁵⁵⁰ AGE Platform Europe, *Submission based on seminar with Europe-based experts on the Human Rights of Older Persons*.

⁵⁵¹ UN Human Rights Council, *Report of the UN Independent Expert on the Enjoyment of all Human Rights by Older Persons, A/HRC/30/43*. UN Human Rights Council. (2015). Para 52

⁵⁵² Council of Europe, "Recommendation CM/Rec(2014)2 of the Committee of Ministers to member States on the promotion of the human rights of older persons," para 14.

⁵⁵³ UN Department of Economic and Social Affairs, *Analysis and overview of guiding questions on long-term care and palliative care received from Member States, "A" Status National Human Rights Institutions and accredited non-governmental organization* (2018), https://social.un.org/ageing-working-group/documents/ninth/OEWGA9_Substantive_Report_LTC_Palliative-Care_DESA.pdf.

⁵⁵⁴ Flynn, "Disability and ageing: Bridging the divide? Social constructions and human rights."

without necessarily requesting consent by users or by offering an alternative. In this regard, the following deliberations of the Independent Expert, who dedicated a thematic report on the human rights implications of the introduction of new technologies in care are particularly relevant.⁵⁵⁵ Unless there are alternatives to the use of technology, there is no real right to choice. Assistive devices should complement and not replace traditional, human care. Additionally, the requirement of informed consent should be extended to the use of assistive devices. The obligation to obtain consent should also be linked with adequate support to make a decision.

All the above aspects are examples of relatively neglected areas of human rights norms and practice. Thus, it could be argued that a specific statement of the right to full legal capacity and autonomy of older persons may be needed, in order to clarify what special measures are necessary to make it effective in the context of older age.⁵⁵⁶

Independence

This part primarily focuses on access to support and long-term care, which despite being considered by participants as one of the key barriers to independence, has not been associated with human rights obligations in a clear and consistent manner.⁵⁵⁷ Other important gaps that emerge from the empirical findings in relation to independence are briefly discussed at the end of this section.⁵⁵⁸

⁵⁵⁵ UN Human Rights Council, *Report of the UN Independent Expert on the Enjoyment of all Human Rights by Older Persons A/HRC/36/48*.

⁵⁵⁶ Robin Allen, *Discussion papers: Legal issues for strengthening international legislation on the rights of older persons*; Flynn, "Disability and ageing: Bridging the divide? Social constructions and human rights."

⁵⁵⁷ Office of the High Commissioner for Human Rights, Normative standards in international human rights law in relation to older persons - Analytical Outcome Paper; European Network of National Human Rights Institutions, *We have the same rights: The Human Rights of Older Persons in Long-Term Care in Europe*.

⁵⁵⁸ Based on the empirical findings (see Chapter 9) independence is understood as being related to aspects of health and long-term care, housing, access to services, social protection and financial independence

Whereas disability discourse and the CRPD standards have established support as a fundamental right, care of older persons is typically problematized as a financial issue rather than a human right that involves State obligations.⁵⁵⁹ There is no universal definition of care or an explicit right to care or support for older persons under human rights law.⁵⁶⁰ Neither do existing standards provide older people with the right to choice and control over the type of service they receive. Instead, they tend to emphasize the role of the family in providing care for older people and to limit formal care in institutional settings.⁵⁶¹

Family care appears prominently in the UN principles.⁵⁶² Mirroring the UN Principles, the General Comment 6 of the ICESCR puts emphasis on community support and self-help as opposed to a State obligation to assist older persons. The MIPAA also calls on Member States to ensure conditions and develop social support systems that facilitate the provision of care within the family.⁵⁶³ The primary focus of human rights standards on family responsibility for the care of older persons may detract attention from State obligations to organise, fund, supervise or provide formal home care.⁵⁶⁴ For example, the prevailing assumption that family members should provide support to their older relatives

⁵⁵⁹ Teppo Kröger, "Care research and disability studies: Nothing in common?," *Critical Social Policy* 29, no. 3 (2009).; Schulmann et al., *From disability rights towards a rights-based approach to long-term care in Europe: Building an index of rights-based policies for older people*.

⁵⁶⁰ European Network of National Human Rights Institutions, *We have the same rights: The Human Rights of Older Persons in Long-Term Care in Europe*; UN Human Rights Council, *Report of the UN Independent Expert on the Enjoyment of all Human Rights by Older Persons*, A/HRC/30/43. AGE Platform Europe et al., *Autonomy, independence, long-term care and palliative care: A discussion paper for the 9th Open-ended Working Group on Ageing* (2018), https://social.un.org/ageing-working-group/documents/ninth/Joint_Discussion_paper.pdf.

⁵⁶¹ It is perhaps emblematic that the first ever attempt to enshrine the rights of older persons made it clear that family members hold the primary responsibility for the care of older persons. The Draft Resolution on a Declaration of Old Age Rights which was submitted by the Argentinian delegation to the UN General Assembly in 1948 Stated that: '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.' For the full text see Doron and Mewhinney, "The rights of older persons." Also notably, the African Protocol on older people's rights stresses in article 10 that States should encourage family-based home care through incentives and enhance the ability of families to care for older people.

⁵⁶² Para 10

⁵⁶³ para. 66 (b), para 102 and 105 (h).

⁵⁶⁴ This is also an example of non-recognizing, i.e failure to problematize the lack of State action to ensure access to care as a form of human rights breach

has meant care and support is rarely part of the implementation of the right to social protection.⁵⁶⁵

While human rights standards are cognisant of the overwhelming reliance on family care, which has also been reflected in the findings of this thesis, they do not explicitly enshrine a right to be supported as a family carer.⁵⁶⁶ This creates a disproportionate disadvantage for older women, who are typically the caregivers. The CRPD on the other hand, clarified in its preamble that support to family is central to the full and equal enjoyment of human rights by persons with disabilities. The CRPD Committee has also recognized the need to support family caregivers in particular through financial assistance, respite care and peer support.⁵⁶⁷

Additionally, existing norms fail to set out clear standards around formal care and support, in community settings.⁵⁶⁸ Recommendations to States in order to ensure adequate staffing, training and quality inspections to avoid abuse, primarily apply to residential settings.⁵⁶⁹ The European Court of Human Rights imposes greater scrutiny for cases of abuse in institutions than in the community, which can be perceived as if *'in return for community living, other human rights must be waived or tempered'*.⁵⁷⁰ The UN Committee on Economic, Social and Cultural Rights has recommended that priority be given to home care rather than institutionalisation

⁵⁶⁵ None of the three countries have a comprehensive right to long-term care in the home as part of their social protection system. On this see also Scheil-Adlung, *Long-term care protection for older persons: A review of coverage deficits in 46 countries*, ESS Working Paper No. 50; Social Protection Committee and Commission, *Adequate Social Protection for Long-Term Care Needs in an Ageing Society*.

⁵⁶⁶ The European Committee on Social Rights has however held that *'the existence of a carers allowance for family members looking after an elderly relative'* should be taken into consideration in the assessment of pension adequacy. Council of Europe European Committee of Social Rights, *Digest of the Case Law of the European Committee of Social Rights*, 1 September 2008 (2008).

⁵⁶⁷ Committee on the Rights of Persons with Disabilities (CRPD), *General Comment No5: The right to independent living*. Para 55

⁵⁶⁸ UN Economic and Social Council, *Report of the United Nations High Commissioner for Human Rights* (2012), <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G12/420/71/PDF/G1242071.pdf?OpenElement>.

⁵⁶⁹ Office of the High Commissioner for Human Rights, *Normative standards in international human rights law in relation to older persons - Analytical Outcome Paper*.

⁵⁷⁰ Clough and Brazier, "Never too old for health and human rights?." P.139 citing Luke Clements, "Disability, dignity and the cri de coeur," *European human rights law review* 6 (2011). P.11

and that it should be affordable.⁵⁷¹ The European Committee on Social Rights has developed some guidelines around help at home, prescribing for instance the need for information on available services and their affordability to make them more accessible.⁵⁷² However, as human rights law begins from a premise where institutionalisation in older age is acceptable and where family care is the norm in community settings, existing standards fail to enshrine a right to receive formal assistance at home or a right to housing with care options. It is also questionable whether they can provide adequate protection from violence and abuse, as they do not set out an obligation for States to monitor the quality of care, to allocate enough resources and to train caregivers to the extent that this obligation exists for institutional settings.⁵⁷³

Furthermore, an analysis of existing standards on ageing reveals very different scope of the concept of care and associated obligations versus that of support as it is understood in disability human rights law. Services cited in the General Comment 6 in order to allow older people to remain at home are limited to food, transportation, nursing and health care.⁵⁷⁴ Under the same instrument the notion of support is considerably narrower than how it is defined under disability law, as it is restricted to home adaptations.⁵⁷⁵ Similarly, the UN principle of independence does not explicitly cover all activities of daily living of older persons but is restricted on aspects of food, water, shelter, clothing and health care. Moreover, unlike for persons with disabilities, States do not have an obligation to provide access to assistive technologies for older persons to carry out daily activities and participate in society. The use of assistive technologies in residential settings is

⁵⁷¹ Martin, Rodríguez-Pinzón, and Brown, *Human Rights of Older People-Universal and Regional Perspectives*; Office of the High Commissioner for Human Rights, Normative standards in international human rights law in relation to older persons - Analytical Outcome Paper.

⁵⁷² Office of the High Commissioner for Human Rights, Normative standards in international human rights law in relation to older persons - Analytical Outcome Paper.

⁵⁷³ However, some positive recent developments can be noted: The CoE recommendation on the promotion of human rights of older persons for example suggests the provision of training and support to informal carers so that they are able to detect elder abuse and deliver adequate care (para 34). Similarly, the OAS convention also creates an obligation to train care personnel in residential and home settings as well as informal carers in order to prevent violence. (art 9)

⁵⁷⁴ Para 31

⁵⁷⁵ Para 33

not mentioned at all. There is a general failure to encompass the full range of technological devices that can help older people fully participate in society on an equal basis with others.

Additionally, under current instruments support is offered only on the basis of disability. But according to the interviews, although frailty and age-related functional limitations count among the contributing factors to their exclusions, older people may require some assistance also on the ground that they are isolated, lack a social network, are digitally excluded or face informational gaps. Moreover, participants stressed that support options are not always adequate, covering only partly their individual needs, being offered only on a short time basis or being overly expensive.

Overall, there is no fully-fledged right to support to remain integrated in the community that covers all spheres of life. Whereas it has been recognized that access to support is a necessary precondition to the enjoyment of all human rights by persons with disabilities and the realisation of their full potential,⁵⁷⁶ the same right is not explicitly extended to older persons. The existing framework focuses on care, which unless is applied in a comprehensive and inclusive way could promote paternalistic approaches.⁵⁷⁷ Care practices tend to prioritize medical needs over freedom of choice and participation and may lead to situations where older persons are kept safe and fed but homebound.⁵⁷⁸ Care needs to expand well beyond assistance for carrying out basic daily activities. It should cover a wide variety of needs, including mobility, interpersonal relations, avoiding segregation and isolation, housing adaptations, as well as help in decision-making, accessing and benefiting from general services, programmes and benefits such as health, education, justice and leisure, among others. It needs to be an integral part of the

⁵⁷⁶ UN General Assembly, *Report of the Special Rapporteur on the Rights of Persons with Disabilities*, 20 December 2016, A/HRC/34/58 (2017). para 15, 90

⁵⁷⁷ AGE Platform Europe, *Submission based on seminar with Europe-based experts on the Human Rights of Older Persons*.

⁵⁷⁸ UN Economic and Social Council, *Report of the United Nations High Commissioner for Human Rights*. UN Human Rights Council, *Report of the UN Independent Expert on the Enjoyment of all Human Rights by Older Persons A/HRC/36/48*.

right to social protection so that support is equally available and accessible for all older persons.

Binding standards need also to be expanded with clear and specific obligations for home care provision. They further need to incorporate the recommendation of the UN Independent Expert and the MIPAA that informal care by families complements and does not replace State obligation to provide professional care.⁵⁷⁹ Bearing in mind the rapid privatisation of public services, it is crucial that also private suppliers of services are subject to human rights norms. It must be clear that even if there is increasing reliance on the private and voluntary sector to provide care and support for older persons, this does not absolve governments from their obligations.⁵⁸⁰ There is also sporadic evidence that older persons do not have equal access to systems of personal assistance.⁵⁸¹ States must abolish such discriminatory practices and extend systems of personalised support, disability allowances and assistive technologies to older persons.⁵⁸² Older persons and their representative organizations should participate in all decision-making processes concerning support systems.⁵⁸³ Finally, the organisation of care entails regulations, standards, training and monitoring to prevent abuses and ensure good quality.⁵⁸⁴

⁵⁷⁹ United Nations, "Political Declaration and Madrid International Plan of Action on Ageing." para. 66 (b), para 102 and 105 (h); UN Human Rights Council, *Report of the UN Independent Expert on the Enjoyment of all Human Rights by Older Persons*, A/HRC/30/43, para 13

⁵⁸⁰ The Committee on Economic, Social and Cultural Rights clarified this obligation in Committee on Economic Social and Cultural Rights (CESCR), *General Comment No. 5: Persons with Disabilities* (1994), <http://www.refworld.org/docid/4538838f0.html>. Para 12, but it did not reiterate it a year later in the General Comment 6 on older persons

⁵⁸¹ European Network of Independent Living, *Ninth session of the UN Open-Ended Working Group on Ageing - Topic Autonomy and Independence - Submission by the European Network of Independent Living*. Titti Mattsson, "Age, vulnerability and disability," in *Ageing, Ageism and the Law - European Perspectives on the Rights of Older Persons*, ed. Israel Doron and Nena Georgantzi (2018).

⁵⁸² UN General Assembly, *Rights of persons with disabilities - Report of the Special Rapporteur on the rights of persons with disabilities - A/74/186*.

⁵⁸³ UN General Assembly, *Rights of persons with disabilities - Report of the Special Rapporteur on the rights of persons with disabilities - A/74/186*. para 58

⁵⁸⁴ UN General Assembly, *Rights of persons with disabilities - Report of the Special Rapporteur on the rights of persons with disabilities - A/74/186*. para 54

The high prevalence of elder abuse in community settings entails two issues with regard to the normative framework. First, there should be a prohibition of any type of forced living arrangement, including in the community. As demonstrated in the findings, segregation, rigidity of routine, paternalistic services, absence of consent and lack of choice over day to day decisions, all of which are criteria of institutionalisation, may also occur in home settings.⁵⁸⁵ In addition, when families cannot afford the costs of residential care, older people may be withdrawn from formal services; this transition which is made without prior assessment of their needs exposes them to a risk of abuse, neglect and loss of autonomy.⁵⁸⁶ Besides, private homes can become places of isolation, alienation and disempowerment.⁵⁸⁷ Thus, a violation of the right to independence could also take place outside of institutions. Research has also shown that some older people believe there are advantages in living in residential settings or rather find several drawbacks in living at home.⁵⁸⁸ The current focus of the CRPD on deinstitutionalisation may serve to idealize home settings and lead to a failure to address human rights breaches that take place in the community.⁵⁸⁹ This is why the Helpage International has suggested that a new convention on the rights of older persons should include a right not to be obliged to live in *any* particular arrangement.⁵⁹⁰

Compared to other forms of violence, elder abuse is a relatively neglected phenomenon, it is often under-reported and appropriate mechanisms to prevent

⁵⁸⁵ Committee on the Rights of Persons with Disabilities (CRPD), *General Comment No5: The right to independent living*, para 16 c

⁵⁸⁶ Georgantzi, "The right to autonomy, health and independent living"; UN Human Rights Council, *Thematic study on the realization of the right to health of older persons by the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*, Anand Grover.

⁵⁸⁷ Hillcoat-Nallétamby, "The meaning of "independence" for older people in different residential settings.", UN Human Rights Council, *Report of the Independent Expert on the Enjoyment of all Human Rights by Older Persons*, A/HRC/39/50 para 80

⁵⁸⁸ Hillcoat-Nallétamby, "The meaning of "independence" for older people in different residential settings."

⁵⁸⁹ Even though in principle institutionalization is not limited to a specific setting, the work of the CRPD Committee is overly focused to preventing segregation in institutions, as opposed to considering cases of segregation and loss of independence in the community.

⁵⁹⁰ Helpage International, *A new convention on the rights of older people: a concrete proposal* (2015), <https://social.un.org/ageing-working-group/documents/sixth/HelpAgeInternational.pdf>.

it and offer remedies are lacking.⁵⁹¹ This why secondly, the human rights framework should include a stronger protection from elder abuse. Human rights mechanisms have recognized that older people are vulnerable to abuse, but primarily in institutional settings.⁵⁹² The regional instruments on the rights of older persons are good examples to extending protection, but the UN framework does not offer adequate protection covering all forms of abuses, in all settings and by all providers.⁵⁹³ There is an urgent need for international law to give more visibility to home and community care settings as susceptible to abuse and to highlight the ways in which certain practices can breach individual autonomy, freedom and dignity, in particular due to lack of resources, lack of training and respite for caregivers, as well as lack of systematic monitoring or clear standards and criteria for their operation. We also need a comprehensive definition of elder abuse under binding standards that covers among other issues financial abuse. The extension of obligations to the private and voluntary sector, as providers of the bulk of care, is also crucial.

Social Protection

Although the right to social protection in older age has been clearly articulated in all the international and regional instruments,⁵⁹⁴ there are still aspects of this

⁵⁹¹ Yon et al., "Elder abuse prevalence in community settings: a systematic review and meta-analysis." UN Department of Economic and Social Affairs, *Analysis and overview of guiding questions on long-term care and palliative care received from Member States, "A" Status National Human Rights Institutions and accredited non-governmental organization*.

⁵⁹² See among others, Council of Europe, "Recommendation CM/Rec(2014)2 of the Committee of Ministers to member States on the promotion of the human rights of older persons." Para 16; Organisation of American States, "Inter-american Convention on Protecting the Human Rights of Older Persons (A-70)." Art. 9; United Nations, "Political Declaration and Madrid International Plan of Action on Ageing." para 107.

⁵⁹³ UN Department of Economic and Social Affairs, *Analysis and overview of guiding questions on long-term care and palliative care received from Member States, "A" Status National Human Rights Institutions and accredited non-governmental organization*; Office of the High Commissioner for Human Rights, Normative standards in international human rights law in relation to older persons - Analytical Outcome Paper; European Network of National Human Rights Institutions, *We have the same rights: The Human Rights of Older Persons in Long-Term Care in Europe*.

⁵⁹⁴ Universal Declaration of Human Rights article 22; International Covenant on Economic, Social and Cultural Rights article 9 ; Convention on the Elimination of All Forms of Discrimination Against Women article 11; Convention on the Rights of Persons with Disabilities article 28; Committee on Economic, Social and Cultural rights General Comments Number 6 on the Economic, Social and Cultural Rights of Older Persons and Number 19 on the Right to Social Security; ILO Convention 102 on Social Security (Minimum Standards); ILO Convention 128 on

right that have not been adequately reflected in norms and practice. First, it can be difficult under the existing standards to challenge the adequacy of pensions and benefits and the adverse impact of cuts to older persons' dignity, health and independence.⁵⁹⁵ Human rights standards also need to address the reconciliation of the right to pension with the right to continue working beyond retirement age. Social security systems may impose penalties for those who choose to continue working despite the European commitment to active ageing and the extension of working lives. The right to social protection could be further expanded in order to comply with participants' understanding of independence and the real-life challenges encountered in the three countries.

Positive Action and Reasonable Accommodation

Participants in the three countries refer to several cases where positive measures or reasonable accommodation could facilitate the inclusion of older persons. These include financial support to adapt their houses to allow older people to live independently in their own homes; reasonable adjustments to continue working or to combine work with care duties; measures to facilitate access to services especially for rural or marginalized populations; training on digital technologies to equalize opportunities to access online services. Whereas some of these examples have a close link with disability issues, in particular aspects of physical and digital accessibility, other aspects are distinct and unique to older persons.

MIPAA calls for appropriate adjustments in the workplace environment and working conditions, for flexible retirement policies and measures to promote work beyond retirement age. It also encourages the development of housing options that reduce barriers to and encourage independence.⁵⁹⁶ Similarly, the Independent expert refers to the need to adapt workplaces, introduce flexible

Old Age, Invalidity and Survivors' Benefits; ILO Recommendation 131; ILO Recommendation 202 on Social Protection Floors ; European Social Charter article 23; Council of Europe Recommendation 2014/2 on the Promotion of Human Rights of Older Persons paragraphs 21-29; European Charter of Fundamental rights article 34.

⁵⁹⁵ Office of the High Commissioner for Human Rights, Normative standards in international human rights law in relation to older persons - Analytical Outcome Paper.

⁵⁹⁶ United Nations, "Political Declaration and Madrid International Plan of Action on Ageing." para 89 and 99

working arrangements, offer learning opportunities and stressed that reasonable accommodations may be needed to ensure older people's participation in political and public life, including for instance, the availability of facilities in residential settings and the transport to and from polling stations, as well as to attend meetings of public authorities and to participate in trade-union and advocacy efforts.⁵⁹⁷ Based on the UN principles, '*older persons should be able to live in environments that are safe and adaptable to personal preferences and changing capacities*'.⁵⁹⁸ In a similar vein the CESCR has noted that homes should be adapted to the abilities of older persons to allow them to remain living at home.⁵⁹⁹ The European Social Charter and the CoE recommendation on the rights of older persons enshrine social protection measures that allow older people to have access to housing that suits their current (and future) needs.

Overall, the scope of reasonable accommodations varies significantly among the different instruments; some pay attention to the workplace, whereas others focus on the care context. But the obligation of positive action and reasonable accommodation linked to a broad range of rights does not explicitly apply in the context of older age under existing norms, neither is the denial of reasonable accommodation defined as a form of discrimination against older persons⁶⁰⁰.

Disempowering

The combined effect of invisibility arising from discounting and lack of norms for its elimination can become drivers of disempowerment. Unless the law helps older people gain consciousness of their harmful experiences as human rights violations and unless the law is equipped with standards to challenge discounting practices, older persons cannot proceed with claiming redress and improvement. It is clear from the findings that there are additional ways in which older persons

⁵⁹⁷ UN Human Rights Council, *Report of the UN Independent Expert on the Enjoyment of all Human Rights by Older Persons*, A/HRC/30/43. para 63, 107

⁵⁹⁸ Para 5

⁵⁹⁹ Committee on Economic Social and Cultural Rights (CESCR), "General Comment No.6: The economic, social and cultural rights of older persons."

⁶⁰⁰ See for example, Doron et al., "Ageism and anti-ageism in the legal system: A review of key themes." Arguing that – unlike for disability – there is not general obligation for reasonable accommodation for age discrimination under EU law

are disempowered. These include lack of information, problems with accessing justice and redress, and barriers to civic and political participation.

Access to information is a form of empowerment of older persons, insofar as they become more aware of how they can benefit from services or how they can claim their rights. Without information, older persons might not know they are eligible for a programme, benefit or complaint. Access to information about their rights, relevant legislation and policies and how to access them has been included in existing standards.⁶⁰¹ However, in practice, lack of awareness remains problematic. For example, as shown also in this study, older persons do not know their rights under the CRPD.⁶⁰² States may need to develop targeted programmes to enable legal literacy, address information gaps and facilitate the exercise of rights. There is also no explicit right to seek support to complain, access judicial or alternative dispute resolution, access information, claim rights, or navigate complex administrative procedures and policy frameworks. Support may also be needed to deal with the emotional impact of conflict.

Civic and political participation of older persons have not received equal attention to social and cultural participation under human rights norms. But influencing the conduct of public affairs directly or indirectly, participating in elections and in political life is an important individual right. Attitudinal and other barriers, in particular the lack of accessible voting facilities and within easy reach and the absence of reasonable accommodation, may limit older people's full participation in elections⁶⁰³. The CEDAW Committee also brought attention to administrative and institutional barriers for older women, such as the absence of necessary documentation to register to vote and run as candidates for election.⁶⁰⁴

⁶⁰¹ Council of Europe, "Recommendation CM/Rec(2014)2 of the Committee of Ministers to member States on the promotion of the human rights of older persons." art. I.4; Council of Europe, "European Social Charter (Revised)." Art. 23; Committee on the Elimination of Discrimination against Women, *General recommendation No. 27 on older women and protection of their human rights*, 16 December 2010 CEDAW/C/GC/27, United Nations (2010). para 33

⁶⁰² AGE Platform Europe, AGE Platform Europe position on article 19 of the UNCRPD.

⁶⁰³ UN Human Rights Council, *Report of the UN Independent Expert on the Enjoyment of all Human Rights by Older Persons*, A/HRC/30/43. para 63

⁶⁰⁴ Committee on the Elimination of Discrimination against Women, *General recommendation No. 27 on older women and protection of their human rights*, 16 December 2010 CEDAW/C/GC/27. para 39

Age also limits to the right to vote or be elected exist in a few countries.⁶⁰⁵ In Greece voting is no longer an obligation for citizens beyond the age of 70.⁶⁰⁶ Although the right to vote is not restricted under Greek law, this stipulation effectively relinquishes the State obligation to facilitate the participation of older persons in voting procedures and signals that their political positioning is less important than other groups.⁶⁰⁷ States should therefore take action to eliminate the discrimination of older persons in political and public life, by abolishing legislative, institutional, physical and attitudinal barriers to the right to vote, to be elected and perform public functions. In addition, they should facilitate the participation of older persons in elections including through the use of new technologies, proxies, accessible voting facilities and the provision of adequate support.⁶⁰⁸

Civic participation is not a right that concerns only individuals but also groups that represent the collective voice and interests of older people. The needs and concerns of older persons must be taken into account in decision-making at all levels.⁶⁰⁹ States must therefore also encourage and support the development of networks, civil society organisations and other forms of participation, such as older people's councils at national, regional and local levels to enhance the capacity to represent the collective interests of older people and increase opportunities for participation and exchange.⁶¹⁰ Particular attention must be

⁶⁰⁵ UN Secretary General, *Follow-up to the Second World Assembly on Ageing, A/66/173*. para 73

⁶⁰⁶ Law 3852/2010 art.11

⁶⁰⁷ Greek law only foresees relevant exceptions for citizens who are abroad or more than 200 km from their voting district on the day of their elections and requires proof that they were in fact outside easy geographical reach. However, the simple fact that one is over 70 years, regardless of their physical and mental abilities, their place of residence and living arrangements, among others, is sufficient to justify lack of participation to the elections. So Greek law can be considered as discouraging the participation of older citizens in elections and therefore acts as a barrier to their full participation.

⁶⁰⁸ On this see also General Assembly United Nations, "Convention on the Rights of Persons with Disabilities: resolution adopted by the General Assembly," in *A/RES/61/106* ed. UN General Assembly (2007). art 29

⁶⁰⁹ United Nations, "Political Declaration and Madrid International Plan of Action on Ageing," para 23a; UN Human Rights Council, *Report of the UN Independent Expert on the Enjoyment of all Human Rights by Older Persons, A/HRC/30/43*. para 25

⁶¹⁰ UN Human Rights Council, *Report of the UN Independent Expert on the Enjoyment of all Human Rights by Older Persons, A/HRC/30/43*. Para 95, 122; United Nations, "Political Declaration and Madrid International Plan of Action on Ageing." para 20, 22, 117, 118, 119; UN

given to the concerns and preferences of older people in care settings, including through the establishment of residential councils representing the voice of users of care services. States should also eliminate any barriers faced by older people in forming and joining such organisations.

Where an obligation to consult older persons exists, this is limited to decisions about one's health, long-term care, individual rights and wellbeing.⁶¹¹ Participants in the study also highlight the requirement to involve older people in the design, implementation and monitoring of mainstream policies and measures that affect their communities in general. They stress that older people, as citizens on an equal basis with others, must have a say about everything that happens in society and not only on issues that are strictly associated with old age, such as pensions or care. They want to use their experience and knowledge to improve laws and policies for the benefit of society as a whole. The meaningful involvement of older persons on a wider range of issues is a way to overcome some of the structural barriers to their participation, to prevent exclusion and isolation, to develop age-sensitive laws and policies and to render more visible their ongoing contributions and their potential. The current framework lacks a general obligation for States to involve older persons through their representative organizations in the development and implementation of law and policies and in other decision-making processes that span beyond old age-specific measures. On the other hand, CEDAW does not limit women's participation in organisations to gender-specific issues, by referring to the political and public life of the country⁶¹². Hence, an explicit obligation to ensure that older persons can participate in public life and decision-making on an equal basis with others may be useful to extend the scope of existing standards. There also needs to be some

Human Rights Council, *Thematic study on the realization of the right to health of older persons by the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Anand Grover*. Para 71d; UN Human Rights Council, *Report of the UN Independent Expert on the enjoyment of all human rights by older persons, A/HRC/33/44*. para 70.

⁶¹¹ Council of Europe, "Recommendation CM/Rec(2014)2 of the Committee of Ministers to member States on the promotion of the human rights of older persons." para 5; Council of Europe, "European Social Charter (Revised)." Art.23

⁶¹² See Article 7

monitoring and accountability mechanisms to ensure that involvement is not tokenistic but can genuinely inform policy decisions. The CRPD is an excellent example in that regard, in that it gave persons with disabilities an official role in the implementation of the convention.⁶¹³

All in all, this chapter has demonstrated that existing standards rely on a limited conception of old age; they perpetuate the processes of non-recognizing, non-enabling and disempowering and therefore cannot offer adequate human rights protection to older persons. The following and final chapter uses this finding to discuss the normative purpose of a new treaty.

⁶¹³ Harpur Paul Harpur, "Embracing the new disability rights paradigm: the importance of the Convention on the Rights of Persons with Disabilities," *Disability & Society* 27, no. 1 (2012).

Chapter 11: Discussion: The Theoretical and Normative Value of a New Human Rights Treaty

This thesis addressed the knowledge gaps that exist with regard to the precise conceptual and normative meaning of older people's rights. Several scholars have written on the adequacy of international human rights standards and partly on the distinct human rights challenges faced by older people.⁶¹⁴ However, existing scholarship is based either on a bibliographical or a jurisprudential/doctrinal perspective and has not engaged in an empirical inquiry on framing of rights in old age. The research conducted for this thesis aimed to bridge this gap by devising an understanding of rights based on older people's advocacy in three European countries. The thesis also examined the theoretical and normative framework contained in international human rights standards, contrasting the empirical findings from the thesis with existing provisions. By engaging in this bottom-up analysis the research concluded that existing human rights standards are not capable of advancing the rights of older people in practice. Instead of reflecting a social model of older age, they perpetuate ageist biases. They sustain views of older people as undeserving, vulnerable or victims and promote restrictive, custodian and deficient policies. Current human rights law then provides less scope for legal intervention to address abuse and more scope for State freedom to take decisions disregarding individual rights and therefore needs to be revised.

This conclusion was not made on the basis of normative gaps, which – as shown in Chapter 2 - are the main arguments used to argue in favour of a new treaty. The point made in this thesis is that there is a need to fill in the extant *interpretative*

⁶¹⁴ See among others, Doron and Apter, "International Rights of Older Persons: What Difference Would a New Convention Make to Lives of Older People? ."; Fredvang and Biggs, "The rights of older persons - Protection and gaps under human rights law." Mégret, "The Human Rights of Older Persons: A Growing Challenge."; Mantovani, Spanier, and Doron, "Ageism, Human Rights, and the European Court of Human Rights: A Critical Analysis of the *Carvalho v. Portugal* Case (2017)."; De Hert and Mantovani, "Specific Human Rights for Older Persons? The inevitable colouring of Human Rights Law."

gap that impedes the equal application of universal human rights norms in the context of older age. The theory of overlooking the injustice has demonstrated that older people's dignity is systematically undermined. As a result, not only are older people denied their human rights, but also some of the key abuses they face, including - among others - access to health and long-term care, adequate income, lifelong learning, violence and neglect are currently excluded from the purview of human rights law and thinking. This means that the exclusion, discrimination and abuse of older persons are potentially seen as minor issues that do not require policy or legal intervention. So implementation and normative gaps are the direct consequences of the existing conceptual limitation that this thesis has helped to surface.

The Case for the Human Rights Model and a New Treaty

Based on the analysis, it can be argued that a new convention would make it increasingly difficult to tolerate practices that are based on a presumed inferior value of older persons and would place on States concrete obligations to take action to prevent and address violations. Compared with the social policy or welfare approach, human rights language is more powerful in that it reflects and releases legal entitlements to address the systemic failures to respect the dignity of individuals as human beings. Rights are not optional; they can influence domestic law and be used in courts against States⁶¹⁵. A human rights narrative could help to present State failures as denials of rights and the meeting of needs as entitlements⁶¹⁶. One of the main advantages of a new treaty is that it involves greater accountability for the apathy and inaction that is currently applied to old age disadvantage. The establishment of a legal framework by which to validate and legally protect human dignity in older age is according to this thesis the primary reason why a new convention might be needed.

But human rights are important beyond their legal implications.⁶¹⁷ The power of human rights as a frame becomes particularly relevant in the face of a rapidly

⁶¹⁵ Simmons, *Mobilizing for human rights: international law in domestic politics*.

⁶¹⁶ Niamh Reilly, *Women's human rights* (Polity, 2009).p. 125.

⁶¹⁷ Amartya Kumar Sen, *The idea of justice* (Harvard University Press, 2009).

ageing population, often pejoratively described as a 'time bomb' for social welfare. Issues like pensions and long-term care are prominent in policy debates today, mainly in relation to their potential costs for public purse. It is no surprise, therefore, that these debates tend not to focus on the securing of individual rights in the face of these challenges. In fact, they often portray today's older generation as responsible for the fate of a system that is no longer sustainable and therefore perpetuate stereotypes of older people as an economic burden on society.⁶¹⁸ Consequently, domestic discourse tend to give precedence to economics or utilitarian approaches over human rights when it comes to policy formulation and policy implementation in these areas.⁶¹⁹

All three countries examined in this thesis have experienced cutbacks in State funded social care provision because they are unaffordable in the current fiscal context. Despite being politically and economically justified, such measures tend to ignore what the impact on the human rights of older people is or whether they treat older people as equals. Participants describe situations where it may be considered justified to sacrifice individual rights to autonomy or participation in the name of greater economic good. Economic arguments prioritize means over outcomes. When the economic argument prevails, rights are left vulnerable; they are more exposed to contrasting interpretations of what is fair and feasible in a certain context. When we begin with the resources and budget constraints, rights may be violated just because restricting them makes economic sense.⁶²⁰ A human rights-based approach could potentially counterbalance some of the negative effects of the policy focus on the costs of an ageing population. It can also act as a safety net against decisions and austerity-related reforms that are blatant forms of discrimination and abuse.

⁶¹⁸ Chris Gilleard and Paul Higgs, "The power of silver: Age and identity politics in the 21st century," *Journal of aging & social policy* 21, no. 3 (2009). p. 278

⁶¹⁹ Dan Seymour and Jonathan Pincus, "Human rights and economics: The conceptual basis for their complementarity," *Development Policy Review* 26, no. 4 (2008); Michael J. Sandel, *Justice: What's the right thing to do?* (Macmillan, 2010). p. 103-116

⁶²⁰ Sandel, *Justice: What's the right thing to do?*

Additionally, the human rights frame can promote positive images of ageing and older persons and move away from the discourse on costs, needs and burden.⁶²¹ Moving away from the biomedical approach to ageing, a new convention could recast a social understanding of inequalities in later life. It could help to reconceptualise older persons as contributors, to reimagine the life-course in a more flexible and open-ended way that does not restrict the potential of later life and by consequence to help fight ageism. Domestic policies are gradually – albeit slowly and inconsistently- grappling with the fact that the life-course can no longer be divided into three distinct stages, where old age is intrinsically linked with inactivity and leisure.⁶²² International human rights law needs to catch up with this changing paradigm. It needs to move beyond the current welfare approach that gives precedence to certain aspects of rights, such as care and pensions over others, including education, digital inclusion and independence among others. A new convention should facilitate participation and diverse roles in later life. Additionally, compared with the prevalent active and healthy ageing policy paradigms that have a limited remit, the consistent application of the human rights narrative could expand policy attention to a wider range of issues. A new treaty would cover the full spectrum of universal rights under the premise that all rights are equally important, inalienable, interdependent and indivisible. Moreover, the human rights narrative draws attention away from individual responsibility to what States can do to facilitate the enjoyment of rights. It can therefore help tackle some of the critique of the active ageing model, which can be both exclusionary and overly concentrated on individualisation.⁶²³

But despite arguing for the potential of human rights, the thesis is also aware of their limitations. It therefore does not consider human rights discourse and

⁶²¹ See similar argument made about the application of the human rights frame on disability Harpur, "Embracing the new disability rights paradigm: the importance of the Convention on the Rights of Persons with Disabilities."

⁶²² See Chapter 5

⁶²³ Moulaert and Biggs, "International and European policy on work and retirement: Reinventing critical perspectives on active ageing and mature subjectivity."; Georgantzi, "The European union's approach towards ageism."

standards as the only valid or useful framework.⁶²⁴ Instead, the findings merely suggest that human rights offer an alternative vocabulary and tools that can enhance knowledge of and distinction between right and wrong, equal and unequal, obligation and intention to an extent that current approaches to ageing have failed to clearly establish. It is not suggested that human rights should replace all other frames; this is neither feasible nor desirable. Older people do not only have rights, they also have responsibilities. Not all problems demand legal solutions. The realisation of rights is cost intensive and will certainly not happen overnight. Economic arguments remain valid and necessary to rethink patterns of redistribution. Soft instruments, such as the MIPAA can be useful even if they have not managed to address the whole spectrum of inequalities in older age. Active ageing strategies have also been at least partially helpful in developing more inclusive labour market policies, even though they exclude older people with high support needs. Human rights are not above and beyond public policy and politics; they both inform them and are informed by them.⁶²⁵ Still compared with extant approaches to ageing, human rights present some key benefits, which are further discussed in a following section, regarding the aims of a new treaty. Finally, a new treaty does not preclude the implementation of existing human rights instruments. The normative analysis undertaken for this study demonstrates that there is great potential in better applying existing standards if a new treaty becomes part of the international legal framework.

Comparing the Three Countries

The three countries under study are at different levels of buy-in of the human rights model. Ireland rates higher in the spectrum of support and implementation of a human rights frame. Advocates and human rights practitioners in Ireland show higher levels of consciousness of human rights breaches against older persons, use a human rights narrative more naturally, are more likely to use

⁶²⁴ Kennedy David Kennedy, "International human rights movement: part of the problem?," *Harv. Hum. Rts. J.* 15 (2002).argues that we need to think about how the human rights frame compares with alternative approaches

⁶²⁵ Several of these arguments and many more are included in Kennedy's seminal critique of the human rights movement

human rights processes and standards to improve the situation of older persons and in their majority are more open to the idea of a new convention. Still, even in Ireland a human rights approach is not consistently applied to issues of ageing and most of the ageing policies are developed on the presumed need to address demographic challenges rather than to fulfil individual rights. Like in the other two countries, some issues have received more attention than others and human rights standards have not been fully applied to the context of older age.

In France rights discourse is used on a selective basis, prioritizing mainly care situations and even demonstrating a narrow understanding of what human rights in these contexts mean. The mainly institutional provision of care, the gaps in service provision and the inequalities in accessing support have not been widely questioned. Aspects that are unrelated to disability have received marginal and ad hoc human rights attention. Participants from this country are particularly skeptical to the idea of a new treaty, which they perceive as an instrument that would provide new and specific rights to older persons. Only very recently some mobilization to protect and promote rights in care settings and to change the image of ageing has been noted.⁶²⁶

Greece has a very low level of preoccupation with human rights and the developments of a new convention for older persons. Whereas pensions rank high in the political agenda – with the exception of the couple of cases that have been lodged to the European Committee of Social Rights - these are primarily seen from a socio-economic perspective and independently from human rights obligations to provide social protection⁶²⁷. Older persons continue to be seen as passive recipients of welfare and to be largely excluded from public debate, with the exception of issues around pensions. Civil society's advocacy focuses on income support rather than policies and services. This may be due to southern welfare State model of Greece where *[t]he self-reliance of families has*

⁶²⁶ Poujoulat, "Mobilisation pour les personnes âgées: Début de rassemblement à Paris."

Champvert and de Hennezel, "Contre l'impératif jeuniste! Changeons le regard sur la vieillesse!."

⁶²⁷ European Committee on Social Rights, Federation of employed pensioners of Greece (IKA-ETAM) v. Greece, complaint No. 76/2012, European Committee on Social Rights, Greek General Confederation of Labour (GSEE) v. Greece, complaint No. 111/2014

*traditionally been taken for granted by governments in matters of social care and material support*⁶²⁸. As a result, citizens take for granted the absence of State intervention and aim to improve their own resources to take care for themselves and their families.

Although it's impossible to be conclusive about the reasons why the findings rank Ireland higher in terms of a rights-based approach to ageing, some tentative assumptions can be made. First, the nature of the liberal welfare State in Ireland, which puts more emphasis on individual responsibility than on statutory entitlements, may also explain why advocates tend to use a language of rights. Second, in France and Greece NGOs are primarily run by volunteers often of an older age, who have no previous exposure to international norms and human rights language. Ireland however has more NGOs employing paid staff. In fact, a couple of the Irish participants admit that their approach is influenced by previous professional experience in other civil society sectors that work more consistently on a human rights basis. Finally, the external funding given to Irish organisations to develop civil society partnerships may have promoted or facilitated the development of a rights discourse.

Even if in the three countries the human rights paradigm has only been sporadically used in relation to older age issues, most NGOs and human rights actors do not disagree with the idea of a new convention. In fact, only the two French human rights bodies and one of the French NGOs explicitly object a new treaty. The rest, despite being critical of the necessity of age-specific measures, see the value of a new treaty as an instrument to bring visibility to older people's challenges and experiences of injustice. While not accepting it as a panacea, they see a new treaty as an additional opportunity to raise awareness of older people as rights holders and to spell out specific State obligations. They believe it could potentially highlight existing gaps and push governments into action. One participant for instance explained that it would make universal human rights

⁶²⁸ Papadopoulos and Roumpakis, "Familistic welfare capitalism in crisis: social reproduction and anti-social policy in Greece."; Moreno and Marí-Klose, "Youth, family change and welfare arrangements: is the South still so different?." p. 75

standards more explicit and effective in the context of older age. For several of the actors involved in the study, a new convention is also an important advocacy tool.

I think it would be really good, I think it would strengthen [protection] but it oughtn't strengthen it at the expense of an elitism, in other words my rights are higher than your rights. So again, I come back to citizenship and the whole debate about how all of that fits into a continuum rather than a sectoral difference. (Participant 10)

[T]he simplest thing to do is just implement the existing human rights treaties, if the ICESCR was being fully implemented by UN Member States, including Ireland, we wouldn't need a convention on the rights of older people. Because it's not implemented, we do need a structure that is in place that allows us to highlight the issues that are particularly important to older people. (Participant 7)

It's about me taking responsibility, being valued for who I am, being able to participate, and to be free from discrimination (...) I can do that through my citizenship but if there are fundamental ways in which I am denied that, I can't fully participate and that's inequality and that's what the UN convention philosophically should be for. (Participant 10)

But as the thesis demonstrated, despite their support, national advocacy groups are not very active in pursuing the goal of a new convention at national level.

The Peculiar Case of Old Age Advocacy

Another key contribution of this thesis is that it has illustrated that the current debate on the need for a new convention has not occurred organically amongst national NGOs; it is rather perceived as exogenous. Domestic advocacy groups have limited influence on the international debate around strengthening the protection of their human rights and the added value of a new convention. Ongoing discussions about expanding the UN human rights system are therefore taking place without the direct input of grassroots entities that are the targets of

this new standard-setting process. Consequently, domestic NGOs don't have a say in defining State obligations, guiding the implementation of existing standards and crafting necessary human rights mechanisms to articulate and pursue human rights. Existing literature on the movement towards a new convention has either focused on the transnational network or on those exceptional cases where national NGOs are actively mobilised around a new convention.⁶²⁹ Yet, these studies have not adequately reflected the reality of the domestic old age movement that does not perceive the pursuit of a new convention as part of their mandate.⁶³⁰ On the contrary, from the outset this thesis was conscious of this reality. In addition to reflecting these views, the study at hand partly aimed at encouraging national NGOs to start thinking about human rights, especially bearing in mind that should a new convention be negotiated, older people's organisations would have a key role to play in supporting, developing and implementing the treaty.

My analysis identified a more general resistance among advocacy groups to engage in human rights discourse and to apply human rights standards in the context of older age. This finding is particularly important for two main reasons. First, it illustrates that whereas advocates are interested in changing social norms around older age, they have so far failed to take advantage of the opportunities of the human rights model to advance their claims. Second, it demonstrates that the extant understanding of older people's rights that is linked with vulnerability and dependency acts as a stumbling block to the adoption of a human rights approach.

⁶²⁹ Herro, "Advocating a UN Convention on the Rights of Older Persons in the United Kingdom: The Case for a Radical Flank."; Herro, "Domestic interest groups and rights mobilization: explaining the case of Slovenia's support for the proposed Convention on the Rights of Older Persons."; Herro, "The human rights of older persons: the politics and substance of the UN Open-Ended Working Group on Ageing." Sciubba, "Securing rights in the twenty-first century: A comparison of the disability and older persons' rights conventions."; Sciubba, "Framing and Power in Aging Advocacy."; Sciubba, "Explaining campaign timing and support for a UN Convention on the Rights of Older People."

⁶³⁰ Herro however did mention that older people's organisations do not always link human rights to key concerns of older people, see Herro, "Domestic interest groups and rights mobilization: explaining the case of Slovenia's support for the proposed Convention on the Rights of Older Persons." Sciubba also argued that NGOs involved in the transnational network do not consistently use a human rights frame Sciubba, "Framing and Power in Aging Advocacy."

The findings demonstrate that NGOs in the three countries are no longer driven purely by claims around welfare and pensions, which have traditionally characterized this sector.⁶³¹ Although aspects of pensions, health and care continue to count among the main priorities of the interviewed organisations, chapter 9 showed that older people's groups are no longer pushing for change only in a small number of policy areas; instead they are increasingly calling for a change in attitudes around older persons and ageing. Motivated by aims like autonomy, participation, independence and equality, old age advocates are – perhaps unconsciously – engaging in rights claims. They are gradually transitioning to a *new social movement* that, instead of asking for incremental changes in specific policies, is interested in wider societal change.⁶³² For example, participants want to disentangle older age from conceptions of weakness and decline. They stress that older people need to be treated as equals and recognized as agents and contributors to the solution of societal problems, not to their formation. They also believe that the moral, social and economic value of older individuals is not yet adequately recognized, especially for those in the fourth age. In raising these issues, NGOs are disrupting the traditional re-distributional claims of the old age movement. Collective action therefore emphasizes older people as agents as opposed to merely making claims about resources. It also stresses, as we have seen, the socially constructed nature of older people's disadvantage as opposed to an inherent vulnerability. All these narratives are reflective of a new social movement.⁶³³ Recent mobilization in France around the quality of care and the valorization of jobs in the sector also reflects this change.⁶³⁴

⁶³¹ Herro, "Advocating a UN Convention on the Rights of Older Persons in the United Kingdom: The Case for a Radical Flank."; Herro, "Domestic interest groups and rights mobilization: explaining the case of Slovenia's support for the proposed Convention on the Rights of Older Persons."

⁶³² Tom Shakespeare, "Disabled people's self-organisation: a new social movement?," in *Overcoming disabling barriers* (Routledge, 2006); Steven M. Buechler, "New social movement theories," *Sociological Quarterly* 36, no. 3 (1995).

⁶³³ Buechler, "New social movement theories."

⁶³⁴ Poujoulat, "Mobilisation pour les personnes âgées: Début de rassemblement à Paris." Champvert and de Hennezel, "Contre l'impératif jeuniste! Changeons le regard sur la vieillesse!."

Still, the findings also illustrate that there is a discrepancy between the paradigm NGOs espouse and the concepts and strategies they use in practice. On the one hand, equality and human rights claims are becoming increasingly important. On the other hand, NGOs have not completely abandoned the discourse and tactics associated with materialistic interests.⁶³⁵ Despite increasingly referring to dignity, choice and participation, the findings have also identified the use of language of needs and protection. But this language can be perceived as 'begging' for charity instead of as an entitlement and a denial of rights.⁶³⁶ In addition, some organisations continue to publicly put the focus of their activities on material interests, even if the interviewed stakeholders are adopting more rights-based claims.⁶³⁷ Participants are also more likely to refer to 'social inclusion' or 'active ageing' than to 'human rights'. Besides, the current focus on economic and social rights in the frame of the OEWG discussions creates the impression that old age advocacy prioritizes welfare rights over fundamental rights and liberties.⁶³⁸ As a result, NGOs active in the ageing field may continue to be perceived as campaigning for material interests and economic security, often at the expense of other groups.⁶³⁹ Failing to consistently adopt a rhetoric and strategy that reflects their transition to a new social movement, NGOs are missing out on an opportunity to hold governments accountable for human rights breaches.

The vulnerability and disability prism through which human rights bodies sometimes see older people issues may act as a disincentive to engage with the human rights framework. It is plausible that if human rights language and standards employed by human rights actors covered aspects of older people's lives more widely, some of the NGOs stakeholders would engage in this type of

⁶³⁵ Marshall B. Kapp, "Law and aging: special persons, special treatment?," *Law, Medicine and Health Care* 18, no. 3 (1990).

⁶³⁶ Niamh Reilly, *Women's human rights*.

⁶³⁷ See for example the website of the FNAR, which stresses in its homepage that the NGO defends the interests of pensioners and puts emphasis on their purchasing power: <https://fnar.info/>

⁶³⁸ Herro, "The human rights of older persons: the politics and substance of the UN Open-Ended Working Group on Ageing."

⁶³⁹ Nina A. Kohn, "Elder rights: the next civil rights movement," *Temp. Pol. & Civ. Rts. L. Rev.* 21 (2011). p. 324-5

work. A human rights frame has the potential to mobilise actors around the shared goal of societal transformation and to help in the creation of a more cohesive movement.⁶⁴⁰ It gives advocates a common focal point for advancing their vision for the future.⁶⁴¹ Human rights language can strengthen NGO campaigns that aim to bring more visibility to experiences of exclusion and to pursue social change.⁶⁴² Human rights could therefore prove to be a better advocacy strategy for NGOs to pursue social justice claims.

So, we are faced with an oxymoron where more human rights advocacy is necessary to help old age representatives advance the cause of a new convention⁶⁴³, but in practice they are not yet ready to use human rights-based approaches and instruments.⁶⁴⁴ Based on the disability experience, negotiations around a new convention could act as a catalyst for NGOs to engage in human rights advocacy.⁶⁴⁵ But in order to reach the stages of negotiation and adoption of a new treaty, NGO advocacy is considered crucial.⁶⁴⁶ The question then remains how to overcome this paradox so that NGOs can benefit from human rights discourse and standards to achieve their goals. The following parts of this chapter address this issue.

Discounting as the Core Element of the Conceptualization of Older People's Rights

The previous parts of this chapter have explained the value of a new treaty for law, policy and advocacy. This section completes the answer to the third research

⁶⁴⁰ Kohn, "Elder rights: the next civil rights movement."; Sciubba, "Framing and Power in Aging Advocacy."

⁶⁴¹ Simmons, *Mobilizing for human rights: international law in domestic politics*.

⁶⁴² Michael Freeman, "The value and values of children's rights," in *Children's Rights*, ed. Antonella Invernizzi and Jane Williams (Routledge, 2017). P. 22

⁶⁴³ Flynn, "Disability and ageing: Bridging the divide? Social constructions and human rights."

⁶⁴⁴ See also Kohn, "Elder rights: the next civil rights movement." arguing that an elder rights movement will not emerge organically. Rather, it is something that must be constructed, p. 325

⁶⁴⁵ Degener and Begg, "From invisible citizens to agents of change: A short history of the struggle for the recognition of the rights of persons with disabilities at the United Nations."

⁶⁴⁶ Sciubba, "Securing rights in the twenty-first century: A comparison of the disability and older persons' rights conventions."; Herro, "Domestic interest groups and rights mobilization: explaining the case of Slovenia's support for the proposed Convention on the Rights of Older Persons."

question by suggesting ways in which the emergent meaning of human rights can be applied in practice so that it reflects the empirical findings and addresses the current conceptual limitations of human rights law.

The thesis has defined discounting as a form of institutionalized denial or undermining of dignity that older persons individually and collectively face. It has argued that it is discounting that creates a specificity of experiences of human rights violations of older persons. Discounting is culturally engrained in society, in a similar way to sexism, ableism, racism and other forms of oppressions. It is particularly difficult to tackle because it is insidious and often indirect.⁶⁴⁷ Putting the focus on discounting the thesis argues that older people are not discriminated against because they are intrinsically vulnerable, but they become vulnerable because they are discriminated. Discounting is therefore posited as the driver of human rights violations in older age.

This finding complements the growing body of literature that refers to ageism, or the stereotypical view of old age, as one of the key causes of human rights breaches against older people.⁶⁴⁸ Still, although ageism and the social construct of old age are increasingly used to explain the processes that generate and perpetuate inequality against the older generation, these frequently appear among, and are given equal weight, with other problems, including individual deficits. Several scholars draw attention on the specific needs of older people that need to be adequately reflected in human rights law in order to advocate for the need for a new convention. For example, despite accepting that human rights violations against the old are related to particular conceptions of older age,

⁶⁴⁷ Clough Clough and Brazier, "Never too old for health and human rights?."

⁶⁴⁸ See among others, McLachlin Beverley McLachlin, "Human Dignity at any age: the Law's response to an aging population," *J. Int'l Aging L. and Pol'y* 6, no. 111 (2013). Doron and Apter, "International Rights of Older Persons: What Difference Would a New Convention Make to Lives of Older People?." Fredvang and Biggs, "The rights of older persons - Protection and gaps under human rights law." Marijke de Pauw, "Global Population Aging from a Human Rights Perspective: The Need for a UN Convention on the Rights of Older Persons.", Kesby, "Narratives of aging and the human rights of older persons."; Office of the High Commissioner for Human Rights, Normative standards in international human rights law in relation to older persons - Analytical Outcome Paper. Mégret, "The Human Rights of Older Persons: A Growing Challenge." Ania Zbyszewska, "An intersectional approach to age discrimination in the European Union: Bridging dignity and distribution," (2015).

Mégret also refers to a '*weakened ability to adapt to change*' as if it is a natural characteristic distinguishing older people from others.⁶⁴⁹ Similarly, Alston makes a rather stereotypical assumption that older people lack familiarity with technology, flexibility and adaptability, instead of highlighting those structural factors that have put older persons in a position that they are less likely to benefit from technology and adapt, for example lack of training and support.⁶⁵⁰ Additionally, he argues that older people's '*condition*' may be susceptible to special protection in a similar way to children, which could be perceived as a presumption of incapacity and dependency.⁶⁵¹ Likewise, some authors even argue that a treaty on older people's rights should be modelled upon the Convention on the Rights of the Child.⁶⁵² Williams discusses older people's vulnerability to falls.⁶⁵³ Illness has also been used as a root cause of vulnerability, alongside other attitudinal, economic and societal factors⁶⁵⁴. In accentuating older people's plight as unavoidable, such views effectively legitimize and reinforce the medical approach, which is patronising and disempowering since it aims to compensate for personal deficiencies, instead of eliminating those structural barriers that are the root cause of inequality. Other studies do not offer a clear understanding of the nature of older people's vulnerability.⁶⁵⁵ So, although we are gradually moving towards recognizing the social construct of older age, these conceptual contradictions, eschew a coherent conceptual basis for the understanding and implementation of older people's rights.

Moreover, whereas extant literature identifies ageism as one of the key factors of the denial of older people's rights, it does not clearly link ageism to other societal

⁶⁴⁹ Mégret, "The Human Rights of Older Persons: A Growing Challenge."

⁶⁵⁰ Chen, Alston, and Levine, "Aging: A New Human Rights Concern—A Policy-Oriented Perspective".

⁶⁵¹ See for example Chen arguing that the idea of old age as a second childhood leads to protectionism, Chen, Alston, and Levine, "Aging: A New Human Rights Concern—A Policy-Oriented Perspective".

⁶⁵² Martin Rodriguez-Pinzón and Martin, "The International Human Rights Status of Elderly Persons".

⁶⁵³ Williams, "When I'm Sisty Four: Lawyers, Law and Old Age."

⁶⁵⁴ Office of the High Commissioner for Human Rights, Normative standards in international human rights law in relation to older persons - Analytical Outcome Paper.

⁶⁵⁵ Love and Lynch, "Enablement and positive ageing: a human rights-based approach to older people and changing demographics."

features that – according to scholars – contribute to older people’s vulnerability, such as invisibility of older people’s roles,⁶⁵⁶ neoliberalism,⁶⁵⁷ industrialisation,⁶⁵⁸ erosion of family ties, illiteracy, lack of information,⁶⁵⁹ lack of awareness of rights⁶⁶⁰ and others. But it is precisely due to discounting that these processes exist in the first place or have an adverse effect on older persons.

Old age advocacy and human rights practice have so far failed to make a sharp split between the natural and the social aspects of old age disadvantage. In contrast, the disability community has purposefully made a distinction between impairment, which is biological and disability, which is socially constructed.⁶⁶¹ Similarly, the feminist movement has differentiated between sex and gender, gradually paying more attention to the latter, because it explains the socio-cultural institutions that lead to women’s oppression.⁶⁶² One of the key contributions of this thesis is that it suggests that a distinction between ageing and ageism is particularly important and enlightening for human rights purposes. Human rights law needs to depart from the medical and welfare approaches, which at least partly, continue to be integrated in existing standards.

The causal relationship between discounting and human rights violations in older age needs to gain the same level of recognition and consciousness with other forms of societal oppression, such as racism or sexism. This finding does not concur with Bytheway who believes that in order to fight ageism we must assume

⁶⁵⁶ NGO Committee on Ageing in Geneva, "Panel Report Lifelong Human Rights: Generation and Ageing Perspectives" (2003).

⁶⁵⁷ Mégret, "The Human Rights of Older Persons: A Growing Challenge."; Tang and Lee, "Global Social Justice for Older People: The Case for an International Convention on the Rights of Older People."

⁶⁵⁸ Mégret, "The Human Rights of Older Persons: A Growing Challenge."

⁶⁵⁹ Bonn UN Department of Economic and Social Affairs, *Report of the Expert Group Meeting "Rights of Older Persons" Convened in Preparation of the Report of the Secretary General to the 64th session of the General Assembly, 5-7 May 2009, Bonn, Germany.*

⁶⁶⁰ Love and Lynch, "Enablement and positive ageing: a human rights-based approach to older people and changing demographics."

⁶⁶¹ Rannveig Traustadóttir, "Disability studies, the social model and legal developments" (2009); Tom Shakespeare, "The social model of disability," *The disability studies reader 2* (2006).

⁶⁶² Shakespeare, "The social model of disability."; Traustadóttir, "Disability studies, the social model and legal developments".

that older age does not exist.⁶⁶³ Instead, at least from a legal and activism perspective, this thesis agrees with other scholars who have argued against 'agelessness'. Andrews for instance wonders if we are to fight ageism solely by challenging its existence, why didn't we do the same with sexism and racism.⁶⁶⁴ She also argues that by ignoring old age we further entrench barriers between young and old. Calasanti, Slevin and King likewise argue that denying old age lies at the heart of ageism⁶⁶⁵. On the contrary, they say that we should point to the systematic inequalities and stigma encountered in old age and theorise old age as a type of oppression, like race or gender. In other words, to fight ageism we should not deny old age but rather disentangle it from the stigma it is associated with.

This thesis demonstrates that unless we pay attention to the commonality of discounting in older age, we will downplay its consequences for human rights and continue to undermine older people's dignity. Targeted attention in a new treaty would affirm that distinctions on the basis of old age are harmful and wrong and therefore must be considered as human rights breaches.⁶⁶⁶ It would also facilitate the development of interventions that aim to realise older people's full potential, for example offering opportunities for employment and participation, instead of maintaining them through welfare benefits and care in segregated settings.

However, so far, ageism has only marginally been used in the OEWG discussions and it has not been consistently applied to the full spectrum of human rights challenges faced by this group.⁶⁶⁷ As shown throughout this study, neither have older people been consistently using the ageism argument as part of their own advocacy. The thesis also demonstrated that the level of awareness of ageism as a structural factor undermining human rights also varies among human rights professionals and policy stakeholders in the three countries. Especially in France

⁶⁶³ Bill Bytheway, *Ageism*, Rethinking ageing series, (Buckingham: Open University Press, 1995).

⁶⁶⁴ Andrews Molly Andrews, "The seductiveness of agelessness," *Ageing and Society* 19, no. 3 (1999).

⁶⁶⁵ Calasanti, Slevin, and King, "Ageism and Feminism: From "Et Cetera" to Center."

⁶⁶⁶ On this see also following section on Recognizing

⁶⁶⁷ De Pauw et al., "Ageism and Age Discrimination in international human rights law."

and partially also in the other two countries, human rights bodies have so far focused on challenges that are related to disability and care settings. Chinsung Chung, who was mandated by the UN Human Rights Council to draft a report on old age rights, limited older people's vulnerability in armed conflict to aspects of physical mobility.⁶⁶⁸ Even in discussions around a new convention for older people, it has been argued that the mere application of disability rights may provide sufficient protection for older people.⁶⁶⁹ However, the findings of this study concur with Harpur and other scholars who argue that later life disadvantages are much broader than ill health and impairment.⁶⁷⁰ Additionally, although the prevalence of disability increases with age, most older people do not have disabilities.⁶⁷¹ In fact, an increasing proportion of the older population are living in good health, are financially secure, and are even supporting younger generations⁶⁷². Consequently, such views that reduce old age inequalities to those associated with the physiological process of loss of functional abilities are theoretically and pragmatically unsatisfying. In contrast, this thesis clearly posits discounting as a form of oppression that is distinct from disability and ableism.

This finding is particularly important for two reasons. First, Allen has argued that agreement on the key principle and utility of a new treaty is necessary to secure endorsement.⁶⁷³ He also added that

⁶⁶⁸ Chung, *The necessity of a human rights approach and effective United Nations mechanism for the human rights of the older person*, para 20.

⁶⁶⁹ European Union, "Opening statement by the European Union" (paper presented at the Open Ended Working Group on Ageing, Second session, New York, 2011); Harpur, "Old Age is not just Impairment: The CRPD and the Need for a Convention on Older Persons."

⁶⁷⁰ Harpur, "Old Age is not just Impairment: The CRPD and the Need for a Convention on Older Persons."; Fredvang and Biggs, "The rights of older persons - Protection and gaps under human rights law."; Kesby, "Narratives of aging and the human rights of older persons."; Paul Harpur, "Time to be heard: How advocates can use the Convention on the Rights of Persons with Disabilities to drive change," *Valparaiso University law review* 45 (2011).; Fundamental Rights Agency (2018) *Shifting perceptions: Towards a rights-based approach to ageing*; Mégret, "The Human Rights of Older Persons: A Growing Challenge."

⁶⁷¹ Grammenos, *European Comparative Data on Europe 2020 & People with Disabilities*.; *Economic Commission for Latin America and the Caribbean (ECLAC), Challenges to the autonomy and interdependent rights of older persons*.

⁶⁷² Committee on Economic Social and Cultural Rights (CESCR), "General Comment No.6: The economic, social and cultural rights of older persons." para 17

⁶⁷³ Robin Allen, *Discussion papers: Legal issues for strengthening international legislation on the rights of older persons*.

'a defining principle would empower ordinary people with an understanding of the purpose of the Convention. It would enable them to be more confident to believe that they know what the Convention entails'.⁶⁷⁴

This thesis clarifies that the main aim of a new treaty should not be to cater for vulnerability, needs, declining capacities or diminishing life expectancy, all of which are positions expressed in literature and in the political arena. Instead, a new convention should have the purpose of acknowledging in a systematic and coherent way all those State and society-wide attitudes, practices and structures that - intentionally or not - attribute less value to the dignity of individuals because of their (perceived) old age.⁶⁷⁵ Based on this premise, a new treaty has a *transformative* potential. Exposing the negative effects of discounting, a new convention could provide a richer, clearer and more accessible interpretation of universal rights. A new convention would therefore have a symbolic value beyond the actual implementation of related obligations in domestic law and policy.

Second, putting ageism in the human rights agenda facilitates an exploration of the complex and multidimensional aspects of older people's disadvantage that extend beyond those that are related to disability or poverty. This is crucial given the virtual silence of international law on ageism and the difficulties of applying an obligation to eliminate stereotypes and prejudicial attitudes around older age and to counter biased laws under the existing UN treaties. A conceptualisation of older people's rights based on the need to combat discounting can extend the protection afforded to older individuals, including those covered partially by other instruments, such as older persons with disabilities, older women and older migrants. In sum, acknowledging the

⁶⁷⁴ P.18, para 12

⁶⁷⁵ See similar argument made for CRPD in Michael Ashley Stein and Janet E. Lord, "Future prospects for the United Nations Convention on the Rights of Persons with Disabilities," in *The UN Convention the Rights of Persons with Disabilities European and Scandinavian Perspectives*, ed. Oddný Mjöll Arnardóttir and Gerard Quinn (Brill Nijhoff, 2009); Michael Ashley Stein and Janet E. Lord, "Future prospects for the United Nations Convention on the Rights of Persons with Disabilities" (2009).

specificity of old age disadvantage that is driven by discounting can help better mainstream older people's issues within the human rights system.

The Threefold Objective of a New Treaty

This part discusses the concrete objectives that a new treaty must pursue in order to achieve its normative purpose, which was described in the previous section. These involve recognizing, enabling and empowering. Recognizing is about making human rights law more conscious of the unique human rights breaches against older persons that are rooted in discounting and currently remain unintelligible, undetected and unaddressed; enabling is about releasing clear obligations for States and rectifying the extant narrow and inconsistent approach to older people's rights; and empowering is about helping individuals and groups access rights and demand the fulfilment of State obligations.

Recognizing

Recognizing is about exposing violations, naming them in the law and linking them to legal obligations and outcomes. Based on the empirical findings, current standards manifest stereotypes, leave wide room for exceptions and restrictions and permit the perpetuation of human rights breaches. Despite generally assigning to a rhetoric of equal rights, older people continue to be treated with less dignity and to face barriers in the equal enjoyment of their human rights, without necessarily recognizing this failure. A new convention would affirm that human rights do not diminish with age. It would represent a sense of moral and legal compass through which to judge whether certain acts and behaviours are legitimate or wrong. Individuals would not have to assert on case by case basis that they are entitled to the same benefits and treatment as everyone else, as this would be clarified by the convention.⁶⁷⁶ Explicitly recognizing older persons as agents with full rights, could elevate the detriments of older people from issues that can be disregarded to human rights violations that cannot be ignored. Integrating a duty to apply universal norms in a non-biased way, a new

⁶⁷⁶ See similar argument about CRPD made by Harpur, "Embracing the new disability rights paradigm: the importance of the Convention on the Rights of Persons with Disabilities."

convention would be better equipped to detect constructions of older age embedded in law provisions, policies and practices that drive human rights breaches and recognize them as unacceptable.

As mentioned by Simmons in her study on the impact of human rights treaties.

[H]uman rights treaties at least provide the possibility of stabilizing boundaries between acceptable and unacceptable practices, making the manipulation of rights less elastic than otherwise might have been possible.⁶⁷⁷

Similarly, prominent disability scholar Gerard Quinn explained that

[O]ne of the most important functions of an international thematic treaty is that it holds up a mirror to each society – it forces us to take a good look at ourselves and to challenge the gap between the myths of the system and the way the system actually operates.⁶⁷⁸

Even if not contested in principle, acknowledging the equal worth and rights of older people is not a simple act; it requires a fundamental shift. The normative analysis demonstrated that existing standards are based on a limited conception of older age and indeed the lifecourse. They start from a premise of loss of autonomy, dependency and social isolation as normal or inevitable. Hence, human rights law is not only inadequate, it is also per se biased. Simply applying current norms in the context of older age, will not improve the legal protection of older person's rights, unless human rights standards are restructured in such a way that they deepen the definition and scope of human rights in older age. This is a key contribution because, whereas the potential of a new treaty to alter societal perceptions on ageing and older persons has been widely commented, the need to bring ageist dimensions of extant human rights norms and practices into the fore has not been adequately reflected in literature.

⁶⁷⁷ Simmons Simmons, *Mobilizing for human rights: international law in domestic politics*. p. 368.

⁶⁷⁸ Gerard Gerard Quinn, "Irish Senate Committee on Public Consultation Hearing on the Rights of Older People 29 November 2011, Statement of Professor Gerard Quinn on the case for a new UN treaty on the Rights of Older People" (2011).

A new treaty would provide a framework to apply rights in a way that recognizes and maximizes older people's potential and contributions. This entails replacing the current focus on weakness and protection with an emancipatory model that incorporates aspects of autonomy, independence and participation as the basis for legal and policy action. In concrete terms, such a cultural change enshrined in a normative framework would have to redefine later life inequalities - that have so far been considered as legitimate or necessary - as fundamental breaches of human dignity. There is currently no clear Statement under international law that old age cannot become the basis of denial or restriction of rights. Age discrimination is often framed as a necessity to achieve intergenerational fairness⁶⁷⁹ or system sustainability. This makes measures aiming to eradicate discrimination against older persons controversial. However, if we are serious about ensuring equal rights at all ages, a new convention would have to move away from the justification of several age-based restrictions, to an acceptance that there are no circumstances where the use of age is justified, unless it leads to maximizing older people's potential for participation, autonomy and independence. Age criteria should promote - and not limit - rights. Such an approach would allow us to unravel a lot more forms of human rights violations than we currently perceive. It would for instance entail challenging many existing institutional arrangements, such as mandatory retirement. Were such a paradigm to be introduced into a new treaty, it would considerably broaden the boundaries of human rights law.

Additionally, a new treaty would include an obligation to abolish laws, policies and practices that are based on the (presumed) inferior worth or contributions of older people or that contribute to their exclusion. For example, to prevent marginalisation we need to recognize that the right to participate and contribute to society does not lessen with age and to revisit language that limits this possibility '*for as long as possible*'. Similarly, a new convention should very clearly acknowledge older people's right to live in the community and to make free

⁶⁷⁹ Sandra Fredman, *Discrimination law* (OUP Oxford, 2011).

choices on an equal basis with others. As a result, institutionalisation would no longer be the default response to care needs.

Recognizing older persons as holders of rights in a new treaty would not only impact international standards, but also have implications at national level. At the very least, a convention could influence domestic human rights practice by giving a specific mandate to human rights bodies to look into issues of older age. Based on the empirical findings of this thesis, NHRIs, Equality Bodies and Ombudspersons in the three countries have only marginally addressed older people's issues. A new convention could put under the purview of these national actors areas that are not necessarily covered by national law, such as discrimination in access to goods and services and home care. As a result, there is potential in improving the current state of inertia due to the absence of an obligation to monitor the state of and progress in the protection of older people's rights.

Enabling

The normative analysis concurs with others that have argued that older people's experiences of human rights breaches have been side-lined in the human rights system.⁶⁸⁰ The theory of overlooking the injustice also demonstrated that conceptual biases and gaps cause difficulty in comprehending what specific changes are necessary to address old age disadvantage. Therefore, the secondary aim of a new treaty would be about providing more clarity in terms of how rights must be implemented taking into account the specific experience of rights violations in older age.

The process of enabling is crucial because – as previous parts of the thesis have demonstrated – national actors lack a consistent language to describe disadvantages in older age as human rights abuses, but also lack a consensus about the States' role to implement the rights of older people. The content and extent of State obligations that support human rights for older people on an equal

⁶⁸⁰ See in particular Office of the High Commissioner for Human Rights, Normative standards in international human rights law in relation to older persons - Analytical Outcome Paper.

basis with others is open to debate. This causes divergent and biased interpretations of universal norms and adversely impacts the ability of human rights bodies, NGOs and individuals to act on human rights violations.

A new convention can provide more visibility to those unique forms of human rights abuses faced by older persons, such as lack of support, neglect, digital exclusion, social isolation, lack of education and capacity building in order to deal with life transitions and take up different roles, among other issues discussed in this thesis. It would detail State obligations to change the institutions, systems, power imbalances and resource distribution that cause and perpetuate older people's disadvantage. The definition of more concrete standards would expand the reach of human rights by incorporating specific provisions that explain how to apply universal standards to the situation of older age.⁶⁸¹ Unless the fulfilment of older people's rights is associated with specific obligations for reforms, there will be little effort to change the structural conditions that lead to abuse in the first place.

The realization of older people's rights does not only involve recognition in law and negative duties; it also includes positive obligations and substantive rights. Enabling involves securing the conditions that allow older people to act as autonomous agents and to participate fully in their communities. It is about enhancing capacities and opportunities to be a full member of society.⁶⁸² Enablement goes beyond redistribution, which focuses on reducing primarily economic barriers to participation. It is also about involving older people in decision-making and adopting positive measures to ensure full inclusion.

First, in terms of equality and non-discrimination there should be an obligation for States to take positive action to eliminate all forms of discrimination against older persons and a duty to tackle ageist biases and raise awareness of the

⁶⁸¹ Mégret, "The disabilities convention: towards a holistic concept of rights."

⁶⁸² Sen, *The idea of justice*.

contributions and role of older persons⁶⁸³. Additionally, there should be a duty for more comprehensive and disaggregated data collection⁶⁸⁴.

Second, a new convention could help reformulate key concepts so that they are relevant for the specific challenges faced by older people. It could for instance include a duty of reasonable accommodation to facilitate working lives or to combine work with caregiving, regardless of whether the individual has a disability. Reasonable accommodation could also be extended in access to education, in order to ensure that older persons can benefit from lifelong learning, training and capacity building regardless of their digital skills, or place of residence. A new treaty could extend the understanding of accessibility to include the need for adequate seating areas, public toilets and measures to avoid long waiting lines in which older people have to queue standing up. These issues are sometimes reflected in age-friendly policies, but they are not necessarily understood as accessibility requirements. Third, a new convention could provide in detail how rights apply in the context of older age. For example, the right to care and support needs to be implemented taking into account community and residential, public and private, as well as formal and informal settings. This right could include an obligation for support and training of informal carers that provide the bulk of care. It could also be interpreted in light of the ongoing trend of digitalisation of the care sector and include a duty to provide assistive technology, but also a right to opt out from it. The right to education needs to reflect the specific challenges faced by older persons to access lifelong learning and capacity buildings, including among others the prohibition of age – based restrictions. Finally, a convention could expand the purview of human rights law in areas like palliative and end of life care, elder abuse in the community and by private actors, and others that have not been adequately covered by existing standards.

⁶⁸³ De Pauw et al., "Ageism and Age Discrimination in international human rights law."

⁶⁸⁴ General Comment 6 does not make reference to data collection and disaggregation by age but includes only a vague obligation for regular monitoring (para 18). CEDAW however in its General Recommendation 27 referred to the need for data disaggregated by age and sex (para 19)

For participants in this study, recognizing and enabling are not distinct processes but complementary and interconnected. For example, one participant distinguishes between a fundamental right to care and a legal protection of the right to care. The former, he explains, is about the freedom to make choices about one's care, to decide where, by whom and how they want to receive support. This right must be recognized equally for people of all ages. The legal point of view is about the establishment of a statutory instrument that is followed by necessary resources. In addition, legislation - according to the participant - is about regulating the sector of services, introducing some standards and monitoring processes that can protect both the older persons and the workers in the sector. So, enablement will typically presuppose recognition, i.e. we first need to acknowledge the equal status of older people before defining the ways in which they are left behind and the action necessary to remove disadvantage. It needs to build on an expanded notion of rights encompassing the ideas of autonomy, independence, equality and participation that NGOs advocate for. In sum, combined, the two categories of recognizing and enabling presented in this section can be translated into the backbone of a human rights-based approach and possibly also of a new treaty.

If the adoption of a new treaty were to be coupled with the establishment of a treaty body, this would also facilitate the translation of standards into concrete actions that need to be taken by States to comply with its provisions. It could also serve as an awareness and education tool for human rights practitioners and wider society about the disadvantaged position of older people, their current and potential contributions, and society's role to support the realisation of their human rights and prevent violations.

From a national perspective, enabling could mean adopting specific laws or policies either with a wide reach or covering some of the key areas of rights of older people, like regulating the sector of care, providing systems of support and ensuring adequate old age income. In Greece, which has not yet adopted a policy or law on ageing, a new convention could steer national policymakers to this

direction. France and Ireland would also have to revisit their existing ageing laws and policies and see where they fail to comply with the treaty standards. For instance, France would probably need to expand beyond the sector of care and work towards the convergence of disability and ageing policies, which entails abolishing the age limit that leads to the discriminatory treatment of older persons with disabilities.⁶⁸⁵ Ireland could be prodded to transfer more resources to community care and to adopt new legislation on home care services.

Empowering

Discounting does not only affect the views and behaviours of others, but also those of rights holders, who may lack consciousness of certain acts as violating rights. The analysis posited lack of awareness of rights as one of the chief reasons for the denial of rights of older persons⁶⁸⁶. When ageism is internalised, it can impact older people's ability to speak for themselves and claim their rights⁶⁸⁷. For example, older people whose rights are violated, do not take action and remain silent because they do not want to make a fuss.⁶⁸⁸ Some even feel that abuse is a price worth paying.⁶⁸⁹

Human rights treaties can empower older persons as holders of rights to exercise and claim their rights and to be actively involved in public affairs.⁶⁹⁰ In this way they can strengthen the enforceability of rights. One participant suggested that

⁶⁸⁵ In March 2020 France decided to abolish this age barrier, see Raphaëlle Murignieux, "Prestation de compensation du handicap : une nouvelle loi supprime la barrière d'âge-Vers une prestation universelle autonomie ?," *AgeVillage* 2020, https://www.agevillage.com/actualite-18592-1-fin-de-la-barriere-d-age-pour-la-PCH.html?utm_source=sendinblue&utm_campaign=News_GP_09032020&utm_medium=email.

⁶⁸⁶ Jimenez Marlon Mora Jiménez, "IS A REAL PROTECTION OF HUMAN RIGHTS OF THE ELDERLY? THE LEGAL DISCOURSE," *Revista Ciencias Sociales* (2010); Love and Lynch, "Enablement and positive ageing: a human rights-based approach to older people and changing demographics."

⁶⁸⁷ Carney and Gray, "Unmasking the 'elderly mystique': Why it is time to make the personal political in ageing research."

⁶⁸⁸ Townsend, "Policies for the aged in the 21st century: more 'structured dependency' or the realization of human rights ? ."

⁶⁸⁹ Williams, "When I'm Sisty Four: Lawyers, Law and Old Age." P. 116

⁶⁹⁰ Simmons, *Mobilizing for human rights: international law in domestic politics*; UN Secretary General, *Follow-up to the Second World Assembly on Ageing, A/66/173*. Ryan Goodman and Derek Jinks, "Measuring the effects of human rights treaties," *European Journal of International Law* 14, no. 1 (2003).

knowing that you have rights increases older people's sense of self-respect and allows them to make free choices about how they live their lives. This finding is important because it illustrates the potential of a new treaty that spans beyond its legal implications. It points to an idea whereby filling the extant void in terms of knowledge of rights and consciousness of wrongdoing could help expand older persons' agency and control over their lives. To the extent that a new convention provides the essential vocabulary to link individual experiences with human rights breaches, it can increase individuals' sense of entitlement, perception of just treatment and feeling of security. In addition, by recognizing older persons as agents, instead of dependent or passive beings, human rights create space for rights holders to participate and demand their rights.⁶⁹¹

By inspiring positive images of ageing and older persons, by reconceptualising inequalities - not as the direct and inevitable result of ageing, but rather as society's failure to include and support older persons- and by increasing individuals' consciousness of discounting and human rights abuses, a new convention could then become a vehicle for older persons to become self-advocates. Through becoming activists around issues of older age, older persons could gain some pride in being old and identify with others in the same age group who may be facing similar experiences countering the current state of inertia due to the stigma surrounding the older person identity.⁶⁹² A treaty could therefore empower older persons to better serve their interests, to make choices based on their wills and preferences and ultimately to mobilise them to claim their rights. It could facilitate the development of a movement. In doing so it could contribute to breaking the vicious impact of discounting at individual and societal level.

The CRPD is a very good example of a treaty that empowers persons with disabilities, by giving them and their representative organisations an official role

⁶⁹¹ Freeman, "The value and values of children's rights."

⁶⁹² This argument is made about individuals who become disabled after forming an identity of self as non-disabled b Doris Zames Fleischer, Fleischer Doris Zames, and Frieda Zames, *The disability rights movement: From charity to confrontation* (Temple University Press, 2012). p.202

in its implementation.⁶⁹³ Article 4 creates an obligation for States to include persons with disabilities in all decisions pertaining to their rights. Article 33 requires the involvement of persons with a disability and their advocacy organisations in monitoring the implementation of the convention. These ground-breaking provisions operationalise the disability motto '*Nothing about us without us*'.⁶⁹⁴ Should a new treaty on older persons integrate such principles, it would give older people 'voice' and equip their organisations with a formal role in policymaking and monitoring. Even if their true effectiveness will rely on several other factors, such obligations have an important symbolic and empowering function. To implement such provisions at domestic level, States would have for instance to establish consultation mechanisms or dedicated bodies to ensure that older persons are included in decision-making. They could also be required to create national focal points charged with the treaty implementation and/or independent monitoring frameworks.⁶⁹⁵

Reframing the Discourse

This thesis has argued in favour of a new treaty that recognizes the rights of older persons, enables their realisation and empowers older individuals to uphold their rights. However, the findings have also identified the danger of constructing a convention around a notion of a distinct older persons' identity. Participants are suspicious of an instrument that can be perceived as imposing a norm of difference of treatment on the basis of age. The findings of this thesis have agreed with others who argue that older persons do not self-identify as old and that NGOs in the field of ageing are not motivated by identity politics.⁶⁹⁶ Old age advocates reject special measures out of fear that being treated as a distinct category may inadvertently lead to the stereotyping and marginalisation of older

⁶⁹³ Harpur, "Embracing the new disability rights paradigm: the importance of the Convention on the Rights of Persons with Disabilities."

⁶⁹⁴ Harpur, "Embracing the new disability rights paradigm: the importance of the Convention on the Rights of Persons with Disabilities."

⁶⁹⁵ Art 33 UN Convention on the Rights of Persons with Disabilities

⁶⁹⁶ Kohn, "Elder rights: the next civil rights movement."; Herro, "Advocating a UN Convention on the Rights of Older Persons in the United Kingdom: The Case for a Radical Flank."; Walker and Naegele, *The politics of old age in Europe*; Gilleard and Higgs, "The power of silver: Age and identity politics in the 21st century."

people.⁶⁹⁷ They see ageing as a normal part of the lifecourse and define older people's rights as having the same rights with everyone else.⁶⁹⁸ Old age is not problematized as a difference of human nature that requires special treatment, but as the continuum of human life.⁶⁹⁹ Participants therefore acknowledge a universality in the experience of inequality and disadvantage and want to be treated within a framework that includes all other age groups.

These concerns demonstrate that the current framing that places older people in the spotlight as potentially vulnerable, different or worthy of special measures is not helping to garner support for a new convention. In fact, it is even perceived by some as polarising and distracting from the objective of ensuring that that rights do not diminish with age. Participants' views oppose the frame adopted by the Interamerican Convention, which enshrines a general principle on the preferential treatment of older people, accepting that older people are subject to special measures by mere virtue of their older age.⁷⁰⁰ This finding⁷⁰¹ also goes against the expressed view that the need for recognition of the old age identity could become the basis of a dedicated treaty.⁷⁰²

In some ways the frame emerging from the findings resembles Fineman's 'vulnerable subject', but in others it departs from it.⁷⁰³ On the one hand, participants see older people not as part of a protected category, but merely as human beings who may experience inequality. This understanding is similar to Fineman's concept of vulnerability, which is not based on identity nor associated

⁶⁹⁷ On this see also Westwood, "I May Be Older, but I Ain't No Elder: A Critique of Elder Law." p 503-504, Martha Albertson Fineman, "The vulnerable subject: Anchoring equality in the human condition," *Yale Journal of Law & Feminism* 20, no. 1 (2008).

⁶⁹⁸ On this see also Morgan and David, "Human Rights: A New Language for Aging Advocacy "; Townsend, "Policies for the aged in the 21st century: more 'structured dependency' or the realization of human rights ? ."

⁶⁹⁹ See also Bergen J. Westerhof, "Age Identity," in *Encyclopedia of the Lifecourse and Human Development*, ed. Deborah S. Carr (Macmillan Reference, 2009).

⁷⁰⁰ Organisation of American States, "Inter-american Convention on Protecting the Human Rights of Older Persons (A-70)." Art 3, 19, 21, 31

⁷⁰¹ This finding has also been echoed in a recent paper by Herro, which partly draws from this research Annie Herro, "Demanding Their Rights? Collective Identity and the Tactics of Older Persons' Organisations at the UN," *Global Society* (2020).

⁷⁰² Israel Doron, "Re-thinking old age: Time for AGEIVISM," *Hum. Rts. Defender* 27 (2018).

⁷⁰³ Fineman, "The vulnerable subject: Anchoring equality in the human condition."

with deficit or dependency. Instead, she argues that vulnerability is universal and inherent in the human condition. She also believes that the State must play a pivotal role in addressing societal inequalities, which is in line with the empirical concept of 'enabling', which foresees positive State obligations against systemic aspects of exclusion. But unlike Fineman's model, which is freed from negative connotations, current policy and legal discourse associate older people's vulnerability with passivity and decline. This is why it is difficult for participants to accept this label and to base their advocacy on the concept of vulnerability. In other words, despite being conceptually close to the empirical findings, Fineman's approach has its limitations as a campaigning frame.

In addition, as mentioned in an earlier section of this Chapter, discounting remains to a large extent unintelligible and unaddressed. This is why older people's organisations are suspicious of any difference of treatment. Dismantling legal impediments, such as mandatory retirement ages, justified age-limits and special schemes that provide fewer benefits requires a strong focus to formal equality, similarly to early stages of the feminist movement, which aimed at levying barriers to equal suffrage and property rights, for instance. Precisely because discounting is not seen as severe as other forms of oppression, it is important for advocacy groups to politicize claims around age-based discounting. It may be a matter of time before we move towards a model of substantive equality that defines State obligations beyond protected categories, but insofar as vulnerability is often used to legitimize the detrimental treatment of older people, Fineman's universal vulnerability paradigm is not fit for the purpose of human rights protection.

The emerging human rights model needs to be grounded on the views and experiences of older persons. Unless the ongoing discussions are cognisant of and responsive to the key concerns of domestic advocacy groups, the support necessary for the adoption of such a new instrument will remain problematic. The challenge then lies in conceptualizing and advocating older people's rights in a way that first, is firmly rooted in an understanding of human rights as a system

that connects older people with the rest of society; second, abandons notions of older age as synonymous with deficit and decline; third, reflects the diversity of the group; fourth recognizes ageing as universal experience; fifth, acknowledges old age as a social construct; and finally, is oriented towards transforming existing institutions and structures in order to fight stereotypes and consolidate a positive affirmation of what it means to be old. Although a couple of scholars have written about the potentially infantilizing and ageist effect of a specialized legal protection on older persons,⁷⁰⁴ extant literature and discourse has so far not reflected on how the narrative and arguments around a new convention would have to change in order to respond to these concerns.

From 'Human Rights of Older Persons' to 'Human Rights in Older Age'

The argument brought forward in this thesis is that a new treaty should move away from portraying older people as a homogeneous group that requires protection. Moreover, it should demonstrate consciousness of the fact that older age disadvantage is not only an issue for those who are now experiencing later life; it should take into account all those who will age and eventually become part of the protected category.⁷⁰⁵ But the current focus on an older persons' identity as the basis for human rights protection does not serve these aims. If instead we were to impose a life-course perspective to human rights law, then we would conceive human rights as unchangeable and at the same time be able to critically examine those unique experiences of human rights breaches that take place during transitions. We would be able to bring to the fore those structures, situations and conditions that create disadvantage, rather than focus on chronological or generational dimensions that are potentially segregating.

⁷⁰⁴ Williams, "When I'm Sisty Four: Lawyers, Law and Old Age."; Doron and Apter, "International Rights of Older Persons: What Difference Would a New Convention Make to Lives of Older People? ."; Westwood, "I May Be Older, but I Ain't No Elder: A Critique of Elder Law."; Nina A. Kohn, "Outliving civil rights," *Wash. UL Rev.* 86 (2009)..

⁷⁰⁵ Fineman, "Elderly as vulnerable: Rethinking the nature of individual and societal responsibility."p.110

This thesis makes the case that we need to take a step back from discussing a treaty for the rights of older people and start discussing everybody's rights in older age. A new treaty should not be about protecting the old, nor about creating a special scheme. It should rather aim at revisiting the original principles of the Universal Declaration of Human Rights and identifying what needs to be done so that human rights do not apply in diverging, fragmented and unequal ways across our lives. Rather than aiming to define a particular and distinct group to which treaty provisions apply, it would put the focus on the situations that render discrimination, exclusion and abuse more typical and more acceptable in later life. Such a lens would make the topic appear as more universal and affecting all groups in society. A frame that poses ageing as a shared experience, would avoid stereotyping older persons as a kind of distinct group. Instead, it would illustrate that we can all benefit from human rights law regardless of the stage of life we are currently in. The debate around a new treaty would then be turned into a collective and universal project to which more of us and not just the old should contribute.

Talking about 'human rights in older age', is by no means a perfect frame. This approach could still be criticized as conceptualizing older age as a life stage that is separate from the rest of the life continuum. But compared to the current discourse on older persons' rights, this narrative is more likely to be able to bring to the foreground the social construction of older age, which as argued in earlier parts of this thesis is essential in order to avoid the pitfalls of the welfare/medical model of ageing. This change in language must not be seen as a way to divide older age from the rest of the life-course, but rather as a way to emphasize that human rights remain the same at all ages and that human rights practice needs to become more inclusive of experiences of transitions in later life. As argued earlier, the focus on older age is considered essential in order to make visible those human rights breaches that have so far been suppressed. Despite bringing its own set of challenges, such a discourse is needed to validate human rights in older age. It can help pursue those structural reforms that are needed to promote autonomy, independence and participation in older age. Finally, a frame centered around

older age is more likely to capture inequalities that are the result of the accumulation or intersection of diverse identities and drivers of disadvantage.

This frame is primarily proposed to address the uneasiness of advocates to mobilise around a new convention. It is not suggested of course that change will happen automatically, but it is likely that convergence will be easier. Thanks to my professional position, I have already been able to introduce this frame in campaigning and advocacy and I was able to witness firsthand its potential to build coalitions with a wider group of society that does not identify with being old, but is active around issues of later life.⁷⁰⁶ Furthermore, this frame may be more appealing for States. Western European States are more likely to support the adoption of human rights treaties when these are perceived as the natural continuation of their existing obligations.⁷⁰⁷ A key barrier to the adoption of a new treaty is State concern about additional financial burdens to support older persons.⁷⁰⁸ But if a new convention is based on the idea that it will not create new obligations, but rather clarify how existing obligations should be implemented in the context of older age, the likelihood of consensus is greater. A frame that – instead of affording special protections to a group – is centered around making equally effective the same human rights that everyone has, can counter perceptions that a new convention may involve new or different rights.

The Thorny Issue of the Definition

This part now turns on how this frame can be applied in practice, in particular with regard to the definition of the target of a new treaty, which as explained earlier in the thesis is considered a key normative challenge. Most international instruments either lack a definition of older people,⁷⁰⁹ or focus on their chronological age.⁷¹⁰ Definitions that are contingent upon membership to the

⁷⁰⁶ See Ageing Equal campaign : www.ageing-equal.org

⁷⁰⁷ Koldo Casla, *Politics of International Human Rights Law Promotion in Western Europe: Order Versus Justice* (Routledge, 2019).

⁷⁰⁸ Poffé, "Towards a New United Nations Human Rights Convention for Older Persons?."

⁷⁰⁹ United Nations, "Political Declaration and Madrid International Plan of Action on Ageing." A

⁷¹⁰ African Union, "Protocol to the African Charter on Human and Peoples' Rights on the Rights of Older Persons in Africa."; Organisation of American States, "Inter-american Convention on Protecting the Human Rights of Older Persons (A-70)."

older people's group or that distinguish older people from the rest of the population are not acceptable to the people interviewed for this thesis. Chronological definitions are therefore to be avoided, primarily because they imply that individuals over a certain age are inherently different from other adults. Additionally, they lump together a wide variety of experiences and challenges,⁷¹¹ without necessarily clarifying what it is specific to this age group that human rights law should protect. Several other drawbacks of a chronological definitions have been noted elsewhere, including the fact that it does not reflect how well people function in society.⁷¹² This is why biological age, or remaining life expectancy is offered as an alternative.⁷¹³ But such a definition, which would for example define as old everyone who has a remaining life expectancy of 15 years or less, would narrow old age inequalities to those experienced in fourth age and would not cover unequal treatment on the basis of presumed older age. Yet, as shown in this thesis the effect of discounting is sometimes felt even before retirement age.

An alternate approach would be to use an open definition with reference points in domestic law.⁷¹⁴ But it seems unlikely that States would be able to agree on a single starting point of old age for the purposes of attributing positive rights, since these will depend on the redistributive goals and understanding of intergenerational fairness within each country.⁷¹⁵ Such an approach therefore entails significant discrepancies among States but also within countries to the extent that age criteria for pensions and long-term care support are different, for instance. A threshold based on welfare entitlements would also colour the conceptualisation of older people's rights as vulnerable and in need of protection,

⁷¹¹ Macnicol, *Age Discrimination, An Historical and Contemporary Analysis*. Westwood, "I May Be Older, but I Ain't No Elder: A Critique of Elder Law." Wilson, "Conceptual frameworks and emancipatory research in social gerontology."

⁷¹² See also Chapter 2

⁷¹³ IIASA International Instituted for Applied Systems Statistics, *IIASA Policy Brief Analyzing Population Aging from a new Perspective* (2016); Allen, *Discussion papers: Legal issues for strengthening international legislation on the rights of older persons*.

⁷¹⁴ Allen, *Discussion papers: Legal issues for strengthening international legislation on the rights of older persons*.

⁷¹⁵ Allen, *Discussion papers: Legal issues for strengthening international legislation on the rights of older persons*.

failing therefore to mirror the plurality of realities in old age and contradicting participants' view of older age.

This thesis argued that instead of concentrating on older people, we should reconverge on the particular experience of older age, which is not dependent on chronological age but is underpinned by prejudicial attitudes against the old. Evidently, this entails that the human rights model must not simply essentialise older people's detriments as those linked with physical and mental weakness or loss of financial resources, as this could perceive deficit and limitations as intrinsic in older age.⁷¹⁶ It would then be difficult to completely depart from the medical model and transfer responsibility for disadvantage from the individual to society.⁷¹⁷ When policies focus on diminishing capacities, pathologies and health needs, they fail to acknowledge the external institutional deficits that may cause disadvantage in older age. Consequently, they also fail to link old age disadvantage with State obligations to eliminate structural obstacles and may even perpetuate stereotypes around older people's abilities and contributions and lead to fewer or restricted rights. Accepting a definition based on a social model would shift the focus from individual problems to societal responsibility to prevent inequalities and to help older people realise their full potential, just like it has happened with people with disabilities.⁷¹⁸

The 2014 Recommendation of the Council of Europe has adopted such an approach by recognizing the interaction of old age with social factors as barrier to the full and effective enjoyment of older people's human rights. This instrument explains that:

[t]he present recommendation applies to persons whose older age constitutes, alone or in interaction with other factors, including perceptions

⁷¹⁶ Herring, *Older people in law and society*.p.16

⁷¹⁷ Kanter, "The law: What's disability studies got to do with it or an introduction to disability legal studies.", Kesby, "Narratives of aging and the human rights of older persons.", Thompson Thompson, *Age discrimination*; UN General Assembly, *Rights of persons with disabilities - Report of the Special Rapporteur on the rights of persons with disabilities - A/74/186*.

⁷¹⁸ Economic Commission for Latin America and the Caribbean (ECLAC), *Challenges to the autonomy and interdependent rights of older persons*.

*and attitudes, a barrier to the full enjoyment of their human rights and fundamental freedoms and their full and effective participation in society on an equal basis.*⁷¹⁹

The empirical findings in this thesis support the approach of the Council of Europe. This approach could become explicit in the first article of the convention, which could clarify that its purpose is *'to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms, and to promote equal respect for individual dignity in older age'*.⁷²⁰

The thesis illustrates that older age needs to be defined as a life stage or transition during which human dignity is potentially undermined. The actual time that this transition takes place is less important and in fact will vary depending on context. What is crucial is how societal perceptions, expectations and attitudes change after such transitions and how they lead to the denial of rights.

So the definition could then state that the convention applies to situations (and not individuals) where older age or perception of older age, alone or in interaction with other factors constitutes a barrier to the full enjoyment of human rights and fundamental freedoms and to full and effective participation in society on an equal basis.⁷²¹ The aim is not to identify who is old, but rather to ensure that all those who are facing barriers in later life for reasons related to older age can seek protection under the treaty. In other words, instead of aiming for a universally accepted definition that would apply in all contexts and disciplines, what is suggested here is that the discussions around a new treaty should merely focus on those characteristics that render older age uniquely relevant for human rights protection.⁷²² As chronological and biological criteria are not useful to

⁷¹⁹ Para 2

⁷²⁰ Paraphrasing the CRPD art 1

⁷²¹ See similar definition suggested by Robin Allen *'Older persons include those who by reason of their having an older age or the perception of their having such an older age suffer barriers to the full and effective participation in society on an equal basis with others'*. Allen, *Discussion papers: Legal issues for strengthening international legislation on the rights of older persons*.

⁷²² On this see also Wilson that argues that no conceptualization of older age will be applicable to all older people all the time, Wilson, "Conceptual frameworks and emancipatory research in social gerontology." P. 477.

define who is old in this context, the treaty could adopt a more flexible approach where everyone who feels that has been discriminated, abused or excluded because they are perceived as old, could be prima facie protected.

Admittedly the adoption of a definition based on a social model can be subject to criticism. For example, it could be argued that such a definition is not easily operationalised and quantified.⁷²³ It could also be accused of lacking legal clarity and being open to divergent interpretations. Moreover, some could say that it ignores the lived experience of age-related functional decline. Despite being pertinent, such critiques should not stand in the way of elaborating a definition based on the societal barriers faced by older persons.

First, as explained by Allen, the issue of the definition cannot be disconnected from the aim and scope of a convention.⁷²⁴ It is precisely because the primary aim of a new convention, as argued in this thesis, should be to render more intelligible State failures to equally protect and support human rights in older age, that such a definition makes sense. If discounting is understood as the systematic undermining of dignity in older age, then a convention should aim to render more visible all those ways in which States (and society in general) - intentionally or not - attribute less value to the dignity of individuals because of their (perceived) old age. A prescriptive definition could lead to more clarity and universal application; yet it would not be able to have a normalising effect in terms of valuing equally and validating human dignity in older age. Second, bearing in mind that human rights standards outline State obligations, it is very important to underline the social causations of inequality in older age, as opposed to those individual characteristics that may lead to disadvantages. Third, adopting such a definition does not imply that biological ageing is not a reality; instead it just suggests that for human rights law, physical and cognitive decline is not the primary experience that creates disadvantage for older persons compared with

⁷²³ Jerome E. Bickenbach et al., "Models of disablement, universalism and the international classification of impairments, disabilities and handicaps," *Social science & medicine* 48, no. 9 (1999).

⁷²⁴ Allen, *Discussion papers: Legal issues for strengthening international legislation on the rights of older persons*.

other groups. But this finding does not necessarily mean that functional limitations cannot become additional risk factors for restrictions of rights. For instance, according to literature, individuals with chronic conditions and impairments, such as dementia are more likely to be victims of elder abuse and to be isolated.⁷²⁵ Still, in defining older persons as rights holders, societal barriers must take precedence over a definition based on biological or chronological factors.⁷²⁶⁷²⁷

Experiences of functional decline and the related State obligations to address are covered under the existing definition of disability under the CRPD, which could still be used to advocate on behalf of older persons with disabilities. The added value of a new treaty that includes a definition of older age as a social construct is that it would put into the human rights agenda the lived experiences of ageism that in addition to disability, gender, poverty, etc can create unique forms of inequalities. In other words, were a new convention to focus on physical and cognitive limitations due to older age, not only would it perpetuate stereotypes and the medical approach to ageing, but it would also have little to add to the existing CRPD standards. But read together, the CRPD and the provisions of a new treaty that would shed a light to the experiences of discounting in older age, could really expand human rights protection for older persons, including those with

⁷²⁵ UN Department of Economic and Social Affairs, *Report of the Expert Group Meeting "Rights of Older Persons" Convened in Preparation of the Report of the Secretary General to the 64th session of the General Assembly, 5-7 May 2009, Bonn, Germany*; Chung, *The necessity of a human rights approach and effective United Nations mechanism for the human rights of the older person*; UN General Assembly, *Rights of persons with disabilities - Report of the Special Rapporteur on the rights of persons with disabilities - A/74/186*.

⁷²⁶ Huenchuan and Rodríguez-Piñero, *Ageing and the protection of human rights: current situation and outlook*.

⁷²⁷ In line with this approach, as argued by Kanter neither does the social model of disability go so far as 'to negate the existence of disability or to deny the existence of a person's impairment, pain, suffering, or need for treatment and rehabilitation. Instead, the social model sees the social meaning of the impairment as the source of the person's difference and oppression rather than the person's impairment itself' Kanter, "The law: What's disability studies got to do with it or an introduction to disability legal studies." P. 428; See also Eilionóir Flynn, *From rhetoric to action: implementing the UN Convention on the Rights of Persons with Disabilities* (Cambridge University Press, 2011). P. 18 who accepts that disability is caused by both impairment and societal barriers; Also Allen says that CRPD is based on both medical and social model Allen, *Discussion papers: Legal issues for strengthening international legislation on the rights of older persons*.

care and support needs, especially bearing in mind the extant lack of prohibition of age discrimination and the absence of a dedicated article on the rights of older persons with disabilities under the CRPD. A new treaty could also include a specific provision to address the intersection of ageing and disability and other dimensions, such as gender, and therefore facilitate the interpretation of extant human rights norms from the perspective of older age.

Resolving the Tensions

Chapter 2 has discussed some of the key tensions in debates around the human rights of older persons and the value of a new treaty. The findings provide some ideas about how to recast the ongoing discussions to avoid some of the identified shortcomings. Bringing to the foreground aspects of participation, autonomy and independence, the thesis has moved away from the narrow focus of welfare rights that has so far monopolized old age advocacy and discussions on a new treaty. The findings however do not promote autonomy over protection. Whereas chapter 9 has underlined how ageing discourse is gradually departing from the narrative of protection towards a more emancipatory paradigm, at the same time by underlying the key role of support and reasonable accommodation, as well as the need for several law and policy reforms, it has implied that the State must play an active role in enabling the full and equal realization of human rights in older age.

Exclusive attention to liberty and autonomy is unable to address the wider needs of older people, who may be more prone to social exclusion than other groups.⁷²⁸ Negative duties, meaning obligations to not interfere with individual rights are not enough. Positive obligations are not exceptional in nature, but rather essential to protect and promote human rights in older age.⁷²⁹ Benefits and

⁷²⁸ Love and Lynch, "Enablement and positive ageing: a human rights-based approach to older people and changing demographics." and positive ageing. P.92 Norah Christine Keating and Thomas Scharf, *From Exclusion to Inclusion in Old Age: A Global Challenge* (Policy, 2012).

⁷²⁹ This argument is made by Colm O'Conneide with regard to CRPD Colm O'Conneide, "Extracting protection for the rights of persons with disabilities from human rights frameworks: Established limits and new possibilities," in *The UN Convention on the Rights of Persons with Disabilities - European and Scandinavian Perspectives*, ed. Oddný Mjöll Arnardóttir and Gerard Quinn (Brill Nijhoff, 2009).

programmes directed to older people, including, inter alia, pensions and long-term care schemes, are common in many countries and are perceived as essential interventions to cater for later life issues. This thesis has brought forward further examples of positive obligations that are necessary to fulfil human rights in older age.⁷³⁰ Moreover, an approach that puts autonomy and independence as the desirable standard that everyone should attain, risks of justifying paternalistic behaviours vis-à-vis those that cannot or are perceived as unable to fit into the norm.⁷³¹

A new convention therefore must not idealize older persons as autonomous and competent, but neither theorize loss of autonomy as normal or inevitable.⁷³² Whereas this thesis cannot discuss in full how to strike this balance in a new treaty, a few concrete suggestions have emerged from the analysis. First, in order to avoid that older people are seen as objects that need '*to be managed, controlled or cared*', this study agrees with Herro that the ongoing discussions need to be embedded with more arguments and examples of the ways in which older persons are deprived of freedom and independence.⁷³³ Second, whereas differential treatment and positive action will likely be necessary at least in some contexts, a general principle of preferential treatment on the basis of age could do more harm than good, as it would rely on a perception of older people as different and in need. Third, applying the principle of 'best interest' to older persons in need of care and support would both undermine their agency and breach CRPD standards. Fourth, a new convention should underline States' role to support individuals in the realisation of their rights, spelling out positive obligations to enable participation, autonomy and independence. Finally, a new convention should not take a non-discrimination approach based on the model of the CEDAW. When asked, all of the human rights actors involved in the study

⁷³⁰ Chapter 10

⁷³¹ Fineman, "Elderly as vulnerable: Rethinking the nature of individual and societal responsibility." Clough and Brazier, "Never too old for health and human rights?."

⁷³² Chen, Alston, and Levine, "Aging: A New Human Rights Concern—A Policy-Oriented Perspective".

⁷³³ Herro, "The human rights of older persons: the politics and substance of the UN Open-Ended Working Group on Ageing." P.12

agreed that such an approach would be insufficient. The findings illustrate that a new convention would need to provide additional detail on how universal rights should be implemented taking into account the specific experience of older age.⁷³⁴

This twofold approach that encompasses both autonomy and protection is not new for human rights treaties. The CRPD for instance has been infused by the principles of autonomy and independence, but also spells out obligations for States to provide special accommodation and support for people with disabilities. In addition, it is now commonly understood that the simple categorisation between civil and political versus economic, social and cultural rights in terms of the positive or negative duties they involve is unrealistic.⁷³⁵ For example, a classic political right such as the right to vote, does not only include an obligation to respect individual freedom and voice during the elections, but also the organisation of the electoral procedure in a fair and accessible way. States therefore need to take specific positive measures to ensure the enjoyment of this right and not just refrain from any restriction. But also, social rights, like access to health, which evidently requires investment in the establishment of a health care system, also involves a negative obligation not to discriminate in the provision of services. A new treaty would better be framed as a comprehensive instrument incorporating all civil, political, economic, social and cultural rights based on the example of the CRC and the CRPD.⁷³⁶

⁷³⁴ On this see also Harpur and Mégret making similar argument about CRPD Harpur, "Embracing the new disability rights paradigm: the importance of the Convention on the Rights of Persons with Disabilities."; Mégret, "The disabilities convention: towards a holistic concept of rights."

⁷³⁵ Ida Elisabeth Koch, "From invisibility to indivisibility: the international Convention on the Rights of Persons with Disabilities," in *The UN Convention on the Rights of Persons with Disabilities - European and Scandinavian Perspectives*, ed. Oddný Mjöll Arnardóttir and Gerard Quinn (Brill Nijhoff, 2009); O'Conneide, "Extracting protection for the rights of persons with disabilities from human rights frameworks: Established limits and new possibilities."

⁷³⁶ Degener makes this distinction in discussing the negotiations of the CRPD in Degener and Begg, "From invisible citizens to agents of change: A short history of the struggle for the recognition of the rights of persons with disabilities at the United Nations.". See also Esther van Weele, "The UN Convention on the Rights of Persons with Disabilities in the Context of Human Rights Law," in *Disability and universal human rights: legal, ethical, and conceptual implications*

Strengths and Limitations of the Thesis

As explained in Chapter 1, the main strength of this study lies in its empirical approach. However, this method also entails some challenges and limitations. The thesis has captured the views of participants as representatives of civil society organisations. It did not bring forward the experiences of individual older persons. However, the advocacy perspective presented in my study makes a valuable contribution to existing scholarship, which has not been adequately reflected in literature.

This approach also means that the poorest, the most isolated, those who suffer from multiple forms of exclusions, those who live in institutional settings, prisoners, people with severe functional limitations and those with dementia, among others, are excluded from the study. The perspectives of these groups have been included only to the extent that the interviewed organisations have engaged with these populations. This may explain why issues of active participation and public consultation have received considerable attention in the findings, compared with palliative care, for instance. Since NGO participants continue to be involved in the life of their communities in various ways and are independent, it is hardly surprising that they tend to underline their role in society instead of focusing on weaknesses, limitations and needs. In fact, as explained by one participant, the people involved in NGOs *'are socially engaged and haven't yet been affected by virtue of being older'*.⁷³⁷ The sample represents people in middle to high social classes, with a good level of education, who are already engaged in politics and convinced about the need to advocate for change. Although evidently the sample cannot reflect the diversity of the old age group, the very fact that discounting is experienced by the selected – fairly privileged - sample, implies the universality of this experience that is distinct from other social disadvantages, such as poverty, gender, disability, migrant status etc. This perspective is new, since a lot of the discourse and scholarship tends to focus on people receiving care or are otherwise vulnerable. Bringing forward the

of the convention on the rights of persons with disabilities, ed. J. H. Anderson and Joseph Pieter Mathijs Philips (Netherlands Institute of Human Rights (SIM), 2012).

⁷³⁷ Participant 8

experiences of those who are not faced with other forms of disadvantage is a key contribution of this study. However, had the study engaged with another subset of older people, like people with high support needs in their everyday life, perhaps they would stress other aspects of their experience more than or in combination with discounting.

Additionally, during the interviews it became clear that many organisations of older people had a very limited engagement with international human rights instruments. Therefore, it is fair to assume that interviewees when asked about the implementation of human rights law and the added value of treaties, were not necessarily reflecting the consensual position of their organisations, since most NGOs seemed to be lacking a systematic reflection around these issues. However, as explained in the second chapter, this thesis perceives NGOs as potential norm entrepreneurs and by including them in the study, it aims to initiate a discussion about their role in shaping future human rights law, reframing current understandings of human rights of older persons and keeping governments accountable.

With the exception of Greece, my sample does not include trade unions. Based on my preliminary research Irish trade unions were not considered influential actors in terms of advocating for the rights of older people nor as having a broad enough remit and they were therefore left out of the selected sample. I had however hoped to have a representative of the French trade unions in my sample, which - based on conversations with key informants - were presented as important and distinct civil society stakeholders. I contacted four different organisations, two of which never replied to my request. One of them decided not to take part due to previous commitments and another one initially agreed to take part in the study, but later declined. Should trade unions have been included in the sample some issues like pensions may have more appeared more prominently in the findings. But bearing in mind that my sample covers most of the other important civil society actors, I do not expect that the inclusion of French trade unions would alter considerably the conceptualisation of older people's rights.

Another key limitation of the study is its geographical scope. The thesis covers only three countries from the European region. Experiences of human rights abuses in other parts of the world may vary significantly and this could impact the conceptualization of human rights in older age, the substantive issues discussed, as well as other factors, including culture and socio-economic context. For instance, traditional practices that may undermine the dignity of older persons and lead to abuse have not been explored here.⁷³⁸ Rights in situations of humanitarian emergency and conflicts have not been discussed by participants.⁷³⁹ Also in other parts of the world a more general concern about access to jobs may be more salient as opposed to this study's focus on mandatory retirement age. Similarly, participants live in urban settings, so naturally challenges affecting rural communities have not been the focus of this research. Moreover, this research did not study the normative framework in other regions, including in Africa and Latin America where new standards on the rights of older people have been established. Instead, it focused in the European region where there is lack of such specific binding norms.

It must also be noted that ageing and human rights are dynamic fields and are largely influenced by the changing policy and legal context. The conception of human rights in older age that emerges from this thesis is based on societal challenges at the time of the interviews. However, the understanding of older people's rights is subject to constant change, as discussions on the OEWG advance, actors become more aware of the debate, consciousness of ageism is increasing, institutions and laws are under revision and so on. The cut-off date for this research was October 2019. The empirical data was gathered between June 2016 and June 2017. Therefore, this thesis cannot take into account any subsequent developments in the field of ageing and human rights and in relevant discourse after that date. To the extent of my knowledge, there are at least some

⁷³⁸ For example, HelpAge International, *Using the law to tackle allegations of witchcraft: HelpAge International's Position* (2011).

⁷³⁹ UN Human Rights Council, *Enjoyment of all Human Rights by Older Persons, Report of the Independent Expert on the Enjoyment of all Human Rights by Older Persons, 4 July 2019, A/HRC/42/43* (2019).

developments that show more consciousness of discounting and human rights than when the interviews were taken. For example, France has very recently decided to abolish the age barrier separating old age from disability benefits.⁷⁴⁰ The UN OHCHR is at the moment of submitting this thesis finalising the update of its 2012 analytical study on the normative standards in international human rights law in relation to older persons where ageism is recognized both as a human rights breach and an enabler of other human rights violations⁷⁴¹. These developments reconfirm the need for a more rights-based approach to ageing and illustrate that national and international actors are increasingly ready to adopt a rights discourse.

Finally, as mentioned in several points of the thesis and in the section on researcher positionality, I am not a neutral observer. My professional experience dictated the bottom-up empirical approach I used for my study. Professional insights also helped in the selection of countries and participants, as well as the design of the interviews. Compliant with the constructivist grounded theory, I used my own experience and understanding to interpret the data and co-construct the theory of overlooking the injustice. Neither was my research value-neutral. As I was interested in developing an empirical understanding of human rights, I did not look at alternative frames, theories or policy approaches that might reduce the need for a rights-based framework. In this sense, my findings are not objective. But all researchers bring certain presumptions into their study. If anything, the fact that I was conscious of this limitation made me more likely to acknowledge my own biases as I was analysing and interpreting the findings.

In my day job, I am asked to develop positions and arguments. But it is precisely because I felt that I could not address existing tensions that I undertook this study in the first place. I wanted to fill in the gaps in my own knowledge and understanding of the human rights of older persons. My motivation for doing this

⁷⁴⁰ Murignieux, "Prestation de compensation du handicap : une nouvelle loi supprime la barrière d'âge-Vers une prestation universelle autonomie ?."

⁷⁴¹ Office of the High Commissioner for Human Rights, Normative standards in international human rights law in relation to older persons - Analytical Outcome Paper.

research was to listen and learn from participants in order to deliver strong and coherent messages that resonated with national older people's groups. So even if the theory of overlooking the injustice is the product of my interpretation, this interpretation is genuinely based on what I was consistently seeing across the three countries.

When I began the research, I did not have a clear idea of what is unique about human rights protection of older persons. But as the research process evolved, I was able to test some of the emerging ideas in my professional work. For example, I have designed the first campaign of the NGO I work for on ageism. This campaign was largely based on the idea of equal rights, which is why it was named 'Ageing Equal'. In several other advocacy material, including regarding the need for a new convention, I have used the frame of 'human rights in old age', as opposed to 'human rights of older persons'. I have also integrated the point about conceptual limitations of human rights law and ageism as a driving force for human rights abuses in studies I have prepared for the OHCHR. In other words, I can confidently say that my research experience has influenced much more my professional practice than the other way around. All in all, an important strength of this thesis lies in my ability – as part of the movement advocating around issues of human rights in older age – to translate the findings into advocacy practice.

Chapter 12: Conclusion

This thesis set out to explore the potential of a new UN convention to drive change in policy, law and advocacy. To do this it followed a threefold approach. First, it explored the meaning of human rights of older persons as defined by key advocacy groups. This exploration demonstrated that old age is not experienced distinctly but as the continuum of human life. As a result, older people's rights are defined as having the same rights with everyone else. However, human rights in old age are systematically undermined due to discounting, which is a form of a socially constructed disadvantage - instead of an intrinsic vulnerability - uniquely experienced in old age.

Second, the thesis demonstrated that international human rights law and its interpretation by human rights mechanisms are conceptually limited to address human rights violations against older persons and may even drive or perpetuate discounting. Current standards address a limited range of issues and mainly reflect a medical or welfare approach to ageing. Existing norms need to be revised with a view to tackling socially constructed inequalities and supporting older people's participation, autonomy and independence on an equal basis with others.

Third, the key contribution of the thesis is that the lack of a legal mechanism to describe certain acts as wrong and harmful violations contributes to the systematic undermining of human dignity in older age. A new convention is presented as having a triple effect. First, as a concrete way to fill in this *interpretative gap*, by recognizing the systematic exclusion of older people as unacceptable and acknowledging that States bear the obligation to treat older people with the same dignity as other citizens. Second, a new convention would be helpful in clarifying in normative language the concrete changes that are necessary to enable the equal realisation of human rights in older age. And third, a new convention could empower individuals and old age groups to better advocate and claim rights.

Although – as shown in this thesis and argued elsewhere - an older persons' movement is unlikely to develop organically, a new convention could potentially empower individuals to become activists to promote positive images of older age. So perhaps unlike other movements where human rights advocacy preceded the adoption of targeted legal protection, in the case of older persons it seems more likely that a treaty could inspire a critical mass of mobilisation around human rights in older age, which would subsequently drive policy and legal change. Finally, the thesis suggests how a new convention should be framed in order to reflect the empirically emerging paradigm and the real-life barriers faced by older persons. It submits that discussing *everybody's* human rights in old age, instead of the human rights of older persons could help resolve some of the existing tensions and move the debate forward.

In sum, the thesis argues that compared with the current situation, a new convention has increased potential to render more visible and counter the systemic discounting embedded in national and international law, policy and advocacy. Even if in principle older persons do not have different rights and universal instruments should apply equally in older age, this does not seem likely to happen without a new legal instrument that clarifies that old age cannot serve as the basis for the denial or restriction of rights. The main value of a new convention then is that it would allow us to better detect human rights violations against older persons and to proactively support their realisation by expanding our current limited notions of participation, independence and autonomy in old age. This is defined as the *transformative* impact of a new convention.

By focusing on how old age advocacy groups understand human rights and how they engage with human rights concepts and standards, this study makes a unique and comparative empirical contribution to existing scholarship. It adds to knowledge about the social construction of older age and also how to change it. It makes explicit the social causations of disadvantage in older age and provides concrete examples of how the absence of rights discourse and legal barriers impact opportunities for participation, exercise of autonomy and independence across three countries, including how they contribute to the stereotypical

construction of older age. The theory of overlooking the injustice demonstrates that the lack of legal recognition of older people's inequalities is a form of disadvantage that impacts both experiences of later life and the likelihood to overcome exclusion and find redress. This finding adds to knowledge about the notion, dimensions and impact of later life exclusion.⁷⁴² It shows how the failure to associate exclusionary practices with breaches of law contribute to the demeaning of individual dignity in older age and may lead to further inequality and exclusion. This is because harmful social experiences of older age are not usually considered as requiring remedy and redress through policy or legal intervention.

Gerontology tends to see law as providing the context within which ageing happens.⁷⁴³ It does not always make a distinction between law and policy⁷⁴⁴ and mainly examines experiences of exclusion within a specific jurisdiction or place.⁷⁴⁵ How law or its absence can reproduce stereotypes and disadvantage is not something that has been reflected often enough in gerontological literature and thinking. This study suggests that gerontologists need to be cognizant of law as an instrument of oppression, but also as a tool for transformation. It also demonstrates a need for gerontology to go beyond the narrow remits of national rules and instead look into how international law and its limitations shape – or is likely to shape- experiences of ageing.

To date there are very few examples of gerontologists using rights language.⁷⁴⁶ Gerontologists but also policymakers need to engage more in this discourse and explore what it entails in terms of understanding of later life issues and strategies

⁷⁴² Walsh, Scharf, and Keating, "Social exclusion of older persons: a scoping review and conceptual framework."; Keating and Scharf, *From Exclusion to Inclusion in Old Age: A Global Challenge*.

⁷⁴³ Nina A. Kohn, Maria T. Brown, and Israel Doron, "Identifying Connections between Elder Law and Gerontology: Implications for Teaching, Research, and Practice," *Elder LJ* 25 (2017).

⁷⁴⁴ Kohn, Brown, and Doron, "Identifying Connections between Elder Law and Gerontology: Implications for Teaching, Research, and Practice."

⁷⁴⁵ Walsh, Scharf, and Keating, "Social exclusion of older persons: a scoping review and conceptual framework."

⁷⁴⁶ Some notable exceptions include Townsend, "Policies for the aged in the 21st century: more 'structured dependency' or the realization of human rights ? ."; Kesby, "Narratives of aging and the human rights of older persons."

for policy change. The findings suggest that human rights constitute a valid alternative policy paradigm to the prevalent old age burden discourse and the proliferation of productive and active ageing models. The adoption of a new treaty could help consolidate this paradigm, but also encourage more coherent and collective rights-based advocacy. Herro and Sciubba have looked into how the transnational ageing network and a few national case studies are advancing the argument for the need of a new convention.⁷⁴⁷ What is missing is to study how the rights frame – independently from or in combination with the call for a new treaty- is or can be used to promote change at national level.

This thesis also contributes to scholarship by disentangling older age from disability and by challenging legal and policy approaches that conflate the two. This is important because it responds to questions about what is unique about human rights abuses against older people that international law should pay attention to.⁷⁴⁸ The finding that the lack of a clear distinction between ageism and ableism acts as a barrier to the development of a clear, coherent and comprehensive rights-based approach to older age is advanced using empirical evidence. The thesis uniquely demonstrates that the lack of distinction between the two impedes not only governments and human rights professionals, but also NGOs from consistently adopting a human rights frame. This points to the need for ongoing discussions on a new treaty to emphasize those experiences that are unrelated with disability or are uniquely experienced in older age due to the impact of discounting. In addition, showing that the intersection of ageing and disability creates distinct disadvantages, the thesis points to the need for better theoretical understanding of the experience of disability in later life, for greater

⁷⁴⁷ Herro, "Advocating a UN Convention on the Rights of Older Persons in the United Kingdom: The Case for a Radical Flank."; Herro, "Domestic interest groups and rights mobilization: explaining the case of Slovenia's support for the proposed Convention on the Rights of Older Persons."; Herro, "The human rights of older persons: the politics and substance of the UN Open-Ended Working Group on Ageing."; Sciubba, "Securing rights in the twenty-first century: A comparison of the disability and older persons' rights conventions."; Sciubba, "Framing and Power in Aging Advocacy."; Sciubba, "Explaining campaign timing and support for a UN Convention on the Rights of Older People."

⁷⁴⁸ De Hert and Mantovani, "Specific Human Rights for Older Persons? The inevitable colouring of Human Rights Law."

interaction and collaboration between disability studies and gerontology and for human rights practice to increase its capacity to address these issues.

The thesis moreover identifies a series of legal incoherencies and anomalies that have not been critically reflected in legal scholarship and practice. The study does not only provide arguments for the revision of existing international standards; it also points to the need for more legal scrutiny in other jurisdictions. Legal scholars and professionals need to become more conscious of and respond to age-related biases in law. A critical examination of court decisions, based on the example of feminist judgements,⁷⁴⁹ could be an interesting approach to increase awareness of these issues from the perspective of older age. The study highlights conceptual limitations, problematic discourse and standards that could become the basis for such an analysis of jurisprudence and legislation.

Another original contribution of this thesis is the argument that older people's groups are transforming into a new social movement that is making implicit claims around rights. The findings draw attention to an emancipatory paradigm promoted by NGOs that seeks to move beyond materialistic interests traditionally associated with these organisations. This study is the first one (that I am aware of) that uses empirical evidence to signal this transition. The fact that this finding is reflected in all of the three countries included in the analysis is particularly important as it shows that it is not an isolated trend.

The thesis also makes an original contribution by taking due account of advocates' understanding of human rights, as well as their concerns. Advocacy groups that are active at national level have so far been able to contribute only in a very limited way to the development of a rights-based approach to older age. The study captures the complementary and diverse meanings and approaches that exist in the three countries. The finding that Ireland, France and Greece are at different levels of engagement with human rights language and standards shows that international norm setting needs to be conscious of variations across

⁷⁴⁹ Rosemary Hunter, Clare McGlynn, and Erika Rackley, *Feminist judgments: From theory to practice* (Bloomsbury Publishing, 2010).

countries and to engage with groups on the ground to make sure first, that the emergent human rights model reflects reality in different contexts and second, that it is comprehensive. The comparative approach of this thesis points to the possible shortcomings of accepting the current a-la-carte and narrow approach that is followed in each of the three countries. It also suggests that the human rights frame requires further refinement based on how rights are understood and implemented in other countries and regions of the world.

From the outset this study has been acutely aware of the complexity of the scholarly debate and the political process surrounding the making of a new treaty. It has used empirical evidence to navigate this contentious space and to make suggestions in order to deal with existing tensions and incoherencies. The findings point to the need to conceptualise human rights in older age as not being distinct in nature from those that are given to other groups; to give a prominent role to the ideas of participation, autonomy and independence; to be conscious and reflective of the diversity of experiences in older age; and to take a comprehensive approach that involves all human rights and goes beyond formal equality.

But these are not posited as definite iterations. International law is a dynamic process, which gerontological thinking – alongside legal scholarship and human rights practice - can help define. This study opens up the potential for gerontology and law to combine forces and further elaborate the paradigm proposed in this thesis. Gerontology can bring forward conceptions of older age, later life transitions, identity and the lifecourse, as well as the experiences of multifaceted disadvantage faced by older people that are both distinct from other forms of inequality and also intersect with them. As argued by Meenan and Doron,

The legal discipline, on its own, lacks the relevant knowledge and empirical evidence to provide the necessary basis for the material legal content of any such future convention. Only a true integrative inter-disciplinary cooperation of legal, gerontological and geriatric knowledge – or, as we

*propose, the development of 'geriatric jurisprudence' knowledge – will enable to fully capture the full scope of the rights of older persons.*⁷⁵⁰

Gerontology and legal scholars should work together to create a theory of older age that can be integrated in a new treaty. Challenging the view of ageing as inevitable decline and burden, the interplay between gerontology and law should propose a model that defines old age as a social construct and helps describe collective responses to address societal barriers. They should also work together to destigmatize older age without ignoring the lived experience of later life, which may include loss of physical, cognitive and financial resources. This study has brought gerontological scholarship into discussions on older people's rights and a new treaty, based mainly on the theory of the political economy on ageing, as understood by someone who is a lawyer and not a gerontologist. Further exchange between the two fields could help develop a coherent theory of human rights in older age and suggest elements of definition for the target of a new treaty.

The call to make linkages between gerontology and law is not new.⁷⁵¹ But a study by Kohn and others demonstrated that, whereas synergies between the two disciplines are seen as desirable and important, in reality these do not happen naturally, nor have a wide scope.⁷⁵² The same study also suggested that the existing (limited) interaction between the two fields is neither systematic nor formal. The debate around a new treaty creates a window of opportunity for gerontology and law to come together to influence the framing of human rights in older age. Yet, gerontologists have not yet been adequately involved in the debate on a new convention and the development of a rights-based approach to

⁷⁵⁰ Israel Doron and Helen Meenan, "Time for geriatric jurisprudence," *Gerontology* 58, no. 3 (2012). p 3

⁷⁵¹ Elias S. Cohen, "Law and aging, lawyers and gerontologists," (The Gerontological Society of America, 1978). Martin Levine, "Research in law and aging," *The Gerontologist* 20, no. 2 (1980); Israel Doron, "Bringing the law to the gerontological stage: A different look at movies and old age," *The International Journal of Aging and Human Development* 62, no. 3 (2006).

⁷⁵² Kohn, Brown, and Doron, "Identifying Connections between Elder Law and Gerontology: Implications for Teaching, Research, and Practice."

ageing.⁷⁵³ In contrast, disability scholars have been instrumental in developing a human rights paradigm and several were also very much involved in the drafting of the CRPD.⁷⁵⁴ If a new treaty were to be adopted, it would form an authoritative understanding of older age that would be integrated in discourse, policy and law. When something becomes hard law, it is difficult to change, so it is particularly important to get this right in the first place. Combined, gerontology and law can not only enrich each other,⁷⁵⁵ but also increase the chances of the adoption of a comprehensive document and its subsequent successful implementation. The findings of this thesis open up the potential for gerontology to build bridges with legal scholarship and human rights practice in order to influence emergent international law.

In coming together gerontology and law could create a new field of ageing studies modelled on women's and disability studies that aim at ending oppression against disadvantaged groups and are located strategically between scholarship and activism.⁷⁵⁶ To achieve this aim, law and gerontology need to engage directly with advocacy groups. Together they need to produce more research that is political and emancipatory.⁷⁵⁷ For example, the findings show the need to expand the understanding of social and civic participation and to reflect the diverse roles and multiple contributions of older persons⁷⁵⁸. This points to the fact that a rights

⁷⁵³ A couple of notable exceptions include Fredvang and Biggs, "The rights of older persons - Protection and gaps under human rights law."; Kesby, "Narratives of aging and the human rights of older persons."

⁷⁵⁴ Katerina Kazou, "Analysing the Definition of Disability in the UN Convention on the Rights of Persons with Disabilities: is it really based on a 'Social Model' approach?," *International Journal of Mental Health and Capacity Law* 2017, no. 23 (2017); Degener and Begg, "From invisible citizens to agents of change: A short history of the struggle for the recognition of the rights of persons with disabilities at the United Nations."; Rannveig Traustadóttir, "Disability studies, the social model and legal developments," in *The UN Convention on the Rights of Persons with Disabilities - European and Scandinavian Perspectives*, ed. Oddný Mjöll Arnardóttir and Gerard Quinn (Brill Nijhoff, 2009).

⁷⁵⁵ Kohn, Brown, and Doron, "Identifying Connections between Elder Law and Gerontology: Implications for Teaching, Research, and Practice."

⁷⁵⁶ Traustadóttir, "Disability studies, the social model and legal developments."

⁷⁵⁷ Wilson, "Conceptual frameworks and emancipatory research in social gerontology.", Minkler and Holstein, "From civil rights to... civic engagement? Concerns of two older critical gerontologists about a "new social movement" and what it portends."

⁷⁵⁸ On the need to redefine civic engagement see Minkler and Holstein, "From civil rights to... civic engagement? Concerns of two older critical gerontologists about a "new social movement" and what it portends."

frame must build on the achievements of the active, positive and successful ageing models, but also be respectful of different capacities and interests⁷⁵⁹.

Moreover, the findings have pointed out to the fact that advocates coming from other movements are now ageing and may be influential in the development of a rights frame for older age. Looking into how other movements are making claims around older age would be really important in order to achieve an inclusive frame that captures experiences of ageing at the intersection with other systems of oppression. Finally, ageing studies should also do research *with* and not just *for* older people. Developing together with organisations of older persons a new social understanding of older age would introduce a unique perspective in scholarship and also inform legal developments at national and international level. This approach would redirect focus from individuals as passive to older persons as agents of change, thus operationalising the emancipatory approach that emerged from this study.

Since I started this PhD in 2014, a human rights approach to ageing has become much more pronounced and common within the EU and beyond. Although the Fundamental Rights Agency is still lacking a specific thematic area on older persons, in 2018, and for the first time, the Agency dedicated the special focus of its annual report on ageing.⁷⁶⁰ The number of academic articles that refer to the human rights of older persons and/or the elderly has multiplied. The fight against ageism has also found its way in national and online media and has been the subject of dedicated campaigns.⁷⁶¹ The UN Special Rapporteur on the Rights of Persons with Disabilities has acknowledged how ageism intersects with ableism

⁷⁵⁹ Taghizadeh Larsson and Jönson, "Ageism and the Rights of Older People."

⁷⁶⁰ European Union Agency for Fundamental Rights, *Shifting perceptions: Towards a rights-based approach to ageing*.

⁷⁶¹ See among others, Champvert and de Hennezel, "Contre l'impératif jeuniste! Changeons le regard sur la vieillesse!"; Caroline Baum, "The ugly truth about ageism: it's a prejudice targeting our future selves," *The Guardian* 2018. Olive Keogh, "Ageism in the workplace is alive and well and employers are missing out," *The Irish Times* 2019. Several anti-ageism campaigns have also emerged, including AgeingEqual: www.ageing-equal.org; Changing the Narrative: <https://changingthenarrativeco.org/>; Every Age Counts: <https://www.everyagecounts.org.au/>

to create unique human rights violations in old age⁷⁶². Experts, professionals, practitioners and activists working on human rights and ageing are becoming increasingly conscious of the ways in which laws, practices, attitudes and structures are instruments of the oppression of older persons. To a certain extent the findings of this thesis have contributed to these developments. Thanks to my strategic position as an advocate, I have had the opportunity to introduce aspects of this study in campaigning and human rights reports before the submission of my thesis.⁷⁶³

However, the movement towards equal rights in older age is only at its infancy. Despite growing acceptance of a social model of ageing, the shadow of older people as dependent and a burden, rather than as agents, still hangs over debates and policies around ageing. Human rights in older age have not crystallised in international human rights law. There is hardly any record of EU action specifically focusing on human rights in older age.⁷⁶⁴ The field of social gerontology has barely grappled with human rights. The emerging field of human rights in older age remains devoid of theory⁷⁶⁵ and still has a long way ahead before it becomes mainstream. The main contribution of this thesis is its emphasis on the rights frame as something that needs to move from the margins to the centre of scholarship, policy and advocacy. Human rights narrative can contribute to the reorientation of general thinking about older age. A new UN convention could become the vehicle through which to embark on this change.

⁷⁶² UN General Assembly, *Rights of persons with disabilities - Report of the Special Rapporteur on the rights of persons with disabilities - A/74/186*.

⁷⁶³ In 2018 I developed on behalf of AGE Platform Europe the Ageing Equal campaign that aimed to raise awareness of ageism as a driver of human rights violations. I have also worked as a consultant to the OHCHR, contributing to reports of the UN Independent Expert on the Enjoyment of all Human Rights by Older Persons and the UN Special Rapporteur on the Rights of Persons with Disabilities. I have informally contributed to the drafting of the FRA report and several other reports at European and international level.

⁷⁶⁴ Georgantzi, "The European union's approach towards ageism."; Parent, "The Impact of the European Year 2012 on Active Ageing and Solidarity Between Generations: A Critical Assessment."

⁷⁶⁵ Israel Doron, "25 Years of Elder Law: An integrative and historical account of the field of law and aging," *Theoretical inquiries in law* 21, no. 1 (2019).

Appendices

Appendix 1: List of Participants

Participants	Gender		Role		Country			Civil society representation		Activities		NHRI	Ombudsperson	Equality authority
	Male	Female	Staff	Volunteer	FR	IE	GR	Of older people	For OP	Social	Advocacy			
Ensemble et Solidaires – Union Nationale des Retraités et Personnes Âgées (UNRPA)	X			X	X			X			X	X		
Fédération Nationale des Associations des Retraités (FNAR)	X			X	X			X				X		
50+ Hellas (1)		X		X			X	X			X	X		
Age & Opportunity	X		X			X			X	X				
Active Retirement Ireland (ARI)	X		X			X		X		X	X			
Ανώτατη Γενική Συνομοσπονδία Συνταξιούχων Ελλάδος (AGSSE)- 2 respondents	X			X			X	X				X		
Third Age/SAGE		X	X			X			X		X			
Active Ageing in Partnership	X		X			X			X		X			

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Irish Senior Citizens Parliament (ISCP)		X	X			X		X			X			
Age Action Ireland	X		X			X			X		X			
Irish Human Rights and Equality Commission		X	X			X						X		X
50+ Hellas (2)	X			X			X	X		X	X			
Office of the Ombudsman – 2 respondents	X	X	X			X							X	
Greek National Commission for Human Rights (EEDA) - 2 respondents		X	X				X					X		
Synigoros (1)		X	X				X						X	X
Synigoros (2)		X	X				X						X	X
Fédération nationale des associations et des amis de personnes âgées et de leurs familles (FNAPAEF)		X		X	X			X	X			X		
Fédération Internationale des Associations des Personnes Âgées (FIAPA)	X			X	X				X					
Commission Nationale Consultative des Droits de l'Homme (CNCDH)	X		X		X							X		
Defenseur des Droits		X	X		X								X	X
Old'Up		X		X	X			X		X	X			
Overall in 21 interviews	11	11	13	8	7	8	6	9	6	6	12	3	4	4
Overall in 24 individuals	12	12	15	9	7	9	8							

Appendix 2: Sample Interview Guide

Interview Guide for NGOs

This is the template used for the second round of interviews with NGOs, including possible prompts.

Interview guide (with possible prompts)

About organisation

- What is your organisation's mission?
- Which are your organization's members?

Substantive issues/challenges

1. What do you understand as 'rights'?
 - Are rights absolute or relative?
 - Can rights be compromised due to the absence of resources or are rights absolute?
 - Do you think there are different categories of rights, such as human rights, social rights, citizens' rights, etc (question particularly relevant for France, where this distinction is most prevalent)?
 - In your experience is rights language used in general in your country? If so, in which policy areas, issues?
 - Why is that? Could you describe...?
 - Do you think it's useful?
2. What do you understand by the term 'rights of older persons'?
 - Do you use the term 'rights of older persons' in your work?
 - Is it a commonly used term in your country?
 - Why/Why not?
 - Do you think it is helpful/makes any difference to frame older people's issues as human rights? Why/why not?
3. People often talk about rights and equality when talking about older people. Do you distinguish between rights and equality?
 - In what way are they different for you?
4. Do you think that older people can enjoy their human rights in an equal manner as everyone else?
 - What rights are currently denied to older people in your country?
 - Could you describe some ways in which older people are denied equality?
 - Do you think that there are particular human rights challenges that people encounter when they get old (due to *bereavement*,

loss, poverty, disability, end of life, care, loss of autonomy, loneliness, etc)?

- *Add prompt about autonomy and dependency: Why do you accept dependency or loss of autonomy in old age? How do you understand (loss) of autonomy as a right? What is the difference between autonomy and independence?*
 - How does your organization work to address these issues and to support older people deal with these challenges?
 - Do you think there is public awareness of human rights or equality in old age?
5. How do you think law and policy should be framed so that rights are equally available at different stages of life?
- What do you understand as public responsibility with regard to older people?
 - Give example of care to discuss mix of responsibilities and how they hold governments accountable for that
 - Can you give an example of a positive change in State law or policy that have addressed rights of older people?
 - Would you advocate for a change of the underlying model (for ex. In care) or for changes within the existing system?
 - What is preventing rights-based approaches to older people in your country?
 - Do you think that resources matter for the exercise of rights? In other words, can one talk about rights without talking about resources?
 - Are there cases where rights can be compromised due to the absence of resources or are rights absolute?
6. How would you define older people's current role in society?
- Do you believe that older people have more to offer than their current role?
 - Where can ground be recovered? Where is the potential?
 - Why do you think that roles shrink in older age?
 - If so, why?
7. People talk about the movement of older people. What do you understand by that term?
- Do you believe there is a political community of older people in your country?
 - Is older people's movement bottom up or top down?
 - What factors are contributing to actual and potential of that movement?
 - Do older people in your country (for example through their representative organisations) have opportunities to participate in decision-making at regional and national level? *(if interviewee*

needs clarification: give example of committees, councils involving older people)

- Do you think that political decision-makers see older people as a key voting constituency and keep that in mind when making political decisions?
8. What do you think are the most important ways to promote and protect the rights of older people?
- Do you think that providing detailed rights for older people in a new convention would make a difference in the daily lives of older people in your country?
 - If the UN decided to draft a convention on the rights of older people, what advice would you give to those drafting it?

Final remarks

- Is there anything else you would like to add?
- Is there something you feel I did not ask and I should have?
- Is there anything that you might not have thought about before that occurred to you during this interview?
- Is there anything you would like to ask me?

Interview Guide for Other Stakeholders

This is the template used for the second round of interviews with NGOs, including possible prompts.

Interview guide (with possible prompts)

About organisation

- How does the organization's mandate cover older persons and/or age discrimination?

Questions

9. What do you understand as 'rights'?
 - Are rights absolute or relative?
 - Can rights be compromised due to the absence of resources or are rights absolute?
 - Do you think there are different categories of rights, such as human rights, citizens' rights, etc (question particularly relevant for France, where this distinction is most prevalent)?
 - In your experience is rights language used in general in your country? If so, in which policy areas, issues?
 - Why is that? Could you describe...?
 - Do you think it's useful?
10. What do you understand by the term 'rights of older persons'?
 - Do you use the term 'rights of older persons' in your work?
 - Is it a commonly used term in your country?
 - Why/Why not?
 - Do you think it is helpful/makes any difference to frame older people's issues as human rights? Why/why not?
11. People often talk about rights and equality when talking about older people. Do you distinguish between rights and equality?
 - In what way are they different for you?
12. What rights are currently denied to older people in your country?
 - Do you think that there are particular human rights challenges that people encounter when they get old (*due to bereavement, loss, poverty, disability, end of life, care, loss of autonomy, loneliness, etc*)? Do you think that there are particular human rights challenges that people encounter when they get old (due to *bereavement, loss, poverty, disability, end of life, care, loss of autonomy, loneliness, etc*)?

- *Add prompt about autonomy and dependency: Why do you accept dependency or loss of autonomy in old age? How do you understand (loss) of autonomy as a right? What is the difference between autonomy and independence?*
- How does your organization work to address these issues and to support older people deal with these challenges?
- Do you think there is public awareness of human rights or equality in old age?

DEPENDING ON ANSWER IN QUESTION 2 ADDRESS THE FOLLOWING QUESTION SEPARATELY OR NOT.

IN ANY CASE ASK ABOUT MAIN REASONS FOR INEQUALITIES AND POSITIVE ACTION.

FOR THE FRENCH ASK ABOUT LOSS OF AUTONOMY AS GROUND OF DISCRIMINATION. WHAT IS THE MEANING? IS THERE CASELAW?

13. Could you describe some ways in which older people are denied equality?
- What do you think is the main reason?
 - In which aspects of life? Why?
 - Should any special measures (namely positive or affirmative action) be provided for to ensure the full participation and inclusion of older people in society on an equal basis with others?
 - In your view, would positive action/targeted law or policy put at risk the equal treatment of other generations/groups?
14. How do you think law and policy should be framed so that rights are equally available at different stages of life?
- What do you understand as public responsibility with regard to older people?
 - Give example of care to discuss mix of responsibilities and how they hold governments accountable for that
 - Can you give an example of a positive change in State law or policy that have addressed rights of older people?
 - Would you advocate for a change of the underlying model (for ex. In care) or for changes within the existing system?
 - What is preventing rights-based approaches to older people in your country?
 - Do you think that resources matter for the exercise of rights? In other words, can one talk about rights without talking about resources?
 - Are there cases where rights can be compromised due to the absence of resources or are rights absolute?
 -

15. Definitions

- How should equality in older age be understood/defined?
- How should discrimination in older age be understood/defined?
 - Should any justifications of discrimination and unequal treatment in older age - such as age limits or preferential treatment - be allowed?

16. Are there forms of discrimination that should be prohibited in older age and are not adequately covered by the existing legal framework in your country?

- For example, but not limited to:
 - Direct, indirect, by association, be perception, harassment
 - Intersectional (combined effect of their age and another factor)
 - Cumulative (on a number of occasions over a period of time; across domains, across generations, or across a life course)
 - List prohibited grounds
 - Areas covered
 - Proof of discrimination
- How should both individual instances of discrimination and structural and systemic ageism be provided for?
- Are there other reasons why older people are not sufficiently protected from discrimination? Ex. Difficulty of proof of discrimination

17. Do you think that older people have sufficient access to means of redress in case of violation of their human rights?

- What means of redress should be available?
- What measures should states take to assist older persons in making claims?
- Is there enough public awareness around systems of redress?

18. What do you think are the most important ways to promote and protect the rights of older people?

- Do you think that providing detailed rights for older people in a new convention would make a difference in the daily lives of older people in your country?
- Do you think that a separate treaty for older persons might be perceived as segregating older people from the rest of population? or conflicting with rights of other generations/groups?
- If the UN decided to draft a convention on the rights of older people, what advice would you give to those drafting it?

Final remarks

- Is there anything else you would like to add?
- Is there something you feel I did not ask and I should have?
- Is there anything that you might not have thought about before that occurred to you during this interview?
- Is there anything you would like to ask me?

Appendix 3: Example of Coding

Initial coding	Excerpt	Revised coding	Notes	Focused coding	Clusters
<i>What is happening here?</i>	<i>Participant's words</i>	<i>What is this telling me?</i>	<i>Ideas/questions to explore</i>	<i>What patterns are there in my data?</i>	<i>Preliminary categories</i>
calling for equal recognition of older people's achievements;	<i>We seek that there should be equal recognition of older people's cultural, supporting, community achievements, all of these achievements that people can get just because they are over 50, over 60, over 70,</i>	identifying older people's achievements; ignoring professional achievements; implying unequal recognition	Why does he not refer to professional achievements? Links with loss of role/function?	Devaluing older people's contributions	discounting
comparing older people's with others' contributions; implying older people's achievement less appreciated	<i>their achievements should be no less valid and no less appreciated</i>	claiming equal recognition; contesting devaluing older people	Why are they less appreciated? Is there a tendency to valorise more professional or monetary contributions?	Devaluing older people's contributions	discounting
trying to show older people's potential	<i>so that's what we seek to shine a spotlight on and sort of showcase the potential that older people have</i>	praising older people's potential; stressing invisibility of older people	Do we need to bring evidence of older people's contributions? Is potential same as actual	recognizing older people's potential	recognizing

Appendices

			achievements? Can human rights frame put such a spotlight?		
aiming to empower older people	<i>and what we do to empower older people to live an active and healthy retirement</i>	Facilitating active and healthy retirement;	Why glorifying 'active' ageing? to counterbalance views of retirement as a stage of inactivity?	Empowering older people	empowering
explaining what empowerment means; supporting grassroots mobilisation;	<i>is we enable them, we try and give them the tools they need to run their own Active Retirement associations, to run their own regions, their own national orgs, we help with capacity building workshops that will enable them to press effectively, to consult with their own members, to get a consensus in running their organisation, we have a volunteer development team that helps set up active retirement group.</i>	defining empowerment; enabling instead of patronising; supporting self-advocacy	Is empowerment and support also targeting how individuals age? Or just strengthening the movement on the ground? Deviation from 'empowering active and healthy ageing'? individual vs collective?	Empowering older people's movement	empowering

Appendix 4: Information Sheet for Participants

This is an example of the information sheet used during the second round of interviews with NGOs. The information was translated in French and Greek.

INFORMATION SHEET

on a comparative research on the rights of older persons



OÉ Gaillimh
NUI Galway

Your organisation is asked to take part in a research study on the rights of older persons, which will be undertaken by Nena Georgantzi, PhD student in the National University of Ireland Galway. Your input is requested as part

of the research investigating how the international legal framework can be improved to better address the realities faced by older people. Older people's organisations are asked to participate in the research to describe the challenges faced by older people and what should be changed to improve the protection of their rights on the ground. If you decide to take part, you will be asked to participate in a maximum of two interviews. Participation in the study is voluntary.

What is the purpose of the research?

The ultimate goal of this research is to contribute to knowledge on the rights of older persons in three European countries and ensure that social and legal change is grounded on the real needs, experiences and expectations of older persons.

What is the aim of the interviews?

The interviews will provide information about how your organisation, as one of the key NGOs representing older people in your country, understands the civil, political, economic, social and cultural rights of older persons and what you foresee as positive change in relation to the realisation of their human rights. The interviews will address the following questions:

1. What do you understand as 'rights of older persons'?
2. Do you think that older people can enjoy their human rights in an equal manner as everyone else?
3. How do you think law and policy should be framed to ensure that human rights are equally available at different stages of life?
4. How would you describe the role and potential of older people in your country?
5. Do older people in your country have opportunities to participate in decision-making at regional and national level?
6. What do you think are the most important ways to promote and protect the rights of older people?
7. Do you think that providing detailed rights for older people in a new convention would secure equal treatment of older persons?

The information that you will provide will be used to identify common themes in the three countries in the study (Ireland, France and Greece). The (anonymized) findings will be included in a thesis for the purpose of an award of Doctorate of Law and may also be included in other academic publications.

Who should take part from my organisation?

The interview targets senior decision-makers within leading organisations of older people. The researcher wishes to speak with senior decision-makers who have been involved in the organisation for many years and/or who have institutional memory. Presidents, directors, members of the Board but also Honorary Chairs, or senior staff members are appropriate candidates for these interviews, but eventually each organisation will decide who should participate on its behalf. The reason why the researcher wants to speak with key decision-makers at the top of the organisational hierarchy is because they are well placed to discuss overall goals, perspectives and principles of the organisation. Please note that the participants do not need to have extensive knowledge/expertise on human rights.

What will happen if my organisation decides to participate?

We will arrange a time that is convenient for the selected representative to meet with the researcher either at the premises of your association or another appropriate setting of your choosing. The interview will last approximately 75 minutes. The researcher may contact your organisation for a follow-up interview, if deemed appropriate. After the end of the interview, the researcher will produce a summary of the findings, which she may share with you, if you wish.

How will the information gathered during the interview be treated?

With your agreement, the researcher will record the interview, in order to allow for a detailed transcription and a better analysis. Only the researcher and the academic supervisors will have access to the transcribed interviews, which will remain anonymous, private and unpublished.

In case single statements will be used for academic purposes (such as journals, conferences, etc), the researcher will contact you in advance to get your approval. Quotations will remain anonymous, unless otherwise requested by your organisation.

The final PhD thesis will include the names of the organisations interviewed, but not of the individuals. Findings will not link to an individual or a single organisation.

The interviews will not disclose personal or private information (i.e. the name of interviewee, age and role in the organisation, will remain private and will not be published). No one will be able to link the data you provided to the identifying information you supplied (i.e., name, position, age).

What are the participants' rights?

You may decide to stop being a part of the research study at any time without explanation. You have the right to ask that any data you have supplied to that point be withdrawn/destroyed. The researcher will present you with an

informed consent form before the beginning of the interview. This will outline procedural aspects of the research, including issues of confidentiality and ethics. You will be asked to sign the form after the end of your interview and only upon your approval will the researcher use the provided information.

You have the right to have your questions about the research or the procedures answered before the beginning of the interview. If you have any questions as a result of reading this information sheet, you may contact the researcher (see contact details below).

You have the right to have access to the findings of the research.

Whom can I contact for more information?

The researcher, Nena Georgantzi, will be glad to answer your questions about this study at any time. You may contact her at:

Nena.georganti@age-platform.eu or A.Georgantzi1@nuigalway.ie

Should you need more information about this research you may also contact the academic supervisors using the following contact details:

- Prof. Eamon O'Shea: eamon.oshea@nuigalway.ie
- Dr. Eilionoir Flynn: eilionoir.flynn@nuigalway.ie

How can my organisation participate?

If you agree to participate, you are kindly requested to contact the researcher by email. She will follow up with details of the date and venue of the interview.

Appendix 5: Published Work

Book Chapters

Georgantzi, Nena. "El derecho de las personas mayores a la autonomía, la salud y la vida independiente en la Unión Europea. In *Autonomía y dignidad en la vejez: teoría y práctica en políticas de derechos de las personas mayores*. Santiago: CEPAL, 2014. LC/L. 3942. p. 309-315 (2014).

Georgantzi, Nena. "Garantías legales e institucionales para los derechos de las personas mayores: una mirada desde Europa. In *Autonomía y dignidad en la vejez: teoría y práctica en políticas de derechos de las personas mayores*. Santiago: CEPAL, 2014. LC/L. 3942. p. 87-102 (2014).

Georgantzi, Nena. "The human rights challenges of older persons in long-term care settings: The experience from the EU." In *International and Comparative Law on the Rights of Older Persons*. Vandepas Publishing (2015).

Georgantzi, Nena. "The European union's approach towards ageism." In *Contemporary perspectives on ageism*, p. 341-368. Springer, Cham (2018).

Doron, Israel Issi, Ann Numhauser-Henning, Benny Spanier, Nena Georgantzi, and Eugenio Mantovani. "Ageism and anti-ageism in the legal system: A review of key themes." In *Contemporary perspectives on ageism*, p. 303-319. Springer, Cham (2018).

De Pauw, Marijke, Sleaf, Bridget, and Nena Georgantzi. "Ageism and Age Discrimination in International Human Rights Law." In *Ageing, Ageism and the Law*, edited by Issi Doron and Nena Georgantzi: Edward Elgar (2018).

Articles

Georgantzi, Nena. "The human rights of older people and end-of-life challenges: is there a need for a new UN instrument?." *Omsorg-Nordisk tidsskrift for palliative medicin (Scandinavian Journal for Palliative Medicine)*, no. 4 (2016).

Georgantzi, Nena. "Human rights advocacy: What's that got to do with older people?." *Human Rights Defender* 27, no. 1 (2018): 36.

Edited Book

Doron, Israel Issi, Georgantzi, Nena. *Ageing, Ageism and the Law, European Perspectives on the Rights of Older Persons*, Edward Elgar Publishing, 2018.

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