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**Master's degree in  
Human Rights and Multi-level Governance**



THE HUMAN RIGHTS PERSPECTIVE ON  
DEMENTIA: FROM PREVENTION TO SOCIAL  
CARE PRIORITY IN NATIONAL AGENDA

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## **LIST OF ACRONYMS**

ADI	Alzheimer's Disease International
CRPD	Convention on the Rights of Persons with Disabilities
GDO	Global Dementia Observatory
MDGs	Millennium Development Goals
MhGAP	The Mental Health Gap Action Programme
NGO	Non-governmental Organization
OHCHR	Office of the High Commissioner for Human Rights
PNRR	Recovery and Resilience Plan
SDGs	Sustainable Development Goals
UN	United Nations
WHO	World Health Organization

## INTRODUCTION

During the last century the number of people affected by dementia is increased.

At the present, people living with dementia are estimated at 35.6 million. According to different research, this data will double in 2030 and triple in 2050<sup>1</sup>.

Given the global impact of dementia in our society, the international system has started to face to this problem<sup>2</sup>.

The World Health Organization defines dementia as “*an umbrella term for several diseases affecting memory, other cognitive abilities and behaviour that interfere significantly with a person’s ability to maintain their activities of daily living*”<sup>3</sup>.

During these years it has been only analysed from a biomedical point, forgetting the social, health and economic consequences of this phenomenon<sup>4</sup>.

It’s important to highlight that there is a gap between prevention and care, in fact there are a lot of people that are not diagnosed<sup>5</sup>.

Indeed, this severe impairment affects not only the person, but also family, caregivers, and society.

The lack of awareness in the world brings negative consequences such as stigmatisation, social isolation, lack in care and diagnosis.

For this reason, the international system has decided to look to dementia as a “*public health priority*”, by adopting “*public health approach*” and “*person-centred approach*”<sup>6</sup>.

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<sup>1</sup> World Health Organization. “The global action plan on the public health response to dementia 2017-2025”. Geneva. 2017. Accessed on 30 April 2024, <https://www.who.int/publications/i/item/global-action-plan-on-the-public-health-response-to-dementia-2017---2025>

<sup>2</sup> World Health Organization, “Dementia: a public health priority”. 2012. Accessed on 30 April 2024, <https://www.who.int/publications/i/item/dementia-a-public-health-priority>

<sup>3</sup> World Health Organization. “Dementia”. Accessed on 30 April 2024, [https://www.who.int/health-topics/dementia#tab=tab\\_1](https://www.who.int/health-topics/dementia#tab=tab_1)

<sup>4</sup> World Health Organization, “Dementia: a public health priority”

<sup>5</sup> World Health Organization. “The global action plan on the public health response to dementia 2017-2025”

<sup>6</sup> Gauthier S. et al. “World Alzheimer Report 2022: Life after diagnosis: Navigating treatment, care and support”. London. Alzheimer’s Disease International. 21 September 2022. Accessed on 10 May 2024, <https://www.alzint.org/resource/world-alzheimer-report-2022/>

The creation and the adoption of a strong system wants to reduce health and social care costs for families, helping and promoting government to adopt specific regulations.

As a result, we can give a “*formal recognition of the rights of people with dementia and their caregivers*”<sup>7</sup> (respecting “*the right to appropriate autonomy and self-determination*”<sup>8</sup>).

The aim of the legal system is to guarantee “*quality of life*”, the “*freedom and respect for autonomy*”<sup>9</sup>, “*social well-being*”<sup>10</sup> of the person living with dementia and its family. These principles are part of the CRPD.

As affirmed in Article 1 of the CRPD “*the purpose [...] is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity*”<sup>11</sup>.

In this thesis I will analyse the historical background, starting from the Convention on the Rights of Persons with Disabilities, the Optional Protocol to the Convention, the Charter of Fundamental Rights of the European Union, the World Programme of Action concerning Disabled Persons and the Standard Rules on the Equalization of Opportunities for Persons with Disabilities.

Then, in this paper various important instruments will be examined as follows: “*The global action plan on the public health response to dementia 2017-2025*”, the “*Decade of Healthy Ageing 2020-2030*” (“*the second action plan of the WHO Global strategy on ageing and health, building on the United Nations Madrid International Plan of Action on Ageing and aligned with the timing of the United Nations Agenda 2030 on Sustainable Development and the Sustainable Development Goals*”<sup>12</sup>) and other policies adopted by states for the protection of rights of people living with dementia will be analysed.

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<sup>7</sup> World Health Organization. “The global action plan on the public health response to dementia 2017-2025”

<sup>8</sup> Ibid.

<sup>9</sup> Gauthier S. et al. “World Alzheimer Report 2022: Life after diagnosis: Navigating treatment, care and support”, p. 176

<sup>10</sup> World Health Organization, “Dementia: a public health priority”

<sup>11</sup> “Convention on the Rights of Persons with Disabilities”, Accessed on 30 April 2024, [https://treaties.un.org/doc/Publication/CTC/Ch\\_IV\\_15.pdf](https://treaties.un.org/doc/Publication/CTC/Ch_IV_15.pdf), Article 1

<sup>12</sup> World Health Organization. “Decade of Healthy Ageing 2020-2030”. 14 December 2020. Accessed on 30 April 2024, <https://www.who.int/publications/m/item/decade-of-healthy-ageing-plan-of-action> p.1

Finally, I will focus on dementia, the instrument adopted by the international system, the role of NGO and civil society. Especially, regarding the Italian system and regulation about dementia, I will also present the project about prevention in dementia in which I'm taking part.

## LITERATURE REVIEW

The main topic of my thesis is represented by looking at dementia from the Human Rights' point of view.

Analysing this particular topic, there are some specific keywords that have driven my research such as: dementia, Alzheimer, old people, disability, caregiver, health, public health, Covid-19, global impact of dementia in our society, national government, international government, World Health Organization, prevention and care, stigmatisation, social isolation, lack in care and diagnosis, care costs, rights, dignity, self-determination, "*freedom and respect for autonomy*", "*social well-being*", CRPD.

The World Alzheimer Report 2022 made by the Alzheimer's Disease International focuses on the main topic and problems caused by the management of dementia.

First of all, it affirms that few people in the world have a diagnosis. In fact, according to the Alzheimer's Disease International in the world there are 75% of people without diagnosis.

As highlighted by the World Health Organization, people with dementia were 55 million in 2019 and in 2050 the number will increase to 139 million.

In this report the authors give a multidisciplinary background to look at different problems related to the different steps after diagnosis. Especially this is true for families and caregivers that don't receive support and help from local actors and national government.

*"This World Alzheimer Report is [...] the most comprehensive exploration of post-diagnosis dementia support across the global to date"*<sup>13</sup>.

Then, this report examines the real life of people and the approach used is "*person-centred*" prospective. It is not only the analysis of people living with dementia, but also of their caregivers.

Finally, it investigates problems related to the lack of information, the right to choice, and the lack of support in care and health.

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<sup>13</sup> Gauthier S. et al. "World Alzheimer Report 2022: Life after diagnosis: Navigating treatment, care and support", p.25



More broadly, this essay is a really great starting point to analyse the topic of dementia from the point of view of human rights.

The World Health Organisation approved and published different instruments related to the managing of dementia and, generally, to present the context and the global situation.

Between these different approved instruments, it is necessary to first analyse an important step: the “*Global action plan on the public health response to dementia 2017-2025*”. It involves actions that have the objective to prevent dementia and support families.

According to the World Health Organization,

*“it is an important opportunity for individuals, communities and Member States to realize the vision of a world in which dementia is prevented and people with dementia and their carers receive the care and the support they need to live a life with meaning and dignity”*.<sup>14</sup>

Then, another tool is the “*Decade of Healthy Ageing*” that represents one of the goals of the Global strategy and the action plan on ageing and health.

This report “[...] will focus on four key actions: changing how we think, feel and act towards age and ageing; developing communities in ways that foster the abilities of older people; delivering integrated care and primary health services that are responsive to the needs of older people; and providing older people who need it with access to long-term care.”<sup>15</sup>

These sources represented a good way to understand how dementia is analysed in the international system.

They symbolize a step forward for the international community and for changing the medical lens by which dementia has been debated until now.

On the other hand, since the international system has adopted different instruments, the problem has become the difficulty to apply them in every state.

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<sup>14</sup> World Health Organization. “The global action plan on the public health response to dementia 2017-2025”, p. 1

<sup>15</sup> World Health Organization. “Decade of healthy ageing: baseline report”. Geneva. 2020. Accessed on 30 April 2024, <https://apps.who.int/iris/handle/10665/338677>, p. VI

In fact, only few states have realized good policies in order to prevent and manage the problem.

The “*problem*” is not the disease, but the absence of a government able to remove economic, political, cultural barriers and able to help caregivers that are alone in the management of persons living with dementia.

The World Health Organisation focuses also on the consideration of dementia as a “*public health priority*”. In the publication “*Dementia: a public health priority*” the goal is “[...] *to raise awareness of dementia as a public health priority, to articulate a public health approach and to advocate for action at international and national levels based on the principles of inclusion, integration, equity and evidence.*”<sup>16</sup>

About data and information, the report affirms that this data come from almost always from rich countries.

Then, another important reflection is about the costs: according to the document,

*“in high-income countries, informal care (45%) and formal social care (40%) account for the majority of costs, while the proportionate contribution of direct medical costs (15%) is much lower. In low-income and lower-middle-income countries direct social care costs are small, and informal care costs [...] predominate.”*<sup>17</sup>

According to the paper, it is necessary to improve the approach to public health. The main issue is discrimination produced by legislation due to the expensive costs related to care. It is highlighted the necessity to improve services for the initial steps of dementia.

Moreover, also the reality of minority groups needs to be considered.

In relation to policies applied, even if in high-income countries there are lots of political actions, there are anyway obstacles for a full realisation of human rights for people living with dementia.

The research wants to demonstrate that “*a range of actions is required to improve care and services for people with dementia and their caregivers. These actions include advocacy and awareness-raising, the development and the implementation of dementia*

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<sup>16</sup>World Health Organization, “Dementia: a public health priority”, p. 2

<sup>17</sup> Ibid., p. 2

*policies and plans, health system strengthening, capacity-building, supporting caregivers and research. These actions need to be context-specific and culturally relevant.”*<sup>18</sup>

For my research this report represents an important step to start but it presents some problems related to the difficulty of finding data from low-income countries and minority groups. Their poverty reality is intersected with other fragilities that we can call “*intersectionality*”. As a consequence, in this context people find lots of barriers for the full enjoyment of their human rights.

“*Global status report on the public health response to dementia*” is direct to all institutional actors and academics, such as national policymakers, planners in the health sectors and so on.

This report wants to highlight that

*“renewed and concerted efforts across all stakeholders are needed to realize the vision of the Global dementia action plan [...]. Too few countries have prioritized dementia in national policies, too many people with dementia continue to lack access to diagnostic and post-diagnostic services, and too high a number of carers remain socially isolated due to a lack of support.”*<sup>19</sup>

If on one hand it wants to be direct to institutional government by giving them data and new mechanisms to apply, on the other hand it remains only theory and it is difficult to persuade politicians to the importance of dementia’s theme.

In this complicated approach, it is important to consider the negative impact of COVID-19 that is centred in this relation. Especially, how the pandemic situation has worsened life of people living with dementia and their caregivers.

This reality has emphasized the gap of international community and local government to face with these frail conditions.

A good document produced by World Health Organization is also “*Preventing and managing COVID-19 across long-term care services*”. It addresses national policymakers

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<sup>18</sup> World Health Organization, “Dementia: a public health priority”, p.4

<sup>19</sup> World Health Organization. “Global status report on the public health response to dementia”. 1 September 2021. Accessed on 30 April 2024, <https://www.who.int/publications/i/item/9789240033245>, p.17

on how preventing and managing disadvantaged situations in case of pandemic. Nevertheless, this report is not so relevant for my research because it focuses on long-term care facilities.

After all, in the topic of dementia, it is also important to deem that when dementia is not prevented, as in many states, it becomes a “*long-term assistance care*”. In fact, very often, the only solution given to people living with dementia is a care structure (but it is not a solution).

The welfare system is not able, as in the case of Italian situation and other countries, to give other responses to relatives and caregivers because the only possible solution is represented by the clinics. Often in these structures there is not specialized staff for people with dementia. The staff could be appropriate for aged people, but not for specific disabilities as Alzheimer disease.

In addition, the pandemic situation has emphasized some situations like isolation and loneliness. In relation to the research conducted by the scholar Garcia, “*social isolation and loneliness can create vicious cycle in older age, with social isolation and loneliness facilitating cognitive and physical decline*”<sup>20</sup>. According to him the development of specific instruments by social and health sectors could reduce this phenomenon.

My sources are in part the material published by the World Health Organization, because it concerns different topics related to the managing of Alzheimer in our society.

I have found few scholars that look at this topic not from the medical point of view.

The first essay published by different scholars is the research “*Caring for seniors living with dementia means caring for their caregivers too*”; it is focused on the reality of caregivers that give assistance to people with disease. The authors look at the difficulties in finding information, having support to take decisions for caregivers. Scholars also affirm the necessity to improve access to information for carers.

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<sup>20</sup> Garcia, E. “Social Connection in Older Age”. *Generations: Journal of the American Society on Aging*, 46(3), 1–8. 2022. Accessed on 30 April 2024, <https://www.jstor.org/stable/48707874>, p. 2

In fact, they highlight that *“our results point to the importance of attending to the needs of caregivers, who are key players in providing care and making decisions with, or on behalf of, seniors with dementia.”*<sup>21</sup>

In the report of the OECD Health Policy Studies, they look at the situation of dementia in the OECD countries, especially for people with diseases, their caregivers, and the policies and strategies applied by states. In general, according to this research, data about care’s quality affirms that it continues to be not satisfying.

The results demonstrate the continuation of a gap in the access to services. Then, it affirms that *“despite the growing attention on the impact of dementia in OECD countries, data for dementia remains very poor, and little measurement of outcomes likely hampers efforts to improve the quality of care.”*<sup>22</sup>

In addition, it is necessary to give attention to post-diagnostic services, that are debated between social and health care.

In conclusion, by analysing the situation of OECD states, this report affirms the necessity to improve care services in states from the early step of diagnosis to long-term care.

In the abstract wrote by T. M. Flavin, *“Human rights in the context of dementia”*, she focuses on the loss of the right of self-determination of an individual with dementia.

According to the scholar, *“[...] the stigma persists at the highest level that when dementia is even suspected, that capacity must be demonstrated to make even the simplest choices. This is a very direct violation of the fundamental human right to self-determination [...]”*.<sup>23</sup>

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<sup>21</sup> Poirier, A., Voyer, P., Légaré, F., Morin, M., Witteman, H. O., Kröger, E., Martineau, B., Rodríguez, C., & Giguere, A. M. “Caring for seniors living with dementia means caring for their caregivers too”. Canadian Journal of Public Health / Revue Canadienne de Santé Publique, 108(5–6), e639–e642. 2017. Accessed on 30 April 2024, <https://www.jstor.org/stable/26586130>, p. 642

<sup>22</sup> OECD. “Care Needed: Improving the Lives of People with Dementia”. OECD Health Policy Studies. OECD Publishing. Paris. 2018. Accessed on 30 April 2024, <http://dx.doi.org/10.1787/9789264085107-en>, p. 40

<sup>23</sup> Theresa M Flavin. “Human rights in the context of dementia”. Alzheimer’s Dement. 07 December 2020. Accessed on 30 April 2024, <https://doi.org/10.1002/alz.036434>

Indeed, as it is highlighted by the author, the community continues to take decisions in place of people living with dementia. This way of acting increases situation of stigma and isolation.

Another important book for my research is represented by “*Aiutami a ricordare*” wrote by Marco Trabucchi. The author focuses on the reality and fragility of the “*person affected by dementia*” and their caregivers. He affirms that he has been pressed to write this book for different reasons.

First of all, inciting the community to create services suitable for dementia.

Then, giving responses that hospital and nursing home not always are able to offer.

In addition, reducing social stigma.

Furthermore, the scholar highlighted that Alzheimer does not eliminate human relation, but it is necessary to adopt adequate attitudes and advice.

The professor Trabucchi, as other experts in this field, talks about the gender factor as in the case of identification of a caregiver and the major attitude of women to fall ill.

In general, the book wrote by the specialist in psychogeriatrics, looks at the person affected by dementia by an emphatic view. His health analysis studies and debates different steps of Alzheimer and the difficulty of people that live with him/her.

This research has given to me a wide overview of the reality in Italy.<sup>24</sup>

Other sources that represented the basis for my research are the followings: the Universal Declaration of Human Rights, the Convention on the Rights of Persons with Disabilities, the International Covenant on Civil and Political Rights, International Covenant on Economic, Social and Cultural Rights, the Charter of Fundamental Rights of the European Union, the 2030 Agenda for Sustainable Development, other resolutions and decisions adopted by the World Health Organization.

In wide terms, every author presents different common points, because the problems emerging from the management of dementia are confirmed by several studies. Each one of my types of research has the same started point such as the definition of dementia, how

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<sup>24</sup> Trabucchi Marco. “*Aiutami a ricordare*”. Edizioni San Paolo s.r.l. Cinisello Balsamo (MI). 2022

many people are affected by this disease, and what are the common problems between different patients.

The different factor is represented by what is the focus of every author: caregiver, patient, costs, role of institution and so on.

Undoubtedly if my thesis was a medical one, I could find, for example, several theories about therapies, because studies continue to look for a “*treatment*” for Alzheimer and other dementia’s disease, that today do not exist.

As mentioned above, in the field of my study, “*political science*”, there are not so many sources about the topic of dementia because only in the last years, the international system is going to push states for major policies to help people. Indeed, all sources cited in this part are recent.

This is due by the exponential number of people living with dementia that will continue to increase in the next years.

Starting from the fundamentals human rights, my research would analyse how the protection of people with dementia is not only a “*moral duty*”, but a protection of a system of value that our system has created through the years.

Employing different textbooks produced by the World Health Organization and looking at the data collected by different sources, I will try to look with an intersectional view the topic of dementia.

In particular, I will look at the instruments guaranteed by the international system and how they have been applied by different countries.

As we can imagine, not so many states have respected the rules given by the international community, neglecting the emerging phenomenon.

Then, I will look to other actors around the person affected by dementia, like caregivers, that are overburden not only of care, but they also have to face with the high costs of treatment.

In addition, I found lots of other sources that have been written by NGO and civil society. In case of dementia the support given by these actors is more relevant than the help given

by states. In fact, associations have a central role in press states in adopting policies about dementia.

According to my research, states have not yet given the right importance to the problem of costs and alternative to old age home. In lot of states, even if there is the “oral” promotion of adequate instruments to people with dementia, state gives only simply solutions that are not good for the patient.

Another important point of my thesis is represented by the concept of prevention.

The World Health Organization demonstrates how prevention to dementia is possible by using the right instruments. This part is particularly important because population is becoming more and more aged. Also, in this case states continue to avoid its responsibility by not adopting decisions about this topic.

I want to highlight how an effective participation of countries is necessary because they could reduce medical costs, that a person alone could not. Then, if states take decisions about the welfare part, they could apply the principles and the instruments proposed by the international system.

Another point highlighted by different sources is the number of people without diagnosis. In fact, data about dementia are in particular from high-income states. There are few data about poor states.

Moreover, about the perception of Alzheimer and dementia in the world, from different texts, scholars also affirm the problem of stigma. People affected by dementia and their caregivers are often discriminated. In this delicate situation, also the concept of gender and its implications, aggravate this situation.

In conclusion, in my research I want to focus on the concept of dementia as a “*public health priority*” for states and the necessity to adopt policies based on “*person-centred approach*”. By using this premise, a complete enjoyment and respect of human rights will be possible.



## CHAPTER I. WHAT IS DEMENTIA?

### 1.1 HISTORICAL BACKGROUND.

For a long time, dementia was considered as an inevitable consequence of ageing.

Different studies have demonstrated that this is a wrong conclusion and for this reason it has been treated as a particular disability that limits individual's ability to perform everyday tasks.

In this first chapter we look at the different tools to approach to dementia rights.

The first tool to consider in the international system is the Convention on the Rights of Persons with Disabilities that wants to protect fundamental human rights of disabled people. It looks at disability as

*“[...] an evolving concept and that [...] results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others”.*<sup>25</sup>

It was adopted on 12 December 2006 by the sixty-first session of the General Assembly through the resolution A/RES/61/106. It entered into force on 3 May 2008.<sup>26</sup>

By adopting this Convention different levels of governance, such as civil society, local governments, regional systems and United Nations started to use a different approach for disability.

According to the Italian minister Sacconi, the wellness of people with disabilities is important in the Welfare system<sup>27</sup>. Indeed, the article 1 of CRPD affirms that

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<sup>25</sup> Convention on the Rights of Persons with Disabilities, Preamble (e)

<sup>26</sup> United Nations. “Convention on the Rights of Persons with Disabilities”. Accessed on 31 May 2024, <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities>

<sup>27</sup> La convenzione delle Nazioni Unite sui diritti delle persone con disabilità, Accessed on 31 May 2024, <https://www.lavoro.gov.it/temi-e-priorita/disabilita-e-non-autosufficienza/focus-on/Convenzione-ONU/Documents/Convenzione%20ONU.pdf>

*“The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.*

*Person with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”<sup>28</sup>*

On 13<sup>th</sup> December 2006 the Optional Protocol to the Convention on the Rights of Persons with Disabilities was approved by resolution of the United Nations General Assembly.<sup>29</sup>

It concerns the individual appeal to the Committee on the Rights of Persons with Disabilities. The Committee supervises the implementation of the Convention. It is composed by eighteen independent experts.<sup>30</sup>

The ratification by European Union of the CRPD highlights an important starting point for the regional system in the context of disability. It was the only regional system that ratified it.<sup>31</sup>

Looking at the history of disability, the 1981 represents an important year. During this year there were lots of new programmes, initiatives concerning people with disability. Then, there was the *“First Founding Congress of Disabled People International”* and before, in 1977, the creation of the Trust Fund for the International Year.<sup>32</sup>

Other instruments that represent the basis for the protection of rights of disabled people are the *“World Programme of Action Concerning Disabled Persons and the Standard Rules On The Equalization Of Opportunities For Persons With Disabilities”*.

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<sup>28</sup> Convention on the Rights of Persons with Disabilities, Article 1

<sup>29</sup> World Health Organization. “Optional Protocol to the Convention on the Rights of Persons with Disabilities. 13 December 2006. Accessed on 30 April 2024, <https://www.ohchr.org/en/instruments-mechanisms/instruments/optional-protocol-convention-rights-persons-disabilities>

<sup>30</sup> United Nations Human Rights. “Introduction to the Committee”. Accessed on 30 April 2024, <https://www.ohchr.org/en/treaty-bodies/ccpr/introduction-committee>

<sup>31</sup> United Nations Human Rights Treaty Bodies. “View the ratification status by country or by treaty”. Accessed on 30 April 2024, [https://tbinternet.ohchr.org/\\_layouts/15/TreatyBodyExternal/Treaty.aspx?Treaty=CRPD](https://tbinternet.ohchr.org/_layouts/15/TreatyBodyExternal/Treaty.aspx?Treaty=CRPD)

<sup>32</sup> United Nations. “History of United Nations and Persons with Disabilities”. Accessed on 30 April 2024, <https://www.un.org/development/desa/disabilities/history-of-united-nations-and-persons-with-disabilities-the-world-programme-of-action-concerning-disabled-persons.html>

On 3 December 1982 the General Assembly adopted the World Programme through the resolution 37/52. It was the first international instrument that looks at the sphere of human rights for people with different disabilities considering their situation. This programme wanted to prevent isolation in the community context.<sup>33</sup>

In the meantime, on 20<sup>th</sup> December 1993 the General Assembly adopted the “*Standard Rules In The Equalization Of Opportunities For Persons With Disabilities*”. It represented “*a strong moral and political commitment of Governments to take action to attain equalization of opportunities for persons with disabilities*”.<sup>34</sup>

After this historical part of particular attention given by international system to the sphere of disabled people, we can analyse the background on the protection of human rights for people affected by dementia.

The first time in which “dementia” became a central topic for the international system was after the publication of the report “*Dementia: a public health priority*” on 11<sup>th</sup> April 2012. It was approved by the World Health Organization in collaboration with the Alzheimer's Disease International (ADI).

The aim was to “[...] *raise awareness of dementia as a public health priority, to articulate a public health approach and to advocate for action at international and national levels based on the principles of evidence, equity, inclusion and integration.*”<sup>35</sup>

This report also takes in consideration “*The Mental Health Gap Action Programme*” (mhGAP) of 2008 and the High-level Meeting of the United Nations General Assembly of 2011.

Another important step was in 2015 in Geneva the “*First WHO Ministerial Conference on Global Action Against Dementia*” between ministers of different countries and experts.<sup>36</sup>

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<sup>33</sup> United Nations. “World Programme of Action Concerning Disabled Persons”. Accessed on 30 April 2024, <https://www.un.org/development/desa/disabilities/resources/world-programme-of-action-concerning-disabled-persons.html>

<sup>34</sup> United Nations. “Standard Rules On The Equalization Of Opportunities For Persons With Disabilities”. Accessed on 30 April 2024, <https://social.desa.un.org/issues/disability/resources/disability-resources/rules/standard-rules-on-the-equalization-of>

<sup>35</sup> World Health Organization, “Dementia: a public health priority”, p. VI

<sup>36</sup> World Health Organization. “First WHO Ministerial Conference on Global Action Against Dementia”. 16-17 March 2015. Accessed on 30 April 2024, <https://www.who.int/news->

It focused on “burden” of dementia that specific policies could limit. They looked at different spheres such as medical, pharmacological, political and human rights.

Then, from 23<sup>rd</sup> to 31<sup>st</sup> January 2017 there was the 140<sup>th</sup> session of the WHO Executive Board in Geneva. In the agenda there was the “draft global action plan on the public health response to dementia”.<sup>37</sup>

This was the direct effect of the request in 2016 to the Director-General by the Executive Board to

*“develop with the full participation of Member States and in cooperation with other relevant stakeholders a draft global action plan on the public health response to dementia, with clear goals and targets, for consideration by the Seventieth World Health Assembly, through the Executive Board at its 140<sup>th</sup> session. The Annex to this report duly includes a draft action plan, covering the period 2017-2025”.*<sup>38</sup>

The report published on 23<sup>rd</sup> December 2016 is found also in other important sources.

Till the elaboration of a specific global action plan, dementia was included in the sphere of mental disability. In fact, we can look a special focus on dementia diseases in the “*Mental health action plan 2013-2020*”<sup>39</sup>, “*Global action plan for the prevention and control of noncommunicable disease 2013-2020*”<sup>40</sup>, the “*WHO global disability action*

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room/events/detail/2015/03/16/default-calendar/first-who-ministerial-conference-on-global-action-against-dementia

<sup>37</sup> Executive Board, 140. 2017. Executive Board 140th session, Geneva, 23-31 January 2017: resolutions and decisions, annexes. World Health Organization. Accessed on 30 April 2024, <https://iris.who.int/handle/10665/259411>

<sup>38</sup> World Health Organization. “Draft global action plan on the public health response to dementia”. 3 April 2017. Accessed on 30 April 2024, [https://apps.who.int/gb/ebwha/pdf\\_files/EB140/B140\\_28-en.pdf?ua=1](https://apps.who.int/gb/ebwha/pdf_files/EB140/B140_28-en.pdf?ua=1)

<sup>39</sup> World Health Organization. “Mental health action plan 2013-2020”. 13 January 2013. Accessed on 30 April 2024, <https://www.who.int/publications/i/item/9789241506021>

<sup>40</sup> World Health Organization. “Global action plan for the prevention and control of noncommunicable diseases 2013-2020”. 14 November 2013. Accessed on 30 April 2024, <https://www.who.int/publications/i/item/9789241506236>

*plan 2014-2021*”<sup>41</sup>, the “*Global strategy and plan of action on ageing and health 2016-2020*”<sup>42</sup>, the “*Global strategy on human resources for health: workforce 2030*”<sup>43</sup>.

The “*Mental health action plan 2013-2020*” highlights the necessity to give particular attention to disability such as Alzheimer, that was defined as a noncommunicable disease that causes mental disorders.

In the “*Global strategy and plan of action on ageing and health 2016-2020*” and in the “*Global action plan for the prevention and control of noncommunicable disease 2013-2020*”, the World Health Organization highlighted the necessity to adopt specific strategies to address dementia.

## 1.2 DEFINITION OF DEMENTIA.

The focal point of this thesis is on people living with dementia. For this reason, first of all, it is necessary to define the meaning of the word “dementia”.

According to lots of studies, it could be considered a “broad term” because it includes different symptoms.<sup>44</sup>

The report of 2012 published by the World Health Organization “*Dementia: a public health priority*” defines this term as follows:

*“Dementia is a syndrome due to disease of the brain – usually of a chronic or progressive nature – in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. [...] The impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social*

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<sup>41</sup> World Health Organization. “WHO global disability action plan 2014-2021”. 30 November 2015. Accessed on 30 April 2024, <https://www.who.int/publications/i/item/who-global-disability-action-plan-2014-2021>

<sup>42</sup> World Health Organization. “Global strategy and action plan on ageing and health”. 2 January 2017. Accessed on 30 April 2024, <https://www.who.int/publications/i/item/9789241513500>

<sup>43</sup> World Health Organization “Global strategy on human resources for health: workforce 2030”. Accessed on 30 April 2024, [https://www.observatoriorh.org/sites/default/files/webfiles/fulltext/2019/global\\_strategy\\_workforce2030\\_who.pdf](https://www.observatoriorh.org/sites/default/files/webfiles/fulltext/2019/global_strategy_workforce2030_who.pdf)

<sup>44</sup> Alzheimer Society of Canada. “What is dementia?”. Accessed on 01 March 2024. <https://alzheimer.ca/en>

*behaviour, or motivation. This syndrome occurs in a large number of conditions primarily or secondarily affecting the brain.*"<sup>45</sup>

As it is highlighted by Alzheimer's Disease International and Dementia Alliance International, dementia is not a mental disability and becoming aged has not as the natural effect the appearance of dementia. According to them, "*dementia is not a mental illness and affects not only memory but attention, orientation and other areas of cognitive functioning.*"<sup>46</sup>

There are different forms of dementia, but the most common are the following: Alzheimer's Disease, Frontotemporal Dementia, Lewy Body Dementia, Vascular Dementia.<sup>47</sup>

In this thesis, we look in particular to Alzheimer, that is considered the most common form of dementia.

Another important point is to focus on the term used.

According to the professor M. Trabucchi, also the use of language is important in defining this word. In particular, adopting the term "*demented*" is very different from "*person affected by dementia*".<sup>48</sup>

The first word is intrinsic of stereotypes, because it has a negative acceptance. Lots of people have negative behaviour towards people with this ill. This social attitude creates barriers and does not protect the dignity of people.

The second term wants to preserve the dignity of the person affected by this illness.

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<sup>45</sup> World Health Organization, "Dementia: a public health priority", p. 7

<sup>46</sup> Alzheimer's Disease International, Dementia Alliance International. "Access to CRPD and SDGs by persons with dementia". 25th August 2016. Accessed on 30 April 2024, <https://www.alzint.org/resource/access-to-crpd-and-sdgs-by-persons-with-dementia/>, p.3

<sup>47</sup> National Institute of Ageing. "Understanding Different Types of Dementia". Accessed on 30 April 2024, <https://www.nia.nih.gov/health/alzheimers-and-dementia/understanding-different-types-dementia>

<sup>48</sup> Trabucchi Marco. "Aiutami a ricordare". Edizioni San Paolo s.r.l. Cinisello Balsamo (MI). 2022

The Alzheimer Society of Canada affirms that stigma could have different forms, that involve language, indifference towards people in this condition, making fun of them, to take distance from them.<sup>49</sup>

An important data is that this type of disability is widespread and compares in particular on people in later life. The fragility of the age and fragility derived from the disability create a relevant sphere of vulnerability.

In the Convention on the Rights of Persons with Disabilities there was an involuntary discrimination of people with dementia. This could be revealed through the difficulty of people affected by this illness to participate in society. The result is also the fear of the diagnosis.<sup>50</sup>

In order to understand dementia and the reality of it, it is necessary to consider the diagnosis of dementia.

According to the Global Action Plan 2017-2025, *“dementia is underdiagnosed worldwide, and, if a diagnosis is made, it is typically at a relatively late stage in the disease process”*.<sup>51</sup>

The reality, in general, is that people that are at the early stages of dementia do not understand to have this ill. This is due to the fact that they continue to be autonomous even if there are some behaviours that are linked with the diagnosis of dementia.<sup>52</sup>

Stigmatisation also characterizes this phase for example when the patient and his/her family deny the diagnosis.<sup>53</sup>

In general, a wrong understanding of dementia creates different misconceptions.

First of all, there is not sympathy by the society that generally tends to isolate people with disabilities.

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<sup>49</sup> Alzheimer Society of Canada. “Stigma against dementia”. Accessed on 30 April 2024, <https://alzheimer.ca/en/about-dementia/stigma-against-dementia>

<sup>50</sup> Alzheimer’s Disease International, Dementia Alliance International. “Access to CRPD and SDGs by persons with dementia”

<sup>51</sup> World Health Organization. “The global action plan on the public health response to dementia 2017-2025”, p. 3

<sup>52</sup> Ibid.

<sup>53</sup> Trabucchi Marco. “Aiutami a ricordare”

Then, other forms of stigmatisation are produced at institutional levels, when norms and structures of legislation are not adapted to persons in particular conditions.<sup>54</sup>

In addition, a person that discovers to have this type of diagnosis tends to isolate itself because of the idea that nothing could help him to not degenerate.<sup>55</sup>

There is also a significant difference in the approach of west and east countries to dementia.

In West countries the patient lives alone the diagnosis with the exclusion of the family, while in East countries the experience of diagnosis is lived together.

The gap that international system wants to focus is the life of a person after the diagnosis. Governments don't give necessary support and don't create policies to replay to necessity of persons affected by dementia and their families. The reason of this is due to high cost of this policies and tools.<sup>56</sup>

Even international human rights instruments have been developed in order to avoid discrimination and violation of human rights, by removing barriers, people affected by dementia continue to be victim of stigmatization and discrimination.

In spite of different programmes have been approved to eliminate stigma, the problem remains the lack of understanding on the topic of dementia.

This phenomenon is verified not only in society but also in healthcare practitioners.

According to the report of ADI and London school of Economy in 2019, the 62% of healthcare practitioners consider dementia as a natural consequence of ageing.

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<sup>54</sup> Long S., Benoist C., Weidner W. "World Alzheimer Report 2023: Reducing dementia risk: never too early, never too late". London. Alzheimer's Disease International. 21 September 2023. Accessed on 10 May 2024, <https://www.alzint.org/resource/world-alzheimer-report-2023/>

<sup>55</sup> Mittelman M., Batsch N. "World Alzheimer Report 2012: Overcoming the stigma of dementia". Alzheimer's Disease International. 21 September 2012. Accessed on 10 May 2024, <https://www.alzint.org/resource/world-alzheimer-report-2012/>

<sup>56</sup> Gauthier S., Webster C., Servaes S., Morais JA, Rosa-Neto P., *World Alzheimer Report 2022: Life after diagnosis: Navigating treatment, care and support*, London, Alzheimer's Disease International, 21 September 2022



As detailed below, some governments are working to solve disinformation, but the impact on the society doesn't give the expected result.<sup>57</sup>

The World Alzheimer Report 2023 describes other different problems linked with the knowledge of dementia.

They are the

*“chronic lack of research funding,[...] the overarching issue of it being easier to prescribe beneficial lifestyle changes than to make them, and how to address the reluctance many people have in following government advice [...], the reality that some of the most important factors are not modifiable by an individual on their own [...] but come from society, the environment, genetics, and so on. [...]”*<sup>58</sup>.

Studies demonstrate that for the patient there is a problem of anosognosia. Through this term we highlight the *“completely aware of their neurological disease”*.<sup>59</sup>

This reaction is originated from the shame and fear to receive this diagnosis. For this reason, people tend to isolate themselves from the social context.

In conclusion, in general, people that discovered to be affected by dementia tends to isolate from the others because of the fear to be not accepted. This reaction improves the ill condition, gradually some phenomena emerge such as dependency from caregivers, not inclusion in decision-making processes and negation of human rights.

For this reason, working on the knowledge of this ill is important for the society but in particular for people affected by dementia and their carers.

### 1.3 DEMENTIA IN THE CONTEXT OF HUMAN RIGHTS.

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<sup>57</sup> World Health Organization. “Global Dementia Observatory (GDO)”. Accessed on 15 May 2024, <https://www.who.int/data/gho/data/themes/global-dementia-observatory-gdo>

<sup>58</sup>Long S., Benoist C., Weidner W. “World Alzheimer Report 2023: Reducing dementia risk: never too early, never too late”, p. 9

<sup>59</sup> Pia L., & Conway P. “Anosognosia and Alzheimer's Disease”. *Brain Impairment*, 9(1), 22-27. Cambridge University Press. 21 February 2012. Accessed on 30 April 2024, <https://www.cambridge.org/core/journals/brain-impairment/article/anosognosia-and-alzheimers-disease/4BCAEBE6E644C6F4303DB81691823408>

Dementia represents one of the major issue of the twenty-one century.

According to data collected by the World Health Organization, people affected by dementia are more than 55 million in the world; in addition, the Organization highlights that every year there are at least 10 million new diagnosis.<sup>60</sup>

As affirmed by The World Alzheimer Report 2023, basing on the data of the World Health Organization (WHO), “*the number of people living with dementia across the world is expected to rise from 55 million in 2019 to 139 million in 2050*”.<sup>61</sup>

This information demonstrates that this ill involves lots of people in the world, and it continues to spread like wildfire. Data collected originated from rich states, where old people are a lot. Through the years we will find lots of cases also in poor states.<sup>62</sup>

For this reason, it becomes necessary to consider this problem at international level. Taking into consideration that there are not right instruments again, if dementia continues to develop in particular to poorer countries, this could have catastrophic consequences on people’s life.

Indeed, people that discover this type of diagnosis have yet lots of negative consequences, due to the lack of system to give adequate social, care and economic instruments.

Different studies conducted in the topic of dementia highlight that it is analysed only through medical point of view.

Medical studies try to find a therapy (that today does not exist) but meanwhile they ask for a social support in order to help people with dementia and their families.

For this reason, it is also necessary to look to dementia through human rights lens.<sup>63</sup>

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<sup>60</sup>World Health Organization. “Dementia”. 15 March 2023. Accessed on 31 May 2024, <https://www.who.int/news-room/fact-sheets/detail/dementia#:~:text=Currently%20more%20than%2055%20million,injuries%20that%20affect%20the%20brain>

<sup>61</sup>Long S., Benoist C., Weidner W. “World Alzheimer Report 2023: Reducing dementia risk: never too early, never too late”, p. 11

<sup>62</sup> Alzheimer’s Disease International (ADI). “Policy Brief for Heads of Governments: The Global Impact of Dementia 2013-2050”. London. December 2013. Accessed on 30 April 2024, <https://www.alzint.org/u/2020/08/GlobalImpactDementia2013.pdf>

<sup>63</sup> Gauthier S. et al. “World Alzheimer Report 2022: Life after diagnosis: Navigating treatment, care and support”

The basis of the human rights perspective is on the Article 1 of the Universal Declaration of Human Rights: “*All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood*”.<sup>64</sup>

This article represents the core of any Human Rights Conventions, and looking at the real condition of disability we could realize how rights of people are constantly endangered.

The Convention on the Rights of Persons with Disabilities is the foundation for the protection of human rights of persons with disabilities, starting from the fundamental rights and freedoms guaranteed by the Universal Declaration of 1948.

Taking into consideration the premise of the Convention, we could analyse the dementia’s condition.

One of the central articles is the “Article 19”:

*“States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:*

- a. Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;*
- b. Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;*
- c. Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.”*<sup>65</sup>

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<sup>64</sup>United Nations. “Universal Declaration of Human Rights”. Accessed on 30 April 2024, <https://www.un.org/en/about-us/universal-declaration-of-human-rights#:~:text=Article%201,in%20a%20spirit%20of%20brotherhood>

<sup>65</sup> Convention on the Rights of Persons with Disabilities, Article 19

The most important concepts as above-mentioned are the participation in the community, freedom to choose for themselves and to live independently. These rights and freedoms affirm that “*persons with disability are subjects of rights and a rights-holders*”.<sup>66</sup>

The article 19 is founded on the general principles cited in the Article 3 that are “*respect for inherent dignity, individual autonomy and independence*”, “*non-discrimination*”, “*participation and inclusion in society*”, “*respect for difference*”, “*equality of opportunity*”, “*accessibility*”, “*equality between men and women*”, “*respect for the evolving capacities of children with disabilities and [...] the right of children with disabilities to preserve their identities*”.<sup>67</sup>

Looking at Article 19 we can affirm that it includes first and second generation of human rights. It is “*an example of interrelation, interdependence and indivisibility of all human rights*”<sup>68</sup>. This means that any right could be fulfilled in relation to the realization of the others.

The organization of the UN system reaffirms that the full and complete realization of the Human Rights of all persons with disabilities is an inalienable, integral and indivisible part of all Human Rights and Fundamental Freedoms.

In this article we find “*the diversity of cultural approaches to human living*” and this could be defined as “*exercising freedom of choice and control over decisions affecting one’s life with the maximum level of self-determination and interdependence within society*”.<sup>69</sup>

The objectives of the Convention on the Rights of Persons with Disabilities face with the real societal context. This is why it is necessary to define fundamental human rights and how they could be applied in the life of every person with disabilities.

In order to take into consideration what we mean by the protection of dementia in the context of human rights is necessary to make reference to disability’s condition.

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<sup>66</sup> Committee on the Rights of Persons with Disabilities. “General comment on article 19: Living independently and being included in the community”. 27 September 2017. Accessed on 30 April 2024, [https://www.ohchr.org/Documents/HRBodies/CRPD/GC/CRPD\\_C\\_18\\_R\\_1.docx](https://www.ohchr.org/Documents/HRBodies/CRPD/GC/CRPD_C_18_R_1.docx)

<sup>67</sup> Convention on the Rights of Persons with Disabilities, Article 3

<sup>68</sup> Committee on the Rights of Persons with Disabilities. “General comment on article 19: Living independently and being included in the community”, p.2

<sup>69</sup> Ibid., p. 2

By the term disability, the Article 1 of the Convention on the Right “[...] *Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis*”.<sup>70</sup>

Therefore, the condition of disability is directly connected with the environment. This because it is based on the barriers that we find in the environment; it affects the person with disability because it could create limitation of functions.

For this reason, in our society disability has become synonymous with dependency. Indeed, as affirmed by Maurizio Sacconi, that was the Italian Minister of Work, Health and Social Policy, disability is also given by the relation between the individual and the environment in which he/she lives.

For this reason, if governments eliminate every form of barrier, it could reduce the level of disability.<sup>71</sup>

Barriers are understood as any type of limitation to participation's forms in relation to other citizens. In this way the principle of equality ends.

According to the Office of the High Commissioner for Human Rights “*persons with disabilities have, however, remained largely ‘invisible’, often excluded in the rights debate and denied from enjoying and exercising the full range of human rights*”.

As highlighted by OHCHR, with the Convention on the Rights of Persons with Disabilities there was the introduction of a “*paradigm shift*”. This because disability was no more looked at the medical point of view and from charity perspective, but from human rights lens.<sup>72</sup>

Concepts of participation, prevention, equal opportunity, rehabilitation and empowerment of vulnerable people become essentials.

Another important point is the definition of “well-being”. It is

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<sup>70</sup> Convention on the Rights of Persons with Disabilities, Article 2

<sup>71</sup> La convenzione delle Nazioni Unite sui diritti delle persone con disabilità

<sup>72</sup> United Nations. “About the human rights of persons with disabilities. Accessed on 31 May 2024. <https://www.ohchr.org/en/disabilities/about-human-rights-persons-disabilities>

“[...] a positive state experienced by individuals and societies [...] and is determined by social, economic and environmental conditions. Well-being encompasses quality of life and the ability of people and societies to contribute to the world with a sense of meaning and purpose.”<sup>73</sup>

There are different topics that are objects of the debates. One is represented by the loss of capacity of people affected by dementia.

Looking at the problem through the human rights perspective, we point out that there is a real restriction of self-determination, equality of opportunity and participation in decision making process.<sup>74</sup>

In fact, according to the Alzheimer’s Disease International and Dementia Alliance International, in reference to the Global Impact of Dementia this has consequences in the possibility to choose for themselves and on active participation in social context.

According to Theresa M. Flavin this barrier represents “a very direct violation of the fundamental human right of self-determination”.<sup>75</sup>

Self-determination represents one of the fundamental human rights and fundamental freedom.<sup>76</sup> In the context of disability, it is understood as the right of people with disabilities “to make one’s own choices”.<sup>77</sup>

For this reason, the concept of “*power of attorney*” risks to be a contradiction. This notion means “the legal right to act for someone else in their financial or business matters, or the document that gives you this right”.<sup>78</sup>

From a medical perspective it is positive in order to help a person to carry out specific procedure and accelerate the process of the request for specific services and applications.

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<sup>73</sup> World Health Organization. “Promoting well-being”. Access on 31 May 2024. <https://www.who.int/activities/promoting-well-being>

<sup>74</sup> United Nations. “World Programme of Action Concerning Disabled Persons”

<sup>75</sup>Theresa M Flavin. “Human rights in the context of dementia”, p. 1

<sup>76</sup> Rhona K. M. Smith. “International Human Rights Law”. Oxford University Press. New York. 2020

<sup>77</sup> Committee on the Rights of Persons with Disabilities. “General comment on article 19: Living independently and being included in the community”

<sup>78</sup> Cambridge Dictionary, “power of attorney”, Accessed on 15 May 2024, <https://dictionary.cambridge.org/it/dizionario/inglese/power-of-attorney>

On the other hand, any possible desire or choice is not considered.<sup>79</sup>

A clear example of the controversy effects of the power of attorney is represented by integrating people in care homes. This choice is developed in particular in Western countries.

This type of “solution” represents one of the most popular and fast decision taking in Europe, in particular in Italy. This because there aren’t other proposals that social system could suggest.

According to Kellyn Lee, in the expert essay “*Introducing material citizenship to dementia care*” in “*World Alzheimer Report 2022*”, “*the lack of freedom and respect for autonomy given to people living with dementia in care homes has been investigated and regarded as a threat to human dignity*”.<sup>80</sup>

This concept is connected with the Convention on the Rights of Persons with Disabilities that affirms at article 19, comma “a” that “*Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement [...]*”.<sup>81</sup>

Human rights want to protect in particular vulnerable people that, given their condition of weakness couldn’t give voice to their rights. The condition of vulnerability is defined by being exposed to violation of human rights.<sup>82</sup>

Focusing on older people with dementia, we can verify a multidimension discrimination: people that are aged and disable.

In fact, there are specific features that together with disability expose people to double risks of stigmatization. These characteristics are age, sex, religion, sexual orientation, refugee

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<sup>79</sup> Human Rights in the context of dementia

<sup>80</sup>Gauthier S. et al. “World Alzheimer Report 2022: Life after diagnosis: Navigating treatment, care and support”, p. 176

<sup>81</sup> Convention on the Rights of Persons with Disabilities, Article 19, comma a

<sup>82</sup> Rhona K. M. Smith. “International Human Rights Law”

status and so on. The discrimination connected to these categories could be defined as intersectional discrimination.<sup>83</sup>

These issues could get worse by poverty. In fact, especially in low-income countries, people with any form of impairment have no protection and no access to services. In addition, any possibility of participation in the decision making process is stopped.

Another particular issue is related to people living in war context or in other emergency situation. In these context they are perceived as “[...] *people with a so-called ‘hidden’ disability like dementia*” and they “*can be left behind in receiving humanitarian assistance and protection [...]*”. The Alzheimer’s Disease International highlighted in the report the necessity of actions by humanitarian actors in order to do not forget persons with disabilities. Therefore, emergency context represents one of discriminatory barriers in which vulnerable people are not considered.<sup>84</sup>

For this reason, as we look in the chapter 2, the international system has considered different projects and programmes in order to support people with disabilities. The issue is that they couldn’t exercise their human rights because they are marginalized in a society that discriminate them.

In this context the international system wants to look to human rights of persons with disabilities taking into consideration the sphere of well-being and person centred approach.

The concept of well-being is defined as “[...] *a positive state experienced by individuals and societies. Similar to health, it is a resource for daily life and is determined by social, economic and environmental conditions.*”<sup>85</sup>

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<sup>83</sup> Bourkel, E., Ferring, D., & Weber, G. “Perceived rights of and social distance to people with Alzheimer’s disease”. *GeroPsych: The Journal of Gerontopsychology and Geriatric Psychiatry*, 25(1), 25–32. 2012. Accessed on 30 April 2024, <https://doi.org/10.1024/1662-9647/a000052>

<sup>84</sup> Alzheimer’s Disease International. “Forgotten in a crisis: Addressing dementia in humanitarian response”. 2019. Accessed on 20 May 2024, <https://www.alzint.org/resource/forgotten-in-a-crisis-addressing-dementia-in-humanitarian-response/>

<sup>85</sup>World Health Organization. “Health promoting glossary of terms 2021”. Geneva. 2021. Accessed on 20 May 2024, <https://www.who.int/publications/i/item/9789240038349> , P.10



In the specific case of dementia, people need to improve the sphere of well-being, due to negative consequences of the ill. It is possible through the “*advance care planning*”, that is a part of “*palliative care*”.

As explained by the essay of Rose Miranda in the “*World Alzheimer Report 2022*”, based on the definition given by the World Health Organization, palliative care are “*an approach that improves the quality of life of patients and their families who are facing problems associated with life-threatening illness [...]*”.<sup>86</sup>

While the advance care planning “*allows people living with dementia to directly participate in the decision-making process for their end-of-life care, while also minimising the need for their carers to make difficult decisions during stressful times.*”<sup>87</sup>

This approach represents the best opportunity for people living with dementia, but in reality, the access to this type of decision is possible only for a little number of people in the world.

In general, all these decisions and new strategies are established by the international system, that wants to take decisions based on a new approach: the person-centred approach.

This new lens is defined by the Secretariat’s report as follows:

*“an approach to care that consciously adopts individuals’, carers’, families’ and communities’ perspectives as participants in, and beneficiaries of, trusted health systems that are organized around the comprehensive needs of people rather than individual diseases, and respects social preferences. [...] Requires that patients have the education and support that need to make decisions and participate in their own care and that carers are able to attain maximal function within a supportive working environment [...]*”<sup>88</sup>

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<sup>86</sup> Gauthier S. et al. “World Alzheimer Report 2022: Life after diagnosis: Navigating treatment, care and support”, p. 179

<sup>87</sup> Gauthier S. et al. “World Alzheimer Report 2022: Life after diagnosis: Navigating treatment, care and support”, p. 171

<sup>88</sup> World Health Assembly, 69. 2016. “Framework on integrated, people-centred health services: report by the Secretariat”. World Health Organization. Access on 31 May 2024, <https://iris.who.int/handle/10665/252698>, p. 2

Based on this approach that reflects the framework to which human rights are founded, we will analyse in the chapter 2 what are the policies, programmes, strategies adopted by international organization.

If in the theory this principle represents the best standard to protect people with dementia disease, in the real application within different states is not so simply.

In fact, we will look at different issues that these international project have in the international context.

## CHAPTER II. INTERNATIONAL LAW AND OTHER INSTRUMENTS

### 2.1 DIFFERENT INSTRUMENTS ADOPTED BY THE INTERNATIONAL SYSTEM.

*“Dementia is our collective social responsibility. We affirm our commitment to improving the lives of people affected by dementia [...]. Dementia requires long term health and social care support. Providing care for those with dementia can present challenges for families and carers. We need to provide better and more concrete measures for improving services and support for people with dementia and their carers, to improve their quality of life and wellbeing.”<sup>89</sup>*

Through this declaration of G8 Summit, that was in London in 2013, the ministers affirmed the necessity to start to adopt a set of policies in order to contrast the negative consequences of dementia because of its expansion.

Starting from the international standards adopted by in the international system in the wide sphere of disability, we will analyse the international instruments create for dementia's issue.

First of all, we look at the international standards about the rights of persons with disabilities. They include the “*Convention on the Rights of Persons with Disabilities*”, that represents the core of human rights about the sphere of disability. Attached to the Convention, there is the Optional Protocol.

Secondly, on 18 March 2015, there was the introduction of the “*Sendai Framework for Disaster Risk Reduction 2015-2030*”, about the role of person with disabilities in disaster risk reduction.

Then, there is the publication of the “*Charter on Inclusion of Persons with Disabilities in Humanitarian Action*” after the World Humanitarian Summit of 2016 in Istanbul.

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<sup>89</sup> Directorate/Division/Branch acronym/cost centre. “G8 Dementia Summit Communique”. 11 December 2013. Accessed on 20 May 2024, [https://assets.publishing.service.gov.uk/media/5a7c8e8ae5274a0bb7cb7d5f/2901669\\_G8\\_DementiaSummitCommunique\\_acc.pdf](https://assets.publishing.service.gov.uk/media/5a7c8e8ae5274a0bb7cb7d5f/2901669_G8_DementiaSummitCommunique_acc.pdf), p.4

In addition, there was the adoption Security Council Resolution 2475 (2019) “*Ground-Breaking Text on Protection of Persons with Disabilities in Conflict*”.

Finally, the “*2030 Agenda for Sustainable Development*” represents the new instrument to address to principal issues for the realisation of human rights.

To all these instruments we have to add all treaties that represents a fundamental part of international system for the protection of every individual: “*International Convention on the Elimination of All Forms of racial Discrimination*” (21 December 1965), the “*International Covenant on Civil and Political Rights*” ( 16 December 1966), the “*International Covenant on Economic, Social and Cultural Rights*” (16 December 1966), the “*Convention on the Elimination of All Forms of Discrimination against Women*” (18 December 1979), “*Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment*” (10 December 1984), “*Convention on the Rights of the Child*” ( 20 November 1989), “*International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families*” (18 December 1990), “*International Convention for the Protection of All Persons from Enforced Disappearance*” (20 December 2006), “*Convention on the Rights of Persons with Disabilities*” (13 December 2006), and all Optional Protocols. <sup>90</sup>

All these international tools could have impact on the different states thanks to other publication of United Nation about disability, with particular reference to dementia.

The first tool in which dementia was considered as a “priority” was the “*Mental Health Gap Action Programme*” (mhGAP), published in 2008. In this programme the WHO wants to help Member States to face with new disability changes.

Then, in 2011 the “*High-level Meeting on Prevention and Control of Non-communicable Disease*” adopted by the United Nations General Assembly about actions to take against the four main noncommunicable diseases that are cardiovascular disease, cancer, chronic lung diseases and diabetes.<sup>91</sup>

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<sup>90</sup> United Nations. “OHCHR and the rights of persons with disabilities”. Accessed on 20 May 2024, <https://www.ohchr.org/en/disabilities>

<sup>91</sup> United Nations. “Leaders Gather at UN Headquarters for a High-Level Meeting on Non-communicable Diseases (NCDs)”. Accessed on 20 May 2024, <https://www.un.org/en/ga/ncdmeeting2011/>

In 2012, the World Health Organization and the Alzheimer's Disease International published in 2012 "*Dementia: a public health priority*". For the first time, through this report dementia is considered a global issue, for which states have to take political actions. This because a fundamental step is represented by a new awareness: dementia is not a normal part of ageing.

In this report the WHO uses three methods: the first is working groups' reports, the second is an online overview of selected countries (that represent different levels of income) and the third is other stakeholders' information.

It starts from analysing how states address to dementia issue, what type of actions they apply, to how social system reply to the necessity of long-term care.

"*Dementia: a public health priority*" has the aim to increase knowledge about dementia, outline a new approach considering dementia as a public health priority and to support policies at all levels of governance in order to protect fundamental human rights of persons with disabilities.

These actions have the purpose to give realization of principles of well-being and quality of life. This necessity is also highlighted by the high costs of healthcare; especially in 2010 costs for this particular condition was about US\$604.

Therefore, this report wants to be considered a "resource", that managed by states in the decision-making process could place at the centre the topic of dementia as a public health priority.<sup>92</sup>

The complexity of dementia issue has caused the difficult for countries to create policies conform to the new World Health Organization's guidelines.

The elaboration of an international action plan about the topic of dementia represents an incisive instrument in order to change direction within every state.

This is the "*Global action plan on the public health response to dementia 2017-2025*". It was adopted by the World Health Organization in 2017. According to the essay of Maikutlo Palesa Mabille, published in the World Alzheimer's Report 2022, "*it could be*

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<sup>92</sup> World Health Organization. "*Dementia: a public health priority*"

*the essential tool to ensure health ministries in governments include dementia and dementia care as a priority.*<sup>93</sup>

The vision highlights in the introduction of the global action plan is about the necessity of prevention and the necessity of services that could guarantee the care of people living with dementia. In addition the goal affirmed is *“to improve lives of people with dementia, their carers and families, while decreasing the impact of dementia on them as well as on communities and countries.”*<sup>94</sup>

Then, it defines *“seven cross cutting principles”* and areas of action to which Member States have to base their decision-making processes.

The principles are defined as follows: *“human rights of people with dementia”*, *“empowerment and engagement of people with dementia and their carers”*, *“evidence-based practice for dementia risk reduction and care”*, *“multisectoral collaboration on the public health response to dementia”*, *“universal health and social care coverage for dementia”*, *“equity”*, *“appropriate attention to dementia prevention, cure and care”*.<sup>95</sup>

Whereas the action areas want to realize the above-mentioned principles proposing actions for states, secretariat and partners at different levels of governance.

The first area is *“dementia as a public health priority”*. What it is highlighted in this part is a coordinated set of policies applied by different actors of public, private, social and health sector. The approach has to be multisectoral and has to found on the application of principles affirmed in the Convention on the Rights of Persons with Disabilities.

The second is *“dementia awareness and friendliness”*. Especially it aims to create a community with these characteristics and with the purpose to eliminate social barriers. This type of area not only wants to suggests plans to avoid social isolation, but also to promote education, prevention, knowledge about dementia.

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<sup>93</sup> Gauthier S. et al. “World Alzheimer Report 2022: Life after diagnosis: Navigating treatment, care and support”, p. 77

<sup>94</sup> World Health Organization. “Global action plan for the prevention and control of noncommunicable diseases 2013-2020”. 14 November 2013. Accessed on 30 April 2024, <https://www.who.int/publications/i/item/9789241506236>, p. 4

<sup>95</sup> Ibid., p.5

This action area is strictly connected with the third: “*risk reduction*”. It involves the necessity of understanding what are the risk factors. There are two types of them: social risks (isolation, depression, inactivity) and health risks (obesity, diabetes, alcohol). If states work on preventions measures in order to educate society, the possibility to develop ill could be reduced.

The fourth is “*dementia diagnosis, treatment, care and support*”. Through the development of coordinated pathways, guidelines and tools between the principal actors of this system is possible to prevent dementia by an early diagnosis.

In this part it is fundamental to develop a planning conform to the patient, that respects the development of its disability; in this phase it is possible to elaborate adequate palliative care.

In this way the treatment could be applied from the first phase of the ill and it could be possible to work with carers and families.

The last affirmation is related to the fifth area: “*support for dementia carers*”. Even if they are not the patient, the international system affirms the necessity to give assistance to caregivers.

They play a crucial role in all steps of dementia. For this reason, discussion about what type of strategies could be elaborated it is crucial for the realization of cross-cutting principles.

“*Information system*” represents the sixth area of action, in which the World Health Organization highlights how the collection of data between different countries is essential for developing strategies. Without data we couldn’t establish goals and policies.

The last is “*research and innovation*”. Without this any type of progression is not possible. It could be emphasised that the only limit of it is based on financing. The best goal in this field is finding a cure. In order to obtain best innovation is necessary that governments start to assign funds to the research for dementia.<sup>96</sup>

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<sup>96</sup> Ibid.

The global action plan recommends global targets for each area, with the aim to achieve the result that every member state begins to adopt this type of proposal practices.

Another important step is involved by the “*First WHO Ministerial Conference on Global Action Against Dementia*”. It was convened on 16 and 17 March 2015 in Geneva.

In this circumstance took part eighty-nine Member States as well as members of UN, civil society and NGOs. They continued to work in line with the above-mentioned Global Action Plan, with the result to arrange a “*Call for Action*”.

In fact, in order to protect the interests of people living with dementia and their carers, they designate a set of actions that they are “called” to apply.

These actions involve first of all, confrontations between leaders of different countries that have committed to add dementia topic in their agendas; later, the commitment to reinforce the work about dementia; then, the task about awareness and knowledge, in order to eliminate social barriers.

In addition, other purposes are following: working on prevention and treatment; financing innovation, research and technological progress; acting on the assistance’s sector; considering the gender dimension in the context of people living with dementia; ministers want to reinforce international framework in order to also guarantee the objectives above-mentioned in developing countries; finally, strengthening the actions of World Health Organization that has a central role to develop policies and programmes to support people living with dementia and their families.<sup>97</sup>

Through this Conference, Ministers started to take action for adding dementia in their national agenda and, based on the indications given by the Global Action Plan, they decide to establish a “*WHO Global Dementia Observatory*” (GDO).<sup>98</sup>

It is “*the monitoring and accountability mechanism for the Global action plan on the public response to dementia 2017-2025. It collates data from WHO Member States on 35*

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<sup>97</sup> World Health Organization. “First WHO Ministerial Conference on Global Action Against Dementia”

<sup>98</sup> World Health Organization. “Consultation on the Development of the Global Dementia Observatory”. Geneva. 2017. Accessed on 10 May 2024, <https://iris.who.int/bitstream/handle/10665/255552/WHO-MSD-MER-17.4-eng.pdf?sequence=1>



*key dementia indicators to strengthen countries' ability to respond to the needs of people with dementia, their carers and families.”<sup>99</sup>*

In the framework of dementia as public health priority, other instruments have been developed from the general topic of disability to mental disabilities and ageing.

Let's take a look at the most important, with the aim to build a clear idea of what type of structure the World Health Organization has framed before the above-mentioned instruments about dementia.

It is also important to highlight that all action plans are strictly connected, because the international system wants to operate considering a multidimensional approach and a synergy between different pathologies and risk factors.

Every individual is not only classifiable in one “category” such as dementia, mental disability, alcoholism, drugs, age, because every person belong to multiple dimensions of vulnerability.

In 2013, the World Health Organization published the “*Mental health action plan 2013-2020*”. In this action plan the Director-General of WHO, Dr Margaret Chan, affirms the necessity to change direction in the international welfare system because people with disabilities, and especially in the case of mental disabilities, are isolated and not supported in the social context.

In this specific report dementia was be classified as a mental disease. As well as in report above-mentioned, the international system asks how to guarantee the best well-being of a person with illness.

It deduced that there are some central ideas we find in all action plans: poverty, education, reduction of social funds to invest in all proposed programmes, fulfilment of human rights.

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<sup>99</sup> World Health Organization. “Global Dementia Observatory (GDO)”

This because all spheres of disabilities argue that, even if what was affirmed in the Convention on the Rights of Persons with Disabilities, there are big limitations to participation and to support of people with different impairments.<sup>100</sup>

Then, on 30 November 2015 there was the publication of the “*WHO global disability action plan 2014-2021*”. Basing on the same goal and principles affirmed up until now, it introduces new approaches to which based the action plan:

*“a human rights-based approach, including the continuum of care; a life-course approach, including the continuum of care; universal health coverage; a culturally-appropriate person-centred approach; multisectoral/community-based rehabilitation; universal design.”*<sup>101</sup>

Subsequently, on 18 March 2015 in Japan, after the Third UN World Conference in Sendai, there was the publication of the “*Sendai Framework for Disaster Risk Reduction 2015-2030*” about the necessity to eliminate barriers for active participation of people with disabilities in case of disaster risk.<sup>102</sup>

In addition, the World Health Organization elaborates in 2018 “*Towards a dementia plan: a WHO guide*”. It is connected with the Global Dementia Observatory and it is an important text about the necessity to look not only on how applying the responsibility of the state, but also to highlight the inefficiency of the welfare structure.

The keywords developed in the guide are “*leadership, governance and multisectoral collaboration*”.<sup>103</sup> In fact on these terms is developed all plan that “*recognizes the value of older people and those with dementia in society*”<sup>104</sup> because “*people with dementia have complex needs that are multisectoral in nature*”.<sup>105</sup>

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<sup>100</sup> World Health Organization. “Mental health action plan 2013-2020”.

<sup>101</sup> World Health Organization. “WHO global disability action plan 2014-2021”, p. 4

<sup>102</sup> United Nations. “Sendai Framework for Disaster Risk Reduction 2015-2030”. 2015. Accessed on 01 May 2024, <https://www.undrr.org/publication/sendai-framework-disaster-risk-reduction-2015-2030>

<sup>103</sup> World Health Organization. “Towards a dementia plan: a WHO guide”. 2018. Accessed on 10 May 2024, <https://www.who.int/publications/i/item/9789241514132>, p. 15

<sup>104</sup> Ibid., p. 9

<sup>105</sup> Ibid., p. 9

In the structure of this document we find the instructions about how to compose a national dementia plan, what type of strategies could be elaborated, the application of them in the territory, considering available resources.

Dementia plan is composed by three steps: preparation, developing and implementation. The first step started from the analysis of situation to outline the priorities. Under examination there are services, policies, stakeholder and data. In this phase government focuses on actions to improve the national strategy. Possible issues are related to stigma, political indifference, budget resources, data about diagnosis.

Based on data collected in the previous step, the second phase involves the elaboration of the plan. It becomes from the definition of the strategic framework, then the evaluation of resources and to stakeholders' feedback.

The third phase is divided in “*develop an operational work plan*”, “*allocate the budget*” and “*monitor and evaluate*”.

Through this last part, national government evaluate the quality of the policy and could adjust it in order to improve the intervention.<sup>106</sup>

Becoming dementia a central topic of public debate, also the Organisation for Economic Co-operation and Development elaborates a report about this topic: “*Care Needed: Improving the Lives of People with Dementia*”. This international organisation affirms that in the last years in rich countries there was an empowerment of the dementia care. Nevertheless, the issues continue to improve in poor countries, where there are not sufficient resources.

According to this report, inefficiencies persist in access to services, care quality and carers support. In addition, data collected are not the real image of the effect of dementia in the world.<sup>107</sup>

In addition, the above-mentioned “*Global action plan on the public health response to dementia 2017-2025*” defined seven areas of action. For this reason, between different

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<sup>106</sup> World Health Organization. “Towards a dementia plan: a WHO guide”, p. 42

<sup>107</sup> OECD. “Care Needed: Improving the Lives of People with Dementia”.

documents, *“Risk reduction of cognitive decline and dementia: WHO guidelines”* elaborated in 2019, represents a way to gain one goal between these actions.

In fact, the unavailability of a medical therapy to stop dementia progression, creates the necessity to act in risk factors such as alcohol, tobacco, hypertension, diabetes depression, dyslipidaemia, hearing loss, weight, and other social factors.

For this reason, researches continue to highlight that dementia is not a normal part of ageing and there are some factors that accelerate the advancement of this disease.<sup>108</sup> This guideline is *“[...] aligned with WHO’s mandate to provide evidence-based guidance for a public health response to dementia”*.

It offers tools to reduce the progression of dementia, by providing instrument to reduce the risk factors *“by supporting health and social care professionals, particularly by improving their capacity to provide evidence-based, multisectoral, gender and culturally appropriate interventions to the general population [...]”*.<sup>109</sup>

About the old population, linked with the issue of disability, the WHO elaborated also the *“Decade of healthy ageing: baseline report”* that is the baseline report of the *“Global strategy and action plan on ageing and health”* published on 2<sup>nd</sup> January 2017.

These reports on ageing highlights another part of society that is discriminated: old people. For this reason, the *“decade on ageing”* could be considered from 2020 to 2030; starting for analysing the general situation, the World Health Organization proposed recommendations, considering the importance to develop actions to reduce stigma against ageing and services directly to them.

The focal point of this decade is “healthy” that, considering the time lapse between 2020 to 2030, we could affirm that there were contradictions caused by Covid 19’s effects.

Nevertheless, the World Health Organization affirmed in the report of 2020 that *“Healthy ageing is the process of developing and maintaining the functional ability that enables*

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<sup>108</sup> World Health Organization. “Risk reduction of cognitive decline and dementia: WHO guidelines”. Geneva. 2019. Accessed on 21 May 2024, <https://www.who.int/publications-detail-redirect/9789241550543>

<sup>109</sup> World Health Organization. “Risk reduction of cognitive decline and dementia: WHO guidelines”, p. 3

*well-being in older age*". It is composed by functional ability, intrinsic capacity and environments.

The first is produced by the connection between the other two elements. In this factor we find different types of abilities: meet basic needs, decision, in relations, in mobile, in society.

The second includes person's capacities.

The third is the environment in which people developed their life.<sup>110</sup>

Generally, the Global Strategy affirms that

*"the 2030 Agenda for Sustainable Development makes it clear that a healthy life and the right to health do not start or end at a specific age".<sup>111</sup> The "[...] goals include implementing existing evidence to maximize functional ability, filling the evidence gaps and establishing partnerships to ensure a Decade of Healthy Ageing from 2020 – 2030".<sup>112</sup>*

Analysing the context of the elderly, in connection with the topic of dementia, another important contribution was in 2021 the work *"Ageing Gracefully: Diversity of Dementia"* elaborated by the WHO and the Regional Office for South-East Asia. It focused on the condition of dementia, its history, its development and its forms.

It highlighted that when a person become elderly it starts to do not remember lots of things, so not all people are affected by dementia in old age because it is not a normal consequence of ageing. This report emphasized the presence of two factors: risk and protective factors.

The first has negative consequences for the development of the disability.

The second has positive effect decreasing the possibility of a fast progression of dementia.

From the headline, the concept of *"diversity"* looked at the different impact on dementia according to the person. Especially, according to the sex, dementia affects differently

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<sup>110</sup> World Health Organization. "Decade of Healthy Ageing 2020-2030", p. XV

<sup>111</sup> World Health Organization. "Global strategy and action plan on ageing and health", p. IV

<sup>112</sup> Ibid., p. 48

women from men. For example, data demonstrates that there are more women than men in care homes and this is due by a factor: assistance.

According to this work, based on data collected, when a woman is affected by dementia, it is most difficult for her husband to be an assistant and for this reason it is more chances she goes in a rest home.

In the report “*Global status report on the public health response to dementia*”, the World Health Organization analysed the general situation of public policies about dementia.

Starting from data collected between 2017 to 2020 by the Global Dementia Observatory, it is possible to highlight different information.

First of all, data have been presented by only sixty-two countries. They involve the thirty-two percent of states.

Secondly, information is based on thirty-five indicator of dementia.

Thirdly, Member States that report about dementia are only one fifth.

In wide terms, we can affirm that collection of data is very limited and it causes negative effective on formulation of policy and its application.

Indeed, it is clear the carelessness of Member states in analysing how many people are affected by dementia even if they affirm to have available a plan for dementia.<sup>113</sup>

It is necessary to consider that this lack also include health sector.

The “*Global action plan on the public health response to dementia 2017-2025*” affirms in the action area number six “*Information system for dementia*” that the Global Target is that “*50% of countries routinely collect a core set of dementia indicators through their national health and social information systems on which they report every two years by 2025*”.<sup>114</sup>

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<sup>113</sup> World Health Organization. “Global status report on the public health response to dementia: executive summary”. Geneva. 2021. Accessed on 30 May 2024, <https://iris.who.int/bitstream/handle/10665/344707/9789240034624-eng.pdf>

<sup>114</sup> World Health Organization. “The global action plan on the public health response to dementia 2017-2025”, p. 42

Basing on the results of “*Global status report on the public health response to dementia*” that demonstrates the gap between different WHO’s recommendations and the policies adopted by Member States about dementia, “*A blueprint for dementia research*”, published on 4 October 2022 by the World Health Organization, continues to analyse countries’ situation.

This research is focused on the data and knowledge. Investigating gap’s issues emerge in different states, the report proposes strategies and policies to structure decisions of politicians, scholars and community.

It demonstrates a wide difficulty linked with the survey about how many people are affected by dementia because information are collected in particularly from high income countries.<sup>115</sup>

Another important instrument is represented by the “*WHO global disability action plan 2014-2021. Better health for all people with disability*” that looks at topic of disability in general.

It was elaborated after the Sixty-sixth World Health Assembly when the Director-General was designated to elaborate the action plan “

*[...] in line with the Convention on the Rights of Persons with Disabilities [...] and the outcome document of the high-level meeting of the United Nations General Assembly on the realization of the Millennium Development Goals and other internationally agreed development goals for persons with disabilities [...]*”.<sup>116</sup>

Starting from the general condition of disability, it analyses on how it is developed in the world, considering also the different types of vulnerabilities that creates multiple forms of discrimination.

It remarks the principles signed in the Convention on the Rights of Persons with Disabilities in order to affirm the importance for Member States to adopt policies to remove social, economic, health barriers.

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<sup>115</sup> World Health Organization. “A blueprint for dementia research”. Geneva. 2022. Accessed on 10 May 2024, <https://www.who.int/publications/i/item/9789240058248>

<sup>116</sup> World Health Organization. “WHO global disability action plan 2014-2021”, p. 1

Focusing on fundamental human rights principles, it elaborates actions for all levels of governance.<sup>117</sup>

This overview has been enhanced by the big contributions of the Alzheimer association, through the elaboration of World Alzheimer Reports.

Analysing reports from 2009 to 2022 it is possible to highlight a development in knowledge and political commitment about dementia.

These documents are elaborated by the Alzheimer's Disease International (ADI) that is a USA's no profit organization that has an official collaboration with the World Health Organization.<sup>118</sup>

The first "*World Alzheimer Report*" was in 2009 in which it is pointed out the topic of dementia, basing on the rapid development of this type of disability. In this document final recommendations are about initially strategies that need to be added in national agenda of every country.<sup>119</sup>

Then, "*The World Alzheimer Report 2010*" concerned economic dimension. According to it, governments have to trace funds to invest in researches and services.<sup>120</sup>

In 2011, the focal point was on the topic of diagnosis and all health interventions that are essentials in this phase.<sup>121</sup>

The "*World Alzheimer Report 2012*" regarded the issue of social discrimination connected to stigma. The necessity of a major awareness about what is Alzheimer and in general dementia could permit to find solution and not to hide the emergence of the ill.<sup>122</sup>

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<sup>117</sup> Ibid.

<sup>118</sup> Alzheimer's Disease International. "About Us". Accessed on 31 May 2024, <https://www.alzint.org/about-us/>

<sup>119</sup> Jackson J., Prince M., "World Alzheimer Report 2009: The global prevalence of dementia". Alzheimer's Disease International. 21 September 2009. Accessed on 10 May 2024, <https://www.alzint.org/resource/world-alzheimer-report-2009/>

<sup>120</sup> Wimo A., Prince M. "World Alzheimer Report 2010: The Global Economic Impact of Dementia". Alzheimer's Disease International. 21 September 2010. Accessed on 10 May 2024, <https://www.alzint.org/resource/world-alzheimer-report-2010/>

<sup>121</sup> Ferri C., Prince M., Bryce R. "World Alzheimer Report 2011: The benefits of early diagnosis and intervention". Alzheimer's Disease International. 21 September 2011. Accessed on 10 May 2024, <https://www.alzint.org/resource/world-alzheimer-report-2011/>

<sup>122</sup> Mittelman M., Batsch N. "World Alzheimer Report 2012: Overcoming the stigma of dementia".



Given the high number of people affected by dementia and the increasing request for long-term care, the report of 2013 was focused on this issue.<sup>123</sup>

Data demonstrates that “*around half of all people with dementia need personal care [...]. Around half of all older people who need personal care have dementia, while four-fifths of older people in nursing homes are people with dementia.*”<sup>124</sup>

For this reason, it is necessary also a dementia formation for caregivers and social workers.

The report published in 2014 was about all risk factors connected with the development of dementia.<sup>125</sup>

In 2015 the work is about the “*global impact of dementia*” especially in terms of costs.<sup>126</sup>

In addition, the Alzheimer’s Disease International highlighted in 2016 the lack of specific health strategies.<sup>127</sup>

Moreover, in 2018 it was mapped data about research<sup>128</sup>, while in 2019 it was analysed the point of view of people towards dementia.

The survey conducted in 2019 demonstrated what is the behaviour of people towards dementia. Research demonstrated that a wide part of social workers believed that

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<sup>123</sup> Guerchet M., Prince M., Prina M. “World Alzheimer Report 2013: Journey of Caring. An analysis of long-term care for dementia”. Alzheimer’s Disease International. 21 September 2013. Accessed on 10 May 2024, <https://www.alzint.org/resource/world-alzheimer-report-2013/>

<sup>124</sup> Guerchet M., Prince M., Prina M. “World Alzheimer Report 2013: Journey of Caring. An analysis of long-term care for dementia: summary sheet”. Alzheimer’s Disease International, Accessed on 10 May 2024, <https://www.alzint.org/u/world-report-2013-summary-sheet.pdf>, p. 4

<sup>125</sup> Albanese E., Guerchet M., Prince M., Prina M., “World Alzheimer Report 2014. Dementia and risk reduction. An analysis of protective and modifiable factors”. Alzheimer’s Disease International. 21 September 2014. Accessed on 10 May 2024, <https://www.alzint.org/resource/world-alzheimer-report-2014/>

<sup>126</sup> Wimo A. et al. “World Alzheimer Report 2015. The global impact of dementia. An analysis of prevalence, incidence, cost and trends”. Alzheimer’s Disease International. London. 21 September 2015. Accessed on 10 May 2024, <https://www.alzint.org/resource/world-alzheimer-report-2015/>

<sup>127</sup> Comas-Herrera A. et al. “World Alzheimer Report 2016. Improving healthcare for people living with dementia. Coverage, quality and costs now and in the future”. Alzheimer’s Disease International. London. 21 September 2016. Accessed on 10 May 2024, <https://www.alzint.org/u/WorldAlzheimerReport2016.pdf>

<sup>128</sup> Patterson C. “World Alzheimer Report 2018. The state of the art of dementia research: New frontiers”. Alzheimer’s Disease International. London. 21 September 2018. Accessed on 10 May 2024, <https://www.alzint.org/resource/world-alzheimer-report-2018/>

“*dementia is a normal part of ageing*”. On the other hand, lots of people do not reveal their health condition, when they discovered this diagnosis.<sup>129</sup>

The report of 2020 focused on dementia planning. Analysing the situation in this year, scholars affirmed the necessity to make progress in it, because the system was backward.<sup>130</sup>

After 2020, and the pandemic situation due to COVID-19, the general situation of dementia gets worse.

The topics debate in these report was influenced by the negative effects caused by the pandemic, in particular linked with health condition, the very difficult situation of caregivers, the increment of costs and so on.

The World Alzheimer Report of 2021 concerned the course of the diagnosis and the social factors connected with it (gender, culture, sex, education, economic situation).<sup>131</sup>

The report of 2022 looked at the situation and services after the moment in which a person discovers to be affected by dementia. According to data collected, third four of people in the world have not a diagnosis. The specific problem affirms in this document is the lack of services and support in states.

Based on the survey conducted by researchers

*“a surprised number of people living with dementia indicated they had not been offered post-diagnosis support beyond the initial information provided immediately after their diagnosis. In lower-income countries, 45% indicated they had not been offered support, while in higher-income countries, 37% indicated they were offered nothing. [...]*

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<sup>129</sup> Alzheimer’s Disease International. “World Alzheimer Report 2019: Attitudes to dementia”. Alzheimer’s Disease International. London. 20 September 2019. Accessed on 10 May 2024, <https://www.alzint.org/resource/world-alzheimer-report-2019/>

<sup>130</sup> Fleming R. et al. “World Alzheimer Report 2020. Design, dignity, dementia: Dementia-related design and the built environment”. Alzheimer’s Disease International. London. 21 September 2020. Accessed on 10 May 2024, <https://www.alzint.org/resource/world-alzheimer-report-2020/>

<sup>131</sup> Gauthier S. et al. “World Alzheimer Report 2021: Journey through the diagnosis of dementia”. Alzheimer’s Disease International. London. 21 September 2021. Accessed on 10 May 2024, <https://www.alzint.org/resource/world-alzheimer-report-2021/>

*64% of respondents living with dementia indicated they did not have a personalised care plan[...].”<sup>132</sup>*

For this reason, the scholars of ADI affirm the necessity to elaborate in every country dementia care model using the person-centred approach. This is caused by the negligence of politician to do not adopted the instruments above-mentioned.

The last report published was the World Alzheimer Report 2023 that concerns modifiable and not modifiable risk factors that influence Alzheimer.

When there is a lack in assistance care models, as highlighted in the report of 2022, it is necessary to concentrate policies in reducing risk factors to limit the dementia progression.

It is important especially for alone person that couldn't avoid risks, for this reason it is necessary a state's interventions, through correct political strategies.

The instruments analysed in this chapter are the most important about dementia and they are elaborated with the aim to push states to adopt political strategies and policies about this issue.

## 2.2 THE APPLICATION OF THESE INSTRUMENTS BY DIFFERENT COUNTRIES.

As it is highlighted on the previous chapters, the premises above mentioned about dementia would create a grounded system, applying a multidisciplinary approach, in order to give instruments to different actors involve in this type of context.

For this reason, in this part we will look at the real situation of political policies and commitments in some regional systems.

In spite of data collected by the Global Dementia Observatory, it is possible to verify a disproportionate collection of information because they come in particular from rich states.

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<sup>132</sup> Gauthier S. et al. “World Alzheimer Report 2022: Life after diagnosis: Navigating treatment, care and support”.

In fact, looking at different regional systems, it is possible to observe that less than half of states in every region submitted data.

Western Pacific Region has ten states on twenty-seven that participated in GDO.

Eastern Pacific counted eight states on twenty-one, while South-East Asia had five states on eleven.

In the African Region four Member States on forty-seven submitted data, while in Region of the Americas eleven states on thirty-five, finally in European Region twenty-four out of fifty-three.

According to data collected by the Global Dementia Observatory (that was referring to the period of 2017, with a last update of information of 2021) there is also a contrast between the existence of dementia national plan and the availability of funding for dementia national plan.

The term “*dementia plan*” refers to “[...] *political commitment to address the challenges and impacts associated with dementia and to improve health and social system readiness to address the needs of people living with dementia and their carers [...]*”.<sup>133</sup>

Starting from a principal focus, that is represented by the triggering factor of dementia, states developed policies and strategies.

Nevertheless, often dementia is involved in other political sectors (social services, mental health, noncommunicable diseases, labour, health, ageing and so on).<sup>134</sup>

The regional system that has most stand-alone dementia plan than other is European Region (that counts seventeen of it).

In general, about data submitted, high-income countries exceed low-and-middle income countries (twenty-five versus two).

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<sup>133</sup> World Health Organization. “Global status report on the public health response to dementia”, p. 69

<sup>134</sup> Ibid.

It could be highlighted that in the following states existed a dementia plan but there are not founds: Czechia, Italy, Malta, Qatar, Slovenia, Sweden, United Kingdom of Great Britain and Northern Ireland.<sup>135</sup>

As a result of these information “[...] countries that have submitted data to the GDO, 56% are HICs, while 44% are LMICs. Together, countries participating in the GDO account for 65.5% of the global population and 76% of the population aged 60 years or older.”<sup>136</sup>

This research demonstrated the non-fulfilment by Member States of World Health Organization’s recommendations.

The indifference towards the dangerous dementia situation highlighted the incompetence of political class to make citizens’ interests. Especially, governments continue to allocate economic resources in other spheres but not in health policies.

This is emerged in particular during the pandemic of Covid-19 in 2020, when the political negligence towards healthcare was revealed.

As it was highlighted in different circumstances, the “*Global action plan on the public health response to dementia 2017-2025*” affirms the necessity to apply targets that every Member States might respect. In this way it is possible to hope for a real change in dementia situation.

In this part, we look at different national dementia plans, creating with the aim to achieve the Global target 1, fixed by the Global action plan: “*75% of countries will have developed or updated national policies, strategies, plans or frameworks for dementia, either stand-alone or integrated into other policies/plans, by 2025*”.<sup>137</sup>

In the action area 1 of the Global action plan, the World Health Organization proposed actions for Member States, Secretariat and stakeholders of different levels of governance.

In the development of a national plan, there are lots of factors to consider.

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<sup>135</sup> World Health Organization. “Global Dementia Observatory (GDO)”

<sup>136</sup> World Health Organization. “Global status report on the public health response to dementia”, p. 206

<sup>137</sup> World Health Organization. “The global action plan on the public health response to dementia 2017-2025”, p. 10

First of all, the government has to decide if creating a care plan only for dementia or add it to another one.

Then, the most important part is about funds. Indeed, to this particular form of disability there are three categories of costs to which dementia is linked: direct medical costs, direct social costs and informal care costs.

The first is for all costs related to medical treatment, examinations and so on.

The second is related to all services that are not about health sphere but social sphere.

The third is not quantifiable because it is about all time that caregivers spent for caring of the person affected by dementia.

Another variable that affects these costs is the phase of dementia; if a person is at the initially step, costs are lesser than a dementia in the last step.<sup>138</sup>

Analysing the Global Dementia Observatory, we can find different Member States that use this platform through the upload of their strategies, policies, plan.

It is interesting to look at what states decide to apply for this platform, creating by the World Health Organization with the aim to monitor real commitments of states in dementia.

The result is that not lots of governments participated in it and it highlights the lack of interest of politician to follow the road of protection of people affected by dementia.

Searching for national policies and strategies it emerges that are present the following documents.<sup>139</sup>

In the Eastern Mediterranean Region only Qatar and Pakistan have policies.

In Qatar the “*National dementia plan for the State of Qatar*” was published in January 2018 and it refers to the period 2018-2022. According to the Ministry of Public Health it presents weakness and strong points.

Especially, if on the one hand there is the existence of a national specific group on dementia, on the other hand there is a lack about data, diagnosis, social support, lack of

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<sup>138</sup> World Health Organization. 2021. “Global status report on the public health response to dementia”.

<sup>139</sup> World Health Organization. “Global Dementia Observatory (GDO)”

health workers, legislations and so on. Nevertheless, this plan could be considered a good starting point to face dementia.<sup>140</sup>

The second country that published a plan in the system was Pakistan: “*Punjab Dementia Plan*”. The general problem that emerges from this document is the opposition of parliament to government proposals about dementia.

For this reason, from it results only a political commitment to look dementia as a public health priority.

In addition to these countries’ publications, the Eastern Mediterranean Region reported the implementation in states of the Global Action Plan. The document “*Eastern Mediterranean Regional Workshop to speed up the implementation of the global action plan on dementia*” is the outcome of the Doha’s workshop, that was between the 16 to 18 September 2023.<sup>141</sup>

About the European Region, there are two important reports on dementia to consider: “*Dementia in Europe Yearbook 2019: Estimating the prevalence of dementia in Europe*”<sup>142</sup> and “*Dementia in Europe Yearbook 2022 Employment and related social protection for people with dementia and their carers*”.<sup>143</sup>

In the first document the Alzheimer Europe looks at the number of people affected by dementia. In general, data demonstrates that there are lots of people with this type of ill, and for this reason, specific policies and national plan are needed.

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<sup>140</sup> Ministry of Public Health. “Qatar National Dementia Plan 2018-2022”. Accessed on 15 May 2024, <https://www.moph.gov.qa/english/strategies/Supporting-Strategies-and-Frameworks/QatarNationalDementiaPlan/Pages/default.aspx>

<sup>141</sup> World Health Organization. “Multiregional workshop on the implementation of the global action plan on public health response to dementia”. *Eastern Mediterr Health J.* 2023; 29(4):302-303. Accessed on 15 May 2024, <https://www.emro.who.int/emhj-volume-29-2023/volume-29-issue-4/multiregional-workshop-on-the-implementation-of-the-global-action-plan-on-public-health-response-to-dementia.html>

<sup>142</sup> Alzheimer Europe. “Dementia in Europe Yearbook 2019: Estimating the prevalence of dementia in Europe”. Luxembourg. 2019. Accessed on 15 May 2024, [https://www.alzheimer-europe.org/resources/publications/dementia-europe-yearbook-2019-estimating-prevalence-dementia-europe?language\\_content\\_entity=en](https://www.alzheimer-europe.org/resources/publications/dementia-europe-yearbook-2019-estimating-prevalence-dementia-europe?language_content_entity=en)

<sup>143</sup> Alzheimer Europe. “Dementia in Europe Yearbook 2022 Employment and related social protection for people with dementia and their carers”. 2023. Accessed on 10 May 2024, <https://www.alzheimer-europe.org/product/dementia-europe-yearbook-2022-employment-and-related-social-protection-people-dementia-and>

Unfortunately, only some states submit a national plan or strategy. In the GDO we find France, Ireland, Austria, Belgium, Germany and Spain.<sup>144</sup>

The work presented by this yearbook highlights the importance to adapt social support to the requirements of dementia disability, by removing stigma, research, high costs.

One of issues emerging from it is the absence of data about young people affected by dementia.<sup>145</sup>

The second yearbook analyses social protection and employment through which people affect by dementia have difficulty in their brain challenge.

It is focused on financial issues in order to guarantee to people adequate access to services. Starting from the real situation in European countries, it proposed strategies with the aim to implement the Global Dementia Action Plan due to the scarcity of states to adopt measures about dementia.

There are some European policies that are cited: the “*European Pillar on Social Rights*” (EPSR) of 2017, the “*European Strategy on the rights of persons with disabilities 2021-2030*”, the “*Disability Employment Package*” (2022).

Then, the European regional system adopts other measures about the topic of this yearbook, especially for protection, work balance, non-discrimination, financial measures.<sup>146</sup>

Looking at the impact of the regional system in different country it is possible analysed first of all France.

In 2014 the “*Plan Maladies Neuro-Dégénératives 2014-2019*” adopts a general vision to face with the problem of neurodegenerative illness.<sup>147</sup> Nevertheless, the topic of dementia

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<sup>144</sup> World Health Organization. “Global Dementia Observatory (GDO)”

<sup>145</sup> Alzheimer Europe. “Dementia in Europe Yearbook 2019: Estimating the prevalence of dementia in Europe”

<sup>146</sup> Alzheimer Europe. “Dementia in Europe Yearbook 2022 Employment and related social protection for people with dementia and their carers”

<sup>147</sup> Ministère des Affaires sociales, de la Santé et des Droits des femmes. “Plan Maladies Neuro-Dégénératives 2014-2019”. Paris. 2014. Accessed on 10 May 2024, <https://www.alzheimer-europe.org/sites/default/files/2021-10/France%20Neurodegenerative%20plan%202014-2019.pdf>



was not directly addressed.<sup>148</sup> Then, another roadmap was adopted for 2021/2022 and the topic of dementia is considered.<sup>149</sup>

Secondly, in Austria, in 2015 the Government elaborated the “*Dementia strategy. Living well with dementia*”. It aimed at help people living with dementia, by elaborating a national plan with recommendations and policies, particularly for improve dementia education. The problem is that this strategy is influenced by the political inclination.<sup>150</sup>

In addition, in 2016 Spain published firstly the “*Estrategia en Enfermedades Neurodegenerativas del Sistema Nacional de Salud*” and then the “*Plan Integral de Alzheimer y otras Demencias (2019-2023)*”.

The first strategy had a broad approach to look problems linked to neurodegenerative diseases<sup>151</sup> while the second addressed to Alzheimer. It started by analysing the general situation in Spain and then the sphere of rights, values and principles.<sup>152</sup>

The Irish Government started to develop a dementia strategy in 2014. In 2018 a working group was appointed by the Alzheimer Society of Ireland to start research about the topic of dementia and loneliness. The publication of the document “*Dementia and Loneliness*” focused on the history of people with dementia and on recommendations, that are the result of research conducted by the working group.<sup>153</sup>

Moreover, Ireland started to give its contribution to digital technology investments. In 2024, the national minister Anne Rabbitte announced the Irish’s donation of € 12.5 million for “[...] *accelerating affordability and availability of assistive technology for*

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<sup>148</sup> Alzheimer Europe. “Dementia in Europe Yearbook 2022 Employment and related social protection for people with dementia and their carers”

<sup>149</sup> Ministère des Solidarités et de la Santé. “Feuille de route maladies neurodégénératives 2021-2022”. 2021. Accessed on 10 May 2024, [https://www.alzheimer-europe.org/policy/national-dementia-strategies/france?language\\_content\\_entity=en#:~:text=On%203%20June%2C%20the%20French,in%202001%2C%202004%20and%202008](https://www.alzheimer-europe.org/policy/national-dementia-strategies/france?language_content_entity=en#:~:text=On%203%20June%2C%20the%20French,in%202001%2C%202004%20and%202008)

<sup>150</sup> Federal Ministry of Labour, Social Affairs, Health and Consumer Protection. “Dementia strategy. Living well with dementia”. Vienna. November 2015. Accessed on 10 May 2024, [www.goeg.at](http://www.goeg.at)

<sup>151</sup> Ministerio de Sanidad, Servicios Sociales e Igualdad. “Estrategia en Enfermedades Neurodegenerativas del Sistema Nacional de Salud”. Sanidad. 2016. Accessed on 10 May 2024, <https://www.sanidad.gob.es/areas/calidadAsistencial/estrategias/enfermedadesNeurodegenerativas/home.htm>

<sup>152</sup> Ministerio de Sanidad, Consumo y Bienestar Social. “Plan Integral de Alzheimer y otras Demencias (2019-2023)”. Sanidad. 2019. Accessed on 10 May 2024, [https://www.alzheimer-europe.org/policy/national-dementia-strategies/spain?language\\_content\\_entity=en](https://www.alzheimer-europe.org/policy/national-dementia-strategies/spain?language_content_entity=en)

<sup>153</sup> The Alzheimer Society of Ireland. “Dementia and Loneliness”. 2019. Accessed on 10 May 2024, [https://alzheimer.ie/wp-content/uploads/2019/01/ASI\\_PP\\_DementiaLoneliness.pdf](https://alzheimer.ie/wp-content/uploads/2019/01/ASI_PP_DementiaLoneliness.pdf)

*those in need*". This decision represents an important step for dementia as a public priority, because through this action the government highlights its interest in social sector. According to different studies, using technologies could be an important instrument to help vulnerable people, especially persons affected by disabilities.

This is due by the capacities of digital technologies to go beyond barriers to access to services.

In addition, this investment is in line with the principle of 2030 Agenda: *no one is left behind*. Technologies could be the future way to remove social and economic barriers.<sup>154</sup>

In 2019, also the state of Belgium started its commitment on this topic by the elaboration of the dementia plan with the aim to create a dementia friendly society, improve care, social and health support.<sup>155</sup>

The last country is Germany, that from 2012 launched a strategy on dementia. This plan wanted to improve collaboration between different actors, data, research, and adopt a multidisciplinary approach by focusing also with linked topics such as technology. It is composed by actions and measures.<sup>156</sup>

In the region of the Americas, the countries of United States of America and Canada participated in the GDO.

The report "*How to Sustain Brain Healthy Behaviours: Applying Lessons of Public Health and Science to Drive Change*" was elaborated by the Global Council on Brain Health made by scholars from all over the world.

This research is based on the brain health and a series of recommendation linked to it. It is founded on three key audiences (individuals, communities, policymakers), on essential elements (knowledge, motivation, confidence) and finally on some pillars that are "be

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<sup>154</sup> World Health Organization. "Ireland and WHO work together to improve access to assistive technology globally". Published on 17 May 2024. Accessed on 6 June 2024, <https://www.who.int/news/item/17-05-2024-ireland-and-who-work-together-to-improve-access-to-assistive-technology-globally>

<sup>155</sup> Alzheimer Europe. "Belgium- Flanders". Accessed on 10 May 2024, <https://www.alzheimer-europe.org/policy/national-dementia-strategies/belgium-flanders>

<sup>156</sup> Bundesministerium für Familie, Senioren, Frauen und Jugend Referat Öffentlichkeitsarbeit. "National Dementia Plan". Berlin. 2020. Accessed on 10 May 2024, <https://www.bmfsfj.de/>

social”, “engage your brain”, “manage stress”, “ongoing exercise”, “restorative sleep”, “eat right”. These factors are important to elaborate a satisfying policy.<sup>157</sup>

Canada presents a grounded program and a relevant social structure about Alzheimer. Especially, the Public Health Agency of Canada published “*A Dementia strategy for Canada: Together We Aspire*”. This document addressed all level of governance, giving specific information for the policymaker process. It is founded on five pillars: “*collaboration, research and innovation, surveillance and data, information resources, skilled workforce*”.<sup>158</sup>

It took into consideration vulnerable groups of people such as person belonging to LGBTQ2+, indigenous, ethnic groups. According to scholars these groups could be at “*higher risk*” if they are affected by dementia.

Basing on the principles affirmed by the World Health Organization, in the national strategy Canada affirms these objectives: “*prevent dementia, advance therapies and find a cure, improve the quality of life of people living with dementia and caregivers*”.<sup>159</sup>

In addition, to highlight the commitment of the government, it has been allocated to the financial statements a budget for dementia research and projects.

It is also important to consider another report, written by the no-for-profit association CanAge, that is called “*Dementia in Canada: Cross-Country Report 2022*”. Through the analysis of all provincial and territorial assessments and by using the metric for dementia defined by the World Health Organization, this document reveals issues connected to the strategy above-mentioned.<sup>160</sup>

These reports are elaborated on the basis of the National Dementia Conference’s guidelines. This conference was organised by the government in Ottawa, between 14 and

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<sup>157</sup> Global Council on Brain Health. “How to Sustain Brain Healthy Behaviours: Applying Lessons of Public Health and Science to Drive Change”. 2022. Accessed on 15 May 2024, [https://www.aarp.org/health/brain-health/global-council-on-brain-health/?cmp=RDRCT-GCBH\\_Main\\_10\\_26\\_015](https://www.aarp.org/health/brain-health/global-council-on-brain-health/?cmp=RDRCT-GCBH_Main_10_26_015)

<sup>158</sup> Public Health Agency of Canada. “A Dementia Strategy for Canada: Together We Aspire”. June 2019. Accessed on 15 May 2024, <https://www.canada.ca/en/public-health/services/publications/diseases-conditions/dementia-strategy.html>, p. 2

<sup>159</sup> Ibid., p. 5

<sup>160</sup> CanAge. “Dementia in Canada - Cross-Country Report 2022”. October 2022. Accessed on 15 May 2024, <https://www.canage.ca/wp-content/uploads/2022/10/CanAge-Dementia-Report-2022-EN-OCT-18-2022-compressed.pdf>

15 May 2018 with the aim to discuss about the topic of dementia and necessities related to it.<sup>161</sup>

This Conference has been the consequence of the “*National Strategy for Alzheimer's Disease and Other Dementias Act*”. The act was approved on 22<sup>nd</sup> June 2017.<sup>162</sup>

The Canadian state demonstrates high interest in respecting World Health Organization recommendations about dementia. The CanAge's report demonstrates that from 2017 started a strong policy-making and coordination focused on Alzheimer's Disease and dementia.

At the same time, from 2018, the Federal Government began to allocate resources in the national Budget for the above-mentioned objectives.<sup>163</sup>

This financial decision highlights a real commitment of the government to face dementia problem. As demonstrated by the data of GDO, there are few states that allocated financial resources after the approval of national dementia plan.<sup>164</sup>

In conclusion, about America Region, it is possible to highlight a general commitment about dementia, also given the high number of people affected by it. Nevertheless, only few countries demonstrate a real action to face this disability.<sup>165</sup>

The regional systems of Africa, South-Est Asia and the Western Pacific Region did not submit reports in the Global Dementia Observatory. Nonetheless, there were some states that participated in the GDO.

For Africa there were Eswatini, Mauritius, South-Africa, Togo.

In South-East Asia there were Bangladesh, India, Maldives, Myanmar, Thailand.

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<sup>161</sup> Government of Canada. “Conference report: National dementia conference”. 2018, Accessed on 15 May 2024, <https://www.canada.ca/en/services/health/publications/diseases-conditions/national-dementia-conference-report.html>

<sup>162</sup> Government of Canada. “National Strategy for Alzheimer's Disease and Other Dementias Act (S.C. 2017, c. 19)”, Accessed on 15 May 2024, [https://laws-lois.justice.gc.ca/eng/annualstatutes/2017\\_19/page-1.html](https://laws-lois.justice.gc.ca/eng/annualstatutes/2017_19/page-1.html)

<sup>163</sup> CanAge. “Dementia in Canada - Cross-Country Report 2022”

<sup>164</sup> World Health Organization. “Global Dementia Observatory (GDO)”

<sup>165</sup> Regional Office for the Americas of the World Health Organization. “Dementia”. Accessed on 17 May 2024, <https://www.paho.org/en/topics/dementia>

In the Western Pacific Region states that participated in the Global Dementia Observatory were Australia, Brunei Darussalam, China, Cook Islands, Fiji, Japan, Malaysia, Republic of Korea, Singapore, Viet Nam.

In the African Region the core issue is represented by the fact that if “[...] *in other regions we need more awareness of dementia as disease, not a normal part of ageing, in sub-Saharan Africa we need to go deeper and challenge the prejudices faced by those who have the disease.*”<sup>166</sup>

In general, African states do not submit dementia plan, but only strategies about older people. In the same way South-Est Asia Region does not present dementia plan but only initiative for dementia.

From the website of each Regional Office, it is possible to highlight that dementia is a health topic of few regional systems: America, Western Pacific and America.

The regional systems of Africa, Europe, Eastern Mediterranean and South-East Asia do not present this topic between the core health topics on their websites.

Summarizing the Global Dementia Observatory it is possible to affirm that it is a good instrument if all Member States participate in it.

The core issue is not only a lack in the involvement of poor countries but there are other factors connected to the weakness of this platform.

First of all, there is too long time between the collection of different data.

Then, not all countries are able to reply to all GDO indicators.

Thirdly, data submission is made by the same Member States’ representatives of WHO. In addition, there are not many indicators for assistance.<sup>167</sup>

Finally, there are problems linked to the research because it comes from rich countries.

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<sup>166</sup> Wimo A. et al. “Dementia in sub-Saharan Africa”. Alzheimer’s Disease International (ADI). London. September 2017. Accessed on 15 May 2024, <https://www.alzint.org/resource/dementia-in-sub-saharan-africa/>, p.3

<sup>167</sup> World Health Organization. “Global status report on the public health response to dementia”.

This last consideration represents a big weak point for all reports of World Health Organization because a wide number of people affected by dementia live in low- and middle-income countries.

The incompleteness of data collection not only have this gap, but also it is possible to reveal other problems about the same available information. Specifically, the essay “*A blueprint for dementia research*” affirms that these data cannot be considered “good” because they are not updated. Moreover, there is not reliable research about dementia in vulnerable groups and death due to dementia.<sup>168</sup>

It becomes necessary to adopt a different approach to data collection in order to reveal weakness of every country and in order to monitor that Member States assure “[...] *legal capacity, self-determination, supported decision-making, power of attorney and protection against exploitation and abuse of people with dementia in institutions and the community*”.<sup>169</sup>

### 2.3 FUTURE PROGRAMS AND PROJECTS.

In this part of the elaboration, it will be analysed another important initiative that has been approved in the context of United Nations: the 2030 Agenda for Sustainable Development.

This document represents an important plan for different human dimensions, from people to environment protection.

Differently from the previous document, the “*Millennium Development Goals (MDGs)*”, also considers the sphere of people with disabilities.

The agenda outlines the goals and between them there are some about disability.

Firstly, at the point twenty-three we find that “*people who are vulnerable must be empowered. Those whose needs are reflected in the Agenda include all children, youth, persons with disabilities (of whom more than 80% live in poverty), people living with*

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<sup>168</sup> World Health Organization. “A blueprint for dementia research”

<sup>169</sup> World Health Organization. “Global status report on the public health response to dementia”, p. 82

*HIV/AIDS, older persons, indigenous peoples, refugees and internally displaced persons and migrants. We resolve to take further effective measures and actions [...] to remove obstacles and constraints [...]*.<sup>170</sup>

Secondly, protection of people with disabilities emerges in the Goal 4 where inclusion is necessary also in the context of education; while in the Goal 8 it is highlighted that the aim to have an appropriate job could be guaranteed also to persons with impairments.

Then, the Goal 10 of the agenda affirms that the objective for the end period is to “*empower and to promote the social, economic and political inclusion of all*” by the elimination of all barriers involved in existing laws, policies and opportunities.<sup>171</sup>

Other goals contained the reference to disable people such as Goal 1 (Eradicating Poverty), 2 (Zero Hunger), 3 (Health), 5 (Gender Equality), 6 (Water and Sanitation), 7 (Energy), 9 (Industry, Innovation and Infrastructure), 11 (Sustainable Cities), 13 (Climate Change), 16 (Peace, Justice and Strong Institutions).<sup>172</sup>

The result of different references to disabilities is originated by the hard work of disabilities associations and movements, such as the International Disability Alliance.

There was the necessity to create a global agenda that include persons with disabilities, because of their exclusion in the previous global programme.<sup>173</sup>

It is important because we can't talk about human rights if we don't consider in global policies an important part of population, that not only front with disabilities, but also with poverties and other social barriers.

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<sup>170</sup> United Nations. “Transforming our world: the 2030 Agenda for Sustainable Development”. Accessed on 15 May 2024, <https://sdgs.un.org/2030agenda>, point 23

<sup>171</sup> Ibid.

<sup>172</sup> International Disability Alliance. “The 2030 Agenda – Comprehensive Guide for Persons with Disabilities”. 2016. Accessed on 15 May 2024, <https://www.internationaldisabilityalliance.org/resources/2030-agenda-comprehensive-guide-persons-disabilities>

<sup>173</sup> International Disability Alliance. “The 2030 Agenda & the CRPD”. Accessed on 16 May 2024. <https://www.internationaldisabilityalliance.org/content/2030-agenda-crpd>

Belonging to the group of “vulnerable people” they continue to have a lack in representation. For this reason, sometimes they are not involved in international agenda.<sup>174</sup>

During the workshop on 2030 Agenda, it emerged a discussion about the necessity to link the Convention on the Rights of People with Disabilities and the SDGs.<sup>175</sup> The result was the reference of disabilities in the goals above-mentioned. Then, it is also important the way of application of the 2030 Agenda.

At Global Level it has been created the High-Level Political Forum.

It is defined as “[...] *the central United Nations platform for the follow-up and review of the 2030 Agenda for Sustainable Development and the Sustainable Development Goals (SDGs) at the global level. [...] The Forum adopts intergovernmentally negotiated political declarations. [...] The HLPF also conducts regular reviews of the Sustainable Development Goals [...]*”.<sup>176</sup>

Regional systems prepared for peer reviews and creation of a specific body.

At national level there are continue reviews about monitoring the implementation of the goals.<sup>177</sup>

Continuing to analyse the Agenda it is possible to highlight the concept “*no one is left behind*”. It comes from the contributions of the CRPD, that it is emphasised from the influence of disability movement in the elaboration. This concept wants to affirm the need to involve people belonging to “*vulnerable groups*”.

About future perspective it is important to consider also the Decade of Healthy Ageing that wants to improve life of ageing people by 2030. The achievement of the decade’s

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<sup>174</sup> International Disability Alliance. “The 2030 Agenda for Sustainable Development”. Accessed on 16 May 2024, <https://www.internationaldisabilityalliance.org/content/2030-agenda-sustainable-development-0>

<sup>175</sup> International Disability Alliance. “Workshop on SDG report writing in line with the CRPD”. Accessed on 16 May 2024, <https://www.internationaldisabilityalliance.org/content/workshop-sdg-report-writing-line-crpd>

<sup>176</sup> United Nations. “High-Level Political Forum on Sustainable Development”. Accessed on 16 May 2024, <https://hlpf.un.org/>

<sup>177</sup> International Disability Alliance. “The 2030 Agenda – Comprehensive Guide for Persons with Disabilities”



goal involves different stakeholders, from government to people. The object of this report is to satisfy the basic needs of elderly.

The term “*healthy ageing*” means “*the process of developing and maintaining the functional ability that enables well-being in older age*”.<sup>178</sup>

The strategy proposed, first of all the analysis of national plans in different states; then, it assess the possibility to allocate resources.

Considering different possibilities to take care of old people, we find in national policies the option to go for nursing home. Especially in rich countries lots of families insert elderly person in old age home.

In general, the possibility to improve their life is influenced by the 2030 Agenda because it aims to reduce economic and social barriers.

It represents one of the three possible scenarios. The others are deterioration or stagnation of people life.

It depends in particular from government and the decision to allocate resources and elaborated policies that aspired to create opportunities and eliminate barriers for people.

According to the document “*The inability of older people to meet their basic needs can be both a cause and an effect of reduced capacity. But their environments, too, play a crucial part.*”<sup>179</sup>

In order to achieve this purpose, it is necessary that countries work on reduce barriers to accede to health services, to prevent people from non-communicable diseases and to improve functional abilities.

The approach of all international policies is person-centred. In fact, the “*Decade of healthy ageing*” highlights that “*Older people are not the subject of the films, but the film-makers, fiving them the opportunity to present their points of view.*”<sup>180</sup>

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<sup>178</sup> World Health Organization. “Decade of healthy ageing: baseline report”, p. 9

<sup>179</sup> World Health Organization. “Decade of Healthy Ageing 2020-2030”, p. 116

<sup>180</sup> Ibid., p. 124

In conclusion, the two documents above-mentioned, the Sustainable Development Goals and the Decade of Healthy Ageing 2020-2030 are directly connected.

They shared the 5P values affirmed in the Agenda 2030, that are people, prosperity, planet, partnerships, peaceful.

They have the same objectives and the same intention to promote Member States to develop policies for ageing people, especially for those who have vulnerable situations.

## CHAPTER III. THE ROLE OF CIVIL SOCIETY

### 3.1 THE ACTIVISM OF NGOs AND CIVIL SOCIETY.

In the context of human rights, non-governmental organizations and civil society play an important role for the protection and implementation of these rights.<sup>181</sup>

Thanks to strong pressures towards United Nation, the problem about dementia is become a central topic of the international agenda.

In fact, as highlighted in previous chapters, dementia was not considered before 2012.

Only the meeting between caregivers starts to evidence issue linked to a specific ill that it is different from ageing.

The action of NGO differs between countries. Data collected by the Global Dementia Observatory observes three central topics in not-for-profits organisations' agendas: awareness-raising, home health and social care services, care training. In general, the first area of action is central in every regional system.

Looking at different realities, NGOs could develop services when the state doesn't guarantee them.

In general, third sector associations are created by caregivers in order to give help to other persons in their situation.

For this reason, they know what are the services not guaranteed in their countries. Specifically, as affirmed in the "*Global status report on the public health response to dementia*"

*"Alzheimer and dementia associations [...] take part in the campaign that enables collaborative engagement with governments and people living with dementia and their families, directly contributing to the global target outlined in the Global dementia action plan"*.<sup>182</sup>

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<sup>181</sup> Rhona K. M. Smith. "International Human Rights Law"

<sup>182</sup> World Health Organization. "Global status report on the public health response to dementia"

The “engagement” of NGOs is not only social, but also economic. Through the available resources collected by associations, lots of initiatives for people with dementia are created by them and not by governments.

In this way, the not-for-profit sector manages to provide for not guaranteed services by the state. Associations create care models to face with dementia, a set of actions directed to help the patient and his/her family.

In this thesis, in considering the problem of dementia, lots of documents come from an important international association: Alzheimer's Disease International.

It collaborates with the World Health Organization for developing and monitoring the effectiveness of dementia policies. Every year the association elaborates a report focused on different topics such as healthcare, life after diagnosis and, more broadly, human rights concepts.

It is composed by different Alzheimer's and Dementia's associations around the world.

In addition, another core concept of NGOs is based on education programmes. According to these stakeholders, a sensibilisation policy in which empathy is at the heart of disability, could help to develop the person-care centred approach.<sup>183</sup>

They aim at an efficient system of training, diagnosis, care, prevention.

Associations have an acting part in the monitoring process of human rights application and in supporting people with dementia. In fact, they are very important for the application of the CRPD.<sup>184</sup>

As mentioned in the expert report of Michael Splain “*The Alzheimer movement was started by family carers of people deeply advanced in the dementia process seeking*

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<sup>183</sup> Gauthier S. et al. “World Alzheimer Report 2022: Life after diagnosis: Navigating treatment, care and support”

<sup>184</sup> Batsch N. et al. “Access to the United Nations Convention on the Rights of Persons with Disabilities by people living with dementia”. Alzheimer's Disease International and Dementia Alliance International. 31st August 2017. Accessed on 16 May 2024, <https://www.alzint.org/resource/access-to-united-nations-convention-on-the-rights-of-persons-with-disabilities-by-people-living-with-dementia-crpd/>

*mutual support. [...] As a global movement, more diverse voices and experiences of persons living with dementia are beginning to influence programs and services.”*<sup>185</sup>

In lot of countries that are examples of the NGOs’ actions through the elaboration of plans, initiatives and so on. This necessity has been highlighted by the inefficiency of states to apply at it, as it has been affirmed by the *Global Status Report*. For this reason, sometimes association become the first actor in this sector, capable of developing important initiatives.<sup>186</sup>

An important topic debates by associations is prevention.

As affirmed above, lots of associations for dementia have developed initiatives and projects directed to support people with dementia and their families.

In fact, according to different studies, taking care of people could generate negative health consequences for the person that have this task.

In the case of Canada, it is possible to analyse the commitment for dementia in a high-income country. Firstly, some Canadian provinces developed dementia policies. Nevertheless, the Canadian association for Alzheimer highlighted the necessity to have a coordination and to give space to research.

In 2009, after a story started in 1977, the Alzheimer Society of Canada and other associations initiated a collaboration with the central government, but it is not sufficient for developing a national strategy. It will be elaborated only in 2019.<sup>187</sup>

Another important step is represented by the formulation of Alzheimer Society of the “*Canadian Charter of Rights for people with Dementia*”. In this charter people affected by dementia declare their rights, that have to be the same of other people. It affirms the necessity to be supported and empowered.<sup>188</sup>

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<sup>185</sup> Gauthier S. et al. “World Alzheimer Report 2022: Life after diagnosis: Navigating treatment, care and support”, p. 206

<sup>186</sup> CanAge. “Dementia in Canada - Cross-Country Report 2022”

<sup>187</sup> Alzheimer Society of Canada. “The history of the Alzheimer Society”. Accessed on 17 May 2024, <https://alzheimer.ca/en/about-us/history-alzheimer-society>

<sup>188</sup> Alzheimer Society. “Canadian Charter of Rights for people with Dementia”. Accessed on 17 May 2024, <https://alzheimer.ca/en/take-action/change-minds/canadian-charter-rights-people-dementia>

In addition, Canadian associations include in their research the focus on indigenous people. The problem related to this minority group is the difficult to accede to health services and for this reason they have higher risk to be affected by this type of disability. According to the Government, they “[...] *have distinct dementia experiences and distinct needs*”.<sup>189</sup> Trying to elaborated policies direct to help them is difficult also because of there are not lot of data available.

According to different studies this particular exposure is also due to colonialization. The latter is just one of several risk factors that increase vulnerability of indigenous people.

According to the research “*The many faces of dementia in Canada*” developed by the Alzheimer Society of Canada, it is important to realize policies for indigenous people based on the “*Calls to Action*” published by the Truth and Reconciliation Commission of Canada.

This body “[...] *was created through a legal settlement between Residential Schools Survivors, the Assembly of First Nations, Inuit representatives and [...] the federal government and the church bodies.*”<sup>190</sup>

The “*Calls to Action*” pushed federal government to consider issue linked with this vulnerable group such as rights, objects, lack of economic resources, health workers, the absence of studies about indigenous health issues and indigenous reality.<sup>191</sup>

Recommendations affirmed in “*The many faces of dementia in Canada*” looked at commitments for the Alzheimer Societies, health-care systems, federal government, provincial and territorial governments and researchers<sup>192</sup>.

The government of Canada has established some initiatives to run into the diffused problem of dementia. They offer the possibility to approach to dementia with a

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<sup>189</sup> Public Health Agency of Canada. “A Dementia Strategy for Canada: Together We Aspire”, p. 4

<sup>190</sup> National Centre for Truth and Reconciliation. “Truth and Reconciliation Commission of Canada”. Accessed on 17 May 2024, <https://nctr.ca/>

<sup>191</sup> Truth and Reconciliation Commission of Canada. “Truth and Reconciliation Commission of Canada: Calls to Action”. 2012. Accessed on 17 May 2024, [https://ehprnh2mwo3.exactdn.com/wp-content/uploads/2021/01/Calls\\_to\\_Action\\_English2.pdf](https://ehprnh2mwo3.exactdn.com/wp-content/uploads/2021/01/Calls_to_Action_English2.pdf)

<sup>192</sup> Alzheimer Society of Canada. “The Many Faces of Dementia in Canada”. 2024. Accessed on 17 May 2024, [https://alzheimer.ca/sites/default/files/documents/ASC\\_The%20Many%20Faces%20of%20Dementia%20In%20Canada\\_Landmark%20Study\\_Vol2.pdf](https://alzheimer.ca/sites/default/files/documents/ASC_The%20Many%20Faces%20of%20Dementia%20In%20Canada_Landmark%20Study_Vol2.pdf)

multidisciplinary vision, considering all problems that a person affected by this ill could face.

Some initiatives are the Canadian Institutes of Health Research, the Correctional Service Canada, Department for Women and Gender Equality, Employment and Social Development Canada, Indigenous Service Canada, Public Health Agency, Veterans Affairs.<sup>193</sup>

Another case of study is represented by Indonesia.

It is one of the most populated states in the world, for this reason every policy could have a significant impact.

Nevertheless, dementia is not the core of political agenda in this country. The “*Indonesia Dementia National Plan*” has been developed thanks to Alzheimer’s Disease International.

It was the first state that adopted a plan in the regional system of ASEAN. In spite of this, the structure of Indonesia meets different barriers in order to follow *Global dementia action plan* objectives.

The cultural obstacle is represented by considering dementia as a consequence of ageing. From the economic perspective, the distinction between rural and urban area has a strong impact. Especially because it differs also in the health system. The general problem linked with dementia is the absence of the long term care, that is a weight loaded to families.

In the context of legislation, the government adopts different guidelines for vulnerable people, but in them dementia is not included.

Indonesia is one of the countries participating in the “*Strengthening response to dementia in developing countries*” project.<sup>194</sup> It was led in

“[...] seven low and middle-income countries- India, Indonesia, Mexico, Jamaica, Brazil, Kenya, and South Africa [...] by the London School of Economics and Political

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<sup>193</sup> Public Health Agency of Canada. “A Dementia Strategy for Canada: Together We Aspire”

<sup>194</sup> STRiDE. “Executive Summary: The Dementia Care Landscape in India”. Accessed on 17 May 2024, <https://stride-dementia.org/india-situation-report/>

*Science (LSE) with funding from the UK Research and Innovation's Global Challenge Research Fund (GCRF)*".<sup>195</sup>

Through this project, there were different reports elaborated such as "*Don't forget I'm human – reducing dementia stigma. The STRiDE Anti-Stigma Toolkit*" about stigma perception<sup>196</sup>, "*Active inclusion of people living with dementia in planning for dementia care and services in low- and middle-income countries*", "*COVID-19 and long-term care in Indonesia*".

From the last cited research emerges that Indonesia population prefers to take care old people in home rather than consider care homes. As highlighted before it is due to a cultural conception of care.

Then, during the pandemic situation, the government attention focused on older people, especially who lives with dementia.<sup>197</sup>

In general, it becomes necessary to incite countries to create dementia friendly communities. This concept wants to claim

*"[...] the rights of people with dementia by giving effect to those rights in the everyday lives of our communities.[...] The need is to give practical expression to the rights of people with dementia including through access to timely diagnosis, opportunities for post diagnostic support and care, participating in the community through social engagement and voluntary and paid work opportunities, and freedom from medical and physical abuse."*<sup>198</sup>

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<sup>195</sup>Alladi S. et al. "Strengthening responses to dementia in developing countries (STRiDE) project". 2022. Accessed on 25 May 2024, [https://www.researchgate.net/publication/371991172\\_STRENGTHENING\\_RESPONSES\\_TO\\_DEMENTIA\\_IN\\_DEVELOPING\\_COUNTRIES\\_STRiDE\\_PROJECT](https://www.researchgate.net/publication/371991172_STRENGTHENING_RESPONSES_TO_DEMENTIA_IN_DEVELOPING_COUNTRIES_STRiDE_PROJECT)

<sup>196</sup> Evans-Lacko S. et al. "Don't forget I'm human – reducing dementia stigma. The STRiDE Anti-Stigma Toolkit. London School of Economics and Political Science". 2022. Accessed on 17 May 2024, <https://stridedementia.turtl.co/story/anti-stigma-toolkit/>

<sup>197</sup> Tara P. et al. "The COVID-19 Long-Term Care Situation in Indonesia". LTCcovid, International Long-Term Care Policy Network. CPEC-LSE. 30 May 2020. Accessed on 17 May 2024, <https://ltccovid.org/wp-content/uploads/2020/06/The-COVID-19-Long-Term-Care-situation-in-Indonesia-30-May.pdf>

<sup>198</sup> Alzheimer's Disease International (ADI). "Dementia Friendly Communities". London. September 2017. Accessed on 17 May 2024, <https://www.alzint.org/what-we-do/policy/dementia-friendly-communities/> p.



In some regional system, like Africa, it is more difficult to develop health initiatives about prevention and support. It is due to the religion believe according to which illness could be cure by spiritual rites.

For this reason, all international recommendations have limited effects.

In the context of Asia Pacific regional system, Austria has adopted lots of initiatives.

In the page of Federal Ministry Republic of Austria, the government dedicated a space for dementia. In general the Austria Government provides some benefits for carers and people living with dementia: “*Long-term care benefit*”, “*Care leave/part-time work for caregiving relatives/ care leave benefit*”, “*allowance towards the cost of a replacement carer*”, “*Quality assurance in care at home: home visits and counselling for caregiving relatives upon request*”.<sup>199</sup>

Another important initiative is represented by the economic relief for public transport for people affected by dementia. The purpose of this incentive was to promote social participation of patients.

From 2014 Austria started to propose a dementia national strategy based on a national plan in which funds were given to local authorities to elaborate initiatives.<sup>200</sup>

The government looks at long-term assistance for people living with dementia as a core objective for the country.

In fact, it creates the “*Competence in Dementia in Care Home*” in order to improve capacities of social operators.

In addition, it aims at strengthening cooperation between different actors by creating a web page for dementia and organising annual meetings.<sup>201</sup>

### 3.2 THE IMPORTANT ROLE OF CAREGIVERS.

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<sup>199</sup> Federal Ministry Republic of Austria. “Dementia”. Accessed on 17 May 2024, <https://www.sozialministerium.at/en/Topics/Care/Dementia.html>

<sup>200</sup> Bundesministerium. “Demenzstrategie – Gut leben mit Demenz”. Accessed on 17 May 2024, <https://www.demenzstrategie.at>

<sup>201</sup> Federal Ministry Republic of Austria. “Dementia”

As we have mentioned above, associations for dementia were created by caregivers, with the aim to create self-help groups. This necessity was the consequence of a lack in the health and social system, capable to help people affected by dementia and their families.

The figure of caregiver was essential in the life of every person with disabilities and for this reason it continues to be object of different studies. It could be defined as “*informal caregivers*”.

“[...] *informal caregivers of people with dementia experience high levels of burden, distress, social isolation, physical ill health, and financial hardship. Depression in the informal caregiver is associated with a reduction in the involvement of the person with dementia in decision.*”<sup>202</sup>

Researches demonstrate that government continues to be uninteresting to carers' requests. This situation reinforces a general dissatisfaction because diagnosis of dementia increases just like the number of relatives with caring responsibilities.

Carers could be members of the patient's family or friends or other people that want to help the person with disability. The World Health Organization highlights that they should be support at the same level of people affected by dementia.

According to the essay of Zelda Freitas in the World Alzheimer's Report 2022, “*Carers are the keepers of dignity and personhood for people living with dementia*”.

Nevertheless, this situation exposes them to several risks, like mental and physical stress, because of the impact of taking care of a person that continues to change (for dementia).<sup>203</sup>

About the concept of dignity, the professor Marco Trabucchi affirms in his book that a person continues to have his dignity even if the disability compromises his being.

According to the scholar, the person affected by dementia doesn't forget the love for the relative, even if during the middle and the last stage of dementia the patient doesn't remember the identity of the carer.

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<sup>202</sup> Poirier, A., Voyer, P., Légaré, F., Morin, M., Witteman, H. O., Kröger, E., Martineau, B., Rodríguez, C., & Giguere, A. M. “Caring for seniors living with dementia means caring for their caregivers too”, p. 639

<sup>203</sup> Gauthier S. et al. “World Alzheimer Report 2022: Life after diagnosis: Navigating treatment, care and support”, p. 266

The big difficult for the family is the change of the person with dementia that appears as another person, different from what is known.

There are some symptoms that are considered particularly stressed for informal carers.

First of all, when they aren't recognised. Then, episode of incontinence that creates wide stress for relatives. For people, incontinence could be viewed as an element of vulnerability, capable to change the person itself.

Generally, the caregiver starts to change his reaction toward the person affected by dementia. It is caused by different behaviours such as getting lost, stealing, becoming aggressive.<sup>204</sup>

Different stages of dementia bring informal carers to be anger, until they decide to include the patient in a rest home.

Linked with the lack of awareness, the situation of caregivers makes worse.<sup>205</sup>

Another confusing aspect is the orientation given by the health system towards services.

During the advancement of ill, the person affected by dementia started to do not taking care of itself.

Every daily activity becomes difficult, creating a dependency to caregiver.

The caregiver has not only the task to take care of the person with dementia, but also he/she becomes a guard because of escapes, rage's acts of the person in question.

For this reason, when different tools recall to "support" they refer to all situation in which the family is stressed because of they don't recognise the dear person.

If the system could guarantee a real support, the caregiver should not be weight down by making decisions.

In addition, studies demonstrate that until the person affected by dementia is assisted by the carer, his/her conditions do not aggravate as in the case of rest homes.

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<sup>204</sup> Trabucchi Marco. "Aiutami a ricordare"

<sup>205</sup> Gauthier S. et al. "World Alzheimer Report 2022: Life after diagnosis: Navigating treatment, care and support"

There are different types of caregivers. According to their characteristics also the scenario changes.

First of all, the single caregiver. During the history, individuals without family have been responsible for taking care of the elderly and relatives with disabilities. With the change of society and the increase of people without a partner, singles are not the only responsible for the infirm in the house.

Today unmarried people choose their condition in order to realize their goals.

This situation has highlighted a wide lack in the welfare state that is not capable to cover care tasks.

Then, the married carer finds it difficult in the management of domestic care and dementia necessities. Often the caregiver dedicates all its time to the person with disability, overlooking the task with its family.

In lots of cases the caregiver neglects itself, with the consequence of worsening his/her physical and mental situation.

Another type of carer is the aged person. In the last decade, due also to longer lives, lots of old people take care of their relatives. What is highlighted in different studies is the vulnerable condition of these persons.<sup>206</sup>

In conclusion, “*the right to health*” is compromised not only for the person affected by dementia but also for the caregiver. This is the consequence of a system that continues to leave behind the topic of dementia.

In the health condition of older people, it is important to consider the principle of healthy ageing. According to “*Decade of healthy ageing: baseline report*” healthy ageing is a “*rights-based response to population ageing*”<sup>207</sup>, for that purpose when we consider the old caregiver’s life it is important to highlight that its adequate standard of living could be damaged.

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<sup>206</sup> Trabucchi Marco. “Aiutami a ricordare”

<sup>207</sup> World Health Organization. “Decade of healthy ageing: baseline report”, p.8

One important instrument adopted by the World Health Organization is about long-term care.<sup>208</sup> This term means “[...] *the range of services which help meet both medical and nonmedical need of people with a chronic illness or disability who cannot care for themselves. Long-term care includes: post-diagnostic services [...]; community services [...]; continuing care [...]*”.<sup>209</sup>

This topic creates debates about what are the possible instruments to help ageing people with disabilities. What is sure it is represented by changing in population, that in the next years become more ageing and vulnerable to develop dementia.

For this reason, the wide part of families hires in-home nurse. Also this type of choice creates problems.

In the case of Italy, irregular assistants are employed without a contract because of the costs. In fact, it is difficult for families to sign a contract when there are not sufficient incomes to support it.

Through Covid pandemic, family's income is decreased and lots of them have changed their decisions because of poverty's situation.

The big problem represented by irregular assistant is that often they are vulnerable subjects, with problem linked to alcoholism, theft and so on. The consequence is that they do not take care of person with disabilities and sometimes they become aggressive toward the infirm.

With the beginning of pandemic situation, lots of this irregular carers return in their countries and the majority of them rest in their original state.<sup>210</sup>

For all this factors, family's balance is destroyed since it is yet weakened by economic, social and health factors.

Other risk factors are presented in the LGBTQ+ communities.

The expert essay elaborated in the World Alzheimer Report 2022 by Julien Rougerie, refers to this particular topic. According to the scholar, people affected by dementia and

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<sup>208</sup> Gauthier S. et al. “World Alzheimer Report 2022: Life after diagnosis: Navigating treatment, care and support”

<sup>209</sup> World Health Organization. “Dementia: a public health priority”, p. 53

<sup>210</sup> Trabucchi Marco, “Una lunga vita buona. Il futuro delle RSA in una società che invecchia”

their carers, belonging to LGBTQ+ communities, are subjected to different discriminations.

This is caused by a series of factors.

First of all, very often there is a deny of these people by their families, so a LGBTQ+ couple is obliged to rest alone also in the case of ill.

Then, if they are in a discriminatory community, they continue to hide their situation. For example, this context could be also verified in rest homes in which a person has to conceal yourself in order to be not discriminated by the other older.

In addition, in the context of assistance the carer and the person with dementia have to isolate and for this reason he/she is the only that could be the caregiver of the person with disability.

This is emphasised also by the difficulty to have a family.

In general, people belonging to LGBTQ+ communities tend to do not benefit from external services because of the scare of discrimination.

Today Canada is one of few states that has developed a strategy to also protect this type of caregiver and people affected by dementia that are submitted by intersectional discrimination.<sup>211</sup>

In the research elaborated by the Alzheimer's association and Sage it is affirmed that

*“With the growing prevalence of Alzheimer’s disease and the swelling population of LGBT older adults, we place a high priority on examining the intersections of Alzheimer’s disease, sexual orientation, and gender identity and expression.”*<sup>212</sup>

What it continues to be highlighted are social and economic barriers that limited human rights for every individual, especially those who are affected by different types of disabilities linked with the belonging to minorities groups.

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<sup>211</sup> Gauthier S. et al. “World Alzheimer Report 2022: Life after diagnosis: Navigating treatment, care and support”

<sup>212</sup> Alzheimer’s associations and SAGE. “Issues brief: LGBT and dementia”. August 2018. Accessed on 17 May 2024, <https://www.sageusa.org/resource-posts/issues-brief-lgbt-and-dementia/>

According to the above-mentioned report, people belonging to LGBT communities face also with other health problems such as HIV, that could be considered a risk factor for dementia.

Then, it is important to consider issue linked to legal protection. In this context a debated topic is about advanced directives.

The problem underlines the lack of married status for which it becomes impossible for the partner to exercise the power of attorney for the person affected by dementia.

The consequence is that the family of person with dementia has to take decision about patient's health. As we have above highlighted, families not always accept the relationship, and for this reason they could take tragic decisions, avoiding the involvement of the partner.<sup>213</sup>

All these problems considered in different researches continue to realize the importance of considering caregiver's reality. For this reason, reflecting on this topic at international level has become necessary.

The “*Global action plan on the public health response to dementia*” affirms at the action area 5 as a global target that “*75% of countries provide support and training programmes for carers and families of people with dementia by 2025*”.<sup>214</sup>

This object is the consequence of the significant impact of these actors, that know all of the patient in order to outline the health plans. In order to realize the cross-cutting principles of the Global Action Plan the involvement of caregivers is necessary.

Member States, the Secretariats and the international, regional, national partners must apply actions to support, assist, provide services and training programmes for them.<sup>215</sup>

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<sup>213</sup> Alzheimer's association. “LGBT Caregiver Concerns”. Accessed on 17 May 2024, [https://www.alz.org/media/Documents/brochure\\_lgbt\\_caregiver.pdf](https://www.alz.org/media/Documents/brochure_lgbt_caregiver.pdf)

<sup>214</sup> World Health Organization. “The global action plan on the public health response to dementia 2017-2025”. Geneva. 2017. Accessed on 30 April 2024, <https://www.who.int/publications/i/item/global-action-plan-on-the-public-health-response-to-dementia-2017---2025>, p. 26

<sup>215</sup> Ibid.

The caregiving system has at the first level the primary family; then, family members and friends; thirdly, the community; in addition, governments and NGOs; finally, the international organization.<sup>216</sup>

Caregiving could be considered an unpaid full-time job. As affirmed in the essay of Matt Del Vecchio, looking at the dilemma about the passage into an old age home, affirms that carer at a certain point during the assistance “[...] *ask the question: ‘Is proper care being provided? Are the support systems in place? Or my loved one at risk despite my good intention?’*” even if “[...] *many carers will manage it the best they can by using their intrinsic with very little formal training [...]*”.<sup>217</sup>

For realizing the goals of global action politic it is necessary to consider some steps. They are for example awareness about dementia, information, possibility to access to a diagnosis, abatement of costs.

In addition, more adequate workforce are required because of the increase of people with healthcare needs.<sup>218</sup>

Some important activities are represented by the creation of “*Dementia-inclusive society*” in which it is guaranteed the full participation of people affected by dementia and their carers.

In the planning of these initiatives, it is important to consider the person-centred approach, in which family and patient are the principal actors.

These initiatives have to be related to community-based services. In fact, if health and social system are not connected, it is possible to improve the quality of the structure.<sup>219</sup>

The World Health Organization has published some instruments to help caregivers in their tasks.

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<sup>216</sup> World Health Organization. “Dementia: a public health priority”

<sup>217</sup> Gauthier S. et al. “World Alzheimer Report 2022: Life after diagnosis: Navigating treatment, care and support”, p. 164

<sup>218</sup> World Health Organization. “Responding to the COVID-19 pandemic in long-term care. In Preventing and managing COVID-19 across long-term care services (pp. 5–32)”. 2020. Accessed on 30 April 2024, <http://www.jstor.org/stable/resrep27994.6>

<sup>219</sup> World Health Organization. “Global status report on the public health response to dementia”. 1 September 2021. Accessed on 30 April 2024, <https://www.who.int/publications/i/item/9789240033245>



The first document published by the World Health Organization about caregiving in dementia was in 2006.

This guide was elaborated by families from different socio-cultural states. Nevertheless, there is a predominant vision, that is the occidental one.

Firstly, it is analysed dementia stages and it presented suggestion to manage this disability;

then, the second part is about “caring for yourself” aimed at help carers. It suggests to take care of yourself, by finding good support in order to avoid mental and health problems.<sup>220</sup>

An important manual is also represented by “*iSupport For Dementia. Training and support manual for carers of people with dementia*”. This document is composed by different chapters, that aims to give support to caregivers and local authorities: introduction to dementia, being a carer, caring for me, providing everyday care, dealing with behaviour changes. It was realized on the basis of the Mental Health Gap Action Programme.

This guide, within its tests, encourages family to ask help to doctor and, in general, to health system.<sup>221</sup>

The guide “*Towards a dementia plan: a WHO guide*” proposes activities in order to fulfil the Global action plan: “*provide accessible and evidence-based information, training programmes, respite services [...]*”; “*Train health and social care providers to identify and reduce carer stress and burnout*”; “*develop or strengthen carer protection*”; “*involve carers in care planning*”.<sup>222</sup>

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<sup>220</sup> Alzheimer’s Disease International and World Health Organization. “Alzheimer’s Disease Help for Caregivers”. Geneva. 1994. Accessed on 17 May 2024, <https://www.who.int/publications/i/item/WHO-MNH-MND-94.8>

<sup>221</sup> World Health Organization. “iSupport for dementia. Training and support manual for carers of people with dementia”. Geneva. 2019. Accessed on 17 May 2024, <https://www.who.int/publications/i/item/9789241515863>

<sup>222</sup> World Health Organization. “Towards a dementia plan: a WHO guide”. 2018. Accessed on 10 May 2024, <https://www.who.int/publications/i/item/9789241514132>, p.37

Then, in this document there are also some implemented considerations about the topic of caregiving. These are about information, awareness, economic help for reducing barriers.<sup>223</sup>

In relation to vulnerable carers, it is important that the objects of 2030 Agenda will be applied also to them. In fact, with the concept “*leave no-one behind*”, caregivers should not find other barriers in relation to the existing ones.

For this reason, the local government has to guarantee their protection, giving to them the necessary support for their unpaid job. In general, to personal situation of carer there are other adds factors that worsen the condition such as costs of health services for dementia, mental and physical decline of caregiver linked to dementia tasks. According to Margaret Chan, that was the Director-General of World Health Organization, “*the catastrophic cost of care drives millions of households below the poverty line*”.<sup>224</sup>

### 3.3 THE IMPACT OF COVID -19 ON DEMENTIA

*“The ongoing COVID-19 pandemic has disrupted health care systems globally and these disruptions threaten to reduce access to timely dementia diagnosis and entry to care pathways.”*<sup>225</sup>

Through the pandemic, all inefficiencies of international health system were coming to light. The terrible data is represented by the high number of elder’s deaths in long term structure. For this reason reinforce long-term services is became a public priority.<sup>226</sup>

Data has demonstrated that the impact of Covid-19 virus on older has been significant, especially for those that have specific ill or disabilities.

The document published by the American Society of Ageing focused on two specific terms: loneliness and social isolation. The first could be defined as “[...] *subjective feeling*

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<sup>223</sup> Ibid.

<sup>224</sup> World Health Organization. “Dementia: a public health priority”, p. V

<sup>225</sup> World Health Organization. “Global status report on the public health response to dementia”, p. 145

<sup>226</sup> World Health Organization. “Decade of healthy ageing: baseline report”

*of a lack of connection to other people and a desire for more satisfying relationships*<sup>227</sup>, while the second refers to a person that has little or no relations.

As it was analysed in previous chapters, they represent risk factors for developing dementia. For this reason, from this creation, the context of dementia friendly communities wants to create groups of people that create relationship.

In fact, lot of prevention initiatives involve especially people without a diagnosis but that are over sixty-five years old.

Thanks to these programmes and other projects organised by other association for older people, the general object become that *“no to leave anyone behind”*.

Covid-19 pandemic has stopped all these proposals because of the problem was the contact between persons. The consequence of 2020 year was the development of risk factors, because of social isolation and loneliness of vulnerable people.

Moreover, when caregiver falls ill, he/she enters in a circle of fear to infect the person affected by dementia. Unfortunately, lots of older people become ill, and this has caused the death of them.

Another big problem was the impossibility to come with the loved in the hospital. For this reason, also today, persons that were carers remember the period of pandemic as full of remorse and stress.

In this case, the community asks still today where are the institutions that must protect dignity of everyone, remembered the wide of dead that were alone in the hospital without the possibility to receive a goodbye from family.

The consequence of this general situation was also an increasing of psychiatric diseases, that represented a possibility to become more vulnerable to other ills.

In spite of the international context, the dementia friendly community has been able to reinvent other modalities to join with person affected by dementia and their families through online means of communication.

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<sup>227</sup> Garcia E. “Social Connection in Older Age”, p. 1

In the essay developed by Mina Chandra and Kalpana Chandra, they analysed the “*tele-interventions in dementia care [...] developed to ensure continuity of care for people living with dementia and carers*”.<sup>228</sup>

They were about cognitive intervention, psychotherapy, grief, mindfulness, physical activity and lessons for carers.

The positive factors of COVID-19 pandemic were the development of these economy activities that still today we continue to use, in the case of impossibility to organise a meet in person.

In order to reduce the impact of the pandemic, the World Health Organization has developed eleven objectives that are the follows.

*“1. Include long-term care in all phases of the national response to the COVID-19 pandemic.*

*2. Mobilize adequate funding for long-term care to respond to and recover from the COVID-19 pandemic.*

*3. Ensure effective monitoring and evaluation of the impact of COVID-19 on long-term care and ensure efficient information channelling between health and long-term care systems to optimize responses.*

*4. Secure staff and resources, including adequate health workforce and health products, to respond to the COVID-19 pandemic and deliver quality long-term care services.*

*5. Ensure the continuum and continuity of essential services for people receiving long-term care, including promotion, prevention, treatment, rehabilitation and palliation.*

*6. Ensure that infection prevention and control standards are implemented and adherent to in all long-term care settings to prevent and safely manage COVID-19 cases.*

*7. Prioritize testing, contact tracing and monitoring of the spread of COVID-19 among people receiving and providing long-term care services.*

*8. Provide support for family and voluntary caregivers.*

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<sup>228</sup> Gauthier S. et al. “World Alzheimer Report 2022: Life after diagnosis: Navigating treatment, care and support”, p.277

*9. Prioritize the psychosocial well-being of people receiving and providing long-term care services.*

*10. Ensure a smooth transition to the recovery phase.*

*11. Initiate steps for transformation of health and long-term care systems to appropriately integrate and ensure continuous, effective governance of long-term care services.”<sup>229</sup>*

The issue linked at the long-term care is that it is considered neither a social task nor health task. This is highlighted especially during the pandemic, when it was clearly that long term care was not a public health priority for years.

In addition, the general problem is about funding. Government does not allocate resources for long-term care, even if it represents a priority topic in multi-level governance agenda.

In conclusion, the COVID-19 pandemic has emphasized the lack of different levels of governance in responding to need of long-term care services, through a coordination system for care needs.

### 3.4 THE ITALIAN CONTEXT.

As affirmed by the Italian Minister of Work, Health and Social Policy, the capacity to reply to needs of people with disabilities is a fundamental characteristic of the welfare state.<sup>230</sup>

Italian system, as lots of states in the world, continues to present a lack to achieve objects of the model of welfare states. Especially, the problem is generated by the allocation of resources that generally are invested in other sector, not always important at the same level.

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<sup>229</sup> World Health Organization. “Responding to the COVID-19 pandemic in long-term care. In Preventing and managing COVID-19 across long-term care services (pp. 5–32)”, p. 6

<sup>230</sup> La convenzione delle Nazioni Unite sui diritti delle persone con disabilità. Accessed on 31 May 2024, <https://www.lavoro.gov.it/temi-e-priorita/disabilita-e-non-autosufficienza/focus-on/Convenzione-ONU/Documents/Convenzione%20ONU.pdf>

As we have mentioned above, dementia is characterized from different stages (early, middle and last stages). Generally, until the middle stage, the caregiver manages to perform the task of care.

The health system should intervene to help the patient thinking about the perspective of the person living with dementia.

Also in this case there is a distinction between the countries. In advanced states, family are able to find “[...] *home care services after a dementia diagnosis* [...]”.<sup>231</sup> In the case of states with middle-income-countries they are involved in available health policies.

When conditions of a person affected by dementia deteriorated, the possibility to find a rest care becomes essential.

In reference to Italian context, with the COVID pandemic the Italian rest homes closed to the possibility to add new patients because of avoid the death of guests.

With the end of emergency status, the request for new entries increases a lot, for this reason rest homes arrive to a saturation point. In fact, public old age homes have long waited lists.

In the context of these structures, some of them decreased the quality of services. This is the effect of families’ absence in the control of their dear and the lack of social workers.<sup>232</sup>

Considering this scenario, we can imagine the general stress of carers that are obliged to continue their informal work because of the impossibility to paid for a private structure.

In conclusion, on the one hand it is very difficult for families to take the decision about rest homes, on the other hand when they are ready to insert the person affected by dementia, they find the impossibility of the structure to receive the patient.

In general, in Italy, care structures are seen as the only solution available. This is the consequence of negligence of national system that persists to do not create adequate instruments for people living with dementia.

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<sup>231</sup> Gauthier S. et al. “World Alzheimer Report 2022: Life after diagnosis: Navigating treatment, care and support”, p. 163

<sup>232</sup> Trabucchi Marco, “Una lunga vita buona. Il futuro delle RSA in una società che invecchia”

For this reason, the role of care has become very difficult, because or family helps the person with dementia or they choose for a nursing home. The problem is that when we take care of a person we expect health improvement. In the case of dementia this improvement is not possible.

What is very interesting, it is represented by the alternative interventions to general pharmacological therapies.

Especially for people living with dementia there was the publication of the guide “*My Life, My Goals*” that was a collaboration between the Alzheimer’s Society, the University of Exeter and Innovation in Dementia. It gives a strategy to patient and helps them during the early stage of ill.<sup>233</sup>

In addition to this document, it is important to make reference to alternative activities in order to maintain cognitive capacities. There are for example activities that using art and music to preserve capacities.<sup>234</sup>

Thanks to these programmes it is possible to avoid immediately the admission in an old-age community and work in the acceptance of progressive deterioration of the patient.

Also in Italy, association for dementia, especially for Alzheimer, have developed some comparable initiatives to them above-mentioned.

In order to analyse it, it could be beginning from the examination of Italian context.

In the case of study of Italy, it is possible to verify that from 2009 that the Ministry of Health started to publish report about dementia.

According to the last collected, in Italy the number of people affected by dementia is around “[...] 1.126.961 in the age group of 65 years or older [...] and 23.730 cases of younger dementia [...]”<sup>235</sup> and 3 million are carers.<sup>236</sup>

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<sup>233</sup> The University of Exeter. “My Life, My Goals”. 2021. Accessed on 23 May 2024, <https://www.alzheimers.org.uk/blog/life-after-dementia-diagnosis-guide-setting-reaching-goals>

<sup>234</sup> Gauthier S. et al. “World Alzheimer Report 2022: Life after diagnosis: Navigating treatment, care and support”

<sup>235</sup> Istituto Superiore di Sanità. “Progetto Fondo per l’Alzheimer e le demenze”. January 2024. Accessed on 17 May 2024, [https://www.demenze.it/documenti/schede/libro\\_nazionale\\_per\\_sito\\_1.pdf](https://www.demenze.it/documenti/schede/libro_nazionale_per_sito_1.pdf), p. 1

<sup>236</sup> Ministero della Salute. “Dati epidemiologici”. Accessed on 17 March 2024, <https://www.salute.gov.it/portale/demenze/homeDemenze.jsp>

The first national project elaborated in Italy for dementia was “*Cronos*”, produced by a collaboration between the Ministry of Health and National Health Institute. It was activated as the consequence of prescription of new medicines to treat people affected by dementia. In addition, it started a monitoring process on people that took this therapy in order to improve research about Alzheimer.<sup>237</sup>

The government has elaborated national plans about dementia from 2010 to 2025.

Then, in the Website of ministry of Health we find some recommendations and national guidelines about governance, assistance, information system, dementia friendly communities.<sup>238</sup>

The Cronos’ project and the other actions adopted by Italian government failed in the creation of only one direction about dementia. The lack of coordination between different regions created services more developed in some cities compared to others.<sup>239</sup>

A big step was represented by the elaboration of the National Plan on Dementia approved on 30 October 2014. The plan was the result of a collaboration between the Ministry of Health, regions, National Health Institute, “Federazione Alzheimer Italia” and “Alzheimer Uniti Italia”.<sup>240</sup>

It treats strategies, necessity of information, awareness about dementia, support for caregivers and patients and other health policies.

The objects are measures about health and care policies, collaboration for the creation of integrated services, strategies for appropriate therapies, awareness on dementia and elimination of stigma.<sup>241</sup>

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<sup>237</sup> Vanacore V. et al. “Terapia dell’Alzheimer: il progetto cronos”. 2022. Accessed on 17 May 2024, [https://www.epicentro.iss.it/cong\\_leb/vanacore](https://www.epicentro.iss.it/cong_leb/vanacore)

<sup>238</sup> Ministero della Salute. “Demenze”. Accessed on 17 May 2024, <https://www.salute.gov.it/portale/demenze/archivioPubblicazioniDemenze.jsp>

<sup>239</sup> Istituto Superiore di Sanità. “Progetto Fondo per l’Alzheimer e le demenze”

<sup>240</sup> Alzheimer Europe. “Italy”, Accessed on 17 May 2024, [https://www.alzheimer-europe.org/policy/national-dementia-strategies/italy?language\\_content\\_entity=en](https://www.alzheimer-europe.org/policy/national-dementia-strategies/italy?language_content_entity=en)

<sup>241</sup> Istituto Superiore di Sanità. “Piano nazionale demenze”. Accessed on 17 May 2024, <https://www.iss.it/le-demenze-piano-nazionale-demenze>



Even if since 2009 Italy published guidelines about dementia, for the first time from 2021 and 2023 there was the allocation of economic resources for the National Plan on Dementia.

These resources were approved by the Parliament in 2020 with the budget law.<sup>242</sup> It was published in the Official Journal on 30 March 2022.

It represents an important step and there was the designation of 14 million and 100 thousand euros for the elaboration of strategies for regions.

In addition, it allocated 900.000 euros for National Health Institute.

Besides that it specifies allocation criteria in which the Ministry of Health makes the following actions in collaboration with the national health institute, associations for dementia, caregivers and persons affected by dementia: drafting guidelines for diagnosis, updating national dementia plans, monitoring strategies and services, promoting awareness, researches and prevention on dementia.<sup>243</sup>

The Conference for Alzheimer and Dementia Found was organised between 22<sup>nd</sup> and 23<sup>rd</sup> January 2024. Different social workers in public health services participated and regions submitted a report about data, services, caregivers.<sup>244</sup>

It represents an important event in which important data appears like the disproportionate creation of dementia services in Italy.

Especially, it is possible to affirm that in Nord Italy there are lots of services than Sud Italy. Moreover, it was created the permanent dementia table that monitors funds allocated about this topic.

In addition, collected data highlights a dissatisfaction for available health services.<sup>245</sup>

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<sup>242</sup> Ancidioni A. et al. "Italy's actions on dementia". February 2023. Accessed on 17 May 2024, [https://www.thelancet.com/journals/laneur/article/PIIS1474-4422\(22\)00521-X/fulltext](https://www.thelancet.com/journals/laneur/article/PIIS1474-4422(22)00521-X/fulltext)

<sup>243</sup> Gazzetta Ufficiale. Decreto 23 dicembre 2021. "Individuazione dei criteri e delle modalità di riparto del Fondo per l'Alzheimer e le demenze". Accessed on 17 May 2024, <https://www.gazzettaufficiale.it/eli/id/2022/03/30/22A01996/sg>

<sup>244</sup> Istituto Superiore di Sanità. "Presentazione Convegno Finale Fondo per l'Alzheimer e le Demenze". 18 January 2024. Accessed on 17 May 2024, <https://www.iss.it/-/presentazione-convegno-finale-fondo-per-l-alzheimer-e-le-demenze>

<sup>245</sup> Istituto Superiore di Sanità. "Comunicato Stampa N°07/2024 - Demenze: forti differenze regionali nell'assistenza, al Nord test diagnostici e centri aperti più a lungo". Published on 11 January 2024. Accessed

Available services on dementia are the Centre for cognitive diseases and dementia (CDCD) , day care centres and rest homes.<sup>246</sup>

Moreover, on 20<sup>th</sup> February 2020 there was the publication of guidelines for the creation of dementia community friendly after the conference, linked with the Joint Action.<sup>247</sup>

In these year Italy participated also in European programmes such as the “*Joint Programme Research Initiative*” and “*Joint Action on dementia*”.

In 2014, for example, Italy signed the Declaration of Glasgow with other European states, in which national government committed to develop strategies about dementia, elaborating strategies in collaboration with families and associations.<sup>248</sup>

Looking at the website of Italian National Health Institute, we find a dedicated part for Alzheimer Disease, in which there are general information about definition, diagnosis, therapies.

About dementia costs, it estimates that every year dementia care amounts at 23 billion euros, and the majority of them fall on families.<sup>249</sup>

Then, it is possible to find a page about dementia services in Italy on the website of Dementia Observatory and results of Dementia founds.<sup>250</sup>

Services related to Alzheimer, in particular, are Centre for Cognitive Disease and Dementia, day care centres and residential structures for people with dementia. This page

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on 25 May 2024, <https://www.iss.it/-/comunicato-stampa-n-07/2023-demenze-forti-differenze-regionali-nell-assistenza-al-nord-test-diagnostici-e-centri-aperti-piu-a-lungo>

<sup>246</sup> Ministero della salute. “Rete dei servizi in Italia”. Accessed on 25 May 2024, <https://www.salute.gov.it/portale/demenze/dettaglioContenutiDemenze.jsp?lingua=italiano&id=4894&area=demenze&menu=vuoto>

<sup>247</sup> Ministero della salute. “Linee di indirizzo”. Accessed on 25 May 2024, <https://www.salute.gov.it/portale/demenze/dettaglioContenutiDemenze.jsp?lingua=italiano&id=4893&area=demenze&menu=vuoto>

<sup>248</sup> Ministero della Salute. “Demenze, siglata la Dichiarazione di Glasgow”. Published on 15 April 2015. Accessed on 25 May 2024, [https://www.salute.gov.it/portale/news/p3\\_2\\_1\\_1\\_1.jsp?lingua=italiano&menu=notizie&p=dalministero&id=2020](https://www.salute.gov.it/portale/news/p3_2_1_1_1.jsp?lingua=italiano&menu=notizie&p=dalministero&id=2020)

<sup>249</sup> Istituto Superiore di Sanità. “Informazioni generali”. Accessed on 25 May 2024, <https://www.epicentro.iss.it/alzheimer/>

<sup>250</sup> Istituto Superiore di Sanità. “Fondo demenze: online la nuova mappa dei servizi”. Published on 18 April 2024. Accessed on 25 May 2024, <https://www.epicentro.iss.it/alzheimer/aggiornamenti>

is available from 18 April 2024 and would stay update and give specific information about every location.<sup>251</sup>

Through the Found, the Observatory for Dementia and Region realized a monitoring system, called “*Passi d’argento*”. It is directed to all persons over sixty-five years old.

It collected information about population, risk factors, care, quality of life.

The object is healthy and active ageing.<sup>252</sup>

Finally, on 7<sup>th</sup> June 2024, it has been published an update in the World Health Organization website: “*WHO and Italian National Institute of Health sign memorandum of understanding to improve care for healthy ageing*”.

The MOU (Memorandum of understanding) focuses on healthy ageing through particular attention on long-term care, research and new instruments to face to dementia.

In conclusion, Italian country is going to implement international recommendations, from the consideration of dementia of a public health priority to the necessity to work on healthy ageing.

This commitment is necessary because of the progressively ageing population.<sup>253</sup>

### 3.5 PREVENTION’S PROJECT

The role of associations was very important in the Italian context. Firstly, we analyse Marche region. Through the act 107 of 23<sup>rd</sup> February 2015, the region adopted the agreement between state and regions on National Dementia Plan.<sup>254</sup>

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<sup>251</sup> Osservatorio Demenze dell’Istituto Superiore di Sanità. “Mappa dei servizi”. Accessed on 25 May 2024, <https://www.demenze.it/it-mappa>

<sup>252</sup> EpiCentro. Istituto Superiore di Sanità. “La qualità della vita vista dalle persone con 65 anni e più”. Accessed on 25 May 2024, <https://www.epicentro.iss.it/passi-argento>

<sup>253</sup> World Health Organization. “WHO and Italian National Institute of Health sign memorandum of understanding to improve care for healthy ageing”. 7 June 2024. Accessed on 11 June 2024, <https://www.who.int/news/item/07-06-2024-who-and-italian-national-institute-of-health-sign-memorandum-of-understanding-to-improve-care-for-healthy-ageing>

<sup>254</sup> Regione Marche. “Delibera della Giunta Regionale n. 107 del 23/02/2015”

For this reason, in this thesis it will be presented a model of prevention applied in Treia town, through a collaboration between this municipality and the association for dementia “Cambiamenti S.r.l.”.

Since 2005, Marche administration started to create a project for dementia. They presented a programme in which the objectives are taking a census on people affected by dementia and increasing formal competences about dementia.

There was the creation of structures like day care centres and health care homes for dementia.

In addition, Marche Region in collaboration with INRCA (an Institute of hospitality and care for ageing people), Asur and Ambito Territoriale Sociale 15, elaborated the project “*Guida per le Famiglie con malato di Alzheimer di Macerata*”. It was supported by the Ministry of Labor and Social Policy with the national found of 2010.

It started from the definition of Alzheimer, then what are the alarm bells, dementia stages.

It illustrated what are the steps to follow in case of first symptoms and the importance of coalition patient-doctor.

It described available services: home help, rest homes, day time centres, economic benefits, medical transport.

About recommendations it is important that family applies some attentions like the following: communication, memory, hygiene, nutrition and domestic environment.<sup>255</sup>

It ended by the rights of person affected by dementia that were affirmed in the Charter of Rights of person affected by dementia; it was approved in 1999 by Alzheimer Europe, Alzheimer Italia and Alzheimer’s Disease International.

*“Right of the person with dementia to respect and dignity [...]; right of person with dementia to be informed, in the early stages of the disease [...] about their disease and its predictable evolution; right [...] to participate [...] in decisions [...]; right of the person with dementia to access every health service and/or welfare like any other citizen: this right implies that particular attention [...]; right [...] to have available specialized*

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<sup>255</sup> Regione Marche, INRCA, Ambito Territoriale Sociale 15, Asur Area Vasta 3. “Guida per le Famiglie con malati di Alzheimer”. 2010

*services that face [...] dementia's issues; right [...] to choice from different option of care [...]; right [...] to a special protection and guarantee against physical and property abuse; right [...] in the absence of legal representatives [...] to have by law an official guardian chosen by court.*"<sup>256</sup>

In this years, Afam Alzheimer Uniti Marche has worked hard for families with dementia. It was created in 2008 by a group of families with the aim to give help for social and health support.

The association activated different initiatives in the region like Caffè Alzheimer and Dementia friendly community in Macerata.

After earthquake and COVID pandemic deteriorates not only population conditions but also waiting time for a first medical visit for dementia diagnosis.

Caused by this situation, Alzheimer Uniti Italia Onlus had to intervene in order to guarantee these services, because of the lack of health system. What it was highlighted by the association was the neglect condition of families due to the ineffectiveness of health care.

The association tried to pressure Marche administration to find solution for dementia's people necessities. Especially it is important to create a unique control point to coordinate dementia.<sup>257</sup>

Then, the Centre for cognitive disease and dementia have to become a point that support families, not only a place that gives drugs (as been highlighted in the national dementia plan).

Dementia-community friendly started to exist in Macerata town.

It means "[...] *a place or culture in which people with dementia and their carers are empowered, supported and included in society, understand their rights and recognise their full potential.*"<sup>258</sup>

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<sup>256</sup> Alzheimer Italia. "Carta dei diritti della persona con demenza". Milan. July 1999. Accessed on 25 May 2024, <https://www.alzheimer.it/carta.html>

<sup>257</sup> AFAM Alzheimer Uniti Marche. Accessed on 25 May 2024 <https://www.afamonlus.org/>

<sup>258</sup> Alzheimer's Disease International (ADI). "Dementia Friendly Communities", p.10

It aims to promote inclusion of people affected by dementia, through different activities. It is based on coordination and collaboration between different actors like patients, families, caregivers, social worker in public health service.

The objects are respect and dignity, elimination of social barriers, quality of life, increasing awareness, attention, hospitality of people affected by dementia in the city.

In this context the association organised formations for population, doctors, public administration operators and law enforcement, about awareness and information on dementia.

Then, there is the opening of a meeting centre, in which on the one hand there are activities for people affected by dementia, on the other hand the professional training above mentioned.

In addition, the creation of dementia support line and counselling centre.

In Macerata there is also a Cafè Alzheimer.<sup>259</sup>

Café Alzheimer was “*founded in the Netherlands [...] have become a popular and easily transferable programme used to connect people, share information, and bolster support in many countries around the world*”.<sup>260</sup>

In Italy there are different types of these initiatives; there are some realities also in Marche.

In the context of Treia, the association AFAM Alzheimer Uniti Marche ODV and Cambiamenti started a project for citizen about the topic on prevention.

Cambiamenti is a social enterprise of Macerata that collaborates with AFAM Alzheimer Uniti Marche in order to expand services for people affected by dementia and their families. It aims to influence general attitude to dementia and promote social policies to protect rights of this vulnerable group.<sup>261</sup>

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<sup>259</sup> AFAM Alzheimer Uniti Marche

<sup>260</sup> Alzheimer’s Disease International. “Alzheimer Cafés”. Accessed on 23 May 2024, <https://www.alzint.org/what-we-do/policy/dementia-friendly-communities/alzheimer-cafes/>

<sup>261</sup> Cambiamenti. Accessed on 25 May 2024, <https://www.cambiamenti2020.it/>

In 2023 Treia administration collaborated with Cambiamenti and AFAM in order to develop a prevention project on dementia.

The object of the project “Vengo Prima Io” was to promote information and awareness on good lifestyle especially during the third age. In addition, through this project the association aspires to encourage to bring together, socialisation and memory training through different activities.

This project would also to realize the goal number three of the Sustainable Development Agenda: “*good health and well-being*”.<sup>262</sup>

This project was directed especially to people over sixty-five years of age residing in Treia. The initiative was divided into three phases: informational meeting, dementia screening and workshops.

The first meeting was directed by Marco Trabucchi and the president of AFAM Alzheimer Uniti Marche. It was about the topic “ageing is not a disease” and the presentation of project.

The other meetings were about nutrition education, physical training, psychological training, socialisation and other topic related to awareness and information on risk factors for Alzheimer. These gatherings were opened to all citizens.

The second part was the submission of free screening about the diagnosis of Alzheimer. In this case fifty people booked this screening test with a association’s specialists (psychologist and geriatricians).

They could book their screening through pharmacies, Cambiamenti association, Social Services Office.

Fifty people decided to make this test. The majority of people were over sixty-five years of age. Nevertheless, there are other people that requested the test even if they were not classifiable as “old person” because of the age.

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<sup>262</sup> United Nations. “Goal 3: Ensure healthy lives and promote well-being for all at all ages”. Accessed on 25 May 2024, <https://www.un.org/sustainabledevelopment/health/>

These requests were related to their families' situation. Lots of them were caregivers and for this reason they would make the test. In these cases emerge the necessity to discover the possibility to have dementia because of home's situation.

On the other hand, who did not a caregiver but had more than the established age, demonstrated less interest for the initiative. This is the consequence of scaring to discover a dementia diagnosis.

So, lot of people prefer to do not discover a possible disease. In this case, it emerged how a dementia prevention test represents a big obstacle as compared to other diagnosis.

This is due also to the lack of information and awareness about dementia, as if a diagnosis of dementia is not the same thing to other tumour diagnosis.

It is a false belief according to which there is not possible to prevent dementia. It seems to be the only ill for which is not worth effort to fight.

In this context the role of general practitioner is fundamental because this actor represents the only figure that could connect patients with this initiative. In addition, this health actor is the only one that knows all situations in the territory.

The general problem of health sector, it is that for the increasing number of patient's requests they do not have time to work hard for this type of projects.

For this reason, the system stopped in different phases of prevention actions, because there is a difficult collaboration between stakeholders.

The tests submitted to people wants to verify the memory and dialect ability through exercises for verifying things, words, events; then, the capacity to maintain concentration and attention; difficulty in language.<sup>263</sup>

During the screening lots of difficulties emerge because of the low level of education (for example people that had not finished elementary school).

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<sup>263</sup> Humana Vox srl. "Alzheimer: test per una diagnosi precoce". Accessed on 25 May 2024, <https://humanavox.it/alzheimer-test-per-una-diagnosi-precoce/>



Then, during these tests come to the surface, different difficult situations. In fact, the loneliness of old people, the stress and depression due to death of relative, could be expressed by the person in the screening tests.

This highlights that lots of people are left alone because the social context does not take care of them, even if they are alone.

For his reason, the third phase of the project that is about laboratories become important.

The creation of groups that for a few months made together the activities has created collaboration and new relations. To be part of a group, especially in the context of third age, become important. This is true especially in the case of person that does not leave the home much.

The laboratories activated in Treia were divided in memory training and low-impact exercises, with professional figures.

The memory training represents a workshop for the improvement of memory and cognitive function, that has the aim to make participants aware of their cognitive functioning, stimulate and enhance mental processes and suggest a strategy.

The workshop about low-impact exercises aim to offer training aimed at strengthening musculoskeletal balance, improving posture and the ability to control and know one's body.

During the summertime in 2022 the activities became "brain walking". It consisted in putting together the Nordic walking and memory training.

Looking at the economic part, the administration participation in the project involve a paltry amount of money, just like citizen participation.

The second part about the work of Cambiamenti and AFAM is a project realized by Treia and other two municipalities.

They aim to create a services network that promote the bio-psycho-social well-being of vulnerable people. Every municipality, looking at the characteristics of its territory, has to applied actions for prevention, information and awareness, formation of social worker and families, psychological support of caregiver.

Then, in this phase the object is to create a personalised care model for people affected by dementia.<sup>264</sup>

In Treia, it is going to be realised while in other municipality it has been realized, such as in Jesi.

For example, in Jesi was started the project “MAPPET” that means personalised and proximity care model supported by technological empowerment.

It was realized through a collaboration between the cooperative COOSS Marche, AFAM Alzheimer Uniti Marche, Cambiamenti, “Ambito Territoriale Sociale 9” and the municipality administration.

This project elaborated services such as digital tool and rehabilitation exercises for cognitive and functional stimulation. Then, support families and caregivers. In addition, specialist consultancy. Finally, communities’ initiatives for socialization.

In general, “MAPPET” means innovative project that promotes an integrated and personalized home care, aimed at slowing down cognitive deterioration and improve elderly autonomy.<sup>265</sup>

Another important initiative created in the territory of Macerata by AFAM Alzheimer Uniti Marche and Cambiamenti association is a beach holiday with old people affected by the first stages of dementia, with other professionals’ figures that accompanied them.

This initiative was given by the desire of a person affected by dementia to look the sea for the first time in her life. Thanks to the association and families, the project was realized and continued to be organized.<sup>266</sup>

AFAM Alzheimer Uniti Marche made some proposals to regional administrations.

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<sup>264</sup> Comune di Treia. “Alzheimer e sostegno alle famiglie, a Treia un progetto di prevenzione e aiuto”. Published on 26 march 2024. Accessed on 25 May 2024, <https://www.comune.treia.mc.it/comunicati-cms/alzheimer-e-sostegno-alle-famiglie-a-treia-un-progetto-di-prevenzione-e-aiuto/>

<sup>265</sup> Afam Marche. “Alzheimer e assistenza agli anziani, a Jesi un convegno per lanciare il progetto MAPPET”. Published on 7 May 2024. Accessed on 25 May 2024, <https://www.viverejesi.it/2024/05/08/alzheimer-e-assistenza-agli-anziani-a-jesi-un-convegno-per-lanciare-il-progetto->

<sup>266</sup> AFAM Alzheimer Uniti Marche. “Una vacanza indimenticabile”. Accessed on 25 May 2024, <https://www.afamonlus.org/citta-amica/combattere-lo-stigma/>

First of all, it is necessary a network between social sector, health sector, civil society in order to create a continuity and coordination in care.

Then, it is highlighted the importance of an only older point, in which there is the intersection between supply and demand about care. This point could offer professional formation also for care attendants.

In Macerata this reality has been created in collaboration between different town managements.

In addition, creating an individualized intervention plan, elaborated by a multidisciplinary equipe, in order to improve home care. In this case the presence of general practitioners is fundamental from the starting point to the end phase.

Moreover, support healthcare of caregivers and their formation.<sup>267</sup>

In Italy, a developed model for is represented by Lombardy.

Especially in Milan, since 2013 it has been created the Alzheimer Network, based on a collaboration between different institutions. In the Milan administration website there is specified that there is an Alzheimer Table and the Milan Alzheimer Observatory; then, there are listed the names of associations for support people with dementia.<sup>268</sup>

In a dedicated page there are different article about the work of this region in dementia disease. This website has the collaboration of other stakeholder such as Caritas Ambrosiana, Cisl, the Institution for social research and other private actors.

There are different articles that talk about dementia, available services in Lombardy, home care, need care, social network.

Between services and policies applied there is since 2007 the “Alzheimer Cafè Milano”, that viewed the participation of lots of caregivers. It represents a point in which families with different situations could talk about their experiences and problems related to

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<sup>267</sup> AFAM Alzheimer Uniti Marche

<sup>268</sup> Comune di Milano. “Rete Alzheimer”. Accessed on 25 May 2024, <https://www.comune.milano.it/aree-tematiche/servizi-sociali/rete-alzheimer>

Alzheimer. In addition, they participated in different dementia's formations. In the main time people affected by dementia made specific activities.<sup>269</sup>

Then, there was the creation of "Island in the city", a place in which different types of therapies were activated for people affected by dementia and their carers.

These services stopped with the COVID Pandemic, through which new modalities of meeting were created: especially online platforms.<sup>270</sup>

Between different services created for people with dementia, it has been created a village for them in Monza in 2018. It represents an interesting reality because it is a little village in which there are all services like a city.

It is composed by house for people with dementia disease, vegetation, square, church. There are lots of social workers that take care of patients.

The approach is based on person-centred, with the aim to preserve the dignity through no pharmacological therapies. The principles are the preservation of autonomy using person's abilities. This village has been created thanks to individual economic resources.<sup>271</sup>

All these initiatives aim to take care in the life places, and not in specific house. In this way it could be possible to reduce stigma and discrimination against people affected by dementia.<sup>272</sup>

In this system also emerges the necessity to support caregivers. Especially after COVID pandemic, the relation of family with the person in care structure has become more vulnerable.

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<sup>269</sup> Tidoli R. "Orientare ai servizi le famiglie di anziani malati di Alzheimer". 15 July 2022. Accessed on 25 May 2024, <https://lombardiasociale.it/2022/07/15/orientare-ai-servizi-le-famiglie-di-anziani-malati-di-alzheimer-il-contributo-di-fondazione-manuli/>

<sup>270</sup> Tidoli R. "L' "universo Alzheimer" a Milano: le tappe di un cambiamento". 31 March 2022. Accessed on 25 May 2024, <https://lombardiasociale.it/2022/03/31/luniverso-alzheimer-a-milano-le-tappe-di-un-cambiamento/>

<sup>271</sup> La Meridiana. "Il paese ritrovato". Accessed on 25 May 2024, [https://cooplameridiana.it/centri\\_e\\_servizi/paese-ritrovato/](https://cooplameridiana.it/centri_e_servizi/paese-ritrovato/)

<sup>272</sup> Tidoli R. "Orientare ai servizi le famiglie di anziani malati di Alzheimer"

For this reason, it becomes important to create a trust relation between patient-family-social workers. The consequence is a change in the whom structure view: from “safekeeping place” to “care place”.

This type of relation permits also to work on the difficult to delegate the care of person affected by dementia.

As above-mentioned, on one hand they are afraid to “abandon” their dear, on the other hand they do not leave the control. What emerges from this research is in general the necessity of personalized care, not only base on the patient, but also on family’s abilities and resources.<sup>273</sup>

In conclusion, it could be interesting the compared lecture of this two regions, Marche and Lombardy, especially looking at the impact of each one in national context.

These two regions are defined by the national report about the Alzheimer Found as two administrations that go beyond the national dementia plan but the implementation of actions and goals is not complete.

There are some regions that have substantially implemented the national dementia plan, such as Veneto, Trento, Piedmont, Emilia Romagna and Tuscany. Instead, there are some regions and districts that have not applied the plan such as Bolzano, Basilicata, Calabria and Friuli Venezia Giulia.

The national report about “*Presentazione Convegno Finale Fondo per l’Alzheimer e le Demenze*” affirms that in Italy there are 57 dementia friendly communities, a low number compared to the other realities in Europe. The 77,2 % are in the Nord Italy, while in Sud Italy they are 14% and in the Middle 8,8%.

About Café Alzheimer the reports highlight that there are 110 official caffè. the others are informal initiatives of associations.

Then, through the Found it has been defined project areas that are about the improvement of early diagnosis of Mild Cognitive Impairment, tests and diffusions of telemedicine

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<sup>273</sup> Tidoli R. “Nutrire le relazioni tra caregiver come atto di cura”. 16 April 2024. Accessed on 25 May 2024, <https://lombardiasociale.it/2024/04/16/nutrire-le-relazioni-tra-caregiver-come-atto-di-cura/>

intervention, tele-rehabilitation and cognitive, psychosocial, psychoeducational treatments.

In addition, the Ministry has to monitor the implementation of national plan, updates the services' map, promotes strategies for prevention, applies initiatives for formation, implements technological medical records.

The national dementia plan is characterized by four goals: measures and intervention on health and social policies; creation of integrated network and management of dementia; implementation of care's strategies; increasing awareness and reduction of stigma to improve the quality of life.<sup>274</sup>

In Italy, another important financial tool has been activated. It was given by European Union and it is the "*Recovery and resilience facility – RRF*". Italian government has obtained 191,5 milliard euros. European Union gives found at the end of every half year, after the evaluation of the goals' achievement.<sup>275</sup>

It is composed by six missions: "*digitalisation, innovation, competitiveness, culture and tourism; green revolution and ecological transition; infrastructure for sustainable mobility; education and research; inclusion and cohesion; health.*"<sup>276</sup>

Within "*Mission 5 component 2*" it is analysed the social topic. In particular, it describes the necessity to include vulnerable people. This mission consists of different reforms.

The first is about framework legislation on disabilities, through a change in disability law and an improvement of their autonomy.

The second is for not self-sufficient people. This measure wants to make easier the access to health and social services. Then, the level of not self-sufficient has to consider the necessity of care. In addition, it is necessary to give a multi-dimensional evaluation and create individual projects.

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<sup>274</sup> Istituto Superiore di Sanità. "Presentazione Convegno Finale Fondo per l'Alzheimer e le Demenze"

<sup>275</sup> Parlamento Italiano. "Il Piano Nazionale di Ripresa e Resilienza". Accessed on 25 May 2024, <https://temi.camera.it/leg19/pnrr.html>

<sup>276</sup> Italian Government. "NRRP: missions and components". Accessed on 25 May 2024, <https://www.governo.it/en/approfondimento/nrrp-missions-and-components/19325>

About investments, they aim to help vulnerable people by the enforcement of social services, the autonomy of older and helping parenthood.

The second investment wants to improve older autonomy that refer to access to houses and job.

The third investment is on “*housing first*” and post house.

The first concept refers to the creation of municipal houses for people in particular conditions of vulnerability that could stay in the home for twenty-four months. This choice has to be followed by the company through specific social project. The second concept involves centres of service for homeless.

In the component three of the same mission, older and people with disabilities are considered only for the improvement of home care and disabled centres.<sup>277</sup>

Initially, looking at the PNRR emerged that there are measures for older people, especially for finding a home, access to services and job. The issue was that dementia in this financial tool adopted by Italian government was not considered.

For this reason, lots of associations pressure on government with the aim that PNRR considered the new policy for not self-sufficient people. The proposal was accepted and it was created through the collaboration of lots of association of Italian civil society, that giving a multidimensional approach to this topic.

In the first phase in January 2021, the government added little information in the PNRR for older with disabilities. As a consequence, civil society presented a proposal for the future of these vulnerable individuals. The following government approved the draft law about a reform on not self-sufficient people.<sup>278</sup>

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<sup>277</sup> Council of European Union. “Allegato riveduto della decisione di esecuzione del consiglio relativa all’approvazione della valutazione del piano per la ripresa e la resilienza dell’Italia”. Bruxelles. Published on 8 July 2021. Accessed on 25 May 2024, <https://op.europa.eu/en/publication-detail/-/publication/c5989846-e08b-11eb-895a-01aa75ed71a1/language-it>

<sup>278</sup> Patto per un nuovo welfare sulla non autosufficienza. “PNRR e riforma”. Accessed on 25 May 2024, <https://www.pattononautosufficienza.it/pnrr-e-riforma/>

The plan becomes legislation on 11 March 2024 with the object “*Delegations to the Government in the field of policies for elderly*”, in which for the first time it is considered a system of Welfare for old people with disabilities.

It treats active ageing, social inclusion and prevention. Some actions could be prevention projects, initiatives to avoid loneliness and social exclusion, interventions for home care, older activities for communities, housing policies, access to services, quality life, socialisation, empowerment of health and social services in the territories.

Then, another important part of this law is about the improvement of caregiving through formation, support and giving economic benefits.<sup>279</sup>

In conclusion, the Plan for Not Self-Sufficient 2022-2024 finds important financial resources in the PNRR at Mission 5 component 2.

It is based on principles of universality and proximity to people and communities. It considered the importance of work on prevention in order to avoid urgency interventions.

These considerations emerged at national level after the COVID pandemic, when the impact of assistance of older people creates big gap. Consequently, the prevention projects, that are usually not relevant, become necessities.

With the PNRR the state wants to integrated health and social sector in order to gain the object of Mission five. The decision to invest also in infrastructures would to give expansion to home care projects.

Different decrees have to base to these areas: disability definition and reorganisation of bureaucratic system, disability ascertainment, realisation of independent individual project, technological development, upgrading of public services about inclusion system, creation of disability national guaranteeing.

The subjects of the plan are older not self-sufficient people with high and low care level.

In conclusion through this Plan the national administration would give reply to wide fragility situation, by legislative tools implemented by programmatic instruments.<sup>280</sup>

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<sup>279</sup> Gazzetta Ufficiale, “Legge 23 Marzo 2023 n. 33”. Accessed on 25 May 2024, <https://www.gazzettaufficiale.it/eli/id/2023/03/30/23G00041/sg>

<sup>280</sup> Ministero del Lavoro e delle Politiche Sociali. “Piano per la non autosufficienza 2022-2024”



## CONCLUSION

In this elaborate it has been treated the topic of dementia.

For a long time it has been considered a “normal consequence” of ageing. In spite of this many people continue to believe in this consideration, today researchers deny this affirmation.

In fact, dementia is not an inevitable effect of ageing, but it is a syndrome that affects the brain and consequently different human functions. Despite of general opinion, it is not involved in mental disabilities.

Given the increasing number of people affected by dementia and considering that for 2050 the number will increase to 139 million,<sup>281</sup> the World Health Organization affirms that dementia and dementia care have become an international “*public health priority*”.

The most important document elaborated by the WHO with these principles is the “*The global action plan on the public health response to dementia 2017-2025*”.

From this report emerges the necessity to look at this disease not only through medical lenses, but also from the human rights perspective. This provokes a “*paradigm shift*” that involves a change in dementia approach.<sup>282</sup>

My research has analysed the protection of dementia, not only as a “*moral duty*” of society, but as the enjoyment of inviolable human rights.

For this reason, governments have to consider it as a public priority in their national agenda. The principal issue is linked with the lack of interest for this topic. This has been demonstrated by the presence of social and economic barriers that continue to exist, despite the international system has elaborated tools and recommendations to influence states.

The missed measures adopted in the field of dementia also highlights the non-fulfilment of the Convention on the Rights of Persons with Disabilities. According to this important international document, the level of disability is also given by the environment. Only

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<sup>281</sup> Gauthier S. et al. “World Alzheimer Report 2022: Life after diagnosis: Navigating treatment, care and support”

<sup>282</sup> United Nations. “About the human rights of persons with disabilities.”

through the removal of social, economic and political barriers a person with disability could realize fundamental rights, reducing the level of dependency on others.

This condition exposes people with different disabilities to be vulnerable, and as a consequence to be subject to human rights violations.<sup>283</sup>

A change in national policies is possible only with the effective participation of people with disability in the decision-making process. In the specific case of people affected by dementia, it is important not only their participation but also the participation of their caregivers.

In this way it could be possible to guarantee the self-determination, right to choose, effective participation, empowerment, equal opportunities, adequate standard of living and quality of life of people affected by dementia.

In addition, the research of data in the literature has been difficult due to lack of medical documents. The human rights lens in the study of dementia is not developed and for this reason it is difficult to think about other types of solutions to protect and prevent this illness.

Then, another issue is linked by the little data collected from poor countries (because most of them belong to rich states).

Moreover, the majority of people in the world has not been submitted to dementia diagnosis because of the stigmatisation related to this disability.

What is highlighted between the different chapter is the problem related to the life after a dementia's diagnosis.

First of all, people affected by this disease are exposed to discrimination by the social context. In fact, the individual is not only discriminated for disability, but also for other factors like age, sex, religion, sexual orientation, refugee status and so on. In this case we talk about intersectional discrimination.

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<sup>283</sup> Rhona K. M. Smith. "International Human Rights Law"

Specifically, it has been analysed the reality of LGBTQ2+ communities in which the carer and the lover with disabilities are obliged to be alone because of the unacceptance of their relation from family and community.<sup>284</sup>

Another example is represented by indigenous people, that don't accede to health services.

In addition, another forgotten situation is represented by people in war contexts. In these cases their disabilities is not considered and humanitarian actors do not protect them.

No form of care is given and international actors lose sight of disability. Dementia seems to be "hidden" and not relevant.<sup>285</sup>

Secondly, health costs represent a relevant point of discrimination. Giving the level of poverty of lots of families, worsen by the global pandemic in 2020, they are excluded from health and social services, care quality and care support.

It is fundamental to consider that stigmatisation is not only towards the person affected by dementia but also towards the informal caregiver. This type of task changes also in relation of sex. Lots of women are involved in the role of carer.

Through this elaborate, it has been observed the fundamental role of caregivers, due to lack of governments to reply to care sector.

Families are obliged to adopt solutions, and this creates stressed situations. Then, they face lots of economic difficult because access to services and a possible admission to a rest home involve lots of money.

Another expensive choice is the hiring of an external caregiver. Often this category of worker is not qualified. For this reason, also the training of specialized workers could be a cost supported by the state.

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<sup>284</sup> Bourkel E., Ferring D., & Weber G. "Perceived rights of and social distance to people with Alzheimer's disease"

<sup>285</sup> Alzheimer's Disease International. "Forgotten in a crisis: Addressing dementia in humanitarian response".

Generally, governments haven't interest in managing care sector and caregivers. Consequently, families face with not qualified carers that have lots of other issues (like dependency, poverty, mental disability and so on).

Unfortunately, given the lack of policies to protect and support people affected by dementia, often social and health services could give a place in an old age home as the only solution.

In addition, through the Covid-19 pandemic, rest homes have been submitted to different problems, such as the decreasing quality of services, lots of death, loneliness, blocked waiting lists because of the necessity to stop virus.

For all these reasons, the consideration of dementia as a public health priority becomes essential. Even if lots of states have adopted policies linked to this ill, the problem was that dementia was involved in other sectors and/or there were not funds to financial possible projects.

So, giving a specific relevance to this topic, it is possible to make the second step: creating a specific legislation on dementia in every state, in which person affected by dementia is the “*film-maker*”.

Then, the third step is the elaboration of policies based on the person-centred approach. It also involves the elaboration of personalized care panning.

This characteristic is essential because a unique model of care doesn't reply to everyone need. Consequently, the care model should be adapted at the individual and environment in which live.

The importance of personalized care plans is also highlighted by the World Health Organization in the “*Guidance on person-centred assessment and pathways in primary care*”. In order to realize this approach, it is necessary a train of social and health workers and the involvement of different stakeholders. It is based on

“*[...] an assessment of individual needs, preferences and goals; the development of a personalized care plan; coordinated services, driven towards the single goal of*

*maintaining intrinsic capacity and functional ability and delivered as much as possible through primary and community-based care”.*<sup>286</sup>

During the elaboration individual planning it should also consider the principle affirmed in 2030 Agenda: “*no one left behind*”.<sup>287</sup>

This concept reflects the intrinsic nature of human rights, in which everyone should have the same rights and possibilities of everyone, without the deny of them because of any type of social, economic, political and cultural barriers.

The fourth step could be the creation of structures able to avoid loneliness and other possible pandemic diffusion.

Moreover, in structures for people with dementia should be specialised social workers that follow professional training.

Today, many rest homes have workers not suitable for this specific disease.

Through the application of the “*The global action plan on the public health response to dementia 2017-2025*” member states should adopt a set of policies and projects in order to realize the objectives of these documents.

In particular, by the analysis of different instruments adopted by the international system, it becomes necessary that states started to work hard on prevention and on risk factors.

Adopting a series of policies and instruments like these, governments could give a strong impact on dementia.

This type of disability couldn't be cured, but the process from a stage to another could be slow down.

In the project presented and activated in Treia, a little town situated in Italy, it was interesting how people were interesting in participating in conferences about this topic.

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<sup>286</sup> World Health Organization. “Integrated care for older people (ICOPE): guidance on person centred assessment and pathways in primary care”. Handbook. Geneva. 1 January 2019. Accessed on 30 April 2024, <https://www.who.int/publications/i/item/WHO-FWC-ALC-19.1>, p. 3

<sup>287</sup> World Health Organization. “Decade of Healthy Ageing 2020-2030”

Also the proposal of a screening test for population, viewed the participation especially of caregivers.

Many people in the third age were worried about the possible result of this test and for this reason they decided to do not take it.

Only when one started this type of initiative understand the stigma toward dementia, and more specifically, on Alzheimer.

It seems to be the only ill for which you must not fight. People prefer other screening tests than dementia screening test.

In this case, it becomes essential the involvement of the general practitioner because of the direct connection with all persons in the territory. The difficulty emerges from their collaboration it is represented by the lack of time because they have lot of job.

If the general practitioner finds people that need for a screening it could be

For this reason, developing awareness and information is essential.

The creation of dementia friendly communities represents an important step to reduce stigmatisation and involve persons affected by dementia in society, involving them in the decision-making process. On the contrary, today lots of cities result unwelcoming for dementia persons.

It depends on the political will to adopt action in line with international recommendations.

What we should hope for the future is the creation of models able to help the person affected by dementia in their house and in the effective participation in social context.<sup>288</sup>

In addition, this initiative could train different stakeholders in society such as municipal administrators, law enforcement agency, social and health workers.

This approach is essential to create a community that is able to adopt right behaviours towards a person with dementia. Especially, in the case of a person in the first stage of the ill, it is important to know what to do in case of memory loss, disorientation and confusion.

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<sup>288</sup> Trabucchi Marco, “Una lunga vita buona. Il futuro delle RSA in una società che invecchia”

This should happen in shops, coffee bar, pharmacy, church, every place frequented by the person in question.<sup>289</sup>

In this way, we should be responsible for each other and we could demolish indifference barriers.

In order to create this social commitment, it is indispensable the coordination of municipal administrators that is part of a national dementia plan. It has based on the cross-cutting principles: human rights; empowerment, universal health and social care, equity, multisectoral collaboration, attention to prevention and care, evidence-based practice.

As affirmed by the World Health Organization, member states have to elaborate national dementia plans, working in collaboration with all levels of governance, in order to give reply to this important human need.<sup>290</sup>

In this process also the using of technology could be relevant for a greater support to dementia care. The investment of Irish government for the international technological empowerment highlights the importance of technologies in the field of disability.

In general Alzheimer and dementia topics start to interest people when one of their lover discover this diagnosis. Moreover, every culture has a different approach to dementia, and generally, to disability. It is important to find the best way to guarantee the protection of human rights in every regional system.

The system has to safeguard the dignity of person with disability, in all context in which it could be damaged. It is also necessary to work on loneliness, that could be the triggering factor of progression of different ill like dementia.<sup>291</sup>

The gap between prevention and care couldn't be not considered, all level of governances should commit to adopt solutions.

In conclusion, "*ageing is not a disease*" but it exposes human beings to be more vulnerable and to ask for caring. It is important to remember that

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<sup>289</sup> Trabucchi Marco. "Aiutami a ricordare".

<sup>290</sup> World Health Organization. "Towards a dementia plan: a WHO guide"

<sup>291</sup> Trabucchi Marco, "Una lunga vita buona. Il futuro delle RSA in una società che invecchia"

*“[...] the person is not their dementia illness; rather, the condition is only one aspect of their current being. It is important to focus on the strengths if the person living with dementia rather than on diminished or lost abilities and capabilities. [...]”*<sup>292</sup>.

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<sup>292</sup> Love K. and Pinkowitz J. “Person-centred care for People with Dementia”. *Generations: Journal of the America Society on Ageing*. Vol. 37. No. 3. 2013. Accessed on 25 May 2024, [https://www.researchgate.net/publication/289724759\\_Person-Centered\\_Care\\_for\\_People\\_with\\_Dementia\\_A\\_Theoretical\\_and\\_Conceptual\\_Framework](https://www.researchgate.net/publication/289724759_Person-Centered_Care_for_People_with_Dementia_A_Theoretical_and_Conceptual_Framework), p. 26



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