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a human rights perspective (theory and practice)

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Mag. Gerda Thenner

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Mag. Mag. Dr. Dr. Ursula Juliane Naue

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DANKE

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ABSTRACTS

II. LIST OF ACRONYMS AND ABBREVIATIONS

AA	Alzheimer Austria
ACA	Austrian Court of Audit (<i>Österreichischer Rechnungshof</i>)
ADI	Alzheimer's Disease International
AE	Alzheimer Europe
AOB	Austrian Ombudsman Board (<i>Österreichische Volksanwaltschaft</i>)
BGBI	Bundesgesetzblatt (<i>Federal Law Gazette</i>)
BMASGK	Bundesministerium für Arbeit, Soziales, Gesundheit und Konsumentenschutz (<i>Federal Ministry Labour, Social Affairs, Health and Consumer Protection</i>)
CBR	Community Based Rehabilitation
CRPD	Convention on the Rights of Persons with Disabilities
CRPD Committee	Committee on the Rights of Persons with Disabilities
CS	CS Caritas Socialis
DAI	Dementia Alliance International
ECHR	European Convention of Human Rights
EWGPWD	European Working Group of People with Dementia
GC	General Comment
GÖG	Gesundheit Österreich GmbH / (<i>Austrian Public Health Institute</i>)
GT	Grounded Theory
ICCPR	International Covenant on Civil and Political Rights
ICESCR	International Covenant on Economic, Social and Cultural Rights
NAP	National Action Plan
NPM	National Preventive Mechanism
OECD	Organisation for Economic Co-operation and Development
OEWG	Open-ended Working Group on Ageing
OPCAT	Optional Protocol of the Convention against Torture and other Cruel, Inhuman or Degrading Treatment of Punishment
SHRCS	Scottish Human Rights Commission
SDG	Sustainable Development Goals

UDHR	Universal Declaration of Human Rights
UN	United Nations
UNTS	United Nations Treaty Series
UPIAS	Union of the Physically Impaired Against Segregation
WHO	World Health Organization

1. INTRODUCTION

NOTHING ABOUT US WITHOUT US NO MORE US AND THEM THIS IS OUR RIGHT¹

"What should I say to a person with dementia?"

Dr. Richard Taylor diagnosed with dementia himself answered, "Try Hello."²

This mini dialog illustrates that interaction with a person living with dementia is often characterized by uncertainty and uneasiness. This is due to stigmatization that persons living with dementia face all over the world. They are frequently denied their basic human rights,³ become invisible in public life and their voices are not heard any longer. Yet, a growing number of persons living with dementia claim their right to full participation and inclusion in society, which requires adequate dementia care provision. Persons' diagnosed with dementia rights must be protected throughout all stages of their dementia journey. They must find new ways and strategies to cope with their life assisted and supported by their partners, families and professionals in dementia care. National dementia strategies and plans have been developed with the aim to protect persons living with dementia and support them and their families to find such new ways in order to be able to live well with dementia. 'Living well with dementia' is the title of the Austrian Dementia Strategy (2015),⁴ which is the study subject of this master thesis.

¹ Dementia Alliance International (DAI), *The human rights of people living with dementia; from rhetoric to reality, first edition*, May 2016, p.6, <https://www.dementiaallianceinternational.org/wp-content/uploads/2016/04/The-Human-Rights-of-People-Living-with-Dementia-from-Rhetoric-to-Reality.pdf> (accessed 03 June 2020).

² P. Barbarino, C. Lynch, A. Bliss et al., *From Plan to Impact II, The urgent need for action*, Alzheimer's Disease International (ADI), 2019, p.26, <https://www.alz.co.uk/adi/pdf/from-plan-to-impact-2019.pdf> (accessed 02 June 2020).

³ World Health Organization (WHO), 'key facts', *Dementia*, 19 September 2019a, <https://www.who.int/news-room/fact-sheets/detail/dementia>, (accessed 20 May 2020).

⁴ English version: Bundesministerium für Arbeit, Soziales, Gesundheit und Konsumentenschutz (BMASGK), *Austrian Dementia Strategy Living well with dementia*, Vienna, November 2015b, (Print 2019); if not stated otherwise, in my master thesis the English version will be used and cited BMASGK, 2015b.

German version: Bundesministerium für Arbeit, Soziales, Gesundheit und Konsumentenschutz (BMASGK), *Demenzstrategie Gut Leben mit Demenz*, Wien, November 2015a, (Druck 2019).

The Austrian Dementia Strategy will be examined from a human rights perspective in theory and practice.

Even if the topic is approached scientifically, giving professionals working in the dementia field a direct voice through an empirical study, the persons living with dementia and their families, the main beneficiaries of the Austrian Dementia Strategy, must not be forgotten. Therefore, on the outset of my scientific journey, I would like to give Angela Pototschnigg, a woman from Austria living with dementia, the stage:

On the one hand, I want to be treated like any other person but on the other hand, I need assistance to participate. I want to be seen holistically as a person with special needs but also as a person who is capable, creative and responsible. To feel well despite my disease, kindness and the opportunity to be heard and understood.⁵

1.1. Problem

Globally, around 50 million people are affected by a form of dementia. This figure is predicted to rise to 130 million by 2030 and 152 million by 2050.⁶ Not surprisingly, dementia has been coined 'the 21st century's biggest health challenge'.⁷

According to the Organisation for Economic Co-operation and Development (OECD), international collaboration promoting dementia as a public health priority started with the formation of the World Dementia Council at the G8 Summit in London in 2013.⁸ Since the World Health Organization (WHO) First Ministerial Conference on Dementia in 2015 dementia-related human rights issues have received increasing global attention recognizing that basic human rights of persons diagnosed with dementia are frequently not upheld.

⁵ A. Pototschnigg, cited in Alzheimer Europe (AE), *Dementia in Europe Ethics Report 2019: "Overcoming ethical challenges affecting the involvement of people with dementia in research: recognising diversity and promoting inclusive research"*, Luxembourg, 2019a, p.16.

⁶ WHO, 2019a.

⁷ World Dementia Council, *Defeating dementia: the road to 2025*, 2018, p.3, worlddementiacouncil.org/sites/default/files/2018-12/Defeating%20Dementia%20Report.pdf (accessed 6 February 2020).

⁸ Organisation for Economic Co-operation and Development (OECD), *Addressing dementia: The OECD response*, OECD Health Policy Studies, Paris, OECD Publishing, 2015, p.9 (executive summary).

All people have the same human rights which must be protected as set out in the Universal Declaration of Human Rights (UDHR) in 1948.⁹ The UDHR and all subsequent international and regional treaties¹⁰ must be applied to everyone, including people diagnosed with dementia,¹¹ a rapidly growing vulnerable group in our society. In human rights discourse, it has been argued for a decade that the International Convention on Rights of Persons with Disabilities (CRPD) is a suitable tool for promoting the rights of people diagnosed with dementia and putting pressure on states to fulfill their obligations.¹²

This has found its reflection in a huge body of literature online¹³ and offline of all sorts, including academic literature¹⁴, official international documents,¹⁵ and also in national dementia plans or strategies.¹⁶

In its global response to dementia the WHO adopted the 'Global Action Plan on the public health response to dementia 2017-2025' at the World Health Assembly in Geneva

⁹ Universal Declaration of Human Rights (UDHR), (adopted 10 December 1948), General Assembly Resolution 217 A.

¹⁰ for example: International Convention on the Rights of Persons with Disabilities (CRPD), (adopted 24 January 2007, entered into force: 3 May 2008) UNTS 2515; International Covenant on Civil and Political Rights (ICCPR), (adopted 16 December 1966, entered into force: 23 March 1976) UNTS 999; International Covenant on Economic, Social and Cultural Rights (ICESCR), (adopted 16 December 1966, entered into force: 3 January 1976) UNTS 993; Council of Europe, European Convention for the Protection of on Human Rights and Fundamental Freedoms (ECHR), as amended by Protocols Nos.11 and 14, 4 November 1950.

¹¹ Alzheimer Europe (AE), Dementia in Europe Yearbook 2018. "Comparison of national dementia strategies in Europe", Luxembourg, 2018, p.14.

¹² see for example: Cross-Party Group on Alzheimer's, *Charter of Rights for People with Dementia and their Carers in Scotland*, October 2009, https://www.alzscot.org/sites/default/files/2019-07/Charter_of_Rights.pdf (accessed 6 February 2020).

see for example in academic research: D. Gove, J. Andrews, A. Capstick, et al., *Dementia as a disability: Implications for ethics, policy and practice*. Ethical Discussion Paper. Alzheimer Europe, Luxembourg, 2017, <http://hdl.handle.net/10454/14923> (accessed 20 January 2020).

¹³ see for example: newsletters, articles and blogs on websites of Alzheimer Austria (AA), Alzheimer Europe (AE), Alzheimer's Disease International (ADI) and Dementia Alliance International (DAI).

¹⁴ see for example: N. Crowther, 'Harnessing the UN Convention on the Rights of Persons with Disabilities to improve the lives of persons with dementia', policy paper, 2016, <https://www.alz.co.uk/sites/default/files/pdfs/harnessing-crp-dementia.pdf> (accessed 20 January 2020);

T. Shakespeare, H. Zeilig, P. Mittler, 'Rights in Mind: Thinking Differently About Dementia and Disability'. *Dementia*, vol.18, no.3, 2019, pp.1075–1088.

¹⁵ see for example: World Health Organization (WHO), *Global Action Plan on the public health response to dementia 2017–2025*, Geneva, 2017, <https://apps.who.int/iris/bitstream/handle/10665/259615/9789241513487-eng.pdf?sequence=1> (accessed 01 Jun 2020).

¹⁶ see for example: BMASGK, 2015a+b (German and English versions).

in 2017, which is aligned with the Sustainable Development Goals (SDG) Agenda 2030.¹⁷ The general aim of the SDG Agenda is to leave nobody behind. As the core target of the SDG3 is 'to achieve universal health coverage (UHC)',¹⁸ which means to ensure well-being and health for all, people diagnosed with dementia must receive adequate quality dementia care.

In 2018, the World Dementia Council called prevention of dementia the 'utmost public health priority'¹⁹ in tackling the dementia challenge, which is in accord with the WHO that published guidelines on 'Risk reduction of cognitive decline and dementia' in 2019.²⁰ According to these guidelines, studies have shown that certain 'lifestyle-related risk factors [...] and [c]ertain medical conditions are associated with an increased risk of developing dementia.'²¹ In fact, two of the seven strategic action areas of the WHO (2017) Global Action Plan are risk reduction and research and innovation.²² No doubt, prevention of dementia and dementia research in general are crucial areas for public health of any country and must be included in future dementia action plans and strategies. However, as dementia is a terminal condition with no long-term effective therapy or cure currently available and in sight,²³ the prime obligation of states in the field of public health must lie in dementia care that ensures quality of life and the well-being of people diagnosed with dementia throughout all stages.

Kate Swaffer, a prominent human rights activist diagnosed with dementia, does agree that research and prevention are important. But she insists that '[p]eople with dementia

¹⁷ WHO, 2017, p.5; also see Dementia Alliance International (DAI), *Dementia, the leading cause of disability, handout at Conference of State Parties on the CRPD*, New York, June 2019, n.p., <https://www.dementiaallianceinternational.org/wp-content/uploads/2019/06/DAI-COSP12-Side-Event-Handout.pdf>. (accessed 20 April 2020).

¹⁸ R. Sadana, A. Soucat, J. Beard, 'Universal health coverage must include older people', *Bulletin of the World Health Organization*, Editorial, vol.96, no.1, Geneva, 2018, p.2, <https://www.who.int/bulletin/volumes/96/1/17-204214/en/> (accessed 01 April 2020).

¹⁹ World Dementia Council, p.29.

²⁰ World Health Organization (WHO), *Risk reduction of cognitive decline and dementia: WHO guidelines*, Geneva, 2019b, <https://apps.who.int/iris/bitstream/handle/10665/312180/9789241550543-eng.pdf?ua=1> (accessed 03 June 2020).

²¹ WHO, 2019b, introduction.

²² see WHO, 2017, Global Action Plan, area three and area seven.

²³ C. Sinclair, K. Gersbach, M. Hogan, et al. 'A Real Bucket of Worms': Views of People Living with Dementia and Family Members on Supported Decision-Making', *Bioethical Inquiry*, vol.16, no.4, 2019, p.589.

and [their] families have undisputed rights to better care.²⁴ According to Swaffer, there is a 'duty of care to improve the outcomes for people diagnosed right now, rather than the research dollars focusing only on a cure.'²⁵ As the number of people being diagnosed with dementia is increasing rapidly, care which improves the well-being and quality of life after diagnosis for persons diagnosed with dementia is required. This can only be achieved if dementia care is reframed and the emphasis is on the individual who is entitled to live a life in dignity throughout his or her dementia journey. A focus on human rights in dementia policy would eventually enhance dementia care,²⁶ 'which must therefore be reflected in national dementia plans.'²⁷

According to the OECD (2015),

better policy can still improve the quality of life of people with dementia and their families experience by promoting a more accommodating society and by ensuring access to high-quality health and care services. Quality of life is an inherently difficult thing to define and measure and there is no single definition of the concept. [...]However, it is important to have in mind what people with dementia see as the key determinants of their quality of life.²⁸

Already in 2014, in the Glasgow Declaration, members of the Alzheimer's Europe,²⁹ committed to promoting rights, dignity and autonomy of people living with dementia and explicitly mentioned the European Convention of Human Rights (ECHR), the Universal Declaration of Human Rights (UDHR), the International Covenants on Economic, Social and Cultural Rights (ICESCR) and Civil and Political Rights (ICCPR), and the Convention on the Rights of Persons with Disabilities (CRPD). They encouraged the European Commission to create a comprehensive European Dementia Strategy. All European countries were asked to make dementia a priority in their public

²⁴ K. Swaffer, 'Human Rights, disability and dementia', *Australian Journal of dementia care*, vol.7, no.1, February, March 2018, n.p., <https://journalofdementiacare.com/human-rights-disability-and-dementia/> (accessed 2 April 2020).

²⁵ K. Swaffer, 'Dementia and Prescribed Disengagement™', *Dementia*, vol.14, no.1, 2015, p.5.

²⁶ see my master thesis, chapter 2.2.2. on dementia care, which discusses a re-framing of dementia care in a broader sense with focus on post-diagnostic care. In this understanding care is considered 'better'.

²⁷ Swaffer, 2018, n. p..

²⁸ OECD, p.30.

²⁹ Alzheimer Austria is a member of Alzheimer's Europe.

health policies and to develop national dementia strategies.³⁰ In addition, it called for a global action plan to dementia,³¹ which was eventually substantiated in the above-mentioned WHO (2017) Global Action Plan. One of the seven cross-cutting principles of this plan is 'human rights for people with dementia'.³²

Member States are highly recommended to take an inclusive, human rights-based approach when initiating and drawing up national dementia plans.³³ As such approach 'is about ensuring that both the standards and the principles of human rights are integrated into policymaking as well as the day to day running of organisations',³⁴ it epitomizes an effective approach to improve dementia care and subsequently the lives of persons with dementia and their caregivers. Already existing national strategies may have to be revised and modified if states really care and want to 'address dementia more effectively and to improve the lives of millions' as the OECD highlighted in 2015.³⁵

In general, human rights treaties can be considered effective tools to bring about social change by challenging existing social practices and structures. In the context of dementia care, it is the CRPD which is promoted as the most effective instrument for change.³⁶ Member States of human rights treaties must be reminded to fulfill their human rights obligations and pressure must be put on them to respect and protect vulnerable groups in order to guarantee the enjoyment of fundamental human rights of persons diagnosed with dementia during all stages in their lives.

In my master thesis the Austrian dementia care strategy as laid down in the Austrian Dementia Strategy will be inspected in this light.

³⁰ see Alzheimer Europe (AE), *Glasgow Declaration 2014*, last updated March 2017, <https://www.alzheimer-europe.org/Policy-in-Practice2/Glasgow-Declaration-2014> (accessed 03 June 2020).

³¹ *ibid.*

³² WHO, 2017, p.4.

³³ World Health Organization (WHO), *Towards a dementia plan: WHO guide*, Geneva, 2018, p.16, <https://apps.who.int/iris/bitstream/handle/10665/272642/9789241514132-eng.pdf?ua=1> (accessed 01 June 2020).

³⁴ Scottish Human Rights Commission (SHRCS), 'What is a human rights based approach?', *Care about rights* n.y., <http://careaboutrights.scottishhumanrights.com/whatisahumanrightsbasedapproach.html> (accessed 14 July 2020).

³⁵ OECD p.3 (foreword).

³⁶ see for more information my master thesis, chapter 2.1.1.

1.2. Research Question

The Austrian Dementia Strategy '*Living Well With Dementia*' was published with the aim to 'provide[s] a framework of objectives and recommendations for taking action to improve the lives of people with dementia as well as their families and friends' in 2015.³⁷ Five years later, at a time when about 100 000 people live with dementia and this figure is set to rise to 230 000 by 2050,³⁸ care and support in general and dementia care in particular have become a top priority for the government. This is expressed in their coalition agreement for 2020 to 2024 highlighting the following need: 'Demenzstrategie österreichweit ausrollen und mit Ressourcen versehen.'³⁹ On the World Alzheimer Day, on 21 September 2019, the Austrian ombudsman (*Volksanwalt*) Bernhard Achitz, even demanded:

Das Recht auf eine fachgerechte, menschenwürdige Pflege für Demenzerkrankte und alle anderen Pflegebedürftigen muss im Zentrum des 'Masterplans Pflege' einer künftigen Regierung stehen.⁴⁰

In the light of this general care situation⁴¹ in Austria, in my master thesis the Austrian Dementia Strategy (2015) is explored from a human rights perspective in theory and practice. My research question is as follows:

What role do human rights play in the conceptualization and implementation of the Austrian Dementia Strategy?

My master thesis investigates to which extent human rights aspects are reflected and perceived in everyday practical work in the field five years after the introduction of the Austrian Dementia Strategy. As illustrated earlier, internationally the CRPD is

³⁷ BMASGK, 2015b, p.6.

³⁸ Österreichische Alzheimer Gesellschaft, 'Zahlen und Statistik', *Informationen*, 2020, <http://www.alzheimer-gesellschaft.at/informationen/zahlen-statistik> (accessed 20 January 2020).

³⁹ Die Neue Volkspartei, die Grünen - die Grüne Alternative, *Aus Verantwortung für Österreich. Regierungsprogramm 2020–2024*, Wien, 2020, p.243, https://www.dieneuevolkspartei.at/Download/Regierungsprogramm_2020.pdf (accessed 29 January 2020); my translation: expanding the Austrian Dementia Strategy nationwide and providing resources/funding.

⁴⁰ B. Achitz, cited in Volksanwaltschaft, 'Achitz zum Welt-Alzheimerstag: Recht auf menschenwürdige Pflege', 21 September 2019, <https://volksanwaltschaft.gv.at/artikel/achitz-zum-welt-alzheimerstag-recht-auf-menschenwuerdige-pflege> (accessed 5 April 2020); my translation: The legal right to professional care for people living with dementia and all other people in need of care must be the focal point of the next government.

⁴¹ see remarks on Covid-19 in my master thesis a few lines later.

promoted as a tool to be utilized to enhance the human rights situation of persons diagnosed with dementia, and a human rights-based approach is recommended. Therefore, the focus of my master thesis is on the CRPD. The question to be asked is: How much of human rights is there to be found in the conceptualization of the official Austrian Dementia Strategy, explicitly and implicitly (on paper) and how are these issues reflected in everyday work with people diagnosed with dementia and their families/care partners?

Since 2015 a great number of initiatives and projects have been introduced nationwide.⁴² The implementation process of the Austrian Dementia Strategy as such is not the focal point of the thesis but the aim is rather to gain an understanding of the strategy's relevance in everyday work from a human rights perspective. Since this area has not received any scholarly attention so far, the intention of my empirical study is to shed some light on it. Professionals faced with human rights issues and their every day challenges are given a voice. As they interact with people diagnosed with dementia and/or their families/care partners, they have gained profound knowledge and experience of dementia care.

Based on the outcome, my research will provide recommendations on how to promote the implementation process of the Austrian Dementia Strategy and/or revising it. Awareness of possible shortcomings in the Austrian Dementia Strategy will be raised, which may help to move towards a human rights-based approach⁴³ as advocated by self-advocating groups and international organizations.

Especially at a time when the urgency of changes in nursing and care in general has become a top priority on the agenda of the Austrian government and discussed broadly in the media, my master thesis aims to give its readers a human rights perspective in the field of dementia care. It can be seen as a contribution to lobbying for comprehensive implementation of the Austrian Dementia Strategy and in dementia policymaking arguing for more commitment to human rights obligations.

⁴² see Gesundheit Österreich GmbH. (GÖG), 'Umsetzung', *Demenzstrategie*, n. y., <https://www.demenzstrategie.at/de/Umsetzung.htm> (accessed 24 July 2020).

⁴³ see for an example of a rights-based approach: Scottish Government, *National Dementia Strategy: 2017-2020*, Edinburgh, 2017, <https://www.gov.scot/publications/scotlands-national-dementia-strategy-2017-2020> (accessed 10 February 2020).

While I was writing the proposal and outline for my thesis, Covid-19 had not yet been pandemic, but rather localized in Asian countries. By the time I started writing my thesis and conducting the first interviews, the Covid-19 virus had spread globally, and Austria was in a state of lockdown and post-lockdown. The importance of quality care and human rights issues linked to dementia found its reflection in the media, e.g. in newspapers in print⁴⁴ and online,⁴⁵ on websites of relevant organizations,⁴⁶ and also in my interviews.⁴⁷ Yet, focusing on the impact of the Covid-19 pandemic and consequences in great detail would go beyond the scope of my master thesis. In fact, the pandemic and its impact have opened up a broad field of further studies, including the field of dementia care. Its impact will or may be of importance for the outlook concerning a national Austrian Dementia Strategy and will be briefly discussed at the end of my master thesis.⁴⁸

By participating in the study, the participants were able to reflect upon their work and experience. Even greater awareness could be raised, on the one hand of their valuable contribution to human rights work, and of possible areas of conflict on the other hand. Especially balancing protection and autonomy of persons diagnosed with dementia is a key issue. As a result, they may become empowered actors in a human rights-based approach to dementia care in future.

A major motivation to look into this issue was my personal experience with people living with dementia during my 2019 internship with CS Caritas Socialis and, what is more, my personal experience with my mother's condition, who had first been affected by a mild form of dementia and later, after a severe stroke, by a progressed form before she died from this comorbidity in September 2019.

⁴⁴ see for example: I. Brickner, 'Quarantäne nur für Ältere würde Gesetze brechen', *Der Standard*, 17 April 2020, p.10.

G. Scherndl, 'Wenig Freiheit für Heimbewohner', *Der Standard*, 25, 26 April 2020, p.17.

⁴⁵ see for example: E. Ziegler, 'Einschränkungen - "Brauchen Ethikberatung in Pflegeheimen"', <https://science.orf.at/stories/3200819/>, 27 May 2020, (accessed 28 May 2020).

⁴⁶ see for example: Gesundheit Österreich, GmbH (GÖG), 'Informationen zum Thema Demenz und Corona virus', *Demenzstrategie*, 2020, <https://www.demenzstrategie.at/> (accessed 27 May 2020).

⁴⁷ see my master thesis, chapters 6.2., 6.3.

⁴⁸ see my master thesis, chapter 8.

2. RESEARCH DESIGN

I have chosen a qualitative, multi-method research design for my master thesis consisting of two text analyses, the first one establishing my human rights framework and the second one dealing with the conceptualization of the Austrian Dementia Strategy. The empirical study will explore the implementation of the Austrian Dementia Strategy in practical work from a human rights perspective.

In this research design chapter I will first present some basic facts on dementia as a medical condition (chapter 2.1.1.) and dementia activism (chapter 2.1.2.) and its conceptualization, including dementia and disability models (chapter 2.2.1.) and dementia care (chapter 2.2.2.). Then I will describe the methodology of the two text analyses and the empirical study (chapter 2.3.). This section of my master thesis will be rounded off with a brief overview of my interdisciplinary approach to the topic of dementia care (chapter 2.4.).

2.1. Dementia - terminology and activism

Only by promoting a new understanding of dementia in general and dementia care in particular the general negative societal perception of persons living with dementia can be changed and eventually a paradigm shift in dementia care can be achieved.⁴⁹ In general, dementia is still solidly embedded in a medical context, which an increasing number of self-advocates have been striving to change.

2.1.1. Terminology

According to the WHO (2019a), dementia is defined as follows:

[It] is a syndrome – usually of a chronic or progressive nature – in which there is deterioration in cognitive function (i.e. the ability to process thought) beyond what might be expected from normal ageing. It affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not affected. The impairment in cognitive function is

⁴⁹ see for example: M. Schmidhuber, A. Frewer, S. Klotz, H. Bielefeld (Hg.), *Menschenrechte für Personen mit Demenz Soziale und ethische Perspektiven*, Bielefeld, transcript Verlag, 2019; C. J. Camp, 'Denial of Human Rights: We must change the paradigm of dementia care', *Clinical Gerontologist*, vol.42, no.3, 2019, pp.221-223.

commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation.⁵⁰

Dementia takes many different forms, Alzheimer's disease being the most common one, accounting for 60–70%, followed by vascular dementia and dementia with Lewy bodies.⁵¹ Due to its degenerative nature, dementia symptoms and signs usually progress in three stages (early, middle and late stage).⁵² The average life span of people diagnosed with dementia is 4.1 for men and 4.6 years for women,⁵³ which may sound very short and worrying. However, this can be explained by the fact that dementia is often diagnosed late in progression due to ongoing stigmatization. A negative perception of the condition itself and also of the people diagnosed with dementia is reflected in the language used by the general public.⁵⁴

A variety of guides to talking about dementia have been issued in collaboration with persons diagnosed with dementia to sensitize people in general.⁵⁵ In these guides the importance of using positive language is pointed out. Basic rules are that the people and their feelings must be seen and not the dementia. Expressions such as demented, dementing should be avoided, their own words should be used as much as possible and the focus must be on their abilities and not deficits.⁵⁶ Furthermore, as symptoms of dementia depend on the type of dementia and the person diagnosed, the change caused by the symptoms should be described and not stereotyped labels used, e.g. wanderer, shouter.⁵⁷ The term dementia itself is sometimes rejected by persons living with dementia⁵⁸ as it stems from Latin, meaning "madness, insanity," literally "a being out of

⁵⁰ WHO, 2019a.

⁵¹ *ibid.*

⁵² *ibid.*

⁵³ Shakespeare et al., p.1079.

⁵⁴ see in the interviews carried out for my empirical study, my master thesis, chapter 6.2.

⁵⁵ see for example: J. Pinkowitz, K. Love, (eds.), *Words Matter: See ME Not My Dementia*, Dementia Action Alliance, Falls Church, VA, 2015, https://daanow.org/wp-content/uploads/2016/03/Words_Matter-See-Me-Not-My-Dementia.pdf (accessed 24 April 2020); Alzheimer's society, *Positive language: An Alzheimer's Society guide to talking about dementia*, London, April 2018, https://www.alzheimers.org.uk/sites/default/files/2018-09/Positive%20language%20guide_0.pdf (accessed 20 July 2020).

⁵⁶ Alzheimer's society, p.5.

⁵⁷ *ibid.*, p.11.

⁵⁸ for example: members of an Austrian self-help group have deliberately chosen the word 'Promenz' (from Latin: "for the mind") for their group in opposition to 'Demenz' ("out of one's mind") in:

one's mind"⁵⁹ (=de-mens). Yet, in general, it has been accepted as an umbrella term for different symptoms, as a diagnostic term, by persons diagnosed with dementia themselves.

Dementia is a degenerative condition and cognitive decline gradually leads to difficulty in coping in everyday life due to '*recall dysfunction*'⁶⁰ and disorientation. There is still little consensus on the most appropriate generic term, but 'cognitive disabilities' is gaining in popularity as a non-derogatory approach,⁶¹ which is in line with the official definition by the WHO (2019a) quoted earlier. In human rights discourse the terms 'intellectual' and 'psychosocial' disability linked to dementia are used as well.⁶²

In addition, the WHO clearly states that '[d]ementia is one of the major causes of disability and dependency among older people worldwide'.⁶³ According to Shakespeare et al., epidemiologists 'generally categorise dementia among the wider category of disabilities' based on sources, such as the ADI and WHO.⁶⁴

In the same article written in collaboration between a disabled person, a person with mental health condition and a person diagnosed with dementia it was maintained that 'dementia highlights the diversity of disability'.⁶⁵ Even if all their experience is lived experience, it is not shared, which is true for the great number of people with dementia as well due to different causes and its progressive nature. This poses a huge challenge in dementia care which requires a paradigm shift.

A human rights-based approach inherently leads to a re-evaluation of dementia care, similar to what the disability movement brought about by participating in the drafting

Promenz, Volkshilfe Österreich, *Selbständig Leben mit Promenz*, Vienna, 2019, p.4, https://www.promenz.at/uploads/dokumente/PROMENZ_Broschuere.pdf (accessed 9 April 2020).

⁵⁹ see D. Harper, 'dementia (n)', *Online Etymology Dictionary*, n. y.

<https://www.etymonline.com/word/dementia> (accessed 24 July 2020).

⁶⁰ this expression instead of 'memory loss' is preferred by Bryden as she explains with help she can 'access feelings, meaning and her flow of awareness within lived experience of dementia.'; C Bryden, *Will I Still Be Me?*, London, Philadelphia, Jessica Kingsley Publishers, 2018, p.33.

⁶¹ R. Harding, 'Care and relationality' (chapter 8), in R. Fletcher, C. Beasley, *ReValuing Care in Theory, Law and Policy*, London, Routledge, 2017, p.115.

⁶² see for example: Special Rapporteur on the Rights of Persons with Disabilities, *Report on the deprivation of liberty of persons with disabilities*, to the HRC at its 40th session on 5 March 2019a, A/HRC/40/54, pp.6-7.

⁶³ WHO, 2019a.

⁶⁴ Shakespeare et al., p.1077.

⁶⁵ *ibid*, p.1084.

process of the CRPD - a paradigm shift by adopting a so-called social model of disability.⁶⁶

Conceptualization of dementia as a disability is crucial within the social model of disability as it has an impact if and how international treaties are referred to and implemented, above all the CRPD, which is reflected in a considerable body of human rights discourse.⁶⁷ What is more, such conceptualization is demanded by human rights-based dementia self-advocacy which is a rather recent movement. The following section gives a brief overview of the development of dementia activism sparked off by and within the disability movement.

2.1.2. Dementia activism

The disability movement was influenced by the civil rights and women's rights movements and started in the USA in the 1960s as an independent movement. Initially people with physical disabilities and sensory impairment self-advocated de-medicalization of disability and de-institutionalization convinced that they knew best what their needs were. They fought for social, economic and political recognition and gradually the movement has broadened to include people with a wide range of different disabilities and impairments, which eventually led to 'the emergence of the social model of disability as an alternative to the dominant medical model.'⁶⁸ Nevertheless, as for people with cognitive disability it had been difficult to stand up for their rights they were under-represented in the early movement and they relied on others to claim their rights.⁶⁹ Thus, it is not surprising that people with dementia had not been part of the disability movement and did not have 'a seat at the table'⁷⁰ during the drafting process of the CDRP, which came into force in 2006 and has been ratified by 182 states by January 2020.⁷¹

⁶⁶ see details on social model of disability, my master thesis, chapter 2.2.1.

⁶⁷ see for example: Crowther; Shakespeare et al.; Gove et al.

⁶⁸ Gove et al., p.11.

⁶⁹ *ibid.*

⁷⁰ J. Graham, 'Don't write us off: People with dementia press for more rights — and respect', *Stat*, 10 March 2017, <https://www.statnews.com/2017/03/10/dementia-human-rights/> (accessed 6 April 2020).

⁷¹ United Nations Human Rights, Office of the High Commissioner, 'Convention on the Rights of Persons with Disabilities', *map*, last updated 19 June 2020, https://www.ohchr.org/Documents/HRBodies/CRPD/OHCHR_Map_CRPD.pdf (accessed 29 July 2020).

The motto of the CRPD has been "Nothing about us, without us" from the very beginning. In this spirit the dementia movement started in 2000.⁷² In 2014 activists diagnosed with dementia decided to make their voices globally heard within the disability movement and founded the Dementia Alliance International (DAI). They started to claim their rights as legitimate right-holders. On a regional level, for example, the European Working Group of People with Dementia (EWGPWD) supported by Alzheimer's Europe was founded in 2012 with the aim to ensure that their priorities are included in European dementia policy.⁷³ Among the first and most prominent self-advocates that 'stepped out of their shadow'⁷⁴ were Peter Taylor (†2015), Christine Bryden, Kate Swaffer, Peter Mittler, Christian Zimmermann (†2015) and Helga Rohra, who is the author of the introduction to the Austrian Dementia Report of 2014.

In Austria the first assisted self-help and advocacy organization 'Promenz' was founded in 2017 by Monika Kripp, former vice president of Alzheimer Austria (AA) and Reingard Lange. AA is a well-established, non-profit organization located in Vienna and a member of AE and ADI. It has been specializing in dementia care for three decades. According to the mission statement of AA, its members are committed to the rights of persons living with dementia. It is not state-funded and relies on donations and volunteer work. Even before the foundation of Promenz, AA had been active mainly in supporting family members of persons diagnosed with dementia. Since 2012 there has been more focus on people living with dementia themselves and self-help group came into existence. AA is cooperating with self-help groups all over Austria.⁷⁵ Promenz goes back to an interview series carried out by Lange in 2014.⁷⁶ Angela Pototschnigg is not only an outspoken self-advocate in Austria, but also a member of the European

⁷² DAI, 2016, p.13.

⁷³ Alzheimer Europe (AE), 'European Working Group of People with Dementia - EWGPWD', *who we are*, last updated 08 May 2019b, <https://www.alzheimer-europe.org/Alzheimer-Europe/Who-we-are/European-Working-Group-of-People-with-Dementia> (accessed 09 April 2020).

⁷⁴ my translation of the title of Helga Rohra's first book after her dementia diagnosis: 'Aus dem Schatten treten'.

⁷⁵ see information on its website: Alzheimer Austria (AA), 'Leitbild', *Über Uns*, n.y., <https://www.alzheimer-selbsthilfe.at/ueber-uns/leitbild/> (accessed 24 July 2010); and also: M. Kripp, *personal notes on the telephone conversation of 10 April 2020, corrected and authorized by M. Kripp in an email*, 4 June 2020.

⁷⁶ see R. Lange, *Soziale Vernetzung als Ressource für Menschen mit Demenz*, Wiesbaden, Best of Pflege Springer, 2018.

Working Group for People with Dementia (EWGPWD).⁷⁷ Bea Gulyn, and Andreas Trubel, two current ambassadors of Promenz, have been very active in raising awareness for persons living with dementia as well and are the current protagonists in a new national TV spot.⁷⁸

The voices of some of these international and national self-advocates resonate in my master thesis through several sources cited.

One problem dementia activism is faced with is so-called 'temporality' as a 'distinctive feature of dementia activism',⁷⁹ which means that activists may not be able to fight for a prolonged period of time due to rapid progression of the condition. Yet, Bryden, Swaffer and Rohra among others have been active for more than 20 years (Bryden and Swaffer) and 10 years (Rohra). It has been argued that these activists are not representative of all people with dementia because of their mild stage of dementia and many years of activism.⁸⁰ Even if they may not be representative for people at a later more advanced stage, they did face and still face the same stigmatization and negativity associated with people diagnosed with dementia. By speaking up and advocating for rights for all people diagnosed with dementia regardless the progression, they do help make dementia visible in society.

2.2. Conceptualization of dementia

Before focusing on the re-conceptualization of dementia care, which is a precondition to a targeted dementia policy guaranteeing human rights to persons diagnosed with dementia and core to any national dementia strategies and plans, different models of disability relevant to re-framing dementia will be looked at.

Although not all persons diagnosed with dementia perceive themselves as being disabled,⁸¹ the self-advocate groups claim that dementia must be reframed within the

⁷⁷ see more on assisted self-help and advocacy groups, my master thesis, chapter 5.3.4.

⁷⁸ Volkshilfe, 'Neue Demenzhilfe-Kampagne stellt Betroffene in den Mittelpunkt', *news/aktuelles*, 19 Februar 2020, <https://www.volkshilfe.at/wer-wir-sind/aktuelles/newsaktuelles/neue-demenz-hilfe-kampagne/> (accessed 1 July 2020).

⁷⁹ see for example: Shakespeare et al., p.1079; Kripp.

⁸⁰ see for example: Rohra, Nachwort, p.122.

⁸¹ see for example: Shakespeare et al., p.1076.

social model of disability as a disability or causing disability,⁸² which can be done best in a human rights-based approach, with focus on the CRPD⁸³.

2.2.1. Dementia and different models of disability

Unfortunately, even today dementia is still 'trapped within the dominant medical discourse'⁸⁴ and is perceived within the traditional (bio)medical model of disability that only focuses on the disease and its deficits.⁸⁵ In the context of dementia, this means that the aim is to find a cure or treatment with a medical intervention. Doctors and other care-providers know what is best and the person diagnosed with dementia is not listened to and heard.⁸⁶ In a human rights-based approach utilizing the CRPD, dementia must be reframed as a disability within the social model of disability. Although the social model of disability has been demanded for decades,⁸⁷ the medical approach to disability in general has not disappeared in practice, which was, for example, highly criticized by the CRPD Committee in its concluding observations on the initial report of Austria in 2013⁸⁸ and also referred to more recently in the Austrian Monitoring Report to CRPD Committee on the Occasion of the Second Constructive Dialogue with Austria in 2018.⁸⁹ The origin of the social model of disability goes back to the Union of the Physically Impaired Against Segregation (UPIAS), which stated in the publication of The Fundamental Principles of Disability in 1976:

⁸² see for example: Gove et al., p.20; see for the Austrian context Promenz, p.19.

⁸³ see CRPD, art. 1.

⁸⁴ Shakespeare et al., p.1078.

⁸⁵ see for example: AE, 2018; Shakespeare et al., S. Fazio, D. Pace, J. Flinner, et al., 'The Fundamentals of Person-Centered Care for Individuals With Dementia', *The Gerontologist*, vol.58, no.S1, 2018, p.11.

⁸⁶ see for example: Gove et al., p.18.

⁸⁷ see my master thesis, chapter 2.2.1.

⁸⁸ Committee on the Rights of Persons with Disabilities (CRPD Committee), *Concluding observations on the initial report of Austria* / adopted by the Committee [on the Rights of Persons with Disabilities] at its 10th session, 2-13 September 2013, 30 September 2013, p.2.

⁸⁹ Monitoringausschuss, Unabhängiger Monitoringausschuss zur Umsetzung der UN-Konvention über die Rechte von Menschen mit Behinderungen, *Monitoring Report to the UN Expert Committee for the Rights of People with Disabilities on the Occasion of the Second Constructive Dialogue with Austria*, Vienna, 2018, p.4, www.monitoringausschuss.at/download/berichte/MA_Geneva_Report_engl.pdf (accessed 7 February 2020).

In our view it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society (UPIAS 1976:14).⁹⁰

According to Mike Oliver, 'this turned the understanding of disability completely on its head by arguing that it was not impairment that was the main cause of the social exclusion of disabled people but the way society responded to people with impairments.'⁹¹ He elaborated on this model and labeled it when trying to use his insight for practical training of social workers. Subsequently he published this new approach in his book *Social Work with Disabled People* (Oliver 1983).⁹² In his understanding there are two models of disability: the individual, medicalized model which focuses on 'functional limitations of individuals with an impairment', a person's deficits, and the social model which emphasizes the 'problems caused by disabling environments, barriers and cultures.'⁹³ In Oliver's view, the social model should be considered a practical tool and applied to achieve social and political change. Switching from a medicalized model to a social model of disability would clearly focus on removing the obstacles for full inclusion and participation as equal citizens in society and requires a radical change in disability policy.⁹⁴

There is no doubt that the social model of disability is a 'powerful tool to analyse discriminatory and oppressive structures of society'⁹⁵ and therefore was a welcome conceptual alternative to the medical model of disability during the drafting process of the CRPD. Nevertheless, according to Theresia Degener, the human rights model of

⁹⁰ M. Oliver, 'The Social Model in Action: if I had a hammer' (chapter 2, pp.18-31) in C. Barnes and G. Mercer (eds.), *Implementing the Social Model of Disability: Theory and Research*, Leeds, the Disability Press, 2004, n. p., <https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/Barnes-implementing-the-social-model-chapter-2.pdf> (accessed 20 May 2020).

⁹¹ *ibid.*

⁹² *ibid.*, pp.2-3.

⁹³ *ibid.*, p.4; also see p.6 - examples of barriers, ranging from inaccessible housing, transport, support services to devaluing presentation of disabled persons in the media.

⁹⁴ *ibid.*, p.20.

⁹⁵ T. Degener, 'A human rights model of disability, Disability social rights', December 2014, p.6, https://www.researchgate.net/publication/283713863_A_human_rights_model_of_disability (accessed 27 May 2020).

disability is 'an improvement of the social model of disability' and a more suitable instrument to implement the CRPD.⁹⁶

Degener had already coined the human rights model together with Gerard Quinn in 1999/2000.⁹⁷ The model does not focus on disability as a social construct to explain exclusion but puts the individual endowed with human dignity in the center.⁹⁸ The human rights model is codified by the CRPD, whose preamble and articles reflect the universality, indivisibility and interdependence⁹⁹ of all human rights for all. Thus, already in the preamble it is set out that the State Parties are obliged to 'recogniz[e] the need to promote and protect the human rights of all persons with disabilities, including those who require more intensive support,'¹⁰⁰ which clearly shows that the individual person with his/her impairment is in the center and has the right to individualized support to enjoy all human rights on an equal basis. Art.12 of the CRPD is a good example where persons with disabilities may require more intensive support in order to be able to exercise their legal capacity, which is a civil right.¹⁰¹ Therefore, it also serves as an example that the CRPD includes civil, political, social, cultural and economic rights, as the need for assistance is a social right which is, in fact, a precondition for a person with disabilities to be able to be equally recognized before the law. The social model of disability rather focuses on removing barriers for persons with disabilities to be fully included in society as citizens with equal civil and political rights, whereas the human rights model 'encompasses both sets of human rights'.¹⁰² Persons diagnosed with dementia require different assistance and support throughout their dementia journey to be able to enjoy all their human rights. Thus, Degener's human rights model is a suitable model of disability in a human rights approach, which was adopted by the Dementia Alliance International (DAI), the biggest international self-advocacy group, in 2015.

Kate Swaffer, one of the founders of DAI, has strongly propagated harnessing the CRPD when adopting a human rights-based approach to dementia in order to claim their

⁹⁶ *ibid*, p.3.

⁹⁷ *ibid*, p.5.

⁹⁸ *ibid*, p.15.

⁹⁹ CRPD Preamble (c).

¹⁰⁰ CRPD Preamble (j).

¹⁰¹ Degener, p.10.

¹⁰² *ibid*, p.8.

rights locally, nationally and internationally within the international legal human rights law.¹⁰³ In cooperation with Alzheimer's Disease International (ADI), the DAI, demanded legal access to the CRPD at the WHO's First Ministerial Conference on Dementia in 2015.¹⁰⁴ According to the preamble of the CRPD, disability is 'an evolving concept' and art.1 states that:

Persons with disability include those who have long-term physical, mental intellectual or sensory impairments which in interacting with various barriers may hinder their full and effective participation in society on an equal basis with others.¹⁰⁵

Today there is little doubt that dementia falls under this category.¹⁰⁶ In Austria Müller and Walter already argued in 2013 that '[w]enn dies auch (noch) kaum beachtet wird, fallen demenzkranke Personen in den Schutzbereich des RMB-Ü'¹⁰⁷ and discusses the failure of the Austrian government to fulfil its obligations in this respect.¹⁰⁸

Following the Ministerial Conference in 2015 a booklet was launched by the DAI to introduce Human Rights-based Approaches (HBRAs) approved by the UN because

What matters to us now is that people living with dementia will be empowered to use their undisputed right of access to this [the CRPD] and to other relevant UN Human Rights Conventions, including a future Convention on the Rights of Older Persons. (Professor Peter Mittler)¹⁰⁹

In his statement Peter Mittler reaffirms that at the time being the CRPD is the most effective tool to propagate the rights of persons living with dementia. Besides, he demands that the Convention on the Rights of older Persons if/when realized as a future additional treaty must explicitly include rights for people diagnosed with dementia

¹⁰³ DAI, 2016, p.6.

¹⁰⁴ *ibid*, p.2.

¹⁰⁵ CRPD, art.1.

¹⁰⁶ see for example: Crowther, p.2; H. Bielefeldt, 'Würde und Rechte von Menschen mit Demenz', in M. Schmidhuber, A. Frewer, S. Klotz, H. Bielefeld (Hg.), *Menschenrechte für Personen mit Demenz Soziale und ethische Perspektiven*, Bielefeld, transcript Verlag, 2019, pp.35-59.

¹⁰⁷ A. Müller, M. Walter, 'Die vergessene Dimension in der stationären Altenhilfe. Implikationen des Übereinkommens über die Rechte von Menschen mit Behinderungen für demenzerkrankte Personen in Alten- und Pflegeheimen', *Recht der Medizin*, vol.3, 2013, p.84;

my translation: Even if this is hardly recognized, people with dementia are protected by the CRPD.

¹⁰⁸ *ibid*, p.90.

¹⁰⁹ P. Mittler, cited in Dementia Alliance International (DAI), *Human Rights*, n. y., <https://www.dementiaallianceinternational.org/human-rights/> (accessed 29 January 2020).

owing to the fact that 5-8% of the general population aged 60+ develops dementia at a given time.¹¹⁰ Ten years ago the Open-ended Working Group on Ageing (OEWG) was established by the UN with the aim to review existing instruments and to identify possible gaps in protection with regards to older people's rights. In its tenth year, the Working Group is still in the process of drafting a convention.¹¹¹ Dementia was already mentioned in the discussion of the main elements of such a new legal international instrument in 2013.¹¹² The opportunity of this new convention would be to reaffirm that human dignity is inherent to all people *in all phases of life*, including older people with dementia.¹¹³ In this context another social model, in fact a human rights model in Degener's understanding, could be seen as a powerful tool for bringing about change in policy, including dementia policy and thus improving dementia care. This 'social model of ageing' as presented by Naue and Kroll¹¹⁴ highlights 'the *relational aspect* of both ageing and disability.'¹¹⁵ Re-thinking the dichotomy of 'non-healthy/non-normal ageing' and 'active/healthy/normal ageing' as propagated in ageing policies could lead to a better understanding and awareness of the diversity among the group of elderly persons, including persons diagnosed with dementia.¹¹⁶

People with young onset dementia may not want to be labeled as 'elderly' or 'old', though. They would not fall under the category 'older people', usually defined as a person older than 60/65.¹¹⁷ According to Kripp, the number of people being diagnosed with dementia younger than 60 is on the rise.¹¹⁸ As long as the UN convention on the rights of older people is still in the making and has not been finalized, the CRPD is

¹¹⁰ WHO, 2019a.

¹¹¹ HelpAge International, 'Towards a UN convention on the rights of older people', *what we do*, n. y., <https://www.helpage.org/what-we-do/rights/towards-a-convention-on-the-rights-of-older-people/> (accessed 10 April 2020).

¹¹² HelpAge International, *Main elements of a new legal international instrument to promote and respect the rights and dignity of older persons*, May 2013, pp.4-5, <https://www.helpage.org/what-we-do/rights/towards-a-convention-on-the-rights-of-older-people/> (accessed 10 April 2020).

¹¹³ Bielefeldt, p.50.

¹¹⁴ see U. Naue, T. Kroll, 'Bridging policies and practice: challenges and opportunities for the governance of disability and ageing', *International Journal of Integrated Care*, vol.10, 12 April 2010.

¹¹⁵ *ibid*, p.4.

¹¹⁶ *ibid*.

¹¹⁷ see for example: Inter-American Convention on Protecting the human rights of older persons, definitions, http://www.oas.org/en/sla/dil/inter_american_treaties_a-70_human_rights_older_persons.asp (accessed 10 April 2020).

¹¹⁸ see Kripp; also see B4, interview 06 May 2020.

considered the most effective instrument for promoting the rights of people diagnosed with dementia of all ages, even though several provisions of the CRPD¹¹⁹ may be a challenge in the implementation in everyday life and dementia care according to Shakespeare et al.. In their article a 'relational disability model of dementia' is propagated, which is a nuanced human rights model in Degener's understanding.¹²⁰

I consider this a suitable model within a human rights-based approach to dementia, as it is a very nuanced and inclusive approach. It attempts to address the complexity of dementia taking lived experience of people diagnosed and inclusive social responses for 'someone who lacks or is losing cognitive ability' into account.¹²¹ Focus is on 'both, the health condition itself, and the social responses to it.'¹²² What is more, such model emphasizes the importance of interrelationship¹²³ and interdependence¹²⁴ of people, as we all do not live our lives detached from each other but in relationship with family and in society as well.¹²⁵ As Zimmermann put it after his diagnosis: 'Kein Mensch ist wirklich unabhängig von anderen Menschen'¹²⁶ and we are all in relationships and need support in most phases of life.

Recently, the concept of relationality linked to dementia has been widely discussed in the context of decision-making with reference to art.12 of the CRPD (legal recognition before the law). Harding and Sinclair et al., for instance, speak of the role of 'relational autonomy' in the decision-making process.¹²⁷ Shakespeare et al. stress the 'persistence of relationality' until the end of life and lays out its implications for decision-making as well.¹²⁸ Relationality in context with art.12 of the CRPD will be discussed in more detailed in chapter 3.1.5. of my master thesis.

¹¹⁹ for example art. 12; see more, my master thesis, chapter 3.5.

¹²⁰ see Shakespeare et al.

¹²¹ Shakespeare et al., p.1081.

¹²² *ibid*, p.1082.

¹²³ Harding, p.118.

¹²⁴ L. Birt, F. Poland, E. Csipke, et al., 'Shifting dementia discourses from deficit to active citizenship', *Sociology of Health & Illness*, vol.39, no.2, 2017, p.203.

¹²⁵ Naue and Kroll also mention the importance of the 'relational element' in an article in 2008; see: U. Naue, T. Kroll, 'The demented other': identity and difference in dementia', *Nursing Philosophy*, vol.10, 2008, p.30.

¹²⁶ C. Zimmermann, P. Wißmann, *Auf dem Weg mit Alzheimer. Wie sich mit einer Demenz leben lässt*, Frankfurt am Main, Mabuse Verlag, 2011, p.40; my translation: Nobody is really independent from other people.

¹²⁷ Harding, p.116; Sinclair et al., p.588; see my master thesis, chapter 3.5.

¹²⁸ Shakespeare et al., p.1084.

Quality dementia care, for which relationality is core, will be discussed in the subsequent section.

2.2.2. Dementia care

In the context of dementia care, it was Tom Kitwood, who challenged traditional dementia care already in 1988 by pointing out the importance of (inter)relationships, and communication.¹²⁹ He suggested 'person-centered care' as an approach to dementia care for the first time.¹³⁰ By the 1990s quality of life in nursing homes had become an important issue in the field of gerontology and nursing.¹³¹ It had become a general trend that people entered nursing homes at a more advanced age and as a consequence there was an increase in the proportion of residents living with dementia in nursing homes. In the past such residents used to be considered cognitively impaired and, generally, care was patient-centered. This meant residents with dementia were a group of patients with a certain disease which was treated a certain way.¹³² Kitwood rejected this (bio)medical model of dementia¹³³ and propagated person-centered dementia care where the 'PERSON-with-dementia' counted and not the 'Person-with-DEMENTIA'. Kitwood and Bredin described this person-centered care concept in more detail in 1992.¹³⁴ As there is no common, linear progress of dementia for people diagnosed with dementia, high-quality interpersonal care with focus on the individual is required. In this context, the personhood or self of a person is crucial, i.e. a person's identity does not cease to exist only because of cognitive decline due to dementia.

Fazio et al. summarize Kitwood's and Bredin's theory of personhood and interdependence in dementia care as follows:

[P]ersonhood is dependent on other people. Recognizing that selfhood persists, learning about the complete self, and finding ways maintaining selfhood though

¹²⁹ see Fazio et al., p.10.

¹³⁰ *ibid.*

¹³¹ E. Seidl, I. Walter, *"Wenn man mich fragt..." Eine Untersuchung zur Lebensqualität demenzkranker Menschen im Pflegeheim*, Verlag HermaGoras Klagenfurt/Wien, 2012, pp.11-12.

¹³² *ibid.*, p.29.

¹³³ also see my master thesis, chapter 2.1.1.

¹³⁴ T. Kitwood, K. Bredin, 'Towards a theory of dementia care: Personhood and well-being', *Ageing and Society*, vol.12, 1992, pp.269-287.

interactions and conversations are fundamental components of person-centered care or people with dementia.¹³⁵

This philosophical concept of personhood and persistence of personhood and self plays an important role in questioning traditional dementia care, especially at an advanced stage. People living with dementia retain their voice, though they are not able to express it verbally, until the very end of life. If 'the possibilities for a more expanded understanding of personhood' is recognized in society, 'we open the doors to a more powerful articulation of the rights of people with dementia and thus their ability to retain their humanity to the end of their lives.'¹³⁶ Shakespeare et al., Harding and Sinclair et al. agree that 'relationality' is key in finding ways of supporting people in their autonomy until the end of their lives.¹³⁷

Stressing her insider's perspective of identity because of lived experience, Christine Bryden questions Kitwood's and Bredin's theory of interdependence of personhood and persistence of a self only through relationships. She prefers the term 'embodied relational self, 'which has a continuing sense of self throughout dementia` and is not bestowed on by others.'¹³⁸ Philosophically, these concepts may be contradictory, Yet, in person-centered practical dementia care, especially at an advanced stage, decision-making relies heavily on relationality.¹³⁹

No matter which term is used for the persistence of wholeness of a person, fact is that in a new approach to dementia care the focus must be on the wholeness of the person to ensure that people diagnosed with dementia are able to live a good life in dignity and respect. (Relational) autonomy must be maintained throughout their journey with dementia, which starts with their diagnosis. It is a fact that a high percentage of old people develop cognitive decline due to dementia, but dementia is wrongly perceived as being a natural inevitable part of ageing. This misconception is the 'reason for barriers to diagnosis and care and [...] eventually leads to stigmatization and discrimination'.¹⁴⁰ The narrative of dementia is full of negativity, deficit-oriented and portrayed as leading

¹³⁵ Fazio et al., p.11.

¹³⁶ Shakespeare et al., p.1084.

¹³⁷ see my master thesis, chapter 2.2.1.

¹³⁸ Bryden, p.54.

¹³⁹ see chapter 3.5. in my master thesis.

¹⁴⁰ WHO, 2017, p.14.

to 'social or living death'.¹⁴¹ Rohra points out that dementia is usually associated with the last stage of dementia which is depicted as a disaster and devastating for families.¹⁴² Bryden recalled that after diagnosis she was 'overcome with feelings of anxiety at a potential future loss of self'.¹⁴³ The only advice after diagnosis has often been to get their affairs in order and arrange for end-of-care (residential care), advice that Swaffer has coined 'Prescribed Dis-EngagementTM' by 2009, and which simply 'disempowers, devalues and demeans the person and lowers self-esteem'.¹⁴⁴ It is very important to raise awareness that people do not go straight to the end-stages of dementia after their diagnosis. As self-advocates claim, there is a life after diagnosis and they rather want to be perceived 'as agents' than 'victims'¹⁴⁵ or even 'sufferers'.¹⁴⁶ In June 2019, these misconceptions surrounding people diagnosed with dementia were referred to as follows

The misguided under-estimations of the potential of people with dementia continue to create oppressive and humiliating barriers to our full and equal engagement in society, and the continuing major breaches of our human rights through the systemic and endemic overuse of chemical and physical restraints, and though segregation and institutionalisation continue.¹⁴⁷

This quote puts prevailing risks and dangers that people diagnosed with dementia are exposed to due to established practices and social structures in a nutshell: They are being denied their basic rights of full and equal inclusion in society and are being segregated and abused.

An 'ethical pathway of care' with emphasis on post-diagnostic support and care was already demanded in 2015.¹⁴⁸ Such pathway requires a re-conceptualization of care which must be person-centered, relational, asset-oriented, rather than deficit-oriented. This is in line with Kittay, who coined the term 'ethics of care', which rejects over-

¹⁴¹ Birt et al., pp.200, 202.

¹⁴² Rohra, p.93.

¹⁴³ Bryden, p.36.

¹⁴⁴ Swaffer, 2015, p.3.

¹⁴⁵ Zimmerman, p.39.

¹⁴⁶ Swaffer, 2015, p.3;

also see my master thesis on preferred use of language by people diagnosed with dementia, chapter 2.1.1.

¹⁴⁷ DAI, 2019, p.3.

¹⁴⁸ DAI, 2016, p.2.

emphasizing independence as 'the norm of human functioning [...] to the degree that the impairment requires a carer for the disabled person to live her life, care (and the carer) is stigmatized by dependency'.¹⁴⁹ Being in need of care or rather assistance should not be seen as a 'sign of dependence but as a sort of prosthesis that permits one to be independent', and thus live in 'assisted autonomy',¹⁵⁰ which is of great importance to keep in mind for supported decision-making at later stages of dementia progression.¹⁵¹

'[C]are should be enabling, something that enhances my autonomy and allows me to participate in civil society, whilst promoting my dignity' as a member of the EWGPWD put it.¹⁵² In this light, society must look at care, dependency and interdependency in a nuanced way and not perceive it as limiting but rather as a way of improving the lives of people.¹⁵³

Thus, the term "care" based on a human rights, relational disability model must be conceptualized in a broader sense.¹⁵⁴ It must range from assistance and support ("enabling care"¹⁵⁵), which in the English version of the Austrian Dementia Strategy is suggested by the term 'social care'¹⁵⁶ to guarantee autonomy and independent living during the early stages of dementia, to hands-on, more complex care,¹⁵⁷ including palliative care, during the later stages and very last stage of life.¹⁵⁸ The ultimate goal of care must be enabling living well until the very end of life, meaning a dignified life and death. In this broad concept of care timely diagnosis is crucial as post-diagnostic care requires individualized care strategies that help individuals and their families 'better

¹⁴⁹ E.F. Kittay, 'The ethics of care, dependence and disability', *Ratio Juris*, vol.24, no.1, 2011, p.51.

¹⁵⁰ *ibid.*

¹⁵¹ see my master thesis, chapter 3.5.

¹⁵² Gove et al., p.36.

¹⁵³ *ibid.*, p.38.

¹⁵⁴ *ibid.*, pp.34, 37.

¹⁵⁵ *ibid.*, p.36.

¹⁵⁶ BMASGK, 2015b, p.12.

The term 'dementia care' is used for the German term 'Demenzgerechte Versorgung', see for example: BMASGK, 2015a, (German), pp.11, 38.

¹⁵⁷ Alzheimer's Disease International (ADI) and Dementia Alliance International (DAI), *Access to CRPD and SDGs By Persons with Dementia*, n. y., <https://www.alz.co.uk/sites/default/files/pdfs/access-crpd-dementia.pdf> (accessed 03 June 2020).

¹⁵⁸ see Swaffer, 2018, who presents her understanding of a new pathway of diagnostic support and care from timely diagnosis to end of life.

navigate complex health and social care systems.¹⁵⁹ It determines the dementia journey of a person and the years to come.

It is believed that the right to full participation and social inclusion of people diagnosed with dementia can only be realized in a 'dementia-friendly' society. According to the ADI, this is a place or culture in which people with dementia and their carers are 'empowered, supported and included in society, understand their rights and recognize their full potential.'¹⁶⁰ There have been a great number of initiatives and guidelines for communities how to become dementia-friendly and thus enable relational autonomy and independent living for people diagnosed with dementia.¹⁶¹ The website of the Austrian Dementia Strategy platform provides links for cities and communities as well.¹⁶²

Within this propagated community model, post-diagnostic follow up support and care must focus on rehabilitation to make it possible for people living with dementia to 'remain in their own homes, follow their interests and remain valued members of their communities.'¹⁶³ It is important to remember that just because people diagnosed with dementia share a common diagnosis, they must not be treated as if they all belong to one group. Swaffer claims that Community Based Rehabilitation (CBR) is a suitable approach to a personalized, community-embedded type of care and support. The aim of CBR is

to help people with disabilities by establishing community-based programs for social integration, equalisation of opportunities, and physical therapy rehabilitation for people with any type of disability.¹⁶⁴

She points out that CBR must be included in the development of national dementia policies. Alongside direct individual support, communities must be inclusive and accessible for people living with dementia in order to guarantee full citizenship for

¹⁵⁹ see for example: World Dementia Council, p.25.

¹⁶⁰ Alzheimer Disease International (ADI), 'principles of a dementia friendly community', *dementia friendly communities*, n. y., <https://www.alz.co.uk/dementia-friendly-communities/principles> (accessed 14 April 2020).

¹⁶¹ see for example: ibid and DAI, *inclusive communities*, <https://www.dementiaallianceinternational.org/dementia-friendly-communities/> (accessed 14 April 2020).

¹⁶² https://www.demenzstrategie.at/fxdata/demenzstrategie/prod/media/Factsheet_Gemeinden_Juli19.pdf; <https://www.demenzstrategie.at/de/Service/Materialien/Materialien-fuer-Staedte-und-Gemeinden.htm>; <https://www.senior-in-wien.at/p/demenzfreundliches-wien>.

¹⁶³ ADI, DAI, *Access*, n.p.

¹⁶⁴ Swaffer, 2018, n.p.

people. Yet, she rejects the term dementia-friendly 'as too often the awareness-raising initiatives are still based on our deficits.'¹⁶⁵ In this context the term dementia-enabling community would be more precise.¹⁶⁶ The ideal is that communities need not be 'friendly' to people diagnosed with dementia which may sound patronizing but rather strive for a universal design that includes everyone not just adapting to the needs and wishes of certain vulnerable groups.¹⁶⁷

CBR could be equated with or could be a component of 'community-based care'. Stoppenbrink prefers the term 'community-based living' as a form of inclusion which people diagnosed with dementia have a right to as laid down in art.19 of the CRPD.¹⁶⁸

Summarizing my section on the conceptualization of dementia care, I would like to state that only re-conceptualized dementia care encompassing a human rights model of disability with focus on relationality as laid out above may guarantee enjoyment of full human rights.

In chapter 3. of my master thesis I will present human rights aspects relevant to dementia, my detailed dementia human rights framework. Before, the following section will provide information on how this framework is established and later is utilized. Besides, this chapter lays out details on my methodology in general.

2.3. Methodology

After having introduced the general theoretical and conceptual foundation relevant to my research question, I will now describe the methods that I have chosen for the two qualitative document/text analyses and the empirical study. The two document/text analyses explore the conceptualization of the Austrian Dementia Strategy from a human rights perspective and provide contextual information for my empirical study, which

¹⁶⁵ *ibid.*

¹⁶⁶ see dementia-enabling support used in: N. Batsch, P. Mittler, D. Kingston, *Brief for Alzheimer associations: Access to the United Nations Convention on the Rights of Persons with Disabilities by people living with dementia*, Disease International (ADI) and Dementia Alliance International (DAI), August, 2017, p.2, <https://www.alz.co.uk/ADI-publications> (accessed 20 May 2020).

¹⁶⁷ Gove et al., p.41.

¹⁶⁸ K. Stoppenbrink, 'Zwischen allen Stühlen – oder besonders berechtigt? Demenz und das Recht auf Inklusion nach der UN-Behindertenrechtskonvention' in M. Schmidhuber, A. Frewer, S. Klotz, H. Bielefeld (Hg.), *Menschenrechte für Personen mit Demenz Soziale und ethische Perspektiven*, Bielefeld, transcript Verlag, 2019, p.89;
also see later, my master thesis, chapter 3.4.

focuses on personal experience and perceptions of practical work in dementia care from a human rights angle linked to the Austrian Dementia Strategy.

2.3.1. Document analysis (human rights framework)

The first analysis is a document analysis and establishes a human rights frame including the main areas or categories relevant for a human rights-based approach to dementia. The established categories serve as a codebook for the subsequent analysis of the Austrian Dementia Strategy.

My document analysis is based on Bowen's understanding of being a 'systematic procedure for reviewing or evaluating documents.'¹⁶⁹ Documents are examined superficially (=skimming), then thoroughly (=reading) and interpreted, an 'iterative process combining elements of content analysis and thematic analysis.'¹⁷⁰

The information gained from a selected body of literature/documents (=content analysis) is organized into categories (= 'the emerging themes').¹⁷¹ I analyze selected documents by coding and category construction, more precisely by developing categories in an inductive or, as in Kuckartz's preferred terminology 'data-driven'¹⁷² way. Thus, I identify key human rights areas relevant for people diagnosed with dementia because they are, to use Bowen's words, 'related to central questions of the research.'¹⁷³

Bowen points out that documents must be looked at 'with a critical eye'.¹⁷⁴ I have chosen documents after critical evaluation on the basis of their relevance to dementia and human rights aspects, and I am aware that they differ in nature, according to their original purpose and target.¹⁷⁵ On the outset of my research on dementia and human rights I came across academic articles from various fields discussing human rights aspects linked to dementia. Within the dementia disability movement that I described

¹⁶⁹ G. Bowen, 'Document Analysis as a Qualitative Research Method', *Qualitative Research Journal*, vol.9, no.2, 2009, p.27.

¹⁷⁰ *ibid*, p.32.

¹⁷¹ *ibid*.

¹⁷² U. Kuckartz, 'Qualitative Text Analysis: A Systematic Approach', in G. Kaiser, N. Presmeg N. (eds.) *Compendium for Early Career Researchers in Mathematics Education. ICME-13 Monographs*. Springer, Cham, 2019, p.185.

¹⁷³ Bowen, p.32.

¹⁷⁴ *ibid*, p.33.

¹⁷⁵ see my master thesis, chapter 4.1.

earlier¹⁷⁶ lived experience plays an important role, and the CRPD is considered a suitable tool for propagating changes in social and disability policies of Member States. This is the reason my documents focus on this particular human rights treaty. In the combined description and discussion of the identified categories content-relevant information taken from General Comments (GCs) on specific articles and reports from the Special Rapporteur on the Rights of Persons with Disabilities.¹⁷⁷ They are included for comprehensive contextual richness and allow me to apply an even sharper human rights lens. By doing so, I establish human rights categories for the subsequent single document analysis, the analysis of the Austrian Dementia Strategy.

2.3.2. Analysis of the Austrian Dementia Strategy

A qualitative content-analysis has been chosen to give information on the conceptualization of the Austrian Dementia Strategy (document) before focusing on its relevance for practical work in the field of dementia care, which is covered in my empirical study. The central question refers to the role human rights play in its conceptualization. I explore how or to which extent key human rights areas (in particular linked to the CRPD) reflected on paper, explicitly and/or implicitly.

In order to answer this question, the content of the Austrian Dementia Strategy is analyzed based on Mayring's content-analytical method,¹⁷⁸ which allows a systematic assessment of the single document by deductive-category assignment applying my human rights categories. The form of interpretation is structuring, i. e. 'the object of the analysis is to filter out particular aspects of the material, to give a cross-section through the material according to pre-determined ordering criteria, or to assess the material according to certain criteria'.¹⁷⁹ But the analysis is not limited to a mere description of the results per categories but will look at the relationship of two or more categories as suggested by Kuckartz.¹⁸⁰

¹⁷⁶ see my master thesis, chapter 2.1.2.

¹⁷⁷ see my master thesis, chapter 3.

¹⁷⁸ P. Mayring, *Qualitative content analysis: theoretical foundation, basic procedures and software solution*, Klagenfurt, 2014, p.95.

¹⁷⁹ *ibid*, p.64.

¹⁸⁰ Kuckartz, p.195.

The human rights categories I have established through the first document analysis are:

1. awareness-raising
2. accessibility
3. health / (re)habilitation
4. participation and independent living
5. equality before the law

Apart from the analysis of the Austrian Dementia Strategy (document), the Dementia Report of 2014¹⁸¹ will briefly be looked at, as it served as the basis of the Austrian Dementia Strategy. In addition, general information and facts on the document and so-called Dementia Platform¹⁸² will be provided to give a more comprehensive picture of the conceptualization of the Austrian Dementia Strategy.

2.3.3. Empirical study (dementia care in Austria)

The information gained in the theoretical/conceptual part and the two document analyses will provide background information on the human rights context relevant to dementia. This will add contextual richness to my empirical study, which is based on Grounded Theory (GT) methodology but not so much in the classic sense of Glaser and Strauss,¹⁸³ who 'talk about discovering theory as emerging from data separate from the scientific observer'¹⁸⁴ but on Charmaz's (2006) constructivist theory¹⁸⁵. As I myself have gained some experience with people diagnosed with dementia during my internship, I do not see myself as a completely detached 'scientific observer'. Charmaz's intention is not to draw an exact picture of the studied world, but in her understanding Grounded Theory only offers an 'interpretive portrayal' and constructions of reality.¹⁸⁶ My study is aimed to do the same: to render an interpretation of my limited studied world of dementia care in the context of the Austrian Dementia Strategy and human rights.

¹⁸¹ S. Höfler, T. Bengough, P. Winkler, R. Giebler, *Österreichischer Demenzbericht 2014*, Wien, Bundesministerium für Gesundheit und Sozialministerium, Jänner 2015.

¹⁸² see <https://www.demenzstrategie.at/> - the website is the digital medium of the Plattform.

¹⁸³ B. Glaser, A. Strauss, *The Discovery of Grounded Theory: Strategies for Qualitative Research*, Mill Valley, CA, Sociology Press, 1967.

¹⁸⁴ K. Charmaz, *Constructing Grounded Theory*, London, SAGE, 1st edition, 2006, p.10.

¹⁸⁵ *ibid.*

¹⁸⁶ *ibid.*

I explored the personal experience, perceptions and opinions of professionals working with people diagnosed with dementia and their families/caregivers in the field of dementia care from a human rights perspective. My research interest lies in the relevance of human rights in the field of dementia care experienced by professionals five years after introduction of the Austrian Dementia Strategy.

The method of my data analysis is GT. The participants were professionals working in the field of dementia (consultancy, care and support, adult protection).¹⁸⁷ The sampling strategy is multi-level purposive, non-probability sampling¹⁸⁸ with an element of convenience sampling allowing easier access to the samples.¹⁸⁹

The data was generated by carrying out semi-structured, intensive interviews as laid out by Charmaz.¹⁹⁰ My 'constructed' not 'ready-made' conceptual framework,¹⁹¹ established in the first part of my master thesis, served as my 'point of departure to form interview questions, to look at data, to listen to interviewees, and to think analytically about the data' to use the original words of the founder of constructivist Grounded Theory, Kathy Charmaz.¹⁹²

After conducting and transcribing¹⁹³ the first two interviews, I began to work with my early data by carrying out grounded theory qualitative coding based on Charmaz.¹⁹⁴ In her understanding, coding consists of at least two phases, initial coding and focused coding. The initial coding process allows to explore 'whatever theoretical possibilities can be found in the data [and] moves us towards decisions about defining our core conceptual categories.'¹⁹⁵ Line-to-line coding produces the most frequent early themes/categories labeled with names (codes).¹⁹⁶ During focused coding the most relevant initial codes for categorizing the data are selected.¹⁹⁷ During the whole coding

¹⁸⁷ for detailed information see my master thesis, chapter 6.1.

¹⁸⁸ see A. Bryman, *Social Research Methods*, Oxford University Press, 2016, 5th edition, pp.408-409.

¹⁸⁹ for details see my master thesis, chapter 6.1.

¹⁹⁰ see Charmaz, pp.25-26; for more details on my interview guide see my master thesis, chapter 6.1. and annex 1.

¹⁹¹ J. Maxwell, *Qualitative Research Design: An Interactive Approach*, 2012, vol.41. Sage publications, p.223.

¹⁹² Charmaz, p.17.

¹⁹³ for transcription rules see my master thesis, annex 2.

¹⁹⁴ Charmaz, chapter 3.

¹⁹⁵ *ibid*, p.47.

¹⁹⁶ *ibid*, p.50.

¹⁹⁷ *ibid*, p.57.

process writing short narratives about a code (memos) helps conceptualize data and tie categories together,¹⁹⁸ especially during/after focused coding before writing up the analysis. Memo-writing often prompts theoretical sampling which is used to elaborate and fine-tune data as Grounded Theory is an iterative approach.¹⁹⁹ My sampling size was due to theoretical saturation which is achieved if, according to Charmaz, new data no longer contributes to shaping the core theoretical categories related to my research question.²⁰⁰

Through the iterative, reflective process comparing data through different stages of analysis my research question is answered by having developed my own ideas and in the end specific concepts.²⁰¹ The readers gain an insight and understanding of the role human rights play in practical work grounded in raw data, namely the experience of professionals working within the area of dementia support and care services of my limited empirical world of study five years after introduction of the Austrian Dementia Strategy.

2.4. General interdisciplinary approach

My master thesis adopts a broad interdisciplinary approach in the analysis of the conceptualization and implementation of the Austrian Dementia Strategy. Its overarching framework is a human rights approach, including legal norms, practices and policymaking. The human rights lens is complemented with a variety of lenses as different disciplines and their concepts are drawn on, generally underpinned by critical theory, which emphasizes the role of lived experience.²⁰² People diagnosed with dementia experience stigmatization and marginalization due to society's generally accepted assumptions and norms. They often become invisible from the time of diagnosis. Yet, their voices must be listened to and heard in order to effectively question and eventually change their social situation and inequality. Throughout my master thesis literature, for example books, articles, position papers, documents written by self-

¹⁹⁸ *ibid*, p.91.

¹⁹⁹ *ibid*, p.72.

²⁰⁰ *ibid*, p.113.

²⁰¹ Charmaz, p.3.

²⁰² D. Kellner, 'Critical theory today: Revisiting the classics', *Theory, Culture & Society*, vol.10, no.2, 1993, pp. 43–60.

advocating groups, people diagnosed with dementia with²⁰³ or without support²⁰⁴ or in cooperation with scholars²⁰⁵ is utilized as valuable sources. Other academic sources describe and discuss studies based on lived experience, and thus the voices of people with dementia are recognized indirectly²⁰⁶.

In the second part of my master thesis (empirical study) lived experience plays an important role as well, but from a different perspective. In order to find out what role human rights play in the implementation of the Austrian Dementia Strategy the voices of experts working in the broad field of dementia care are listened to, and the voices of people living with dementia resonate rather indirectly.

In fact, participation of vulnerable groups is an inherent aspect of a human rights-based approach to social inequality and shared by disability studies.²⁰⁷ In the context of dementia, a closer look at the concept of dementia as a disability and its models and, in particular, a re-conceptualization of dementia care is required as it is the precondition for a good life in dignity and respect for people living with dementia. Only with adequate and appropriate support and care participation and inclusion of people living with dementia in society can be achieved. Therefore, my thesis draws on findings in the fields of healthcare (especially aged care), gerontology, philosophy, bioethics and sociology, which all give valuable input for a critical assessment of the Austrian national dementia policy towards quality dementia care within a human rights-based approach.

Yet, in order to apply a sharp human rights lens throughout my analyses of the Austrian Dementia Strategy, a solid human rights frame must be established, which will be done in the subsequent chapter.

²⁰³ see for example: Bryden.

²⁰⁴ see for example: Swaffer, 2018.

²⁰⁵ see for example: Shakespeare et al.

²⁰⁶ see for example: Sinclair et al.

²⁰⁷ L. Löve, R. Traustadóttir, J. Rice, 'Shifting the Balance of Power: The Strategic Use of the CRPD by Disabled People's Organizations in Securing 'a Seat at the Table'', *Laws*, vol.8, no.11, 2019, p.1.

3. HUMAN RIGHTS FRAMEWORK

A comprehensive human rights framework for my master thesis is important for the analysis of the document of the Austrian Dementia Strategy and also as a starting point for the empirical study.

As briefly mentioned in chapter 2.3.1., my selected sources for the following analysis differ in nature²⁰⁸ but all cover human rights issues linked to dementia and the CRPD. Even if it may seem unusual to include academic articles in a document analysis, I decided to do so, as they fulfill the criteria of my selection.²⁰⁹ The common elements of my body of documents are the explicit reference to the CRPD (among other human rights treaties) linked to dementia and their time of publication between 2016 and 2019.²¹⁰

Generally, they take or mention different approaches, e.g. the PANEL approach,²¹¹ or discuss human rights issues within cross-cutting themes and priority areas.²¹² Others identify articles of the CRPD, either generally²¹³ relevant for people with dementia or relevant for its different stages of progression.²¹⁴

By means of data-driven coding I organized the information into a category system, which is a synthetic category construction, where 'the category system actually constitutes the findings of the analysis.'²¹⁵ The five major categories are: 1. awareness-raising, 2. accessibility, 3. health/(re)habilitation, 4. independent living and participation 5. equal recognition before the law. Under these categories, specific articles of the CRPD and themes have been subsumed and cover both, obligations of duty bearers as well as rights to be upheld.

²⁰⁸ Policy paper: Crowther (2016, for DAI, ADI collaboration).

Position papers: ADI, DAI, *Access to CRPD* (n.y.); Gove et al. (2017, for Alzheimer Europe).

Brief for Alzheimer's associations): Batsch et.al. (for ADI, DAI, 2017).

Handout for UN conference: DAI, 2019.

Charter of Rights (self-advocates): Cross-Party Group on Alzheimer's, *Charter of Rights* (2009)

Official WHO document: WHO; 2017.

²⁰⁹ Academic articles published in different areas of studies: Shakespeare et al. (disability studies); Steele et al. (law) (in collaboration with self-advocates); Sinclair et al. (bioethics) and Harding (law).

²¹⁰ apart from the Cross-Party Group on Alzheimer's, *Charter of Rights*, published in 2009.

²¹¹ Cross-Party Group on Alzheimer's, *Charter of Rights*.

²¹² WHO, 2017.

²¹³ DAI, 2019; Crowther; Gove et. al.

²¹⁴ Gove et al.; ADI, DAI, *Access*.

²¹⁵ Mayring, p.40.

Before focusing on details, the findings can be summarized as follows:

The two categories awareness-raising and accessibility are a good starting point in a human rights-based approach to dementia, as they are the preconditions for enabling well-being for persons diagnosed with dementia and their care-partners throughout all stages. Quality of life for all is only possible with equal access to health and rehabilitation (category 3) that - by providing adequate dementia care - enables people to live independently, be included and participate in society (category 4). Finally, being recognized as a full citizen with legal rights must continue until the end of life by guaranteeing equality before the law (category 5).

3.1. Awareness-raising

Throughout my body of selected literature the importance of overcoming stigmatization and discrimination surrounding dementia resonates or is explicitly stated, which is not surprising in documents focusing on or promoting human rights for persons living with dementia. Art.8 of the CRPD prompts State Parties to 'combat stereotypes [and] prejudice by 'adopt[ing] immediate, effective and appropriate measures'.²¹⁶ Not long after adoption of the CRPD, the Charter of Rights for People with Dementia and their Carers in Scotland was published. One general goal was and still is 'to raise awareness and campaign for the rights of people with dementia and their carers to be recognized.'²¹⁷ One of the reasons for having drawn up the Charter was to address the attitudes in society where persons diagnosed with dementia 'still face stigma and discrimination in society as well as lack of equity of access to high-quality dementia care services.'²¹⁸

The ADI and DAI expressed their position based on lived experience as follows:

The greatest single obstacle to the continued participation of persons with dementia in society arises from the stigma and fear of dementia in the general population and under-estimation of their capacity by politicians, professionals, researchers and the community.²¹⁹

²¹⁶ art.8 of the CRPD.

²¹⁷ Cross-Party Group on Alzheimer's, *Charter of Rights*, n. p.

²¹⁸ *ibid.*

²¹⁹ ADI, DAI, *Access*, n. p.

In June 2019 during the Side Event of the States Parties to the CRPD, self-advocates of DAI bluntly reaffirmed the importance of tackling misconceptions by 'countering the myth that people with dementia go from the point of diagnosis immediately to the end-stages of the disease.'²²⁰ They have experienced that immediately upon diagnosis their legal and social status as equal citizens and their human rights are taken away, which is terribly disabling.²²¹ Even if my selected documents do not discuss the intersectionality of ageism and disability linked to dementia directly, a lot of misconceptions are rooted in it, as two recent reports by the Special Rapporteur on the Rights of Persons with Disabilities, Catalina Devandas Aguilar, suggest.²²² According to her,

[...] ageist perceptions and attitudes regularly preclude the provision of full and equal access to universal health care for older persons with dementia. Little attention is paid to persons with early onset dementia who experience ageism, owing to the common misperception that dementia is only an older person's condition. Fear of labelling and discrimination on the basis of a dementia diagnosis is also common given the limited knowledge about dementia among health-care professionals, poor diagnostic tools [...]²²³

Thus, misconception that dementia is a natural part of ageing and therefore inevitable constitutes a barrier to timely diagnosis and care.²²⁴ Such stigmatization, discrimination and social isolation are experienced by a great number of persons living with dementia and hinder them to participate in society and to achieve the social change required to guarantee their well-being and inclusion.²²⁵ Crowther compiled a policy paper for the DAI/ADI collaboration in their advocacy for the enjoyment of human rights for persons diagnosed with dementia. In this paper he suggests avenues for harnessing the CRPD, the international human rights treaty, as an effective tool to bring about social change on

²²⁰ DAI, 2019, n.p.

²²¹ *ibid.*

²²² see Special Rapporteur on the Rights of Persons with Disabilities, *Report on older persons with disabilities*, to the GA at its 74th session, 21 October 2019b, A/74/186; and Special Rapporteur on the Rights of Persons with Disabilities, *Report on the impact of ableism in medical and scientific practice*, to the HRC at its 43rd session, 28 February 2020, A/HRC/43/41.

²²³ Special Rapporteur 2019b, para.21, p.10.

²²⁴ WHO, 2017, p.16.

²²⁵ Crowther, p.2.

a domestic level.²²⁶ He stresses the fact that change can only be effected by involving persons diagnosed with dementia from the very beginning in order to raise awareness for their families' and their own situation.²²⁷ On a national and local level awareness-raising could start by developing dementia-friendly, age-friendly and inclusive communities, which must entail changing all aspects of the social and built environments. The promotion of amenities, goods and services to meet the needs of people with dementia must be included in national dementia strategies.²²⁸ All this is laid out in detail in action area 2 of the global response to dementia by the WHO (2017) document, which suggests as effective awareness-raising the following:

In collaboration with people with dementia, their carers and the organizations that represent them, the media and other relevant stakeholders, organize national and local public health and awareness campaigns that are community- and culture-specific. [This] will improve the accuracy of the general public's knowledge about dementia, reduce stigmatization, [...], promote early diagnosis, and [...] recognition of human rights and respect for the autonomy of people with dementia.²²⁹

This kind of awareness-raising is definitely aligned with the provisions of art.8 of the CRPD. In 2017 the WHO set as an ambitious global target for 2025 to have 'at least one functioning public awareness-raising campaign on dementia to foster dementia-inclusive society in all countries of the world.'²³⁰

Together with awareness-raising, accessibility is another precondition for dementia-inclusive communities, eventually leading to universal design of a community where no adaptations or specialized design are needed any longer to be 'usable by all people, to the greatest extent possible.'²³¹ Only if all people, including people living with dementia, are able to access community services, amenities and information equally,

²²⁶ *ibid*, p.1; he suggests a great number of steps to be taken internationally and regionally as well, see Crowther, pp.5-6.

²²⁷ *ibid*, pp.4-5.

²²⁸ *ibid*, p.4.

²²⁹ WHO, 2017, p.15.

²³⁰ *ibid*.

²³¹ see CRPD, art.2. definition of 'Universal Design'.

independent living and full participation in all aspects of life in our communities is equally possible.

3.2. Accessibility

According to art.9, States Parties have the obligation to guarantee the right to accessibility. In addition, to being a self-standing article accessibility is one of the general principles of the CRPD.²³² Its importance is furthermore affirmed by General Comment (GC) no.2 (2014),²³³ whose aim is to provide guidance to States Parties on how to practically implement accessibility standards and relevant legislation. It refers, inter alia, to the fact that accessibility is often perceived too narrowly and how closely awareness-raising and accessibility are interconnected:

Awareness-raising is one of the preconditions for the effective implementation of the [CRPD]. Since accessibility is often viewed narrowly, as accessibility to the built environment [...] States parties should strive systematically and continuously to raise awareness about accessibility among all relevant stakeholders. The all-encompassing nature of accessibility should be addressed, providing for access to the physical environment, transportation, information and communication and services.²³⁴

In the context of dementia, the focus must be on substantive equality linked to the right of access, i. e. accessibility must be viewed from the specific perspective of dementia, which entails specific obligations for State Parties.²³⁵ It is pointed out that people experiencing 'cognitive fatigue' may have problems in orientation in the physical environment.²³⁶ As in general it may be difficult for them to grasp information and to communicate, adequate signage, easy-to-read and understand information off-line and online or live assistance and support services must be provided to ensure full enjoyment of human rights.²³⁷ Even if in my analyzed documents the right to accessibility per se is

²³² see art.3(f).

²³³ Committee on the Rights of Persons with Disabilities (CRPD Committee), *General Comment No.2 – Art.9: Accessibility*, CRPD/C/GC/2, 22 May 2014.

²³⁴ *ibid*, para.35, p.10

²³⁵ *ibid*, para.14, p.5.

²³⁶ *ibid*, para.20, p.6.

²³⁷ *ibid*.

not discussed in great detail, the importance as a cross-cutting principle has become clearly evident and justifies a separate category. As, in fact, all the documents are underpinned by a human rights-based approach to dementia, access of self-advocating dementia groups and organizations to decision-making bodies is claimed. The right to involvement of these groups is stipulated by art.4.3 and art.33, which will be dealt with in subchapter 3.4. of this section.

The subsequent three major human rights thematic areas worked out as categories in my analysis refer to the right to health and (re)habilitation, the right to independent living and full participation and the right to equality before the law, which are only possible if accessibility is fully respected and promoted.

3.3. Health and (re)habilitation

In public opinion surveys persons diagnosed with dementia have reported as 'first priority [...] rehabilitation and support'²³⁸ and their 'right to know their own diagnosis and obtain the information needed in order to understand the progression of their condition.'²³⁹ In June 2019 at the CRPD Side Event '[t]he overarching theme [was] social inclusion and health, which are two of the determinants of well-being.'²⁴⁰ The prime focus of all the documents analyzed was on the importance of quality dementia care. In the Scottish Dementia Charter of 2009 it was clearly stated that dementia care comprises a 'comprehensive service, [...] proper support, care and treatment which they need to continue to live fulfilling lives',²⁴¹ which must be mainstreamed in health and social systems and made available to all from early diagnosis to end of life care.

Although in the analyzed documents different labels are used for dementia care, e.g. 'long term care supports' and 'multi-level supports'²⁴², 'long-term care pathways',²⁴³ 'care and support'²⁴⁴, they all imply quality health and social care and support throughout all

²³⁸ ADI, DAI, *Access*, n. p.

²³⁹ Batsch et al., p.3.

²⁴⁰ DAI, 2019, n.p.

²⁴¹ Cross-Party Group on Alzheimer's, *Charter of Rights*, n. p.

²⁴² Batsch et al., p.5.

²⁴³ WHO, 2017, p.3.

²⁴⁴ Steele et al. throughout their article.

stages of the dementia journey, from diagnosis until the end of life.²⁴⁵ The WHO (2017) Global Action Plan to dementia criticizes that this type of care for persons living with dementia is 'frequently fragmented if not entirely lacking.'²⁴⁶ However, the right to personalized, highly individualized (health) care in order to be able to fully participate and be included in society is reflected in art.25 (right to health) and art.26 (right to habilitation and rehabilitation).²⁴⁷

Art.25 asserts the right to 'the enjoyment of the highest attainable standard of health without discrimination on the basis of disability.'²⁴⁸ The States are obliged to make the following services available and accessible:

[H]ealth services needed by persons with disabilities specifically because of their disability, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons.²⁴⁹

The right to timely diagnosis of dementia is clearly laid out, but limited access to diagnosis has been an obstacle in providing quality dementia care, which still prevails due to lack of general awareness and understanding of dementia in society and resulting stigmatization.²⁵⁰ The WHO (2017) in its global response to dementia dedicated action area 4 exclusively to diagnosis, treatment, care and support²⁵¹ and has chosen universal health and social care coverage for dementia as one of the cross-cutting principles:²⁵²

Designing and implementing health programmes for universal health coverage must include financial risk protection and ensuring equitable access to a broad range of promotive, preventive, diagnostic and care services (including palliative, rehabilitative and social support) for all people with dementia and their carers.²⁵³

Again, this quote summarizes the need of dementia care to be long-term and multi-disciplinary, integrating different support services to guarantee well-being for persons

²⁴⁵ see for more detailed information on the concept of dementia care, my master thesis, chapter 2.2.2.

²⁴⁶ WHO, 2017, p.3.

²⁴⁷ CRPD, art. 25 and art. 26.

²⁴⁸ *ibid*, art. 25.

²⁴⁹ *ibid*, art. 25(b).

²⁵⁰ WHO, 2017, p.3.

²⁵¹ *ibid*, pp.22-25.

²⁵² *ibid*, p.5; also see DAI, 2019, n. p.

²⁵³ WHO, 2017, p.5.

living with dementia and their care-partners throughout the dementia journey. Yet, according to Devandas Aguilar, 'in many countries, persons with dementia are offered no rehabilitation services, nor is the condition yet seen or managed by health-care professionals as a condition leading to disability.'²⁵⁴

Good health is closely linked to the right to rehabilitation laid down in art.26, which obliges States Parties to take effective measures and provide services that

(a) Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths.

(b) Support participation and inclusion in the community [...]²⁵⁵

(Re)habilitation is thus a precondition for independent living and full inclusion in society for persons diagnosed with disability. In order to support them adequately and professionally to make it possible for them to remain as active citizens in their own homes²⁵⁶ and continue living well,²⁵⁷ initial and continuing training and education for professionals and staff must be promoted and funded by the States Parties. The same is true for family members, who are often informal care-partners.²⁵⁸

The provision of the above discussed articles 25 and 26 are crucial for person-centered, high-quality dementia care. If provided, they would guarantee the following rights, which I consider sub-themes in this category:

- liberty and security of person (art.14)
- freedom from torture, inhumane or degrading treatment (art.15)
- freedom from exploitation, violence and abuse (art.16)

These three rights have been mentioned as being breached in various documents.²⁵⁹ Above all, art.14²⁶⁰ is often associated with later stages of dementia²⁶¹ and, together with art. 15 and art. 16 especially with regards to Lower and Middle Income Countries, may be infringed upon at all stages of dementia. This is 'regardless of a country's

²⁵⁴ Special Rapporteur, 2019b, para.25, p.11.

²⁵⁵ CRPD, art. 26, 1(a), (b).

²⁵⁶ Batsch et al., p.2.

²⁵⁷ DAI, 2019, n. p.

²⁵⁸ CRPD, art. 26, 2; also see for example: Batsch et al., p.4; WHO, 2017, p.23.

²⁵⁹ see for example: Cross-Party Group on Alzheimer's, *Charter of Rights*; Crowther; ADI, DAI, Access; Batsch et al.; DAI, 2019.

²⁶⁰ see for in depth discussion of violation of art.14 in Steele et al.

²⁶¹ see for example: Batsch et al., p.4; Steele et al.

income level',²⁶² as Devandas Aguilar outlined in her report (2019a) on disability-specific forms of deprivation of liberty in spring 2019. She mentions that deprivation of liberty is particularly common for persons with intellectual or psychosocial disability, among those, 'older persons with dementia are frequently impeded from leaving their own homes purportedly for their own safety.'²⁶³ This is due to the prejudice that they may be violent and dangerous, and it is a 'necessary evil'²⁶⁴ to restrain them physically, mechanically and/or chemically in order to manage their challenging behavior.²⁶⁵ In this context during the Side Event in June 2019 it was pointed out that according to UN Treaty Bodies, forced medication, disproportionate use of anti-psychotic drugs, detention in psychiatric institutions and care facilities without a chance to return to the community constitute a violation of freedom from torture, inhumane or degrading treatment.²⁶⁶

In her report of spring 2019, Devandas Aguilar (2019a) criticized States'

inaction to implement human rights, particularly the rights to legal capacity, integrity, access to justice, living independently in the community, the highest attainable standard of health, [...]'²⁶⁷

She continues that due to a lack of adequate support and care persons with disabilities are placed in institutional care, which causes grave structural discrimination. It is the Member States' obligation to overcome these inequalities by implementing deinstitutionalization policies.²⁶⁸ They are urged to adopt a clear human rights approach including plans of action with 'clear timelines and benchmarks [...] and the development of adequate community support.'²⁶⁹

Her October 2019 report with focus on the intersection between old age and disability calls for a paradigm shift in the perception of and interaction with older people in societies all over the world, which could be achieved by more legal commitment of governments to support the autonomy of older people with disabilities and their full

²⁶² Special Rapporteur, 2019a, para.29, p.8.

²⁶³ *ibid*, para.22-23, pp.6-7.

²⁶⁴ *ibid*, para. 86, p .19.

²⁶⁵ DAI, 2019, n. p.

²⁶⁶ *ibid*.

²⁶⁷ Special Rapporteur, 2019a, para.86, p.19.

²⁶⁸ see more in subsequent category.

²⁶⁹ *ibid*, 87(c).

inclusion in society.²⁷⁰ Her latest report (February/March 2020) outlines how ableism and ageism are obstacles for persons with disability to be fully included, as the general societal perception of older persons with disability is one of not being able to live a life in dignity, simply to have quality in life.²⁷¹ This brings me to my fourth category, which subsumes several articles²⁷² that provide the foundation for full inclusion in society.

3.4. Independent living and participation

The importance of dementia-inclusive communities as precondition for full inclusion in society resonates throughout my selected body of literature and has been referred to in my master thesis before as precondition for quality dementia care²⁷³. In 2009 the Dementia Charter, for example, claims that '[p]eople with dementia and their carers have the right to live as independently as possible with access to recreational, leisure and cultural life in their community.'²⁷⁴ Other documents explicitly use the term 'dementia-friendly communities'²⁷⁵ or 'dementia friendly community programmes'²⁷⁶. Shakespeare et al. point out the problematic use of the term 'dementia friendly' as

People with dementia have lived independently and been fully participating members of their community all their lives but encounter deep-rooted and systemic attitudinal and societal obstacles to continue to do so following diagnosis.²⁷⁷

They believe that 'dementia friendly' even if meant in a positive way could be considered patronizing because it is not as simple as that 'the solution to the dementia problem is for people without dementia to be kind and welcoming of people with dementia.'²⁷⁸ They continue arguing that being 'friendly' as a response to 'socially imposed barriers, devaluing and even human rights violations' would not be used for

²⁷⁰ see Special Rapporteur, 2019b.

²⁷¹ see Special Rapporteur, 2020.

²⁷² for example, art.19, art.4(3) and art.33(3).

²⁷³ see my master thesis, chapter 2.2.2.

²⁷⁴ Cross-Party Group on Alzheimer's, *Charter of Rights*, n. p.

²⁷⁵ ADI, DAI, *Access*, n.p.

²⁷⁶ Crowther, p.4.

²⁷⁷ Shakespeare et al., pp.1080-1081.

²⁷⁸ *ibid*, p.1081.

other excluded groups and thus inappropriate.²⁷⁹ A more suitable term is 'enabling' community, which is also preferred for example by Swaffer.²⁸⁰

Dementia-friendly initiatives could be a good starting point in order to draw attention to ongoing structural discrimination as already discussed before. Nevertheless, they must not focus on the difference and deficits of people living with dementia to which the environment and society must be adapted but rather genuinely listen to what they themselves and their care partner need and wish for in order to fully be able to participate and continue living as full equal citizens.²⁸¹

States are required to enable persons diagnosed with dementia 'to choose and decide how, where and with home to live, [which is] the central idea of the right to live independently and be included in the community,' as GC no.5 stresses in its clarification of art.19.²⁸² In her report the Special Rapporteur (2019b) expresses particular concern of so-called dementia villages in developed countries that are not best practice for independent living but rather a 'systemic form of disability-based segregation and isolation' in disguise,²⁸³ which actually goes against the core message of GC no.5. States are obliged to implement deinstitutionalization policies to eradicate any form of segregation and isolation of disabled people as art.19

is ultimately about transforming communities. Stereotypes, ableism and misconceptions that prevent persons with disabilities from living independently must be eradicated and a positive image of them and their contributions to society must be promoted.²⁸⁴

In their article of August 2019 Steele et al. are in line with this and also the earlier cited Special Rapporteur's (2020) claim transforming society by building communities 'free from ableism, ageism and other systems of oppression', which eventually ensure full inclusion of persons diagnosed with dementia as well.²⁸⁵ Yet, it is pointed out that it

²⁷⁹ *ibid.*

²⁸⁰ see Swaffer, in my master thesis, chapter 2.2.2.

²⁸¹ see Gove et al., p.41; Crowther, p.3.

²⁸² Committee on the Rights of Persons with Disabilities (CRPD Committee), *General Comment No.5 – Art. 19: Living independently and being included in the community*, CRPD/C/18/1, 29 August 2017, para.24, p.6.

²⁸³ Special Rapporteur. 2019b, para.32, p.12.

²⁸⁴ *ibid.*, para.77, p.14.

²⁸⁵ Steele et al., p.4.

does not suffice simply 'unlocking doors or closing large-scale institutions',²⁸⁶ but that structural and resource reforms are required that are

transformative in bringing about new ways of living and relating to each other - that are directed towards providing meaningful alternatives and appropriate support to choose from a range of alternative residency and support options.²⁸⁷

GC no.5 clarifies States Parties' immediate obligation to tackle deinstitutionalization which

requires a systemic transformation, which includes the closure of institutions and the elimination of institutionalizing regulations as part of a comprehensive strategy along, with the establishment of a range of individualized support services, including individualized plans for transition with budgets and time frames as well as inclusive support services. Therefore, a coordinated, cross-government approach which ensures reforms, budgets and appropriate changes of attitude at all levels and sectors of government, including local authorities, is required.²⁸⁸

No doubt, art.19 entails the need of a paradigm shift in dementia care as discussed in chapter 2.2.2. because it challenges long established social practices. Perceiving dementia within a human rights approach as a disability requires Member States to provide persons diagnosed with dementia with personalized support 'tailored to the specific activities and actual barriers to inclusion in the community', thus it must be 'available, accessible, affordable, acceptable and adaptable [...]'.²⁸⁹

In order to achieve such structural transformation, full collaboration across relevant sectors and full political commitment of decision-makers on national, regional and local levels is required. Shakespeare et al. argues that it is 'vital to situate the individual experience of dementia in the broader social context' and that '[w]e need to articulate a human rights perspective in which self-advocacy is core.'²⁹⁰

²⁸⁶ *ibid.*

²⁸⁷ *ibid.*

²⁸⁸ GC no.5, para.58, p.11.

²⁸⁹ *ibid.*, p.12.

²⁹⁰ Shakespeare et al., p.1084.

In fact, full inclusion of persons with disabilities in society is not possible without their full and effective participation in the 'decision-making processes concerning issues relating to persons with disabilities [and therefore] States Parties shall closely consult with and actively involve persons with disabilities [...] through their representative organizations', as art.4(3) states.²⁹¹ This applies to art.33(3), which sets the provisions for national implementation and monitoring of the CRPD, too.²⁹² According to GC no.7 (2018), '[f]ull and effective participation can also be a transformative tool for social change, and promote agency and empowerment of individuals', as it empowers them to express their opinions and views through their representative organizations. Eventually, if ensured by States Parties, inclusion in society can be achieved and discrimination fought.²⁹³ Thus, the motto 'nothing about us, without us' is clearly reflected, which is referred to either directly or indirectly in all my selected documents.

GC no.7 gives in-depth information on the definition of representative organization. It explicitly refers to dementia stating that the scope also encompasses organizations 'including family members and/or relatives of persons with disabilities [...] supporting the autonomy and active participation of their relatives with intellectual disabilities, dementia [...]'.²⁹⁴ It stresses the importance of their role of providing assistance and empowerment to persons with disabilities to have a voice by actively promoting and using supported decision-making processes. Only by doing so, the right of persons with disabilities to be consulted and to express their own views is guaranteed.²⁹⁵

Already in 2009, one year after adoption of the CRPD, the Dementia Charter points to the importance of the role of caregivers stating:

People with dementia and their carers have the right to be assisted to participate in the formulation and implementation of policies that affect their well-being and the exercise of their human rights.²⁹⁶

²⁹¹ CRPD, art. 4(3).

²⁹² CRPD, art. 33(3).

²⁹³ Committee on the Rights of Persons with Disabilities (CRPD Committee), *General Comment No.7 - Art. 4.3 and 33.3: Participation with persons with disabilities in the implementation and monitoring of the Convention*, CRPD, C/GC/7, 21 September 2018, para.33, p.7.

²⁹⁴ *ibid*, para.12(d), p.4.

²⁹⁵ *ibid*.

²⁹⁶ Cross-Party Group on Alzheimer's, *Charter of Rights* n. p.

Ten years later in June 2019, DAI demanded that persons with dementia are included on the 'boards of aged care facilities' as this would potentially also 'improve practice and outcomes for residents and their families or advocates.'²⁹⁷

Within the past decade various effort have been made to promote self-advocacy and the right to effective participation, especially since 2015.²⁹⁸ In this light, my selected documents for this analysis can be considered a humble representation.

In his policy paper of 2016, for instance, Crowther gives concrete examples of possible involvement. He suggests that persons diagnosed with dementia should be supported for example by national human rights institutions and utilize the CRPD as a political tool for (re)shaping local, regional and national laws and policies on issues highly related to their cause and situation. For instance, they must be involved in working out national action plans, dementia enabling community programs but also in monitoring the implementation process of the CRPD²⁹⁹, which is covered by art.33(3).³⁰⁰

In relation to full and effective participation by persons living with dementia, in the ADI and DAI documents the importance of a range of other important articles³⁰¹ is pointed out.

Persons living with dementia can only achieve full and effective participation in the community and, as a result, full inclusion in society, if they are able to exercise choice and control over their own lives. A genuine community-based approach to dementia care that respects the wishes and preferences of persons with cognitive impairments is prerequisite for guaranteeing full legal capacity as laid out in art.12 of the CRPD, which will be discussed in the subsequent category.

3.5. Equal recognition before the law

The particular interest and, in fact, importance of art.12 is reflected in the fact that art.12 is the only article of the CRPD, which is explicitly mentioned in the Charter of 2009.

²⁹⁷ DAI, 2019, n. p.

²⁹⁸ see WHO's First Ministerial Conference on Dementia in 2015, see my master thesis, chapter 1.1.

²⁹⁹ Crowther, p.4.

³⁰⁰ For involvement on an international level see Crowther, p.5.

³⁰¹ for example art.21 (Freedom of expression) and art.29 (Participation in Political and Public Life), see in Batsch et al., p.3; art. 30 (Participation in cultural life, recreation, leisure and sport), see in ADI, DAI, *Access*, n. p.

Furthermore, the very first General Comment issued by the Committee on the Rights of Person with Disabilities in 2014 gives guidance on art.12,³⁰² the reason being that states have misunderstood the scope of their obligation under this article:

Indeed, there has been a general failure to understand that the human rights-based model of disability implies a shift from the substitute decision-making paradigm to one that is based on supported decision-making.³⁰³

Art.12 of the CRPD protects the right to 'recognition everywhere as persons before the law', which is a basic principle of international human rights law, and all analyzed documents reflect this basic principle.

Unfortunately, this right is still denied to persons with disabilities all around the world, including persons with dementia, due to the general, negative misconception that, as Devandas Aguelar put it in her report(2019b),

[p]ersons with dementia in particular have been assumed to possess weak or even no agency. The diagnosis of Alzheimer's disease or dementia alone is often the justification for the denial of the exercise of rights [...]³⁰⁴

GC no.1. highlights the normative content of art.12 explaining the difference between legal capacity and mental capacity, which are two distinct concepts. It says

Legal capacity is the ability to hold rights and duties (legal standing) and to exercise those rights and duties (legal agency). It is the key to accessing meaningful participation in society. Mental capacity refers to the decision-making skills of a person which naturally vary from one person to another and may be different for a given person depending on many factors, including environmental and social factors. [...] "[u]nsoundness of mind" and other discriminatory labels are not legitimate reasons for the denial of legal capacity, [...] perceived or actual deficits in mental capacity must not be used as justification for denying legal capacity.³⁰⁵

³⁰² Committee on the Rights of Persons with Disabilities (CRPD Committee), *General Comment No.1 – Art.12: Equal recognition before the law*, CRPD/C/GC/1, 19 May 2014.

³⁰³ *ibid*, para.3, p.1.

³⁰⁴ Special Rapporteur, 2019b, para. 29, p.12.

³⁰⁵ GC no.1, para.13, p.3.

The right to legal capacity must never be denied and must not be conflated with the concept of mental capacity, which cannot be simply assessed as being an 'objective, scientific and naturally occurring phenomenon.'³⁰⁶ The implication of art.12 is that adequate support must be provided for a person with disability to exercise legal capacity by the State and 'shall not be limited by the claim of disproportionate or undue burden,'³⁰⁷ thus making it an absolute obligation for State Parties. In his position paper of 2016 Crowther stresses that it is highly relevant for persons diagnosed with dementia to be provided with 'independent advocacy for support with major decisions, such in relation to health, financial matters or their fitness to drive or travel', as persons diagnosed with dementia 'commonly find their autonomy automatically undermined or removed following diagnosis.'³⁰⁸ In fact, the exact wording was used in the handout of the 2019 Side Meeting by the DAI.³⁰⁹

Due to the degenerative and progressive nature of dementia, persons may require different kinds of support for decision-making as is comprised in the broad concept of dementia care,³¹⁰ ranging from assistance with communication to more intensive, personal care in later stages of life, which General Comment no.1 lays out in depth.³¹¹

Devandas Aguelar points out in her report (2019b) that especially older persons with dementia are often

restricted from making autonomous decisions without the consent of their family members, or their informed consent is not sought for medical treatment and social care, including palliative care and end-of-life decisions.³¹²

Especially for the last stage of dementia, often entailing palliative care, a new way of thinking about capability and agency of people diagnosed with dementia has emerged called 'social-emotional agency' leading to 'assisted autonomy',³¹³ where body language and subtle emotional changes and changes in mood may help decipher their wishes and

³⁰⁶ *ibid*, para.14, p.4.

³⁰⁷ *ibid*, para.34, p.14.

³⁰⁸ Crowther, p.3; DAI, 2019, n. p.

³⁰⁹ DAI, 2019, n. p.

³¹⁰ see chapter on concept of dementia care, my master thesis 2.2.2.

³¹¹ GC no.1, para.17, p.4.

³¹² Special Rapporteur., 2019b, para.30, p.12.

³¹³ G. Boyle, 'Recognising the agency of people with dementia', *Disability & Society*, vol.29, no.7, 2014, pp.1130–1140, cited in Gove et al., p.10.

desires. GC no.1 refers to such ways as 'recognition of diverse, non-conventional methods of communication'³¹⁴ and in the same paragraph addresses the right of persons with disability to be supported in advance planning, if desired, which may be of particular relevance for persons with dementia. In an advance directive they can set out their will and preferences for treatment in different areas for the advanced stage of their dementia journey. This is extremely useful, as it supports the exercise of legal capacity until the very end and is considered another form of appropriate support.

A great number of scholars have widely discussed a re-conceptualization of autonomy as 'relational' or 'assisted' over the last two decades.³¹⁵ In human rights discourse linked to the CRPD, supported decision-making and cognitive disability, especially dementia, Harding, Shakespeare et al. and Sinclair et al. propagate a nuanced, contextualized approach to decision-making³¹⁶ focusing on the concept of 'relationality' in care.

In this context, it is important to remember that relational contexts do not only refer to family and friends, 'loved ones', but include various interpersonal and social contexts and not to forget, as Harding points out, 'broader forces that shape everyday life, like regulatory frameworks.'³¹⁷ These multiple forms of relations influence and shape our decisions and contribute to lived experience. They can be positive and / or negative, which means that relationality can be enabling (a benefit) or disabling (a constraint).³¹⁸ Harding suggests applying the lens of relationality as a concept on supported-decision making with focusing on the 'embodied individual, whilst also keeping in mind the interpersonal and structural contexts.'³¹⁹ In this light, Sinclair et al.'s concept of spectrum (or transitional) model for supported decision-making in dementia must be looked at.³²⁰ Due to the progressive nature of dementia a person's need for different types of support moves 'across a spectrum'³²¹ over time, which requires

³¹⁴ GC no.1, para.17, p.5.

³¹⁵ see Harding, p.116 (citing: Nedelsky, 1989; Mackenzie and Stoljar, 2000); also see Naue, Kroll, 2008, p.28.

³¹⁶ Harding, p.116.

³¹⁷ *ibid.*, p.118.

³¹⁸ *ibid.*; also see Sinclair et al., pp.598-599.

³¹⁹ Harding, p.120.

³²⁰ see Sinclair et al., p.601.

³²¹ *ibid.*

ongoing formal (e.g. professional) and informal (e.g. family member) monitoring underpinned by a (rebuttable) presumption of decision-making being directed by the person's will and preference and a least restrictive approach to supportive interventions.³²²

The role of supporters (formal and informal) may become more active in later stages and must always strike a balance

between eliciting and acknowledging the person's current will and preference where possible while also respecting their previously established will and preferences (e.g. via advance directives), along with a prevailing respect for their human rights, of which "legal capacity" is just one (UN, 2006-CRPD).³²³

In fact, this kind of 'stepped approach' means that the role of supporter becomes more one of a 'representative'³²⁴, which must be guided, though, by the principle '[b]est interpretation of will and preferences if it is not 'practicable to determine the will and preferences of an individual.'³²⁵ According to GC no.1 in general, 'the "will and preferences" paradigm must replace the "best interests" paradigm to ensure that persons with disabilities enjoy the right to legal capacity on an equal basis with others.'³²⁶

Sinclair et al. point out that for a support system including informal and formal networks to be established, time and financial resources are required. Professional supporters should be able to develop a trusting relationship with the person diagnosed with dementia over time to be able to support him or her together with family supporters, if possible. In addition, of course, such a 'paradigm-shifting nature of supported decision-making 'requires comprehensive education and change in attitude.'³²⁷

The Austrian new Adult Protection Act can, in fact, be considered paradigm-shifting and adopts an approach similar to Sinclair et al.'s above described 'stepped approach', which will be illustrated in the subsequent section.

³²² *ibid.*

³²³ *ibid.*, p.601.

³²⁴ *ibid.*

³²⁵ GC no.1, para.21, p.5.

³²⁶ *ibid.*

³²⁷ Sinclair et al., p.604.

4. DEMENTIA SITUATION AND POLICY IN AUSTRIA - A LEGAL AND HUMAN RIGHTS PERSPECTIVE

When the Austrian Dementia Strategy was drawn up in 2015, the new Adult Protection Act had not yet been finalized, but was being drafted. However, it was already mentioned in the Austrian Dementia Strategy. As this law is, no doubt, crucial for the protection of persons with cognitive and psychosocial disabilities, including dementia, it deserves a separate subchapter (4.1.). The subsequent subchapter will deal with the general situation of dementia care in Austria from a legal perspective and human rights angle (subchapter 4.2.). It aims to give an overview of recent developments and the current situation referring to the official care policy with focus on dementia.

4.1. Adult Protection Act

The Second Revised Protection of Adults Act (2. *Erwachsenenschutz-Gesetz/2. ErwSchG*)³²⁸ entered into force on 1 July 2018 and replaced the old guardianship system for adults with cognitive or psychosocial disabilities, which was a form of substitute decision-making and not aligned with art.12 of the CRPD. In the first concluding observations on the initial report of Austria (2013) the Committee on the Rights of Persons with Disability expressed its concern that 'in 2012, approximately 55,000 Austrian were under guardianship, half of whom were under guardianship in respect of all aspects of life.'³²⁹

A model pilot project working out supported decision-making structures was launched under the National Action Plan (NAP) on Disability (2012-2020) involving relevant stakeholders, e.g. courts, lawyers, the Austrian Ombudsman Board, and most importantly, disabled people themselves and their respective organizations. This joint working process eventually led to the new Adult Protection Act, whose aim is to maintain and recognize a person's autonomy for as long as possible by providing decision-making guidance. A wide range of possible support forms and instruments is

³²⁸ Second Revised Adult Protection Act (2. *Erwachsenen-Schutzgesetz/2.ErwSchG* 2017) BGBl I 2017/59,
https://www.ris.bka.gv.at/Dokumente/BgblAuth/BGBLA_2017_I_59/BGBLA_2017_I_59.rtf
(accessed 15 May 2020).

³²⁹ CRPD Committee, 2013, para.27, p.4.

laid down in the law (§239 Abs.2 ABGB). Legal capacity is not restricted in general and not automatically lost in the case of impaired decision-making capacity (§242 Abs.1 ABGB).³³⁰ The golden rule is respecting the wishes, will and preferences of the person represented at all times (§241 Abs.1 ABGB).

There are four different types of official representation, also called pillars, if persons with impairments need assistance for exercising their legal capacity.³³¹

- 1) Enduring power of attorney (*Vorsorgevollmacht*):
- 2) Elective representation (*Gewählte Erwachsenenvertretung*)
- 3) Statutory representation (*gesetzliche Erwachsenenvertretung*) and
- 4) Court-appointed representation (*Gerichtliche Erwachsenenvertretung*)

Any choice of one of the four pillars must be recorded in a centralised national register, which is administered by the Austrian Chamber of Notaries.

Lawyers and notaries are able to act as representatives for a maximum of 15 individuals. The fact that representatives can be held accountable for their actions as any type of representation must be registered and is supervised by local courts, an independent authority, 'marks a milestone for intellectually disabled adults'.³³² According to Bzdera, who compared the new Second Austrian Adult Protection Act to the British Columbian Representation Agreement in an article in 2019, the Austrian current law 'corrects the two main flaws of the British Columbian model',³³³ which had been the major source of inspiration for the Austrian legislation.

An important component of this law is a so-called 'clearing' process which aims to identify alternatives to the still valid old guardianships and to find alternatives to the court-appointed representation by looking into vulnerable persons living arrangements, and family situation. In this context adult protection associations, for example the Vertretungsnetz, which is represented in all Austrian federal provinces but one,

³³⁰ Federal Ministry of Constitutional Affairs, Reforms, Deregulation and Justice, *The New Adult Protection Act*, Vienna, n. y., p.10.

³³¹ *ibid*, more details pp.7-9.

³³² A. Bzdera, 'Supported Decision-Making Replaces Adult Guardianship in Austria', February 2019, p.6, https://www.researchgate.net/publication/331633846_Supported_Decision-Making_Replaces_Adult_Guardianship_in_Austria_An_innovative_guardianship_reform_puts_Austria_at_the_forefront_of_efforts_to_provide_equal_recognition_before_the_law_for_persons_with (accessed 14 May 2020).

³³³ *ibid*.

Vorarlberg, play an important role. They are publicly funded and commissioned by the Austrian Federal Ministry of Constitutional Affairs, Reform, Deregulation and Justice to give advice on adult protective representation measures. For instance, they help set up enduring powers of attorney, can register court appointed representation schemes and also provide representatives if necessary. In addition, they carry out 'clearing' processes. Clearing is also required if a so-called 'requirement or authorization for approval' (*Genehmigungsvorbehalt*; §242 Abs.2 ABGB) is issued to a court-appointed representative. This means that certain legal and procedural acts undertaken by the person represented will not be valid until they have been approved by their court-appointed representative. However, these legal acts must be clearly defined and described and only enacted in the exceptional case that the persons could be seriously and significantly harmed by their decisions. (in German: '*ernste und erhebliche Gefahr*')³³⁴ Although it is the measure of very last resort within the Austrian Adult Protection Act, it is still a limitation on legal capacity and, as Bzdera' points out, 'substitute decision-making is not however entirely eliminated in the new Austrian Adult Protection Act.'³³⁵

Despite this limitation Bzdera considers it a progressive law and 'very far removed from traditional plenary guardianship based on the best interests rule'.³³⁶ Krammer, head of regional offices of the Vertretungsnetz in Salzburg and Tirol, stresses this fact as well.³³⁷ He concedes that the law may seem ambitious and its stipulations may not yet be perfectly implemented in every single case where representation is required. But it is important that the necessary assistance for supported decision-making is available nationwide. In his opinion there is still a considerable lack of offers in federal provinces and communities which must be overcome as soon as possible in order to comply with

³³⁴ see Federal Ministry of Constitutional Affairs, Reforms, Deregulation and Justice, p.10.
N. Krammer, 'Erwachsenenschutzgesetz: Gesetzlicher Genehmigungsvorbehalt endet - mehr Selbstbestimmung', *Rundbrief* 4/2019, pp.17-18,
https://Vertretungsnetz.at/fileadmin/user_upload/5a_SERVICE_Wir_in_der_Oeffentlichkeit/2019/2019-06_Genehmigungsvorbehalt_Rundbrief.pdf (accessed 15 May 2010).

³³⁵ Bzdera, p.5.

³³⁶ *ibid*, p.6.

³³⁷ Krammer, p.17.

the obligations of the ratified CRPD. He continues saying that changes in the law must become transparent and the general public must be aware of them to fully be applied.³³⁸ Positive consequences of the law have been presented recently on the Vertretungsnetz website stating that by 1 January 2020, one and a half years after introduction of the new law, 45.709 court-appointed representation were in effect, which is a reduction of 13% compared to 1 July 2018.³³⁹ It is stressed that for only 6% of the court-appointed representations legal capacity is limited by 'requirement or authorization for approval'. Before introduction of the new law in 2018 all persons represented by a court-appointed representative would have experienced such limitation of legal capacity. Thus, the current development is a significant step towards guaranteeing equal recognition before the law to persons with cognitive and psychosocial impairment. Nevertheless, there is concern that statutory representation overweighs elective representation and especially elderly people diagnosed with dementia are recommended to choose an adult that they trust for representation as long as their mental capacity still allows them to do so in order to be ensured that their will, wishes and preferences are respected.³⁴⁰ In this context the stipulation of the law that for medical decisions about treatment a circle of supporters must be consulted to support a person with cognitive impairment in decision-making is highly relevant to persons diagnosed with dementia, as it is a safeguard to respect a person's dignity and autonomy³⁴¹ in the more advanced stage of dementia and until the very end of life.

The same is true for the so-called VSD Vorsorgedialog® (*advance care dialog*) and VSD Vorsorgedialog® Mobil. They are legally anchored within the Adult Protection Act in Austria for nursing facilities as a possible low-threshold instrument to support people in need of care to make autonomous decisions (§239 Abs.2ff., ABGB). It is called 'a conversation process about a good life and dignified dying in nursing homes.'³⁴² The

³³⁸ *ibid*, pp.17-18.

³³⁹ Vertretungsnetz, 'Positive Bilanz nach eineinhalb Jahren', *aktuell*, 27 February 2020, <https://Vertretungsnetz.at/nd/news/positive-bilanz-nach-eineinhalb-jahren>, (accessed 15 May 2020).

³⁴⁰ M. Marlovits, cited in Vertretungsnetz, 'Positive Bilanz nach eineinhalb Jahren', *aktuell*, 27 February 2020, <https://Vertretungsnetz.at/nd/news/positive-bilanz-nach-eineinhalb-jahren> (accessed 15 May 2020).

³⁴¹ see in this context concept of relational or assisted autonomy, my master thesis, chapter 3.5.

³⁴² S. Beyer, N. Dzaka, 'Der VSD Vorsorgedialog: Wie stellen Sie sich Ihre letzte Lebensphase vor?', *Lebenswelt Heim*, vol.81, April, 2019, p.24. (my translation).

patient's wishes and will are documented in a 'palliative sheet' (*Krisenblatt*) and must be accepted by staff and doctors. This applies to people who can still make their own informed decisions but also to people within adult protection. Even if the patient cannot take legal decisions that require informed consent, he/she may still be able to indicate a choice and show some understanding in a certain situation.

The Adult Protection Act, which was only introduced in 2018, epitomizes a substantial improvement in legislation relevant for guaranteeing basic human rights to persons living with dementia. The subsequent section will give a brief overview of the development of the dementia care situation in Austria from a human rights and legal perspective, with focus on the past 15 years, as 2005 marks the introduction of another important law.³⁴³

4.2. Dementia care situation in Austria

Since adoption of the UDHR in 1948 Austria has ratified and implemented all major international human rights treaties. As a member of the Council of Europe the ECHR holds the status of constitutional law and the jurisdiction of the European Court of Human Rights guides all actions of the state, its courts and its administrative authorities. Besides, as a member of the European Union, the country's human rights performance is evaluated based on the rights guaranteed by the EU Charter of Fundamental Rights.³⁴⁴

Despite this commitment to promoting fundamental rights to all citizens of Austria, basic human rights were frequently and, unfortunately, are still denied to persons with disability, including persons diagnosed with dementia, which the Austrian Ombudsman Board (AOB / *Österreichische Volksanwaltschaft*) points out in their annual reports.³⁴⁵

The AOB has been responsible for monitoring public administration in Austria since 1977 based on the Federal Constitution.³⁴⁶ In 2012 the AOB and its six regional committees were transferred the responsibility of the national prevention mechanism

³⁴³ see my master thesis, this subsequent chapter.

³⁴⁴ Federal Ministry of Europe, Integration and Foreign Affairs, *Building Bridges for Human Rights, Austria Candidate for the Human Rights Council*, n. y., 2019-2021, p.3, www.bmeia.gv.at/fileadmin/user_upload/Zentrale/Aussenpolitik/Menschenrechte/Pledges_and_commitments__AT_HRC_candidacy_edited.pdf (accessed 20 July 2020).

³⁴⁵ see my master thesis, later in this chapter.

³⁴⁶ Volksanwaltschaft, Preventive Human Rights Monitoring, n.y., <https://volksanwaltschaft.gv.at/en/preventive-human-rights-monitoring> (accessed 29 July 2020).

(NPM) for implementation of the Optional Protocol of the Convention against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment of 18 December 2002 (OPCAT)³⁴⁷, which Austria had ratified on 4 December 2012. Besides, it enacts the mandate as an independent authority for the prevention of exploitation, violence and abuse in accordance with art.16 para. 3 of the CRPD.³⁴⁸ In this capacity it monitors and controls public and private institutions and facilities where freedom is or can be restricted.

In fact, an important federal law regulating restriction of freedom was introduced already in 2005. Up to 2005 it had been common practice to restrict residents in their personal freedom without any legal basis.³⁴⁹ This gap in legislation was closed by the Nursing Home Residence Act (*Heimaufenthaltsgesetz/HeimAufG*), which entered into force in July 2005, followed by amendments in 2006, 2010 and 2018.³⁵⁰ This law regulates and controls the admissibility of restrictions of personal freedom on nursing home residents. It includes persons diagnosed with dementia, which a recent information brochure by the VertretungsNetz explicitly states saying 'Der Rechtsbegriff der "psychischen Erkrankung" beinhaltet auch demenzielle Erkrankungen.'³⁵¹ A year later the Federal Disability Equality Act (*Bundes-Behindertengleichstellungsgesetz / BGStG, BGBl. Nr. 82/2005*) came into force marking an important step in disability policy guaranteeing persons with disabilities equal treatment and non-discrimination.

On 26 September 2008 Austria ratified the CRPD and submitted its first State Report in 2010. In its concluding observations (2013) as a response to this report the CRPD Committee heavily criticized that Austrian legislation concerning persons with disabilities is still guided by the medical model.³⁵² It urged the state to change its adult

³⁴⁷ *ibid.*

³⁴⁸ *ibid.*

³⁴⁹ P. Schlaffer (Hg.), *VertretungsNetz, Heimaufenthaltsgesetz, Information über das Recht auf Bewegungsfreiheit in Alten- und Pflegeheimen, Einrichtungen der Behindertenhilfe, Einrichtungen zur Pflege und Erziehung Minderjähriger und Krankenanstalten*, Wien, Februar 2019, p.6, https://www.Vertretungsnetz.at/fileadmin/user_upload/6_Bewohnervvertretung/2019_Broschu__re_HeimaufG.pdf (accessed 20 May 2020).

³⁵⁰ Nursing Home Residence Act (*Heimaufenthaltsgesetz/HeimAufG*), BGBl I 2004/11, as last amended by BGBl I 2017/59, <https://www.ris.bka.gv.at/GeltendeFassung.wxe?Abfrage=Bundesnormen&Gesetzesnummer=20003231> (accessed 20 July 2020).

³⁵¹ Schlaffer, p.10; my translation: The legal term "mental illness" comprises dementia.

³⁵² see my master thesis, chapter 2.2.1.

guardianship law, which was not in line with art.12.³⁵³ On 24 July 2012 the National Action Plan (NAP) on Disability 2012-2020 was passed constituting the government's long-term strategy for the implementation of the CRPD.³⁵⁴ It also supports the goals of the European disability strategy 2010-2020.³⁵⁵ Rudolf Hundstorfer, at that time Social Minister, stressed the fact that persons with disabilities actively participated in the whole process of establishing the NAP. This claim was countered, though, inter alia, in a lecture by Ursula Naue in 2015.³⁵⁶

2015 - this was the same year, when in the annual AOB report violations of the right to liberty and security explicitly for persons diagnosed with dementia were pointed out. saying that '[d]ementia patients are increasingly likely to be subject to measures that restrict freedom'.³⁵⁷ Yet, this Annual AOB report conceded that '[t]en years after the Nursing and Residential Homes Residence Act (*Heimaufenthaltsgesetz*) came into force, many facilities and institutions are aware that use of milder measures makes it possible to forego mechanical restraints'.³⁵⁸ Nevertheless, based on the opinion of the NPM Commission it was recommended that 'training regarding prevention of falls and dealing with behavioural abnormalities, as well as specific care concepts for dementia patients, are essential approaches in order to prevent measures that restrict freedom'³⁵⁹ for the first time. This recommendation was repeated in subsequent annual AOB

³⁵³ see more details on the new law, my master thesis, chapter 4.1.

³⁵⁴ see Federal Ministry of Labour, Social Affairs and Consumer Protection, *National Action Plan on Disability 2012–2020. Strategy of the Austrian Federal Government for the implementation of the UN Disability Rights Convention*, Vienna, 2012. (English version).

³⁵⁵ see Federal Ministry of Social Affairs, Health, Care and Consumer Protection, 'National Action Plan on Disability', *People with Disabilities*, 21 November 2019, <https://www.sozialministerium.at/en/Topics/Social-Affairs/People-with-Disabilities/National-Action-Plan-on-Disability.html> (accessed 28 July 2020).

see Council of Europe (CoE), *Disability Strategy 2017-2023 entitled "Human Rights: A Reality for All*, Strasbourg, 2017.

³⁵⁶ see U. Naue, *Vortrag von Ursula Naue im Rahmen eines WuV-Vortrages (Arbeitskreis Wissenschaft und Verantwortlichkeit) und Kommentar von Volker Schönwiese*, Innsbruck, 27 April 2015, <http://bidok.uibk.ac.at/library/naue-partizipation.html> (accessed 19 May 2020); Österreichischer Behindertenrat, *Positionspapier 2019*, Wien, Oktober 2019, p.6, https://www.behindertenrat.at/wp-content/uploads/2020/02/POSITIONSPAPIER-2019_-20191015.pdf (accessed 20 May 2020).

³⁵⁷ Austrian Ombudsman Board (AOB) (ed.), *Annual Report 2015*, international version, Vienna, October 2016, p.101; <https://volksanwaltschaft.gv.at/downloads/1047g/AOB%20Annual%20Report%202015.pdf> (accessed 10 July 2020).

³⁵⁸ *ibid.*

³⁵⁹ *ibid.*, pp.99, 108.

reports³⁶⁰ and is also included in the most recent list of recommendations by the AOB published on the presentation of its annual report of 2019 on 20 May 2020.³⁶¹

As a response to the demographic changes resulting in a growing number of older persons diagnosed with dementia in need of 'specific care concepts' as quoted above, dementia has gained increasing political and societal attention over the years. Finally, in November 2015, the Austrian Dementia Strategy was introduced with the aim to improve the life of persons diagnosed with dementia and their families. In the AOB 2015 annual report it was already referred to.³⁶² The year 2018, on the one hand, marked a step forward in the implementation of the CRPD by introducing a new Adult Protection Act aligned to art.12.³⁶³ On the other hand, the annual AOB NPM report for 2018³⁶⁴ and the Monitoring Report to the UN Expert Committee for the Rights of People with Disabilities on the Second Constructive Dialogue with Austria (Geneva Report),³⁶⁵ which relies on information provided by the AOB, gave evidence of ongoing human rights violations and structural inequalities for persons with disabilities. In the AOB NPM report for 2018 persons diagnosed with dementia are frequently referred to as falling victim to structural violence in nursing homes because of inadequate care. Due to structural conditions characterized by a lack of qualified staff and time, person-centered dementia care is difficult to administer:

It is thus indisputable for the NPM that the type of care required for persons with disabilities that caters to their individual needs (especially with dementia and chronic mental illnesses) is underrated in the different nationwide staffing targets for long-term care facilities. [They] were developed predominantly at a time when

³⁶⁰ see for example, Austrian Ombudsman Board (AOB), *Annual Report on the activities of the Austrian National Preventive Mechanism (NPM) 2018*, Vienna, June 2019, p.169, https://volksanwaltschaft.gv.at/downloads/2ga09/Austrian_NPM_-_Annual_Report_2018_%28EN%29_-_Barrierefrei.pdf (accessed 20 May 2020).

³⁶¹ Volksanwaltschaft, *Empfehlungsliste der Volksanwaltschaft und ihrer Kommissionen 2012 – 2019*, n. y., <https://volksanwaltschaft.gv.at/downloads/8n2rb/empfehlungen-der-volksanwaltschaft-2019.pdf> (accessed 20 May 2020).

³⁶² AOB, 2016., p.111.

³⁶³ see my master thesis, chapter 4.1.

³⁶⁴ AOB, 2019.

³⁶⁵ Monitoringausschuss, Unabhängiger Monitoringausschuss zur Umsetzung der UN-Konvention über die Rechte von Menschen mit Behinderungen, *Monitoring Report to the UN Expert Committee for the Rights of People with Disabilities on the Occasion of the Second Constructive Dialogue with Austria*, 2018, www.monitoringausschuss.at/download/berichte/MA_Geneva_Report_engl.pdf (accessed 7 February 2020).

care process planning that complies with scientific care management requirements, evaluation and quality assurance, and the application of holistic care concepts or the palliative approach to long-term care had not even been discussed. Amendments made to these targets since then have done nothing to alter the fact that their basis is no longer adequate.³⁶⁶

The 2018 Geneva Report to the CRPD Committee does not only reaffirm this assessment but includes a number of points of criticisms referring to art.14, art.15 and art.16 of the CRPD.³⁶⁷ It heavily criticizes the government for not showing any commitment for creating and implementing a 'consistent concept for the reduction of institutions ("residential home")',³⁶⁸ as de-institutionalization is a precondition of fulfilling art.19, the right to independent living.

In fact, the lack of nationwide concerted approach to disability legislation is a general point of criticism, which was stated in the Concluding Observations (2013) after the first CRPD Committee review. Fragmented legislative responsibilities lead to different standards in disability policy, and thus constitutes inequality within one country. The state was recommended to 'ensure that federal and regional governments consider adopting an overarching legislative framework and policy on disability in Austria, in conformity with the Convention'.³⁶⁹

The fragmentation of political responsibility concerning disability policy between federal (nationwide) and provincial government is the result of the federalist structure of Austria. It has come up in a great number of documents and discussions about major reforms in the field of long-term care, including dementia care, as it is reflected in a fragmentation of the health care and social care sector.³⁷⁰ The Austrian Court of Audit (ACA) (*Rechnungshof*), for instance, 'calls for a coordinated overall management

³⁶⁶ AOB, 2019, pp.21-22.

³⁶⁷ Monitoringausschuss, pp.15-18.

³⁶⁸ *ibid*, p.19.

³⁶⁹ CRPD Committee, 2013, III.A.11, p.2.

³⁷⁰ see Monitoringausschuss; Österreichischer Behindertenrat, 2019; Rechnungshof, *Pflege in Österreich, Bericht des Rechnungshofes*, Wien, Februar, 2020a, p.13, https://www.rechnungshof.gv.at/rh/home/home/004.682_Pflege_Oesterreich.pdf. (accessed 20 June 2020).

and the consideration of the interfaces between health care and old-age care' in its recent comprehensive care report.³⁷¹

In the context of dementia care, apart from the earlier described Nursing Home Residence Act, two further important federal laws are providing care allowance based on need-assessment.³⁷² The Long-Term Care Allowance Act is criticized for being strictly based on physical support needs for coping with everyday life. There are seven stages, according to the increasing amount of time needed for support and care. Even if for persons diagnosed with dementia there is a lump sum (*Demenzzuschlag*) in each stage because of the challenges carers at home are faced with, this does not reflect the actual needs of individual persons, as the most recent report for 2019 by the AOB highlights.³⁷³ This AOB report implies that individual care situations are frequently not comprehensively recognized for correct assessment of care levels (*Pflegegeeldeinstufung*), which is due to a lack of expertise, as well as lack of training. Consequently, highly individual personal care is not guaranteed.³⁷⁴ Especially for persons with mild psychosocial disabilities, among those onset dementia, appropriate care would mean support and assistance in order to be able to live an independent life. A personal assistant could provide this type of support. The right to a personal assistant has been demanded for a long time as well.³⁷⁵ Yet, providing social care, e.g. personal assistance, psychosocial support and other assistance, for example assistance in care homes (*Heimhilfe*) or assistance for daily routines (*Alltagsbetreuer*), lies

³⁷¹ Rechnungshof, 'Reforming old-age care in Austria: ACA notes difficulties in quality and funding', *news*, 14 February 2020b, https://www.rechnungshof.gv.at/rh/home/news/Reform_der_Pflege_in_Oesterreich__Rechnungshof_sieht_Heraus.html, (accessed 24 May 2020).

³⁷² Federal Long-Term Care Allowance Act (*Bundespflegegeldgesetz/BPGG*), BGBl 1993/110 last amended by BGBl I 2020/34, <https://www.ris.bka.gv.at/GeltendeFassung/Bundesnormen/10008859/BPGG%2c%20Fassung%20vom%2020.07.2020.pdf> (accessed 20 July 2020). Federal Long Term Care Allowance Reformed Act 2012 (*Pflegegeldreformgesetz*), 2012/BGBl I 2011/58, https://www.ris.bka.gv.at/Dokumente/Begut/BEGUT_COO_2026_100_2_660426/BEGUT_COO_2026_100_2_660426.html (accessed 20 July 2020).

³⁷³ Volksanwaltschaft, *Bericht der Volksanwaltschaft an den Nationalrat und an den Bundesrat 2019. Kontrolle der öffentlichen Verwaltung*, Wien, März, 2020, pp.68-70, https://volksanwaltschaft.gv.at/downloads/cbhfk/PB%2043_Kontrolle%20C3%B6ffentliche%20Verwaltung%202019.pdf (accessed 24 July 2020).

³⁷⁴ *ibid*, p.69.

³⁷⁵ see for example: Monitoring Report, p.20.; Österreichischer Behindertenrat, pp.3, 21.

within the scope of the different social legislations of the nine provinces. Thus, they are responsible for education and qualification of social care professions³⁷⁶ and the allocation of these services, which leads to huge differences in standards in the nine provinces. In its comprehensive, nationwide analysis of the Austrian care situation the ACA (*Rechnungshof*, 2020a) criticizes the vast differences in quality standards and funding, explicitly referring to nursing care homes and mobile care services across Austria.³⁷⁷ The management and monitoring of nursing homes and mobile services lies within the responsibility of the federal provinces and it is their obligation to create and ensure quality standards.

The ACA appeals to all stakeholder to establish and provide data on costs, services and quality for proactive care planning and to coordinate their approach.³⁷⁸ Only by doing so, the care system in Austria can be sustainably funded and guarantee high-quality care for its citizens. No doubt, considering ongoing demographic changes, this is one of the major challenges in our society. In this context, a national Austrian Dementia Strategy must be seen as an integral part of a national long-term care reform.

The subsequent part of my master thesis will focus on the already existing Austrian Dementia Strategy and explore it from a human rights perspective, first its conceptualization (document) (chapter 5.) and then its implementation (chapter 6.).

5. AUSTRIAN DEMENTIA STRATEGY

The Austrian Dementia Strategy is based on the Austrian Dementia Report of 2014,³⁷⁹ which has been commissioned with the major aim to convey a comprehensive overview of the current situation of dementia care in Austria including specific challenges and needs of people diagnosed with dementia and their relatives and

³⁷⁶ whereas the education and training of nursing professions in a stricter sense (*gehobener Dienst*) is regulated by the Federal Law of nursing professions (*Gesundheits- und Krankenpflegegesetz / GUKG*), BGBl 1997/108 amended by BGBl 2017/131 (accessed 20 July 2020); for an overview of professions see: Bundesministerium für Arbeit, Soziales, Gesundheit und Konsumentenschutz (BMASGK), *Gesundheitsberufe in Österreich*, January 2019.

³⁷⁷ see Rechnungshof, 2020a, p.32.

³⁷⁸ *ibid*, p.40.

³⁷⁹ S. Höfler, T. Bengough, P. Winkler, R. Giebler (Hg.), *Österreichischer Demenzbericht 2014.*, Wien, Bundesministerium für Gesundheit und Sozialministerium, Jänner 2015.

informal carers.³⁸⁰ Basic information on this report will help to gain a more precise picture of the conceptualization of the Austrian Dementia Strategy that was worked out a year later.

5.1. Dementia Report

The report was compiled in cooperation with a multidisciplinary expert panel, including, *inter alia*, the field of neurology, gerontopsychiatry, dietology, social work,³⁸¹ in order to 'serve as foundation for the development of an Austrian National Austrian Dementia Strategy'.³⁸² Thus, a holistic approach to dementia is implied as an integral part of its conceptualization.

The Dementia Report had been commissioned by the Federal Ministry for Health and the Federal Ministry of Labour, Social Affairs and Labor Protection with the objective to describe epidemiological aspects, causes and risk and preventive factors of dementia.³⁸³ The report points out that a 'nationwide concerted approach' to dementia care has not yet been in existence at that time due to the fragmentation of the Austrian health and social system.³⁸⁴ The importance of cooperation between all stakeholders, ranging from political decision-makers to experts and various organizations and institutions on a national (federal) and regional (9 provinces, communities), is highlighted in order to provide best dementia care and support for people diagnosed with dementia and their relatives and caregivers. In the foreword of the Dementia Report the Austrian minister for health at that time, Sabine Oberhauser, claimed that care and support of people diagnosed with dementia will be 'one of the biggest challenges for our society'.³⁸⁵

From a human rights perspective it is striking that in this allegedly holistic approach of the report persons diagnosed with dementia were not asked about their personal experience and needs directly, apart from Helga Rohra,³⁸⁶ the prominent self-advocate

³⁸⁰ *ibid*, p.3.

³⁸¹ see a list of authors contributing to the report in Höfler et al., pp.III-VI.

³⁸² *ibid*, p.XII.

³⁸³ *ibid*.

³⁸⁴ *ibid*, p.12; also see more recent reports referred to in my master thesis, chapter 4.2.

³⁸⁵ see S. Oberhauser, cited in Höfler et al., foreword, p.VIII.

³⁸⁶ see H. Rohra, cited in Höfler et al., foreword, p.VII;

of people diagnosed with dementia. In the first foreword of the report Rohra addresses the utmost importance of participation and autonomy for a life in dignity of persons living with dementia. Croy and Natlacen,³⁸⁷ both representatives of Alzheimer Austria, dealt with the perspective of people affected (*Betroffenenperspektive*) but focus on the difficult situation and experiences of relatives in the report.³⁸⁸ Nevertheless, they acknowledge the importance of supporting the growing number of persons diagnosed with dementia seeking support and information themselves and started to set up self-help groups in order to support and, at the same time, to empower persons diagnosed with dementia.³⁸⁹

Furthermore, I was surprised that in a comprehensive report that focuses on the situation of a highly vulnerable group of the Austrian society relevant human rights treaties and articles were not explicitly dealt with and not mentioned at all.

As my research interest lies in the human rights perspective of the Austrian Dementia Strategy, I will focus on the contents of the Austrian Dementia Strategy as laid down in the document complementing it with information gathered online and through personal contact via email, telephone or video conferencing. Preceding the content-analysis of the Austrian Dementia Strategy from a human rights perspective, as described earlier, the following section will provide some general information on the layout and structure of the Austrian Dementia Strategy.

5.2. General information

In my master thesis the English version of the Austrian Dementia Strategy is analyzed.³⁹⁰ The language in the English version is not always in accordance with the terminology that I would or have used in my master thesis so far, which is particularly

Helga Rohra is one of the first self-advocates for the rights of people diagnosed with dementia in German-speaking countries. She has been an activist since her diagnosis of Lewy body dementia in 2008 and is the founding member and chairperson of the European working group people with dementia (EWGPWD), board member of Alzheimer's Europe (AE) and of the International Alliance of people with dementia (DAI).

³⁸⁷ also see later, my master thesis, chapter. 5.3.4., Natlacen, now Monika Kripp.

³⁸⁸ A. Croy, M. Natlacen, 'Betroffenenperspektive', in S. Höfler, T. Bengough, P. Winkler, R. Giebler, *Österreichischer Demenzbericht 2014*, Wien, Bundesministerium für Gesundheit und Sozialministerium, Jänner 2015, pp.128-129.

³⁸⁹ *ibid*, pp.130-132.

³⁹⁰ BMASGK, 2015b (cited short for the English version - also see my master thesis, 1. Introduction).

true for the use of the expressions 'people with dementia-related impairments' (*Menschen mit demenziellen Beeinträchtigungen*) and 'people with dementia' (*Menschen mit Demenz*) used '[f]or reasons of readability'³⁹¹ in the Austrian Dementia Strategy. I will continue using the terms 'persons diagnosed with dementia' and 'persons living with dementia' for reasons that I have explained earlier.³⁹² Another term used in the Austrian Dementia Strategy for readability is 'family and friends' when referring to people that are addressed including 'family members, friends and neighbours, as well as other people who are important to the person with dementia-related impairments.'³⁹³ When the authors refer specifically to the people who provide care and support, the terms 'informal and formal carers or caregivers' are used which are as well my preferred terms.

The Austrian Dementia Strategy, 'Living well with Dementia' (original German title: '*Gut leben mit Demenz*') was published by the Federal Ministry Labour, Social Affairs, Health and Consumer Protection (*Bundesministerium für Arbeit, Soziales, Gesundheit und Konsumentenschutz/BMASGK*) in December 2015 and was 'approvingly taken note of'³⁹⁴ by the Council of Ministers (*Ministerrat*) in August 2016. The Austrian National Public Health Institute (*Gesundheit Österreich GmbH, GÖG*) had been commissioned to organize and accompany the drawing up process of the Austrian Dementia Strategy and subsequently, to coordinate its implementation.³⁹⁵

According to the authors of the Austrian Dementia Strategy, generally it is intended to form a 'joint orientation framework for targeted cooperation between stakeholders'³⁹⁶ to improve the life of persons diagnosed with dementia and their families and friends, worked out by six working groups, including people diagnosed with dementia, (political) decisions-makers as well as various experts, between March 2015 and

³⁹¹ *ibid*, p.13.

³⁹² see my master thesis on language preferred by persons diagnosed with dementia, chapter 2.1.1.

³⁹³ BMASGK, 2015b, p.13.

³⁹⁴ my translation of German: 'zustimmend zur Kenntnis genommen'

Bundesministerium für Arbeit, Soziales und Konsumentenschutz, *Bericht der Bundesregierung über die Lage der Menschen mit Behinderungen in Österreich* 2016, III-426, vom 22.08.2017 (XXV.GP), Wien, 2017, p.31,
https://www.parlament.gv.at/PAKT/VHG/XXV/III/III_00426/imfname_667392.pdf (accessed 27 July 2020).

³⁹⁵ BMASGK, 2015b, p.10.

³⁹⁶ *ibid*.

October 2015. Thus, this participatory approach to the drafting process of the Austrian Dementia Strategy suggests a human rights-based approach (at least on paper).³⁹⁷

This approach would be in line with the spirit of the CRPD, which is explicitly mentioned in the introduction of the Austrian Dementia Strategy. In a brief paragraph of the introduction it is suggested that the Austrian Dementia Strategy is based on the social model of disability promoted by the CRPD. It does not explicitly refer to any specific articles of the CRPD relevant to persons diagnosed with dementia, but it points out that full, effective and equal participation must be guaranteed to persons living with dementia. This can be achieved by overcoming obstacles, such as attitudinal and environmental barriers in society that hinder full participation and inclusion. It says 'breaking down of such barriers also forms one of the goals of the Austrian Dementia Strategy.'³⁹⁸ Thus, a human rights perspective seems to play an important role in the conceptualization of the Austrian Dementia Strategy. This is suggested by Alzheimer Europe's summary of the seven general objectives of the Austrian Dementia Strategy as well, which is as follows:

- Enhanc[ing] participation and autonomy of people with dementia
- Disseminat[ing] information about the available help and services for carers
- Provid[ing] high-quality care to people with dementia, irrespective of their place of residence
- Ensur[ing] better education and training for professional carers
- Encourag[ing] better understanding of dementia and defeating stigma.³⁹⁹

In the subsequent content analysis of the seven objectives I will explore this implied human rights perspective applying my previously established human rights categories.

³⁹⁷ see more my master thesis later, chapter 5.3.4.

³⁹⁸ BMASGK, 2015b, pp.12-13.

³⁹⁹ Alzheimer Europe (AE), 'Austria', *National Dementia Strategies*, last updated January 2016, <https://www.alzheimer-europe.org/Policy-in-Practice2/National-Dementia-Strategies/Austria> (accessed 27 July 2020).

5.3. Analysis of the Austrian Dementia Strategy

The framework of objectives and recommendations of the official Austrian Dementia Strategy that was developed by the working groups consists of seven objectives and 21 recommendations for action as illustrated below:

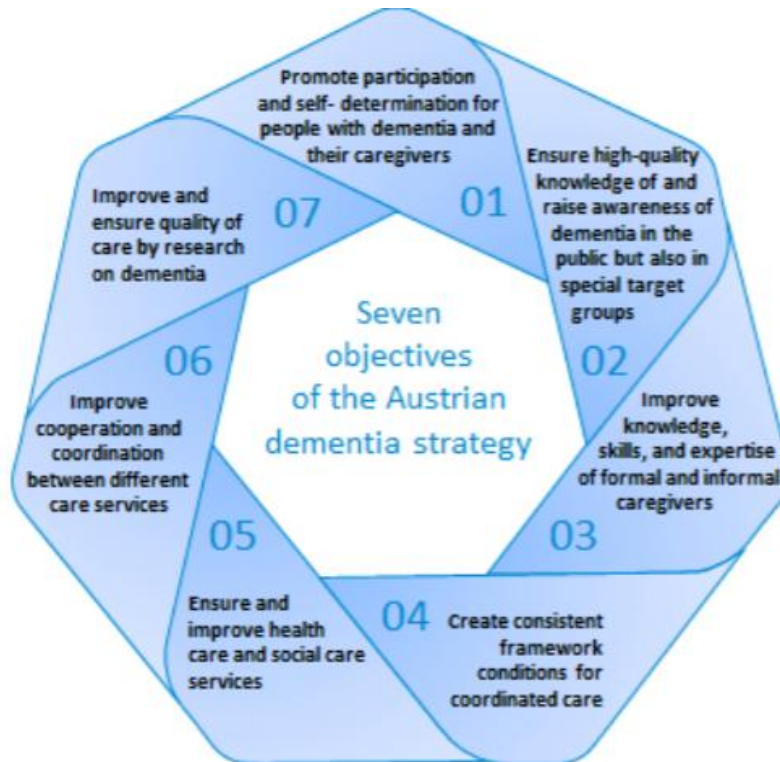


Image 1: Seven objectives of the Austrian Dementia Strategy⁴⁰⁰

In the Austrian Dementia Strategy (document) these objectives are dealt with in detail in separate chapters, which follow a common structure. The seven chapters are divided into two sections, called 'Explanation and challenges' and 'Recommendations for action' which is made up by the sub-sections 'Target groups' and 'Levels of realisation' (e.g. federal government, provinces, science, health care and social services, etc.).

With the help of a deductive content-analysis I have assessed the contents of the seven objectives of the document. The analysis is based on the following categories:

- 1) awareness-raising

⁴⁰⁰ source: BMASGK, 2015b, p.12.

- 2) accessibility
- 3) health/ (re)habilitation:
- 4) participation and independent living
- 5) equal recognition before the law

These categories are my human rights criteria and constitute the coding frame, which has been established in chapter 3. of my master thesis. The findings of my analysis are described and interpreted in a structured way.⁴⁰¹

5.3.1. Awareness-raising

'Awareness of the impact, symptoms and relevance of dementia is needed before other targets of the Global plan can be met.'⁴⁰² In this quote the Global plan referred to is the 'WHO Global Action Plan (2017) on the public health response to dementia 2017-2025,' which calls Member States to draw up national dementia action plans. The Austrian national action plan, the Austrian Dementia Strategy, is aligned to this requirement, as awareness-raising is a cross-cutting priority addressed throughout the document. It is a precondition for health and (re) habilitation, participation/ inclusion (independent living) and enabling equal recognition before the law. Besides, having access to services simply relies on people knowing about their existence.

In objective 1 of the Austrian Dementia Strategy the importance of improving the living conditions of persons diagnosed with dementia 'particularly through dialogue in civil society',⁴⁰³ is stressed. Organizing national information campaigns⁴⁰⁴ and promoting dementia-friendly communities at a regional and local level is recommended, which would require 'reinvent[ing] their areas of activity, for example via supporting structures, awareness-raising and information work with targeted campaigns and events, [...]'.⁴⁰⁵ According to the authors of the Austrian Dementia Strategy, by doing so stigmatization caused by 'misunderstandings, prejudice, taboos and the exclusion of people with dementia-related impairments and their families and

⁴⁰¹ see detailed information on methodology, my master thesis, chapter 2.3.2.

⁴⁰² Barbarino et al., p.24.

⁴⁰³ BMASGK, 2015b, p.18.

⁴⁰⁴ *ibid*, p.19.

⁴⁰⁵ *ibid*.

friends'⁴⁰⁶ could be reduced, and a general 'societal discourse on the topic of dementia and a change in social values'⁴⁰⁷ could be initiated. In fact, this is the major aim of objective 2 stating: 'public relations work on dementia should [...] be as broadly-based as possible and target group-specific as necessary.'⁴⁰⁸ Recommendations for action for tackling stigmatization include stressing positive images and core messages when information and communication and campaigns are devised, and utilizing a broad range of channels of dissemination. For instance, this comprises information brochures, different events and conferences newsletters and magazines for caregiving family members, outreach information, etc.⁴⁰⁹

In this context the Austrian Dementia Strategy briefly addresses ageism in the following way:

Alongside series of information material in a wide range of media, high-profile activities and benefit events such as regular balls, solidarity concerts etc. can be organised in order to support positive images of getting older and to thus contribute towards the breaking down of stigma and taboos.⁴¹⁰

No doubt, it is important to convey positive images in campaigns and activities, but the danger of focusing too much on 'benefit' and 'solidarity' activities suggests rather an approach based on a charity model of disability than a human rights model,⁴¹¹ which is a more nuanced social model of disability. In its annual NPM report of 2019 the AOB criticizes this still prevailing attitude, stressing that disability policy must be human rights-based:

Charity events and fundraising campaigns for the benefit of persons with disabilities will never be a substitute for human-rights-based policies.⁴¹²

Developing a 'code of good practice for media reporting,'⁴¹³ though, as suggested in recommendation for action 2f, must be considered an indispensable part of an

⁴⁰⁶ *ibid*, p.24.

⁴⁰⁷ *ibid*, p.26.

⁴⁰⁸ *ibid*, p.24.

⁴⁰⁹ for more examples see *ibid*, p.26.

⁴¹⁰ *ibid*, p.27.

⁴¹¹ see my master thesis, chapter 2.2.1.

⁴¹² Austrian Ombudsman Board (AOB), *Annual Report 2019 on the activities of the Austrian National Preventive Mechanism (NPM)*, Vienna, June 2020, section 2.4.1., n. p., https://volksanwaltschaft.gv.at/downloads/bfds6/Report%20on%20the%20activities%20of%20the%20NPM_2019_bf.pdf (accessed 27 July 2020).

Austrian Dementia Strategy, as 'media writers bear a great deal of responsibility' in shaping society's image of old age and dementia.⁴¹⁴

Reducing misconceptions surrounding dementia by positive and informative reporting in the media could contribute to the fact that people in general become aware of the importance of timely diagnosis. This would lead to an 'earlier start of preventive and therapeutic measures,' which is crucial for care planning of a person diagnosed with dementia, as highlighted by the authors of the Austrian Dementia Strategy.⁴¹⁵ They continue that in order to have access to and receive adequate support and assistance for social inclusion, group specific awareness must be raised among various occupational groups in health care, nursing and social system, the authorities, the police, emergency services (e.g. ambulance), service providers, retailers, trades (public transport, banks etc.).⁴¹⁶

No doubt, this requires training and education. This important aspect is laid out in recommendation for action 3a, called 'Raising awareness and the development and strengthening of competences, and skills training for medical and non-medical personnel in facilities of the health care and social systems'.⁴¹⁷ According to the authors, raising awareness for the needs and rights of persons diagnosed with dementia must be an integral part of initial and further training and education, as the persons concerned and their family have the right to receive high-quality support.⁴¹⁸ In addition, in order to heighten the family's and friends' awareness of dementia-sensitive interaction and communication, the Austrian Dementia Strategy points out that nationwide programs and trainings for caregivers must be developed and expanded. In such programs low-threshold and affordable information must be provided,⁴¹⁹ which leads over to the category accessibility. Only a low-threshold and affordable approach to or provision of information and services enables persons diagnosed with dementia

⁴¹³ BMASGK, 2015b, p.30.

⁴¹⁴ *ibid*; according to Kripp, a publication on sensitization of language use in the media is in process; also see E. Rappold, *Die österreichische Demenzstrategie „Gut leben mit Demenz“, Wertschätzung, Achtung und Respekt, "Zeit für Pflege“ – Symposium, Krems, 2019, n. p., <https://www.pflegefortbildung.at/datei/Demenz-Rappold.pdf>* (accessed 28 July 2020).

⁴¹⁵ BMASGK, 2015b, p.25.

⁴¹⁶ *ibid*, p.27.

⁴¹⁷ *ibid*, p.32.

⁴¹⁸ *ibid*.

⁴¹⁹ *ibid*, p.33.

and their families and friends to access them, and consequently, facilitate their dementia journey.

5.3.2. Accessibility

Awareness-raising and accessibility are closely linked, which resonates throughout the Austrian Dementia Strategy. Thus, for example, information and training targeting persons diagnosed with dementia and their caregivers must be easily accessible, which does not only refer to financial matters (affordable) but also to the way the information is disseminated. The Austrian Dementia Strategy considers low-threshold information and services fundamental in order to reach the target group, for instance outreach programs for rural areas.⁴²⁰

Apart from physical accessibility the importance of accessible, easy language in print media and online is highlighted. Already existing websites from the federal government or provinces providing relevant information must be made available to the public by providing links, and by using a 'uniform system so that affected persons can find their way more easily.'⁴²¹ Furthermore, the Austrian Dementia Strategy stresses the fact that not only easy access to the information on services and offers must be guaranteed, but the offers themselves ranging from 'health promotion measures to palliative care',⁴²² must be available, affordable and accessible as stated in objective 5:

Low-threshold and affordable offers of support and care for people with dementia-related impairments and their families and friends are to be made at a regional level in order to enable an individualised and - as far as possible - needs-oriented approach [...] This requires the cooperation of system partners in the health and social sectors. Synergies are to be used in the planning, realisation and further development of measures in order to minimise differences in quality and parallel structures.⁴²³

⁴²⁰ *ibid*, p.28.

⁴²¹ *ibid*, p.29.

⁴²² *ibid*, p.39.

⁴²³ *ibid*, p.35.

The quote refers to the fragmentation of the Austrian health and social care system,⁴²⁴ which makes it difficult to provide high-quality person-centered, integrated dementia care throughout the dementia journey as a result of 'inefficiencies at the interfaces'.⁴²⁵ That is the reason why the Austrian Dementia Strategy demands a 'uniform design of the framework conditions' (heading of objective 4) in order to establish a 'nationwide structure of comparable offers'.⁴²⁶ In fact, an 'extension of coordination and cooperation focused on those affected' (heading of objective 6) and guaranteeing high-quality dementia care, which enables 'Living well with dementia', as the title of the Austrian Dementia Strategy suggests, is the ultimate goal. In objective 6 the fragmentation of the health and social care system is criticized, and multi-professional teams made up by health care and social care professionals are recommended to be introduced in all Austrian provinces.⁴²⁷ The aim is to guarantee personalized dementia care on an equal basis to all individuals diagnosed with dementia. The desired effects of objective 6 which are in detail:

Low-threshold, barrier-free and close-to-home contact points for information, advice, early recognition and support have been established nationwide and provide competent and holistic advice and support for those affected. Cooperation across occupational groups and sectors has been realised in a structured process and is oriented towards the needs of people with dementia-related impairments and towards those of their families and friends.⁴²⁸

Such 'structured process' as quoted above in order to achieve the major goal of the Austrian Dementia Strategy has manifested itself in the so-called Austrian Dementia Strategy Platform (*Plattform Demenzstrategie*). Its establishment was recommended in the Austrian Dementia Strategy⁴²⁹ when published in 2015. The Platform was set up in 2018 as a forum for professional dialog and information. A coordination group consisting of representatives of the federal government, provincial and local authorities, social insurance (health and social care), experts and representative

⁴²⁴ also see my master thesis, chapter 4.2.

⁴²⁵ BMASGK, 2015b, p.35.

⁴²⁶ *ibid.*

⁴²⁷ *ibid.*, pp.44-45.

⁴²⁸ *ibid.*, p.44.

⁴²⁹ *ibid.*, pp.37-38.

organizations of persons diagnosed with dementia and their relatives was established as a permanent body. The website www.demenzstrategie.at is the digital medium of the Platform. Its major aim is to encourage and enable targeted and coordinated action and realization of the implementation of the Austrian Dementia Strategy across and between different sectors and stakeholders. It gives space to all relevant (political) decision-makers and stakeholders to exchange and coordinate knowledge, expertise and experience. The progress of implementation is documented on the website by presenting already realized projects and initiatives or examples that are being implemented within the seven objectives of the Austrian Dementia Strategy. Furthermore, it provides information and material that can be accessed by and should raise awareness among professionals and support them in their everyday interaction with persons living with dementia.⁴³⁰ In fact, all this material and examples are aimed at promoting and serving as good practice for improving dementia care, which is elaborated on in the next section.

5.3.3. Health and (re)habilitation

The importance of availability and easy accessibility of health and social offers and support throughout all stages of dementia has already been addressed before in the criticism of the fragmented health and social care system by the authors of the Austrian Dementia Strategy. The right to 'the highest attainable standard of health without discrimination on the basis of disability' is laid down in art.25 of the CRPD. Even if the Austrian Dementia Strategy does not explicitly refer to this article, its spotlight is on the urgency of developing and delivering nationwide high standard dementia care. Objective 5 is exclusively dedicated to 'the design and guaranteed provision of suitable dementia care offers',⁴³¹ and in this context the importance of the 'care chain'

⁴³⁰ see for example, brochures: E. Reitingner, B. Egger, K. Heimerl, et al. *Menschen mit Demenz im öffentlichen Verkehr, Handlungsempfehlungen für Mitarbeiterinnen und Mitarbeiter in Verkehrsunternehmen*, Wien, BMASGK, 2018, <https://www.demenzstrategie.at/fxddata/demenzstrategie/prod/media/Menschen-mit-Demenz-im-oeffentlichen-Verkehr.pdf> (accessed 10 June 2020); B. Juraszovich, E. Rappold, *Demenzkompetenz im Spital. Eine Orientierungshilfe*, Gesundheit Österreich GmbH., Wien, 2017.

⁴³¹ see objective 5, BMASGK, 2015b, pp.39-42.

(*Versorgungskette*) and 'coordinated care',⁴³² (*aufeinander abgestimmte Versorgung*) which can be equated with the term 'integrated care',⁴³³ for persons diagnosed with dementia is highlighted. The Austrian Dementia Strategy recognizes the urgent need for action for the provision of integrated care referring to all actors of the care chain:

regarding doctors in private practice (general practitioners, specialists), in acute care in hospitals, in the field of mobile services (such as home helps and nursing care at home) and in semi-inpatient and inpatient long-term care (such as day centres, nursing homes and assisted living for people with dementia-related impairments), but also in the field of psychosocial and therapeutic offers.⁴³⁴

A high-quality continuum of dementia care delivery can only be guaranteed if medical professionals and non-medical professionals from the health and social sectors cooperate and are integrated into the care system. In addition, already discussed accessibility is key for persons diagnosed with dementia and their families and friends to be able to enjoy a continuum of dementia care. In objective 6 it is recommended that low-threshold contact points are expanded nationwide and integrated into existing systems. The task of such contact points would be

to provide people with dementia-related impairment and their families and friends with low-threshold advice, support and treatment throughout the different stages of the conditions. Multi-professional teams plan individual measures together with all affected persons, and coordinate the measures with service providers. Working methods such as case and care management can be applied here.⁴³⁵

Objective 5 focuses on the multi-disciplinary approach being the core of integrated dementia care. Various areas that need to be developed systematically based on regional needs assessment plans are laid out in the document, ranging from initial screening to more complex care at an advanced stage and finally palliative care.⁴³⁶ The importance

⁴³² *ibid*, p.39.

⁴³³ see definition of integrated care in: World Health Organization (WHO), Regional Office for Europe, *Integrated care models: an overview, working document*, Copenhagen, October 2016, http://www.euro.who.int/__data/assets/pdf_file/0005/322475/Integrated-care-models-overview.pdf (accessed 04 June 2020).

⁴³⁴ BMASGK, 2015b, p.39.

⁴³⁵ *ibid*, p.44.

⁴³⁶ *ibid*, p.41.

of early diagnosis is clearly reflected in the Austrian Dementia Strategy⁴³⁷ as a precondition for longitudinal dementia care provision, because the needs of persons diagnosed with dementia and their caregivers are highly individual and complex. Case management, as suggested in the quote above, together with information management is considered to be an effective tool to achieve long-term coordinated, integrated dementia care, as it connects different areas and their offers and services.⁴³⁸ In fact, the concept of integrated care is not new in the Austrian health system.⁴³⁹ In 2011 the Competence Center 'Integrierte Versorgung' (*integrated care*) published a model called 'netzwerk aktiv - besser leben mit demenz' (*network active - living better with dementia*),⁴⁴⁰ which is a comprehensive, integrated care model based on the core components of multi-professional education and further training care and case management, empowerment, information and data management, quality management and evaluation.⁴⁴¹ According to the Dementia Report, in future it should serve as a model for implementation in the nine Austrian provinces. Some pilot projects are in progress right now and information on them can be obtained from the Austrian Dementia Strategy website.⁴⁴² These models are based on case management, where persons diagnosed with dementia and their informal caregivers move from a single entry point to the system (first contact with case manager) with needs-assessment to coordinated, community-based medical and social services provision. The case manager guides and supports persons living with dementia and their families.

From a human rights perspective this approach implies high-quality, person-centered dementia care and seems to be in line with the right to highest attainable standard of health and also with art.26, the right to habilitation and rehabilitation. Art.26 obliges

⁴³⁷ *ibid*, p.25.

⁴³⁸ K. Eger, S. Höfler, G. Levinsky, et al., *netzwerk aktiv - besser leben mit demenz*. Abschlussbericht, Competence Center Integrierte Versorgung, Wien, 2011, p.28, <https://www.sozialversicherung.at/cdscontent/load?contentid=10008.550848&version=1391172815> (accessed 05 June 2020).

⁴³⁹ see for a definition: Federal Health Reform Act 2013 (*Gesundheitsreformgesetz*), 2013/BGBl I 81, para.3(5), p.4, https://www.ris.bka.gv.at/Dokumente/BgblAuth/BGBLA_2013_I_81/BGBLA_2013_I_81.pdf#sig (accessed 20 July 2020).

⁴⁴⁰ see Eger et al.

⁴⁴¹ *ibid*, p.29.

⁴⁴² see Gesundheit Österreich GmbH (GÖG), 'Wirkungsziel 6', Demenzstrategie, n. y., https://www.demenzstrategie.at/de/Wirkungsziele/iEffGoal__6.htm (accessed 24 July 2020)).

Member States to take effective measures that ought to start as early as possible, are based on individual needs assessment and support participation and inclusion in the community.⁴⁴³ In addition, art.26 calls for promotion of the 'development of initial and continuing training for professionals and staff working in habilitation and rehabilitation'.⁴⁴⁴ The obligation of ensuring qualification and thus adequate training and education in health care professions is also implied in art.25.

Objective 3 of the Austrian Dementia Strategy focuses on 'strengthening knowledge and competence'⁴⁴⁵ of all people involved in providing dementia care. It criticizes the lack or insufficient knowledge of dementia-specific aspects and recommends the 'inclusion of specialist aspects and the implementation of dementia-specific contents in initial and further training and continuing education [...]'.⁴⁴⁶ of professionals. Furthermore, informal caregivers must be offered information and training in interacting with persons diagnosed with dementia.

It is in this context that rights are addressed. In dementia-specific education and training awareness should be raised for rights of persons with dementia. Yet, the only examples referring to particular rights are legal representation and the prevention and recognition of violence.⁴⁴⁷

So far, from a human rights perspective, implicitly human rights are reflected in the Austrian Dementia Strategy. It recognizes the need of awareness-raising and accessibility as precondition for delivering person-centered dementia care as conceptualized in chapter 2.2.2. of my master thesis. The need for individualized support and assistance is identified. Yet, it is not a clear human rights-based approach to dementia care, especially linked to post-diagnostic support, which I will illustrate with the help of the Scottish Dementia Strategy after having analyzed the document for the subsequent categories independent living and participation and equal recognition before the law.

⁴⁴³ for detail on art. 25 and art. 26, see my master thesis, chapter 3.3.

⁴⁴⁴ CRPD, art. 26.

⁴⁴⁵ BMASGK, 2015b, pp.31-34.

⁴⁴⁶ *ibid*, p.2.

⁴⁴⁷ *ibid*, pp.32-33.

5.3.4. Independent living and participation

The provision of post-diagnostic, coordinated dementia care is fundamental for independent living, participation and full inclusion in society. Objective 1 of the Austrian Dementia Strategy is called 'Ensuring the participation and self-determination of those affected'⁴⁴⁸ and implicitly refers to the basic principle of all human rights, the respect to inherent dignity. It is the first of the seven listed general principles of the CRPD⁴⁴⁹ and must be protected and promoted in order for all persons with disabilities to be able to fully and equally enjoy all human rights.⁴⁵⁰ Even if the word 'dignity' is not found in the text of the Austrian Dementia Strategy, respecting inherent dignity throughout the dementia journey is implied. It is stated that '[t]he fundamental human need to experience respect does not end in old age, nor due to health impairments, and is a key element of quality of life.'⁴⁵¹ It continues addressing one of the biggest challenges in dementia care that formal and informal carers and the society at large face, which is how to maintain autonomy for persons diagnosed with dementia and, at the same time, not exposing them to harm.⁴⁵² A comprehensive dementia report on community care in Europe found on the Austrian Dementia Strategy website expresses the human rights implication of this dilemma as follows:

An over-emphasis on safety can come at the cost of individual freedoms and disregards the right of people with dementia to choose to take risks in order to participate in society and in life more fully. This raises key issues for policymaking considering that the stringency of legal provisions can, in effect, mandate the primacy of safety concerns over autonomy, or vice versa.⁴⁵³

The important role of policymaking and legal provisions for guaranteeing independent living, participation and full inclusion is highlighted in the report, which the Austrian Dementia Strategy recognizes but does not elaborate on.

⁴⁴⁸ *ibid*, see pp.17-23.

⁴⁴⁹ CRPD, art.3(a), general principles.

⁴⁵⁰ CRPD, art.1, purpose.

⁴⁵¹ BMASGK, 2015b, p.17.

⁴⁵² *ibid*.

⁴⁵³ K. Schulmann, S. Ilinca and K. Leichsenring, *Community care for people with dementia: A handbook for policymakers*, EURO.CENTRE.REPORT no.10, European Centre, Vienna, 2017, p.8.

The Austrian Dementia Strategy puts its spotlight on the role of the community at large in order to enable independent living and greatest possible self-determination. As mentioned earlier, for a society to become aware of the situation and needs of persons living with dementia and their families, promotion of dementia-friendly communities is recommended.⁴⁵⁴ According to the authors, the ultimate goal of developing dementia-friendly communities must be:

[...] a community in which those affected and their families can live well and where participation in the life of the community is a reality.⁴⁵⁵

What follows is a number of recommendations how to 'design' a community in a 'dementia-sensitive way'.⁴⁵⁶ For instance, social barriers, predominantly stigmatization of persons diagnosed with dementia, could be overcome by promoting campaigns in which the community at large becomes aware that persons living with dementia are to be considered as active members of the society. Such members participate in singing or sports clubs, go to the hairdressers etc.⁴⁵⁷ But dementia-sensitivity must go beyond the level of friendliness and acceptance to(wards) vulnerable groups. It must rather be enabling, which the Austrian Dementia Strategy points out as well when referring to environmental and structural barriers:

Participation improves with structures which facilitate more social involvement in local communities. This refers to aspects of urban and rural planning, traffic and transport and mobility planning, the construction of accessible social housing, and the establishment of dementia-sensitive facilities and businesses such as the local council office, pharmacies etc.⁴⁵⁸

The implementation of these recommendations of the Austrian Dementia Strategy for achieving objective 1 could lead to 'a dementia-friendly environment [that] is pleasant for everyone'.⁴⁵⁹ In this light it could be considered transformative as laid out earlier and which is the claim of a human rights-based approach to dementia care.⁴⁶⁰ It would

⁴⁵⁴ see my master thesis, chapters 2.2.2. and 5.3.1.

⁴⁵⁵ BMASGK, 2015b, p.18.

⁴⁵⁶ *ibid.*

⁴⁵⁷ see my master thesis, chapter 5.3.1.

⁴⁵⁸ BMASGK, 2015b, p.20.

⁴⁵⁹ *ibid.*

⁴⁶⁰ see my master thesis, chapter 2.2.2.

guarantee, above all, the provisions of art.19 of the CRPD, 'Living independently and being included in the community'.

Yet, precondition is that persons diagnosed with dementia and their families are actively involved in developing such dementia-enabling communities. Only they themselves due to their lived experience know and can inform stakeholders in communities what dementia-sensitivity actually is. Persons living with dementia must be involved in decision-making processes and research on dementia from the very beginning, which the authors of the Austrian Dementia Strategy focus on in recommendation for action 1c 'Enabling the self-determination of people affected' and for action 1d 'Participatory science - carrying out research with the involvement of those affected'.⁴⁶¹

Objective 7 called 'Quality assurance and quality improvement through research'⁴⁶² is exclusively dedicated to the urgency of developing a 'dementia-sensitive research culture'⁴⁶³ involving persons diagnosed with dementia taking into account clear ethical research and funding guidelines.⁴⁶⁴ Furthermore, it is highly recommended to 'convey research results directly (whereby they are presented in a way which is suited to the target group) to those in practice, to those affected, but also to the relevant decision-makers'.⁴⁶⁵ This simply means making the findings accessible by transferring knowledge to all sectors and stakeholders, including persons diagnosed with dementia and their families, so that it can be used for enhancing quality of life for them.

Apart from involvement in research, participation must take place in all 'decision-making processes concerning issues relating to person with disabilities' as art.4(3) of the CRPD⁴⁶⁶ stipulates and the following statement in the Austrian Dementia Strategy seems to be aligned to:

Strengthening self-help groups [...] can encourage the participation of people with dementia-related impairments, and support their self-advocacy and self-organisation. People can lead a largely independent life over a longer period in spite of dementia. Involving them in decisions and the recognition of their

⁴⁶¹ see BMASGK, 2015b, p.21-23.

⁴⁶² see BMASGK, 2015b, pp.46-49.

⁴⁶³ *ibid*, p.22.

⁴⁶⁴ *ibid*.

⁴⁶⁵ *ibid*, p.49.

⁴⁶⁶ art. 4(3), see my master thesis, chapter 3.4. for more information on this art.4(3).

individual competences by society facilitate participation and self-determination and contribute towards the breaking down of stigma. As Helga Rohra, chair of the European working group of people with dementia says: "*Nothing about us, without us.*"⁴⁶⁷

This is a clear reference to the spirit of the CRPD fueled by the disability movement, whose motto has been from the beginning 'Nothing about us, without us', and which is the core of human rights-based approach. Yet, in the document of the Austrian Dementia Strategy there is no clear evidence to the fact whether persons diagnosed with dementia were fully and actively involved in the drafting process. There is only a general claim made in the executive summary that persons diagnosed with dementia developed the objectives and recommendations for action together with (political) decision-makers as well as experts in six working groups.⁴⁶⁸ Besides, statements by persons diagnosed with dementia from consultations on the Austrian Dementia Strategy and from a poster series in Vorarlberg, one of the Austrian provinces, were interspersed in the text.⁴⁶⁹

Monika Kripp provided insider information about the nature of participation of persons diagnosed with dementia in a telephone conversation,⁴⁷⁰ which I found reconfirmed in a presentation about the Austrian Dementia Strategy at a conference on care of September 2019.⁴⁷¹ As the former vice-president of Alzheimer Austria, Kripp was a participant of one of the working groups. In 2015, when she brought two self-advocates, who had been participants in the interviews carried out by Reingard Lange,⁴⁷² along to the working sessions, she was met with resistance by stakeholders. They argued that the self-advocates would need a great amount of time, would not be able to follow the process and the strict timeline could not be kept.⁴⁷³ Kripp was backed by Erich

⁴⁶⁷ BMASGK, 2015b, p.21.

⁴⁶⁸ *ibid*, p.6.

⁴⁶⁹ see for example, BMASGK, 2015b, pp.25, 36, 40.

⁴⁷⁰ see Kripp; also see my master thesis, chapter 2.1.2.

⁴⁷¹ Rappold, n. p.; She claims that participation of self-advocates was not planned but 'happened by incident.' (my translation for: 'ist passiert') due to pressure from organizations representing persons living with dementia.

⁴⁷² see my master thesis chapter, 2.1.2.; today she is the chairwoman of the executive board of Promenz.

⁴⁷³ see Kripp.

Fenninger,⁴⁷⁴ who was the head of one of the working groups. Together they put pressure on the project manager of the Austrian National Public Health Institute (GÖG), the responsible agency for the drawing up process of the Austrian Dementia Strategy, to actively involve the two persons diagnosed with dementia in the working process. According to Kripp, in 2015 the manager's and other stakeholders' opinion was that 'we are the experts and we know what they need'.⁴⁷⁵

Today, though, the Social Ministry proudly claims that persons diagnosed with dementia have always participated in developing the Austrian Dementia Strategy. Self-advocates are invited to the annual conferences organized by the Austrian Dementia Strategy Platform, where the implementation process of the Austrian Dementia Strategy is discussed. In September 2019 the Platform's second conference took place in Vienna focusing on participation in society. In various workshops the needs and requirements for promoting participation of persons diagnosed with dementia were discussed together with self-advocates.⁴⁷⁶

Even if this conference is evidence of some progress and the voices of persons diagnosed with dementia are listened to, there is still a long way to go. According to self-advocates, it is high time for self-help and self-advocacy to be reevaluated and appreciated in Austria in order to become a genuine tool of empowerment.⁴⁷⁷ In this context they claim official funding by the state for an Austrian working group for people with dementia.⁴⁷⁸ Although Angela Pototschnigg, who was present at the conference, is a member of the European Working Group for People with Dementia (EWGPWD), there is no nationwide assisted self-advocacy group of persons living with

⁴⁷⁴ he is the managing director of the Volkshilfe Austria, a large non-profit NGO providing social services, especially in the care sector.

⁴⁷⁵ see stakeholders' words cited by Kripp;

⁴⁷⁶ Plattform Demenzstrategie, 2. *Arbeitstagung der Plattform Demenzstrategie* Wien, 19. September 2019 Im Fokus: Gesellschaftliche Teilhabe, 19. September 2019, Wien, [https://www.demenzstrategie.at/fxdata/demenzstrategie/prod/media/2-Arbeitstagung-Demenzstrategie%20\(3\).pdf](https://www.demenzstrategie.at/fxdata/demenzstrategie/prod/media/2-Arbeitstagung-Demenzstrategie%20(3).pdf) (accessed 08 June 2020).

⁴⁷⁷ *ibid*, n. p.

also see Kripp; R. Schönborn, 'Selbsthilfe für Menschen mit Demenz braucht Unterstützung', *Pflege professionell*, 17 May 2020, <https://pflege-professionell.at/selbsthilfe-fuer-menschen-mit-demenz-braucht-unterstuetzung> (accessed 08 June 2020).

⁴⁷⁸ *ibid*.

dementia in Austria, in contrast to other countries, for example Germany and Switzerland.⁴⁷⁹

According to Raphael Schönborn, a member of the coordination group of the Dementia Platform and managing director of Promenz, persons diagnosed with dementia are still not directly involved in further developing the Austrian Dementia Strategy. They rather contribute their lived experience by discussing relevant issues in focus groups.⁴⁸⁰ Besides, in the last coordination group meeting in Vienna his suggestion to focus on the intersectionality of disability and dementia for future policy-making, was rejected. It was argued that officially labeling dementia as a disability would be too stigmatizing. From this perspective, even if important human rights aspects are identified and recognized in the Austrian Dementia Strategy, the general conceptualization is not a human rights-based one in the spirit of the CRPD. The Scottish Dementia Strategy, for instance, has adopted such approach from the very beginning. The Scottish Dementia Strategy will be looked at more closely after having applied my last human rights category for the analysis of the contents of the Austrian Dementia Strategy.

5.3.5. Equal recognition before the law

Legal matters and the right to be recognized before the law are only marginally addressed in the Austrian Dementia Strategy. Objective 1 refers to adequate legal protection linked to the right to self-determination in the following way:

In order to support the self-determination [...] existing models of legal representation (guardianship) should be further developed and simplified. Instruments of advance planning such as a power of attorney for health care, living wills and supported decision-making must be affordable. Complaints bodies (sic!) should be established.⁴⁸¹

During the drafting process of the Austrian Dementia Strategy a new Adult Protection Act⁴⁸² was being worked on. It entered into force on 1 July 2018 and, in fact, developed

⁴⁷⁹ German working group: Alliance for People with Dementia, Swiss working group for people with dementia.

⁴⁸⁰ see R. Schönborn, *virtual Zoom conversation*, 12 June 2020.

⁴⁸¹ BMASGK, 2015b, p.21.

⁴⁸² Second Revised Adult Protection Act (2. *Erwachsenen-Schutzgesetz/2.ErwSchG 2017*) BGBl I 2017/59

supported decision-making further by including various forms of representation, which are highly relevant for persons diagnosed with dementia.⁴⁸³ In the context of supported decision-making, the focus lies on advance healthcare planning. According to the authors of the Austrian Dementia Strategy, listening and taking time for conversations with persons living with dementia is key in order for family and friends and professional caregivers to discuss and plan with them for the time when they are no longer capable to make their own decisions. One way of doing so that is recommended by the authors of the Austrian Dementia Strategy is 'documenting wishes and ideas' for respective sectors and institutions.⁴⁸⁴

As laid out in my master thesis earlier, supported decision-making may become more and more intensive throughout the different stages of dementia.⁴⁸⁵ Dementia care reframed by adopting a relational social model of disability must provide highly individualized, inclusive support service, as suggested in the Austrian Dementia Strategy. The new Austrian law on adult representative has been considered a landmark legislation and is aligned with art.12 of the CRPD,⁴⁸⁶ which reflects political commitment to highest human rights standards. Yet, so far such legal commitment guaranteeing the right to post-diagnostic and intensive personal care at the last stage of dementia does not exist.

The following brief excursus on the Scottish Dementia Strategy serves as an illustration of what political commitment could look like if a human rights-based approach were adopted to dementia care policy, especially post-diagnostic support.

5.4. Scottish Dementia Strategy - an excursus

Timely diagnosis and post-diagnostic care are crucial in a human rights-based approach to dementia care. Even in countries with access to high-quality healthcare, studies have shown that only 50% of people with cognitive impairment caused by dementia receive a

https://www.ris.bka.gv.at/Dokumente/BgblAuth/BGBLA_2017_I_59/BGBLA_2017_I_59.rtf (accessed 15 May 2020).

⁴⁸³ see for detailed information on this new law, my master thesis, chapter 4.1.

⁴⁸⁴ BMASGK, 2015b, p.21.

⁴⁸⁵ see my master thesis, chapters 3.5. and 4.1.

⁴⁸⁶ see my master thesis, chapter 3.5.

diagnosis.⁴⁸⁷ In Austria the diagnosis rate is only 20-30%.⁴⁸⁸ Like almost all national dementia strategies the Austrian Dementia Strategy focuses on post-diagnostic care, but does not really provide comprehensive solutions. Besides, a great number of strategies lack sufficient funding.⁴⁸⁹

It was as early as 2002 that the Scottish Dementia Working group of people with dementia was appointed to advise the government supported by Alzheimer's Scotland.⁴⁹⁰ It was the first country to include people diagnosed with dementia in its implementation of the CDRP in 2009. In this context, the Scottish Human Rights Commission promoted a human rights approach, the so-called PANEL approach, to both disability and dementia when working out a Charter of Rights for People with Dementia. This groundbreaking Charter was adopted by the Scottish Parliament in 2009.⁴⁹¹ Since 2010 Scotland has published three national 3-year-time limited dementia strategies. The first one (2010-2013) focuses on timely diagnosis and improving dementia care and treatment, the second one (2013-2017) on enhancing post-diagnostic support and integrated, person-centered support and the third one (2017-2020)

maintains a focus on improving the quality of care for people living with dementia and their families through work on diagnosis, including post-diagnostic support; care co-ordination during the middle stage of dementia; end of life and palliative care; workforce development and capability; data information; and research.⁴⁹²

The Scottish Government Post-diagnosis Support (PDS) Guarantee 'ensures that every person who receives a dementia diagnosis and their families receive support in planning for future care and decision-making, understanding the disease and managing symptoms and building peer support networks'⁴⁹³ for a minimum of one year. PDS practitioners,

⁴⁸⁷ K. Engedal, 'Standards in Dementia Care', in M. Schmidhuber, A. Frewer, S. Klotz, H. Bielefeld (Hg.), *Menschenrechte für Personen mit Demenz Soziale und ethische Perspektiven*, Bielefeld, transcript Verlag, 2019, p.22.

⁴⁸⁸ S. Auer, cited in Donauuniversität-Krems, 'Zukunftslösungen für das Thema Demenz', *News*; 4 Oktober 2019, <https://www.donau-uni.ac.at/de/aktuelles/news/2019/zukunftslösungen-für-das-thema-demenz-0.html> (accessed 20 July 2020).

⁴⁸⁹ see Barbarino et al., p.56.; also see my master thesis, later this chapter.

⁴⁹⁰ DAI, 2016, p.8.

⁴⁹¹ Cross-Party Group on Alzheimer's, *Charter of Rights*.

⁴⁹² Scottish Government, National Dementia Strategy: 2017-2020, Edinburgh, 2017, p.1, <https://www.gov.scot/publications/scotlands-national-dementia-strategy-2017-2020> (accessed 10 February 2020).

⁴⁹³ Schulmann et al., pp.8-9.

also called dementia link workers, are part of community mental health teams (psychiatry service) and professionally accompany and support every person with a dementia diagnosis and their families. Scotland has been successful in delivering high-quality PDS to a great number of people in need. Yet, as in some areas the waiting lists have been very long,⁴⁹⁴ accessibility and delivery of PDS are being reevaluated.

Based on Commitment 2 of Scotland's third National Dementia Strategy, which states 'We will test and independently evaluate the relocation of post-diagnostic dementia services in primary care hubs as part of the modernisation of primary care,'⁴⁹⁵ a pilot project started in 2017. It will be running until September 2020 to explore 'whether a relocation of dementia expertise into primary care will make dementia support more accessible and "normalised" to individuals and families.'⁴⁹⁶ This policy to dementia care has been called 'a landmark application of the rights-based approach to dementia care'⁴⁹⁷ and clearly shows the Scottish government's commitment to a person-centered, rights-based approach in a time-limited dementia strategy, whose goal is for support to be 'truly transformational in helping to come to terms with [the diagnosis]'.⁴⁹⁸ Contrary to the Scottish dementia policy, the Austrian policy does not reflect a clear human rights-based approach to dementia care.

5.5. Summary of findings

After thorough analysis of the objectives of the Austrian Dementia Strategy, it can be concluded that awareness-raising for the situation of persons living with dementia has been identified as a key priority for a dementia policy with the aim to improve quality of life of persons diagnosed with dementia and their families. Stigmatization must be tackled by making the general public aware of the vulnerable situation of people diagnosed with dementia. The focus of possible strategies is on nationwide awareness-

⁴⁹⁴ Healthcare Improvement Scotland ihub, 'Redesigning Primary Care to provide Post-diagnostic Support for people with dementia', *new-events*, 20 June 2019, [https://ihub.scot/news-events/redesigning-primary-care-to-provide-post-diagnostic-support-for-people-with-dementia/#:~:text=Scotland%20is%20the%20only%20country,to%20plan%20for%20the%20future.\(accessed 10 June 2020\)](https://ihub.scot/news-events/redesigning-primary-care-to-provide-post-diagnostic-support-for-people-with-dementia/#:~:text=Scotland%20is%20the%20only%20country,to%20plan%20for%20the%20future.(accessed 10 June 2020)).

⁴⁹⁵ Scottish Government, p.15.

⁴⁹⁶ Healthcare Improvement Scotland ihub.

⁴⁹⁷ Schulmann et al., p.8.

⁴⁹⁸ Healthcare Improvement Scotland ihub.

raising campaigns, where the responsibility of the media is to present this vulnerable group by means of sensitive use of language and images.

In addition, developing dementia-friendly communities could contribute towards making the situation and needs of persons living with dementia and their families visible and, consequently, enable full inclusion and participation in society. In order to achieve such transformation, the need for education, training and research is highlighted. Besides sensitization of the society at large, professionals from various disciplines must be adequately qualified. Especially professionals from the health and social care sector need to acquire skills and experience in order to develop and provide high-quality care, which is emphasized in the Austrian Dementia Strategy. Simultaneously, dementia care of this nature must be easily accessible for everyone. Low threshold accessibility to services and offers, equally available to everyone, is a major objective of the Austrian Dementia Strategy. Legislation that constitutes the right to post-diagnostic care could foster accessibility. In Scotland post dementia care is delivered by a qualified link worker. So far, in Austria such legislation does not exist and is not claimed by the Austrian Dementia Strategy either.

As already pointed out during the analysis of the Austrian Dementia Strategy, human rights issues relevant for persons diagnosed with dementia and country-specific structural inequalities due to a fragmented system have been identified. The urgency for change is reflected in the seven objectives and its recommendations on paper. The great variety of initiatives and projects as well as already existing services that are presented on the Dementia Platform's website are evidence of an ongoing implementation process including research in the field of dementia care.

Generally, the medicalized approach to dementia that has been the norm for so many years in dementia care does not predominate the conceptualization of the Austrian Dementia Strategy, rather a social model of disability approach prevails. The current reluctance to officially labeling dementia as a disability because of the stigmatizing nature of such label is a clear contradiction to the reference made to the CRPD in the introduction of the Austrian Dementia Strategy in 2015. Yet, it must be added that its approach has never really been based on a human rights social model of disability because participation of persons diagnosed with disabilities was not part of the

conceptualization of the Austrian Dementia Strategy in 2015. The participation of two self-advocates was only possible because of the personal initiative of one working group participant. Based on insider expert information,⁴⁹⁹ the Austrian Dementia Strategy's nowadays alleged participatory approach involving persons living with dementia is rather lip service than reality and therefore not in the spirit of the CRPD.

Furthermore, the Austrian Dementia Strategy lacks a timeframe that sets clear parameters for assessment whether the objectives have been achieved. What is more, there is insufficient funding for implementation, which is required for an effective national dementia policy.⁵⁰⁰ In this light, a lack of political commitment by the federal and provincial governments is suggested. For an effective dementia policy not only political commitment is required in budgeting matters, but also a political will to adopt legislation guided by human rights standards.⁵⁰¹

In the subsequent chapter my empirical study with professionals working in the field of dementia care in a broader sense will be presented. So far the Austrian Dementia Strategy has mainly been analyzed as laid down on paper complemented with insider information of people involved in the original drafting or developing and assessing of the implementation of the Austrian Dementia Strategy. Now it is high time to listen to professionals working in dementia care to explore the human rights relevance in the field and to find out whether the Austrian Dementia Strategy has already found its reflection in practical dementia care from a human rights perspective five years after its introduction.

6. DEMENTIA CARE IN PRACTICE - EMPIRICAL STUDY

For my empirical study I have chosen Grounded Theory (GT) based on Charmaz (2006), as laid out in detail in chapter 2.3.3. of my master thesis. This qualitative research method provides me with flexibility for the exploration and pursuit of emerging themes in my studied field. My constructed theory is intended to reflect the

⁴⁹⁹ see Kripp; Schönborn, *virtual Zoom conversation*; also see my master thesis, chapter 5.3.4.

⁵⁰⁰ see Barbarino et al., p.56, a global comparison of national dementia plans.

⁵⁰¹ this aspect will be elaborated in the final chapter (chapter 8.) of my master thesis after presentation of my empirical study.

lived experience and perspectives of people working in the practical field of dementia care from a human rights perspective.⁵⁰²

General information will be provided on the nature and process of the study before the focus will be on the presentation of the findings and finally their discussion.

6.1. General information

My study is based on interviews with professionals working in dementia care in a broad sense. In the course of my study I sampled different areas, different in their nature in dementia work: a day center, long-term residence care, consultancy (for people diagnosed with dementia, their relatives), assistance in self-advocacy and self-help support, and adult protection. For sampling of the participants, I asked three potential participants directly for participation as I know them personally from my internship with CS Caritas Socialis. In addition, I asked my supervisor, a colleague from university, and Monika Kripp, former vice president of AA, to refer me to potential participants, thus utilizing convenient sampling. My sampling size of seven was due to theoretical saturation.⁵⁰³

I contacted all my potential participants by email and asked for permission to interview them personally. They were provided with written information about the nature of the study and were asked to give written consent for participation and using data in the research.

My participants are all female, with different educational backgrounds and length of professional experience. The following overview will give brief information on their current job position:⁵⁰⁴

⁵⁰² C. Dunne, B. G. Üstündağ, 'Successfully Managing the Literature Review and Write-up Process When Using Grounded Theory Methodology—A Dialogue in Exploration [42 paragraphs]', *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research*, vol.21, no.1, art. 25, January 2020, 2.1 (the choice), <http://www.qualitative-research.net/index.php/fqs/article/view/3338/4555#gref> (accessed 10 June 2020).

⁵⁰³ see my master thesis, chapter 2.2.3.

⁵⁰⁴ The full names of participants are not used in my master thesis. The letter B stands for participant (German word: *Befragte* = interviewee) and numbers 1-7. See further information on interviews in annex 2.

- B1: representative of individual adults (*Erwachsenenvertreterin*) with cognitive disabilities with Vertretungsnetz (biggest Adult Representation Association in Austria)⁵⁰⁵
- B2: representative of adults living in residential care (nursing homes) (*Bewohner*innenvertreterin*) with Vertretungsnetz
- B3: representative of individual adults with cognitive disabilities with Vertretungsnetz
- B4: counselor for persons diagnosed with dementia and their families (focus on self-advocacy support) with Alzheimer Austria⁵⁰⁶ as a volunteer and private counseling
- B5: supervisor of day center for persons living with and without dementia with CS Caritas Socialis⁵⁰⁷
- B6: counselor for persons diagnosed with dementia and their families (information/guidance) with Caritas Socialis
- B7: head of department for residential long-term care (nursing homes with emphasis on dementia) with CS Caritas Socialis

Due to the Covid-19 restrictions and regulations for personal interaction issued by the Austrian government, the interviews were carried out by video call on the platforms Zoom and Skype. Furthermore, as my participants work in dementia care, usually in direct contact with persons living with dementia, they were faced with the dilemma that they could not meet them directly, as the persons living with dementia belonged to a so-called 'risks group' (*Risikogruppe*) of people who are at greater risk of contracting COVID-19. At the same time persons diagnosed with dementia and their families had to cope with isolation and uncertainty in their daily life without any real professional help.⁵⁰⁸ The participants' worries and fears of the impact of the Covid-19 restrictions and crisis is reflected in the interviews.

⁵⁰⁵ see chapter 4.1. for more details.

⁵⁰⁶ see chapter 2.1.2.

⁵⁰⁷ CS Caritas Socialis GmbH is a non-profit patient care provider in Vienna specializing, inter alia, in dementia care (consultancy, day centers, long-term residence care, assisted living arrangements for people with dementia and assisted living at home/mobile care).

⁵⁰⁸ see especially interview with B5, situation for day center visitors and their relatives.

My interviews took place in April/May 2020 and were recorded after asking the participants for written consent. All interviews were conducted in German and direct quotations used in my master thesis were translated by me. After each interview I transcribed the interview reflecting its contents and semantics as much as possible, keeping to errors in syntax (e.g. sentence fragments), however, not including filler words (e.g. signaling reception, e.g. *ah*, *mhm*). My transcription rules are a modified version based on Udo Kuckartz's transcription rules for qualitative content-analysis.⁵⁰⁹

My interviews were guided by a semi-structured interview guide consisting of open-ended questions to encourage unanticipated statements. Spontaneous questions were asked trying to keep an open mind and not be too suggestive. My theoretical and conceptual framework and the analysis of the Austrian Dementia Strategy served as starting points and resources for formulating questions.

The first three questions were actually identical for all participants. The first one was about the educational background, professional development and current position of the interviewee. It was meant as a warm-up to the interview and at the same time it gave me the opportunity to get to know the participants better professionally. The second one was about the interviewees' perception of the term 'dementia care' to tune into the topic, and the third one was about the main responsibilities in their positions. Subsequent questions were the same or similar in all interviews presenting slightly different aspects and dimensions of the same phenomenon. But due to the nature of GT, being an iterative and reflective approach, new questions were added to explore emerging categories in more detail in the ongoing interview process.⁵¹⁰

The coding of my interview transcripts was done in traditional style by hand. The theoretical method of my coding has been laid out in chapter 2.3.3. in more detail. During the initial stage of the coding process a great number of codes (themes) emerged. Through focused coding and analytically connecting them, I strove to

⁵⁰⁹ U. Kuckartz, *Qualitative Inhaltsanalyse: Methoden, Praxis, Computerunterstützung*, Auszug aus Unterabschnitt 8.1.1: 'Transkriptionsregeln und Transkription', 3. Auflage, Weinheim und Basel, Beltz Juventa, 2016, pp.166-169, <https://qualitativeinhaltsanalyse.de/documents/Kuckartz-Qualitative-Inhaltsanalyse-2016-Transkription.pdf> (accessed 1 May 2020); see for transcription rules, my master thesis, annex 2.

⁵¹⁰ see a translation of the semi-structured interview guide in the annex 1. (it gives an idea of the topics/areas covered but does not claim to be complete and cover all spontaneous questions).

conceptualize them and constructed major categories, which will be presented in the subsequent chapter.

6.2. Presentation of findings

Ob man die Vorstellung hat 'Oh, das ist ein ganz schwieriges Problem', auf das man pflegerisch oder finanziell oder wie auch immer reagiert, oder ob man sagt, 'Schauen wir uns da einmal doch das Menschenbild an und fragen uns, was normal ist oder [...] mit welchen Vorstellungen oder Ressourcen könnten wir vielleicht ein bisschen konstruktiver da weiterrufen?'⁵¹¹

This is one participant's direct quote⁵¹² when asked for a final statement regarding the field of dementia care. In the light of the growing number of persons diagnosed with dementia she depicts two major avenues to take in dementia care.

It is this second attitude, the focus on the vision of humanity (*'Menschenbild'*), which is a common characteristic in the work of the seven participants in my studied field. The question is what is generally perceived as being 'normal' and which ideas or resources could contribute to improving dementia care. My interviewees agree that there has been progress with regard to the societal perception of dementia and in dementia care in general. But all in all, their personal opinion and perception is that for persons with dementia and their families to enable 'living well with dementia' (the title of the Austrian Dementia Strategy) substantial changes and resources are required and there is still a long way to go. Metaphors such as 'we are on the way' and 'there has been a step forward' frequently found their way into the interviews, contrasted with 'there is room for improvement', 'still not arrived', and 'nothing is finished up'.

This general tenor of an ongoing process is reflected throughout my study. One participant believes that 'nothing is static, but there is always movement, because a goal is never once and for good achieved, because there will be something new, the system

⁵¹¹ B2, lines 484-488; my translation: Whether to think "Oh, this is a very difficult problem" that is reacted to focusing on solely nursing care or financial means or whatever reaction, or whether to say, "Let's rather look at the vision of humanity and ask ourselves what is normal or [...] which ideas or resources could we use here to continue in a constructive way?".

⁵¹² as I consider this quote highly significant and suitable as an introduction to the findings of my study, I decided to quote in German. It is the only longer quote in original German in this section.

will change [...],⁵¹³ which is definitely true for dementia care. The question here is: What is this process like, which direction will it take, and what role do human rights play? From a human rights perspective what can actually be considered 'static' in the sense of being an integral part of my participants' work is their commitment to basic human rights principles.

6.2.1. Basic human rights principles

Respecting the 'inherent dignity' that all human beings are endowed with is the foundation of all human rights. Even if only one participant explicitly refers to this principle and even criticizes that it is not included in the Austrian Constitution as a fundamental right,⁵¹⁴ it clearly underlies professional dementia care work performed by my participants despite their difference in age, experience and job position.

The way they describe their job responsibilities reflects their vision of humanity. They try to perceive the wholeness, the personhood of the person diagnosed with dementia and not just a client or patient diagnosed with dementia. It is the mindfulness that prevails in their approach. Participant B1 stresses the need to 'look carefully and to take time for asking questions again and again,'⁵¹⁵ especially to find out if a relative is fit to be chosen for adult representation for the person diagnosed with dementia. Personal conversations with the persons diagnosed give her the opportunity to 'detect hints'⁵¹⁶ how far the dementia has progressed. It is important to focus on the clients and not be distracted by relatives who tend to be overprotective and answer questions for the person diagnosed with dementia.⁵¹⁷ Participant B2 in her function as representative of residents in residential long-term care concedes the danger of only seeing the dementia and not the person⁵¹⁸ but she claims that she tries

not to confuse the people even more than this might inevitably be in this setting [*as official representative*]. I try to ask questions to find out how people feel, [...] I look what their physical condition is like, whether they are still mobile.⁵¹⁹

⁵¹³ B6, lines 220-222.

⁵¹⁴ *ibid*, lines 502, 503.

⁵¹⁵ B1, lines 427, 428.

⁵¹⁶ *ibid*, lines 128-129.

⁵¹⁷ *ibid*, lines 133-135; 145-147.

⁵¹⁸ B2, lines 494-497.

⁵¹⁹ *ibid*, lines 99-103.

Interviewee B3 is also aware that she may misjudge a situation even if she has the best interest of her clients in mind and therefore says to herself 'Okay, I will talk with the persons themselves, every single time'⁵²⁰

This dilemma of protecting and acting in the best interest of the person diagnosed with dementia and respecting his or her right to self-determination and choice, the basis for individual autonomy, is raised in the interviews. Not only as a personal dilemma like B3 expressed above, but also in their work when cooperating with nursing staff and family.⁵²¹ As residents' representative B2, for instance, recognizes some nursing staff members' concern when restricting the personal freedom of residents with cognitive disability. On the one hand they know that they do not have the right to deprive them of their liberty but on the other hand they say to themselves, '[...] I have to do that, because I do not want him to hurt himself or to put himself in danger.'⁵²² Family members believe, for example, that they act in the best interest of their relatives diagnosed with dementia and put pressure on them to do certain things which are clearly against their will, e.g. to eat more than they want or to get mobilized. According to B7, 'the person, the old person, is very often not quite taken seriously.'⁵²³

Only when taking the persons living with dementia seriously despite cognitive impairments and listening attentively will respectful interaction and communication take place. This must not only be a guiding principle in interacting with the persons diagnosed with dementia outside an institution, but within residential nursing care as well. B7 explains that a part of their corporate philosophy is to respect the resident's integrity and will at all time, even if asked by relatives to pretend to the resident entering residential care that he/she will be spending a vacation or doing rehabilitation.⁵²⁴ The staff will never lie to the resident just to make the family feel at ease, because it is always about building trusting relationships and respecting the will of the person living with dementia.⁵²⁵ The importance of the relational aspect in dementia care is clearly reflected in the interviews. In the residential setting it is the nursing staff

⁵²⁰ B3, lines 203-204.

⁵²¹ see B3 and B7.

⁵²² B2, lines 400-402.

⁵²³ B7, lines 145-155.

⁵²⁴ B7, lines 147, 148.

⁵²⁵ *ibid*, lines 150-151.

that knows the people best, even better than the relatives, as B2 and B7 recognize in their monitoring and supervising functions. For B1 as adult representative building up trust by personally talking to the person diagnosed makes up an important part of her work. The manifold reactions at first encounter with her clients reflect the diversity of dementia. Some enjoy talking to her, some are scared, while others are quite reluctant. She also realizes that some of her clients have already noticed their cognitive decline and are glad about the opportunity to voice their concerns.⁵²⁶ B3's contacts are similar, although she admits that her first contact is often characterized by 'a lot of insecurity. [...] But also on my side, because I do not know in how far they still understand and if you do not know the people they hide a lot at the beginning.'⁵²⁷ Later she either meets them in town, visits them at home and chats or just sits there and sings children's songs. If this is the only type of communication the person she supports and represents in certain legal matters can relate to, she respects that. 'Relationality' is still at place, which is important for supported decision-making.⁵²⁸

The German expression 'auf Augenhöhe', which literally means 'on the same level of eyes', was used as a suitable metaphor for respectful interaction on an equal basis in two interviews.⁵²⁹ Interviewee B5 believes that 'it is always about the person him/herself in the center of attention. It is about meeting the person with mindfulness, respect and openness,⁵³⁰ which must be the general attitude in our society. She considers such respectful interaction to be the precondition of 'caring communities', where everyone is accepted and included, whether with or without disability.⁵³¹ For interviewee B6 mindfulness is inclusive in the sense that we respect ourselves and our fellow-beings. We need to accept boundaries but also find out what our fellow-beings might need.⁵³² B4 assists Angela Pototschnigg in self-advocacy activities. She provides her with explanations for certain activities and situations that Angela P. may not be able to grasp cognitively right away; she allows her to take more time for certain activities; she is

⁵²⁶ B1, lines 165-171.

⁵²⁷ B3, lines 55-57.

⁵²⁸ *ibid.*, lines 43-49; see my master thesis, chapters 2.2.2. and 3.5.

⁵²⁹ see B4, line 278; line 464; B5, line 51.

⁵³⁰ B5, lines 42-44.

⁵³¹ B5, lines 150-151.

⁵³² B6, lines 228-234.

honest and avoids stigmatizing phrases and language and much more. And this is what self-advocates need to feel accepted and included in society as an equal citizen.⁵³³

In fact, listening to self-advocates and their lived experience and involving them in decision-making processes was and still is the guiding spirit of the CRPD. At the same time it is a human right laid out in art. 33(3).⁵³⁴ It is simply a prerequisite for fighting stigmatization of persons living with dementia and providing high-quality dementia care. This has been recognized and highlighted by B4 saying that '[...] she [*a self-advocate*] wants to empower others as well. Because only by doing so the stigma can be changed in the public, which is actually a goal - to break this taboo.'⁵³⁵ Stigmatization is often the reason why a dementia diagnosis is not sought despite cognitive decline or, in the case of diagnosis, deters the person diagnosed and his or her family from asking for support.

6.2.2. Person-centered post-diagnostic support

It is the topic of stigmatization afflicting persons diagnosed with dementia and their families that resonates in all interviews, often in the context of diagnosis. Some interviewees do believe that there is a growing awareness of what dementia is, 'to a certain degree [...] and at least on a way'⁵³⁶ and the 'taboo of dementia has diminished'⁵³⁷ due to initiatives like dementia-friendly communities and districts, according to interviewee B6 and B7. Generally, the negative perception of the impact of dementia prevails, though. Examples of stereotypes that are still around as mentioned in the interviews are:

- All persons diagnosed with dementia are old and end up in a nursing home (see B3).
- They are no longer a productive member of society and thus pushed to the side (see B1).
- They are stupid (see B1, B4).

⁵³³ B4, lines 441-451; B4 reports Pototschnigg's thoughts that she has voiced in her advocacy work.

⁵³⁴ see details on that right, my master thesis, chapter 3.4.

⁵³⁵ B4, lines 206-208.

⁵³⁶ B5, lines 221-222.

⁵³⁷ B7, lines 66-67.

These prevailing stereotypes make people in general afraid of dementia and persons living with dementia are not included in society. One participant bluntly says 'when you get the diagnosis, you have a label [*dementia*] on your forehead, an invisible one' and no one talks to you anymore.⁵³⁸ This condition is not talked about much, as long as there is not relative or friend diagnosed with dementia.⁵³⁹ Participant B5 admits that it is simply not pleasant to think about all the changes that such 'life changing' diagnosis entails.⁵⁴⁰ Yet, all the professionals of my study point to the diversity of dementia. On the one hand, it makes their work challenging and varied in their interaction with the persons living with dementia. On the other hand, in the context of diagnosis, not knowing about the diversity of dementia scares people and keeps them from accepting a diagnosis. According to B5, the supervisor of a day center and B7, the head of the long-time care department, valuable time is lost, as people either get a diagnosis quite late or do not seek post-diagnostic care due to reasons laid out below.⁵⁴¹

It is the availability and accessibility of person centered, post-diagnostic support that all my participants consider crucial for the dementia journey after diagnosis, and which is highly criticized. Due to their different responsibilities in the broad field of dementia care, they may focus on different aspects of support and care or on the consequences of the inadequacy of such care and support. But the lack of resources and structural inadequacy in Austria in the provision of high-quality, person-centered dementia care are clearly identified. Some of them elaborate on the time right after the diagnosis and others on the nature of support and care.

For B7, the head of the long-term care department, post-diagnostic care is 'an enormous weakness in Austria. Nowadays there are, for sure, good initiatives somewhere. But I do notice that there is a huge need and demand for support how people can adapt to this new life.'⁵⁴² She continues saying that 'it simply does not suffice making a diagnosis with the best tests in the world and then nothing happens for years.'⁵⁴³ The time right after diagnosis is crucial for the journey every single person diagnosed with dementia

⁵³⁸ B4, line 292.

⁵³⁹ see B1, lines 282-283; B3, lines, 299-303.

⁵⁴⁰ B5, lines 207-209.

⁵⁴¹ see B5, lines 110-114; B7, lines, 351, 352.

⁵⁴² B7, lines 266-269.

⁵⁴³ *ibid*, lines 351-352.

embarks on. This is focused on as well by B5, the supervisor of a day center, and B6, the consultant for dementia care. No doubt, the diagnosis is usually shocking for the person and his or her family, and it is obvious that they need guidance and orientation. That is where heavy criticism by some of my participants sets in. Even if there are exceptions to the rule, most doctors do not adequately support the persons diagnosed who feel left alone and isolated. Reasons cited are that doctors or specialists are either in a rush, use technical language or rather speak about the person with family members than with the person himself or herself.⁵⁴⁴ B7 does not want to put the blame on doctors in general, but rather considers it a systemic problem characterized by inadequate qualification for dementia due to lack of time.⁵⁴⁵ Right after diagnosis there is a missing link, as the majority of my interviewees do believe that a range of professional services is already around - at least in Vienna, where almost all of my participants work.⁵⁴⁶ It would be highly important for the persons diagnosed with dementia to receive relevant information and to be linked to suitable support so that they can start with advance care planning upon diagnosis. B7 mentions Great Britain as best practice in dementia care. In Scotland, post-diagnostic care is provided for a year 'by a qualified person who accompanies them on this way [dementia journey],⁵⁴⁷ and this type of care can be claimed as a legal right.⁵⁴⁸

In fact, three of my participants refer to the gerontopsychiatric center (*Gerontopsychiatrisches Zentrum in der Modenacenterstraße*) and the memory clinic in the general hospital of Vienna (*Gedächtnisambulanz, AKH*) as best practice in Vienna. There, persons diagnosed with dementia are communicated with respectfully and are provided with adequate information for further steps to take.⁵⁴⁹ So far this has not been the standard in Austria, and people who receive their diagnosis in these highly acclaimed institutions are rather lucky and privileged.⁵⁵⁰

⁵⁴⁴ see B4, lines 292-294; B5, lines 102-106.

⁵⁴⁵ B7, lines 282-286.

⁵⁴⁶ see B1.

⁵⁴⁷ B7, lines 290-303.

⁵⁴⁸ see my master thesis, chapter 5.4. (excursus).

⁵⁴⁹ see B4, B5, B6.

⁵⁵⁰ B5, lines 131-133.

The type and nature of support, not only upon diagnosis, is another focus of attention in my interviews. It is agreed that it must be personalized to ensure autonomy and independent living as long as possible. The two adult representatives, B1 and B3, are convinced that with the right assistance and support the persons living with dementia will be able to cope with their daily routines. That such support would alleviate their professional work as well,⁵⁵¹ is illustrated by an example by B3. Once the Vertretungsnetz, her employer, was contacted by the social service provider of Vienna (*Fond Soziales Wien*) because one person diagnosed with dementia was not able to sign a care contract. She believes that if this person had had low-threshold support, a legal adult representative would not have been required. With assistance this person would have been able to understand the great number of pages of the contract easily,⁵⁵² and therefore B3 calls for 'great expansion of social work'.⁵⁵³ Even if she does not explicitly refer to such service personal as assistance, it is implied that a social worker could take over this kind of support. The fact that in Austria there is no legal right and no funding for personal assistance as a low-threshold support for persons diagnosed with dementia is criticized by B4.⁵⁵⁴ She renders that Angela Pototschnigg, whom she assists as a volunteer in her self-advocacy activities, has frequently articulated that she can do a lot, but with the right assistance she is capable of doing even more.⁵⁵⁵ B6, an expert in consultancy for dementia and care issues, has recognized that a growing number of persons diagnosed with dementia seek information on what they themselves can actually do. This made her realize that it is her responsibility in her job to shift her professional attention from supporting the family members to focusing on the persons living with dementia themselves. When persons diagnosed with dementia focus on their abilities and strengths, rather than deficits, and in addition receive tailored support, they will be empowered and their self-confidence will be increased. A boosted self-esteem is a precondition for independent living and participation in society, which is a human right laid out in art.19 of the CRPD.⁵⁵⁶ That is the reason why assisted peer-to-peer

⁵⁵¹ B1, lines 177-180; B3, line 336.

⁵⁵² B3, lines 333-335.

⁵⁵³ *ibid*, line, 343.

⁵⁵⁴ B4, line 37.

⁵⁵⁵ see B4, line 395.

⁵⁵⁶ see more on art.19 in my master thesis, chapter 5.3.4.

support must be expanded and equipped with resources as well, which is elaborated on by B4, but also highlighted by B6 and B7.

In fact, it is assisted peer-to-peer consultancy (*Peer-to-Peer-Beratung*) and self-help groups which should play a major role in post-diagnostic support because persons living with dementia themselves are qualified best to share lived experience and to empower others for the dementia journey ahead of them or 'to get over the mountain' ('*Über den Berg kommen*'), to cite the name of a recently founded self-help group by AA for persons diagnosed with young or early onset dementia.⁵⁵⁷ Building up self-esteem and self-confidence must happen in a sensitive setting right after diagnosis because with a diagnosis of young onset dementia there are still many years of quality of life ahead that the people are entitled to.

By supporting and funding assisted self-advocacy groups, a growing number of persons living with dementia will become visible in our society. Only thus their stigmatization can be tackled and, hopefully, one day be overcome. B6 and B7, who are volunteers and very active in developing the network of dementia-friendly districts in Vienna, do believe that such districts can only be dementia friendly if persons living with dementia are involved in its development. B6 admits that in 2014, at the very first meeting when the network was founded, highly motivated volunteers were convinced that they knew what people living with dementia need. However, they changed their opinion immediately after listening to a group of persons diagnosed.⁵⁵⁸ This group of persons were the first official group of self-advocates, which later became 'Promenz'. It was Reingard Lange, who interviewed this group for her master thesis and later continued assisting them.⁵⁵⁹

The role of dementia-friendly communities that provide community-based support in everyday life is stressed by B4, B5, B6 and B7. Unfortunately, today there are still a great number of obstacles around that do not only obstruct persons' with physical and

⁵⁵⁷ B4, lines 97ff. - according to B4 '*Über den Berg kommen*' is a holistically conceptualized assisted self-help group, apart from peer-to-peer exchange offering common leisure activities and short presentations in simple language by experts from different disciplines, e.g. medicine, nutrition, psychology, law. The first meeting took place in February 2020, due to Covid-19 the meetings in March, April and May had to be cancelled.

⁵⁵⁸ B6, lines 207-209.

⁵⁵⁹ *ibid*; also see my master thesis chapter 2.1.2.

intellectual disabilities way in a literal sense, but also hinder their full inclusion in society. This is pointed out by almost all interviewees and illustrated with concrete examples, especially by B4 and B6.⁵⁶⁰ It is also in this context that the Austrian Dementia Strategy, which supports such communities and dementia-friendly initiatives, is explicitly mentioned. The existence of the Austrian Dementia Strategy is positively acknowledged to have the potential of raising awareness for the pressing dementia situation, and it could be considered a tool for change if promoted and taken seriously. Dementia-friendly communities started out as a volunteer project with the aim to improve the life of persons living with dementia and their family by involving stakeholders and players relevant for persons living with dementia.⁵⁶¹ An important aspect of this network is that it serves as a platform where exchanging knowledge, information and experience can be exchanged. In fact, the German word 'Austausch' ('exchange' in English) crops up in all interviews in the context of learning in and for various situations linked to dementia. Furthermore, the importance of formal education and training in dementia care where transfer of knowledge and experience takes place as well, has become evident from the interviews. Therefore, I would like to present the important concept of transferring knowledge and experience in different directions next linked to dementia care of my studied field.

6.2.3. Transfer of knowledge and experience

As already laid out in the above section, persons diagnosed with dementia are often great supporters for others. Since they share their lived experience and knowledge acquired on their dementia journey with persons with a recent diagnosis, empowerment is promoted for both respectively. Besides providing orientation and guidance right after diagnosis, assisted self-help groups can point out the environmental and social barriers they have to cope with every single day to the society at large. That is the reason why B4 holds the opinion that self-advocates must be involved in all decisions and matters concerning their lives, be it developing dementia-friendly communities or 'only' a brochure on a certain aspect of their life.⁵⁶² They are the experts and their knowledge

⁵⁶⁰ see for example: B4 on public transport, lines 256-258; and B6 on hospitals, lines 167-170.

⁵⁶¹ see B7 and also more information on Austrian Dementia Strategy website.

⁵⁶² B4, lines 308-310.

and experience, alongside research findings and professional experience in relevant scientific disciplines, must be transferred for transforming society into a genuinely inclusive one.

No doubt, exchange of information, knowledge and experience is of great significance for the family of persons living with dementia as well. My interviewees agree that a dementia diagnosis is not only life-changing for the person diagnosed but for the whole family and friends. There are low-threshold offers, e.g. the Alzheimer cafe, where anyone interested in sharing experience is invited to participate without registration. Another reason for visiting this cafe is providing an opportunity for people to simply enjoy time carelessly together. Besides, there are offers where registration is required, e.g. separate offers for partners and children of persons diagnosed with dementia and the opportunity for volunteers to exchange their experience.⁵⁶³ In this context, B6 agrees that support and provision of information for the family is, no doubt, extremely important. From her professional experience such services and offers have been around for many years, though. Therefore, the focus must shift to expanding offers and services to persons diagnosed. The insufficient funding of all of the above-mentioned services and offers has been a major point of criticism throughout the interviews.⁵⁶⁴

After years of relying purely on volunteering, the Viennese network of dementia-friendly districts now receives some permanent professional support for organizational matters from the city of Vienna. Thus, the valuable contribution of the network is officially acknowledged. Based on my interviews, it can be concluded that transfer of information and knowledge has been initiated by this network, which is considered to be an indispensable part in the professional work of B5, B6 and B7. It could be argued that the reason is that all three work with the CS, the organization that started the project in 2014, and they are involved as volunteers. However, cooperation and mutual referral to the respective organization or institution has become common practice among major care providers, such as the Red Cross and Caritas, at least in some areas of dementia care. B6 illustrates this practice with the help of two examples: if relatives of a person

⁵⁶³ see B4 and B6.

⁵⁶⁴ see above all B4, B6, B7.

diagnosed with dementia seek support from Caritas and a day center seems to be suitable, they are referred to the CS, as Caritas does not operate day centers with focus on dementia. If the CS is looking for training offers, for example for relatives, they contact the Red Cross.⁵⁶⁵ In addition, they do not consider the network their project any longer, but dementia-friendly communities are promoted all over Austria, which the Austrian Dementia Strategy Platform encourages. B7 has 'the feeling that there has been progress in the past ten years [and] this is, also because of the dementia-friendly initiatives all over Austria of course. This clearly shows that there is progress, but the need is still great.'⁵⁶⁶ For her any projects and initiatives aiming at improving quality of life for persons living with dementia can be called 'dementia-friendly' in the broad sense. Even if she along with B6 is aware that the term dementia-friendly might not be the most suitable one, considering the fact that self-advocates themselves often reject the word 'dementia' as being too stigmatizing, they stick to it. In the broad public it has been the most widely used and recognizable term for the condition. By combining it with 'friendly', the expression 'dementia-friendly' is positively connoted and contributes to awareness-raising evoking positive feelings. Yet, she emphasizes that volunteers must be realistic because

there is also some danger: if I have a town, for example a small town, and I think I can get rid of all the loneliness in the world, because I am now dementia friendly, this is also a bit of an overestimation of one's abilities - one has to stay realistic.⁵⁶⁷

The initiative 'first dementia-friendly school' in Vienna seems to be of great importance for her, as children and pupils are sensitized for the topic dementia at a young age and, in fact, have the opportunity to exchange their experience with dementia. This is especially important if they have grandparents living with dementia. Again, it is the exchange in different settings that is encountered frequently in the interviews as being of great significance. In this context, the fact that dementia awareness-raising has started and is growing is identified. Yet, there is a long way to go:

⁵⁶⁵ B6, lines, 364-372.

⁵⁶⁶ B7, lines, 60-63.

⁵⁶⁷ *ibid*, lines, 111-114.

And I do have the impression that this [topic] is growing into our society as an incentive. But there is a lot to do still, too, because, yes, there are still not many schools [...]⁵⁶⁸

B4 does not focus on single initiatives, but rather addresses the requirement of transfer of knowledge in the general public in order for a community or district to become dementia friendly, in the sense of dementia-enabling. This would entail extensive professional training for staff, such as in banks, stores, pharmacies and especially in public transport.⁵⁶⁹ Simply, to put it in her words, 'where people take part in public life.'⁵⁷⁰ The focus must be on the way how to communicate and interact with persons diagnosed with dementia in a dementia-sensitive manner, which brings me back to the role of self-advocates. They must be consulted when devising training courses because only they can convey what dementia-sensitive actually means. To B4, it would often only mean taking more time and using simpler language for explaining processes, or showing respect by, for example, not pointing out how many times something has already been said. B6's example of hospitals with poorly-qualified staff, in contrast to those hospitals that take part in dementia-friendly initiatives, reconfirms this urgent need of extensive training for the staff in general. Only qualified, understanding staff can make persons living with dementia feel at ease, which would also alleviate hospital staff's work.

Formal initial and further education and training of healthcare professionals is a prerequisite for high-quality dementia care provision, not only, but certainly important for a more advanced stage of dementia, which B6 and B7 consider crucial.

When B7 taught nursing staff in initial education in the 1990s dementia care was not a focal point in the curricula of healthcare professions. Nowadays, considering the growing numbers of persons living with cognitive impairment caused by dementia, it is obvious to her that dementia must definitely be included in the curriculum of any healthcare profession. She knows that the scientific knowledge about the symptoms of dementia is taught, 'transferred', to the students at university, but she doubts that there is

⁵⁶⁸ *ibid*, lines, 76-78.

⁵⁶⁹ B4, lines, 297-299.

⁵⁷⁰ *ibid*, line, 299.

any serious focus on how to communicate and interact with persons diagnosed.⁵⁷¹ In the three-year training qualifying for a professional nurse basic validation therapy courses are included in the curricula. According to B7, by attending such validation course the basic strategies for communication with persons diagnosed with dementia are learned, which the nurses later can try out and develop in practical work in a reflective way.⁵⁷² However, it is not enough for single members of a staff in a nursing home to attend a course once in a while, but as head of nursing department B7 clearly states that all the staff must be trained. For the CS the concept of person-centered dementia care is an integral part in their curriculum for further education.⁵⁷³ Further training would also be required for doctors who work in primary care. They should be able to provide their patients with symptoms or persons with a dementia diagnosis with the right, enabling support, which takes sensitive interaction and communication with the persons diagnosed themselves and their family. It is denoting that hardly any general practitioners volunteer in dementia-friendly networks, which might be due to a lack of time. But could simply suggest a lack of interest and awareness of the vulnerability of people living with dementia, as B7 surmises.⁵⁷⁴

Based on her experience, B6 believes that the field of dementia care has seen a great development in education and training in Austria, ranging from low-threshold crash courses to an extensive master's program. Nevertheless, a major problem nowadays she sees in trying to economize dementia care by introducing several hours of low threshold assistance for daily routines (*mehrstündige Alltagsbegleitung*). In its original conceptualization this is a great concept for delivering personalized support for persons at beginning or intermediate stage of dementia. However, this mobile staff is poorly trained and receives the minimum pay. Besides, due to allocation of their working hours and a lack of time, the persons living with dementia may be supported by several different members of the mobile staff. As building up trust and relationship is key for effective personalized dementia care as a prerequisite for enabling independent living and inclusion in society, this type of support by mobile care teams must be questioned.

⁵⁷¹ B7, lines, 297-302.

⁵⁷² *ibid*, lines 303-307.

⁵⁷³ *ibid*, lines 47-52.

⁵⁷⁴ *ibid*, line 284.

For B6 this is clearly a structural weakness, which can only be tackled by changing the system of education, remuneration and mobile in-house care organization (allocation of time per patient).

Moving away from the transfer of knowledge and experience in a formal educational setting, I would like to address a more informal but still professional exchange of experience. Above all in the interviews with the legal adult representatives working for the Vertretungsnetz, the importance of the opportunity to exchange experience among colleagues emerged. There is a spectrum of possible exchange, starting with a one-year mentoring program, where a more experienced colleague can be consulted any time if needed. Later, more official further training takes place once a year, where apart from refreshing some hard facts, they share their experience with experts. But for B, talking to the colleagues, for example at the breaks during further training, is even more important. She says that '[...] of course then, during the breaks, there is time for informal exchange and to get to information or to talk about certain problem that you have with clients and to get some ideas.'⁵⁷⁵ By ideas she means possible strategies how to interact with persons diagnosed with dementia in specific situations. She needs this exchange for developing new, different strategies saying 'you have to try out a lot. There is no one way of doing it and this simply works. No, this is a confusing construct, and therefore it is important that you exchange ideas.'⁵⁷⁶ This 'trying out' after asking colleagues for advice how to cope in a difficult situation is transfer of knowledge into practice, which both B1 and B3 appreciate in their practical work.

B2, the residents' representative, engages in transferring knowledge and experience as well, but in a different, more complex form. On the one hand, she holds lectures for the nursing staff in residential care institution about the contents of the Nursing Home Residence Act, which puts her in an official position of a formal trainer. On the other hand, at such lectures and in her every day monitoring activities, the nursing staff recount situations where they experience the dilemma of balancing the protection with the right to freedom of residents. Both directions of transfer of knowledge and experience she considers extremely important and rewarding, yet, exhausting as well:

⁵⁷⁵ B1, lines 93-95.

⁵⁷⁶ *ibid*, lines 101-104.

When I start a lecture [...] - this is the law concerning personal freedom and this is the European Convention of Human Rights and this is the legal framework we have to operate in, then it helps saying actually that this is an area of conflict, you do not get that wrong, it really is an area of conflict. [...] It helps a little bit to shift the focus on alternatives [*to certain coercive measures*] in the conversation, but we have already talked about that. It is often quite tiring to remind again and again, "But this is the legal framework." And it is extremely pleasant to notice that people realize that they can use it themselves [...]⁵⁷⁷

Giving information and explaining laws and legal instruments, are not only responsibilities of B1, B2 and B3 in their positions with the Vertretungsnetz but as well for the other interviewees. The focus here is on the Adult Protection Act with its four pillars and other legal instruments that guarantee as much autonomy as possible until the end of life. This new law is guided by the concept of supported decision-making for legal matters but also medical and everyday life matters. In fact, B5 acknowledges the work of the Vertretungsnetz, but she considers it her organization's and her responsibility to give information about the differences of the four pillars of the Adult Protection Act. At the same time she believes that it is her duty to inform about further instruments, such as the advance care directive and advance care dialog, which is in line with B6 and B7.⁵⁷⁸ They all believe that upon diagnosis or not long after, the persons' diagnosed with dementia and their families' awareness must be raised of the opportunities to make decisions concerning their will and wishes for the time, when they may not be capable of doing so anymore.

In this context, almost all interviewees address the difficulty of terminology, as the Adult Protection Act has only been in existence since July 2018.⁵⁷⁹ The majority of the persons diagnosed with dementia and their families that my participants work with are not aware of the exact stipulations of the new law. It is the obsolete concept of guardianship (*Sachwalterschaft*) associated with substitute decision-making in all legal and medical matters that prevails. B6, for example, believes it would be important to use the new term consistently. In her opinion, the term 'Adult Protection Act' connotes

⁵⁷⁷ B2, lines 403-414.

⁵⁷⁸ see B6, line 287; B7 line 131.

⁵⁷⁹ see for example: B1, B3, B6.

the positive shift from something passive (the German word '*Sache*' meaning 'thing / matter' in English) to the person, i.e. the adult who is in need of protection by receiving support for decision-making. Yet, as she is realist enough, she opts for a compromise in her work, trying to bring in the new terminology as often as possible in conversations, but referring to the old terminology when she notices that people simply are not able to follow.⁵⁸⁰ In fact, this is the approach especially B1 and B3 have adopted for their professional work as well.⁵⁸¹

So far in the thematic presentation of my findings, it has become obvious that basic human rights but also specific laws and legal instruments play an important role in dementia care. The final spotlight in the presentation of my findings will be on relevant Austrian laws, legal instruments, rights and also the Austrian Dementia Strategy in the actual work of my interviewees, and how volunteerism is linked to this field.

6.2.4. Laws and legal instruments versus volunteerism

The two major Austrian laws which were referred to by my participants are the Nursing Home Residence Act (2005) and Adult Protection Act (2018).⁵⁸² These two laws are highly relevant for persons diagnosed with dementia, as they encompass the basic human rights to respect for inherent dignity and autonomy, and in particular the rights to liberty and equal recognition before the law. As the Nursing Home Residence Act regulates and controls the conformity of deprivation of liberty with the law in nursing homes, it affects B2's and B7's professional work most. In their opinion, this law has established itself firmly within the past 15 years and, according to B2, nowadays there is a

fairly pragmatic cooperation. I try to explain what my responsibility is, but of course, it is important for me to listen to the assessment of nursing staff, the management of the institution to be able to receive a comprehensive picture of the situation.⁵⁸³

Even if her work still involves a lot of awareness-raising for possible alternatives to deprivation of liberty of persons diagnosed with dementia, the law has contributed to substantial improvement as far as coercive measures are concerned. For B2, this is due

⁵⁸⁰ B6, lines 240-245.

⁵⁸¹ B1, line 307; B3, lines 127-129.

⁵⁸² see more details in my master thesis, chapter 4.

⁵⁸³ B2, lines 149-152.

to the fact that there is a legal framework and jurisdiction, which has sparked off a process that has led to systemic change. In her execution of the law, she epitomizes a 'monitoring control organ, the legal representation of residents [...] and to a certain degree it is my responsibility to ask unpleasant questions so that something changes.'⁵⁸⁴ She tries to raise awareness that rights are extremely precious that 'people in institutions are very, very quickly deprived of'⁵⁸⁵ because of the noble claim that this vulnerable group must be protected. Although former common methods of restraints, such as beds with bars or cage beds or tying residents to their wheel-chair, are unlawful and have almost completely disappeared in institutional settings, application of drugs as chemical restraint to sedate residents are on the rise, and therefore are nowadays a focal point of residents' representatives' work. B3 doubts if such widely used chemical restraints are really clearly classified as coercive measures by the authorities.⁵⁸⁶

The fact that the Nursing Home Residents Act has played a major role in bringing about change in institutional care and contributed its share in the protection of human rights, especially the right to liberty and security laid out in art.14 of the CRPD, has been acknowledged by two of three of my participants.

As far as the Adult Protection Act is concerned, there is agreement that its introduction two years ago was a decisive moment for legislation guaranteeing persons with intellectual and psychosocial disabilities equal recognition before the law. Its actual implementation process is evaluated differently, though.

This new concept of supported decision-making has not yet, 'arrived'⁵⁸⁷ in the broad public's awareness, and the differences of possible types of representations and legal instruments supporting or complementing the law are still confusing.⁵⁸⁸ Nevertheless, systemic change in some professional areas is already suggested. An example cited by B2 and B3 is that courts do genuinely look into alternatives to court-appointed representation, the last resort of official adult representation, or a formerly established guardianship. The clearing process as a measure to prevent relatives from forcing a

⁵⁸⁴ *ibid*, lines 194-197.

⁵⁸⁵ *ibid*, lines 408-409.

⁵⁸⁶ B3, lines 377-378.

⁵⁸⁷ B1, lines 282-284; B6, lines 249-250.

⁵⁸⁸ see for example: B5, lines 271-273; B6, line 287.

person diagnosed with dementia to change his or her place of residence is mentioned positively as well.⁵⁸⁹ Besides, there is hope as, for instance B1 and B3 express, that the new law will eventually lead to a shift how people who need support are perceived, B1 calling it a 'cultural value shift'.⁵⁹⁰

Yet, there are some critical statements in how far its implementation is really effective and really aligned with art.12 of the CRPD.⁵⁹¹ B3 believes that it highly depends on 'how the law is lived'⁵⁹² by the adult representatives. She implies that, generally, the 'old law still prevails',⁵⁹³ which B1's statement referring to the situation of persons diagnosed with dementia in particular reaffirms. In her opinion, for persons living with dementia frequently almost all areas of activities (*Wirkungsbereiche*) are represented by an official guardian⁵⁹⁴ although, according to the new law, they are never completely deprived of their legal capacity. B6 considers this a weakness as well, referring to the two pillars, statutory representation (*gesetzliche Erwachsenenvertretung*) and court-appointed representation (*Gerichtliche Erwachsenenvertretung*). Above all the latter is more or less the same as the former guardianship.⁵⁹⁵ In this context B6, to a lesser extent also B3, B5 and B7, stress the importance to promote advance (care) planning, such as power of attorney (*Vorsorgevollmacht*) and advance care directive (*Patientenverfügung*).⁵⁹⁶ The professionals working with the CS highlight the importance of offering persons diagnosed with dementia the opportunity to lay down their wishes and will during an advance care dialog. B5 honestly doubts the effectiveness of the new Adult Protection Act with regard to guaranteeing individual autonomy to persons diagnosed with dementia if there is no legally accepted advance directive in written form.⁵⁹⁷

All of the above-mentioned instruments are considered integral parts of effective offers for supported decision-making. However, they will not lead to effective implementation

⁵⁸⁹ B3, lines 213-214.

⁵⁹⁰ B1, line 222.

⁵⁹¹ see details on art. 12 of the CRPD, my master thesis, chapter 3.5.

⁵⁹² B3, lines 88-91.

⁵⁹³ *ibid*, line 340.

⁵⁹⁴ B1, lines 201-205.

⁵⁹⁵ B6, lines 274-277.

⁵⁹⁶ see this section 6.4.3.

⁵⁹⁷ B5, lines 239-245.

of the new law, as long as they are not more easily accessible and not funded, which B3 implies⁵⁹⁸ and B6 elaborates on. Dementia consultancy aims at raising awareness and informing society at large of different advance directives. Yet, lack of funding of this type of consultancy and of the actual notarization of the legal documents on advance directives is a systemic problem. B6 considers this fact a 'great obstacle,' which makes it difficult for persons diagnosed with dementia to be able to determine their end of life autonomously.⁵⁹⁹ Besides, the reluctance of general practitioners to inform their patients about medical matters in the case of setting up advance care directives is another reason for ineffective implementation of the law.⁶⁰⁰

A lack of resources has resonated as the major point of criticism for the provision of high-quality personalized dementia care to enable a good life throughout the interviews. When addressing the Austrian Dementia Strategy 'Living Well with Dementia' explicitly, this was even voiced more outspokenly by all the participants.

It was interesting to find out that four of my interview partners have never heard of the Austrian Dementia Strategy before and were not familiar with its objectives. One of them, out of curiosity, did some research online one day before the interview. She speculates that some impact of certain initiatives and projects might be recognized in hospitals where she personally has experienced dementia-friendly wards. She also reflected on possible ways how this policy paper could be relevant for practical dementia care.⁶⁰¹ The majority of the interviewees who had never heard of the Austrian Dementia Strategy were rather skeptical and expressed their doubt whether the document will really bring about change in dementia care. It is difficult for them to imagine that the Austrian Dementia Strategy will improve persons' diagnosed with dementia lives, and also their own professional lives, as long as the resources for consultancy, for offers of personalized dementia care, in particular personal assistants, education and training staff are not adequately funded.⁶⁰²

⁵⁹⁸ see B3, 344-347.

⁵⁹⁹ B6, lines 254-259.

⁶⁰⁰ *ibid*, lines 317-319.

⁶⁰¹ B2, lines 330-340; lines 353-377.

⁶⁰² B5, lines 326-329; see also B2, B6 and B7.

The participants who are familiar with the Austrian Dementia Strategy have been volunteers in the field of dementia for years. B6 and B7 had been actively involved in founding the network of dementia-friendly districts in Vienna, even before the Austrian Dementia Strategy came into existence. B6, B7, as well as B4, consider the codification of objectives to improve dementia care a milestone,⁶⁰³ and therefore welcomed the sparking off of the implementation process. They do believe that there has been some recognizable progress, for example in the field of assisted self-advocacy, as B4 acknowledges.⁶⁰⁴

For B6 and B7 the further development of dementia-friendly initiatives and dementia sensitive activities, e.g. certain hospitals and institutions⁶⁰⁵ has been fostered by the Austrian Dementia Strategy. Yet, their statements referring to the inadequacies and systemic flaws in health and social care sector suggest current frustration and raises the question of the role of the government with regard to sustainability of the Austrian Dementia Strategy. This is exactly where volunteerism was brought up by some of the participants, rather what volunteerism cannot be the substitute for.⁶⁰⁶

The criticism of insufficient funding of the Austrian Dementia Strategy is stressed by B6 and B7. According to B6, idealism, which is the core of volunteerism, is not enough for a strategy to have a lasting impact, which she puts bluntly in the following way:

And I think, something is needed which is not simply financing of projects [...]
But if I want to implement something, such project is finished one day and it is only sustainable when I have implemented it and it has become part of common practice. Sustainability - we simply have to talk about money. Anything else is idealism - that is wonderful, but it is simply not enough.⁶⁰⁷

The implementation of the Austrian Dementia Strategy seems to rely predominantly on idealism of individuals who are involved in various great projects and initiatives. Even consultancy work and further education for staff members is highly dependent on good will of organization, as there is no adequate funding for these areas. although they are

⁶⁰³ B6, lines 435-436; B4, line 367.

⁶⁰⁴ B4, lines 373-374.

⁶⁰⁵ see best practice as laid out in this section, chapter 6.2.2.

⁶⁰⁶ see B4, B6, B7.

⁶⁰⁷ B6, lines, 438-444

key objectives of the Austrian Dementia Strategy. Services providing information on dementia and advance dementia care planning can only be offered for free to persons diagnosed with dementia and their families if its financing is budgeted within the non-profit organizations.⁶⁰⁸

As stressed by my participants throughout the interviews, post-diagnostic care is simply crucial for high-quality dementia care which guarantees living well with dementia until the end of life. That is why apart from being assured that there are services that provide the right information and support for further planning for the persons diagnosed and the families, personal assistance is another area where volunteerism cannot take over the responsibility of the state, which B4 clearly points out.⁶⁰⁹ In general, in her opinion, in Austria the state relies too much on volunteer work which is high-quality work and time-consuming.⁶¹⁰ But it is simply not paid, as people do not have a legal right to it. For her, the right to personal assistance would be extremely important for persons diagnosed with young onset dementia. Angela Pototschnigg, whom she assists as a volunteer for AA, herself claims this right referring to the CRPD.⁶¹¹ In fact, B7, mentions AA and finds their budget, which is mainly dependent on donations and volunteer work, ridiculous compared to other European Alzheimer's Associations. She suggests that AA should be funded by the Austrian government, as the organization has been active in dementia care for three decades. The volunteers there are professionals who have gained valuable experience over the years and offer great services to persons diagnosed with dementia and their families.⁶¹² Their expertise should be utilized for tackling the systemic weakness of providing that missing link in coordinated dementia care. Besides, B7 recounts her own experiencing when she had to put a halt to being exploited by volunteering for the network dementia-friendly districts. In this instance, she at least succeeded in convincing the city of Vienna that the expansion of the network cannot be done purely on a volunteer basis. A newly founded umbrella

⁶⁰⁸ *ibid*, lines 425-427.

⁶⁰⁹ B4, lines 36-40.

⁶¹⁰ *ibid*, lines 33-35.

⁶¹¹ *ibid*, lines 491-493.

⁶¹² B7, lines 354-356.

organization of dementia-friendly districts now is operated by employees of the city of Vienna encouraging cooperation between initiatives.⁶¹³

B7 believes that volunteering is still necessary for the provision of highly individual leisure activities, e.g. in the field of art, especially music, but the approach to volunteerism, despite all the idealism involved, must be a professional one, including some basic training for volunteers when directly interacting with persons living with dementia.⁶¹⁴ B5 also highly appreciates volunteers for the visitors of her day center calling them a 'valuable resource' that must not be taken for granted and integrated in the team.⁶¹⁵

Such as volunteers who show tremendous personal commitment in supporting and spending time with persons diagnosed with dementia for years, it has become obvious that my professionals in the field of dementia care do not simply do a job to earn a living but are dedicated to improving the life of a highly vulnerable group of people in our society. Therefore, I would like to call them human rights practitioners in their daily professional activities, although they would never perceive themselves that way. When asked about the relevance of human rights and human rights conventions explicitly, human rights were first associated with human rights violations in the context of restriction of freedom and violence against persons living with dementia.⁶¹⁶

The only human rights convention cited by some of my participants as having relevance in their practical work was the CRPD.⁶¹⁷ Generally, the rights to autonomy, a self-determined life, inclusion and a life in dignity and respect until the end of life were mentioned as well.⁶¹⁸ But for them, these basic rights are self-evident, and they are personally committed to them, which clearly reflects in their reactions to Covid-19.

Last but not least, a brief rendering of the impact of this highly contagious virus on the professional work of my interviewee will finish off the presentation of my findings.

⁶¹³ *ibid*, lines 324-329.

⁶¹⁴ *ibid*, lines 255-260.

⁶¹⁵ B5, lines 376-386.

⁶¹⁶ see for example: B3, line 375 (restrictions); B1, line 422 (violence).

⁶¹⁷ B1, B2, B3, B4.

⁶¹⁸ see for example: B7, lines 363 (self-determination); lines B6, lines 478-479 (inclusion); B5, lines 467-471 (respect).

Elaborating on it would, in fact, go beyond the scope of this master thesis, and it is definitely worth doing empirical research on its impact in the near future.

At the time of my interviews from the end of April to mid-May the pandemic caused by Covid-19 evoked deep concern among my participants. They worried about the impact on their professional work, as there were still major restrictions in place. B2 in her function as residents' representative in nursing homes raised her concern that the deprivation of freedom in a great number of nursing homes was not based on any legal grounds and a violation of international human rights law. She had to communicate that fact to the managers of the nursing homes, which, she admits, required a lot of courage. She herself was in a personal dilemma because she understood the management's concern balancing responsibility to protect the residents with not unlawfully violating the right to liberty and movement.⁶¹⁹ It was the question of protection against danger versus violation of rights on a macro-level, which she usually discusses with nursing staff on a micro-level.

Great uncertainty and fear for her visitors was expressed by B5, as she had to close her day center. At the time of the interview she did not yet have any information on when and how to open it up. Working from home, she tried to communicate as much as possible with family members of her visitors, who reported to her that the condition of their relative or partner living with dementia was deteriorating. Some of them simply could not cope any longer and registered their relative for residential long-term care. She did not only convey her clients' fear and despair but her own as well.⁶²⁰

My participants working in adult representation were deeply concerned about how to continue their relationship with their clients and how to build up trust, if they cannot see them for a long time and later have to wear mouth and nose protection, when interacting with them.⁶²¹

B7 was concerned about the impact of Covid-19 on the running of the CS nursing homes in future. She gave account about the difficult situation during lockdown and the uncertainty of the future when opening up again.⁶²² Yet, she also admitted that one

⁶¹⁹ B2, lines 426-441.

⁶²⁰ B5, lines 391-411.

⁶²¹ B1, lines 478-485; B3, lines 399-402.

⁶²² B7, lines 386-393.

striking lesson learned was that a considerable percentage of the residents were not worried or missed their relatives, but they enjoyed the peace and quiet, as they did not have to pull themselves together for their relatives. The staff realized that they expressed their wishes and will more freely if not pressurized by family members. In her words, as far as the autonomy of their residents is concerned, this is an aspect that needs to be considered even more in future in their relationships to relatives.⁶²³

All in all, Covid-19 has shown how vulnerable persons diagnosed with dementia are in our society and how easily their basic human rights are infringed upon in times of crisis and emergency. Despite the fact that they are part of the so-called risk group that requires special protection against a deadly virus, they are still right-holders and cannot be made invisible by simply locking the doors and not allowing them to move freely.

6.3. Summary of findings

The question what role human rights play in the implementation of the Austrian Dementia Strategy has proved to be a complex matter.

The three participants of my study who are familiar with the Austrian Dementia Strategy and its objectives point to its importance and acknowledge some progress in dementia care and change of perception concerning persons diagnosed with dementia and their families. They refer to some best practice and the development of dementia-friendly networks all over Austria, which can be considered community-based support. The four professionals who were not aware of the existence of the official Austrian Dementia Strategy as well acknowledge some change in perception and progress, which suggests an ongoing implementation process. Yet, they rather refer to specific laws and the impact of this legislature on their work. For them there does not seem to be a direct link between the Austrian Dementia Strategy and their work. But after some research on the Austrian Dementia Strategy, one participant speculates about the impact and points out some possible initiatives that she has encountered in her work.

Basic human rights principles underpin all the professional activities of my interviewees due to their general vision of humanity. In this light, human rights obviously play a huge role in the implementation of the Austrian Dementia Strategy, but there would be

⁶²³ *ibid*, lines 183-200.

no difference whether the official Austrian Dementia Strategy existed or not. It is rather the personal deep conviction about human rights principles that is decisive. Their professional approach is based on the understanding of dementia care being a broad person-centered concept, where the wholeness of a person diagnosed with dementia and the persistence of his or her personhood is in the center of attention.⁶²⁴ In such person-centered broad concept, relationality is core as it enables assisted autonomy until the very end of life.⁶²⁵ This is an important aspect for persons at an advanced stage of dementia. For my participants establishing a trustful relationship is simply key for their professional work. This is especially true for providing supported-decision making, which is an integral part of guaranteeing the right to equal recognition before the law laid out in art.12 of the CRPD. As the CRPD is referred to in the introduction of the Austrian Dementia Strategy, it is suggested that as a Member State the Austrian government will have certain obligations to implement rights relevant for dementia care. Due to the uniqueness of every individual and the diversity of dementia highly personalized dementia care is required. Timely and suitable support could enable persons diagnosed with dementia to live independently, and full social inclusion could be guaranteed, which is a human right clearly laid out in art.19 of the CRPD.⁶²⁶ My study has shown that it is person-centered post-diagnostic care where the focus of my interviewees lies and which has evoked criticism. The right to timely diagnosis and post-diagnostic care is enshrined in articles 25 and 26 of the CRPD. These two articles also stipulate the State's obligation to foster initial and further education and training to the highest human rights standards in health and social care to be able to provide support for participation and inclusion in society.⁶²⁷ Formal education and training as well as informal transfer of knowledge and experience take in significant space for my participants, as they perform the function of awareness-raising and are prerequisite for provision of high-quality support.

⁶²⁴ see details on person-centered dementia care, my master thesis, chapter 2.2.2.

⁶²⁵ see details on relationality and assisted autonomy, *ibid.* and chapter 3.5.

⁶²⁶ see details on art. 19, my master thesis, chapter 3.4.

⁶²⁷ see art. 25(d) and art 26(2); also see more details on these two articles, my master thesis, chapter 3.3.

Based on my study, there is a concrete lack in resources concerning not only formal education but consultancy work, too. It must be funded by the state and promoted broadly, as it is part of post-diagnostic support. It is key in providing valuable information for advance planning of the further dementia journey. In addition, federal legislation should include the right to personal assistance, which is particularly important as an integral part of post-diagnostic support for persons diagnosed with onset dementia. This could tackle the problem of the missing link in the coordinated, integrated dementia care concept. Another element of policy could be looking into the best practice of Scotland passing legislation for a legal right to post-diagnostic support. My study in dementia care has shown that personal commitment and conviction about human rights for delivery of quality dementia care is definitely important, but effective dementia policy must not exclusively be based on idealism of individuals nor good will of organizations.

There is evidence that laws make a difference and may contribute to systemic change. Thus, the Nursing Home Residence Law closed a gap in human rights legislation strictly regulating restriction of liberty and contributed to enhancing the human rights situation of persons with intellectual and psychosocial disabilities.⁶²⁸ The same holds true for the Adult Protection Act that initiated a paradigm shift from substitute decision-making to supported decision-making and is aligned to art.12 of the CRPD. In order to effect this law, a range of person-centered support offers and legal instruments must be available and accessible for persons diagnosed with dementia. Consequently, there must be adequate state funding, and they must be included in dementia policy in order to guarantee fundamental rights to persons living with dementia. It is the lack of insufficient funding from the time of introduction of the Austrian Dementia Strategy which has been widely criticized and which reflects back on the practical work of professionals in the field.

⁶²⁸ also see my master thesis, chapter 4.2.

I am aware of the fact that this law is currently under scrutiny because of the restrictions of freedom due to Covid-19 and re-evaluation of the law in order to be prepared for times of emergency is called for; see: M. Mattersberger, cited in Lebenswelt Heim, Bundesverband für Alten- und Pflegeheime Österreichs, 'COVID-19 in Alten- und Pflegeheimen', *Presseaussendung APAots*, 01 July 2020, https://www.ots.at/presseaussendung/OTS_20200701_OTS0023/covid-19-in-alten-und-pflegeheimen-bild (accessed 3 July 2020).

At the end of chapter 5. I stated that it is high time to listen to the professionals to explore whether the Austrian Dementia Strategy has already found its reflection in practical work from a human rights perspective. After listening to them, I would like to wrap up the findings of my analysis of the document (conceptualization) and my findings of my empirical study (implementation).

7. THE AUSTRIAN DEMENTIA STRATEGY - 'A PROCESS WITHOUT POLITICAL COMMITMENT'

The title of this chapter summarizes all my findings in a nutshell.

As a reminder, the Austrian Dementia Strategy has identified dementia relevant human rights areas as priorities within its objectives that are aimed at guaranteeing 'living well with dementia.' Even if it refers to the CRPD in the introduction, it does not explicitly refer to specific human rights and its articles. The importance of awareness-raising and accessibility is highlighted even if not explicitly stated as a precondition for protecting basic human rights. A variety of human rights and thus articles of the CRPD are implied, in particular art.19, art. 25 and art.26 and art. 4(3).⁶²⁹ These human rights as well as art.12 and art.14 resonate in the implementation of the Austrian Dementia Strategy and play an enormously important role in practical work. Yet, when sharpening my human rights lenses for my studied field, the weakness of the implementation of the Austrian Dementia Strategy takes shape in the lack of commitment to fulfill its obligations as a Member State of the CRPD.

In its official conceptualization the document refers to the CRPD and its social model of disability, but this remains lip service. It does certainly not adopt a human rights-based approach to dementia policy. As has already been illustrated before, there was reluctance to fully involve self-advocates diagnosed with dementia in the drawing up process of the Austrian Dementia Strategy⁶³⁰. My interviews have shown that five years after its introduction lip service in this context continues. Despite the fact that there has been some progress in making self-advocates visible by inviting them to events and the annual meetings of the Dementia Platform, sustainable financial support for developing

⁶²⁹ see my master thesis, chapter 5.3.

⁶³⁰ see my master thesis, chapters 5.3. 4. and 5.5.

nation-wide assisted self-advocating groups in Austria does not exist. As long as they are not fully involved in matters relevant to their cause, there is no clear commitment to the CRPD. The implementation of the Austrian Dementia Strategy based on the CRPD would require the adoption of a human rights model of disability.⁶³¹ The social model of disability focuses on the removal of social and environmental barriers for full inclusion. In contrast, the more nuanced human rights model recognizes the individual person with his/her impairment who has the right to individual support to enjoy all human rights on an equal basis. It has been the common experience of my interviewed professionals that it is often this individual post-diagnostic support which is not provided sufficiently or not easily accessible although it is widely promoted in the Austrian Dementia Strategy. The systemic weakness stems from inadequate resources due to a lack of commitment. As long as there is no political will for commitment, the Austrian Dementia Strategy will simply remain a policy paper, a document with a virtual platform, whose objectives look great on paper or online, but do not reflect upon and definitely not support practical work. Besides, dissemination and communication of the Austrian Dementia Strategy is rather weak if it is not known to professionals working in the field five years after its introduction. All in all, volunteerism and idealism cannot be the substitute for a lack of political will to adapt legislation. In order to ensure sustainability and equality of high standards in dementia care in Austria, resources for an effective implementation of the Austrian Dementia Strategy must be allocated.

⁶³¹ see Degener's human rights model of disability, my master thesis, 2.2.1.

8. CONCLUSION

Throughout my master thesis, I have included international and national voices of self-advocates indirectly. It was Angela Pototschnigg's voice that frequently resonated as a self-advocate's in Austria in the context of the Austrian Dementia Strategy. In the introduction of my master thesis, she pleaded to be heard and understood, for the conclusion I have chosen a statement by her addressed to policy-makers during the first Demenz Meet (*dementia meeting*) in July 2019:

Reden sie nicht über uns, reden sie mit uns!⁶³²

This is her way of expressing criticism of the lack of political awareness of dementia issues in Austria and of the fact that persons with cognitive disability are not included in decision-making processes.

Her statement is a perfect beginning for my conclusion as it hints to my major findings in the attempt to answer my research question, which is:

What role do human rights play in the conceptualization and implementation of the Austrian Dementia Strategy?

My research question cannot be answered straightforwardly. The role of human rights must rather be looked at from two different perspectives/angles - implicitly and explicitly.

On the basis of my deductive content document analysis of the Austrian Dementia Strategy (5.3. and 5.5.), it can be concluded that human rights issues play a significant role in its conceptualization implicitly. The seven objects of the document reflect the main stipulations of relevant human rights articles as laid out in detail in chapter 3., my 'human rights framework' chapter. A category system consisting of five important dementia relevant human rights areas has been established with the help of an inductive document analysis. These areas encompass awareness-raising, accessibility, health/rehabilitation, independent living and participation in society and equal

⁶³² A. Pototschnigg in W. Fastl, 'Erstes Demenz Meet in Wien unter dem Motto "Zusammenleben in der Stadt"' *Lebenswelt Heim*, no.83, November 2019, p.26, https://www.lebensweltheim.at/images/zeitschrift/LWH_83_V8.pdf (accessed 10 July 2020); my translation: Do not talk about us, but speak with us.

recognition before the law. All of them are covered in the Austrian Dementia Strategy. The CRPD, which has been considered the most effective tool for enhancing quality of life for the highly vulnerable group of persons living with dementia (chapter 2.2.1.), served as the foundation of my human rights framework for analyzing the Austrian Dementia Strategy from a human rights perspective. My five human rights categories cover the following rights substantiated in various CRPD articles: art.8 (awareness-raising), art.9 (accessibility), art.12 (equal recognition before the law), art.14 (liberty and security of person), art.15 (freedom from torture, inhumane or degrading treatment), art.16 (freedom from exploitation, violence and abuse), art.19 (independent living and participation), art.25 (health), art.26 (rehabilitation) and art.4(3) and art.33(3) (participation of persons with disability in decision-making and implementation processes).

In order to sharpen my human rights lens for the analysis of the Austrian Dementia Strategy, I included information of relevant General Comments issued by the Committee and recent reports of the Special Rapporteur on the Rights of Persons with Disabilities in my human rights framework chapter (chapter 3.) These documents provided substantial clarification of my established human rights categories, explicitly for art.12 (GC no.1), art.9 (GC no.2), art.19 (GC no.5) and art.4(3) and art.33(3) (GC no.7). The GCs clearly point to the accountability of Member States and their resulting obligations for full implementation of the CRPD.

This is where my explicit angle comes in when answering my research question. The CRPD is mentioned in the introduction of the Austrian Dementia Strategy, which would imply a clear commitment to human rights. Nevertheless, based on my research, I would argue that explicitly human rights do not play a major role in the Austrian Dementia Strategy. Neither in its conceptualization nor in its implementation, which is suggested by the outcome of my empirical study with professionals working in the field of dementia care applying Grounded Theory (chapter 6.). In a human rights approach in general and in particular in the spirit of the CRPD, participation of the beneficiaries of a strategy is essential. Furthermore, policymaking must reflect the standards and principles of human rights. Both aspects are lacking in the conceptualization and implementation of the Austrian Dementia Strategy, as will be laid out below.

Throughout my research and writing process the year 2015 crystallized as being crucial for my studied field of dementia care linked to human rights. The introduction of the Austrian Dementia Strategy coincided with the first WHO Ministerial Conference on Dementia. At this conference the DAI, as the international representative self-advocacy organization of persons diagnosed with dementia, claimed their undisputed right of access to the CRPD and other UN human rights treaties to improve dementia care, which was a milestone and initiated a human rights-based approach to dementia care (chapter 2.2.1.).

In Austria dementia activism was ignited at the same time (chapter 2.2.), which led to the participation of two self-advocates in one of six working groups during the drafting process. Yet, this involvement was and is still not guided by the spirit of the CRPD and clearly not aligned to art.4(3). Their participation was initially met with reluctance by stakeholders and the agency responsible for the drafting and implementation of the Austrian Dementia Strategy. In its original conceptualization participation by persons living with dementia and their families was only devised in the form of consultation (interviews) and emails (chapter 5.3.4.), but not in the actual drafting process.

The importance of empowering persons diagnosed with dementia and their families is clearly identified in the Austrian Dementia Strategy, but not clearly reflected in its implementation based on my empirical study and additional sources.

A major finding of my research is that the Austrian Dementia Strategy sparked off an important process in 2015 and there has been some progress in the field of dementia care. But due to lack of political will in policymaking, explicit human rights commitment remains lip service.

With regard to self-advocacy there has been progress due to dementia-friendly initiatives, which are promoted by the virtual platform of the Austrian Dementia Strategy and partly financed. The assisted self-help and self-advocacy organization Promenz was founded within such an initiative. Its ambassadors are invited and listened to at official events and the annual conferences of the Austrian Dementia Strategy Platform, but in the end their status remains representative and even decorative, as they are still not involved in the actual decision-making process (chapter 5.3.4.). What is more, strengthening of self-advocacy would be an integral part of post-dementia care as

pointed out frequently in the interviews. It would require consistent funding by the state which so far has not yet happened. The same is true with Alzheimer Austria (AA), which purely relies on private donations and volunteer work. AA had had great expertise in the field of support and assistance for persons diagnosed with dementia and their families for decades, even before Promenz was founded. Contrary to other European countries, there is no umbrella organization of representative groups dedicated to the cause of dementia. Full funding provided, AA could expand and serve as such umbrella organization. Fully supporting self-advocacy and an umbrella organization for dementia are two concrete examples where political decision-makers would have to be reminded of Austria's obligations as a Member State of the CRPD to guarantee the enjoyment of human rights to persons with disabilities. This would certainly bring in a clear human rights focus in dementia policy. Without funding of relevant representative groups, empowerment of self-advocacy groups and family members of persons living with dementia will simply not be possible. Policymakers have to be reminded of international human rights obligations, which could happen, for instance, during meetings of the Austrian Dementia Strategy Platform. These meetings take place regularly to evaluate and discuss the progress of implementation of the Austrian Dementia Strategy (chapter 5.3.4.).

Since 2015 official documents on a global and regional level have called for drawing up national dementia plans or strategy adopting a clear human rights approach based on international human rights treaties, above all the CRPD (chapter 2.1.). Such approach would require sufficient funding of the goals of dementia strategies, as well as a clear timeframe for certain targets to be achieved. The absence of both constitutes a major flaw in the Austrian Dementia Strategy. Again, for example, during a coordination group meeting of the Dementia Platform, participants who represent organizations supporting persons living with dementia could raise awareness of this weakness pointing to international human rights obligations. By doing so the CRPD could be used as a tool to advocate change by challenging existing practices and structures.

In fact, one member of a coordination group already raised the importance of synergies between disability policy and dementia policy in Austria. Yet, his suggestion to discuss this intersectionality was rejected with the argument that officially labeling dementia as

a disability is too stigmatizing and should be avoided. This is a clear contradiction to the reference to the CRPD in the introduction of the Austrian Dementia Strategy and again is evidence of a non-committal human rights approach to dementia despite referring to the social model of disability strongly propagated by the CRPD (chapter 5.2.). The highly active German self-advocate Helga Rohra, who is even mentioned in the Austrian Dementia Strategy by name, and Promenz advocate for utilizing the CRPD to claim their rights. In such advocacy conceptualizing dementia as a disability is core and aligned with the WHO (chapter 2.1.1.).

Only looking at the contents of the Austrian Dementia Strategy, the social model of disability seems to prevail. As laid out in chapter 2.2.1., this model aims to overcome the environmental and social barriers in society to achieve full inclusion of persons with disability. In this light my analysis finds that in 2015 the Austrian Dementia Strategy identified major obstacles in Austria that hinder full inclusion and pointed out the important areas that could foster equality and full inclusion of persons diagnosed with dementia.

The fragmentation of the Austrian health and social care system due to the country's federalist structure with political responsibility lying either in the scope of the federal government (healthcare) or provincial governments (social care) is criticized and a coordinated approach to dementia care is a major goal of the Austrian Dementia Strategy. In this context the right to accessibility to dementia care services of equal standards is implied and the Austrian Dementia Strategy seems to be aligned with human rights obligations. The CRPD Committee already pointed out the fragmentation of the system as a weakness in 2013. In its concluding observations after the first state report an overarching legislative approach to disability policy was already recommended. Another recommendation was to introduce equal access to personal assistance for persons with cognitive disabilities. So far there has been no substantial progress in establishing such a nationwide disability legislation, which must include dementia policy as well (chapter 4.2.).

Most recently the need for concerted legislation as an integral part of a comprehensive general care reform in Austria was voiced by the ACA (see also chapter 4.2.). Other recent points of criticism with reference to dementia care specifically come from the

NPM that monitors nursing homes. Due to structural conditions, above all a lack of time for their residents and inadequate training of staff, person-centered dementia care cannot be administered. In consequence, persons living with dementia are often denied their basic human rights, especially their right to freedom. Such violations could be avoided by delivering high-quality person-centered dementia care at all stages of the dementia journey.

Person-centered dementia care is, as has already been hinted at, identified as being crucial for enhancing the life of persons diagnosed with dementia. Thus, again implicitly another human right takes the stage in the Austrian Dementia Strategy, the right to health and rehabilitation.

This is where I would like to focus on answering the question which relevance human rights have in the implementation of the Austrian Dementia Strategy based on my empirical study. The professionals in practical dementia care have pointed out major flaws in post-diagnostic dementia care in Austria. After interviewing my participants, it is obvious to me that human rights play an important role in their professional lives, regardless of the existence of the Austrian Dementia Strategy. Generally, their work is underpinned and guided by their personal conviction and commitment to human rights principles. However, in their everyday job routine human rights are not in the spotlight. Besides, the majority of the participants are not familiar with the Austrian Dementia Strategy itself. Their professional work is rather influenced by legislature that reflect human rights standards and principles, the Nursing Home Residence Act and, more recently, the Second Adult Protection Act (chapter 4.2. and chapter 4.1. respectively).

In this context the Austrian Dementia Strategy could be a significant support for professionals in their responsibility implementing these two laws and would give human rights more significance in its implementation. Nevertheless, it would only be an effective instrument for improvement of quality of life if a human rights model of disability or even a more nuanced relational model of disability were adopted (chapter 2.2.1.).

The human rights model of disability is codified by the CRPD and focuses on the individual person with disability who is endowed with dignity and has the right to autonomy at all times. This is intrinsically linked to his or her right to individual support

to enjoy all human rights on an equal basis. Obviously, this applies to persons diagnosed with dementia who may require support and assistance at the beginning of their journey and more intensive personal care at the very end of life. The Second Adult Protection Act is a progressive law attempting to guarantee equal recognition before the law until the end and reflect art.12 of the CRPD (chapter 3.5.). Its full implementation is only possible if a broad range of support and care offers are provided to support persons with cognitive and psychosocial disabilities in their decision-making concerning legal but also more personal matters, for instance medical matters. They must never be denied their autonomy and full citizen rights. In recent years a variety of legal instruments to guarantee autonomy and self-determination until the very end of life despite declining mental capacity have been developed in Austria (chapter 4.1.). The outcome of my study finds that it would be high time to raise awareness for these instruments and make them more accessible to persons diagnosed with dementia and their families. Awareness-raising for dementia in general and accessibility to support services have been identified in the Austrian Dementia Strategy as key objectives. From a human rights perspective the implementation of art.12 is a priority for Member States entailing State obligations. Awareness for support services and legal instruments could be raised by national campaigns but, what is more, also at dementia information and consultancy services. They must be fully funded by the state to make them more accessible to persons diagnosed with dementia and their families, which obviously, would require sufficient funding of the Austrian Dementia Strategy.

The above-mentioned support services and legal instruments are all part of dementia care which is conceptualized broadly in a human rights-based approach. In such concept care is individualized and person-centered. Originally person-centered dementia care was first laid out by Tom Kitwood (chapter 2.2.2.). The person living with dementia is perceived in his or her wholeness and personhood is pertained until the end. Interpersonal relationships are core, and the concept of relationality plays an important role for assisted or relational autonomy in supported decision making (chapters 2.2.2 and 3.5.).

As briefly mentioned above, it is the weakness of individualized post-diagnostic care which has evoked strong criticism with the professionals in my studied field. Reforms

and resources are required to make the Austrian Dementia Strategy an effective and explicitly human right-based one, which is also supportive for professionals in the field. The right to health and rehabilitation is implied in the Austrian Dementia Strategy by putting its spotlight on the need for action of coordinated, integrated care. Enabling dementia care is the precondition for independent living and full inclusion in society, which is another human right highly relevant for persons living with dementia.

Upon diagnosis they are often denied this right immediately. The Austrian Dementia Strategy does not explicitly refer to this right but suggests that self-determination and participation must be fostered. In this context it promotes the development of dementia-friendly communities where dementia care should be enabling and community based. Besides, the environment must become dementia-sensitive and inclusive. It has been acknowledged by some of my participants that in this context, at least in Vienna, the Austrian Dementia Strategy has brought about some change and progress in the field of awareness-raising with the broad public and with decision-makers. This has manifested itself in permanent city council assistance, whose responsibility is to further develop dementia-friendly districts. In addition, there are a number of projects and initiatives financed by the State. However, promoting dementia-friendly communities still predominantly relies on highly idealistic volunteers. This is simply a non-committal, non-sustainable strategy, certainly not a human rights-based approach guaranteeing equal access to high-quality post-diagnostic dementia care across the country. To my mind, there is only one possible avenue to be taken to tackle the systemic weakness of unequal, insufficient post-diagnostic care:

The fragmentation of the health and social care system in Austria must be overcome by introducing overarching supportive legislature across the nation. Upon diagnosis, a person needs individualized, post-diagnostic care strategies to address the diverse forms dementia takes. The Austrian Dementia Strategy could take the Scottish Dementia Strategy as a role model for a human rights based approach to dementia care (see chapter 5.4.) and promote the legal right to post-diagnostic care. In order to navigate complex health and social systems, the missing link to already existing services could be a link worker or a case manager, similar to case managers in some already existing projects of dementia care provision (see chapter 5.3.3.). Link workers or case managers

must be professionals qualified in dementia care who support persons diagnosed with dementia to plan their future dementia journey. Such avenue in policymaking would clearly be human rights-based, as individualized, post-diagnostic care is the precondition for substantiating the right to independent living and participation.

Personal assistance is mentioned or implied by my study participants as being a way of providing low-threshold assistance in performing everyday life routines, especially for early or young onset dementia. Synergies between disability and dementia policy should be highlighted in the specific context of post-diagnostic care, even if it has already been rejected as an item of the agenda to be discussed at the Austrian Dementia Strategy Platform before. A number of personal assistants could specialize in dementia care and take on the tasks of a link worker right after diagnosis if required. Cooperation with the Austrian Disability Council (*Österreichischer Behindertenrat*) is highly recommended as the Council has had expertise in lobbying for the legal right to personal assistance for persons with intellectual and psychosocial disabilities in Austria for a long time (see chapter 4.2.). Representation of assisted dementia self-advocacy groups in the Disability Council could contribute to their empowerment. I personally do not believe that their representation in the Disability Council would stigmatize persons with disability even more, but rather make them visible in society. They could illustrate that they may need appropriate assistance for certain everyday life activities, but that they do not require intensive personal care after diagnosis. To the contrary, they are active right-holders outspokenly claiming their rights.

Self-advocacy within the disability movement could lead to a fruitful transfer of knowledge for persons diagnosed with dementia and their families. The urgent need of establishing and supporting various types of transfer of knowledge has been another focal point in the interviews during my study.

Education and training are identified in one of the seven objectives as an area of priority called 'strengthening knowledge and competence' of persons working in dementia care (see 5.3.3.). As it is the obligation of the Member States of the CRPD to ensure education and training of professionals to guarantee the enjoyment of the right to health and rehabilitation, insufficient funding in this area is a further systemic weakness. A human rights-based dementia policy would have to focus on this flaw, which would

encompass sufficient funding of formal initial and further education and training for qualification of staff for dementia-specific issues, but also of informal training of family members.

In this context I would like to touch upon another weak or non-existent transfer of knowledge, which is actually caused by the fact that professionals in the field are not efficiently made aware of the existence of the Austrian Dementia Strategy. Its virtual platform contains a great variety of information on dementia issues, projects and description of best practice in the field. As the Austrian Dementia Strategy's aim is to disseminate this information; inter alia, to professionals working in the field, its existence should be known to them. The majority of my participants, though, were not aware of it. Effective implementation of a strategy can only be achieved if the strategy itself is widely known in the respective field. In this light, a revised Austrian Dementia Strategy should target professionals working in the field more specifically, for example, by presenting it in workshops in relevant institutions. By discussing its objectives, ideally interlinked with the CRPD, professionals working in the field may acquire a human rights lens and eventually become explicit human rights actors.

During my study participants became interested and curious about the Austrian Dementia Strategy. In a revised human rights-based version specifically targeted at professionals in actual dementia care provision, the Austrian Dementia Strategy could turn into a tool of social change.

The Austrian Dementia Strategy's ultimate goal implies transforming society into a dementia-sensitive one by developing dementia-friendly communities that eventually ensure inclusion for all people on an equal basis. Integrated, coordinated dementia care would ideally be community-based and offer inclusive support options which have been demanded by the Special Rapporteur for persons with disability in 2019. Referring to art.19. (see chapter 3.4.) de-institutionalization policies have been a key priority as supportive policy. The Austrian government was criticized in the NPM report of 2018 for its lack of commitment for creating a concept to reduce the number of residential homes.

In a broad sense, dementia policy as laid out in the Austrian Dementia Strategy could be seen as part of such de-institutionalization policy and contribute to fulfilling the CRPD

regarding art.19 (chapter 4.2.). The fact that 80 percent of nursing home residents are persons diagnosed with dementia in Austrian nursing homes is partly due to inadequate individualized dementia care upon diagnosis. Therefore, post-diagnostic support must be an integral part of a consistent de-institutionalization policy. To put it bluntly, from my explicit angle, art.19 does not play a role at all in the conceptualization and implementation of the Austrian Dementia Strategy. Yet, it is art. 19, which is central for persons with disabilities and enables them to live an autonomous, self-determined life.

As suggested by my empirical study, there has been progress in dementia care manifesting itself in a broad range of post-diagnostic support, including assisted self-advocacy, dementia consultancy, initiatives of dementia-friendly districts and more. Yet, for the most part, this progress has not been the result of an effective implementation of dementia policy in Austria, but can rather be attributed to volunteerism and, in general, personal conviction to human rights, the 'vision to humanity' (chapter 6.2.).

However, de-institutionalization is an internationally called for obligation by the CRPD Committee and must not rely on idealism and volunteering. The same is true for dementia policy in general, whose ultimate goal is structural transformation of society. As frequently stated, this can only be achieved through reforms in the health and social care sector, which would require coordinated, governmental approach and change in attitude at all levels and sectors guided by human rights standards. Laws can make a huge difference.

Nevertheless, societies and their living conditions are constantly changing, which requires a critical stance to policies and legislature at all times. The Covid-19 pandemic has definitely taught me that lesson.

The Nursing Home Residency Act will serve as illustration. Introduced in 2005 as a landmark piece of legislation that regulates, the restriction of freedom by law, it has led to significant improvement in protecting human rights of persons with cognitive disabilities. Besides, over the years it helped nursing staff cope with the dilemma of balancing protection and autonomy of a resident diagnosed with dementia. Nevertheless, a critical eye must be kept on violations, nowadays especially in the form of chemical restraints. Furthermore, the Act has come under scrutiny because of the

Covid-19 pandemic. It has become obvious that in a public health emergency, balancing the rights of individuals belonging to a risk group with protecting these groups against a deadly virus may put vulnerable individuals at risk of human rights infringements. At the same time it causes legal uncertainty for an institution when taking restrictive measures.

On the one hand, this illustrates that it is important to have clear legislation at hand to guarantee the enjoyment of human rights to vulnerable groups and prevent grave human rights violations (chapter 4.2.). On the other hand, laws and policies are not static and must be revised if flaws and gaps are detected.

All in all, my master thesis has shown that implicitly human rights play a role in the Austrian Dementia Strategy and it would have some potential as a tool of social change if there were political will and commitment of decision-makers on all levels to allocate resources and adapt legislature that reflects high human rights standards.

Considering the demographic changes in our fast ageing society, dementia policy must be an integral part in a future master plan for care. Especially after the outbreak of the Covid-19 pandemic and lockdown, it is high time that the topic care returns to the top of the agenda.

As a Member State of the CRPD Austria is obliged to take measures to guarantee the full realization of the human rights laid down in the CRPD. By re-conceptualizing and adopting a genuine human rights-based approach to the implementation process of the Austrian Dementia Strategy the Austrian government could prove that human rights play a crucial role in its commitment to achieving its ultimate goal as the title claims: *Living well with dementia*.

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11. LIST OF AUSTRIAN LEGISLATION

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ANNEXES

Annex 1. Interview questions⁶³³ / Interviewfragen (English / German)

I. Introductory questions (Einstiegsfragen)

1. Could you please tell me briefly about your professional education, training and career and as well about your motivation for your current work with people living with dementia?

*Erzählen Sie mir bitte kurz über Ihre berufliche Ausbildung, Stationen und Beweggründe für die aktuelle Arbeit mit Menschen mit einer Demenzdiagnose?*⁶³⁴

2. In the English-speaking literature the term 'dementia care' is used in the context of dementia. What does this term mean to you personally?

In der englischsprachigen Literatur wird im Zusammenhang mit Demenz von 'Dementia Care' gesprochen. Was bedeutet für Sie persönlich dieser Begriff?

Welchen Begriff/ Begriffe würden Sie auf Deutsch dafür verwenden?

II. Core questions (Hauptfragen)

3. In a few sentences, how would you describe your work with persons diagnosed with dementia? What are your main responsibilities?

Wie würden Sie in ein paar Sätzen Ihre Arbeit mit Menschen mit einer Demenzdiagnose beschreiben? Was sind Ihre Hauptaufgaben? (Jobprofil)

4. What kind of personal, direct interaction do you have with persons living with dementia and their families? What is this contact like?

Welchen persönlichen, direkten Kontakt haben Sie mit Menschen mit einer Demenzdiagnose und ihren Angehörigen und wie gestaltet sich dieser Kontakt?

⁶³³ This list of questions gives you an idea of the aspects covered in the interviews. The introductory and final questions were asked in all seven interviews. Due to the nature of Grounded Theory methodology certain question were only addressed to some interviewees to achieve theoretical saturation. (see my master thesis, chapter 2.3.3. and 6.1.).

⁶³⁴ in this written German version of the interview questions I have decided to consistently use the expression 'Menschen mit einer Demenzdiagnose' (translation: 'persons diagnosed with dementia') although other expressions were used as well, e.g. 'Menschen mit dementiellen Beeinträchtigungen' (translation: 'persons with dementia disabilities/impairment').

5. Do you have contact with official authorities, institutions, (other) organizations in your job? If yes, what kind of contact and what is this contact or cooperation like?

Gibt es mit offiziellen Behörden, Institutionen, (anderen) Organisationen in Ihrem Arbeitsbereich Berührungspunkte? Falls ja, inwiefern und wie gestaltet sich dieser Kontakt/diese Zusammenarbeit?

6. In your opinion, what is the situation concerning dementia care like in primary care?

Wie schaut es Ihrer Meinung nach mit der Unterstützung und Betreuung für Menschen mit einer Demenzdiagnose in der Primärversorgung / im niedergelassenen Bereich aus?

7. In Austria, a new Adult Protection Act has been in force since 2018. Based on your professional experience, which specific benefits and drawbacks do you see in this law?

Seit 2018 gilt in Österreich das Erwachsenenschutzrecht. Aufgrund Ihrer beruflichen Erfahrung welche konkreten Vor- und Nachteile sehen Sie in diesem?

8. In your opinion, how much does the broad public (society) know about the Adult Protection Act? In how far are persons diagnosed with dementia and their families informed about the new Adult Protection Act?

Wie schätzen Sie das allgemeine Wissen und die Meinung unserer Gesellschaft zum Erwachsenenschutzgesetz ein? Inwieweit sind Menschen mit einer Demenzdiagnose und ihre Angehörigen darüber informiert?

9. In how far does the law contribute to protecting the right of persons living with dementia to independent living/autonomy and participation in society?

Inwieweit trägt ihrer Meinung nach dieses Gesetz dazu bei, das Recht von Menschen mit einer Demenzdiagnose auf selbstbestimmtes Leben und Teilhabe am gesellschaftlichen Leben zu schützen?

10. In your opinion, what is the situation concerning independent living/autonomy and participation in society like in Austria?

Wie steht es Ihrer Meinung nach mit selbstbestimmtem Leben und gesellschaftlicher Teilhabe von Menschen mit einer Demenzdiagnose in Österreich?

11. What is your opinion about the structural (pre)conditions for such self-determination and participation?

Wie schätzen sie die strukturellen Bedingungen dafür ein?

12. There are a few initiatives for developing dementia-friendly communities/districts. What do you think about them? What does 'dementia-friendly' mean to you?

Es gibt einige Initiativen zur Entwicklung von demenzfreundlichen Gemeinden/Städten. Was halten Sie davon? Was bedeutet für Sie der Begriff 'demenzfreundlich'?

13. To your mind, what do people know about the living situation of persons diagnosed with dementia in general?

Wie schätzen Sie das allgemeine Wissen und die Meinung unserer Gesellschaft zur Lebenssituation von Menschen mit einer Demenzdiagnose ein?

14. What do you think about education and training for practical work in dementia care?

Wie schaut es Ihrer Meinung nach mit der Ausbildung im Bezug auf Menschen mit einer Demenzdiagnose aus?

15. What role does volunteerism play or should it play in dementia care?

Welche Rolle spielt das Ehrenamt in diesem Bereich (kann/soll es spielen)?

16. An Austrian Dementia Strategy was introduced in 2015. Are you familiar with it? If yes, what is your personal opinion about it? If not, what could such strategy effect?

Es gibt seit 2015 eine Österreichische Demenzstrategie. Sind Sie mit dieser vielleicht vertraut? Falls ja, was halten Sie von dieser? Falls nicht, was könnte/sollte eine solche Strategie bewirken?

17. In the new government coalition program that was presented before the outbreak of the Covid-19 pandemic the Austrian Dementia Strategy is on the agenda stating that the Austrian Dementia Strategy must be implemented nationwide and resources must be

allocated. Which areas are in urgent need of resources and which measures should be taken and why?

Im neuen, prä-Covid-19 präsentierten Regierungsprogramm steht, dass die Demenzstrategie österreichweit ausgerollt werden soll und mit Ressourcen versehen werden soll. Welche Bereiche und Maßnahmen sollten ausgebaut und mit Ressourcen versehen werden und warum?

18. What would you personally request for the time being and future referring to a 'dementia strategy'? (of politicians, policy/decision-makers/society in general)?

Was würden Sie sich für die Gegenwart und Zukunft bezüglich einer "Demenzstrategie" (von der Politik/Entscheidungsträgern / Gesellschaft allgemein) wünschen?

19. In your practical work, do human rights and human rights conventions in particular play a role specifically for persons living with dementia

Spielen Menschenrechtskonventionen und Menschenrechte konkret für Menschen mit einer Demenzdiagnose in ihrer Arbeit eine Rolle? Falls ja, welche und inwiefern?

III. Final questions (Abschlussfragen)

17. Does the Covid19 pandemic affect your work with persons living with dementia? If yes, how? Which impact will the pandemic have on your everyday work with persons living with dementia?

Beeinflusst Covid-19 ihre Arbeit mit Menschen mit einer Demenzdiagnose? Falls ja, wie? Welche Auswirkungen wird es durch Covid-19 in Ihrer Arbeit für Menschen mit einer Demenzdiagnose. geben?

18. Is / are there any further aspect(s) that you consider highly important in your work but has not been touched upon in the interview and that you would like to add?

Gibt es noch einen oder mehrere Aspekte, den / die Sie als sehr wichtig in ihrer Arbeit mit Menschen mit einer Demenzdiagnose erachten, der / die im Laufe unseres Interviews nicht erwähnt wurde(n) und Sie noch hinzufügen möchten?

Annex 2. Overview of interviews and transcription rules

I. Overview of interviews

Participant	Job position	Employer ⁶³⁵	Date	Length
B1	Adult representative (<i>Erwachsenenvertreterin</i>)	Vertretungsnetz	30 April 2020	46'43"
B2	Residents' representative (<i>Bewohnervertreterin</i>)	Vertretungsnetz	01 May 2020	62'14"
B3	Adult representative (<i>Erwachsenenvertreterin</i>)	Vertretungsnetz	05 May 2020	46'23"
B4	Counselor (also volunteer)	Alzheimer Austria private	06 May 2020	61'39"
B5	Supervisor of a day center	CS Caritas Socialis	07 May 2020	52'48"
B6	Counselor (also volunteer)	CS Caritas Socialis	11 May 2020	56'36"
B7	Head of residential long-term care department (also volunteer)	CS Caritas Socialis	13 May 2020	48'04"

II. Transcription rules⁶³⁶

- filler words (*e.g. ahm, mhm / signalling reception*) not included
- errors in syntax kept
- dialect expressions polished (standard German)
- [xxx] - information not important for content (*e.g. technical problems, interruptions*)
- (*längere Pause*) - longer pause
- (*Pause*) - pause
- (*unv.*) - unclear
- (*yyy*) - non-verbal information (*e.g. description on emotions, laughing, gestures*)

⁶³⁵ see for more details on these employers in my master thesis: for Vertretungsnetz, chapter 4.1.; for Alzheimer Austria (AA), chapter 2.1.2.; for CS Caritas Socialis GmbH, see chapter 6.1.

⁶³⁶ these transcription rules are a modified version based on Udo Kuckartz's transcription rules for qualitative content-analysis. See U. Kuckartz, *Qualitative Inhaltsanalyse: Methoden, Praxis, Computerunterstützung*, Auszug aus Unterabschnitt 8.1.1, 'Transkriptionsregeln und Transkription', 3. Auflage, Weinheim und Basel, Beltz Juventa, 2016, pp.166-169; <https://qualitativeinhaltsanalyse.de/documents/Kuckartz-Qualitative-Inhaltsanalyse-2016-Transkription.pdf> (accessed 01 May 2020).

ABSTRACTS

ABSTRACT (English)

My master thesis explores the relevance of human rights in the Austrian Dementia Strategy (2015) in its conceptualization and its implementation in current practical dementia care five years after its introduction.

A qualitative, multi-method research approach has been adopted. Re-conceptualization of dementia care based on a human rights model of disability is crucial for high-quality dementia care provision. A human-rights category-system based on the Convention on the Rights for Person with Disabilities (CRPD) and established through an inductive document-analysis serves as codebook for a deductive content-analysis of the Austrian Dementia Strategy. By carrying out an empirical study based on interviews, the impact of its implementation is explored from a human rights perspective.

Human rights are implied in the conceptualization and implementation of the Austrian Dementia Strategy. The importance of delivering person-centered dementia care was clearly identified. However, research finds that the Austrian Dementia Strategy does not take an explicit human rights-based approach in its conceptualization. Full inclusion of persons diagnosed with dementia in decision-making was and is still absent. The lack of a clear timeframe and sufficient funding impede effective implementation, which resonates in the claim for insufficient resources for individualized, post-diagnostic dementia care. Despite legislative shortcomings, professionals in my studied field are guided by personal conviction to human rights. An explicit human rights-based Dementia Strategy could alleviate their work, and sustainability in Austrian dementia policy could be achieved. This would require political commitment to fulfill human rights obligations as Member State of the CRPD.

Keywords: *Austrian Dementia Strategy, person-centered dementia care, human rights model of disability, Convention on the Rights of Persons with Disabilities*

ABSTRACT (German)

Meine Masterarbeit untersucht die Relevanz von Menschenrechten in der Österreichischen Demenzstrategie (2015) in Theorie und Praxis.

Es wurde eine mehrstufige, qualitative Forschungsmethode gewählt. Eine Rekonzeptualisierung von Demenzversorgung (*Dementia Care*) basierend auf einem Menschenrechtsmodel von Behinderung spielt eine zentrale Rolle für die Versorgung von Menschen mit einer Demenzdiagnose. Die Strategie wird einer deduktiven Inhaltsanalyse unterzogen um Aufschluss über ihre konzeptuelle Ausrichtung zu erhalten. Dazu dient ein mit Hilfe einer induktiven Dokumentanalyse entwickeltes Kategoriensystem, das auf der UN Behindertenrechtskonvention (UN-BRK) gründet. Eine empirischen Interviewstudie untersucht, wie sich Menschenrechte in der praktischen Arbeit fünf Jahre nach Veröffentlichung der Strategie widerspiegeln.

Menschenrechtsaspekte sind in der Konzeptualisierung und Implementierung der Strategie impliziert. Die Dringlichkeit einer personenzentrierten Demenzversorgung zur Steigerung der Lebensqualität ist klar ersichtlich, jedoch fehlt der Demenzstrategie ein expliziter menschenrechtsbasierender Ansatz. Eine gleichwertige Einbeziehung von Selbstvertretern*innen in der Ausarbeitung der Strategie war und ist in ihrer Weiterentwicklung nicht gegeben. Die Nichtexistenz eines klar definierten Zeitrahmens und einer ausreichenden Finanzierung verhindert eine effektive Implementierung und unterstreicht die Forderung der Studienteilnehmerinnen nach Ressourcen für die Gewährleistung qualitativ-hochwertiger, personenzentrierter post-diagnostischer Demenzversorgung. Ihre praktische Arbeit ist stark geprägt von ihrem humanistischen Menschenbild, das Würde und Autonomie verletzlich Menschen bis zuletzt hochhält. Eine explizite menschenrechtsbasierende Demenzstrategie könnte ihre Arbeit jedoch unterstützen und zu einer nachhaltigen Demenzpolitik in Österreich führen. Dies würde ein verpflichtendes politisches Bekenntnis des Staates zur Umsetzung der in der UN-BRK kodifizierten Rechte von Menschen mit kognitiven und psychosozialen Beeinträchtigungen erfordern.

Schlagwörter: Österreichische Demenzstrategie, personenzentrierte Demenzversorgung, Menschenrechtsmodel von Behinderung, UN-Behindertenrechtskonvention