Dementia in Europe Yearbook 2024

Independent living and housing

Alzheimer Europe

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Contents

1. Preface 4
2. Introduction 6
 2.1. Background to this report 6
 2.2. Methodology 6
 2.3. Caveats to this report 8
3. Key themes within the concept of independent living 9
 3.1. Definition of independent living 9
 3.2. Definition of deinstitutionalisation 9
4. Current policy context 11
 4.1. United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) 11
 4.2. The Charter of Fundamental Rights 14
 4.3. European Pillar of Social Rights 14
 4.4. European Strategy on the Rights of Persons with Disabilities 2021-2030 16
5. National policies and strategies 18
 5.1. Strategies for people with dementia 18
 5.2. Strategies on independent living 22
 5.3. Strategies for older persons or persons with disabilities 23
 5.4. Safeguarding of people 28
 5.5. Strategies for deinstitutionalisation 32
6. Housing 36
 6.1. Housing strategies 36
 6.2. Housing advice services 39
 6.3. Social protection or support services 41
 6.4. Adapted housing and residential facilities 46
 6.5. Design guidelines (housing, built environment or urban planning) 49
 6.6. Technology and adaptations 53
 6.7. Rehabilitation 58
7. Alternative concepts/models for community-based living 61
8. Good practice resources and further information 68
 8.1. Alzheimer’s associations 68
 8.2. Government and other associations 72
9. Experiences of people with dementia and carers 76
 9.1. Key issues raised by people with dementia and carers 76
 9.2. Testimonials of people with dementia and carers 81
10. Observations and conclusions 89
 10.1. Observations and conclusions 89
 10.2. Recommendations 92
11. Acknowledgements 93

1. Preface

It gives me great pleasure to introduce the Dementia in Europe Yearbook 2024, which this year focuses on independent living and housing for people with dementia across Europe.

Independent living is a well-established concept within the disability rights community, and has been at the forefront of campaigns and activism from people with disabilities and civil society organisations for a number of decades.

The concept covers a wide range of issues focusing on policy areas such as autonomy, social protection, health and care services, deinstitutionalisation, legal capacity, transport, accessibility and housing, amongst many others.

The interplay of these elements is key in ensuring that people are able to live as well as possible, as independently as possible and for as long as possible, in their communities. A number of these themes have been the focus of Alzheimer Europe's previous work, including our Dementia in Europe Yearbooks, our European Dementia Monitors and our ethics reports. Our work to date has not examined housing and/or independent living policies, nor the extent to which these concepts are applied to or include people with dementia. As such, we felt that it would be a useful opportunity to consider the two together in the 2024 Yearbook.

Dementia is recognised as a disability in the definition set out in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and should therefore be included within any policies and frameworks related to disability, including where there are references to independent living and housing. However, we know from the experience of our member organisations, that many countries still do not recognise dementia as a disability and even in those that do, the condition is not necessarily addressed in disability policies. It is disappointing to see that although there are many policy areas, practices and programmes related to disabilities more broadly, dementia is not always specifically identified within them or, in some cases, the government does not recognise that the policy should apply to dementia.

One key area which Alzheimer Europe felt was important to explore in detail was that of housing and how people living with dementia are supported to remain in their own homes or to live in a residential setting within their communities. It was encouraging to see that there is a variety of work taking place across Europe in this area, including design guidance to ensure that housing and residential settings allow people to live as independently as possible, some state support for persons to make adaptations to their housing, as well as emerging models of community-based residential living which aim to support people to continue living independently. However, the variation in approaches between countries is striking and too often, more traditional residential facilities emerged as the primary approach within countries.

I would like to draw attention to the contribution of our European Working Group of People with Dementia and European Dementia Carers Working Group. Their contributions and insights brought out a number of key issues and themes which otherwise may have been overlooked in our overview

of country policies. These included the importance of knowledge and understanding of dementia within the communities in which people live, the need for tailored support which recognises the unique circumstances of individuals, as well as the importance of maintaining the social connections that people have within their communities. As well as providing an overview of these themes, we are pleased to include testimonials written by members of both working groups, where they highlight their own experiences and views.

I also wish to thank our national member associations for their contributions, without which, this publication would not be possible. Finally, I would like to acknowledge the work of our Policy Officer, Owen Miller, in compiling this information and writing the Yearbook.

Jean Georges
Executive Director
Alzheimer Europe

2. Introduction

2.1. Background to this report

This is the first Dementia in Europe Yearbook dedicated to the subject(s) of independent living and housing. Whilst Alzheimer Europe has explored many of the related and underlying principles associated with independent living (for example, Yearbooks on social protection, legal capacity etc.), the focus of these has not specifically been on independent living.

As such, the Dementia in Europe Yearbook 2024 aims to identify the extent to which countries have concepts of independent living established within their policy frameworks, and the extent to which these apply to people with dementia. Additionally, the Yearbook 2024 seeks to identify the situation in Europe in relation to housing for people with dementia, with a particular focus on the policies and measures in place to support people to stay at home or in their communities for as long as possible.

The Dementia in Europe Yearbook aims to provide a snapshot of the current situation in relation to these different aspects across Europe, highlighting good examples in law, policy or practice, as well as reflecting the views of people with dementia, their families and carers through testimonies from the European Working Group of People with Dementia (EWGPWD) and the European Dementia Carers Working Group (EDCWG).

2.2. Methodology

In February 2024, Alzheimer Europe sent out a draft survey to a small number of members, asking for input into the questions. At its public affairs meetings attended by national member organisations in March 2024, Alzheimer Europe presented the policy context of independent living and housing, whilst also setting out its proposed approach for the Yearbook, its structure and a proposed timeline, as well as sharing the revised draft questionnaire for comments and revision from members.

In April 2024, Alzheimer Europe distributed the finalised survey to its member organisations, with a deadline set for receipt by the beginning of June 2024. In total, Alzheimer Europe received 28 responses, from 28 countries. The table shows the countries which responded to the survey, with these countries also shown in blue on the map on page 7.

Alzheimer Europe analysed the findings from the completed surveys, identifying overarching trends and themes, as well as examples and resources which may be of interest to other organisations working in the field of dementia.

Table 1 – Countries which responded to the survey

Armenia	Iceland	Poland
Belgium (Flanders)	Ireland	Portugal
Bulgaria	Italy	Slovenia
Croatia	Lithuania	Spain
Czechia	Luxembourg	Sweden
Estonia	Malta	Switzerland
Finland	Montenegro	Turkey
France	Netherlands	United Kingdom (Scotland)
Germany	North Macedonia	
Greece	Norway	

Countries which responded to the survey

2.3. Caveats to this report

The Dementia in Europe Yearbook is written with the following caveats.

The findings in sections 5 through 8 reflect the information received through the survey responses, which were completed by our national member organisations. The good practice examples and resources included within this report in section 8 are those which have been suggested by our members. The process for the development and distribution of the survey is outlined in the previous subsection, "2.2. Methodology".

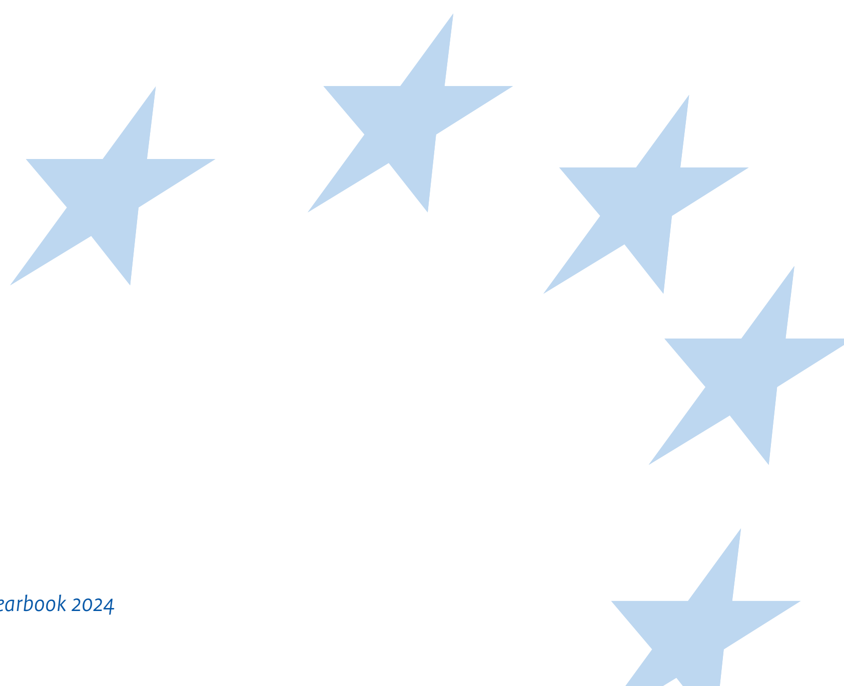
The concept of "independent living" as defined in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and by organisations in the disability movement are broad in nature and cover a range of policy areas (explored more fully in the following section). Due to the breadth and depth of the themes encapsulated, the Yearbook cannot cover all of these areas. It will therefore be more narrowly focused on the policy drivers associated with independent living, as well as those related to housing, which have relevance to people with dementia. Other related themes have been covered in previous Alzheimer Europe publications, including previous Dementia in Europe Yearbooks, European Dementia Monitors and ethics reports.

Alzheimer Europe tries to include the information collected from its survey of member organisations as fully as possible. Where a country is omitted in a section, it is because the country either has no activities in this area (for example, the country does not have a national dementia strategy) or the member from that country did not provide information on that area.

It is important to note that the existence of policies or legislation in a country, for example within a dementia strategy or other policy document, does not guarantee that the specific measures are being implemented or universally applied across that country.

Whilst Alzheimer Europe uses the UNCRPD and other frameworks as a basis for comparison across countries, we recognise that there are limitations to the UNCRPD, particularly in its applicability in practice of professionals and in the day-to-day lives of people living with complex conditions such as dementia. As such, there are examples of policy and practice from countries which have been included here, even where they may not be compliant with the UNCRPD. Alzheimer Europe does not seek to make a judgement about these resources, policies or practices; it is solely our intention to highlight that they exist within countries.

In the conclusions section, we have reflected on the common themes emerging between the different countries, as well as noting what this means for independent living and housing, in the context of the rights of people living with dementia and the UNCRPD. Where there are gaps or significant issues, these have been addressed in the recommendations.



3. Key themes within the concept of independent living

In understanding the policy context of independent living and its relevance for people living with dementia, it is important to include key definitions of some crucial aspects of the concept. The following section includes some of the definitions set out by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which we have used as the basis for the work of the Yearbook.

3.1. Definition of independent living

The UNCRPD General Comment No.5 on Article 19 – "the right to live independently and be included in the community" (also highlighted on pages 12-13) provides the following definition of independent living:

> "Independent living/living independently means that individuals with disabilities are provided with all necessary means to enable them to exercise choice and control over their lives and make all decisions concerning their lives. Personal autonomy and self-determination are fundamental to independent living, including access to transport, information, communication and personal assistance, place of residence, daily routine, habits, decent employment, personal relationships, clothing, nutrition, hygiene and health care, religious activities, cultural activities and sexual and reproductive rights. These activities are linked to the development of a person's identity and personality: where we live and with whom, what we eat, whether we like to sleep in or go to bed late at night, be inside or outdoors, have a tablecloth and candles on the table, have pets or listen to music.
>
> Such actions and decisions constitute who we are. Independent living is an essential part of the individual's autonomy and freedom and does not necessarily mean living alone. It should also not be interpreted solely as the ability to carry out daily activities by oneself. Rather, it should be regarded as the freedom to choose and control, in line with the respect for inherent dignity and individual autonomy as enshrined in article 3 (a) of the Convention. Independence as a form of personal autonomy means that the person with disability is not deprived of the opportunity of choice and control regarding personal lifestyle and daily activities".

This definition makes clear that independent living encompasses almost all aspects of a person's lived experience. Central amongst this is the ability of a person to exercise choice and control in their day-to-day life and in relation to decisions which affect them. The place in which a person resides (e.g. within their own home, a residential care setting etc.) will often affect their ability to make decisions and exercise control over decisions which affect them.

3.2. Definition of deinstitutionalisation

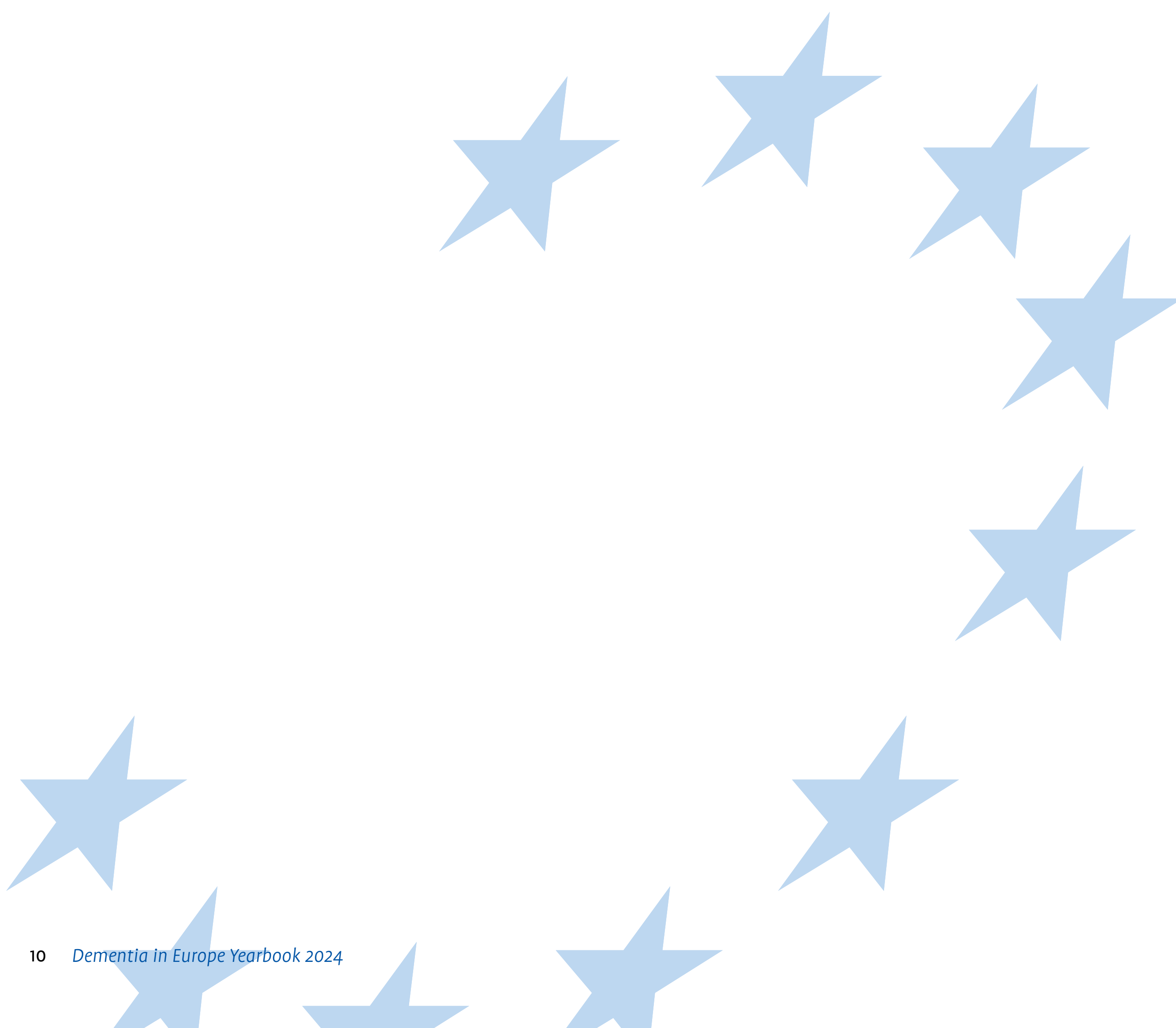
Another key theme within independent living is that of deinstitutionalisation. Again, referring to the UNCRPD's General Comment No. 5, deinstitutionalisation is addressed:

> "Both independent living and being included in the community refer to life settings outside residential institutions of all kinds. It is not 'just' about living in a particular building or setting; it is, first and foremost, about not losing personal choice and autonomy as a result of the imposition of certain life and living arrangements. Neither large-scale institutions with more than a hundred residents nor smaller group homes with five to eight individuals, nor even individual homes can be called independent living arrangements if they have other defining elements of institutions or institutionalization.

Although institutionalized settings can differ in size, name and set-up, there are certain defining elements, such as obligatory sharing of assistants with others and no or limited influence over whom one has to accept assistance from; isolation and segregation from independent life within the community; lack of control over day-to-day decisions; lack of choice over whom to live with; rigidity of routine irrespective of personal will and preferences; identical activities in the same place for a group of persons under a certain authority; a paternalistic approach in service provision; supervision of living arrangements; and usually also a disproportion in the number of persons with disabilities living in the same environment.

Institutional settings may offer persons with disabilities a certain degree of choice and control; however, these choices are limited to specific areas of life and do not change the segregating character of institutions. Policies of deinstitutionalization therefore require implementation of structural reforms which go beyond the closure of institutional settings. Large or small group homes are especially dangerous for children, for whom there is no substitute for the need to grow up with a family. "Family-like" institutions are still institutions and are no substitute for care by a family".

This definition of institutions is likely to include certain kinds of residential care and/or nursing homes, as well as certain other models of care in which the responsibilities of health, social and/or personal care are carried out by staff not specifically chosen by residents, and whereby choice and control is limited to some aspects of day-to-day life.



4. Current policy context

In this section, Alzheimer Europe provides a high-level overview of the key points in relation to the current policy context at a European and international level. In particular, this section sets out key policy developments, including those relating to independent living and housing, which have been developed and have come into effect in the past two decades.

4.1. United Nations Convention on the Rights of Persons with Disabilities

4.1.1. Relevant articles of the Convention

The United Nations Convention on the Rights of Persons with Disabilities UNCRPD) was adopted on 13 December 2006, opened for signatures on 30 March 2007 and entered into force on 3 May 2008.

For the European Union (EU), the Convention entered into force on 22 January 2011, with Ireland becoming the final Member State to ratify the UNCRPD in 2018. Each signatory is subject to reporting to the UN Committee on the Rights of Persons with Disabilities on a five-year cycle, with the most recent cycle of the review of the EU taking place early in 2022.

The Convention is intended to be a human rights instrument with an explicit social development dimension, affirming that persons with disabilities must be able to exercise all human rights and fundamental freedoms. It clarifies and qualifies how all categories of rights apply to persons with disabilities and identifies how adaptations should be made for persons with disabilities to effectively exercise their rights.

The UNCRPD contains 50 articles in total, of which the first 30 are directly relevant to the rights of the individual. Alzheimer Europe has identified 23 articles for which this subject matter has direct or indirect relevance in relation to persons with dementia, independent living and housing:

- Article 1 - Purpose
- Article 2 - Definitions
- Article 3 - General principles
- Article 4 - General obligations
- Article 5 - Equality and non-discrimination
- Article 8 - Awareness-raising
- Article 9 - Accessibility
- Article 10 - Right to life
- Article 11 - Situations of risk and humanitarian emergencies
- Article 12 - Equal recognition before the law
- Article 14 - Liberty and security of person
- Article 15 - Freedom from torture or cruel, inhuman or degrading treatment or punishment
- Article 16 - Freedom from exploitation, violence and abuse
- Article 17 - Protecting the integrity of the person
- Article 18 - Liberty of movement and nationality
- Article 19 - Living independently and being included in the community
- Article 20 - Personal mobility
- Article 22 - Respect for privacy
- Article 25 - Health
- Article 26 - Habilitation and rehabilitation
- Article 28 - Adequate standard of living and social protection
- Article 29 - Participation in political and public life
- Article 30 - Participation in cultural life, recreation, leisure and sport.

There is also an Optional Protocol to the UNCRPD, to which 22 EU Member States are signatories. However, as the Protocol deals primarily with governance and operation of the UNCRPD, rather than the rights of persons with disabilities, the articles of the Protocol have not been included here.

4.1.2. General Comments

The UNCRPD Committee provides guidance, called General Comments, about the provisions of the Convention, through detailed documents which set out how States Parties should interpret and implement the Articles of the Convention, as well as how the Committee will do so when conducting reviews of the adherence of States Parties. In this section, we briefly outline four of the General Comments which are most relevant for independent living and housing, highlighting the key themes identified by the guidance.

General Comment No. 1 (2014) – Article 12: Equal recognition before the law

General Comment No. 1 notes that equality before the law is a general principle of human rights and is indispensable for the exercise of other human rights, elucidating that Article 12 does not set out additional rights for people with disabilities, but rather describes the elements and conditions which must exist to ensure equality before the law for people with disabilities.

The Comment places a specific focus on the position that all people with disabilities have full legal capacity, specifically that equal recognition before the law is a universal attribute inherent in all persons by virtue of their humanity, which should therefore be upheld for persons with disabilities on an equal basis with others. Furthermore, it is explained that legal capacity is necessary for the exercise of civil, political, economic, social and cultural rights. The General Comment also highlights that persons with cognitive or psychosocial disabilities are disproportionately affected by substitute decision-making regimes and denial of legal capacity.

In the context of independent living and housing, the key concept within this article is ensuring that individuals are able to exercise choice and control over decisions which affect them, including where they live and how they participate in the communities in which they live.

General Comment No. 2 (2014) – Article 9: Accessibility

General Comment No. 2 highlights that accessibility is a necessary precondition for people with disabilities to live independently and participate fully and equally in society, explaining that without access to the physical environment, transportation, information and communication etc., people with disabilities would not have equal opportunities for participation. It is also noted that people with disabilities face both technical and environmental barriers, often in the built-environment, which can prevent or discourage access to places or services.

In the General Comment, the Committee notes that as part of its interactive dialogues with States Parties, a common challenge has been the lack of an adequate monitoring mechanism for practical implementation of accessibility standards and relevant legislation. In some States Parties, monitoring was the responsibility of local authorities that lacked the technical knowledge and the human and material resources to ensure effective implementation.

It is important to note that the General Comment examines accessibility across a broad range of areas, including the built environment, services, digital infrastructure etc. However, in the context of independent living and housing, our report is primarily concerned with those relating to the built environment and design of accommodation etc.

General Comment No. 5 (2017) – Article 19: Living independently and being included in the community

General Comment No. 5 is specifically focused on the equal right of all people with disabilities to live independently and be included in the communities in which they live, with the freedom to choose and control their lives. It primarily concerns the obligations of States Parties, whilst also noting that Article 19 is one of the widest ranging and most intersectional articles of the Convention.

It is noted that the article stems from civil and political, as well as economic, social and cultural rights including aspects such as the right to liberty of movement, freedom to choose one's residence, as well as having an adequate standard of living, clothing, food and housing. Specifically, it is noted that liberty of movement, an adequate standard of living, as well as the ability to understand and have one's preferences, choices and decisions understood are foundational elements of human dignity. Additionally, it is noted that the article is intended to incorporate a diversity of cultural approaches to human living and ensures that its content is not biased towards certain cultural norms and values, irrespective of race, colour, descent, sex, pregnancy and maternity, civil, family or carer situation, gender identity, sexual orientation, language, religion, political or other opinion, national, ethnic, indigenous or social origin, migrant, asylum seeking or refugee status, association with a national minority member, economic status or property, health status, genetic or other predisposition towards illness, birth, and age, or any other status.

The guidance highlights that people with disabilities have often been denied the ability to exercise choice and control over all areas of their lives, with many unable to live within the communities of their choice, often as a result of insufficient community supports and infrastructure, as well as the use of state funding for institutional-type facilities, which can lead to dependence, isolation and segregation. Within the General Comment, it is noted that the Committee has identified a number of barriers to the implementation of Article 19, specifically:

> "(a) Denial of legal capacity, either through formal laws and practices or de facto by substitute decision-making about living arrangements;
> (b) Inadequacy of social support and protection schemes for ensuring living independently within the community;
> (c) Inadequacy of legal frameworks and budget allocations aimed at providing personal assistance and individualized support;
> d) Physical and regulatory institutionalization, including of children and forced treatment in all its forms;
> (e) Lack of deinstitutionalization strategies and plans and continued investments in institutional care settings;
> (f) Negative attitudes, stigma and stereotypes preventing persons with disabilities from being included in the community and accessing available assistance;
> (g) Misconceptions about the right to living independently within the community;
> (h) Lack of available, acceptable, affordable, accessible and adaptable services and facilities, such as transport, health care, schools, public spaces, housing, theatres, cinemas, goods and services and public buildings;
> (i) Lack of adequate monitoring mechanisms for ensuring the appropriate implementation of article 19, including the participation of representative organizations of persons with disabilities;
> (j) Insufficient mainstreaming of disability in general budget allocations;
> (k) Inappropriate decentralization, resulting in disparities between local authorities and unequal chances of living independently within the community in a State party."

General Comment No. 6 (2018) – Article 5: Equality and non-discrimination

General Comment No. 6 is concerned with clarifying the obligations of States Parties regarding non-discrimination and equality, noting that too often the approach is one of a charity and/or medical model, which fails to acknowledge people with disabilities as rights holders.

The General Comment notes that national laws and policies often perpetuate the exclusion and isolation of people with disabilities, frequently lacking recognition of multiple and intersectional discrimination or discrimination by association, as well as acknowledging that denial of reasonable accommodation is a form of discrimination. It is also explained that laws and policies in this area are frequently not considered by States Parties as disability-based discrimination, with justifications made that the laws are necessary for the protection of individuals or to allow for actions to be taken in the best interest of individuals.

Additionally, within the guidance there is a specific focus on the repeated use of the term "dignity", highlighting the inherent dignity and worth and the equal and inalienable rights of all people, as a foundation for freedom and justice. Furthermore, it is noted that equality and non-discrimination are at the heart of the Convention and are referenced throughout, with the phrase "on an equal basis with others" linking all the non-discrimination principles.

4.2. The Charter of Fundamental Rights

The Charter of Fundamental Rights of the European Union outlines the key personal freedoms and rights enjoyed by citizens of the EU into a single legally-binding document. The Charter was declared in 2000, and came into force in December 2009, along with the Treaty of Lisbon.

The purpose of the Charter is to promote human rights within the EU. Many of the rights that are contained in the Charter were previously set out in the EU Treaties, the European Convention on Human Rights and various case law of the Court of Justice of the European Union. These contain 54 articles, spread across seven titles, including:

- Dignity
- Freedoms
- Equality
- Solidarity
- Citizen's rights
- Justice
- General provisions governing the interpretation and application of the Charter.

As with the section on the UNCRPD, the following articles taken from the Charter are those we consider as having the greatest relevance for people living with dementia and their carers, in the context of independent living and housing.

Dignity

Article 1 – Human dignity – everyone has the right to be treated with dignity.

Freedoms

Article 6 – Right to liberty and security.
Article 7 – Respect for private and family life.
Article 17 – Right to property.

Equality

Article 20 – Equality before the law.
Article 21 – Non-discrimination.
Article 25 – The rights of the elderly.
Article 26 – Integration of persons with disabilities.

Solidarity

Article 34 – Social security and social assistance.
Article 35 – Health care – under the conditions established by national law.

Citizens' rights

Article 4 – Right to good administration.
Article 43 – European Ombudsman.
Article 45 – Freedom of movement and of residence.

4.3. European Pillar of Social Rights

4.3.1. Articles of the European Pillar of Social Rights

The European Pillar of Social Rights (EPSR) was proclaimed in 2017 by the EU to act as a compass for a strong social Europe. The EPSR sets out 20 principles in three main areas:

- Equal opportunities and access to the labour market
- Fair working conditions
- Social protection and inclusion.

Unlike the UNCRPD or the Charter of Fundamental Rights, the EPSR is not a legally binding document, rather a strategic outline of the principles which should underpin and guide the policies and legislation developed by the European Union. The focus of the EPSR is primarily about access to and participation in the labour market, however, it also features a number of principles regarding

All 20 principles relate to some extent to the lives of people with dementia, their families and carers, persons with disabilities, however, we have only included those with direct relevance.

Equal opportunities and access to the labour market

Principle 3 – Equal opportunities

Fair working conditions

Principle 5 – Secure and adaptable employment
Principle 9 – Work-life balance

Social protection and inclusion

Principle 12 – Social protection
Principle 13 – Unemployment benefits
Principle 14 – Minimum income
Principle 15 – Old age income and pensions
Principle 16 – Health care
Principle 17 – Inclusion of people with disabilities
Principle 18 – Long-term care
Principle 19 – Housing and assistance for the homeless
Principle 20 – Access to essential services

4.3.2. European Pillar of Social Rights Action Plan

In March 2021, the European Commission published the European Pillar of Social Rights (EPSR) Action Plan, setting out how to implement the principles of the EPSR. Few of the Commission's commitments and recommendations are directly relevant for this subject, however, some have broader relevance, which we have included below.

It is necessary to note here that there are a number of areas within the EPSR (and thus the Action Plan) which are either joint competences or the competence of Member States. As such, we have split out the Commission's commitments (where it can act) and its recommendations (where it calls on other stakeholders to act).

The European Commission committed to:

- Launching the Affordable Housing Initiative piloting 100 renovation districts
- Proposing an initiative on long-term care to set a framework for policy reforms to guide the development of sustainable long-term care that ensures better access to quality services for those in need
- Launching a high-level expert group to study the future of the welfare state, its financing and interconnections with the changing world of work
- Starting a pilot project to explore a digital solution to facilitate the interaction between mobile citizens and national authorities, and improve the portability of social security rights across borders (European Social Security Pass), building on the initiative for a trusted and secure European e-ID
- Adopting a delegated act to define a methodology for reporting on social expenditure under the Recovery and Resilience Facility
- Continuing to steer (by means of the European Semester Process) national reforms and investments, including in the implementation of the recovery and resilience plans, in a way that furthers the implementation of the principles of the Social Pillar
- Agreeing a revised version of the Social Scoreboard with Member States to better reflect the policy priorities and actions set out in this Action Plan.

The European Commission encourages:

- Public authorities to ensure the effectiveness and coverage of social safety nets and access to enabling services for those in need
- Member States to further extend access to social protection, in line with the Council Recommendation on Access to Social Protection
- Member States to use the EU funding opportunities, notably through their national recovery and resilience plans and their Social Fund Plus (ESF+) and Regional Development Fund (ERDF) operational programmes to support the national implementation of the EPSR
- Member States to advance and conclude the negotiations in Council on the Commission proposal for a horizontal Equal Treatment Directive
- Member States to transpose the Work-life balance Directive.

4.4. European Strategy on the Rights of Persons with Disabilities 2021-2030

In March 2021, the European Commission adopted "Union of Equality: Strategy for the Rights of Persons with Disabilities 2021-2030", aiming to improve the lives of persons with disabilities in Europe and around the world. It builds on the previous European Disability Strategy 2010-2020 and aims to address the barriers which remain and which leave people with disabilities at a higher risk of poverty and social exclusion. The Strategy also acknowledges the importance of recognising and meeting the needs of the full diversity of disabilities, including those with long-term physical, mental, intellectual or sensory impairments, including disabilities which may be "invisible".

The objective of the Strategy is to progress towards ensuring that all people with disabilities in Europe, regardless of their sex, racial or ethnic origin, religion or belief, age or sexual orientation:

- Enjoy their human rights
- Have equal opportunities, equal access to participate in society and economy
- Are able to decide where, how and with whom they live
- Move freely in the EU regardless of their support needs
- No longer experience discrimination.

The Strategy is divided into the following sections:

- Accessibility – an enabler of rights, autonomy and equality
- Enjoying EU rights
- Decent quality of life and living independently
- Equal access and non-discrimination
- Promoting the rights of persons with disabilities globally
- Efficiently delivering the strategy
- Leading by example.

From the Strategy, we have included examples of European Commission commitments and recommendations relevant to the topic of independent living and housing, however, it is not a comprehensive list of all those contained within the strategy. As with the EPSR, there are a number of policy issues contained within the strategy which are either joint competences or the competence of Member States. As such, we have split out the Commission's commitments (where it can act) and its recommendations (where it calls on other stakeholders to act).

The Commission committed to:

- Review the passenger rights regulatory framework including rights for persons with disabilities and reduced mobility in transport by air, water, bus and coach
- Revise its Urban Mobility Package to strengthen Sustainable Mobility Planning which requires Member States to adopt local mobility plans, taking into consideration the needs of different groups, including persons with disabilities
- Launch a study on social protection and services for persons with disabilities to examine good practices on disability benefits, old-age income, health insurance, cash and non-cash benefits as well as on extra-costs due to disability
- Provide guidance to support Member States in further reforms of social protection focusing on persons with disabilities and disability assessment frameworks, including upon requests through the Technical Support Instrument
- Work with Member States to implement the 2000 Hague Convention on the international protection of vulnerable adults in line with the UNCRPD, including by way of a study on the protection of vulnerable adults in cross-border situations, notably those with intellectual disabilities, to pave the way for its ratification by all Member States
- Explore funding opportunities through the new Citizens, Equality, Rights and Values Programme (CERV) to foster engagement of citizens with disabilities on equal basis with others
- Support Member States to use EU Funds in compliance with the UNCRPD and respecting accessibility ensuring that EU funds do not support actions that contribute to segregation or exclusion.

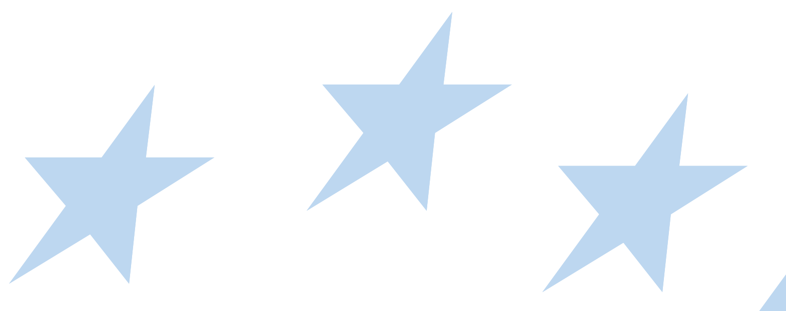
The Commission called on the Member States to:

- Implement good practices of deinstitutionalisation in the area of mental health and in respect of all persons with disabilities, including children, to strengthen the transition from institutional care to services providing support in the community
- Promote and secure financing for accessible and disability-inclusive social housing, including for older persons with disabilities, and address challenges of homeless persons with disabilities
- Define measures to further tackle gaps in social protection for persons with disabilities to reduce inequalities, including by compensating extra costs related to disability and eligibility for disability benefits
- Enable the adoption of the Commission proposal for a horizontal directive on implementing the principle of equal treatment outside the field of employment, including disability
- Support cooperation between the EU and the national UNCRPD frameworks and members of European networks of rights defenders
- Ensure partnership with regional, local authorities, representative organisations of persons with disabilities, civil society, fundamental rights bodies and other stakeholders in the design and implementation of EU funds.

Additionally, the Strategy contains a number of "flagship initiatives" which the Commission is committed to delivering, including:

- AccessibleEU: a knowledge base providing information and good practices on accessibility across sectors
- European Disability Card: the European Commission will propose a European Disability Card that would apply to all EU countries. The card will make it easier for persons with disabilities to get the proper support when they travel or move to another country in the European Union
- Guidance recommending improvements on independent living and inclusion in the community. This will contribute to enabling persons with disabilities to live in accessible, supported housing in the community or to continue living at home
- A framework for social services of excellence for persons with disabilities
- A package to improve labour market outcomes of persons with disabilities
- Disability Platform: The Disability Platform brings together national authorities responsible for implementation of the Convention, organisations of persons with disabilities and the Commission. It supports the implementation of the strategy and enhances cooperation and exchange on implementing the Convention.
- Renewed HR strategy for the European Commission, including actions to promote diversity and inclusion of persons with disabilities.

On 20 November 2024, the European Commission released a Notice on "Guidance on independent living and inclusion in the community of persons with disabilities in the context of EU funding". The guidance provides recommendations to Member States on the use of EU funding to support the transition from institutional care to community-based services and independent living for people with disabilities. As well as highlighting the existing policy context for independent living, the Notice provides practical guidance on the use of EU funding to promote the realisation of the right of people with disabilities to live independently and be included within their communities. The guidance also highlights examples of measures funded by the EU in Member States, which have fostered the development of community and family-based services, as well as support for independent living and the implementation of deinstitutionalisation strategies. Additionally, the Annex to the Notice provides a self-assessment tool for operations and projects, in the context of both the Charter of Fundamental Rights and the UNCRPD.



5. National policies and strategies

Alzheimer Europe wished to determine the strategic and policy positions of countries in relation to independent living and housing, examining the provisions of strategies or other relevant policy documents (e.g. strategies for older people or people with disabilities etc.). As such, we asked our members to outline what, if any, governmental policies were in place.

5.1. Strategies for people with dementia

Armenia

Armenia reported that its National Dementia Plan, launched in March 2023, includes a commitment to develop a dementia facility, however, the details of this facility are not clear and funds still need to be allocated for this initiative.

Czechia

In the Czech National Action Plan for Alzheimer's and Related Illnesses 2020-2030, launched in 2021, goal 1.3 specifically commits to "creating the conditions for dementia patients to stay in their own social environment for as long as possible", through the use of assistive technologies, such as monitoring.

Estonia

Whilst Estonia does not have a dementia strategy, there is a state-funded Dementia Competence Centre (DCC), founded in 2018, which deals with development activities related to dementia. The DCC's own strategic plan (2023-2027) takes into account the objectives of Alzheimer Europe and as well as the structure of the World Health Organization's (WHO) Global Dementia Observatory.

The aim of DCC is to improve the care and quality of life of people with dementia, with a focus on integration of service provision, training of service providers and stakeholders, supporting people with dementia and their families, as well as coordinating academic research, communication and social awareness of dementia-related topics. The DCC also coordinates support groups and organises memory cafés, and provides education and training seminars on various topics regarding dementia.

France

Currently, there is no national dementia strategy in France, however, work had commenced to develop a national neurodegenerative diseases strategy (2024-2028), prior to the change in government in 2024. The measure would have stated: "Explore/evaluate new ways of living at home with cognitive, psycho-behavioural, motor and non-motor physical symptoms (intermediate housing, Alzheimer's shared accommodation, Alzheimer's village etc.)"

The specific goals of the measure were:

- To study the conditions, including financial ones, allowing people with neurodegenerative diseases to remain in intermediate housing (independent residence, inclusive housing) throughout the progression of their illness
- To define development priorities.

The dedicated actions included:

- Evaluating the impact of existing Alzheimer's villages in France and abroad (measure the risks of segregation and stigmatisation, evaluate the costs in relation to the high level of supervision observed etc.)
- Identifying the added value of intermediate housing for people with neurodegenerative diseases compared to other structures.

Germany

The German National Dementia Strategy contains a broad range of commitments across different domains and is divided into four fields of action:

1. Developing and establishing dementia-inclusive communities to enable people with dementia to participate in society
2. Supporting people with dementia and their relatives
3. Advancing health and long-term care services for people with dementia
4. Promoting excellent research on dementia.

Under the first field of action, there is a dedicated strand on housing: "1.8 Developing housing concepts for people with dementia". Under this, sits a number of specific action points:

- 1.8.1 Housing counselling services for people with dementia
- 1.8.2 Updating the digital aids listed in the Nursing Care Aids Directory
- 1.8.3 Support for housing in older age
- 1.8.4 Counselling on living in group homes for people with dementia
- 1.8.5 Neighbourhood integration of nursing homes.

Greece

Greece's national dementia plan was published in 2016, with implementation commencing in 2018. It has been incorporated into the National Mental Health Action Plan 2021-2030. The strategy contains 10 axes, the 1st which states "Completion of the abolition of institutional care, abolition of the departments of chronic patients in the remaining psychiatric hospitals, with the parallel development of services for people with Alzheimer's disease and related disorders as well as the development of psychogeriatrics." Under this axis, a number of specific actions are envisaged to support people with dementia to remain at home for as long as possible, including:

- Creation of more mobile units and home care services to support patients and families at home in all regional units of Greece
- Completion of a network of older people centres for people with dementia in all Greek cities with a population of over 10,000. Establishment and operation of at least one older people centre for dementia per mental health sector
- Enhancing the care of people who have different care needs through third parties, including incentivising neighbourhood caregivers
- Providing incentives to relatives to take care of their family members, such as financial support, facilitation of working hours or teleworking, support from community structures with immediate response in case of relapse crisis management and home treatment.

Iceland

Iceland's national dementia plan was launched in April 2020 and contains six overarching areas:

1. Self-determination, patient involvement and legal framework
2. Prevention
3. Timely diagnosis of dementia at the right place and follow-up after diagnosis
4. Functionality, self-help and support
5. Proper service based on the level of dementia
6. Scope, research, knowledge and skills.

In relation to independent living, it specifies that people with dementia should have access to services at the right place, at the right time. Additionally, it notes that all service providers should be coordinated, with the need for the person to be assessed using the RAI-homecare instrument.

Ireland

The Irish National Dementia Strategy was launched in 2014. One of the frameworks cited in this Strategy is Future Health (A Strategic Framework for Reform of the Health Service 2012-2015) which commits to caring for more people in their homes for as long as possible, rather than in residential care. It commits to keeping people healthy throughout the life course, and to treating people at the lowest level of complexity that is safe, timely, efficient and as close to home as possible.

Under this Strategy, the Health Service Executive (HSE) also considers how best to configure resources currently invested in home care packages and respite care so as to facilitate people with dementia to continue living in their own homes and communities for as long as possible and to improve support available for carers.

Further to this, The Model of Care for Dementia in Ireland was published in 2023, and it is the guiding framework under which work is completed. Target 30 under this framework outlines, "Every person with dementia assessed as requiring home-based care should be provided with personalised and flexible supports that meet both their personal and psychosocial care needs in their home."

Italy

Italy's national dementia plan was launched in 2015 and covers four main areas:

1. Promote health and social care interventions and policies
2. Strengthen the network of services for dementia based on an integrated approach
3. Implement strategies for promoting appropriateness and quality
4. Improve the quality of life of people with dementia and their families by supporting empowerment and stigma reduction.

However, there are no specific actions for achieving independent living in the plan.

Luxembourg

Luxembourg's national dementia plan was published in 2013 and has continued through work such as the national Dementia Prevention Programme. Section 4.2 of the Luxembourgish national dementia plan outlines the importance of supporting people to remain living at home for as long as possible, under section 4.2 "Dementia as a societal issue".

Malta

In January 2024, the Maltese government launched The National Dementia Strategy for the Maltese Islands 2024 – 2031, titled "Reaching New Heights", which aims to significantly improve the quality of services and the quality of life of persons living with the condition. It lays out a vision for how people with dementia might live their lives, as well as the necessary societal, policy, and service adjustments needed to facilitate this. The objectives include:

- Increasing awareness and understanding of dementia by improving inclusivity and accessibility in community settings that maximise the opportunities for health, involvement, and security for everyone
- Reducing the risk of developing dementia by taking precautionary measures, such as increasing physical activity, preventing and reducing obesity, promoting balanced and healthy diets, quitting smoking and alcohol use, encouraging social engagement, promoting cognitively stimulating activities, preventing and managing diabetes, hypertension, and depression
- Obtaining an early diagnosis to enable individuals to make advance care and legal planning while they are still able to make important decisions
- Instilling a positive approach and empowerment, focused on helping persons with dementia and their families to live well with the condition
- Improving education and training to develop a dementia-capable workforce with skills to deliver high-quality services and support
- Strengthening seamless integrated person-centred care across all settings
- Advancing towards better dementia prevention, diagnosis, treatment, and care by implementing dementia research.

Netherlands

The Dutch national dementia strategy 2021-2030, was launched in November 2020 and contains three parts: Research, participation in society and support/care for people with dementia. Whilst there is overlap with independent living and housing, neither are specifically addressed within the plan.

Norway

The Norwegian Dementia Plan 2025 was launched in December 2020. It contains few direct measures addressing independent living for people with dementia, however, the topic is widely covered in the plan. Among other things, it describes the need to develop new living arrangements for people with dementia, as well as stating that housing policy must consider that people with dementia have various needs and that the proportion of older people living alone is higher than in the rest of the population. Many of the housing-related measures mentioned in the dementia plan are anchored in other policies, such as the importance of universal design and the development of age-friendly communities. However, the plan does include a number of measures which may help people with dementia stay at home longer, such as the importance of a cohesive care service system, the development of a more dementia-friendly society, and a variety of activity programmes adapted to the individual needs of people living with dementia.

Poland

Poland does not have a national dementia plan, however, the Polish Ministry of Health has announced its intention to create a National Dementia Action Plan 2025-2030. The plan is under development, however, it is not clear if the future plan will contain measures relating to independent living or housing for people with dementia.

Portugal

In Portugal, the Dementia Health Strategy was launched in June 2018. It contains a number of structural topics referring to community-based care, however, it contains nothing more specific related to independent living.

Slovenia

The Slovenian Dementia Management Strategy until 2030 was approved in July 2023, orientated towards both independent living and accommodation for people with dementia. It also emphasises the arrangement of independent living within the community framework. Measures to improve the availability and diversity, as well as the accessibility of services and programmes include:

- Establishing a network of diverse services and programmes that are interconnected, complementary, and operate in accordance with the principles and guidelines of the resolution (available evenly throughout Slovenia under the same financial and professional conditions, accessible, including the use of modern information and communication technology; primarily community-oriented work)
- Promoting and developing, as well as introducing innovative approaches in the field of public, developmental, experimental, and supplementary social welfare programmes, primarily designed based on the specific needs of users (such as residential units, crisis accommodations, work with users experiencing complex distress and associated mental health issues, support for people with dementia, their family members, and caregivers)
- Establishing comprehensive and quality services for individual users
- Integrating public social welfare programmes into the public network as a form of community services or community support
- Ensuring the cooperation of the state, local communities, users, and providers in defining the network of public services and programmes in the local community
- Participating in the introduction of a unified long-term care system with connected health and social services for all who need long-term care; alongside this, developing an additional social care system for individuals who will not meet the entry threshold for obtaining rights from long-term care
- Improving the information and awareness of potential users about the possibilities for inclusion in services and programmes
- Ensuring plurality and diversity of service and programme providers, with an emphasis on encouraging the involvement of volunteers.

Spain

Spain's plan for Alzheimer's and other dementias was adopted in October 2019 and contains a number of measures related to dementia. The plan establishes four axes of action, under which sit a number of specific and dedicated actions:

- Research on the determinants of the disease
- Development of health promotion policies, as well as progress in the early diagnosis and the selection of the most appropriate treatments
- Improvement in services, supports and benefits
- Raising awareness and improving societal attitudes in relation to dementia.

Action point 1.2.1 commits to: "Coordinate and generate synergies, optimising the resources and networks generated in the local initiatives currently underway in relation to IMSERSO's 'Age-Friendly Communities' and Confederación Española de Alzheimer y otras demencias (CEAFA) 'Town Councils in Solidarity with Alzheimer's."

Sweden

Sweden launched its national dementia strategy in May 2018, with actions spread across seven key strategic areas in which the government wants to secure improvements:

1. Collaboration between health and social care
2. Staffing
3. Knowledge and skills
4. Monitoring and evaluation
5. Family and friends
6. Society
7. Digital and assistive technologies.

In the strategy there are several initiatives concerning daily life for people with dementia. For example, guidance for day activities and a coordinated care pathway concerning health and social care for people with dementia.

UK – Scotland

Scotland's most recent national dementia strategy was published in May 2023 and covers a 10-year period. Delivery plans will be published every two years to address specific aspects of the strategy, with the first delivery plan produced in February 2024.

Within the strategy itself there is mention of the importance of support for independent living but no specific measurable actions or programmes.

Within the 2024-2026 Delivery Plan, there is no specific action relating to housing. However, in relation to independent living, there is a section on 'Resilient Communities', under which a number of statements are made about the need to spread good practice in community initiatives to enable people to remain at home. There is a measurable action, which is to set up a programme board, however, there is no detail of how the work of the programme board will be assessed, and no measurable deliverables that the board will be expected to achieve. There is a statement that dedicated funding will be allocated to enable a sustainable community infrastructure to grow across Scotland but no further detail.

5.2. Strategies on independent living

Belgium – Flanders

In Belgium, there are guidelines for people with mental or physical disabilities, however, for people with dementia there is no national strategy for individual independent living.

Italy

In Italy, Law No. 112/2016 "Provisions on assistance in favour of persons with severe disabilities deprived of family support", so-called "Dopo di noi". This regulates measures for the assistance, care and protection of people with severe disabilities, which are not determined by natural ageing or dementia-related pathologies, and who lack familial support. However, none of the provisions contained within the law are dementia-specific in nature.

Netherlands

In the Netherlands in 2023, the Dutch Government announced support for the WOZO (Wonen, Ondersteuning en Zorg voor Ouderen - Housing, Support

and Care for the Elderly) programme. This consists of various measures, initiatives and projects which aim to ensure that care for older people continues into the future and reflects the needs and wishes of individuals as they grow older. The key message of this programme is: "Do it yourself if possible, stay home if possible and deliver care digitally if possible". The primary aim of the programme is to ensure the independence of older people by maintaining their functionality and strengthening their self-reliance as much as possible through (re)learning skills, staying fit, using technical aids and drawing on help from their environment and communities.

Within the new programme, technology and digitalisation play a leading role in the delivery of care. This includes technology and services such as video calls with the district nurse, a robot that gives vocal prompts to take medication or a sensor that alerts the nurse if a person has fallen.

Norway

In Norway, the Bo trygt hjemme reform (Live Safely at Home Reform), launched in June 2023, aims to enable older adults to live in their own homes for as long as it is safe to do so. The reform includes an Older Persons Housing Programme. The reform and the programme have several measures directly relevant to people with dementia. Among these are more age and dementia friendly communities, an improved home care service which aims at ensuring users meet fewer and more consistent healthcare personnel, better training for healthcare professionals and increased support for next of kin. The Elderly Housing Programme stresses the importance of the construction of care homes, secure housing and nursing home places, which is necessary for people with advanced dementia who require more comprehensive care. Additionally, it includes funding and loan schemes for home adaptation.

Portugal

In Portugal, the Act of the Government nº 129/2017 establishes the Independent Living Support Model Programme that allows people with disabilities to be provided with personal assistance to carry out a set of activities that they cannot carry out alone. Personal assistance may include, among other things, activities to support hygiene and personal care, health and nutrition, travel, higher or professional training, culture and sport, job searches, participation in society and citizenship.

Eligibility is for people aged 16 or over who have a certified disability of at least 60% or who have an intellectual disability, mental illness or autism spectrum disorder, regardless of the degree of disability. This supports the person to lead an independent life, supporting them in carrying out the activities outlined in the programme.

Switzerland

In Switzerland, there has been a parliamentary debate on financing assisted living also for people receiving social welfare support. This form of housing is not yet financed for people in poorer financial situations, however, with a decision expected at the end of 2024.

5.3. Strategies for older persons or persons with disabilities

Bulgaria

In Bulgaria, there is a national concept for promoting the active life of older people, however, it only applies to people over 65 without dementia. Bulgaria continues to have a medical model for dementia and the needs of people with dementia.

Estonia

In Estonia, the Welfare Development Plan 2023-2030, has an overarching goal that Estonia becomes a country where people are cared for, and inequality and poverty are reduced, and a long and high-quality working life is supported for all. One of the central principles of the development plan is support for dignified life and independent subsistence. As part of this, the quality and availability of services for older people with dementia will be improved in order to prevent and reduce the responsibilities of informal caregivers, as well as to support the participation of informal carers in the labour market.

The aim of care services is to support people to live at home for as long as possible, however, most local authorities lack support services to help prevent cognitive conditions from worsening and to help people with dementia maintain their independence for as long as possible.

Finland

In Finland, the government programme "A strong and committed Finland Programme of Prime Minister Petteri Orpo" contains provisions on housing for older people, including: timely and adequate home care services (ympärivuorokautinen asuminen), community housing (yhteisöllinen asuminen) and 24-hour care services in accordance with individual needs. Family care for older people will be increased. The government programme includes provisions relating to older carers, such as enabling carers to take days off through service vouchers, home care services, respite care and family care.

Finland also has a "National Programme on Ageing 2030 for an Age-Competent Finland" which recognises and acknowledges the housing and service needs of older people and the growing number of people with dementia. Some of the key factors for this programme include equality, more efficient coordination and economic sustainability of services for older people, increasing the age-friendliness of housing and residential environments, and highlight the development and utilisation of Finnish technology for ageing. However, the government has not provided any financing to implement this programme.

France

In France, the law relating to the adaptation of society to aging (l'adaptation de la société au vieillissement – ASV), came into force on 1 January 2016, and gives priority to home support so that older people can live at home in good conditions. The ASV law contains measures to enable older people to best preserve their autonomy and their close caregivers to receive support adapted to their situation.

France published an "Ageing Well Strategy" in November 2023, setting out a number of measures to develop intermediate housing and to support independent living. It highlights some of the policies implemented to date, including:

- 2018-2023: Strengthening the intermediary housing supply for older people, with 7,000 people in inclusive housing, 120,000 in independent living residences, 27,000 in retirement homes and almost 15,000 living with family
- 2022: Creation of territorial resource centre, to allow older people to age at home as long as possible thanks to reinforced support at home and thus develop an alternative to the entry into an institution
- 2022-2023: Creation and deployment of independent home services in order to offer a one-stop counter to people and provide a coordinated and simplified response for support and care at home, while strengthening the attractiveness of professions and financing of services
- 2023: Creation of 4,000 places of home care nursing services and implementation of a new financing model, to strengthen home support for people with higher care needs like people with dementia.

This strategy also sets out its future priorities in this area until 2030:

- Strengthening inclusive housing to enable 27,000 people to live there by 2030, with an extension of funding in assisted integration rental loan
- Strengthening the 15,000 family reception places
- Developing independent residences by creating nearly 3,000 new homes with strengthening of financing (initiative for the development of independent residences)
- Strengthening the offer of priority districts in cities, with the renovation and modernisation of independent residences and experimentation with new support methods for elderly people residing in social housing.

In parallel, in April 2024, parliamentarians adopted a new law "Taking measures to build a society of ageing well and autonomy" which provides the legal conditions for the deployment of inclusive housing, for older people or people living with disabilities, including dementia.

Germany

In Germany, the Federal Participation Act of 2017 covers a broad range of topics related to disability, including housing. The Act amends several laws, intending to strengthen the participation of people with disabilities and improve their autonomy. For example, it reorganises supports outside of the social protection, increases the income and monetary thresholds before a person loses federal benefits, establishes independent counselling centres and peer counselling. Additionally, it simplifies procedures, and improves workplace integration management mechanisms in order to better identify the type of assistance or support needed to overcome a worker's inability or difficulties in work.

Greece

In Greece, there is a National Action Plan for the Rights of People with Disabilities, which was published in 2020. Goal 11 is focused on independent living, with the actions to achieve the goal including:

- The implementation of the personal assistant programme for people with disabilities (aged over 60) promoting independent living
- The development of a range of care services within the community to address the needs of people with disabilities who live at home or are cared for by relatives and friends
- The creation of mobile intervention units in each community centre in collaboration with social services and local authorities
- The separation of welfare benefits from employment
- The establishment of more supported living houses
- The gradual closing of the institutional structures of closed care. In collaboration with the European Association of Service Providers of Persons with Disabilities (EASPD) preparing a national strategy for deinstitutionalisation and its implementation action plan
- The delivery of autonomous housing and accessible neighbourhood programmes, including:
  - Promotion of programmes for the creation of autonomous homes based on the current legislation and the planning guidelines "Designing for All"
  - Promotion of programmes to create accessible neighbourhoods based on current legislation and planning guidelines "Designing for All"
  - Promotion of the "Live at Home" programme.

The Protected Apartment of article 9 of Law 2716/99 sets out provisions for housing in apartment buildings or single-family houses, for people with mental disorders, developmental-autism or sensory disabilities or mixed disabilities who have increased but not full self-care and self-service abilities. The main objective is the social and possible professional (re)integration, as well as avoiding the loss of acquired social or professional skills.

Protected apartments are a reflective structure within a wider programme of mental rehabilitation and are intended as the final stage of reintegration of people with mental health needs, who are not fully capable of self-care and independence. These apartments are funded by the Ministry of Health (currently 78 operate and are funded).

Protected apartments are a form of sheltered housing which aims to complete the process of transition from institution to life and reintegration into the community. It is focused on activities, skills and functionality of the individual, with an emphasis on social-type care with limited medical or nursing characteristics, and on supporting people towards social integration. The psychosocial care provided to the people living in the Protected Apartments aims to achieve the greatest possible independence, autonomy and more effective management of their daily life, so that they can function in the community successfully and aim for full independent living. It is one of the final stages of the therapeutic chain that the Mental Health system offers to people with mental illness with the ultimate goal of their treatment and resocialisation.

Iceland

In Iceland, there is a strategy called "Gott að eldast" ("Good to Grow Older") which aims to enable people to live at home as long as they can. However, the strategy is unfunded and does not contain anything specific to dementia.

Ireland

In Ireland, the National Positive Ageing Strategy includes National Goal 3: "Enable people to age with confidence, security and dignity in their own homes and communities for as long as possible.". Objectives that fall under this goal include a commitment to facilitate older people to live in well maintained, affordable, safe and secure homes, that are suitable for their physical and social needs. Another objective under this pillar includes supporting the design and development of age friendly public spaces, transport and buildings.

The National Housing Strategy for People with Disabilities 2011–2016 and its accompanying Implementation Framework aim "to facilitate access for people with a disability, to the appropriate range of housing and housing-related support services, delivered in an integrated and sustainable manner, which promotes equality of opportunity, individual choice and independent living." This continued in a second strategy, the National Housing Strategy for Disabled People 2022-2027, this strategy aligns to the principles of the Housing for All: A New Housing Plan for Ireland. The vision for this strategy is "to facilitate disable people to live independently with the appropriate choices and control over where, how, and with whom they live, promoting inclusion in the community". It also aims to enable equal access for disabled people to housing with suitable integrated support services.

Italy

In Italy, in March 2024, the government approved the Legislative Decree implementing Delegated Law 33/2023 containing the reform of non-self-sufficiency. This legislation develops the blueprint for the future of care for older people. Within this decree, the issue of independent living during ageing is addressed and guidelines are provided for senior co-housing (supportive home living for the elderly) and intergenerational co-housing. With regard to persons with dementia, an integrated individual care plan is drawn up, in which the ability to express consent to participate in the care plan and subsequent decisions, is assessed.

Lithuania

In Lithuania, there is a social services law (Socialinių paslaugų įstatymas), which indicates that adults that have a disability have a right to receive services at home, living with the family, to support their independence. As part of this, there is a social services catalogue, which indicates the provision of social services in the independent living facilities.

There was a National Social Integration Programme for the Disabled 2013-2020 that was limited to children and working age people with disabilities, with a focus on housing (home adaptation), integration into the labour market, social integration (accessibility) and access to information.

Malta

Disability

In Malta, there is a National Disability Strategy, "Freedom to Live (2021-2030)", which recommends that Malta commits to address deinstitutionalisation of persons with disabilities through the formulation of a National Deinstitutionalisation Strategy and better provision and coordination of community based-services. Specific actions on dementia are not highlighted in the National Disability Strategy, although several objectives in the National Dementia Strategy focus on independent living.

Older people

Malta also has a National Active Ageing Strategy 2023-2030 stipulating that older people with dementia are provided with post diagnostic support to live active ageing lifestyles to reduce isolation, overcome barriers imposed by the condition, and preserve or bolster self-worth by continuing contributing to society and feel useful. It also places emphasis on the provision of psycho-educational interventions to caregivers of people with dementia as this has positive effects on the success of people with dementia to live well. One of the specific recommendations in this Strategy was the establishment of a directorate responsible for dementia care. This was achieved in Q4 of 2023 and was fundamental in the creation of the second National Dementia Strategy 2024-2031.

Netherlands

As referred to on page 22, section 5.2.1, the WOZO-programme is dedicated to supporting older people, through a combination of care, housing and social supports.

North Macedonia

In North Macedonia, there is a national strategy for the rights of people with disabilities (2023-2026), where independent living and social protection are listed as priority areas in the action plan. The strategy defines a person with a disability a person with an intellectual, mental or sensory disability that, in interaction with societal barriers, can interrupt their complete and effective participation in society as equally as others. This definition of disability applies to dementia, therefore the action plan should also apply to people affected by the condition, even though it is not specifically mentioned within the document.

Portugal

In Portugal, the Resolution of the Council of Ministers nº 14/2024 approves the Active and Healthy Ageing Action Plan 2023-2026. One of the Strategic Pillars (Pillar II) is Autonomy and Independent Living, within which there are three sub-pillars:

1. Independent living
2. Safe and age-friendly environments
3. Accessible environments.

This section recognises that maintaining autonomy in the population is fundamental. It includes implementing measures intended to maintain both independent living and the population in their homes, as well as noting that independent life at home is strongly related to the existence of safe environments, whether in homes or in the community. Additionally, it is noted that maintaining autonomy and independent living implies safeguarding, accessibility and necessary services, with conditions which take into consideration at-risk populations, including people with either physical or mental disabilities.

Spain

In Spain, some regions do have strategies of this type in place, however, there is no cross-border alignment between them and they are highly dependent on the regional governments. These are mapped out in national documents such as the Mapa de Recursos Sanitarios de Esclerosis Lateral Amiotrófica (Map of Healthcare Resources for LAE), published in 2023.

Switzerland

In Switzerland, there are different initiatives on the financing of care and support for people living at home. Because care is covered by the health insurance compared to support services, it is especially important for people with dementia. At the time of writing there is an ongoing national political initiative about equal financing for outpatient and inpatient services. This is intended to shift the financial responsibility from the (better financed) outpatient services to better financed inpatient services, in an effort to support people to stay longer at home.

Turkey

In Turkey, there is a 2023-2025 strategic plan within the scope of the National Action Programme on Elderly Rights published by the Ministry of Family and Social Services, with actions set out under the following headings:

- Active and healthy ageing
- Participation in social life
- Age-friendly and accessible environments for all
- Disaster and humanitarian emergencies
- Older people's rights.

However, none of the actions or programmes are specifically related to dementia.

UK – Scotland

In Scotland, there was previously a strategy called Age, Home and Community: A strategy for Housing Scotland's Older People 2012 – 2021, which sat under the National Strategy for Older People 2011 – 2021.

The Age, Home and Community strategy has a paragraph about dementia that references the national dementia strategy that existed at the time, but there are no specific actions. There is reference to good practice in developing new-build housing suitable for people with dementia in one geographic area.

In 2017, the Chartered Institute of Housing published a Housing and Dementia Framework to help organisations to support people to live well with dementia. The framework sets out five person-centred outcomes that people living with dementia have said are important to them:

1. I receive valuable housing advice when I need it
2. My home has been adapted or designed to suit me and support me to stay at home
3. I feel listened to and involved in decisions that matter to me
4. I know about housing choices and feel able to plan for my future
5. I am supported to live safely and independently at home and to participate in the life of my community.

However, this is a self-assessment framework and there is no compulsion for its use.

5.4. Safeguarding of people

Armenia

In Armenia, Alzheimer's Care Armenia (ACA) developed dementia training for the police academy which trains new police cadets on how to recognise dementia, as well as addressing how to assist people with dementia who wander and how to assess their risk of harm.

Additionally, there is a National Dementia Helpline managed by Alzheimer's Care Armenia and a National Helpline for mental health managed by the Ministry of Health.

Belgium – Flanders

In Belgium, in recognised dementia-friendly cities and municipalities, missing persons protocols are used and updated when a person with dementia is reported missing. Another widely used tool is the emergency buttons worn around the neck or wrist, which can be pressed when in distress, such as after a fall. The response centres which receive these calls are organised by home care organisations.

Czechia

In Czechia, the Ombudsman carries out systematic visits to care facilities in which there are likely to be people who are deprived of their liberty, where the reason for the restriction of liberty is the decision of a public authority (typically a court) or the person's dependence on the care provided.

Finland

In Finland, there are models for dealing with situations such as the disappearance of a person, with searches carried out between authorities and the Red Cross Voluntary Rescue Service. Organisations concerned with the care and support of older people also share information on the prevention of elder abuse and financial exploitation. The Consumers' Association has updated material, for example, on preventing cold calls and distance selling. Additionally, the police provide information on the abuse of older people and financial abuse, including information on scams.

France

Legal protections

In France, there are legal protections for people living with "incapacity", where the person is unable to exercise their rights by themselves and representation is necessary (by a parent, guardian or curator). A system of protections exists according to the seriousness of the acts in question and can relate to independent living, including specific provisions on the preservation of housing and personal objects (for example, relating to sale of the protected person's home).

Additionally, the law guarantees adults under legal protection a stable and secure living environment and provides an obligation to keep the person's home and possessions within it for as long as possible (regardless of whether the protected adult is a tenant or owner,

under guardianship or curatorship). Decisions or advice must not expose the protected person to terminating their rental lease without ensuring that they have a new home, or lead them to sell their main or secondary residence when this is not necessary. For personal items, the representative must act to ensure that they are not separated (e.g. where the person moves to a residential setting such as a nursing home or if the sale of the home is planned). In general, guardianship judge must be contacted to authorise any provision on this subject (whether for a curatorship or a guardianship measure).

Strategy on abuse

Since March 2024, France has had a national "Strategy to Combat Abuse 2024-2027". France Alzheimer actively contributed to the development of this strategy to specifically address the situation of people with dementia. The strategy is organised around five major axes:

1. Enforce people's rights, particularly in residential facilities
2. Develop adapted, relevant and effective tools to collect reports, monitor them and respond quickly
3. Strengthen prevention, vigilance and training of professionals in contact with older people or people with disabilities (at home or in nursing homes)
4. Promote a common culture of well-treatment and develop "the power to act" of the people concerned and professionals
5. Establish a long-term control policy for medico-social establishments welcoming the older people or people with disabilities.

There is also an "Understanding Committee" ("Avancée en âge"), of which France Alzheimer is a member, run by the French organisation The Defender of Rights ("Le Défenseur des droits"), where discussions are held about abuse of rights and discrimination of people, related to their disability or age.

Germany

In Germany, there are research projects or initiatives in the field of "safety in old age", as well as a focus on this issue within the Committee for Family Affairs, Senior Citizens, Women and Youth, however, there is no national strategy.

Greece

In Greece, there are a number of phonelines and helplines which operate and aim to provide for safeguarding for older people:

- 1102 Dementia Help Live is run by Alzheimer Athens and staffed by specialised consultants and health professionals, to provide instant information, guidance, and advice. Alzheimer Athens, with the support of the Ministry of Health, the Region of Attica and the Hellenic Intermunicipal Network of Healthy Cities, created this helpline.
- Silver Alert, operated by Lifeline (a non-profit voluntary organisation), is the national coordinating programme for timely notification of citizens in cases of disappearance of older people
- National Psychosocial Support Line 10306, run by the Ministry of Health, allows all to call for any mental health issue (e.g. stress, family issues, bereavement, panic attack) to provide support, information and guidance
- National SOS Helpline 1065, also operated by Lifeline, allows for anonymous and named complaints regarding incidents of abuse or ill-treatment of older people, while also providing counselling for older people, their families and caregivers.

Ireland

In Ireland, the Health Service Executive (HSE) published Safeguarding Vulnerable Persons at Risk of Abuse National Policy and Procedures in 2014. Under this policy, people with degenerative, neurocognitive disorders such as dementia are specifically identified as part of groups that may exhibit self-neglect and thus may require safeguarding. In addition to this policy, the HSE set up the National Safeguarding Office, as well as nine Safeguarding and Protection Teams in 2015. Furthermore, an inter-sectoral national safeguarding committee was established called Safeguarding Ireland. Any suspected cases of abuse can be reported to the HSE's National Safeguarding Office or Safeguarding and Protection Teams, as well as to local GPs.

North Macedonia

In North Macedonia, different types of safeguards are referred to within the national strategy for the rights of people with disabilities, including relating to human rights protection, protected healthcare, protective measures against violence and harm. However, dementia is not specifically addressed.

Norway

In Norway, home care services and GPs are responsible for the health and well-being of a person with dementia living at home, whether alone or with relatives, and as such are key stakeholders in a safeguarding role, including identifying signs of abuse.

Portugal

In Portugal, as part of the "Active and Healthy Aging Action Plan 2023-2026", the Radar Social Programme previews the implementation of an integrated system to identify isolated older people, with the intention to include them in a social network, and ensure that people are regularly contacted. Additionally, "Senior Census, solidarity has no age" (Census Senior – A solidariedade não tem idade) carries out national operations, on a large scale, to raise awareness to identify older people in at-risk situations. Neither of these programmes are specifically focused on people with dementia (instead on older people and at-risk people), however, dementia is included under both.

Slovenia

In Slovenia, according to the Family Code, adults placed under guardianship enjoy special protection, with the guardian primarily responsible for asserting the rights of the person. The Centre for Social Work monitors the implementation of guardianship through annual guardianship reports, where the following aspects are checked: the health condition of the person placed under guardianship, their education and training, their property, their monthly income, their monthly expenses and other relevant circumstances.

According to the Domestic Violence Prevention Act, everyone, especially professionals in healthcare, childcare, educational and social institutions, must immediately notify the Centre for Social Work, the police or the state prosecutor, regardless of professional confidentiality provisions, when they suspect that a child or a person who is unable to care for themselves is a victim of violence.

Spain

In Spain, there are some provisions for safeguarding under laws modified by Royal Decree 675/2023 of 18 July – Laws for the Promotion of Personal Autonomy and the Assistance of High-dependency Persons ("Ley de la Promoción de la Autonomía Personal y Atención a las Personas en Situación de Dependencia").

Switzerland

In Switzerland, the Children and Adult Protection Authority (KESB) must set up a guardianship if the protection of the person concerned is not otherwise guaranteed. Any person can submit a risk report to the KESB, which checks whether a measure is necessary and if so, which one.

The four types of guardianship are support, representation, co-operation and comprehensive guardianship. Guardianships should be individually tailored to the person in need of protection and only go as far as necessary, as they restrict the person's right to self-determination (e.g. they can no longer dispose of their assets without restriction).

The person affected and their relatives have the right to propose a guardian; this can be a relative of the person. If a relative is appointed, the rules for reporting to the KESB are simplified. The latter can also cancel a guardianship if the protection and interests of the person in need of protection are guaranteed in another way.

If an advance care directive designates a trusted person to look after the affairs of the person with dementia, the KESB does not usually intervene. However, even in this case, KESB must still review the advance care directive and put it into effect.

Turkey

In Turkey, the National Action Plan on Older People's Rights contains targets to protect older people from treatments that harm human dignity, such as neglect, abuse, exploitation and violence. In this context, action areas are as follows:

1. Informing and raising awareness of older people regarding their protection from treatments that harm human dignity and dignity, such as neglect, abuse, exploitation and violence
2. Strengthening practice in combating treatments that harm human dignity and dignity, such as neglect, abuse, exploitation and violence against older people
3. Empowering older people against treatments that harm human dignity, such as neglect, abuse, exploitation and violence.

Although these are not specific for people with dementia, they are likely to be relevant for people living with the condition.

UK – Scotland

The Adults with Incapacity (Scotland) Act 2000 creates a duty on local authorities and the Mental Welfare Commission for Scotland (MWC) to investigate any circumstances where the personal welfare of an adult who might lack capacity seems to be at risk, and on the Mental MWC and the Public Guardian to investigate any circumstances where the property or financial affairs of an adult who might lack capacity seem to be at risk.

The Mental Health (Care and Treatment) Act 2003 creates a duty on local authorities to investigate if it believes that a person aged 16 or over has a mental disorder and may be suffering ill treatment, neglect or another deficiency in care and treatment. The duty also applies where there is a risk of financial abuse or loss of their property

The Adult Support and Protection (Scotland) Act 2007 is designed to protect adults at risk of harm. The Act defines adults at risk as people aged 16 years or over who:

- May be unable to safeguard their well-being, rights, interests, or their property
- May be harmed by other people
- Because of a disability, illness or mental disorder are more at risk of being harmed than others who are not so affected.

For an adult, including a person with dementia to be considered at risk under the Act, all three parts of the definition must be met. The Act contains the following measures:

- Requiring councils to make the necessary enquiries and investigations to see if action is needed to stop or prevent harm from happening
- Requiring specific organisations to cooperate with councils, and each other, about adult protection investigations
- The introduction of a range of protection orders including assessment orders, removal orders, and banning orders
- A legislative framework for the establishment of local, multi-agency, Adult Protection Committees across Scotland.

The National Missing Persons Framework for Scotland was launched in 2017 and updated in 2020, outlining current best practices in relation to missing people, such as return discussions. Return discussions with a person who has been missing are designed to identify and acknowledge the underlying issues, to reduce the risk of the person going missing in future.

Alzheimer Scotland, in partnership with Police Scotland, launched "SafeConnect", a community-based service using NFC (Near Field Communication) fobs to help missing people in their community. Alzheimer Scotland and Police Scotland also signed a Memorandum of Understanding affirming their commitment and partnership around missing people with dementia, including using "return discussion" for people with dementia who have been missing. Alzheimer Scotland is currently supporting the implementation of return discussions in three local authority areas. Return discussions with a person who has been missing are designed to identify and acknowledge the underlying issues, to reduce the risk of the person going missing in future.

5.5. Strategies for deinstitutionalisation

Bulgaria

In Bulgaria, deinstitutionalisation is included within the national strategy for long-term care, which includes a focus on:

- Developing long-term care through innovative cross-sectoral services (with a focus on the integration of social and health services) to be provided in a person-centred way
- Building an adequate network of services in the community and home environment (exploration of new social services, including the provision of hourly services)
- Improving access to preventative social and health services for adults with a focus on early-stage interventions
- Providing comprehensive support to families caring for dependent people
- Reviewing and discussing sustainable finance mechanisms and institutional arrangements for long-term care
- Encouraging volunteerism and implementing closer interaction with the non-governmental sector.

Czechia

In Czechia, there is an action plan for the transition of social services to community-based care and greater individualisation of care, as well as promoting the deinstitutionalisation of social services for the period 2023-2025. Its strategic objectives are to assess existing legislation, then prepare legislative solutions to support the development of social services infrastructure on a community basis. There are also a number of non-legislative strategic objectives, including:

- Creating conditions for individuals to exercise free choice of the direction of further assistance, support and care with emphasis on respect for natural dignity, personal independence, autonomy and the right to integration into society
- Supporting changes from a non-community model of social service provision to a model of community-based care
- Ensuring available financial support during the implementation process of the deinstitutionalisation of social services
- Raising general awareness of the importance of deinstitutionalisation of social services.

Estonia

In Estonia, deinstitutionalisation started in 2006, with a reorganisation plan for state care institutions and services, with 14 large special care homes having closed since then. In 2017, a person-centred special care services model on the basis of the local government organisation was established. It has been tested since 2019, aiming to improve access at local level and to implement person-centred care services.

According to the model the local government must assess in which areas of life the person needs assistance (primary support). After assessment, one service provider shall arrange constant assistance and support to the person (basic support). Where necessary, the person is provided with other supporting or rehabilitating activities as necessary (additional support).

Finland

In Finland, policies for dismantling institutional care for older people have been in place for decades.

Germany

In Germany, deinstitutionalisation is supported through the Federal Participation Act, which includes provisions to ensure that people with disabilities can exercise self-determination in relation to housing. Prior to this, people with disabilities who received integration assistance could live in inpatient, semi-inpatient and outpatient housing forms – these distinctions have been repealed. The provisions of the Act now divide the entire package into the components of social participation benefits (services for the preservation of practical competences for living, as well as costs of accommodation and support to live).

The integration provider determines the needs for every person with a disability, on the basis of their functional

ability, with people with disabilities supported to design goals for their personal development for the years ahead. The integration provider then reaches an agreement with a suitable service provider on the necessary interventions, whilst the social welfare office, as the second service provider, meets the costs of accommodation and help for living. However, people with disabilities pay as tenants, whatever the form of housing.

Greece

In Greece, the transition from the institutional psychiatric facilities to social and community-based psychiatric and psychosocial rehabilitation (with the development of an overall system of community mental health services), started in Greece in 1983, with the passing of the law on the National Health System (N.1397/83). This commenced the process of deinstitutionalisation, improving the conditions of hospitalisation within institutions, preparing and transferring patients to sheltered or independent living structures in the community and creating new community-oriented mental health services.

More recently, there has been a shift in focus towards interventions that allow the treatment of mental health problems, without preventing the person from remaining an active citizen, within their home environment. One of the goals of the new National Mental Health Action Plan 2021-2030 is the completion of the psychiatric reform by:

- Completing the discharge of chronic patients from wards of psychiatric hospitals into supports in the community
- Developing equivalent beds of psychiatric admission departments in general hospitals
- Developing community-based mental health structures to provide integrated services including prevention, diagnosis, treatment and rehabilitation of mental health conditions
- Respecting and protecting the rights of people with mental health conditions with an emphasis on elimination of restrictive measures, as well as the development of appropriate support structures for psychosocial rehabilitation and reintegration
- Implementing a certification scheme for care for older people.

Ireland

In Ireland, a report was published in 2011 on institutions called "Time to Move on from Congregated Settings", defined as ten or more people sharing a single living unit/campus-based. A key recommendation was that all congregated settings would be closed by 2018, however, in 2018, at least 2,580 people with disabilities were still living in such institutions according to Inclusion Ireland.

Italy

In Italy, there is no law that addresses the deinstitutionalisation of people diagnosed with dementia. However, there is the Basaglia Law (Law 180/1978), which aims to deinstitutionalise persons with psychiatric distress. This law, led to the closure of asylums and promoted the development of community mental health services. It also stipulated that the treatment of persons with mental health problems should take place mainly through community and territorial services, rather than in institutional facilities, thereby favouring recovery through the participation of persons with mental health conditions in the community.

Lithuania

In Lithuania, there was an Action Plan for the Transition from Institutional Care to Family and Community-Based Services for Disabled and Unaccompanied Children 2014-2020. The strategic goal of the plan was to create a system of comprehensive services that would create opportunities for every child, disabled person or their family (e.g. guardians, carers) to receive individual services according to their needs.

It was intended to develop services and infrastructure in communities for non-independent disabled adults, according to their individual needs, as well as to develop the infrastructure of group living homes, day centres, temporary respite services, community transportation, social skills training and support. Additionally, it envisaged measures to implement employment programmes, to create conditions for disabled people who need individual care or nursing, to receive services in specialised nursing and care homes. Furthermore, it committed to develop integrated care

and social care in homes for people with disabilities and carry out independent human rights monitoring in psychiatric hospitals and social care institutions.

It also envisaged drawing on the expertise to carry out assessments of the health status, social and independent life skills of the residents in social care institutions, to prepare an individual assistance plan for each resident, actively involving the person and their relatives.

Finally, the plan contained measures to assess the competences and motivation staff within social care institutions, whilst also preparing development plans so that employees can provide community services, etc.

Malta

In Malta, there is not a specific national strategy on deinstitutionalisation, however, it features within "Freedom to Live", Malta's 2021 – 2030 National Strategy on the Rights of Disabled Persons. The strategy tackles deinstitutionalisation in Objective 10 – Living independently and in the community, and deinstitutionalisation. The objective focuses on addressing care gaps in mainstream services in the community, strengthening personal assistance and community living schemes, better coordination between service providers and curtailing abuse.

Netherlands

In the Netherlands, there is not a specific programme or strategy for deinstitutionalisation. However, the Vilans organisation (a knowledge organisation for care and support) has a dedicated programme, "opendeurenbeleid" (open-door policy), which aims to support healthcare organisations with closed wards for people with dementia, to open them.

North Macedonia

In North Macedonia, there was a specific strategy on deinstitutionalisation (2017-18), with the main goals of transformation and closing down of institutions, moving service users to the community, creating conditions for life in the community and preventing institutionalisation. The underlying aim was to transform all residential care in the community through conversion or substitution of their purpose, driven by a person-centred approach and independent living. It recognised that independent living does not imply unsupported living. The three workstreams included children, adults under 65 and adults over 65. Whilst, there were no specific actions for people living with dementia, it mentioned that specialist workstreams might be needed to address the needs of people with dementia.

The strategy also identified that transforming institutions into community services would involve discontinuing the use of the residential care institutions. During this, all staff would keep their jobs and start working within the community. The process included measures for strengthening communities and local authorities in creating conditions for the active participation of the people receiving care. Some other measures included, inter alia, coordinated policy, changes to legislation, changes to financing and repurposing funds for community care and providing housing.

Norway

In Norway, there were previously strategies for deinstitutionalisation and living in care facilities is voluntary. When sheltered living is necessary, the decision is as far as possible made in cooperation with the person who has dementia and/or their relatives. According to the Patient and User Rights Act, every individual has the right to necessary health and care services and to an individual assessment of their needs. Living arrangements may be part of a person's health and care services, if the municipality finds it necessary. One issue arising is not institutionalisation per se, but a lack of adequate care facilities when the need arises. The national dementia strategy in Norway prioritises the need for people with dementia to live at home as long as possible.

Poland

In Poland, Resolution No. 135 of the Council of Ministries of 15 June 2022 adopted the strategy for the development of social services until 2030 (with a perspective until 2035). As part of this, the deinstitutionalisation of services is envisioned and is intended to prevent people from being placed in institutional care.

Portugal

In Portugal, the Active and Healthy Aging Action Plan 2023-2026 outlines some measures to keep people at home or independent living facilities, including the following measures:

- Fighting isolation of the older population living in low-density territories by creating programmes of regular visits
- Innovative housing solutions promoting autonomy and independent living
- Creating facilities that strengthen and preserve autonomy
- Creating differentiated home support and using new technologies, focusing on independence and autonomy
- Empowering older people to use new technologies that may contribute to their autonomy.

Slovenia

In Slovenia, the Ministry of Labour, Family, Social Affairs and Equal Opportunities, together with its project partner, the Institute of the Republic of Slovenia for Social Protection (IRSSV), has implemented a programme titled "Establishment of a Project Unit for the Implementation of Deinstitutionalisation." The key purpose of this operation is to provide the foundations for completing the deinstitutionalisation process and to establish a comprehensive system. The project is currently in the phase of establishing new day care units, temporary accommodations, and residential groups for individuals up to 65 years of age. The establishment of the project is co-financed by the Operational Programme for the Implementation of the European Cohesion Policy (OP EKP).

Spain

In Spain, there is a dedicated national strategy, "Hacia un nuevo modelo de cuidados en la comunidad: un proceso de desinstitucionalización" 2024-2030 ("Towards a new model of community-based care: a deinstitutionalisation process"). It is primarily aimed at people with disabilities, older people in dependent situations, children and adolescents in the care system, young people who have gone through the care system, and the homeless. The strategy has five axes:

1. Prevention of institutionalisation dynamics
2. Participation of people and social awareness
3. Transformation of care and support models
4. Development of services for the transition to life in the community
5. Enabling conditions for deinstitutionalisation.

UK – Scotland

In Scotland, an independent report "Transforming Specialist Dementia Hospital Care" was produced for Scottish Government by Alzheimer Scotland in 2018. The report set out a model of modern specialist hospital units based on quality of care for people with dementia who have intensive and complex clinical care needs and require high level expert care. It also set out an approach to build community capacity to support the safe transition of those who do not have a clinical need to remain in specialist hospitals and who could be supported to live in more homely settings in the community. However, whilst the report was fully accepted, progress on delivering the recommendations has stalled and there is no direct reference to progression in either the national strategy or the delivery plan.

Alzheimer Scotland's Long-Term Care Commission report highlights that Scotland currently has no plan for ensuring that people with long-term care needs have a range of options available including more community-based settings. In the absence of a coherent plan or commissioning strategy, care homes remain the mainstay of long-term care provision. The report sets out key recommendations for the Scottish Government.

6. Housing

Alzheimer Europe wanted to understand how housing strategies and policies incorporate the needs of people with dementia, including how they support the independence of people, improve their wellbeing and ensure their inclusion in the community in which they live. As part of this it was necessary to consider different policies and programmes which contribute towards housing, including strategies, housing advice services, social protection, support services, different types of housing, design guidance, adaptations and rehabilitation services.

6.1. Housing strategies

Bulgaria

In Bulgaria, there is a dedicated housing strategy, however, it contains no measures of relevance for people with dementia, older people or people with disabilities.

Czechia

In Czechia, there is a strategy called "Housing 2021+", however, there are no measures relevant for people with dementia.

Estonia

In Estonia, there is no dedicated national housing strategy. Municipalities are responsible for the organisation of housing and communal services. The national development plan "Energy Economy Development Plan until 2030" was adopted in 2017 and deals with the residential sector, focused on reducing the energy consumption of buildings.

From 2017 to 2019, municipalities were able to apply for funds for the construction and/or renovation of residential real estate up to 50% of the total cost of the design through the national support programme. The subsidy was intended to improve the availability of high-quality and affordable housing, including for people who are socioeconomically disadvantaged and cannot rent housing under market conditions.

Finland

In Finland, there is no specific strategy for housing, however, housing is addressed in other strategic documents.

The programme for government (A strong and committed Finland Programme of Prime Minister Petteri Orpo) contains provisions on housing for older people, including: timely and adequate home care services, community housing and 24-hour care services in accordance with individual needs. Family care for older people will also be increased.

The National Programme on Ageing 2030: For an Age-Competent Finland recognises and acknowledges the housing and service needs of older people and the growing number of people with dementia. Some of the key aspects of the programme are to ensure the equality and efficient coordination and economic sustainability of services for older people; to increase the age-friendliness of housing and residential environments; and to highlight the development and utilisation of Finnish technology for ageing.

France

In France, Law no. 2018-1021 of 23 November 2018 on housing, land management and digital technology (ELAN) makes significant changes to urban planning and property legislation. The objectives of the law include:

- Building more housing, better and cheaper
- Restructuring and strengthening the social housing sector
- Meeting everyone's needs and promoting social diversity
- Improving the living environment and strengthening social cohesion.

Within this law inclusive housing is "intended for disabled people and older people who choose, as their main residence, a grouped model of housing, between themselves or with others. This mode of living is accompanied by a project of social and shared life."

Germany

In Germany, there is a national strategy against homelessness, but without specific measures for older people, people in need of care or people with dementia. Additionally, there have been ongoing political discussions about the low level of new housing construction and rising rental costs, also without specific focus on older people, people with disabilities or people with dementia.

Ireland

In 2021, the Irish Government published the Housing for All – A New Housing Plan for Ireland which runs until 2030. It contains 213 actions which aim to deliver a variety of housing options for families, couples and individuals. This is underpinned by commitments in the Programme for Government. There are four key pathways: supporting home ownership and increasing affordability; eradicating homelessness, increasing social housing delivery and supporting social inclusion; increasing new housing supply; and, addressing vacancy and efficient use of existing stock. This plan is supported with EUR 20 billion in funding over five years.

As part of the Housing for All plan, there is a section that explores expanding housing options for older persons. This includes providing funding for housing for older people and people with a disability through the Capital Assistance Scheme and other social housing schemes. This supports facilitating ageing in place, with dignity and independence, in their own homes and communities for as long as possible. This work aligns to the programme for government's vision of an age friendly Ireland. Appropriate social housing provision that addresses the needs of older people will also be addressed under the Local Authority Housing Delivery Action Plans. The Housing Need and Demand Assessment framework was published in April 2021 and considers the housing needs of older people.

The National Housing Strategy for Disabled People was published in 2022 and is a high-level document that places an emphasis on independent living and community inclusion. It is based on the principles of the UNCRPD and has a focus on universal design. The strategy places an emphasis on disabled people having choice and control over their living arrangements. Some of the themes that fall under this strategy include, accessible housing and communities, affordability of housing and knowledge, capacity and expertise.

Italy

In Italy, there is no dedicated unified national housing strategy, but there are several policies and programmes aimed at addressing housing needs through interventions at national, regional and municipal levels. Many Italian regions and municipalities implement housing plans and social services that include measures for the older people or people with disabilities. These plans often include social housing with support services, integrated home care to support the independence of older persons and persons with disabilities.

Lithuania

In Lithuania, the government adopted the Lithuanian Housing Strategy in 2014, which includes a programme "Housing Adaptation programme for Persons with Disabilities".

Luxembourg

In Luxembourg, the Ministry of Housing and Spatial Planning launched a "National Affordable Housing Strategy" which aims to ensure that everyone in Luxembourg can live with dignity and realise the right to housing for all. The Affordable Housing Law of 7 August 2023 (loi relative au logement abordable du 7 août 2023) and the Individual Assistance Law of 7 August 2023 (loi relative aux aides individuelles du 7 août 2023), replace the previous housing aid legislation. Several measures have been implemented to strengthen the offer of public housing, especially for people with disabilities, including:

- Allowance for special facilities (prime pour aménagements spéciaux)
- The reform of access criteria for the category "dedicated housing" (logements dédiés) reserved for people over 60.

Malta

In Malta, "Sustainable Communities – Housing for tomorrow" was published in 2019 by the Parliamentary Secretariat for Social Accommodation and the Housing Authority. It states that inclusive homes are about flexibility and adaptability, thoughtfully and inclusively designed to create and encourage better living environments for everyone. This entails housing options for older persons with disabilities, such as dementia, which are as home-like as possible, moving away from housing models which resemble hospital settings.

Netherlands

In the Netherlands, the government has a policy to support the building of 900,000 houses by 2030, of which 290,000 are intended to be for older people.

North Macedonia

In North Macedonia, there is a national housing strategy and a housing law. There is a section on providing housing for at-risk groups, including people with disabilities, but no specific mention of dementia. The housing law describes units for housing of older and at-risk people that are adapted to their needs and which offer 24-hour support as separate housing units. However, in Macedonia only care homes match that description. Additionally, the law differentiates between minimal and adequate housing; the latter includes all necessary adaptations and conditions for safe living, however, no strategy or action plans are linked to it.

Norway

In Norway, "Boligmeldingen" is a Norwegian government white paper outlining the housing policy, published in 2024. It reinforces the policies in the Older Peoples Housing Programme and anchors the responsibility across several ministries.

Portugal

In Portugal, the Active and Healthy Aging Action Plan 2023-2026, Strategic Pillars (Pillar II) includes a sub-pillar on Accessible Environments. The measures cover affordable and accessible housing programmes, removal of barriers in cities and towns, the existence of adequate spaces for health activities leisure, public transport and the existence of nearby services.

Many municipalities have specific programmes for the renovation of homes for older people and citizens with disabilities. The objective is to promote the ability of the beneficiaries to remain autonomous in their respective homes, reducing functional risks and adapting spaces in terms of comfort, safety and accessibility.

In the framework of the PRR (Rehabilitation and Resilience Programme) there is a programme named "360° Accessibility Programme – Interventions in Housing" focused on the renovation of homes for older people and citizens with disabilities. This programme is coordinated by INR (National Institute of Rehabilitation) and implemented by municipalities.

Slovenia

In Slovenia, the Resolution on the National Housing Program 2015–2025 contains a package of measures aimed at the older population. The package primarily focuses on housing forms that provide quality health and other care (assisted living or sheltered housing) while ensuring social inclusion and mutual assistance (mixed neighbourhoods, proximity to social activities, functional adaptation of single-family houses for intergenerational living). Attention is also given to finding solutions in the field of energy efficient renovation, to enable higher quality living in one's own home, renovation of apartments in terms of functional adaptation and adjustment to the needs of older people.

UK – Scotland

In Scotland, a strategy called Housing to 2040 was published in March 2021, however, there are no specific actions for people with dementia.

6.2. Housing advice services

Belgium – Flanders

In Belgium, some home care organisations and health insurance providers can offer advice, but it is not organised structurally. As with many areas of interest concerning the topics of housing and independent living, actions are reactive instead of proactive.

Finland

In Finland, many municipalities and large landlords offer housing advice services. Additionally, welfare centres have advice services for older people.

France

In France, there is a dedicated organisation for housing, the national housing agency (ANAH), whose stated aim is "Improving housing, everywhere, for everyone". ANAH's primary goal is to improve the existing private housing stock by granting financial aid to owners and supporting communities in implementing their private housing policy. People living with dementia may be entitled to have access to their funds or support.

Germany

In Germany, in addition to the Alzheimer's associations, there are various advice centres that are available for people with dementia and their relatives, including:

- Housing advice centres (for adapting the home)
- Care support centres (especially on care insurance benefits and support with applications)
- Consumer advice centres
- Advice offered by care insurance companies
- General advice centres for older people.

Greece

In Greece, the seven mobile care units and home care units operated by Alzheimer Associations can provide guidance in relation to housing.

Iceland

In Iceland, municipalities provide advice on matters relating to housing.

Ireland

In Ireland, each city and county has a local housing authority where individuals can seek advice or support. The Citizens Information service is a countrywide service that can provide information on housing in Ireland to individuals.

Italy

In Italy, many Italian municipalities have dedicated social services offices that provide information, advice and support about the adaptation of homes to the needs of older people and people with disabilities. These offices can help with the application for contributions and facilities for adapting the home environment.

Lithuania

In Lithuania, there is no information about a dedicated service but social support departments in the municipal administration can provide information on this subject.

Luxembourg

In Luxembourg, the Association Luxembourg Alzheimer offers advice, support and practical help. It has a counselling service that receives requests for support for people with dementia and contacts the families or individuals concerned. The counselling service also provides support in administrative processes such as applying for long-term care insurance.

Malta

In Malta, advice on housing modifications and how to make the residential area safer and more accessible is currently provided by occupational and physical therapists who assess the home environment and advise on changes which need to be made.

These professionals can also assist the person to apply for subsidised equipment which might be needed via the Empowerment Scheme. This is a fully subsidised service provided by Active Ageing and Community Care.

Montenegro

In Montenegro, centres for social work are responsible for submitting and issuing decisions for placement in a home for the older people.

Netherlands

In the Netherlands, some municipalities have "ouderenmakelaars" (senior brokers) to help older people find a more suitable place to live.

North Macedonia

In North Macedonia, there are organisations that provide free legal support, including advice on housing and disability rights.

Norway

In Norway, municipalities are responsible for providing affordable housing and to allocate funds for social services such as financial aid for home care services or assistive technologies, which can significantly impact independent living. They may also provide advice on home adaptation. Additionally, the Age-Friendly Norway centre, which is under the auspices of the Directorate of Health, has been tasked with running a campaign aimed at the population to increase awareness about the importance of planning for old age, in particular concerning housing.

The Norwegian State Housing Bank offers grants and affordable loan programmes to modify housing and/or to purchase accessible housing. There are specific programmes aimed at older people and disabled people who do not have the financial means to modify or purchase homes, or to otherwise obtain loans from private banks to do so. The State Housing Bank also provides advice to both individuals and municipalities.

Portugal

In Portugal, at national level there is no specific service to provide advice but there is the Institute of Housing and Urban Rehabilitation, a public entity that promotes national housing policy. The institute has the responsibility for ensuring the implementation, coordination and monitoring of the national housing policy and the programmes defined by the government for the areas of housing, housing rental and urban rehabilitation, in conjunction with regional and local housing policies. Additionally, the National Institute of Rehabilitation also provides information about programmes about housing and people with disabilities (removing architectural barriers, replacing bathtub with shower etc.)

Slovenia

In Slovenia, the Resolution on the National Housing Programme 2015–2025 defines a Public Service for Rental Management, which will ensure greater security for both tenants and landlords. The purpose of establishing the organisation is to increase the rental housing stock at more favourable rental prices than the market rate and consequently increase access to rental housing. It will operate as an intermediary, manager and maintainer of rental housing included in the rental housing fund scheme.

Spain

In Spain, there are a number of services which provide both information and support in relation to housing:

- Servicio Housing First (C.A. Madrid), funded by the EU Programme FSE+ 2021-27
- Programa "Sal a la Calle": Centro CEDIA (Día y Noche) (C.A. Madrid) ("Come Out to the Streets" Programme: CEDIA Centre (Day and Night): 24/7 emergency services, occupational activities and basic services
- Unidad de Acompañamiento e Inserción UACI (C.A. Madrid) (Service for Support and Integration): psychosocial office that assesses, mentors, and gives support to homeless people.

Sweden

In Sweden, questions relating to housing relate to social services, therefore, municipalities have the responsibility for providing advice.

Switzerland

In Switzerland, some communities have a dedicated contact point and, where they have a strategy for older people, it often also includes housing. Some localities will also provide advice or counselling but not direct support, such as finding a new or adapted home.

UK - Scotland

In Scotland, some local authorities can provide advice on matters relating to housing, as can Citizens Advice Scotland centres. Additionally, the Dementia Services Development Centre, a research unit within the University of Stirling, provides resources for people supporting someone living with dementia, whether personally or professionally. Additionally, they offer consultancy and training on designing living environments for people with dementia.

6.3. Social protection or support services

Armenia

In Armenia, a small stipend programme is available for informal caregivers.

Bulgaria

In Bulgaria, people with dementia who have a medical document for disability are entitled to support.

Croatia

In Croatia, people with dementia are generally only able to remain at home due to care provided by their family members, who are unpaid informal caregivers.

Czechia

In Czechia, sheltered housing is a social service, usually used by people with mental health conditions or intellectual disabilities. If registered, it can be partly covered by public funding. For general housing support or social protection dementia isn't a specific criterion. The Ministry of Labour and Social Affairs supports people with disabilities through a special assistance allowance in the form of financial support, for building work associated with home adaptations.

Estonia

In Estonia, there is no special housing support for people with dementia but there are some offers. The local government assists in adapting housing or finding suitable housing for people who, due to disabilities, have difficulties in moving around the living space or coping by themselves. In order to enable the person to live in their own home as long as possible, the local authority provides support for housing adaptations. Ensuring the possibility to use a dwelling is based on the principle that the disabled person should be able to live at home for as long as possible.

Finland

In Finland, tax credits can be used to support living at home and services such as renovation, cleaning or home rehabilitation can be provided tax-free for illness or disability.

Housing allowance for pensioners is possible if they are living permanently in Finland, they have a low income and they receive a pension which entitles them to housing allowance for pensioners. The allowance is available for both permanent rental and owner-occupied homes.

The Housing Financing and Development Centre (ARA) provides grants to improve housing conditions for special groups, with the aim of increasing the supply of affordable and suitable rental housing for people with dementia or a disability.

France

In France, support is available through the legal and public compensation system, and through the “Family Allowance Fund” (La CAF). This national fund provides support in different areas: personal life, professional life, housing, disability and life incidents. The disability programme provides allowances for children with disabilities, for adults with disabilities, for parents of children with disabilities and for caregivers of a person with a loss of autonomy.

If the person with dementia lives alone, they are eligible for Personalised Autonomy Allowance (APA) for the intervention of professionals at home, however, the hours covered are low and do not always compensate for the loss of autonomy when the illness progresses. People with dementia are not always able to afford additional hours of home help outside of the APA's personalised assistance. A similar issue exists, for under 60s recognised as an “adult living with a disability” and receiving the “disability compensation benefit” (PCH).

Despite coverage by the French Health Insurance, the complexity of the condition and the level of adapted services, structures and multidisciplinary support, mean that the actual level of supports needed on a daily basis, is not fully covered. Additionally, adapted services or structures are lacking in some locations, leading to geographic inequalities.

Germany

In Germany, housing allowance was reformed on 1 January 2023, increasing the level of payments and the number of people eligible, as well as introducing a permanent heating cost component and a climate component. The housing allowance will double on average and the number of recipients is tripled. The allowance is aimed at low-income households in society, including pensioners, families and single parents and people on the minimum wage.

Housing allowance is a supplement for rent and is intended to reduce housing costs. The claim and amount of the housing benefit depends on the number of household members, the amount of the total income and the amount of the rent eligible for payment.

Greece

In Greece, there is a "Help at Home" programme in the country's municipalities. The programme is aimed at older people who are not fully self-sufficient and people with mobility impairments, with priority given to those who live alone, do not have family care or whose income does not allow them to ensure the required services to improve their quality of life. A total of 120,000 older people and disabled people benefit from the programme. It is staffed by qualified professionals, including:

- Social workers who have the overall supervision of the beneficiaries, evaluating the incidents, providing social support, contacting other agencies and referring incidents that are not related to the services of the programme
- Nurses who offer primary health services and which involve home visits to measure and record vital signs, prescribe medications as well as accompany them to hospitals for their scheduled examinations
- Domestic helpers who undertake outside tasks, supplying older people with items of immediate need, as well as cleaning their home. An additional responsibility of the family assistants, perhaps the most important for these people, is the companionship they offer, proving in practice the social character of the programme.

Additionally, there are day accommodation units for older people who cannot completely take care of themselves, whose carers may be working or may have other difficulties (health, financial etc.) which prevent them from caring for the person. The service runs in specially designed spaces on a daily basis and can accommodate the older people for a short period of the day, providing care services (daily hygiene and nursing), entertainment and creative employment.

Furthermore, there are state-funded dementia units in Greece (27 Alzheimer's day care centres, 20 memory clinics in hospitals, 10 municipality interconnection programmes, 94 Alzheimer's counselling stations) and other voluntary based initiatives, which can contribute to the goal of supporting people to continue to live at home.

There are also some state benefits (absolute disability allowance, non-institutional allowance, severe disability allowance and paraplegia allowance for state insured and uninsured) that may also be used for house modifications. However, it was noted that the level of benefits usually only covers a percentage of more basic care needs for the person.

Iceland

In Iceland, disabled people receive housing benefits only if they live alone.

Ireland

In Ireland, Invalidity Pension is a weekly payment to people who cannot work because of a long-term illness or disability and who are covered by social insurance (PRSI). In order to get an Invalidity Pension, a person must have five years paid PRSI contributions and be unable to work because of an illness or disability for at least 12 months, and likely to be incapable of work for at least another 12 months. Alternatively, one must be permanently incapable of work due to illness/disability.

A Medical Card issued by the Health Service Executive (HSE) allows the holder to receive a range of health services free of charge including the provision of prescribed aids and appliances.

There are a number of schemes and grants which can be sought by older people, disabled people and people with dementia, many of which are managed by local authorities:

- The Housing Aid for Older Persons Scheme aims to improve the living conditions of older people by carrying out minor repairs to the main areas of their homes
- The Housing Adaptation Grant for People with a Disability can help people to make changes and adaptations to homes, e.g. making it wheelchair-accessible, extending it to create more space, adding a ground floor bathroom/toilet or installing a stair-lift
- The Mobility Aids Grant Scheme provides grants for works designed to address mobility problems in the home, e.g. the installation of handrails in homes
- The Better Energy Warmer Homes Scheme aims to improve the energy efficiency and warmth of homes owned by people on lower incomes.

Italy

In Italy, there is no housing allowance for people with dementia, but there are other measures aimed at enabling people to stay at home. However, these measures are not aimed at independent living *per se*. Some measures include:

- People with dementia may be entitled to an Accompanying Allowance, a monthly economic support intended for those who have a severe disability and need continuous assistance. This allowance is provided by the National Social Security Institute
- Many municipalities offer day centres for older people and people with disabilities, where they can participate in social and recreational activities
- In the City of Rome, the CAD (Home Assistance Centre) is a service for non-self-sufficient persons who cannot reach the health services of the district or hospital. In this service it is possible to make an assessment of the requirements for home care (through a Territorial Assessment Unit), which is followed by the development of a care plan that may include specialist visits, nursing services, physiotherapy services, assessment for the granting of health care facilities, etc.
- Law 104/1992 provides various forms of support for people with disabilities and their families, including paid work leave and tax breaks
- Integrated Home Assistance (ADI) services provide health and social care at home, enabling people with disabilities or dementia to live at home, reducing or delaying the need for admission to care facilities. The services available include medical, nursing and rehabilitation care
- Respite care/temporary hospitalisation a temporary stay in a healthcare nursing home (in Italy referred to as RSAs) for non-self-sufficient older people or people with disabilities who cannot be cared for by their family members or carers for a short period of time. The solution of respite is usually adopted by a patient's family member or caregiver to avoid permanent hospitalisation.

Luxembourg

In Luxembourg, there is no social benefit that is specifically for people with dementia. Long-term care insurance in Luxembourg helps people to live at home for as long as possible if they are entitled to social protection. There are special dementia day centres operated by Association Luxembourg Alzheimer, in which people with dementia can spend a structured day with activities with other people, establishing social contacts and reducing social isolation.

Malta

In Malta, there are many community services which offer support at home so that families are provided with long-term care in their communities, including: Community geriatric service; community psycho-geriatric service; Dementia Activity Centres; Dementia Intervention Team; Daily Domiciliary caring and nursing; occupational and physiotherapy service; phlebotomy at home; podiatry at home; psychotherapy at home; respite at home and in residential settings; social work services; carer at home scheme; continence service; handyman service; domestic cleaning services; meals on wheels; night shelters; free transport service; telecare+ and telecare on the move service.

In the case of families living with dementia these services are offered and coordinated after an assessment by Dementia Practice Nurses within the Dementia Intervention Team who serve as case managers, helping the family navigate the services and supporting them during the progression of the condition.

Montenegro

In Montenegro, the Commission of the Centre for Social Work provides, with the necessary documentation, assistance that is less than EUR 100 per month. This situation represents an improvement, as previously, people with dementia did not receive this support even though they had a diagnosis and the relevant documentation.

Netherlands

In the Netherlands, there is support for housing, however, it is not specific for people with dementia, rather it is for people with lower incomes.

North Macedonia

In North Macedonia, there is housing benefit but it is not given on the basis of diagnosis, for people who have no income or property. There is also some financial benefit (similar to Personal Independence Payments in England) and caregiver benefit for looking after a person diagnosed with dementia. There is an option to use the services of a personal assistant or home care workers. Personal assistants or caregivers should be licensed or certified, ensuring they meet certain standards of care. The costs for services are covered by the Centre for Social Work.

Norway

In Norway, anyone who is below a certain income threshold qualifies for housing benefits, including people with dementia. In addition, there is affordable council housing available. Other measures, such as home care services, are essential in enabling people to live safely and comfortably in their own homes for as long as possible.

The home care system in Norway provides various services like personal care, meal preparation, and housekeeping. Additionally, qualified health care professionals provide services such as medication administration, wound care, monitoring vital signs, and managing chronic health conditions.

Poland

In Poland, people are eligible for support if the person with dementia has a disability certificate.

Portugal

In Portugal, whilst there are no specific housing supports for people with dementia, older people or people with disabilities, there are home services and

programmes such as tele-alarm and house adaptation to create better conditions to remain at home.

Slovenia

In Slovenia, in the Resolution on the National Social Protection Program 2022-2030, within the framework of programmes for active and quality time, there are descriptions of programmes that offer users activities, encouraging people to develop and maintain their knowledge and skills, gain new ones, expand their social network and socially engage in various areas, in a safe environment. This includes programmes that enable more independent and autonomous living for people with disabilities and are intended for groups such as people with mental health conditions, older people and people with disabilities.

This builds on work started in 2020 by the Ministry of Labour, Family, Social Affairs and Equal Opportunities which co-financed 44 day centre programmes, including:

- Seven programmes for people with mental health issues
- Two programmes for older people
- Six programmes for people with disabilities.

People with dementia can additionally apply for the help and service allowance, which can be granted to eligible individuals based on an opinion from the disability commission at the Pension and Disability Insurance Institute of Slovenia (ZPIZ). The help and service allowance can be granted at one of three levels:

1. For assistance with most basic life needs
2. For assistance with all basic life needs
3. For pensioners who require 24-hour supervision by family members and mandatory professional assistance for continuous health care.

Spain

In Spain, support is provided through the provisions of the Royal Decree 675/2023 of 18 July – Laws for the Promotion of Personal Autonomy and the Assistance of High-dependency Persons (“Ley de la Promoción de la Autonomía Personal y Atención a las Personas en Situación de Dependencia”).

Sweden

In Sweden, older people who want and are able to remain in their own home receive the support and care from the municipalities, to be able to do so. By law the municipalities are required to offer “Special Housing” to older people that have for care needs, which requires closeness to staff around the clock.

Switzerland

In Switzerland, people are not eligible for support automatically as a result of their diagnosis. Only once the disease has progressed do people receive home care, paid for by health insurance.

UK – Scotland

In Scotland, there is a wide and complex range of social security benefits and other sources of financial support available. As well as UK-wide social security benefits administered by the Department for Work and Pensions, Social Security Scotland has responsibility for a range of devolved benefits in Scotland. The social security system provides a broad spectrum of financial support including support for those who have low incomes, carers, people with illness or disability and the state retirement pension. Each benefit has qualifying conditions and include a mix of means tested and non-means tested benefits.

Help is also available with housing costs through Universal Credit or Housing Benefit. Housing Benefit is administered by Local Authorities and is a means tested benefit. Local Authorities also administer discretionary housing payments which can provide additional support for those who have housing benefit or housing costs paid within universal credit but still have difficulty making their rent payments. There are no social security benefits which are specific to people with dementia, however, people with dementia are entitled any benefits for which they meet the conditions of entitlement.

Those with social care support needs can ask for an assessment and may qualify for Self-Directed Support (SDS). SDS is the main delivery for social care support and is intended to put the principles of independent living into practice so that people can exercise greater choice about how their needs are met. They can choose between one of four options including having a budget which can be paid directly to them as a direct payment to purchase the care and support they need. SDS is subject to eligibility criteria and each Health and Social Care Partnership sets the level of threshold for eligibility criteria. Pressure on social care budgets means thresholds for eligibility are set at the most critical and substantial levels of need, meaning only those with the highest level of need qualify. In addition, there is geographic variability in how well people are supported to make use of SDS and few people with dementia are offered full choice and control.

6.4. Adapted housing and residential facilities

Armenia

In Armenia, there are six facilities that are dedicated to caring for older people, however, none of them are specific to people with dementia. Alzheimer's Care Armenia has conducted dementia training with the staff at these facilities, however, more training and hands-on didactic-type training is needed.

Belgium – Flanders

In Belgium, there is adapted housing which is generally available.

Czechia

In Czechia, adapted housing is not widely available. The Ministry for Regional Development has a funding scheme called Residential Buildings without Barriers, which aims to remove barriers in residential living facilities e.g. ensuring that entries are accessible, ensuring buildings have lifts etc.

Estonia

In Estonia, adapted housing is not widely available.

Finland

In Finland, housing for people with dementia, older people or people with disabilities is mainly service housing under social services. However, there are or have been individual projects for the design of living environments for people with dementia.

France

In France, there is only one experimental type of housing dedicated only to people with dementia. In general, adapted housing consists of specific secure areas located inside traditional nursing homes for older people [called reinforced housing units (UHR)] or in hospitals [called long-term care units (USLD) or cognitive and behavioural units (UCC)]. These units provide people with social and therapeutic activities, and support from specially trained professionals. The duration of stay in those units is variable and depends on the needs of the person and of their ability to adapt themselves to a more traditional environment.

For people living with disabilities or dementia who are under the age of 60, there are different types of housing depending on their needs. For example, the specialised care home (MAS) is specifically for people presenting heavy disabilities, and the medical-care home (FAM) is for people who are less dependent.

People aged under 60 living with dementia are not yet fully recognised as living with a disability, which impacts the offer in terms of adapted housing. Families supported by France Alzheimer report that MAS or FAM are not adapted to receive people living with dementia and the professionals may even refuse people living with dementia. Additionally, people with dementia themselves express that these are not the environments they want to live in (nor do they want to go to nursing homes). France Alzheimer is asking the government to support the deployment of adapted housing for people with dementia aged under 60.

Private initiatives have been created, such as "Les Maisons de Crolles", a MAS dedicated to people living with dementia under 60. In general, specialised housing solutions are in high demand, with the demand greater than the number of places available and long waiting lists. Consequently, people with dementia or disabilities may have to access a specific housing solution far from their previous home or family.

Germany

In Germany, there are no apartments specifically designed and furnished for people with dementia, however, accessible apartments exist. These mainly contain structural adaptations such as lifts, no thresholds, doors wide enough for wheelchairs, accessible bathrooms etc.

Ireland

In Ireland, there are a number of specialist care units provided by private services. These units are a long-term residential care model designed for people living with dementia and are purposed to provide specialist dementia care to small groups of people in a more homely, safe environment. These are rare in Ireland, with traditional models of nursing homes prevailing.

Dedicated (sheltered) housing schemes are available and are developed, managed and operated by either a local authority or an Approved Housing Body (AHB) under the Capital Assistance Scheme Grant.

There are several private retirement villages/independent living providers that offer a range of alternative care options. The Alzheimer Society of Ireland provides information and a full list of options for people, however, does not recommend one option over another, as such choices are personal for the individual or families involved.

Cowper Care is an approved charity owned and operated service, which offers sheltered independent living for older persons and also offers dementia care until the end of life. Fold Housing is a not-for-profit limited company that offers apartments and housing for older people and families in Ireland. They also offer 24-hour housing with care for older people and people with dementia. Currently, they operate two independent living schemes in the Dublin area. Sue Ryder is another charity organisation that provides retirement housing for older persons within residential villages and communities that support independent living.

CareBright Community, in County Limerick, was Ireland's first purpose-built community for people living with dementia. This space offers residents independent living with private rooms, but also offers communal living spaces and gardens. There is also a new independent living purpose-built housing currently under construction at Marymount Care Centre in County Dublin which has specifically been designed as a secure setting but one that supports independent living.

Italy

In Italy, there are some examples of senior co-housing initiatives and some healthcare nursing homes, which are specifically adapted to the needs of persons with dementia. However, these are uncommon and not present in all Italian regions. Adaptations usually refer to:

- Ramps, lifts and wide corridors to facilitate movement with wheelchairs or walkers
- Bathrooms equipped with grab bars, shower seats and raised toilets
- Adapted kitchens with worktops and cabinets accessible from a seated position
- Adequate and automated lighting to avoid accidents, especially at night
- Clear signage for easy orientation within the facility, using contrast between the lettering and the background
- Familiar environments to allow the person with dementia to feel at ease by reducing stress and disorientation
- Common areas designed to facilitate and stimulate socialisation and interaction.

Luxembourg

In Luxembourg, there is a dementia care home operated by Association Luxembourg Alzheimer, which is planned and designed specifically for the needs of people with dementia. It is the only home dedicated exclusively to people with dementia in Luxembourg.

Montenegro

In Montenegro, publicly operated residential facilities, for example, nursing homes, are adapted to support people with dementia and have specific departments for them.

North Macedonia

In North Macedonia, there are only private care homes that are specialised for people with dementia, with varying approaches and adaptations to the environment for their residents.

Norway

In Norway, there are several types of adapted housing aimed at people with dementia, including specialised units in nursing homes for people with dementia, which provide 24-hour care and support. There are also dementia communities inspired by the Dutch model of dementia villages, which offer a secure and familiar environment for residents with dementia to live as independently as possible. Additionally, there are "omsorgsboliger" (assisted living facilities), which provide affordable and adapted living spaces that individuals with dementia can rent from the municipality and which may have various levels of care depending on the individual's needs. Care homes include shared common areas and are sometimes referred to as housing collectives or shared housing. The Bo trygt hjemme-reform aims at further developing a variety of housing types suitable for people with dementia.

Poland

In Poland, until 2023, there were sheltered apartments that could be run by any social assistance organisations or NGOs, focused on support with various assistance profiles e.g. specifically for people with mental issues or older people etc. In 2023 the name "sheltered apartments" was replaced by "training and supported apartments". This reflects a more comprehensive term and concept, focusing on training, as well as developing everyday functioning and social skills. It offers more advanced support, especially for people who need strengthening in various areas of their lives. Supported housing interferes less with daily lives, allowing users to be more independent, whilst providing care and support services.

Training housing offers an intensive programme that aims to develop skills and abilities through organised activities, therapies and support. It is often a temporary solution to prepare people with disabilities to live in a more independent setting, such as supported housing or community housing. Supported housing is a more flexible form that offers support depending on individual needs. People in assisted living may have access to various services, such as medical support and assistance with daily activities, but are not subject to such intensive training programmes.

Training apartments are most often a temporary solution. People stay there for a specific period of time to acquire the necessary skills and be prepared for a more independent life. Assisted housing is a more long-term solution – people with disabilities can live there permanently or for an extended period of time, receiving appropriate support in everyday life. Supported housing is intended for people who become independent and have left certain types of care and educational facilities, shelters, correctional facilities or other facilities for people with mental health issues.

Another possibility for housing is a family care home, which is a form of care service provided for 24 hours by any social assistance organisation or an NGO for between three and eight people living together, who require support as a result of their age or disability. In 2020, there were 47 such homes with 354 places.

Additionally, social welfare homes (nursing homes) may also provide care and specialist care services for people who do not live there. The organisation, scope and level of services provided by the social welfare home take into account aspects such as the freedom, intimacy, dignity and sense of security of residents, as well as their physical and mental health.

The majority of people with dementia in Poland live either in their own homes or in the homes of their families (daughters, sons, sisters, etc). When the family caregiver can no longer take care of the person, the person is often transferred to a 24-hour social welfare home (nursing home).

Spain

In Spain, there are private and public-private nursing homes, as well as assisted-living facilities, both of which are widely available across the country.

Sweden

In Sweden, there is no specific legislation or housing for people with dementia, instead the legislation is based on the general needs of a person in their day-to-day life. Specifically, older people who want and are able to remain in their own home, receive the support and care offered by the municipalities, to be able to do so. By law the municipalities are required to offer "Special Housing" to older people who have care needs requiring close proximity to staff around the clock.

The design of special housing for older people can vary. For example, they may be smaller apartments, with alarm systems which allow the person to call for help when needed. However, the consistent aspect of their design is the inclusion of a mix of housing and public spaces. The accommodation must be adapted to the individual's needs and be designed so that the person can continue to live as independently as possible, whilst providing a high degree of safety and security. The majority of people who live in special housing need extensive help several times a day, with many residents having cognitive conditions, such as dementia.

Switzerland

In Switzerland, there are a few examples of co- or shared-living environments, as well as some dementia villages based on the Dutch model. Additionally, there are specialised care units in nursing homes and nursing homes which are specifically for people with dementia.

Turkey

In Turkey, there are a few models available for adapted housing, however, it is not common.

UK – Scotland

In Scotland, specially adapted housing is available in some places, but is not widely available. Some areas have redesigned existing social housing using dementia good practice design, whereas others are ensuring new builds include a proportion of specially adapted housing. However, there is no nationally mandated policy around this.

6.5. Design guidelines (housing, built environment or urban planning)

Belgium – Flanders

In Belgium, the regional government works has undertaken work on this, however, there is no structural implementation.

Czechia

In Czechia, the Ministry of Regional Development published a "Methodology for applying the principles of universal design and lifelong living in housing construction" in 2021, however, this is not widely implemented.

Estonia

In Estonia, when planning new buildings offering public services (including social and welfare services) the local government must take into account the mobility, vision, hearing and intellectual disabilities of people, in order to meet their specific needs. This is part of broader legislation on accessibility, specifically: Regulation No. 28 "Requirements for buildings arising from the specific needs of disabled people" from the Ministry of Entrepreneurship and Information Technology. As well as buildings, the regulation also sets out specifications for how aspects of the urban realm, e.g. transport stops, should be designed in order to be accessible.

Finland

In Finland, the accessibility of buildings is guided by the Decree of the Government (since 2018), which is then implemented by designers and planners, as well as being monitored. Recently, a recent statement issued by the Ministry of Environment stated that accessibility is relatively well realised in Finland, in relation to the built environment, whilst noting that more attention should be paid to accessibility for people with sensory issues.

France

In France, there is no official or legal guidelines for housing, environment or architecture, for public establishments or urban planning, which specifically considers the needs of people with dementia.

The Village Landais Alzheimer has information on their website, which addresses the need for "familiar and welcoming architecture" in their residential setting. It also highlights drawing on inspiration from a real village, allowing for freedom of movement for residents, as well as noting that the shapes, materials and equipment associated with the village were chosen to favour natural lighting, to ensure the sustainability of the spaces and guarantee simple, scalable and economical operation.

They also provide an overview of social and spatial analysis of different types of places for people with dementia: dedicated units, specialised nursing homes and innovative projects. The first two accommodation models studied seek either to control all aspects of the illness in a closed environment, or to provide for all the needs of residents (illness, leisure, etc.) by creating a self-sufficient life. The third model, aims to be more inclusive in its approach, removing focus on the pathology of the illness and providing integrated support in a way which reduces the signs of the disease and makes treatment "invisible".

Germany

In Germany, the municipalities, communities and cities are responsible for urban planning, however, it is not clear the extent to which they incorporate the needs of older people and people with disabilities.

Greece

In Greece, there are "Designing for All" guidelines produced by the Ministry of Environment and Energy, which aim to promote the autonomy and mobility of people living with disabilities. The guidance is divided into the following sections:

- General Principles - Anthropometric Data
- Layout of outdoor pedestrian movement areas
- Ramps for persons and wheelchairs
- Ladders or stairs
- Mechanical means of bridging differences in height
- Signage
- Entrances to buildings
- Public sanitary facilities
- Buildings used by the public
- Housing.

Iceland

In Iceland, there are design guidelines for people with disabilities in general.

Ireland

In Ireland, the National Disability Authority developed "Research for Dementia and Home Design in Ireland looking at New Build and Retro-Fit Homes from a Universal Design Approach: Key Findings and Recommendations Report 2015" which utilised a universal design approach to consider the needs of people with dementia. The guidelines are intended to be implemented via incorporation into Irish regulations, which are then inspected by the Health Information and Quality Authority (HIQA).

In February 2024, The Alzheimer's Society of Ireland supported members of the Irish Dementia Working Group and the Dementia Carers Campaign Network to provide feedback on the design of long-term care facilities in Ireland, which was submitted to the HSE/Department of Health/HIQA.

Italy

In Italy, at the national level there are laws that consider the needs of older people or disabled people

when accessing public spaces, including:

- Law 13/1989: "Provisions to promote the overcoming and elimination of architectural barriers in private buildings". This law establishes criteria for the adaptation of residential and public buildings to make them accessible to people with disabilities, including standards for ramps, lifts and accessible toilets
- Presidential Decree 503/1996: "Regulations containing standards for the elimination of architectural barriers in public buildings, spaces and services". This decree regulates the accessibility of public buildings and urban spaces, defining the requirements to make these environments usable by all citizens.

There are only a few examples in practice, e.g. care homes, which are designed and structured specifically for the needs of people with dementia or which have seen the intervention of architects or town planners trained specifically on the topic.

To date, there are no guidelines or regulations that specifically address the needs of people with dementia. However, researchers and academics are noted to be interested in the topic, with some architecture departments studying this area. Federazione Alzheimer Italia has frequently been contacted by university researchers to provide information on the needs of people with dementia in accessing communal spaces (community facilities, gardens etc.). Despite this academic interest, there are no officially adopted guidelines.

Luxembourg

In Luxembourg, there are specific guidelines, not specifically for people with dementia but people with disabilities, which are produced by ADAPTH, a consultancy office specialised in "design for all". They assist building professionals in the execution of construction or renovation projects that are accessible to everyone, particularly people with reduced mobility. Their services are also available to individuals who want to adapt their homes. They manage over 250 housing adaptation files annually on behalf of the long-term care insurance.

As part of the long-term care insurance, the therapeutic service of the Association Luxembourg Alzheimer also offers individual assistance measures aimed at preserving and developing autonomy in daily and social environments. Beyond technical aids (e.g. mobility aids), advice on adapting the home environment (e.g. reducing the risk of falls) is among their offers.

Additionally, for older people or people with a disability, the new Accessibility Act (law of 8 March 2023) generally applies, as does the law of 7 January 2022, on the accessibility for all to public places, public roads and collective residential buildings.

Malta

In Malta, design guidelines for housing are in place in Malta through the Accessibility Standards for All in a Built Environment Regulations 2019 and the Access for All Design Guidelines. These regulations are made for all persons with disabilities and do not specifically address the needs of people with dementia. These were developed by the Commission for the Rights of Persons with Disability and public spaces must, by law, meet these requirements.

Additionally, the National Active Ageing Strategy recommends that outdoor safety is improved, such as accessible walkways and developing standards in the area of age-friendly road design. It recommends that processes in long-term care should ensure mechanisms to protect resident rights, the safety of buildings and establish a quality assurance committee.

Montenegro

In Montenegro, there are clear conditions for the licensing of care facilities for older people and people with specific conditions, such as dementia. NGO Futura has given lectures and held meetings with providers, to give guidelines and advice on the design of such facilities. This was informed by resources from Alzheimer's associations in Slovenia and Croatia.

Netherlands

In the Netherlands, on 15 July 2024, Alzheimer Nederland published a "Dementia Friendly Residential Toolkit", which is intended to provide a guidance and

instructions on inclusive living environments for people with dementia, considering the perspectives of the developer, manager and tenants. The toolkit is divided into several chapters, each with a specific focus:

- Dementia and positive design principles – Provides insight into the everyday experiences and challenges of people with dementia and introduces positive design principles for a dementia-inclusive environment.
- Roles and tips by space – Describes the roles and influence of developers, complex managers and tenants. For each space, tips are provided with sketches and text.
- In-depth themes – Provides depth on topics such as light, colour, acoustics, smell and technology and how these contribute to a dementia-inclusive environment.

The guide examines both the design and interior of buildings, whilst also looking at how design decisions in the public realm.

Additionally, there is a separate guide "Programme for a dementia-accessible public space", which provides guidance on how public spaces can be adapted to allow people with dementia navigate public spaces more easily and independently, including the importance of landmarks, dropped kerbs, clear signage etc.

Norway

In Norway, new buildings are required to follow principles of universal design, creating accessible environments for everyone and universal design principles have to be followed as much as possible when adapting existing buildings.

The "Bo trygt hjemme" reform encourages municipalities to consider the need of older people and disabled people in urban planning and in public transportation.

Poland

In Poland, NGOs publish and distribute manuals for caregivers, which include chapters and advice on how to prepare an apartment for a person with dementia.

Portugal

In Portugal, the Act of the Government nº 163/2006 of 8 August articulates the standards for buildings and establishments that receive the public, public roads and residential buildings. Municipalities have the duty of ensuring that the rules are respected and only certify buildings that fulfil all requirements. According to Article 7º NGOs for people with disabilities and people with reduced mobility have the right to know the status and progress of the licensing or authorisation processes for urban operations and construction, expansion, reconstruction and alteration of buildings, establishments and equipment.

Slovenia

In Slovenia, the Dementia Management Strategy notes that individuals with dementia may experience difficulties in their environment, highlighting that a well-organised and adapted environment helps maintain the person to maintain their abilities, enhances their independence, and encourages activity and inclusion. It specifies that a dementia-inclusive environment:

- Unobtrusively reduces risks
- Respects and creates a humane scale
- Allows individuals to be seen and to see
- Reduces unnecessary stimulation
- Optimises beneficial stimulation
- Enables and supports movement, inclusion, and engagement
- Creates a familiar space that reflects their life story
- Provides opportunities for socialising while respecting their need for solitude
- Creates pathways and connections to the local community
- Follows, respects, and enables their own vision of living.

It further states that such environments must be provided on both micro and macro levels, from cities, towns, streets, individual or sheltered housing to the renovation or construction of new building projects, nursing homes, hospitals, and day centres.

Separately, the Ministry of the Environment and Spatial Planning has issued the "Universal Housing Construction" manual, which provides guidelines for adaptable housing construction.

Switzerland

In Switzerland, recommendations for good design are available, however, they are not mandatory and not well known by architects. For example, the foundation "Age-Stiftung" promotes research and projects about different kinds of living arrangements or environmental recommendations, however, these are not mandatory. However, for people with disabilities, the Swiss Society of Engineers and Architects have published guidelines describing the mandatory objectives for barrier-free housing.

Turkey

In Turkey, barrier-free city projects are carried out by municipalities.

UK - Scotland

In Scotland, there is a Housing for Varying Needs Design Guide, which was produced in 1998, that reference the needs of people with dementia and emerging evidence on good practice in design. An update of this guidance is planned and has been consulted on. It is planned to introduce a Scottish Accessible Homes Standard, although this may have a focus on building design rather than internal components.

Additionally, the Dementia Services Development Centre provides consultancy and training on designing living environments for people with dementia. Furthermore, the Chartered Institute of Housing in Scotland, published in 2017, a "Housing and Dementia Framework" to help organisations to support people to live well with dementia. The framework sets out five person-centred outcomes that people living with dementia have said are important to them. However, there is no record of whether or how well the guidelines are accessed and used.

6.6. Technology and adaptations

Belgium – Flanders

In Belgium, although it is noted that there is an urgent need for this kind of support, specifically for the 70% of people with dementia and their informal caregivers who live at home, technology is only available to a very limited extent. Additionally, there is little funding for housing adaptations.

Czechia

In Czechia, technology and adaptations are possible to some extent, for example, the safe emergency button service is a social service. Additionally, sheltered housing can be partly funded by public funding.

Estonia

In Estonia, some types of technology are available but not specifically to support people to remain at home and these are not paid for or reimbursed by the state. A comprehensive plan is under development, due for completion by the end of the year, which will address how to increase the innovation capacity of the social sector and how to speed up the introduction of technology. The local government can provide reimbursement for adapting homes, however, such support is not widely available.

Finland

In Finland, technology and home automation are used to help people stay at home. A variety of assistive devices and equipment are available free of charge on short or long-term loan from assistive services. Last year, the National Criteria for the Provision of Assistive Devices for Medical Rehabilitation 2023 were updated to include memory-related aids.

If a person meets the criteria of the Disability Services Act and the Regulation, they can receive equipment and aids free of charge. Under the Social Welfare Act or the Disability Services Act, it is possible to get funding from the state for home modifications.

The Housing Financing and Development Centre (Ara) provides grants to improve housing conditions for special groups, with the aim of increasing the supply of affordable and suitable rental housing for people with dementia or a disability. The level of subsidies are scaled according to the recipients, with the subsidy percentage increasing according to the number of exceptional arrangements required. The maximum percentages are 15, 25, 40 and 50 % of approved investment costs.

France

In France, since 1 January 2024, "MaPrimeAdapt" is financing housing adaptation works for older people and people living with disabilities. It is also accessible to landlords to make necessary adjustments. It is not specifically dedicated to people living with dementia, however, some will be able to access it, according to the eligibility criteria, which are:

- You are the owner of your home or a tenant and you have informed your landlord of your desire to carry out work to adapt to the loss of autonomy
- You or a member of your household:
  - Is 70 years or older; or
  - Is aged 60 to 69 years old and have a legal level of loss of autonomy calculated (GIR); or
  - Has a disability rate greater than 50% or benefits from the disability compensation benefit (PCH)
- Your income is classified as "modest" or "very modest".

Examples of work financed by the programme include, replacement of the bathtub with a walk-in shower, the installation of an electric stair lift, the installation of handrails, the widening of doors, the adaptation of coverings or even direct access to housing.

Additionally, in order to advise households in their home renovation projects, accelerate the energy transition in homes and support more households towards efficient renovations, the government created "France Rénov'" in January 2022. The national housing agency (ANAH) is piloting this public service, to allow each household to improve the comfort of their home, reduce their energy consumption or adapt it in the event of loss of autonomy (e.g. disability, ageing).

Germany

In Germany, a wide range of technical and digital aids are available, however, most have to be paid for privately. Products included in the list of assistive products or the list of nursing aids of the National Association of Statutory Health Insurance (GKV-Spitzenverband) are covered by the statutory health and long-term care insurance funds. To date, digital assistance systems are barely included in these directories, nor are many household safety systems, such as stove safety devices. For people with disabilities, a subsidy can be granted to the individual if:

- Home care is made possible in the first place by the measure to improve the living environment
- Home care is made considerably easier, thus preventing the person in need of care or the caregivers from being overburdened, or
- The person in need of care can lead as independent a life as possible again, i.e. dependency on personal assistance is reduced.

Up to EUR 4,000 can be granted for:
- Measures that adapt the specific living environment to the needs of the person in need of care (e.g. elevators, stair lifts)
- Measures that require significant intervention in the fabric of the building (e.g. replacing the bathtub with a level-access shower, widening doors)
- Technical aids in the household (e.g. installation and conversion of furniture that is individually adapted to the requirements of the care situation).

Greece

In Greece, the "Red Button", operated by NGO "Lifeline", through the tele-notification service, enables older people to communicate directly with the Call Management Coordination Centre. The system is two-way and hands-free, activated by pressing a portable red button, with help available 24 hours a day and every day of the year. Appropriately trained staff (consisting of social workers, psychologists, nurses, general practitioners and volunteering neighbours), who have direct access to each person's file, respond immediately to an arising need. In cases the person does not answer, the NGO can immediately send help.

Additionally, there are tele-services for neuropsychological assessment, diagnosis and tele medicine, opportunities for participation in online educational programs and non-pharmaceutical interventions, online psycho-educational group for carers and family/group psychological support programs. All these services are provided by the Alzheimer's units. Home care units run Alzheimer's associations in Athens, Thessaloniki and Patra, can also suggest housing adaptations for people with dementia.

From the beginning of 2023 and until the end of 2025, people with mobility problems and sensory impairments can apply for the aid given by the project: "Enhancing Independent Living for People with Special Needs: Accessibility and Support Infrastructure for People with Mobility Impairments and Sensory Impairments". The goal of the project is to create accessibility and support infrastructure for people with mobility problems and sensory impairments, through the provision of financial support for interventions to improve accessibility in homes and private workplaces.

Iceland

In Iceland, it is possible to apply for access to technology to support a person remain at home. Additionally, people with disabilities can apply for support to make home adaptations.

Ireland

In Ireland, there are a number of telecare devices such as automatic fall detectors or location devices that are available to help support people to remain at home. Most suppliers of assistive technology are privately owned, however, people with a medical card in Ireland may be entitled to certain aids and appliances for free from the Health Service Executive via contact with local public health nurses/occupational therapists who will make an assessment for aids to daily living. These include wheelchairs, mobility aids, specialised chairs, bath, shower and toilet aids, stairlifts, hoists, etc.

Additionally, there is a Housing Adaptation Grant available where changes need to be made to a home to make it suitable for a person with a physical, sensory or intellectual disability or mental health condition to live in. The grant can be used to make changes and adaptations to a home, for example, making it wheelchair-accessible, adding a ground-floor bathroom or installing a stairlift etc. This grant is means-tested and is administered by local authorities. The maximum grant is EUR 30,000 or 95% of the cost of the work and is available to people with a gross household income of up to EUR 60,000.

Italy

In Italy, some people with dementia use GPS tracking devices as a result of difficulties with orientation and the risk of becoming lost, with examples of bracelets or necklaces highlighted. However, there is no state reimbursement for the purchase of these devices.

The state does provide subsidies for the removal of architectural barriers in private buildings and funding is intended to cover part of the costs incurred for adaptations. The adaptations envisaged are ramps, lifts, stair lifts, accessible bathrooms, widening of doors and adaptation of kitchens.

Lithuania

In Lithuania, there is a "Housing adaptation programme for people living with disabilities", however, there are no actions specifically for dementia. The programme is implemented at a municipality level, with a focus on the needs and abilities of the individual, with funding provided by both the government and the municipality. Physical environment adaptations include adaptations to the entrance to the house, installation of lifts, adaptation of bathrooms etc. The service is available for:

- People with mobility, mental and intellectual disabilities
- People for whom the level of working capacity has been determined
- People with a defined level of special needs
- People who are prescribed permanent care.

Luxembourg

In Luxembourg, the long-term care insurance can cover technical aids to allow the person to maintain or increase their autonomy in the areas of personal hygiene, nutrition and meal preparation, mobility inside and outside the home, dressing, assistance activities for household maintenance, and verbal or written communication. These aids can meet needs in terms of safety, prevention, and pain relief. They also aim to facilitate the task of those providing help and care. Examples include wheelchairs, medical beds, patient lifts or other technical aids such as a video magnification system for a visually impaired person, communication aids, etc.

The technical aids are made available free of charge to the person in need. However, the coverage amount cannot exceed EUR 35,000 per technical aid. The long-term care insurance also covers the costs incurred for the installation and commissioning of the technical aids. The technical aids, as well as the costs incurred for installation and commissioning, are only covered by the long-term care insurance upon prior approval from the Evaluation and Control Administration (AEC) of the long-term care insurance.

Luxembourg's long-term care insurance can also provide financial support for home adaptations for people with dementia, such as remodelling the bathroom or installing a stair lift for example.

Malta

In Malta, the National Dementia Strategy recommends the use of assistive technologies which can increase the ease and safety with which daily tasks are performed. It also recommends collaboration between governmental and non-governmental organisations, to make changes to the built and social environments. This includes the provision of amenities, goods and services, to make them more age- and dementia-inclusive and to promote respect and acceptance in a way that meets the needs of those who have dementia and those who care for them, enabling participation, safety, and inclusion.

Telecare+ and Telecare on the Move services help individuals with dementia to live safer in the community and offer reassurance to family carers. The aim of the Telecare+ service is to provide peace of mind to older people, their carers and relatives when assistance is required at the person's home, encouraging the individual to continue living in their own home and in the community. Telecare on the Move is specifically for persons living with dementia. It is a GPS-enabled telecare service with geo-fencing and geo-tracking features and has two-way communication with relatives or a call centre. It works anywhere in Malta and Gozo, can detect if the person has fallen and has a 3-to-10-day battery life. These services are both heavily subsidised by the government or else given free (subject to means-testing). Additionally, add-ons to the Telecare+ service can be made available – such as fall bracelets, gas-leak detectors, flooding detectors, door/window sensors to help the individual to be safer at home.

People with dementia are eligible to apply for a scheme to help the individual to adapt their property to make it accessible and safe. The Scheme for Persons with Disability provides financial assistance so that a property may be adapted for the needs of people with disabilities, such as through the installation of a stairlift or the installation of a wheelchair-accessible bathroom etc. Additionally, people with dementia are eligible for the government scheme to lease motorised variable-height adjustable beds. If the individual chooses to purchase the bed, they are eligible to apply for a subsidy via the "Empowerment Scheme".

Montenegro

In Montenegro, there is limited support available for using technology. There is no support for home adaptations and it is not recognised by authorities as an issue which should be prioritised.

Netherlands

In the Netherlands, different technologies are available, however, there is no budget to support individuals to buy it, only for healthcare organisations buying eHealth technology. Alzheimer Nederland is currently conducting research about the adaptiveness of older people and people with dementia living at home to use technologies. It is possible to make adjustments to the home (e.g. installing a stairlift) with a budget provided by the municipality.

North Macedonia

In North Macedonia, the health fund can cover orthopaedic aids such as crutches, wheelchairs, walkers and other medical aids, but not home adaptations.

Norway

In Norway, assistive technology and home automation play a central role in the strategy aimed at allowing older people, including people with dementia, to live at home for as long as is safe. The extent of financial aid or reimbursement depends on the type of technology. Generally, technology which is deemed as part of a health care service, e.g. medicine dispensers, is free to the users, while other types of technology may only be partially subsidised, or not funded by the state at all. However, Nasjonalforeningen for folkehelsen is concerned that assistive technology such as GPS or sensors are not offered or used widely enough.

Additionally, the Norwegian State Housing Bank offers grants and affordable loan programmes to modify housing and/or to purchase accessible housing aimed at older people and people with disabilities.

Poland

In Poland, if a person has a disability certificate, they can apply for reimbursement of the costs of housing adaptations (e.g. adapting a bathroom for a person with dementia).

Portugal

In Portugal, many municipalities have a Tele-assistance Service. The Teleassistance Service is a free service from Lisbon City Council, aimed at the most at-risk older people and people with disabilities, providing an immediate response in urgent/emergency situations, 24 hours a day, seven days per week. This service is operationalised by providing people, without any additional charges to the telephone line, with telephone equipment capable of making a connection to the Joint Operations Room (SALOC), where civil protection elements are located. To monitor the service, a group of volunteers was set up, whose objectives are to promote the proximity of the municipality, as well as to combat the loneliness and/or social isolation of the individuals through regular telephone contact.

Several municipalities have developed programmes to finance some adaptations at home, others provide the adaptations directly. For instance, the Municipality of Amadora has the programme "Mobility and Accessibility" aiming to eliminate architectural barriers, through the provision of technical and financial support to people with reduced mobility who have a disability equal to or greater than 60%, and who require adaptation works or installation of equipment in their homes. Residents can apply for the following interventions:

- Rectification of floors for adhesion coating
- Rectification of openings and doors
- Rectification of sockets, electrical switches and taps
- Rectification of sanitary installations and placement of appropriate sanitary equipment
- Installation of handrails and support bars in common areas
- Installation of lifting systems (elevators, stair platforms, vertical platforms for wheelchairs, stairlifts, stair climbers).

Slovenia

In Slovenia, the Long-Term Care Act provides for the e-care service, which will be operated remotely and will ensure the user's independence and safety in the home environment. As stipulated by the Act, the right to e-care services will be co-financed in the amount of EUR 25 per month, per person. The person is also entitled to co-financing of a one-time cost of EUR 50 for the installation of equipment and the establishment of a connection for the provision of e-care at the person's residence. The value of the right to e-care services in the first month will be recognised in a proportionate share of the full value of the right. Additionally, the Act defines a service for housing adaptation advice which will be provided by the long-term care provider.

Spain

In Spain, there is some limited support through the previously mentioned Law for Dependency.

Sweden

In Sweden, the individual can apply for interventions in the form of technology through an application to social services, which then examine this against the Social Services Act. The individual can also receive certain welfare technology from the health and medical care if the technology in question is deemed to be an aid according to the Health and Medical Care Act.

Switzerland

In Switzerland, technology is still not widely used, with some persistent negative stereotypes associated with the use of technology and a technology literacy gap amongst older people and people with dementia. However, GPS trackers are one form of technology that are more commonly used.

Turkey

In Turkey, there are some local projects on the use of technical aids, however, it is generally not available and not reimbursed.

UK – Scotland

In Scotland, technology-enabled care, such as personal alarms and movement sensors, is provided to some extent across the country, however, what is provided and how it is paid for varies. Help can be provided through health, social care and council services to make home adaptations. Some or all of these can be funded, but there may be a means-tested element. Under the Chronically Sick and Disabled Persons Act 1970, if the local authority thinks that a disabled person in its area needs specific services it must arrange to provide these. The services include practical help at home, meals, telephone equipment, home adaptations and help with transport to services.

Alzheimer Scotland developed the Technology Charter for People Living with Dementia in Scotland setting out the rights of people with dementia and the principles for the use of technology.

6.7. Rehabilitation

Belgium – Flanders

In Belgium, rehabilitation is available through certain home care organisations, municipalities or health insurers.

Czechia

In Czechia, rehabilitation is not widely available.

Estonia

In Estonia, there is social rehabilitation for people of working age and older people, however, it is not widely available. Occupational therapy is also difficult to access.

Finland

In Finland, rehabilitation and occupational therapy services for older people are becoming more common, however, there are no uniform criteria for rehabilitation or occupational therapy. The services are organised differently in different welfare areas and the length and intensity of rehabilitation sessions vary. The purchase of private services for home rehabilitation (licensed physiotherapist or occupational therapist) services is tax deductible.

France

In France, specifically for people with dementia, the general practitioner plays a major role in organising support at home by coordinating the interventions of different professionals: speech therapists, physiotherapists, nurses, Alzheimer's specialist teams, occupational therapists etc. In addition, home care and support services will help with everyday activities and complement

the action of the family caregiver by intervening in washing, meals, activities, etc. Furthermore, services such as day care centres or temporary accommodation, allow respite for the caregiver while offering people living with dementia adapted activities and local support.

The majority of services and structures adapted to people living with dementia have been created and deployed during the Alzheimer Plan 2008-2012. One such measure from this plan was the development of "Specialised Alzheimer's Teams" (Equipes spécialisées Alzheimer – ESA). They intervene at home and are composed of several professionals including occupational therapists and psychomotor therapists. It is necessary to have a prescription issued by a doctor to use an ESA, with a maximum of 12 to 15 sessions spread over a period of three months during a year. After one year, it is possible to renew the prescription.

Germany

In Germany, there are various offers for rehabilitation, including physiotherapy, speech therapy and occupational therapy, all of which are used to maintain the physical wellbeing and everyday abilities of the person. In addition, there are full-time and voluntary offers for hourly support and care, as well as various group activities: sports, art, music, leisure activities. Additionally, people with dementia are also entitled to rehabilitation sports. However, services are not available everywhere and in more rural areas, services are more difficult to access.

Iceland

In Iceland, "Seiglan" (resilience) is a day care centre for people with dementia in the early stages of their disease and the support provided is grounded in occupational therapy.

Ireland

In Ireland, occupational therapy can be delivered in the home by the Health Service Executive, which is paid for by the state. Additionally, private service providers can also deliver this service to people nationwide.

Italy

In Italy, there are rehabilitation interventions at a national level through the integrated housing assistance (ADI). There are also other services present only in some regions, such as the CAD (Home Assistance Centre) in Lazio and the RSA Aperta in Lombardy. The latter service makes it possible to receive at home, free of charge, interventions that are normally provided in RSAs (nursing homes), including occupational therapy interventions aimed at maintaining autonomy.

Lithuania

In Lithuania, visiting care for a specific number of hours can be received according to the level of individual need. However, it was noted that the number of hours is often insufficient and therefore this does not meaningfully support people to live longer in their own homes.

Luxembourg

In Luxembourg, the Association Luxembourg Alzheimer offers individual support through specialised services, including occupational therapy, memory training and physiotherapy to maintain motor skills or psychological support for people with dementia or their families.

Malta

In Malta, there are several rehabilitation services in the community which are offered via Active Ageing & Community Care (AACC). These include domiciliary services for occupational therapy, physiotherapy, dieticians, podiatry, nursing care and psychotherapy for people who live in the community and have difficulty in attending clinics. These services are paid by the government.

Montenegro

In Montenegro, NVO Futura is the only organisation that provides support and assistance through dementia counsellors, day centres and other support services.

Netherlands

In the Netherlands, rehabilitation services can be accessed through a referral from GPs.

North Macedonia

In North Macedonia, there are non-profit organisations that provide help in the house, through domestic tasks including cooking, cleaning etc., however, they do not provide rehabilitation or any kind of training. There are no occupational therapy services available in the country.

Norway

In Norway, there are rehabilitation services available to people with dementia, depending on the level of need. However, there are few designated rehabilitation services directly aimed at people with dementia, though other services targeted at people with dementia, such as home care services, activity programmes and so on, play an important role in rehabilitative care.

Poland

In Poland, people with dementia can access some forms of rehabilitation including cognitive therapy and occupational therapy through day care centres for people with dementia that provide cognitive therapy, occupational therapy, etc.

Portugal

In Portugal, many non-profit organisations, including Alzheimer Portugal, and for-profit organisations, provide home services that include personal care, as well as occupational therapy, physiotherapy etc.

Slovenia

In Slovenia, there are home care services available to support older people, people with dementia and people with disabilities so they can continue living at home, including household assistance, personal care and support for building social networks. These services are co-financed by municipalities. There are privately operated rehabilitation services (including physical and occupational therapy), however, these are not covered by health insurance.

Spain

In Spain, rehabilitation services are available as part of the Law for Dependency.

Sweden

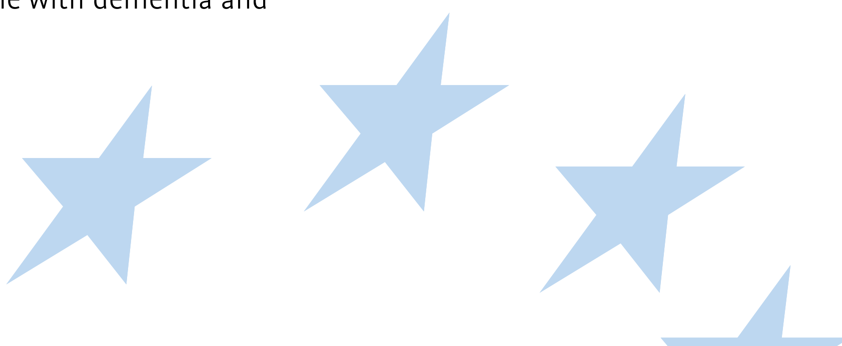
In Sweden, rehabilitation services are available in the country with the responsibility for rehabilitation being shared between regions and municipalities. The Social Services Act states that social services should promote the economic and social security of individuals, as well as equality in living conditions and active participation in social life, whilst also developing individuals' and groups' own resources.

Turkey

In Turkey, there is a quality standards study in nursing homes and care rehabilitation centres by the Ministry of Family and Social Services. There are day care service models and studies to develop them, however, there is currently no comprehensive rehabilitation programme.

UK – Scotland

In Scotland, all areas provide rehabilitation and re-enablement services. There is a strategy describing the support available for people from Allied Health Professionals (AHPs) "Connecting People, Connecting Support", which is a national framework that describes the integrated and co-ordinated approach that AHPs bring to supporting people to live well with dementia.



7. Alternative concepts/models for community-based living

Alzheimer Europe was aware of a number of alternative and emerging models of care for people with dementia across Europe, for example dementia villages, intergenerational living, co-housing etc. As such, we were keen to learn more about these models, how they worked in practice, and the extent to which they aligned with the concept of independent living and international rights-based frameworks. To this end, in our survey we asked for examples of community-based concepts or models of housing, especially those seen as alternatives to nursing homes or institutional settings, which provided care and support for people living with dementia. In addition, we asked whether care and support services were responding to the needs of intersecting population groups, including people from minority ethnic groups or members of the LGBTQ+ community.

Belgium – Flanders

In Belgium, there are small-scale co-housing projects, as well as intergenerational housing projects. However, as there is no funding by the government for these types of initiatives, availability is only based on location and with limited numbers.

Estonia

In Estonia, in the spring of 2024, a support measure was launched titled, "Supporting community-based subsidised housing". The support measure enables the local government to improve low and medium assistance for coping at home for people with support needs, by creating for this subsidised housing (service building) that meets the requirements of accessibility, to prevent them from being placed in a welfare institution. In addition to subsidised housing, it is guaranteed the person is assisted with the social services they need and opportunities are created to be involved in the community on a daily basis. With the allocated support, local governments can build accessible buildings for people with lower-level needs, whose existing housing does not meet the criteria for support and which is not practical to rebuild due to their technical condition, location, size etc.

There is some community-based supported housing, owned by the government, with one- and two-bedroom apartments, with a kitchenette, a toilet, a laundry room, auxiliary rooms (storage, care, household rooms) and shared-space for the provision of supported joint activities and supportive services. The building's surroundings, architecture and interior space must correspond to a complete and sustainable living environment, innovation and technological solutions are combined, in line with universal design principles.

Finland

As a bilingual country, care home services are naturally provided for Finnish- and Swedish-speaking older people and people with dementia.

The German community has operated a retirement home, Deutsche Seniorenwohnheim, since 1928, originally intended to provide the immigrants from St. Petersburg with a secure environment for old age in a German-speaking setting. In 1961, the building was expanded with an additional wing. The buildings were completely renovated between 2010 and 2011 and converted into a senior residence. Currently, the house offers 13 places. It is situated by the sea, in Munkkiniemi, a district of Helsinki. Life in the house offers several community groups: Senior Meeting, Bible Study Group and Ecumenical Circle. During the summer, a bi-weekly summer café is held in the garden or indoors, open to all community members. Residents pay privately for this home.

Helena Care Home is a specialised care home in Helsinki dedicated to preserving Russian-speaking and Orthodox traditions, offering round-the-clock assisted living for older people. The care home has 59 resident places. Becoming a resident is managed through the social and health services of one's own municipality.

The fee for long-term residential services is based on the Client Fees Act for Social and Health Services. It can be up to 85 percent of the resident's net monthly income, ensuring that a certain annually determined amount of money is left for personal use. The income of a spouse living at home can also affect the fee. Helena Care Home does not invoice the residents directly, instead the municipality that has procured the care service handles the billing.

The association Mummolaakso (Granny valley) was originally founded 1994 with the vision for special care and service home for bisexual and lesbian older women based on some international examples. However, the project has turned out financially demanding and the association has focused on other social activities.

France

In France there are a number of initiatives looking at alternative models of care.

Legislation and reports

In France, legislative and policy developments, already covered in section 5.2, moves away from a binary choice between staying at home or in a nursing home, including as outlined in the ASV or ELAN laws, both of which seek to strengthen the autonomy of the person in exercising decisions about where they live.

The Libault Report (March 2019) introduced the notion of intermediate housing as an "offer which must evolve towards an approach more attentive to people's needs", providing a step in between home and nursing homes, proposing solutions such as autonomy residence, serviced residence, inclusive and intergenerational housing etc.).

A report by Denis Piveteau and Jacques Wolfrom, "Tomorrow, I can choose to live with you!" (June 2020) advocates for, in continuity with the ELAN law, API housing (habitats accompagnés, partagés et insérés – supported, shared and inserted into local life). The authors of the report propose a mode of housing which allows people to choose their path and place of life in a welcoming and caring environment, with high-quality support and at the heart of local life.

Alternative models

The operator "Cette Famille" is developing "Seniors Colocations", a model of shared housing for older people or people living with dementia, who are no longer able to live alone. Older people live together in these homes, allowing them to remain independent with the support of professionals and creating social links with others. The units vary in each location, however, residents have private rooms within the shared house, with support coordinated with local health professionals (including nurses and doctors), as well as having its own staff on site 24/7 and access to outside garden spaces.

In such models, there is a difference between the initial cost of housing and the actual amount that the person will pay once social assistance and the tax credit have been received, namely out-of-pocket costs. The structure of the costs of these new options in France have yet to be consolidated to find the right balance between public funding, support for project promoters, support from private actors and out-of-pocket costs for families. France Alzheimer notes that these alternative living concepts must be part of a range of accessible solutions, financially and geographically, so that each person living with dementia and their caregivers can make choices about independent living freely.

Dementia Village

Located in Dax, France, and opened in June 2020, Village Landais, is a French "dementia village" inspired by "De Hogeweyk" in the Netherlands. The village is based on a social model, rather than a medical model, emphasising:

- Benevolent architecture
- The removal of medical symbols
- Personalisation of support
- Respect for tastes and rhythms of life
- Maintaining close ties with loved ones
- Integration into the urban fabric and city life.

The Village has 120 residents, including 10 under the age of 60 (who are therefore considered as people living with disabilities according to the social protection system) supported by 120 staff and 120 volunteers.

The Landais Village provides support focused on the person and non-drug approaches, driven by an attitude and therapeutic activities, which aim to preserve the cognitive and practical abilities of people living there. All staff are expected to foster a supportive mindset, particularly through attention to individuals' abilities. As part of its work, the Village hosts a Resource and Research Centre bringing together French specialists in Alzheimer's disease and the training of health professionals and medico-social care in order to disseminate best therapeutic practices.

The accommodation price can be partly covered by the social assistance for accommodation, whilst other costs can be met by the personalised autonomy allowance (for people aged over 60) or the disability compensation benefit (for people aged under 60).

LGBT initiatives

GreyPRIDE is an associative group that brings together interested associations to highlight the specific problems faced by LGBTQIA+ people aged over 55, including health matters or issues once they have retired.

The association has worked to develop an approach to certify nursing homes as being welcoming to LGBTQIA+ people, aiming to raise awareness of sexuality, sexual orientation, gender identity and HIV-positive people, in support and reception of older people LGBTQ+ individuals who may be moving into nursing home settings. This approach is deployed with the help of TLC Conseil, a training organisation, who deliver training to employees in this sector. As part of this, the certified residential facilities commit to:

- Respecting a dedicated charter
- Implementing a training plan for employees
- Being evaluated over time on criteria defined by GreyPRIDE.

The steering group in charge of developing this approach is made up of nursing home directors, geriatricians and home help organisations. In return, GreyPRIDE offers to be a resource centre through a hotline and offers to mediate in difficult situations.

Germany

In Germany, dementia residential communities are well established under the care insurance system and are considered as an outpatient form of living. These assisted living communities accommodate six to twelve people, who usually live together in a large flat. People with dementia are looked after by an outpatient care service. Residents are represented by relatives, legal carers or authorised representatives and are tenants. People pay rent for their individual living space and a proportion of the shared rooms (living room, kitchen, bathrooms) and have domestic authority, power of the keys and can come and go, as well as receive visitors, as they wish. They also decide who is accepted as a new tenant and how the rooms are furnished. They commission a care service that provides round-the-clock care with an outpatient team employed by the care service.

Additionally, there are two dementia villages in Germany, which are in turn treated in the care insurance system as care homes, i.e. inpatient forms of living.

In Berlin, the Schwulen Beratung Berlin operates "Lebensort Vielfalt" (Place of life Diversity), a housing project, which welcomes people of all ages, genders and every sexual orientation. The goal is to create cross-generational homes that provide space for diversity, community and mutual support. The project aims to actively counteract discrimination and loneliness and to create a strong network for all those who are dependent on mutual support. The place of life diversity is not only a home, but also a safe place that puts solidarity, inclusion and respect at the centre. One of the projects in Charlottenburg has an apartment for gay men with care needs and dementia, which includes a 24-hour nursing service.

Ireland

In Ireland, there are a small number of privately-run residential services such as CareBright Community, in County Limerick. It was Ireland's first purpose-built community for people living with dementia, which offers residents independent living with private rooms, but also offers communal living spaces and gardens. Other models operating in Ireland are listed in section 6.4

Italy

In Italy, there is no uniformity across the country. Some regions (e.g. Emilia Romagna and Lombardy) have projects dedicated to independent living, aimed at older people and from which people with mild-stage dementia can also benefit, or which are designed specifically for people with cognitive condition. In the Lombardy Region there is the CASA project – Comunità Alloggio Sociale Anziani (Social Housing Community for the Elderly), which is a residential unit, based on a social model. It aims to guarantee protection and housing for older persons (aged 65+) who are at risk of social isolation, mostly self-sufficient or with a partial impairment in basic activities of daily life.

In addition, there are some initiatives (on a small scale) that have the specific objective of independent living for people with dementia. One example is "Ca' Nostra", an innovative model of co-housing for older people with cognitive conditions, launched in 2016 in Modena. It can accommodate four people and is managed by the families, with the support of the community. The family members bear the costs equally (e.g. for utilities, hiring caregivers etc.) and are supported by third sector organisations (e.g. with the constant presence of volunteers) and by the social health service (e.g. geriatric supervision and shared doctor).

Lithuania

In Lithuania, there is no specific housing for people living with dementia. There are forms of housing, such as sheltered housing, however, there are only a few such cases, which are still at the pilot phase and receiving project funding.

People with intellectual disabilities are eligible to live in group and sheltered housing, with the former the result of the Action Plan for the Transition from Institutional Care to Family and Community-Based Services for Disabled and Unaccompanied Children 2014-2020. There are 21 group houses of this kind in the country, with the municipality and residents jointly covering living expenses.

Luxembourg

In Luxembourg, there are no dementia-specific living concepts. However, there are living units for older people where people with dementia can also live. Small living units where people with physical or psychological disabilities can live do exist, which are usually subsidised by the state.

Malta

In Malta, alternative living models in the community have so far taken the form of specialised Dementia Activity Centres where persons with dementia are invited to spend their day in a safe environment where cognitive, physical and social activities are carried out by trained staff throughout the day. Support from NGOs such as the Malta Dementia Society has been sought so that specialised activities are carried out regularly in these centres.

Malta's small size is highlighted as one of the reasons it is possible for people using services to travel back to their private residence to spend the night and then return to one of the centres again to spend the day. The centres have been successful and have proven to be a cost-effective alternative to sheltered housing and residential care. Attendance at these Dementia Activity Centres is totally subsidised by the government (free of charge for the user) to encourage community-based living.

Another scheme which enables people with dementia to continue living at home with support is the Carer at Home Scheme. Applicants are given a financial incentive of EUR 8,000 per year to employ their own qualified private carer, either part-time or full-time, to help the family continue to care for the individual at home. This financial scheme is provided by the government, after an assessment of the needs and the carer's qualifications by Active Ageing and Community Care (AACC).

Montenegro

In Montenegro, NVO Futura has opened a day care centre for people with dementia, for eight-hour stays and 24-hour counselling available for advice and consultation.

The day care service currently supports 10 people. The Ministry of Labour and Social Welfare pays EUR 250 per user of the day care centre. However, the financing is not sufficient to cover all of the incurred expenses, including transport costs, food and drinks, medical assistants etc.

Netherlands

In the Netherlands, there are a number of examples of shared living arrangements for older people and people with dementia, which place an emphasis on maintaining the independence and choice for residents, activities to avoid social isolation and care available when it is needed. These include: Lang-leven-thuis flat, Liv-Inn, GeWoon thuis or the Thuisplusflat.

Additionally, "The Butterfly Effect" is a community building organisation which works with care organisations, housing corporations and municipalities, to create caring communities where people with and without care needs shape daily life together. This is done through the recruitment, selection and coaching of "neighbourhood connectors", residents who use their talent in strengthening social cohesion in the neighbourhood.

Another example is Residentie Gerlachus, an intergenerational residence in which students and older people (with and without dementia) live together. There are 130 independent apartments, ten participation studios, a common living room, a brasserie and four guest rooms. There is also a physiotherapy practice in the complex. The apartments are rented by a real estate company to people aged 55 and older, with twenty apartments rented by Envida (a care provider), for older people who need support but who do not yet need to move to a nursing home. The participation studios are rented to students who study a health- or care-related course; the students pay rent for their room and also have an employment contract with Envida for 12 hours per week. Envida is present in the complex with a hybrid care team, organised in response to the demand of the residents, not from rules and procedures. Before participating in the team, the students receive training in basic care, meaning they can perform light care tasks and provide individual guidance.

A well-known model is that of De Hogeweyk, the world's first dementia village, which opened in 2009, though it is noted that the model is a long-term care facility supporting people whose dementia has reached a severe stage. The village has 188 residents, housed in 27 houses, with six or seven residents per house. Professional care and support is available to residents around the clock, with home supporters, individual healthcare professionals, nurses, practice nurses, doctors, psychologists, physiotherapists and social coaches working to provide care to residents. Each house has a living room, kitchen, private bedrooms, bathrooms, a storage and laundry room including a tumble dryer and washing machine and a private outdoor space (terrace/balcony).

The village has streets, courtyards, alleyways and squares in the "Randstad" style appropriate to the surroundings, with a restaurant, café, supermarket, theatre, office, various club rooms, a physiotherapist and a hair and beauty salon available for residents to use. The aim of the care approach is to create a familiar and safe environment in which people with dementia live, retaining their own identity and autonomy. De Hogeweyk is financed by the Long-term Care Act (Wet Langdurige Zorg, WLZ).

North Macedonia

In North Macedonia, community-based models with support are envisaged by the strategy for deinstitutionalisation, but has not yet been implemented.

Norway

In Norway, several types of adapted housing aimed at people with dementia exist, including dementia communities inspired by the Dutch model of dementia villages, which offer a secure and familiar environment for residents with dementia to live as independently as possible. These communities are a type of housing that is equivalent to nursing homes and are paid for by the residents. The calculation of nursing home fees in Norway is typically based on the resident's income and wealth. This calculation considers factors such as pension income, assets, and any additional sources of income.

The individual's ability to pay is assessed, and they may be required to contribute a portion of their income and assets towards the cost of care.

There are also regulations in place to ensure that individuals do not have to spend all of their assets on care expenses, allowing them to retain a certain amount for personal use. Residents in "omsorgsboliger" (assisted living facilities) are generally required to pay rent for their accommodation and additional fees may apply for services such as meals, housekeeping, and personal care assistance. The rent can vary depending on factors such as location, size, the level of care provided and the individual's financial situation, however, it is often subsidised by the government to make it more affordable for residents. The Bo trygt hjemme-reform aims at further developing a variety of housing types suitable for people with dementia.

There are some community-based living offers for minorities living with dementia, but they are generally integrated in other offers. For example, the Dronning Ingrids Hage community for people with dementia caters specifically for people from the Sami minority, but does not provide separate living quarters.

Poland

In Poland, people with dementia with a certificate of disability can get a sheltered apartment. However, it was noted that people with dementia do not generally wish to live in such accommodation, as it is generally not suitable and is designed primarily for younger people with mental health conditions such as schizophrenia or bipolar disorder.

Portugal

In Portugal, some alternative care concepts exist for autonomous older people, but not for people with dementia.

Slovenia

In Slovenia, protected housing, intergenerational centres and supported accommodation are available but are only provided within the framework of nursing homes for older people.

Spain

In Spain, there are some models in the private sector, however, they are not easy to access.

Switzerland

In Switzerland, there are few examples of co- or shared/ livings facilities, as well as some dementia villages based on the Dutch example. Additionally, there are specialised care units in nursing homes and some nursing homes specialised for people with dementia. There are a small number of nursing homes offering “Mediterranean style” living units, which fall within the scope of the regular health insurance and are therefore reimbursement is provided.

UK – Scotland

Croftspar Place is a small purpose-built supported housing development in the east end of Glasgow for people with dementia. Developed over 20 years ago Croftspar place is a partnership between Alzheimer Scotland, the Wheatley Group and Glasgow City Council and aims to provide an alternative long term care option for people who may not be able to continue live within their own home and where the only other alternative is a care home place. Croftspar Place is specifically designed for people living with dementia. Alzheimer Scotland staff are based on site and provide housing support and care at home to Croftspar Place tenants on a twenty four hour basis. This enhanced supported accommodation model has eight single-level one-bedroom flats available as individual tenancies each with its own front and back door, a patio area and a shared but private garden.

A particular strength of Croftspar Place is that it provides an option for people from within that area of

Glasgow to have their own tenancy, create a home and with appropriate support be able to continue to live in the community which they are familiar with. As part of its activities for Dementia Awareness Week 2024, Alzheimer Scotland highlighted the story of one of the residents.

Whilst there are some examples of alternative models of community-based living, the report published in May 2024 by Alzheimer Scotland's Commission on the Future of Long-Term Care in Scotland, highlighted the paucity of alternative models and the need to invest in these.

8. Good practice resources and further information

In this section, we have collated links and further information in relation to resources, activities and projects related to the topic of independent living and/or housing.

Even where countries do not have policies, activities or information resources related to "independent living" per se, many have some information or services relating to housing and supporting people to live at home or in their communities for as long as possible. The level of information varies by country and by source (i.e. our members, governments or other organisations). This section is not intended to be exhaustive, however, is intended to provide a range of examples which may be beneficial for people working in relation to dementia.

8.1. Alzheimer's associations

Bulgaria

In December 2023, Alzheimer Bulgaria started a group for people in the early stages of dementia in collaboration with a psychotherapist. The group meets every week, with the meetings tailored to the needs and attitudes of the people in it. The therapeutic process is led by certified therapists, with the theme of each gathering related to the lives and memories of its participants, which creates a warm and friendly atmosphere of sharing between them. Small items related to the traditions and holidays of the Bulgarian people are also made. With the active participation of the members of the group, its name was also chosen: "Friends of Memory". A logo is also being developed.

To help counter the social isolation that can occur for people with dementia, the participants create trusting relationships and actively communicate with each other. They are empathetic to the problems of the others, they support each other and approach the specific experiences of their illness with understanding. As there is no active day care centre for people with dementia in Sofia, the group is a significant step forward in providing support and building a safe and friendly environment where they can have social and therapeutic engagement. Alzheimer Bulgaria is currently working to create a second group of this kind.

Czechia

The Czech Alzheimer Society published a brochure called: How to adapt the home of a person with dementia. Additionally, as a part of its consultancy work, the society provides information about adaptations, practical support and aids for people with dementia to stay longer in their homes.

Estonia

MTÜ Elu Dementsusega is a non-profit dementia advocacy organisation in Estonia that distributes information to people with dementia and their family members, as well as organising dementia cafes.

Finland

In 2022, the Alzheimer Society of Finland published a brochure, Memory-friendly living – think, know and act, as part of a project supported by the Ministry of the Environment, which encourages people with dementia to think about their own housing and provides suggestions on how to prepare for the future.

Additionally, together with other organisations, the Alzheimer Society of Finland has updated a housing database for older people.

France

France Alzheimer was contacted by the National Solidarity Fund for Autonomy (CNSA) for a study partnership on inclusive housing and small living units, in particular for people living with a neurodegenerative disease. This proposal is the result of the commitment of France Alzheimer to the Lab of Tomorrow's Solutions (CNSA's Lab) working group running since July 2022. This recognises France Alzheimer's experience and expertise with people with dementia and their families.

Inclusive housing is one of the CNSA's priority projects and is governed by the French ELAN Law of 2019. The main objective of the study partnership is to create a framework for the establishment of habitats between home environments and nursing homes. One of Lab's areas of work is to identify the conditions for the success of small-scale living environments welcoming people whose autonomy may be declining and to examine economic viability.

Alzheimer France's involvement in the study will allow it to engage in a dialogue with public institutions on this topic and respond to the needs of its beneficiaries, in relation to the framework and support of the move towards inclusive housing.

The CNSA has supported France Alzheimer through a grant, for the recruitment of a full-time post-doctoral fellow over 18 months. The signing of the agreement was made official on 12 September 2023 in Paris, with the post-doctoral fellow commencing work in April 2024.

The objectives of the project will be to carry out monographs of low-capacity collective housing, including presenting different economic models in varied territories (urban, semi-urban, rural) and different statuses (public, private profit, private non-profit). These monographs will be published on the CNSA website for the general public. A review of international literature will also will be developed, as will a national survey in order to gather data.

Separately, France Alzheimer's 2024 call for projects in the research field of human and social sciences contains the category "environment and living spaces: independent living after diagnosis, alternative habitats to the home, inclusive spaces, residential mobility, inclusiveness actions, optimized environments".

Germany

The German Alzheimer Society has produced a number of different printed resources, including:

- Outpatient assisted living communities for people with dementia
- Living Alone with Dementia
- Tablets, sensors & Co. Technical and digital aids for living with dementia.

Greece

Local Alzheimer associations operate mobile care units and home care services to support patients and families in all regional units of Greece, providing diagnosis, medical care and support services.

Furthermore, the Panhellenic Federation and the Alzheimer's Associations offers training resources such as conferences, workshops, group and individual sessions, lessons, tele-conference group programmes, TV programs to health professionals, general public and caregivers in order to inform, educate and help overcome issues of everyday living with the disease. Some examples include:

- Educational lessons
- TV programmes
- Online speeches
- Videos for Caregivers.

Iceland

Alzheimer Iceland provides help and guides people living with dementia and their carers through the process of applying for funding, using technology etc.

Ireland

The Alzheimer's Society of Ireland (ASI) has a brochure, "Practical steps to support your independence", which illustrates how assistive technology can help people

with dementia and their families. It explains how assistive technology can support the person living with dementia to live more independently, as well as how to stay safe and where to find these technologies.

Moreover, as part of The ASI's training for family carers, there is a module, "Safety in the Home" which also focuses on the applicability and use of assistive technology and aids available to support care at home.

Additionally, the ASI's frontline Dementia Advisers can connect people to local Health Homes Age Friendly Co-ordinators (a role within a limited number of local authorities), who can undertake an assessment and support them with grant applications, advice and other queries that they may have in relation to living well in their homes for independent living.

Luxembourg

In order to remain independent in everyday life, specialised care services from the Association Luxembourg Alzheimer can support and care for people with dementia at home. People with dementia can also attend specialised day centres where their cognitive capacities, social contacts and resources are specifically promoted, whilst individual therapeutic sessions are also offered by the association. The association is also working to create dementia-inclusive communities, which is a relatively new initiative in Luxembourg.

The association also offers various forms of information and support, for example, organising regular information events (Info-Dementia) to educate the public on the subject of dementia and training courses for people with dementia and families.

Malta

In Malta, the sole non-governmental organisation which specialises in dementia is the Malta Dementia Society, which offers the following services to help families to continue living independently: "Reaching hands" (a caregiver support group), "DancingtoDementia" and "Kuluri u tifkiriet" (craft sessions focusing on reminiscence). These sessions take place in all governmental homes and dementia activity centres in Malta and Gozo. The society also carries out these sessions in a number of private care homes.

Montenegro

In Montenegro, NVO Futura holds regular media campaigns, as well as producing brochures and guides for caregivers. Additionally, it holds consultations and free medical examinations by neurologists, as well as offering support through psychologists and psychotherapists. In addition, it provides help to individuals to prepare documentation and obtain assistance from the commission of the centre for social work.

Netherlands

Samen dementievriendelijk (Together Dementia Friendly) is a joint initiative of Alzheimer Nederland and the Ministry of Health, Welfare and Sport, with the aim of making people with dementia and their caregivers feel better supported in a dementia-friendly society.

The initiative includes a free online training course for employees of housing corporations, developed with the housing corporation Thuisveste. This training is based on the 'Do GOOD method' consisting of four parts: recognising, reassurance, making eye contact and thinking along. Each part contains three questions and when completing the training several times, different questions appear and different situations occur, teaching people that are in contact with people with dementia important skills, step-by-step, so that they can help when needed.

North Macedonia

Whilst the Institute for Alzheimer's disease and Neuroscience (IAN) doesn't offer specific training or publications, they support individuals by connecting them with resources for housing and independent living. For instance, they provide information about support services available in the community, such as those offered by the Red Cross for people with dementia. They also provide advice about health and social services for older people and support them in navigating application procedures.

Norway

Nasjonalforeningen for folkehelsen (the Norwegian Health Association) provides advice and information on how to create a safe home environment and how various aids and measures can be used to support independent living. Their volunteers participate in caregiver schools, user schools, and support groups and offer advice on how people with dementia can safely live independently at home.

On a national and policy level the association is an advocate for increasing and implementing the use of welfare technology and the digitalisation of the health care system. Their view is that care and support systems need to work around the user, without the user having to have an active participatory role and that with adequate and appropriate use of e.g. welfare technology, people with dementia may live safely at home for longer. The association is, among other things, part of the National eHealth Board, which is the highest advisory body within the national eHealth governance model. It is responsible for providing strategic guidance on eHealth matters, recommending priorities, and overseeing the implementation of measures to ensure a comprehensive eHealth development that effectively utilises resources.

During the development of the "Bo trygt hjemme" reform, the association gained understanding and support from politicians to regard dementia-friendly initiatives as part of the age friendly work, and they are currently involved in the implementation of the reform together with central authorities.

Nasjonalforeningen for folkehelsen has also taken part in the development of "Veiviser demens" (Dementia guide) which is designed to offer guidance, information, and support for individuals affected by dementia. It aims to help them live as independently and securely as possible. The Dementia Guide is part of a broader effort by the Norwegian Directorate of Health to improve dementia care and support across the country. It involves collaboration with various stakeholders, including healthcare providers, voluntary organisations, and policymakers. The association and its working group of people with dementia provided input about what topics should be covered and on how the text and wording of the guide could be made more accessible.

Poland

Members of Alzheimer Polska offer information, training and publications on how to cope with dementia when a relative is living with the disease with the family at home. Additionally, the Siedlce Alzheimer's Association runs two social welfare houses for people living with Alzheimer's disease, support them to live with the condition, once they are unable to remain at home.

Sweden

The local associations of Demensförbundet offer discussion groups and host lectures on various topics, often in collaboration with the municipality to get information on what support is available. Demensförbundet also conducts webinars with information and advice, which are recorded and shared online, for people to access afterwards.

Switzerland

Alzheimer Schweiz Suisse Svizzera publishes a number of resources and information related to living at home with dementia, including:

- Articles in their magazine about housing – Living in a nursing home
- A practical guide and handbook for family carers for care planning at home
- An information sheet on considerations for admission to a nursing home
- An information sheet on home adaptations
- An internet guide on nearby services and supports called Alzguide.

Additionally, the organisation's national hotline offers advice for independent living at home.

UK – Scotland

Alzheimer Scotland has Dementia Resource Centres across Scotland which offer accessible environments for people to come for information, advice or support from staff and volunteers. Each Dementia Resource Centre also hosts different groups and activities. Additionally, the organisations has information sheets on living well with dementia and living independently, including:

- Getting out and about
- Staying connected
- A meaningful life
- Safe and secure
- Everyday living.

The organisation also developed the Technology Charter for People Living with Dementia in Scotland setting out the rights of people living with dementia and the principles for the use of technology.

Additionally, Alzheimer Scotland and the Scottish Government collaborated on the "Connecting People, Connecting Support" framework, a commitment of Scotland's third National Dementia Strategy (2017-2020). It focuses on transforming the way in which Allied Health Professionals - AHPs (physiotherapist, speech and language therapists, dieticians etc.) support people living with dementia and their families. Since its generation, the report's findings have been implemented by the Alzheimer Scotland National AHP Consultant in tandem with the newly formed Alzheimer Scotland AHP Dementia Forum and other key stakeholders.

8.2. Government and other associations

Finland

The Finnish Association for the Welfare of Older Adults (VTKL) has a service called: Home repair advice, for older people aged over 65. They have 14 regional home repair experts who help veterans and older people assess and plan housing renovations, as well as to apply for repair allowances. If necessary they can also help in finding contractors to carry out the work. The repair advice is provided free of charge.

France

On 14 December 2021, the "Alzheimer Ensemble Collective", created by la Fondation Médéric Alzheimer (of which France Alzheimer is a partner), hosted a webinar in the Landais Alzheimer Village on the subject of inclusive housing entitled: "Encourage new forms of housing". The webinar examined new models of housing, including inclusive and intermediate housing, examining how to move beyond current choices of care at home or nursing homes. Discussions also explored the idea that need for development of such intermediate offer is based on a double challenge: demographic and ethical.

In 2022, la Fondation Médéric Alzheimer issued a report titled "Alzheimer's: overview of alternative habitats. Presentation and analysis of issues related to living spaces alternatives for people living with Alzheimer's or a related disease". The report notes that despite a number of initiatives being developed in this area since the 2000s, there is not a clear approach to independent living for people who have or are developing cognitive conditions. Additionally, it highlights that reports and policies in this area often address issues of at-risk people or people with disability more broadly, however, with little consideration of independent living in relation to people with dementia.

Germany

There are a number of brochures, flyers and websites on the subject of dementia, published by different organisations. Some include a focus on the topic of housing, including:

- The Federal Ministry of Family, Seniors, Women and Young People have a "Wegweiser Demenz" (Dementia Signpost) website with information and resources, including a designated section on housing
- The website of the Verbraucherzentrale (Consumer Advice Centres) contains resources and information on how to make homes more liveable for people with dementia, including advice on design and technology

- Local Alzheimer's associations have also published their own resources including Alzheimer Brandenburg's "People with dementia in shared flats - self-organised and accompanied: A guide and more".

Iceland

In Iceland, the "Gott ad eldast" ("Good to Grow Older") project runs from 2022 to 2027 and aims to provide a comprehensive review of services for older people, as well as identifying solutions which integrate social and healthcare services. The overarching goal is to ensure a healthier and more active older population with services that will enable as many people as possible to continue to participate in society. The plan is structured around five pillars:

1. Home
2. Integration
3. Activity
4. Development
5. Information.

Ireland

The Model of Care for Dementia in Ireland was published in 2023, and is the guiding framework under which work is completed. Target 30 under this framework outlines, "Every person with dementia assessed as requiring home-based care should be provided with personalised and flexible supports that meet both their personal and psycho-social care needs in their home."

The National Disability Authority developed "Research for Dementia and Home Design in Ireland looking at New Build and Retro-Fit Homes from a Universal Design Approach: Key Findings and Recommendations Report 2015" which utilised a universal design approach to consider the needs of people with dementia. The guidelines are intended to be implemented via incorporation into Irish regulations, which are then inspected by the Health Information and Quality Authority (HIQA).

The Health Service Executive (HSE) published the "Safeguarding Vulnerable Persons at Risk of Abuse National Policy and Procedures" in 2014. Under this policy, people with degenerative, neurocognitive disorders such as dementia are specifically identified as part of groups that may exhibit self-neglect and thus may require safeguarding. In addition to this policy, the HSE set up the National Safeguarding Office, as well as nine Safeguarding and Protection Teams in 2015. Furthermore, an inter-sectoral national safeguarding committee was established called Safeguarding Ireland. Any suspected cases of abuse can be reported to the HSE's National Safeguarding Office or Safeguarding and Protection Teams, as well as to local GPs.

Luxembourg

The Info-Zenter Demenz is the national information service for all questions related to dementia. It provides information and helps to better understand the disease. It can be used by people with dementia, their relatives, health professionals and anyone else with an interest in the condition. The Info-Zenter Demenz also guides people with dementia and/or their relatives to the services available in Luxembourg.

The Programme for Dementia Prevention (PDP) is a programme for effective dementia prevention within Luxembourg in a target population presenting with a Mild Cognitive Impairment (MCI) or a Subjective Cognitive Decline (SCD), such as problems with memory, attention, language or visuo-spatial skills. The PDP aims to support people belonging to this target population by introducing them to new ways on how to stay cognitively and physically active.

Malta

A lot is being done in Malta to encourage independent community living. As examples of good practice, there are three main services designed specifically for persons with dementia, managed by the Dementia Care Directorate within Active Ageing and Community Care (AACC):

1. National Dementia Helpline 1771 – a 24hr helpline operated by dementia practice nurses, offering practical information, emotional support and information to callers who need it. Referrals to other services and printed material can also be supplied

2. Dementia Intervention Team – an interdisciplinary team of professionals providing a holistic community-based support service for persons with dementia and their caregivers. A holistic assessment of the caregivers' and care recipients' situation is carried out at the applicants' private residence, with a tailormade care plan developed, which can include education, training, support and advice on safety and coping strategies. The main aim of the team is to enable people with dementia to continue living actively in the community and to improve their quality of life. Core team members include dementia practice nurses, general practitioners and occupational therapists, with input from other professionals such as social workers, geriatricians, psychogeriatricians, etc.
3. Dementia Activity Centres – situated in different localities in Malta and Gozo, these provide day care that is specifically designed to cater for the needs of people living with dementia. They provide respite and support, relief for caregivers and therapeutic activities for person with dementia. Trained professional carers also facilitate and provide therapy to people who attend the centres, to help manage the condition.

Netherlands

The campaign "Praat vandaag over morgen" (talk today about tomorrow) was delivered by public approach to involve the whole of the Netherlands in the future of care for older people. It is an initiative of ActiZ,(the umbrella organisation of Dutch care organisations) and the Ministry of Health, Welfare and Sport (VWS). The work was first undertaken in 2019 and was refreshed in 2024 with a public campaign "What do you think is important for later?" encouraging people to have conversations with those closest to them about their wishes for later life and considering issues such as care, staying fit and housing.

In addition, the Seniorencoalitie, the Senior Network Netherlands, ActiZ and others will organizes activities and meetings in the next two years to allow as many people as possible to have a conversation about their future.

A specific project "Regiotour Dementie", which at the invitation of the Ministry of Health, Welfare and Sport Alzheimer Nederland, the VNG and Movisie, hosted meetings in meeting centres across the Netherlands. The purpose of these meetings was to hear the experience of people living dementia and exchange knowledge and information between municipalities and others, to find out what matters most for people with dementia who still live at home. The insights and information gathered from the day have been published online.

Poland

In Poland, for about three years, several social welfare homes have been operating places for 24-hour stay, called respite care places, where people with dementia can stay for between two weeks and eight months, to provide an informal family caregiver with respite.

Slovenia

The Republic of Slovenia provides and partially co-finances home care, which is primarily intended for elderly individuals who live in their own homes but, due to illness or other age-related issues, can no longer fully take care of or look after themselves, nor can their relatives or neighbours adequately do so. Home care substitutes the need for institutional care, allowing individuals to remain in their home environment for as long as possible, although home care is not tailored for individuals with dementia.

Sweden

There are some projects in municipalities in Sweden that address better brain health for older people, in the form of exercise and social activities, including:

- The Lidingö municipality, in collaboration with the Karolinska Institute, developed the "Träna hjärna!" (Training the Brain!) programme to inspire older people in the municipality to make changes to improve their brain health. The training is based on the FINGER model, which advocates examining five lifestyle factors: healthy diet, physical activity, cognitive

stimulation, social activities and relaxation, and cardiovascular health. The programme runs from September 2024 to June 2025 and includes both group and individual activities. It is a comprehensive programme with training twice a week and lectures on good dietary habits, physical activity and the importance of recovery
- The Väastra Götaland County established the "Senior Sport School" where people aged over 60 can try out various physical activities at local sports clubs in the municipality, combined with lectures. The programme runs for twelve weeks, with two meetings per week, twelve physical activities at local sports clubs and twelve theoretical meetings, focused on health, cooking etc.

In 2017, the Nordic Welfare Centre published a report titled "Welfare technology is not about technology but about people" which aims to inspire practitioners and decision-makers at municipal and national levels by allowing different Nordic voices to speak about issues raised around welfare technology. The report examines issues around the different kinds of technology available, how municipalities can actively implement new technology and some of the ethical challenges around the use of technology.

UK - Scotland

The Dementia Services Development Centre (DSDC) is a research unit within the University of Stirling, which uses research to inform practice and vice versa providing comprehensive resources for anyone supporting someone living with dementia, whether personally or professionally. As part of this, they offer consultancy and training on designing living environments for people with dementia.

In 2017, the Chartered Institute of Housing in Scotland, having worked with Healthcare Improvement Scotland's iHub and Alzheimer Scotland, launched "Housing and dementia: a practice framework", outlining how housing organisations can support people with dementia to live well. The framework sets out five person-centred outcomes that people living with dementia said were important, underpinned by 11 commitments and a self-assessment for organisations to assess their position.

9. Experiences of people with dementia and carers

As with previous years, Alzheimer Europe wanted to ensure that the voices of people with dementia and carers were reflected in our Yearbook. Whilst the Yearbook itself provides the policy and legislative context of housing and independent living, this does not necessarily represent the personal priorities and experiences of people living with the condition. We therefore asked members of the European Working Group of People with Dementia (EWGPWD) and the European Dementia Carers Working Group (EDCWG) to contribute their experiences and views, to underscore the importance of policy, legislation, services and supports responding to the needs of people with lived experience.

In the first part of this section, we provide a brief overview of some of the issues which emerged during meetings with each group in October 2024. In the second part, we hear from people with dementia and carers who have written testimonies about their experiences and views on independent living and housing.

9.1. Key issues raised by people with dementia and carers

9.1.1. Views of people with dementia

Understanding and awareness

During the discussion, the need for understanding and awareness about dementia was a recurring theme, both in relation to the wider public but also for health professionals. A number of members of the groups shared that their health and social care professionals often lacked knowledge about dementia, making assumptions about the abilities of people with the condition. In one experience shared by a member of the group, the person with dementia was told that they couldn't have dementia because they could talk. In another, the GP told the person with dementia that they probably had more knowledge than them. The group agreed that healthcare professionals needed to have a greater understanding of dementia in general.

Additionally, it was felt that the understanding of dementia amongst politicians remained poor, as did their understanding of how people with dementia experienced care systems and supports. For example, one person shared that within their country, the difference between written policies and practice was significant. They expressed the view that society isn't interested or involved, therefore the policies "stay on paper" and don't translate into real life.

A number of members talked about the importance of being open and honest about the condition. One member shared that it was important for them to let people in their closer network know about the illness, in order for those people to be able to provide help and support. Another member shared that it was important for people with dementia to be open about their condition to educate others about dementia and so that people don't rely on what they read after searching for dementia online and challenge misinformation about the condition.

Stigma and social isolation

Related to the topic of understanding and stigma, a member shared that they perceived that it wasn't that the community had to adjust to them, they had to adjust to their community. They felt the need to "prove" that something was wrong (despite having a diagnosis) and that it was particularly challenging to stay part of the community and avoid becoming socially isolated.

Some members shared that they experienced people avoiding them following their diagnosis. Others people explained that their friends were scared to come talk to them and were worried that the person with dementia wouldn't recognise them.

One member described feeling "in between". They explained that they lived a normal life, they didn't feel different, but that people treated them differently. For example, people wanted them to move to a nursing home, which the person attributed to stigma. They noted that if you are not scared to show your face and publicly speaking about your diagnosis, then you can get lucky and find new opportunities. In this case, the person with dementia found a new job. Related to this, another member shared that they were able to stay in their job until retirement age, even after their diagnosis, as their employer took steps to add supervision, help and support.

It was also discussed that the media often focus solely on the negative aspects of dementia and that there needs to be a better balance in reporting on the condition, for example, by highlighting that it is possible to live well with the condition and emphasising the importance of treating people with equal respect.

Social and support networks

A number of members spoke of the importance of building their support network, reliable people that, if necessary, can help support the person with dementia. For some, this was a broad group that they gathered around them. For example, one shared that in the village in which they lived, there were people who knew that they had been a caregiver for their mother – as such, they knew them well and had some understanding of dementia. The person elaborated that for them having people in their network who have knowledge about dementia is vitally important. Others shared that for them, their closest friends and family were the most important part of their network, as these were the people who helped recognise their condition and who continued to provide the greatest source of support.

People living alone/without family networks

One member of the group highlighted their experience of not having any close family to support them, so that to live independently they needed the support of other people. They noted that they didn't need help at home but they needed help to live. Explaining this, they talked about the importance of community spaces to meet other people and make friends, with whom they could connect and ask for help. As part of this, continuity and routine were seen as important, as they noted that when they stop seeing friends or doing these activities, they are alone and "shut down". They expressed the view that in future it is likely that there will be more people in a similar position and that the needs of this group need to be considered.

Services – stage of intervention/accessibility/suitability

The group discussed a number of different aspects relating to care and support services, including the need for stage-appropriate, suitable and accessible services. It was noted that for a person with dementia, it can be difficult to access services, especially in the early stages of the condition. This may also include assistance other than personal or health care. Too many of the available services were seen to be reactive, rather than proactive and were not provided until dementia has progressed significantly.

Where services and supports do exist, a number of members expressed the view that they are not always easy to find, as people are not made aware of them. It was felt that information should be given to people with dementia as part of a clear pathway following diagnosis, setting out what will happen, which professionals they will meet etc. One member noted the existence of caseworkers in their country, who know the whole system and help the person to find the type of services they are looking for. Another member highlighted the value of memory cafés, where they could receive help, support and advice – this was helpful for the person as they knew where they could go for support, to meet people and to take part in activities.

One member encouraged other members to ask their local politicians, as well as doctors about the services available in their community, noting that they had previously been afraid to ask questions of them. However, they noted that they should be aware of this information and if they weren't, they should find out more about such services!

A number of group members discussed the importance of "stage-appropriate" services, reflecting the unique circumstances and situation of the individual. It was noted that too often available services were focused on the more advanced stages of the illness, which was not suitable or appropriate for people with less severe dementia. The different types of dementia, the different points where diagnosis is made and the circumstances of the individual require a person-specific approach. It was felt that once the diagnosis was made, the local community should have a leading role, taking over to support the person and create a schedule for services and supports, reflecting the needs and preferences of the person with dementia.

Early-onset dementia

An important theme for some members of the group was the lack of knowledge and awareness on early-onset dementia. Partially, related to the previous topic, services were noted to be more orientated towards older people, most of which were unsuited for younger people with dementia. One member shared the view that systems intervene too late. In their country, the group they were part of was the only one for younger people with dementia and that they receive little support for their work.

Some members returned to the subject of employment (touched on by others), noting that when they got a diagnosis, they were still employed but had to stop working. However, they felt they could have continued to work and still had a lot to contribute in the workforce. Instead of retiring and immediately relying on other services, people felt they could have continued to earn and work. Another member noted that there are laws, e.g. requiring reasonable accommodations, which can support people to continue working, but that people need to know about them

Transportation

A theme that was important for a number of members, particularly people living in rural areas, was good public transport. This is also true for people who are no longer able to drive themselves, as a result of their diagnosis. It was highlighted that for those in more rural areas, activities such as attending medical appointments were sometimes only possible by public transport. As such, the operators of such services (e.g. buses, trains etc.) should be aware of the specific needs of people with dementia. It was discussed that especially in countries with large rural areas and smaller populations, this needs to be addressed if people are to live independently.

Technology

Members shared a broad range of technologies they used in their homes on a day to day basis which helped them to live independently.

Many highlighted the use of computers and tablets, with alerts, voice reminders and lists set up as reminders for activities/appointments etc. Tablets and phones were also mentioned by many members, who also highlighted the use of apps for their day to day life and wellbeing (e.g. brain training applications, yoga etc.). Digital assistants, such as Amazon's Alexa or Google Home, were also highlighted as useful by a number of members.

One member specifically identified Global Positioning Systems (GPS) features as important for him, as it allowed them to go walking without fear of becoming lost. As another, example of location tracking, one person with dementia mentioned that they contactless payment card, with notifications which showed on the application, allowing the carer to see where the person was.

However, some members also shared that some low-tech approaches were also helpful for them. For example, a clear, easy-to-read screen with the day, time and year, helped them to orientate. Another member shared that they used a whiteboard with their six-week schedule, as having a visual reminder was the most helpful thing for them. Similarly, another member shared that having a notebook with them was helpful for their day to day life.

9.1.2. Views of Carers

Technology and adaptations

During the sessions, carers shared their experience of some of the technology and adaptations they used in their own lives, to support the person with dementia to remain as independent as possible. Examples included the use of GPS trackers, which allowed carers to locate the person with dementia, should they become lost. The group noted that GPS trackers helped keep the person safe, whilst also ensuring the carer is less stressed about the person going missing.

Additionally, some carers shared their experiences using remote assistance, for example with the use of screens and phones. One specific example, KOMP, is a screen with a single button kept in the home, which allows a supporter to communicate easily with the person with dementia when they are not there. Calls can be made to the device and photos can also be sent to the screen. The carer shared that their spouse felt safer with the device, as they know where their partner or family are. The screen can be placed anywhere in the house, as needed. Whilst the carer noted that they have to pay for this service, they also mentioned that it was not expensive and that in some locations, it was paid for by the state. Other members in the group highlighted other types of technology that can be used in home settings, for example to detect activity or falls, ensuring that people can remain in their own homes, but be assisted in case of an accident.

In relation to adaptations in the home, it was noted that changes such as accessible bathrooms and showers may be helpful but that the disruption caused by such renovations may mean that people with dementia are reluctant to make such changes within their home. Another carer shared that they were advised by their occupational therapist to take their time with adaptations. In particular, it was highlighted that too many changes, made too quickly, may not benefit the person with dementia. Another carer explained that adaptations do not have to be complex or major interventions within the home. For example, removing doors from cabinets (to allow the person with dementia to see objects and access them more easily) or removing carpets, were highlighted as changes which could promote the independence of the person living with dementia. Additionally, one carer shared that it was important to ensure consistency, i.e. making sure that objects or items were kept in the same place, to make them easier to find for the person.

People living alone *vs* people living with a spouse/family/carer/supporter

During the session, carers discussed the type of people who may move to independent living facilities. Some shared that they were not aware of people with dementia who had been cared for by an informal caregiver, who had then moved into an independent living facility. It was suggested that this was more likely where the person with dementia lived alone or had another health condition.

This developed into a conversation about the differences between people with dementia who lived alone, compared with people who lived with an informal carer. The role of the carer in supporting people with dementia to remain at home was central to this topic, noting that carers often supported the person to remain at home, even where the condition had progressed and more symptoms develop, delaying the transition to a care facility.

It was noted that the needs of these two groups are distinct and that systems should respond to the unique circumstances of individuals. Health and care must ensure adequate support and services for people who do not have the informal support of family or others. Conversely, where there is a spouse or close family member, there is still a need for support from health and carer services. In particular, one carer noted that when supporting someone at home, the carer needs someone to talk to and who can help them make or come to a decision. The carer noted that in their circumstances, they were fortunate to have a relative who was a nurse and understood dementia.

A recurring theme which emerged from carers in the group was the safety and security of the person with dementia. Many spoke about their role as a carer in keeping the person at home for as long as possible, creating an environment that allowed the person to remain active, whilst also keeping them safe.

One carer shared that their country's national policy promotes staying at home for as long as possible but noted that there is a big difference between people living alone or with family. For them, safety was of paramount importance and that once the person no longer felt safe staying at home, that was the time to explore other options, such as care homes.

As part of this caring role, the transition to formal care settings (e.g. nursing homes) was a topic raised by a number of carers. One shared that when they had decided with their children that the best option was for the spouse to move to a care home, they did not feel guilty, as they had done everything they could to allow their spouse to live as independently as possible, for as long as possible, at home. However, they expressed that had they taken their spouse to an independent living facility, they would have felt as if they were giving up, as it was their job to keep the person independent.

Another carer shared a similar view, that they were worried about moving the person with dementia to a care facility too early in the course of the condition, when they could have remained at home. They expressed that they wanted their home to be safe and secure for the person with dementia and that technology helped to do this.

Finally, one carer noted the importance of keeping a routine with the person following their diagnosis, continuing to do the things they enjoyed and had done before, for as long as possible. To do so is to give their loved one ultimate respect and gives joy to the carer to see their relative functioning at their best.

Stage of intervention

Carers discussed that the needs of people with dementia vary and change depending on the progression of the condition. It was agreed that the earlier the intervention, the better, as people in the earlier stages of dementia can still clearly communicate their needs, wishes and feelings.

It was highlighted that one care setting in Shankill in Dublin had revamped its model of care provision, with people with dementia staying in different lodges according to the level of support needed. Some lodges provided more support than others depending on the needs of the individual. However, the primary focus of the care provided is to ensure that people are encouraged to maintain their independence for as long as possible.

9.2. Testimonials of people with dementia and carers

Kevin Quaid, Chairperson, EWGPWD

Sometime after my diagnosis of Lewy Body Dementia, my GP suggested that I may benefit from meeting with a dementia advisor, which I did and she in turn introduced me to The Alzheimer Society of Ireland. I soon became an advocate and realised that there was such a need for people with lived experience to be heard. I was also lucky that my wife took on the role of my spousal carer and with some modifications to our home, like easier access to the bathroom from my bedroom, my life was so much easier. The use of my laptop for writing and Zoom meetings has become a very big part of my life, as has my iPhone.

Getting involved with both The Alzheimer Society of Ireland and Alzheimer Europe through their working groups has completely changed my life, as well as the way I look at not just my type of dementia, but all types of dementia. It helped me to understand the struggles and the abilities of those of us who have been diagnosed with dementia, regardless of the type.

I live in a small community of about 2,500 people and when I launched my books, it gave people who knew me (and indeed didn't know me) a better understanding of dementia – more and more people began to talk about it. It took probably six months but I used my voice in the media a lot and spoke a lot about the importance of community, that it has benefited me so much. I am no longer seen as a person who just has dementia – I am seen as a person with all my capabilities. Getting involved in my local community is of vital importance not just for my dementia but also my mental health.

Carers for people who have dementia need to look at a person's abilities and not their disability. For example, if a person likes to cook a little, they may be able to do everything right but may need help with the controls on the cooker. The most important thing of all is to build up enough trust so that the person with dementia can honestly say whether or not they need help with something. The biggest thing in any relationship are trust and loyalty. If the person who you are caring for trusts you, then they will feel safe with you and when a person feels safe with you, then they will completely trust you.

Ireland has a massive problem with bed shortages in hospitals and a lot of that is because people who could be in care homes have no place to go because most of those facilities are full. Likewise, there are a lot of people who are in care homes who could be living at home but cannot because of a lack of support for their carer and a lack of supports and services, especially in rural areas. If family carers were paid a decent wage for staying at home and looking after their loved ones, it would literally free up hundreds of beds and essentially save the government so much money in the long run. It seems like common sense!

Lieselotte Klotz, Vice-Chairperson, EWGPWD

My journey from diagnosis to a somewhat adequate care situation was initially a rocky march through a labyrinth of misunderstanding and sorrow. A patchwork of fragmented information, ignorance, regulations, forms and hurdles repeatedly shattered my hope for help, support and answers.

In those early years following my Lewy Body Dementia diagnosis, each day felt like a new battle against the overwhelming sense of being completely alone and abandoned in an empty room. Instead of receiving helpful, well-structured and person-centred support, I encountered overwhelming rejection, loneliness, bureaucracy, ignorance, as well as confusing, disjointed processes, which only added to the despair caused by the burdensome diagnosis. The structures that were supposed to assist me were, in fact, nonexistent. Fear, loneliness, and uncertainty often weighed heavily on me, leaving me feeling trapped in a situation I was unprepared for, within a system that was not designed to meet my needs.

The reality is that in the early phase of my life with Lewy Body Dementia, I lacked helpful and supportive points of contact that could have assisted me in stabilising or improving my situation.

It was only through close contact with the Alzheimer's community and my volunteer work in various committees for, and with, people with dementia, that I found a positive, meaningful path back to a life that felt worthwhile and liveable.

Today, my personal toolkit for coping with my condition includes radical acceptance, compassion, courage—but also occasional outbursts of anger, a healthy dose of patience, and the ability to recognise the beauty in life despite all challenges.

My own painful experiences have made it clear to me how crucial it is for people with dementia—particularly young individuals with a dementia diagnosis—to receive timely, qualified, phase-appropriate, and person-centred support and guidance. This can spare them the descent into deep despair and depression.

We need immediate, respectful, and effective support and care that addresses the here and now. Only then can people with dementia lead a self-determined life for as long as possible. Particularly important is comprehensive support for family caregivers, who provide about 80% of care in Germany. Their relief is crucial not only for their well-being but also for the quality of care that people with dementia receive.

Overall, a holistic approach that integrates housing options, technology, education and community concepts can significantly contribute to ensuring that people with dementia live in a supportive environment that respects their autonomy and grants them access to necessary resources.

Our society needs more cross-generational knowledge about dementia. Awareness-raising and training in both the medical and caregiving sectors must be made mandatory. Infrastructure measures and clear political commitment to funding are essential to sustainably enhance and secure the quality of life and autonomy of people with dementia.

To effectively address the challenges of dementia, decision-makers must finally move beyond bureaucracy and theoretical approaches, focusing instead on

practical solutions and more participatory research in meaningful dementia care that centres on the actual needs of those affected. In light of the current cost explosion in care – driven by demographic change and the shortage of skilled workers – sustainable solutions must be developed. A key aspect is the demand for a direct, accessible and hierarchically inclusive network of all relevant stakeholders, from local caregivers and medical personnel to physicians and social and governmental institutions, as well as those affected. This implies not only improved infrastructure but also a culture of open and respectful exchange.

People with dementia have a right to care that exists, not just on paper, but that truly works in practice and significantly eases their lives.

Nigel Hullah, Member, EWGPWD

Continuing to live at home after a diagnosis of dementia has made possible through a combination of personal, social, and technological support. For me, the following aspects are necessary:

- Support from Family, Friends, and Caregivers – Emotional and practical support from family and friends has made a significant difference, including having trusted individuals to assist with daily tasks, accompany appointments, and provide companionship helps maintain independence.
- In-Home Support Services – Access to in-home care services such as dementia care workers, healthcare professionals or personal assistants who assist with daily activities, personal care and health monitoring helps people stay in familiar surroundings. Although, I don't need these services now, knowing they will be there when I need them is comforting.
- Dementia-Specific Support Services – Local dementia support services, such as memory clinics, day centres or community groups, provide practical support, activities and social engagement to help people remain connected with their community and manage their condition.
- Housing Adaptations – Simple modifications, such as installing grab bars, stair lifts, non-slip flooring or extra lighting, can make the home safer and more navigable, helping to reduce confusion and prevent accidents. Creating clean and consistent home environments with labelled drawers, memory aids and simple room layouts can also help orient a person and reduce stress.
- Technology and assistive devices – These are invaluable in managing dementia. Practical tools like GPS trackers, reminder apps, automatic pill-dispensers and voice-activated assistants (e.g. Amazon's Alexa or Google Home) play a significant role in aiding medication management, personal reminders, and navigation. Sensors and smart home systems (e.g. fall detectors or bright lighting) enhance safety by monitoring for emergencies and enabling remote assistance. I have been fortunate to be involved in discussions on these subjects as a member of the EWGPWD.
- Home Health Monitoring – Telehealth services allow for remote consultations with healthcare providers, reducing the need to leave the home for routine appointments. Services like blood pressure monitors, heart rate sensors, and other home health monitoring tools provide ongoing tracking of health conditions.
- Local and International Community and Social Networks – Staying socially active through local groups, religious organisations, or hobby-based activities helps maintain a sense of purpose and belonging.

Support groups for people with dementia and their caregivers offer a place to share experiences, get advice, and receive emotional support.
- Personal Routines and Memory Aids – Maintaining a structured daily routine can provide a sense of normalcy and reduce confusion. Memory aids such as calendars, notes, whiteboards, or apps can help people keep track of appointments, medications, and tasks.
- Financial and Legal Planning – Ensuring that financial and legal affairs, such as powers of attorney, wills, and access to dementia-related benefits, are well-organised can reduce stress and provide peace of mind for the individual and their family.

Erla Jónsdóttir, Member, EWGPWD

My name is Sigríður Erla Jónsdóttir, I'm 68 years old, happily married, and a proud mother and grandmother.

I have a diverse work background and consider myself a talkative extrovert who loves being with people and helping out. Togetherness with family, friends and partners is very important to me. I was diagnosed with Alzheimer's a few years ago – my family and I navigate life with this disease together.

When I became ill, I held a management position in a large public forum. Having a job is not just about earning money. It provided me with a rich purpose, a daily routine, satisfaction, and I benefited from the relationships and connections formed through work. All of these factors affected my daily life and well-being. But the day I was diagnosed, I was forced to quit the job I valued so much.

Eventually, I found a life-saving substitute for my previous work: Seiglan, a fantastic daycare centre run by Alzheimer Iceland. Individuals with Alzheimer's disease, like everyone else, have important values. Seiglan assists me in maintaining and upholding those values. Maintaining relationships with my loved ones is of utmost importance to me. But creating new relationships with people who meet me on my terms is highly valued. It provides a sense of continuity and belonging.

I want to be treated with respect and dignity. Involving me in decisions about my daily care helps preserve my sense of self-worth. Maintaining my independence is important and finding ways to support it empowers me. Activities that bring comfort, pleasure, and a sense of accomplishment can greatly add to my everyday quality of life.

Ultimately, preserving and enhancing the overall quality of life is a fundamental value. This includes physical comfort, emotional well-being and meaningful engagement with the world around me. By understanding and honouring these values, Seiglan provides compassionate and effective support.

Seiglan is a resource I currently have access to and cherish so much. But what about resources I do not currently have, but would like to have access to? The wish list is of course long, but I will focus on two issues I find very important.

First and foremost, I would like to see more support for family members. Support for family members is crucial for several reasons. It helps to manage feelings of sadness, frustration and anxiety, reducing the risk of burnout and depression. Continuous care without proper support is unsustainable. We need to develop better support systems for our family members.

My second wish is for improved living facilities that better accommodate our diverse needs. Current options and methods lack diversity, neglecting personal needs. Additionally, the most convenient solutions in care are often prioritised. I am not so concerned about my illness itself, I am more concerned about how we treat it. Or as Maslow concluded: "If the only tool you have is a hammer, it is tempting to treat everything as if it were a nail".

My husband and I often talk about how great it would be to move to an apartment in a supportive community that aligns with the values we discussed regarding Seiglan, fostering stronger relationships with family and friends. Today, people listen to what I want, feel and think. I can decide what to do and I am free to go wherever I want to go. Will this still be the case when we have to move to a special care home? Will we be forced to move too early?

After a lifetime of freedom and independence, who would want to be locked up in a place where loneliness echoes through endless corridors and you only get to experience the outside world through a window? Who wants to spend their final years, in a system, where your voice is no longer relevant?

We need a twofold solution. Firstly, we require living arrangements that enable us to live happy, meaningful lives, independently. Secondly, in care homes, we must focus on caring for each person as a unique individual with a rich emotional life.

It is vital to prioritise quality of life over merely counting years. Our feelings, needs, and desires are as important as anyone else's. And please remember, we are human forever!

Angela Pototschnigg, Member, EWGPWD

Before I retired, I had imagined how I would enjoy my life: travelling, dance classes, supporting my daughters, spending lots of time with my grandchildren. But things turned out differently. My everyday life is now characterised by memory problems and has many stumbling blocks.

I live alone and realised that I had to make sure that important and everyday things were done reliably and on time. Despite all the difficulties, I don't want to miss out on things that make my life rich, colourful and worth living! I am an active person – I am interested in many things and I still want to try out new things! But the question that concerns me the most is "how can I manage to live independently in my own home for as long as possible"? I don't need anyone to tidy my flat or cook for me – I can still manage all that quite well on my own and I can have food delivered. I also don't need anyone to keep me occupied or entertained because luckily, I have many friends.

I've been open about my limitations from the start - that makes a lot of things easier for me because people help me when I'm in trouble. Family, neighbours and friends can only support me if they know what problems I have and what support I need.

I received a lot of help and knowledge about my disease from Alzheimer Austria. They encouraged me from the beginning, but also challenged. To my delight, I was nominated to the EWGPWD in 2018!

At EWGPWD meetings, I learnt for the first time what it means to have personal support at my side – and what I experienced was great! I have travelled with Johanna Pueringer to Brussels, Luxembourg and other conference venues. Johanna has a great deal of knowledge about

dementia, she made it easy for me and gave me a sense of security right from the start. She reminds me when I need to be somewhere, looks after me and helps me to find my way around. We prepare documents together and during the meetings she supports me with translations or helps with technical difficulties (e.g. during video conferences).

This support was a key experience for me! It was useful to realise that what I can no longer do well on my own, I can still do wonderfully in pairs! That boosts my self-confidence!

I started offering peer counselling for people in similar situations at Alzheimer Austria, talking about my experience of living with dementia. It works well because Johanna accompanies and supports me. It clearly shows how important personal assistance is.

I asked Johanna to support me in my private matters - and she agreed! I am now fortunate to have personal assistance for activities such as medical consultation visits and correspondence with the authorities, filling out forms, monitoring medication and many more! To put it simply: I can call Johanna (almost) any time, but we don't meet that often in person. An important point for me is how to deal with information or situations, because it happens that I can't categorise complex things properly or I misunderstand things. That's where assistance is really important!

My daughters are relieved and safe in the knowledge that Mum has everything she needs – that's why they still spend their holidays with me and we can share beautiful moments in life! I am really grateful for this!

I'm lucky to have a respectful and friendly relationship with Johanna that allows me to tackle any task without stress. I set the tone and Johanna supports me when I ask her to. However, it is important to emphasise that personal assistance is a service that should not be provided on a voluntary basis. Our needs and lives are diverse, personal assistance should cover variable and different aspects for everyone - just as it does for people with physical disabilities.

My wish and vision for the future is that all people with cognitive disabilities have access to affordable personal assistance! Our disability is not obvious at first glance, which is why I would all the more like to see decision-makers not only recognise dementia as a disability in theory, but also give us a legal right to personal assistance!

Dementia strategies of most countries state that participation and involvement of people with dementia is the primary goal but without personal assistance, this goal cannot be achieved.

Chris Roberts and Jayne Goodrick, Member and supporter, EWGPWD

After Chris' diagnosis we found out that he would be entitled to a disability "bus pass +1". The "+1" allows a second person to travel with Chris on his bus journeys. This works admirably as it means that I, as his wife, don't always have to drive everywhere. I too, can sit back and enjoy the ride. It also means that Chris isn't limited to going out with me; when our daughters were younger and did not drive, they could accompany him on journeys, giving me some respite time, and him respite from me. This was beneficial all round! This has helped him to maintain some independence and choice in his day to day activities, not being solely reliant on his main carer. This is a cheap but very effective support for both of us.

Trevor Salomon, Chair, EDCWG

Growing up I was extremely lucky to have two wonderful grandmothers in my life. One was of Polish heritage and the other was born in Latvia. Although very different, they had one thing in common: both believed that everything in life was destined to happen for a reason.

Had they been alive at the time of my wife Yvonne's diagnosis of young-onset Alzheimer's disease they would have agreed it was my destiny both to be a carer and to use my voice to speak up for carers, and nothing I might have been able to say would have convinced them otherwise.

Having observed my father succumb to Alzheimer's I was determined that, post diagnosis, Yvonne and I would continue to lead our lives to the full, engaging support from many sources and with a primary objective of maintaining Yvonne's independence, self-respect and dignity for as long as possible. I recalled hearing Alzheimer's Society talk about disclosing the diagnosis to all who needed to know and embracing help from family and friends who expressed a desire to be there for us. And that's exactly what I did.

This approach certainly meant I never felt alone but it also ensured I found time to understand the likely progression of the disease and how, in all probability, Yvonne would be stripped of her abilities and capabilities. This gave me some insights into how I would cope but also how our lives would change.

In a nutshell, and maybe this is overly simplistic, we just switched roles, with me taking on responsibilities which Yvonne hitherto would have undertaken without even thinking about it. I'm referring to things such as cooking, doing all the household chores, planning holidays and even ironing which, I confess, was something I really did not enjoy.

As a family we used humour a great deal to help us overcome some of the more challenging aspects of losing her capabilities. When Yvonne was told she could no longer drive, which from her perspective was a devastating blow to her independence, the kids bought me a chauffeur's hat which I wore as her driver. She thought this was extremely funny and soon forgot that she was banned from driving.

I did not need to use technology, seek help from social services or charities to maintain our lifestyle. And I did not hide behind closed doors, in denial of our issues, but instead I chose to be upfront about Yvonne's decline and the challenges of confronting this sad and baffling disease.

When the time eventually arrived that she needed full time professional care in a care environment, we had enjoyed ten years of creating new norms and when I reflect on this period in our lives, I know that I would not have done anything differently.

If this was my destiny then I'd like to think my grandmothers would say I handled it as best I possibly could.

Annick Germeys, Member, EDCWG

My husband Geert, who has young-onset dementia, can still stay home alone, therefore, for now, we haven't had to make any big adjustments at home. At the moment, we use a shared online calendar which shows our daily appointments, where everyone is going, what we planned to do and at what time.

In the future, I fear this may no longer work. The need we will likely have, and what I am thinking about, is, for example, a large screen in the living room with the support of Artificial Intelligence (AI). On this large screen, the day's schedule would be displayed. If Geert can no longer read it, this would eventually need to be with sound or shown using icons, or possibly pictures of us. For instance, who has to do something at what time, with the corresponding photo projected. Or, if we go outside the house, a photo of family or friends. A large clock projection, with a reference to something that needs to happen and, if possible, with a voice reminder at the right time. This should be remotely controlled (online), so that everything is up-to-date at any time of the day. This way, we would not yet need help from others, hopefully for a long time.

It is important that our community knows what young-onset dementia is. Geert is still young, 55 years old, and you can't tell by looking at him that he has Alzheimer's. He is no longer as quick in certain things, even though he is still very physically active. What I mean is tasks like performing actions, making payments, carrying out assignments, etc. If people take into account that Geert, despite his limitations, can still be part of society, then he can continue to do enjoyable things. He can still live a part of his life effectively, without needing help. People just need to accept that he has a limitation in this.

However, it is not only the people who care for people with dementia, but all carers that need to know how to communicate with people with dementia. Sometimes you need to repeat things, rephrase the sentence, or use different words, so the person with dementia clearly understands what you mean. You also need a lot of patience because things don't happen as quickly anymore. This is very important.

Decision-makers should ensure that technological tools, like those mentioned in my first point, are fully reimbursed. Digital tools that allow these people to live independently should be fully covered. This way, the person with dementia does not need to be placed in a care home, saving the government a lot of money. Therefore, it's better to invest in digital tools first as supporting help for the care givers. Additionally, they should focus more on raising awareness. If there is more understanding of people with dementia, they can also do a lot more on their own. Our government should also invest in the informal caregivers who voluntarily support these people. They are invaluable and make it possible for the person with dementia to continue living at home. It would be best if they listened to them, developed policies together, and provided financial support so that they can continue this work without falling into poverty as a result.

10. Observations and conclusions

The first part of this section will provide some observations based on the findings provided by our national member organisations and members of our European working groups, identifying key points themes which have arisen, any trends emerging between countries, as well as any other observations. In the second section, we make specific recommendations for actions which can be taken at a European and/or national level to facilitate the implementation of concepts of independent living and housing, in the context of people living with dementia.

10.1. Observations and conclusions

Policies and strategic documents

Alzheimer Europe sought to understand in which policy context issues relating to independent living, housing and dementia sat within countries. In countries where there were specific dementia plans or programmes, it was reassuring to see that the majority included a reference to people being able to stay at home as long as possible, with an additional focus on maintaining the independence and maximising the abilities of the person to live as well as possible with the condition.

Another positive aspect was the number of countries reporting programmes or strategies related to older people or people with disabilities, which had commitments or programmes relevant for and applicable to people with dementia. Included in this were the overarching programmes for ageing in Malta (through the Active Ageing and Community Care programme), Norway (through the Bo trygt hjemme reform) and the Netherlands (through the WOZO programme).

However, broader policy measures are not always applied to people with dementia. For example, where a country does not recognise dementia as a disability (thereby failing to adhere to the UNCRPD definition), measures or commitments related to services or social protection in these strategies will be unlikely to benefit people with dementia. This is an issue which has been raised on a number of occasions by our national member associations.

Few countries report having specific strategies for independent living or for deinstitutionalisation. However, for both these topics, references were usually made within other strategies, particularly those related to disabilities.

For independent living, there was overlap in some countries with strategies or programmes for older people. Whilst the terminology varies, the concepts of maintaining the independence of the person through inclusion in their communities, exercising choice and control over their lives (for example over the use of services or where to live) are similar in nature.

In terms of housing, few countries had dedicated strategies and in those that did, few had measures which had relevance to dementia directly, for example through the building of adapted and specialised housing. Given the demographic trends in Europe, it was surprising that there is not a greater focus on such policies, whether on building new housing or adapting existing stock.

It is helpful to consider the interplay of the policy issues examined here – when grouping together the strategies for this report, some policy drivers could have been placed in two or more sub-headings in the policy sections. Taking into consideration the cross-references to other policy areas, there is an evident need for good coordination and collaboration between different departments of government and different stakeholders.

Safety, security and safeguarding

During discussions with the European Dementia Carers Working Group (EDCWG), a strong focus was placed on the security and safety of the person with dementia. Members of the group highlighted this as the main priority in their caregiving role, noting that adaptations to the home or the use of technology, were part of this overarching aim. This was one area (services and support being the other), where the group also noted that a person with dementia living alone or who have no carer or close relatives, requires a different approach than those who have family (including chosen families) or a caregiver.

As part of this, Alzheimer Europe had sought information on safeguarding, to establish what protective measures countries had in place to reduce the risk to people with dementia (or other groups at a greater risk of harm). Whilst some countries, including Ireland, France and the UK (Scotland) have particularly strong measures in this regard, it was not apparent that legislation for this is widespread and a number of countries only reported on projects in relation to missing persons.

Social protection and support services

The intention of this Yearbook was to examine independent living and housing, recognising the interdependencies between the two. Whilst it was not the intention to focus on health and care services, it was notable that they were a key focus of the responses from many member organisations, especially insofar as social protection or other forms of support were concerned. It was also a recurring theme which emerged in the discussions of the European Working Group of People with Dementia (EWGPWD).

From the responses of members, there was a division in countries for whom there was a separate and specific housing benefit, and those whose support was given as part of broader social protection (e.g. disability benefits, health insurance). No benefits are dementia specific, with support determined on the basis of the level of disability, age and/or level of other income (means-tested benefits). This is consistent with the findings of the Dementia in Europe Yearbook 2022 on employment and social protection.

Many countries highlighted care services available for people with dementia, particularly those health and social care services delivered at home or community-based services such as day-centres. These are invariably vital for supporting people with dementia to continue living at home, however, we know from other work (for example the Dementia Monitor publications), that the availability and affordability of care services is highly variable between countries. We also saw within this report that there are significant regional differences within countries.

It is also worth noting that services and activities which support the reduction of social isolation and allow people to participate in their communities are vitally important for people living with dementia. The EWGPWD was clear about the importance of support and services they attended within their communities (including but not limited to memory cafés or day centres) and wanted information about activities and services to be better highlighted and signposted more proactively. It is important to note that such services and support are not exclusively about health or care services per se, but also social activities which contribute to the wellbeing of the person. Additionally, there are two key points raised by both the EWGPWD and EDCWG. The first is on the need for services and support to be stage appropriate to the individual. The second is to consider the differences in needs of people living alone/without a carer/close family and people with close families (including families of choice).

Adaptations, technology and design guidance

It was encouraging to see that many countries had measures in place to provide some level of assistance to people with dementia to make modifications to their homes, allowing them to remain in the home for longer. As with social protection, most of these are not related specifically to dementia, but to age or level of disability, though sometimes reimbursements are also means tested.

Conversely, it was disappointing to see that the use of technology was not widely reimbursed by the state, despite its potential in supporting people to live independently and stay safe within their communities. Of the types of technology reported by members, the most frequent included community alarms, forms of telecare and sensors. Both working groups referenced GPS technology as a way of ensuring the safety of a person to continue to be active and independent, whilst ensuring a degree of safety in the event of the person becoming lost. However, the EWGPWD noted that the technology most helpful in their day to day lives included smartphones, computers, tablets and digital assistants. As such, governments should consider how they can adapt their offer to make greater use of technology to support individuals to remain at home. It is important to consider the ethical implications for the use of technology, especially where it has the potential to be used to restrict the freedom of people with dementia, even done so with intention of keeping the person safe. Alzheimer Europe explored this in our 2012 ethics report "The ethical issues linked to restrictions of freedom of people with dementia".

It was also welcome to see that within a number of countries there is some form of design guidance, examining the accessibility of housing and buildings. This is vitally important in providing an environment which is accessible and promotes mobility. Although some measures are included in legislation, usually in broader Accessibility Acts, most measures are simple recommendations in policy reports or guidance. As such, it is difficult to determine the extent to which these are applied in practice.

Rehabilitation

It was promising to see that the majority of countries offer some form of rehabilitation or services which aim to maximise the independence of individuals. The role of professionals such as occupational therapists, physiotherapists, dieticians etc., is essential in ensuring that the person exercises their abilities and skills for as long as possible. There was a notable divide between countries where this type of support was delivered to individuals in their own home and those where rehabilitation was provided by community-based services, including day care.

Adapted housing and models of residential care

It was disappointing to see that there were few specific examples of adapted housing for people with dementia, with most focused on for older people or people with disabilities. The only dementia-specific examples in this section were in relation to specialist care units for people with dementia or other types of more traditional types of residential facilities, such as nursing homes. In the context of the UNCPRD's definition of institutions, it is evident that many traditional nursing homes or residential settings referenced in this report would likely be considered as institutions and thus not compliant with the Convention.

However, new and emerging models such as "dementia villages" (with the original De Hogewyk model in the Netherlands, as well as others cited in France, Norway and Switzerland), although providing a greater level of autonomy and independence for a person with dementia, may still be considered as institutions insofar as a person's ability to exercise choice over certain aspects of care is not complete. Moreover, these villages are not necessarily located within existing communities.

Other models of care such as shared or cohabiting houses, (e.g. those highlighted in France, Germany and the Netherlands), may not be considered as compliant with the UNCRPD and General Comments, despite the high level of autonomy they grant individuals. This is as a result of residents not having full control and choice over certain aspects of day to day living and types of care available. One model which aligned closely to principles of the Convention, was the Croftspar Place model in Scotland (described in section 7).

The progressive nature of neurodegenerative conditions such as Alzheimer's disease, means that a person's need for care and support services is likely to increase as the condition progresses. The rate of progression will vary from person to person and will be influenced by their unique circumstances. As such, Alzheimer Europe is aware that the aims and goals of the Convention should be the primary overarching ambition. However, there is a complex interplay between the rights of the individual as defined in the Convention, the needs and wishes of the person and the context of the family and carer which also need to be considered.

Ultimately, the choices around housing and care, including where the care is delivered, the types of services a person wishes to receive and who provides them, are for the person to discuss with their family and/or carers and decide on themselves (with support if needed). Where decisions are made on behalf of the person, for example through powers of representation, the decision taken should be in line with the wishes and preferences of the individual.

Relevant for this latter point, Alzheimer Europe asked members specifically about models of care for minority groups, including minority ethnic communities or members of the LGBTQ+ community. It was disappointing to see that few countries had examples in this regard, with Finland and France having examples in nursing homes, and Germany having an example of co-habitation for LGBTQ+ men. However, given the intersection of people with dementia and other communities, we hoped to see additional examples of dedicated care and housing for these groups.

Transport

During the discussion with the EWGPWD, transport emerged as an important theme for members, especially for people in rural areas, who noted its importance in keeping them connected to services and activities. For people with dementia, this may be their primary mode of transport and a key foundation of their independence, especially if they have had to give up their driving licence. For carers, this may provide them with freedom or a small measure of respite, if they do not have to be responsible for driving all of the time. Although a key part of independent living, our greater focus on housing means that this theme did not emerge strongly in responses from members. As such, transport will be a focus for future Alzheimer Europe work.

10.2. Recommendations

Recommendations for national governments

- Embed training for health and social care professionals on dementia as part of the curriculum and training for practicing professionals, to significantly address continued stigma and poor understanding experienced by people with dementia and their carers.
- Support public-facing awareness campaigns to improve public understanding about the condition, challenging the stigma and harmful pre-conceptions about the condition.
- Provide sufficient and sustainable funding and resources for the development and operation of resource centres/day care centres etc. that allow people with dementia to continue to be active and engaged in their communities.
- Through collaboration with professionals, municipalities, service providers, non-governmental organisations and people with lived experience, explore alternative models of community-based care (including residential care), alternatives to existing nursing home or institutional settings.
- Ensure that social protection and social/health insurance systems provide reimbursement for assistive technologies, home adaptations and mobility aids, to ensure the ability of people with dementia to live at home for as long as possible.
- Work to ensure better alignment between policies, strategies and laws relating to inter alia social protection, health, older people, disabilities and housing, to ensure that the needs of people with dementia are addressed in a coordinated manner.
- Develop structures, both legislative and structural, to ensure the safeguarding of people with dementia (and other conditions), to reduce the risks associated with harm (physical, mental, financial etc.) that may arise as a result of their condition.

Recommendations for European Commission

- Support care-focused research within the Horizon Europe programme and future framework programmes, to explore innovative models of independent living for people with dementia living in community settings.
- Ensure greater funding through both the Social Fund Plus (ESF+) than the Regional Development Fund (ERDF) for Member States to reform long-term care systems within their countries, to move towards home- and community-based models of care.
- In line with the UNCRPD obligations and European Strategy on the Rights of Persons with Disabilities, encourage Member States to adopt a definition of disability which includes cognitive disabilities and dementia.

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