SERVICE PROVISION TO PEOPLE WITH DISABILITIES THAT ARE AGEING

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European Association of Service providers for Persons with Disabilities

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Executive Summary: Service provision to people with disabilities that are ageing

Aim

The aim of this research is to outline the existing services delivered to people with disabilities that are ageing. This includes the background of the long-term care, lessons from European countries which are providing these services and the implications for service recipients.

Methodology

In order to conduct a comprehensive analysis, the desk-based research of reports and articles (mainly from Europe) was undertaken. Findings are based on evaluated initiatives and existing services and experiences, although new trends are also mentioned.

Important issues to be considered

The findings are set in the context of demographic concerns about the rise in number of old, disabled people, institutional care, poor care in institutions, financial constraints and complexity of funding.

The findings and key points

Practical examples of community-based services were examined, as well the extent to which examples enable the older person with disabilities to be at the heart of any decisions on their care – a person-centered approach. Case studies of community-based services are given in order to show the state of play of these services, along with the barriers that people with disabilities that are ageing are experiencing with regards to service provision and the quality of life.

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Background

As a result of advances in medicine, nursing and technology, we are witnessing the increase in life expectancy of the population, as well as the resulting growth of the elderly population, accompanied by desire to age in familiar environments. Several national and international studies have examined the ageing profile of people with disabilities, making a universal consensus that this population is living longer and with it, such trend in life expectancy is expected to continue.[1]

The ageing in the European population has presented health, long-term care and welfare systems with new challenges, resulting with the need to improve the response and reaction with regards to them, especially when talking about the elderly disabled population. The importance in achieving this is seen in the ability to help people to stay active in old age, and more importantly to include people with disabilities in their respective communities.

These factors, as well as international policy frameworks have become the driving forces behind the development of various types community-based services as an alternative to institutionalization of elderly people, especially disabled elderly people.[2] Consequently, they require both specialized care that would address their diseases and disabilities and easy access to supportive services in the community.[3]

Older people (aged 65 and over) accounted for more than two fifths (42.2 %) of all disabled people aged 15 and over in the EU-27 in 2012, while just over one third (35.5 %) of the total number of disabled people were aged 45–64 and the remaining 22.3 % were aged 15–44. In the EU-27 35.6 % for the age group covering those aged 65 and over are people with disabilities. In all of the EU Member States, the share of people with disabilities in 2012 was lowest in the age group 15–44 and highest in the age group 65 and over. This situation was also observed in Iceland, but in Norway the share of the population reporting a disability was higher in the age group 45–64 than the age group 65 and over.[4] Also, people aged 65 and over with a difficulty in personal care activities were more likely to report a need for assistance than younger people: in the EU-27, a need for assistance was reported by 44.0 %

[1] Bittles et al., The Influence of intellectual disability on life expectancy, 2002.

[2] Fänge A., Ivanoff SD., The home is the hub of health in very old age: Findings from the ENABLE-AGE Project.

[3] Cheek J., Ballantyne A, Byers L, Quan J. From retirement village to residential aged care: what older people and their families say, 2006.

[4] Eurostat, Disability statistics – prevalence and demographics, p.6, 2015.

of people aged 65 and over with such difficulties, compared with 37.3 % for people aged 45–64 and 34.4 % for those aged 15–44.[5]

These facts are presenting the basis for questions regarding the services that people with disabilities that are ageing are in need, such as health, housing, social, and transport services. These issues have been accompanied by the current projections and trends, such as projections of population ageing, a growing number of late-onset disabled people, the ageing of the disabled population, making these issues extremely important and relevant. Also, on the other hand for actors providing these services, relevant questions arise as to how best address the needs of people whose issues relate to both ageing and disability.

Having in mind the current and future growth in older people's demand for adequate health and social services, the question on how societies respond to the care needs of disabled older citizens becomes more and more pertinent. Creating and developing services that enable full participation of older people with disabilities, whilst at the same time ensuring that they receive the support they need in the manner they prefer, will be relevant topics for the years to come.

The following discussion provides an overview of developments on ageing and disability and service provision for people with disabilities that are ageing. Chapter Two defines the key terms of 'disability', 'ageing' and 'long-term care' within the context of current social policy debates. Chapter Three describes the key policy themes arising in current international policy and practice literature. Chapter Four considers current alternative service providers to institutional care in Europe and types of services exiting. Chapter five provides insight into the barriers people with disabilities that are ageing experience along with the SWOT analysis of the service provision. Discussion is given on the finding relevant to the services provision for the people with disabilities that are ageing, along with the case studies and conclusion.

The Aim of the Research

The aim of this paper was to review the literature on existing services for disabled people that are ageing across Europe. In more detail the idea was to outline the case for the community-based care and explore not only how care for adults with disabilities that are ageing is managed, but also how can they have a good quality of life; one that is more dignified and more enjoyable. This includes:

[5] Ibid, p.7.

summarizing the current position of the long-term care, noting the problems and the attempts to change the system, summarizing the challenges of the present system, current status of community-based care in particular, consider living arrangements of the elderly disabled people, community involvement and the barriers that are influencing further development of these services and accessibility of care-related services to elderly disabled people. The findings are restricted to evaluated literature, current long-term care services and case studies from services providers. The case studies provided additional aspects on the existing research and includes:

a. Association Latvian Movement for Independent Living, Latvia

b. Fundació Ramon Noguera, Spain

The case studies aim to provide relevant information with regards to the various types of services and care, with examples of innovation and good practices in adult social care services in EU countries. The main goal is to inform relevant bodies in relation to new approaches needed in the service provision.

Issues to be considered

Below are summarized some of the main issues.

a. Availability of data and selection

As should be pointed out, there is scarce research on the types of services available for person with disabilities in each EU Member State and little is known how the countries are ensuring that the new systems of care and support respect the rights, dignity, needs and wishes of each individual. There is present lack of publically available data, in terms that information needs to be specifically requested from relevant authorities, as well as no systematic compilation of data on the national level. Also, where data on specific social services are collected, there is rarely a selection on categories of beneficiaries, making it impossible to identify number of persons with disabilities using a particular service. The selection of material for inclusion in this review involved sifting through articles/publications/studies and reports, which process enabled the identification of material to be included in the review.

b. Terminology used when discussing services provided to elderly disabled people

Recognizing that the concept of alternative care services relates to the wide range of international and national practices, it is important to clarify the terminologies used in this review. There are different

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understandings of what constitutes "institutional care" through European countries, depending on the country's legal and cultural framework. This can also refer to "residential institutions" which are related to the community-based services, especially in terms of housing and other living accommodations. A lack of commonly agreed definitions means that there is lack of consistency in the terms used to refer to services for persons with disabilities, as well as with regards to the service providers. Also, information on experiences of people with disabilities that are ageing and their independent living is visibly absent, especially in terms of the quality of service they receive. This is only exacerbated by using unsuitable methods for collecting survey data, such as not taking into consideration of their specific impairment and their difficulties in taking part in the survey.

Disability, Ageing and Long-term care

Disability

Disability has traditionally been equated with physical, sensory and/or intellectual impairment. The classic 'medical model' locates disability as an individual problem, directly caused by disease, trauma or other health condition. The World Health Organization (WHO) defines disability as "an impairment in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations."[6]

Numerous researchers and studies have identified the role of social and physical barriers in disability, recognizing a shift from the "medical model" to a "social model", in which people are viewed as being disabled by society rather than by their bodies[7]. The medical model and the social model are often presented as dichotomous; however, disability should be viewed from both aspects in a more balanced approach, understanding appropriately different aspects of disability.[8]

Ageing and the Life Course

Ageing has traditionally been associated with physical and mental decline. It is conceptualized in terms of loss of faculties. Recent social policy statements have sought to re-define ageing in a positive way.

[6] WHO, https://www.who.int/topics/disabilities/en/, seen 2019.

[7] Oliver M. The politics of disablement,1990.

[8] Forsyth R Et al. Participation of young severely disabled children is influenced by their intrinsic impairments and environment, 2007.

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The World Health Organization (WHO) defines healthy ageing' as the process of developing and maintaining the functional ability that enables wellbeing in older age".[9] The term 'healthy ageing' puts an emphasize on having the capabilities that enable all people to be and do what they have reason to value. Healthy Ageing is the focus of WHO's work on ageing between 2015 – 2030. Healthy Ageing replaces the World Health Organization's previous Active ageing: a policy framework developed in 2002. Healthy Ageing, like Active Ageing, emphasizes the need for action across multiple sectors and enabling older people to remain a resource to their families, communities and economies.[10]

Long term care

There are many definitions of the long-term care in the literature on the subject. It could be uniformly defined as a range of services required by persons with a reduced degree of functional capacity (physical or cognitive) and who are consequently dependent for an extended period of time on external assistance with basic activities of daily living. Based on the WHO definition, long term care (LTC) systems "enable older people, who experience significant declines in capacity, to receive the care and support of others consistent with their basic rights, fundamental freedoms and human dignity".[11]

According to the World Health Organization (WHO), the goal of LTC systems is "help reduce the inappropriate use of acute health-care services, help families avoid catastrophic care expenditures and free women – usually the main caregivers – to have broader social roles."[12]

Long-term care has been traditionally provided in an informal manner, predominantly by the family. However, and due to changes in the family model and life-styles, family care (or informal care) is no longer the dominant form of care for dependent people. In response to the growing care needs of the population, formal care organized by the state or private institutions is progressively replacing traditional informal care provision, thus responding to the social needs that cannot be fulfilled within the family.[13]

Formal LTC can be provided in three main types of settings: institutions (residentially), home and the community. In most existing research, home and community-based care refers to professional care at the home of the recipient or within the community in which he/she lives, while institutional residential

[9] WHO, https://www.who.int/ageing/healthy-ageing/en/, seen 2019.

[10] Ibid.

[11] WHO, https://www.who.int/ageing/long-term-care/en/, seen 2019.

[12] Ibid.

[13] World Bank, The Present and Future of Long-Term Care in Ageing Poland, 2015.

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care refers to professional care in an institutional setting outside the home. In order to support families caring for older dependent people, many countries have developed public schemes focused on LTC provision at home (formal home care), community-based care and care at 24/7 care institutions. Such schemes include care services or cash support to assist dependent older people aged 65 and over living in their own homes. Home care covers all activities that are undertaken in the home where the dependent older person usually lives, with the objective of enabling people to stay in their own homes as long as possible. Usually, a small part of care for dependent people is organized in residential institutions.

In most of European countries LTC is governed by various organizational levels: from central government to regional and/or local administration. The most decentralized countries in these matters are **Finland** and **France** with decisions on resources allocation, planning and organization of LTC made either at regional or local level of administration. In **Belgium** responsibilities are shared between national, regional and local authorities. Overall capacity planning, budget and finances allocation are decided on centrally, with some responsibilities on quality monitoring and allocation of services shared between central and regional administration. Home care services are allocated regionally and managed locally. **Eastern European countries** differ with respect to governing long-term care with some countries (i.e. **Czech Republic, Hungary, Lithuania**) managing care in more centralized manner and other (i.e. **Slovakia, Bulgaria**) in less centralized way, sharing responsibilities between national and regional or local administration.[14]

Capacity planning is also shared between the central and regional or local administration. Only in **Hungary** capacity planning for both types of formal care (residential and home care) is fully centralized. In **the Netherlands** capacity planning was centralized until 2009, when planning responsibilities were decentralized as a result of previous under provision of care and increasing waiting times in institutional residential care. Since then, individual long-term care facilities decide upon the supply of services. In **Germany**, with insurance companies operating at the regional level, capacity planning is also a regional responsibility.

The case for revolutionizing long-term care for the provision of community-based services is based on the understanding of how people with disabilities that are ageing want to live when they need help and care, sometimes very high levels, and with everyday life. Studies on alternatives to institutional

[14] Riedel M., Kraus M. The long term care system for the elderly in Austria, 2011.

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care indicate that people with disabilities desire to have quality of life, as well maintain autonomy of life, which everyone seeks thorough their lifetime. Improvement of long-term care ought to include supported self-care and home-based services which enable older people to stay in their homes, or at home-like environment as long as possible. Interventions are needed to help maintain basic activities of daily living of older people, allow ageing at home and prevent long-term institutional care.[15]

Key themes in international policy and practice

Without going into the extensive illustration of these instruments, several will be mentioned below in order to articulate the obligations of European countries to ensure that every person is able to enjoy a standard living adequate for their physical, mental and social development.

In December 2006, the United Nations General Assembly adopted the Convention on the rights of persons with disabilities (CRPD).[16] The CRPD is the first human rights treaty to expressly articulate a right for people with disabilities to live independently and be included in the community. The right is set out in the Article 19 of the convention, requires States to ensure that people with disabilities have access to community services "necessary to support living and inclusion in the community; and to prevent isolation or segregation from the community". It means that everyone should have the opportunity to live and participate in the community they choose. They should be involved in decisions about the care and/or support they receive and have maximum control over their lives. This vision of what people can achieve in their lives if appropriate support is in place should be at the heart of national, regional and local plans for the transition from institutional to community-based care. This article entails the principles of equality, autonomy and inclusion, which are the base of the human rights-based approach to disability established in the Convention. It gives the rights for persons with disabilities to live in the community and not in institutionalized settings.

In other aspects, Article 8 of the EHCR[17] guarantees the right to respect for private and family life to all citizens. Institutionalization at any age interferes with this right, as people with disabilities have a right to live independently and to be included in the community.

[15] Vickerstaff S. et ali. Work, health and well-being: the challenges of managing health at work, 2011.

[16] UN Convention on the Rights of Persons with Disabilities, Article 19.

[17] European Convention on Human Rights, Article 8.

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The key European Union policy instrument in the area of disability is the European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe.[18] The Strategy lists participation as the right to choose where and how to live, with one objective under this area being to "achieving full participation of people with disabilities in society by providing quality community-based services, inclusion access to personal assistance."

Types of services for aging adults with disabilities

An "Institution"

The deficiencies and shortcomings of the institutional care have been documented since the early 20th century, and more urgently articulated in 1962 Peter Townsend's seminal study of residential care homes for older people.[19] The frailties of this system that have been lingering for a long time include lack of privacy and personal space, while the possibilities for social interaction, and with it, social inclusion and the option to return home, remain scarce. Since the 1960s, numerous attempts have been made by governments to reform residential care by placing additional measures and more radically from 1990s by recognizing the community benefits in terms of care. The goal has been both to improve the quality of life for disabled people and to reduce the costs of residential institutions. Policy documents have endorsed the need for dignity and a high quality of life to be achieved through the delivery of long-term care, whilst considering the adequate resources. Institutions were once seen as the most comprehensive way of caring for vulnerable groups, however there is a spectrum of evidence that institutional care invariably provides inadequate outcomes, than high-quality services in the community, often leading to a lifetime of exclusion and segregation.[20]

It is widely accepted that investment in institutional care represents poor public policy. However, even with the demonstrated evidence that community-based models of care are not innately more costly than institutions, the institutional care is still widely perceived by counties as a cheaper option, especially with regards to people with complex support needs, who may require 24-hour care.[21] Based

[18] European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe https://ec.europa.eu/eip/ageing/standards/general/general-documents/european-disability-strategy-2010-2020_en

[19] Townsend P., The last refuge, 1962.

[20] Smyke, A.T. et al. Placement in Foster Care Enhances Quality of Attachment Among Young Institutionalized Children, Child Development, Vol. 81, Issue, 1, 2010.

[21] Townsley, R. et al., p.25.

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on a major comparative report on progress towards community living in EU has shown increasing levels of expenditure on institutional care in nine countries.[22] It has also showed that some countries are doubling down on this, allocation major funds towards upgrading or extending these residential institutions.[23] Research into the cost of community-based mental health care versus institutional care has shown that the costs remain broadly the same, except the most significant part – the quality of life of service users and their satisfaction with services has shown tremendous improvement.[24]

Based on the Report of the EU Commission and the number of people in institutions provided by Member States, about one fifth of the dependent elderly population receive long term care in institutions. **Malta** and **Sweden** have the highest proportion of dependent elderly in institutions, whereas the lowest proportion being that of **Italy** and **Latvia**.[25] There are more elderly dependent people receiving formal care in all countries except **Belgium** and **Poland**. Therefore, almost half of the dependent population aged 65 and above receive no care, informal care or other forms of care that are not public funded. This proportion is substantially higher in **Poland** (83%) and the **UK** (75%).[26]Based on the results, as well as on the adoption of several human rights instruments, institutionalization has been increasingly confirmed as a poor policy and a violation of human rights.

The vision is for alternatives to institutional care

The rapid growth in the number of older people along with the growing need to deliver a quality of later life has brought the reform on the long-term care to the forefront in the last three decades. This trend has been focusing on providing and endorsing alternative and sustainable forms of long-term public/state provision for later life. Ageing populations have also been accompanied by public budget reforms and with that comprehensive welfare state which were focused on reform, social inclusion, justice and tackling health and economic poverty at older ages.[27] Shifting away from (formal)

[22] Ibid, p.22

[23] Ibid.

[24] McDaid, D. & Thornicroft, G. p.10.

[25] European Commission Directorate-General for Economic and Financial Affairs, Long-term care: Need, use and expenditure in the EU-27, 2012.

[26] European Social Network, Services for older people in Europe https://ec.europa.eu/health/sites/health/files/mental_health/docs/services_older.pdf, 2008.

[27] Tinker A. et al. Assisted Living Platform – The Long-Term Care Revolution, 2013.

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institutional care to formal services provided in the home or community is more cost-effective and is associated with a better quality of life for the elderly, as have many reports through the years proven.

Through EU funded programmes, there are efforts to promote solutions to living in homes adapted to the needs of older people with disabilities, including innovation using new technologies, to improve the urban environment ensuring that pavements, public transport and public services are even more accessible and user-friendly for older people.

With regards to the standards of housing for older frail people and people with disabilities that are ageing in the EU, they are particularly high, particularly in the **Netherlands**, and the lowest in **Greece**, **Italy** and **Poland**. The provision of separate public institutional care for the increasing number of relatively frail older people is no longer considered financially viable, nor as a whole, acceptable for older people, who have in repeated surveys expressed their desire to stay in their own homes. The implication is that future policies and practices will increasingly require the development of various programmes which would serve frail and people with disabilities in their homes and communities.

Special housing adapted to frail elderly people and people with disabilities that are ageing, e.g. sheltered housing, or other kinds of community-based residential care remain relatively scarce. The Member States with more financial resources and better welfare are those for which such community living, special housing solutions are more likely to be found. There is a clear need to promote adaptable "care-ready" housing solutions and other which allow multi-unit apartments and clustered living centers to develop shared facilities that are also included in the community. Throughout the EU a high number of apartments are in the residential blocks, where with the help of innovative technologies, would allow older people with disabilities to sustain more independent and autonomous life.

Based on the study[28] persons with disabilities living in the community, experience worse independent living arrangements than persons without disabilities, particularly when talking about persons with more severe disabilities and among those in the lower economic groups. It has also been established that persons with disabilities are less likely to feel free to decide how to live in the society in comparison to the people without disabilities, as well be less satisfied with their living arrangements

[28] FRA, Summary overview of types and characteristics and community-based services for persons with disabilities available across the EU, 2017.

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in the community. As previously stated, this too study has reported that a large number of persons with disabilities continue to live in institutions across Member States.

What this research will also show, there is a variety of community-based services to persons with disabilities, such as personal assistance in 22 Member States, however too many persons with disabilities living in the community this does not represent sufficient options to meet their needs, especially with regards to the everyday tasks. It has been reported that nearly half of persons with disabilities face difficulties in using common everyday services, such as shopping, banking, postal services, primary healthcare and public transport.[29]

In order to achieve independent living for persons with disabilities, individualized, user-controlled support is essential, and requires appropriate services in place, as well as respect of the autonomy and dignity of persons with disabilities. [30]

As previously stated, there are gaps in provision of community-based services in EU Member States, and where available, they are often not sufficient to meet users' needs with regards to their daily living conditions, as well as healthcare needs. Many persons with disabilities lack sufficient appropriate accommodation and services in the community and are afraid that they are a burden to their family members, which can make institutions the only viable option. [31]

It has been shown that older disabled people show tendency to avoid increased dependency on the close family circles and with it, resist in seeking alternative for their care, despite being in need of it. This has been shown by their desire to take control of their autonomy as long as possible.[32]

Community-based services

The circumstances and expectations of people with disabilities have evolved over recent decades, mainly due to the change in practice and policy. In practice, person centered approach towards the support has become the focal point, with an emphasis on inclusion and community-based services and living.

[29] Ibid, p.9.

[30] Ibid, p.9.

[31] Ibid, p.15.

[32] Grootegoed E., & Van Dijk, D. The Return of the family? Welfare State Retrenchment and Client Autonomy in long term care, 2012.

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The concept of "community-based services" seeks to achieve respect for human rights and a good quality of life for all those who require care and/or support. This requires integrating multi-actor collaboration and societal engagement initiatives into research and innovation process of transforming the way countries provide care and support to children and adults with a variety of support needs. This paper looks to contribute to the existing literature and research on the existing community-based service for elderly people with disabilities by reviewing types of community-based services as well as exploring the barriers that affect the services provision, particularly with respect to adults with disabilities that are ageing.

Community-based services or community-based care refers to the spectrum of services that enable individuals to live in the community as opposed to an institution or residential institution. It encompasses mainstream services, such as housing, healthcare, education, employment, culture and leisure, which should be accessible to everyone regardless of the nature of their impairment or the required level of support. This can also include specialized services, such as personal assistance for person with disabilities, respite care and others.

The term "independent living" is often used interchangeably with "community living" in relation to people with disabilities and older people. It does not refer to "living or your own" but rather for people to be able to make choices and decisions as to where they live, who they live with and how they go about in organizing their daily life. This among others requires access to community-based services.[33]

Independent Living is possible through the combination of various environmental and individual factors that allow disabled people to have control over their own lives. This includes the opportunity to make choices and decisions regarding where to live, with whom to live and how to live. Services must be accessible to all and provided on the basis of equal opportunity, allowing disabled people flexibility in their daily life. Independent Living requires that the built environment and transport are accessible, that there is availability of technical aids, access to personal assistance and/or community-based services. It is necessary to point out that Independent Living is for all disabled persons, regardless of the level of their support needs.

For older people, especially older people with disabilities, advance long-term care is of special importance, as well as integrating prevention and rehabilitation specifically at the national, systemic

[33] European Network on Independent Living (2009), ENIL's Key definitions in the Independent Living Area, available at https://enil.eu/policy/

level and is becoming widely acknowledged amongst EU countries. Services that constitute community-based services should enable individual user and their families to participate equally in the community, not just in terms of community living (residential group homes), but also a wide range of services such as access to mainstream services, which would contribute to actual social inclusion.[34]

Service user also need to have a choice of control over their care arrangements, which in fact recognizes their right to make decisions about their lives and to have control over the support they receive.[35] With the right access information, user will be able to make an informed decision on the support they desire and the treatment they want, which also correlates to the idea of a person-centered support, meaning that the users and families should be actively involved in designing and evaluation of services.[36]

As of lately, the principle of personalization in home care services, which allows the older person the decide on their care management, has gained acceptance. The person-centered approach to social care seeks for a greater involvement by older individuals, as they become the ones who are actively involved in the care arrangements. This would in practice mean that the older persons can decide on their care providers, as well as on the type and timing on the formal care, as to complement any informal care. Nevertheless, this approach makes older persons more responsible for co-producing their care services, which has not been universally accepted, as they are already struggling with disabilities and poor health.[37]

As previously mentioned, in most European countries the change in long term care has transitioning from institutions toward home care. An emphasis has been on a new social construct known as personalization, as to social care services to be designed to match dependent's individuals' needs and care through individualized needs assessment and within their familiar social circle, in their home. The person centered approach has been accompanied with a change in understanding how the housing options in the favor of dependent individuals.[38] As have many researchers shown, older people with and without disabilities have a strong opinion to receive long-term care in their home, than to move

[34] Common European Guidelines on the transition from Institutional to Community-based care, p.83, 2012.

[35] Ibid, p.83.

[36] Ibid.

[37] Housing LIN, Assisted Living Platform – The Long Term Care Revolution: A study of innovatory models to support older people with disabilities in the Netherlands, 2013.

[38] WHO, World Report on ageing and health, 2015.

to a residential or nursing home.[39] Over the years there have been many concerns over institutional care, due to the treatment of people, lack of privacy and other concerns. This has fostered new approaches in offering people with disabilities to stay in their communities as long as possible, which led to further advocacy that individuals should be provided with various resources in order to promote and enhance their autonomy and independence at home.[40] The notion that care receivers actually are in control of their care, has shifted the bar from passive to active engagement.[41]

An important part stemming from the concept of community-based services is the separation of housing and support provided, which inherently means that the type of support individuals receive should not be based on the place they life, rather support should be arranged in a way that it follows users, as in the case if they decide to change their place of residence.[42]

Community-based services in that sense refer to a wider range of services, developed in part as a prevention of institutionalization and at the same time, support of re-integration and transition back to the community. They can include services, particularly for elderly with disabilities:

- ✓ *Personal assistance*

One of the most important services for independent living for adults with disabilities, which is also the only type of community support service specifically mentioned in Article 19 of the CRPD. This reflects its particular importance for ensuring independent living, particularly for persons with more sever impairments. In order for users to have full control over their assistance, the service provided needs to be a self-directed needs assessment; cash benefits, which are paid directly to the user to purchase the service from providers and/or organize the services; and peer support. Personal assistance differs from home help or home care services, based on the control which is given to the service user.[43] Some form of personal assistance is available most European states, however the number of personal assistants varies considerably across countries.[44]

[39] Support and Advocacy Service for Older People. Responding to the Support & Care Needs of our Older Population, 2016.

[40] Wiles et all, The Meaning of "Aging in Place" to Older People 2012.

[41] Assisted Living platform, The Long Term Care Revolution, 2013.

[42] Common European Guidelines on the transition from Institutional to Community-based care, p.84, 2012.

[43] Ibid, p.84.

[44] FRA, Summary overview of types and characteristics and community-based services for persons with disabilities available across the EU, 2017.

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The vast majority of Western countries have been putting the home-based elderly care to the forefront of their policies. In **Sweden**, the transition from strong state support for residential care to a more mixed care, as well as final departure from residential care provision to home-based services had had a great impact on the community of people with disabilities. Less frail individuals were given the chance and opportunity to find alternative arrangements to meet their needs, and people with high demands and disabilities had been given home assistance, as well as medical support.[45]

This model of transformation, where the large shift from public provision of long-term care to mixed models of care has been evident throughout European countries. These changes have resulted on de-institutionalization of social care provision, where the state is no longer the sole provider and organizer of care services and funding. This has, naturally led to the point of 'marketization' of care and fears it would be the main factor for private services providers to engage in this type of service provision. To this end, in many countries, cash for care schemes, have been introduced, where the individuals gain greater control of their care provision, and at the same time have to obligation to be more responsible for managing their care funds, which also correlates with the person-centered approach which demands a greater active involvement by an individual.[46]

Although **the Netherlands** introduced this policy in 1995, it has been abandoned; with **Spain** and **Germany** and **Denmark** also introducing this scheme, and the **UK** as one of the earliest countries to introduce cash for care provisions, during the early 1980s. Similarly, **France** has introduced cash for care services for older people who need help with their daily activities, which there are entitled to get cash benefit for a home caregiver.[47] In **Germany**, however, long-term insurance has not stimulated the growth and development of private for-profit services, due to the preference for traditional family carers.[48]

Cash benefits are provided either directly to the person in need or in relation to the care provided by an informal caregiver. In **Austria**, for instance, cash benefits are provided to persons in need for care irrespectively of age, income or assets. The benefits can be used either to buy home care services or to pay for an informal caregiver. In **Finland** most of care is provided in the form of services, although cash benefits are also granted to persons in need for care and in relation to extra costs related to their

[45] Ibid

[46] Assisted Living platform, The Long Term Care Revolution, 2013.

[47] Ibid, p.9.

[48] Glendinging, C. & Moran N., Reforming long term care: recent lessons from other countries, 2009.

disability or illness. In Germany care recipients can choose between benefits in cash and in kind. Typically, individuals receiving informal care tend to choose cash benefits, while individuals receiving formal home care choose services in kind. In **Italy** cash benefits are available for persons with assessed needs for care.

- ✓ *Physical adjustments to the place of residence*

This service is placed into highly important services, due to the negative impact inaccessible housing has, and its wide prevalence within the older population with disabilities. Many people with disabilities are forced to leave their homes, and to look for other types of residential housing, due to home not being accessible or is not suitably adapted for their specific needs. Various research has shown that majority of older people, as well as older people with disabilities prefer to stay in their own homes instead going to a nursing home or any other type of residential housing.[49]

Home modifications include repairs, aids and adaptations. These services can include assisting older, disabled and vulnerable people with small building repairs, minor adaptation such as the installation of grab rails and temporary ramps and other small jobs around the house. These services could bring to reduce the risk of accidents and injuries and with that enable independent living, increase people's safety, reduce the hospital stay length. In addition, the research also showed the cost benefits in terms that home modifications and adaptations could postpone moving into residential care while also saving financial resources. Another study endorsed these findings by summarizing the research finding which show that improving people's homes produced real benefits in health and wellbeing, while producing cost savings at the same time.[50]

In **Spain**, in 2011 research was conducted for the programme of home modification which was aimed at individuals aged 65 and older who have telecare services in order to promote personal autonomy.[51] Various services and jobs were done, where positive effects were found regarding the security, quality of life and autonomy to perform daily activities.[52]

[49] Assisted Living platform, The Long Term Care Revolution, p.9, 2013.

[50] Papworth Trust, Home solutions to our care crisis, 2012.

[51] Centre da vida independent, 2012.

[52] Common European Guidelines on the transition from Institutional to Community-based care, p.90, 2012.

However, most European countries have no regular updates and publically available data on the number of people with disabilities who receive physical adjustments and assisted devices, which is even less for elderly people with disabilities.

✓ *Technical aids and assistive technologies*

The term 'assistive technologies' refers to a variety of products and services that allow or make easier the implementation of certain tasks by the user, or improve his or her safety.[53] Some examples include: augmentative communication devices, reminder systems, speech recognition software and personal emergency response systems, which combined with technical aids make crucial step in recognizing community living for people with disabilities.

✓ *Home help and home care services*

These types of services include home visits to assist with household tasks, such as shopping, cleaning, cooking, laundry and minor maintenance, while home care services include assistance with daily routine tasks such as getting up, dressing, bathing and washing.[54] In Ireland, The Home Support Service is available to people aged 65 or over who may need support to continue living at home or to return home following a hospital stay. For example, it can provide support with everyday tasks such as getting in and out of bed, bathing and dressing. The services might be needed due to illness, disability or after a stay in hospital or following rehabilitation in a nursing home.

✓ *Day-care centers for adults and older people*

Provide advice, support, meals and some aspects of personal care, as well as social and cultural activities. For older and especially frail people, they may be of considerable advantage as they can be effective in combating loneliness and isolation.[55]

✓ *Home nursing*

This service is designed as an assistance by medical personnel, who can provide home visits to assist with medical care needed by users.

[53] Ibid, p.90

[54] Ibid, p.92.

[55] Ibid, p.93.

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In addition to services provided at home, services mentioned above (home help, means-on wheels, personal care, etc.) the provision of appropriate accommodation (permanent and temporary residential care, sheltered housing, home adaptations, etc.) and transport services can significantly influence and extend an older person's independence and autonomy, despite increasing levels of disability.

It needs to be pointed out that these changes have been aimed at lowering the public spending on long-term care, and whilst there has been an increase in financial support, this could possibly be as a consequence of more individuals needing care and/or more individuals with greater need for care for a longer period of time.[56] To this could also be added the rising age of population, and with that the needs to be addressed. The increasing number of users of home-based care has led to more people with higher disabilities living at home. Although home care provided by public authorities has been in decline, there are still countries, such as **Denmark** (publicly fund and provide care for older adults)[57] and **Sweden** (targeting individuals with higher needs)[58], which have kept their public organization and funding.[59]

Living arrangements for the future: an alternative to institutions

The living environment should be designed in a way that every person, regardless of its impairments is able to lead dignified and fulfilled life. An institutional setting does not offer any quality of life, with spaces compressed and altered in a way that make domestic life impossible, with privacy and control of access almost non-existent. This only makes people with disabilities excluded from any form of social interaction and participation in the community life.

To be able to continue living at home, for elderly people and people with disabilities, it is of great importance to their quality of life. Many studies and experts have shown that housing conditions have a significant effect on life, which only becomes more important with age, when conditions worsen and people are more prone to accidents and other living conditions. [60]

[56] Pfau-Effinger B., Women's employment in the institutional and cultural context, 2012.

[57] Rostgaard, T. and Szebehely, M. Changing policies, changing patterns of care: Danish and Swedish home care at the crossroads, 2012.

[58] Ibid.

[59] Assisted Living platform, The Long Term Care Revolution, p.29, 2013.

[60] Singh A. & Misra N. Loneliness, depression and sociability in old age, 2009.

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Accessible Housing

For many people with disabilities and older people, the availability of affordable, accessible, non-isolated and safe housing is crucial. Therefore, policies should be adopted to ensure access to social housing and to increase the number of universally designed flats or houses in the community. The term 'universal design' means "design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design".[61]

Supported living

Supported living was developed as an alternative to group homes. In group homes, people cannot choose with whom they want to share their accommodation and the support they receive is provided as part of a package with housing. By contrast, in supported living people can choose who they want to live with, in housing that they own or rent. They also receive personnel support from agencies that do not control the accommodation, giving them more control over the services they receive and the same housing rights as other citizens.

There are different ways in which supported living could be organized, for example with personnel on the site only during the day, 24/7, or without permanent staff. Some of the examples are:

- ✓ ***Dispersed housing***: "apartments and houses of the same types and sizes as the majority of the population live in, scattered throughout residential neighborhoods among the rest of the population"[62]
- ✓ ***Access to mainstream health and social services***: ability to organize the housing as a living place, with access to services needed.
- ✓ ***Provision of flexible, individualized support*:** support that will allow the person to live independently in his/her own home and be included in community.

[61] United Nations Convention on the Rights of Persons with Disabilities, Article 2.

[62] Goering, P. et al., op. cit.; Mansell, J. & Beadle-Brown, J., op. cit.; Ericsson, K. (2005) A home for participation in community life: on a key task for disability services, Uppsala University, Department of Education; Health Service Executive.

- ✓ ***Individual choice***: personal and individual decision on participation in activities in the community.[63]

Group Homes

Group homes or similar residential care, where adults with disabilities live together in a house or a flat with support from staff, are being increasingly used in the process of de-institutionalization. For older people, residential arrangements such as group homes are sometimes considered preferred options. People live in their own flat with their own belongings while benefiting from common services (such as a restaurant and other facilities) and enjoy the company of peers.

The level of public supply of residential and home-based care varies considerably between countries. Northern European countries (**Sweden**, **Denmark**) are characterized by a high supply of institutional residential care, although in recent years there have been attempts to reduce the number of residential facilities and beds and move patients towards home-based care. In countries of Western Europe (**France**, **Germany**, **Austria**) the provision of residential care is moderate, while in **Eastern European countries** the provision of residential care is low. The provision of home-based care also strongly varies, whereas in countries such as **Denmark** a high level of home-based care can be observed, those services are more limited for instance in **Sweden** or **Germany**. In Eastern Europe the provision of home care is also rather low, as it only reaches a few percent of those in need (European Commission, 2015). In almost all Eastern European countries informal care largely dominates, and a high degree of resilience to formal care exists.

Home sharing

Home sharing enables adults to stay longer at their homes, providing independence as long as possible, preventing exclusion from the community, while saving costs for both, the home sharer and the government, as well as reducing hospital stay, residential care. It is highly beneficial for both parties involved, in terms of accommodation for one, and inclusion and better quality of life for the other.

Home sharers in the **UK** are vetted by staff of a charity or statutory body, who are responsible that both parties understand the agreement, which can be open in terms that a home sharer is free to

[63] Common European Guidelines on the transition from Institutional to Community-based care, p.95, 2012.

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leave, in which case the staff seeks replacement. Home sharer is a person who can provide some support, whether that is with bills or help with the other chores. Their role is preventive, in terms that they do not provide personal care, which is provided separately.

In other countries, similar home share schemes exist, such as in **Spain**, where they are usually managed by public or private non-for-profit agencies, with a distinction between older households who are relatively independent, and those who need more care and support (rare).[64]

In **Czech Republic**, the homes sharer pays a small rent and provides a few hours of services, while in **Germany** and **Austria**, combination of rent and services is an option. Often, the schemes are managed by Universities with focus on inclusion of students in these schemes, as it is in **Italy**. In **France**, several programs exist, that matches students and older individuals with different options – rent or services, or mixed options.[65]

"Out of home''

For people who experience higher levels of impairment, a specially designed homes are available, where they can get care and service they need, and which is usually designed to disability or wheelchair standards. Specialized grouped housing – sheltered and very sheltered/extra care housing has been developed in several European countries.

In the **UK** specialist housing started in the form of sheltered housing, with a group of flats or bungalows with communal facilities, a warden and an alarm system, which however proved to be difficult to keep frail people there as there was not enough support[66], out of which developed more comprehensive form of housing which included needed support.[67] Extra care, or very sheltered care with a 24 hour a day care, with the communal services enhanced is considered to be one of the attractive alternatives to hospital od residential care. Later evaluation of this scheme provided more insight and an overall conclusion, even though it was popular with elderly people and staff, it was generally more expensive

[64] Assisted Living platform, The Long Term Care Revolution, p.20, 2013.

[65] Ibid.

[66] Tinker, et al. Difficult to let sheltered housing, 1995.

[67] Assisted Living platform, The Long Term Care Revolution, p.20, 2013.

than staying at home, but still cheaper than hospital or residential care.[68] The most recent study[69] found that the most important factors of extra care housing were – having their own front door, flexible on-site care and support, security, accessible living arrangements and bathrooms, the size of accommodation available. The overall conclusions have been very positive, especially in terms that "people had generally made a positive choice to move into extra care housing, with high expectations, often focused on an improved social life. After they had moved in, most people reported a good quality of life, enjoyed a good social life, and valued the social activities and events that were offered." The study concluded that while comparing residents with similar characteristics in care homes, residents in extra care homes had better outcomes and costs were not higher.[70]

In **Sweden**, cluster housing or *Fokus housing* has its origins in the late 1960s, which only experiences further development, towards 280 apartments in 12 cities. Most of the cluster housing building consists of 50 or 60 units with 10 to 15 special apartments for individuals with extensive care needs.

In **Spain**, the city of Barcelona has recently promoted 925 units of apartments for older individuals that serve over 1000 people. All apartments are adequately designed for specific needs, and are equipped with telecare technologies and 24 hour a day staff support.[71]

In **the Netherlands**, residential group living has similarities with the 'housing services', called *Apartments for life*, and developed by the non-for-profit organization Humanitas Foundation Rotterdam in the mid-1990s. They are designed as 'age proof' apartments that can be adapted as disabilities develop, and they now rose to 1700 apartments housing an estimated 2,500 individuals. The apartments are available to couples as well as individuals and residents can organize whatever care provision they need. Apartments may be purchased or rented and in the 195 apartments of Humanitas-Bergweg the rent is subsidised. The Humanitas Foundation stresses the value of enabling individuals to remain in control of their daily living as long as they can.

[68] Tinker et al.

[69] Netten et al., Improving Housing with Care choices for Older people, 2012.

[70] Ibid.

[71] Ibid.

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Also an innovation solution for individuals with dementia who can no longer live independently in their own home is **Hogeweyk village** in Weesp, near Amsterdam. Care is available 24 hours, seven days a week. The aim is to replicate daily life in a village of households, thus making residents as comfortable as possible and enabling them 'to continue to live in the manner to which they were accustomed prior the onset of dementia'[72]. To that end, they have created seven different life styles within the village as 'homes within homes'. Each home is planned so as to reflect a particular set of social circumstances: 'Het Gooi'for welloff residents attaching importance to etiquette and appearance; Culturel, for those with interests in art and other culture; Amsterdamse for city dwellers; Indische for those with an Indonesian background; Christelijke for practising Christians; Ambachtelijke for those who had a skilled trade; and Huiselijke for those whose focus had been family caring and domestic life. They all have their own house and are in charge of a small budget to buy groceries, medicine and other necessities. There are also three different groups of individuals with different needs and capabilities: mildly impaired or largely autonomous, moderate to severe impaired people with dementia who need professional supervision on a daily basis and the bed-ridden individuals. The design of the village promotes normal life and local residents may use the Hogeweyk facilities amenities and act as volunteers if they wish. The buildings enclose a spacious area with landscaped gardens, squares and streets where residents can walk and mingle safely around the ponds and benches. The village has a full range of amenities such as a supermarket, café and restaurant with outdoor terraces, clubroom, theatre and facilities for games such as boule. Residents may visit their doctor, physiotherapist or hairdresser within the village and shop for groceries at the supermarket, accompanied if necessary. The design and care programme is intended to promote residents' self-esteem, autonomy and independence, within a secure and familiar environment.[73]

Cohousing

Cohousing is recognized as intentional community of private homes clustered around shared space, which can be intergenerational or restricted to those over 50. These communities are designed so people can share activities, and especially for older people in need of their privacy and autonomy, with desire for assistance in return.

Denmark has about 350 collective housing schemes, mostly in groups of 15-30 units, with around 140 intergenerational schemes, however only 1% of Danes aged 50+ live in the collective housing, although

[72] Notter et al. Taking the community into the home, p.449, 2004.

[73] Abramson et al. Residential Mobility Patterns of Elderly – Leaving the house for an Apartment, p. 582-604, 2012.

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they are more and more attracted by the sense of community, reciprocal support and arranged activities.[74] A 2009 survey of 23 seniors aged 60-90, living in cohousing indicated that they feel happy, safe and had better health, and they were active in associations, sports, and benefited from help with regards to the small tasks and from company.[75]

Sweden has 45 cohousing schemes, which was the result of the civil society campaigns and overall positive responses. They are concentrated in main urban parts, in blocks of flats. Communal facilities are designed, and as being very popular, waiting lists exist.

In the **Netherlands**, cohousing **(centraalwonen)** movement started in the 1960s, mainly founded by young people, and the number of schemes has increased since then. Each household has the normal rooms but shares facilities such as laundries, meeting places, hobby rooms, workshops and garden space. Schemes usually have 30 to 70 households, sometimes in self-managing clusters. Most are rented from a housing cooperative but some are owner-occupied.[76] In the 1980s, communities for seniors, 'living groups of the elderly' were developed, to meet the needs of the growing proportion of the population aged over 50. These are supported by local government as they are expected to reduce care costs. An age range from 55 to over 90 years, where the younger and not so disabled members are providing help for the most disabled.

For those with relatively modest care needs, **telecare and telehealth** offer remote monitoring of individuals' health and needs, avoiding the need for them to visit their doctors. In the Netherlands, telecare services are currently little used among individuals aged 65 and over, although public and private initiatives have been developing since 2000, however the evidence as to positive outcomes for the health and wellbeing of older people through use of telecare is inconsistent.[77]

Smart Homes, although at early stages in Europe, can meet a variety of needs, including through use of assistive technologies. This can promote growing old in good health and maintaining independence. In **the Netherlands**, devices include alarms, grab rails, level thresholds, raised seats on toilets, raised

[74] Kahler, 2010.

[75] Ibid.

[76] Bakker, P.J. Cohousing in the Netherlands, 2009.

[77] Tinker, A. The impact of demographic change on public services, 2012.

beds, height-adjustable work surfaces and stair lifts that cope even with winding staircases.[78] These services are in **the Netherlands** are largely promoted by public authorities.

In **Germany**, project OFFIS has introduced smart home technologies, designed for older people, and 65 other projects have been also launched, whereas in **Denmark**, a programme that has been introduced is directed to funding smart home solutions for older people with dementia. In **Sweden**, a similar development of smart homes and assisted technologies have been in progress, where county councils and municipalities are in charge of funding and providing services for people with disabilities, with the aim to maintain individuals' independence for as long as possible by using ICT. These concepts are on the rise in other European countries, such as **Italy, Poland** and **France**, although it has to be noted that the implementation is still in its inception phase, and not reachable to many users.

In the last two decades of the 20th Century, long term care in the Netherlands experienced the shift from a publicly subsidized institutional care system to a more privatized home-based care system. The person-centered approach to care was encouraged through the introduction of Personal Budgets ('Persoonsgebonden Budget') in 1995 which were intended to promote choice and flexibility of care and at the same time encourage competition between private service providers. In this system individuals were offered a choice between a cash transfer or public services, where the end goal was for older people take more responsibility for their own health and wellbeing. This has lead, in the last two decades, to a transformation of the long term care for older adults, from a universal public provision, to a subsidiary model of care, where care and costs and shared between public services and private households.[79]

Along with already mentioned care services, in order to empower older people and promote independence for various types of needed care, a variety of initiatives have been developed in the Netherlands:

Care Cooperative village - Hoogeloon. In 2005, residents built on a traditional model of the farm cooperative and organized a care cooperative – now with 200 members including volunteers, paid coordinators and professional healthcare staff. The aim was to meet older people's need for health and social care in their own village, instead of having to travel to a town. Volunteers take part in a

[78] Tinker et al., Assistive technology: some lessons from the Netherlands, 2003.

[79] Arksey, H. & Kep, P. Dimenssions of choice: A narrative of cash-for-care schemes, 2008.

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rotation to cook meals for older disabled residents, provide other domestic help required and transport when necessary. Start-up subsidies (under the Social Support Act) were used in 2008 to build 14 serviced homes and a Support Centre for older people. Day care is available twice a week, giving relief to informal carers. Staff are recruited locally so that they can provide a rapid response in emergencies. Garden maintenance is done by workers in sheltered employment. Running costs of services are met from Personal Budgets of users and from cooperative members' annual subscription of 20 Euros, the aim being to make the services entirely self-funding. This initiative demonstrates the viability of a small-scale approach to social care and the advantages of services being embedded in a community and thus able to build on the work of motivated volunteers.

'City Village South' (StadsdorpZuid) a citizen's initiative near Amsterdam, inspired by the Village movement in the USA. The aim is to help older people remain active, healthy and safe in their own home and neighborhood as long as possible. The importance of social interaction is emphasized, creating activities where people meet, to combat loneliness.

The Netherlands has examples of residential homes that are carefully designed to offer a more home-like, normal and enjoyable life. **Innovative residential complexes** designed to prolong independent living, while ensuring 24-hour care is available, are outlined below:

WiekslagKrabbelaan. This scheme is described as a satellite nursing home, designed for dementia care in an environment that is familiar, enabling, 'home-like' and secure; the home is connected to its neighborhood and promotes interaction with the wider community. Each household has its own front door, private bedrooms each of 25 square meters with a basin, one bathroom and a shared living area with kitchen, dining and sitting. There is access to gardens, from where residents can see activities in the neighborhood. The two households share large multipurpose areas for creative and cultural activities with staff or family members. The care organization (Zorgpalet/Barn-Soest) arranges welfare and support for the residents and for others in the neighbourhood from an office located on an upper floor.

The same care organization also runs a nearby home for physically disabled older people, in WiekslagBoerenstreek. This has a similar philosophy of care – to maximize independent choices and integration with the neighbourhood. Each resident has a studio flat with ensuite bathroom and small kitchen. Residents share a dining area, large kitchen, laundry day care centre and gym on the ground

floor, with all facilities wheelchair accessible. A café has sheltered terraces leading onto gardens with a pond and views of the neighbourhood.[80]

Weidervogelhof consists of nine buildings scattered through the neighborhood and is run by collaboration between housing associations and a care organization. The philosophy is to provide housing, at-home care and welfare services in close proximity, enabling people to live independently in their own home but with support available in the same neighborhood when needed. This allows couples to be close when one partner needs care. Apartments are offered to older people with care needs but also to others needing shelter or care, some of the units being 'affordable'. Each apartment has its own garden or balcony. Weidervogelhof is a 'lifetime' neighborhood, with 201 rented sheltered housing apartments (176 affordable). A one cluster of apartments of 'Care Hotel' is for severely physically disabled people, while another has 100 affordable apartments for people aged over 55. Weidervogelhof also has a range of primary care, dentistry, pharmacy, physiotherapy, speech therapy, welfare and other services.[81]

In **Sweden** municipalities which are in process of planning housing and residential areas are required to ensure that they meet the needs of elderly people and those with disabilities. It has been shown that a growing number of elderly people in Sweden want to live in 'senior housing', which are ordinary homes for people aged 55 and over, making accessibility a priority. This has been done by building new homes, as well as adapting in order to be more accessible. With regards to the funding schemes most elderly care is funded by municipal taxes and government grants with only 4 per cent of the cost financed by patient themselves, which are also subsidized and based on special rate.

The trend of privatization is also notable, as more municipalities are choosing to privatize parts of their elderly care, making it to 24% of provided services for elderly people needing help in 2013. As a person-centered approach, all recipients can choose whether they want their home help or special housing to be provided by public or private operators, with the municipality as the overall responsible actor.

With respect to the elderly people who continue to live at home, various kinds of support care are available, such as ready-cooked meals that can be home-delivered. Almost half of the country's

[80] Abramson et al. Residential Mobility Patterns of Elderly – Leaving the house for an Apartment, p. 582-604, 2012.

[81] Ibid.

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municipalities also provide communal meals for the elderly at special day centers, while a few organize small groups of elderly people into teams that cook their own meals.

For the elderly people with disabilities full assistance is available, providing the opportunity for them to remain at home throughout their lives. The severely ill, too, can be provided with health and social care in their own homes, as well as daytime activities are offered for elderly and disabled people in need of stimulation and rehabilitation, which also provide the chance for them to continue to live in their homes. Transportation services are available for the elderly and disabled.[82]

As previously discussed the models of care, **France** is to considered as a part of the familial models of southern Europe (**Spain**, **Italy** and **Greece**) where the human assistance supplied to the elderly is considered to be the a family matter and with that a children's responsibility, comparing to the some of the norther European countries, like **Germany** and **Sweden**, where elderly dependence and their impairments are a societal issues, in which case they need to be addressed and settled by collective approach and decisions. Study performed in **France** on the formal and informal care for disabled elderly living in the community[83] showed that one-third of disabled elderly people receive no care, and among those who are helped, 55% receive informal, 25% informal and 20% mixed care. The study comprised of the sample of disabled people aged 60 and over, and was restricted to those with sever disability, and in need of assistance on a daily basis with daily activities, such as bathing, dressing, eating, etc., or instrumental, such as shopping, preparing meals, doing housework.

In **Ireland**, people with disabilities who are unable to live at home may be provided with residential services, which may include institutions, which usually provide accommodation for 10 or more people, clustered housing, or housing associated with an institution (it may be on the grounds of or near the institution), supported community living, which is houses within an ordinary neighborhood that may have supports for the people with disabilities living there and residential respite services.[84]

Barriers for people with disabilities to reach services

[82] Care in Sweden. https://sweden.se/society/elderly-care-in-sweden/ seen December 2019.

[83] Paraponaris et al., Formal and informal care for disabled elderly living in the community: and appraisal of French care composition, 2011.

[84]https://www.citizensinformation.ie/en/health/health_services/health_services_for_people_with_disabilities/health_services_for_people_with_intellectual_physical_or_sensory_disabilities.html, seen December 2019.

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Prevalence of institutional services

In many countries around the world, disabled people continue to be placed in long-stay residential institutions, often housing hundreds of disabled people and located in remote places. Institutionalization is a fundamental barrier to the realization of disabled people's right to independent living, as it deprives disabled people of the opportunity to make even basic decisions about their daily lives and condemns them to isolation. As abovementioned, there has been serious mistreatment of disabled people placed in institutional care, with occurring violence and abuse, in both high and low income countries. Disabled people often have no choice beside the institutional care, due to the lack of quality, accessible and affordable community services in their respected countries, as well as face various restrictions related to the access to services, and the attitudes of professionals.

However, even though there has been progress in terms of new and innovative solutions with regards to their care and accommodation, there has also been reporting on 'institutionalization' in the contemporary institutions, which are referred as 'community living centers', being based in the community and existing many countries in Europe. The problem reported is that with such institutions is that they group people based on their single characteristic – the presence of impairment – and set them apart from the community, adding to the separation and segregation. And although these living communities are downsized to 10-12 people, it has been viewed that these settings remain institutional with regards to restricting residents' every-day-choice. It has been reported that these residents often are not allowed to make their own decisions, are lacking of privacy and are under constant surveillance.[85]

A key problem which is seen with many contemporary institutions is that the provision of support is connected to provision to housing. Thus, people who need support are forced to accept a 'group home' type living arrangement, and vice versa – people who need a place to live are forced to accept the support provided there.[86] It is seen that this unjust and poor quality of service provision is only exacerbated by the process of de-institutionalization itself, especially in high-income countries, where privatization of these services has led to development of specialized services only in the name of monetization.[87]

[85] European Union Agency for Fundamental Rights (n. 60), p. 40.

[86] ENIL. The right to live independently and the be included in the community, 2017.

[87] Towell, D. 'The 21st century challenge: building sustainable and inclusive communities', p.2, 2003.

Barriers related to community support services

Access to quality, affordable and accessible support services in the community is an essential precondition for ensuring that disabled people can live and participate in the community as equal citizens. Support services can also help overcome environmental barriers, many of which stem from inaccessible mainstream services. At the same time, the lack or the inadequate provision of such services can reduce disabled people's ability to make choices about their lives and can condemn them to isolation – at home or in a residential institution. Some of the key concerns, related to the provision of community support include a) poor availability, accessibility and affordability of support, b) restrictions placed on disabled people's access to services, c) poor quality of services, and d) inadequate funding.[88]

Availability of support

As previously mentioned, community support for disabled people comprises a wide range of measures and interventions, such as personal assistance, communication assistance, technical aids and assistive technologies, support persons, peer support, housing and other. For many disabled people, support is an essential precondition for overcoming environmental and attitudinal barriers and realizing their right to live independently and be included in the community. In most high-income countries, there is a wider range of support services. Despite that, funding and development of community-based services in many countries remains inadequate. It has also been reported that often available services are not sufficient to meet the full range of support needs and disabled people are put on waiting lists. These lists can include tens of hundreds of people, some of whom are waiting for several years to access crucial services related to housing, personal assistance and employment.[89] The long waiting times for residential care are observed in most European countries, including Denmark, Estonia, Latvia, Hungary, Netherlands, Slovakia, Spain, Sweden. Long waiting times might be related to the poor supply of care, waiting for receiving a service at the preferred facility or to means testing.

In most countries, low and high income, availability of services depends on where the person lives. This related to a person's address which determines the support they receive and whether they will

[88] ENIL. The right to live independently and the be included in the community, 2017.

[89] For example, in 2010 in the Flemish Community in Belgium nearly 22 000 disabled people were on waiting lists, of whom 14 155 were related to an urgent situation (See European Committee for Social Rights (2013).

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be able to participate in the community or they will have to live a restricted life. Disabled people's rights to freedom of movement and choice of residence are also restricted, as they may not be able to keep the same type and level of support when moving to another neighborhood or region. Disabled people living in the European Union face similar problems, as the lack of support between the EU Member States does not allow them to move freely, unlike other EU citizens.[90]

Often, there is an urban-rural divide – more diverse services are available in the cities, while people living in the rural areas may find it difficult to access even the basic services. Even pilot projects and services provided by NGOs tend to be concentrated in the cities. In the countries of Central and Eastern Europe (CEE), certain community services are financed on the basis of short-term, project-based initiatives, supported by the state and the EU funds. Such funding leads to constant uncertainty among disabled people in relation to their support and takes away their control over their assistance and lives. Countries such as the Czech Republic, Slovenia or Spain tend to have large variations in supply of different types of care between regions. In the Netherlands, on the contrary, the supply of care is geographically distributed in an equal manner, as facilities are made available in the closest neighborhood (up to 5.2 km).

Sustainable provision of services is essential for independent living and inclusion in the community of those disabled people who require long-term support. However, sustainability remains a key challenge in all parts of the world. In low-income countries, formal services, where available, are usually provided by charities and international non-governmental organizations.[91]

Restricted access to services

Even when there is a range of support services in the community, disabled people's access can be significantly restricted. States can introduce specific eligibility criteria and terms, aimed to limit the number of people using services. Often, there are additional structural barriers in the application and assessment process, such as an overly complicated and long application process or the requirement for financial contribution.

[90] Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions, European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe, COM/2010/0636 final, p.5.

[91] Report of the Special Rapporteur on the rights of persons with disabilities, A/HRC/34/58, para. 60, 2016.

Eligibility criteria are used by the countries to determine who is entitled to use a particular service. These criteria are often discriminatory, as they exclude certain groups of disabled people, directly or indirectly, and fail to adequately take into account disabled people's support needs, one of which is 'means testing', which makes the use of services conditional on income. It means that people with income above a certain threshold, determined by the authorities, do not have free access to services, regardless of their needs. If they want to use a service, they are required to contribute financially to its cost, either partially or fully. Other formal restrictions of access to services, applied in many countries, include the *'type' and 'severity' of impairment and age.* Disabled people who live with their spouse or other family members can also have limited access to state-funded assistance. The responsibility for their support is transferred to their extended family, regardless of their preferences and the family's willingness and ability to provide adequate support.

Some countries have introduced limits ('cost ceilings') on the support people can receive to live in their own homes, which effectively restricts access of people with higher support needs to services in the community. The limits are usually set in relation to the comparative costs of residential care. Expenses for community support services are covered 'if this service does not entail "disproportionate additional costs" when compared to a "reasonable" … in-patient option (such as living in a care facility…)'.[92] Since support in the community for people with very high support needs is likely to cost more, when compared to residential care, they are not given a choice but to opt for the latter. Thus, 'cost ceilings' discriminate against people with the highest support needs and serve as a barrier to their independent living.[93]

Barriers in Mainstream Services and Facilities

The insufficient attention paid to making community services and facilities accessible hinders disabled people's full inclusion and participation in society. For example, the lack of accessible and affordable housing limits people's choices of where and with whom to live to two options – either to live in a segregated setting for disabled (or older) people or staying with their family. The lack of accessible transportation, seen as a priority service, restricts disabled people's mobility and contributes to their exclusion from other services, such as health care itself. Inaccessible mainstream services also

[92] HLIN. Assisted living Platform-The Long Term Care Revolution: A study of innovatory models to support older people with disabilities in the Netherlands, 2013.

[93] ENIL. The right to live independently and the be included in the community, 2017.

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perpetuate a view of disabled people as being of less value, which is another barrier to full inclusion.[94] The development of accessible mainstream services is often hindered by the lack of a vision of community living and the lack of knowledge about the nature of inclusion and how it can be realized in practice.[95]

[94] Ibid.

[95] Ibid.

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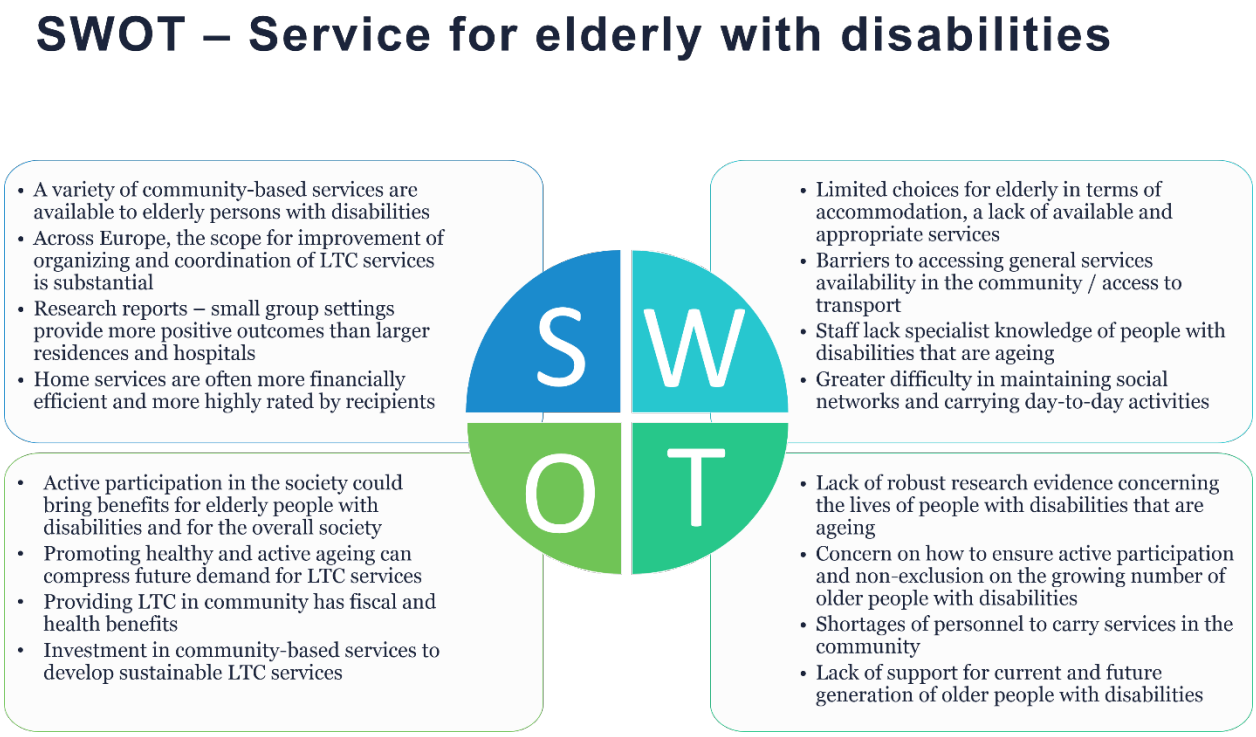
SWOT analysis for the service provision

The SWOT analysis is provided below with regards to the service provision for people with disabilities that are ageing, along with the inclusion of all relevant topics and issues of the general long term care.



Box 1: SWOT analysis of service delivery for elderly with disabilities

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CASE STUDY 1:

Association Latvian for Independent Living is an NGO that offers services to people with disabilities, based on the principles of community based care.

The Association works according to the following model:

- Assisted living flats / one room with personal assistance with the admission criteria that person has psychosocial disability, which are not severe.
- Daily activities center with the admission criteria that person has severe intellectual disability with complex care needs.
- Staff of 18, provides advisory support, planning of budget, support in personal care, support in shopping and cooking together with person, as well as support that is available according to individual needs.
- Staff is available to accompany residents to different events, cultural activities, as well as in organizing various joint events.
- Residents have the freedom to express the choice and control in terms of the support they receive, and have full responsibility over the quality of their lives.

Additional comments were pointed towards the attitude the persons with severe developmental disabilities are seen as potential residents of long term care institutions, with almost no community based assisted living opportunities for people with severe intellectual disabilities, lowering their quality of life.
Potential solutions of inclusion are seen in social services programs, availability of mainstream services, social benefit system, inclusive lifelong education, inclusive labor market; creation of inclusive community based service system, deinstitutionalization to be perceived as process and not as project, training of staff to be able to provide person-centered social services. Current programs of inclusion are being developed for people with less severe disabilities.
Actors involved in the creation of solutions should be, but not limited to, decision-makers on

Box 2: Case study 1

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CASE STUDY 2:

Fundació Ramon Noguera is an NGO founded in 1965 that is oriented towards the person centered planning (PCP).

The Association works according to the following model:

- Residencies/ Assisted living apartments/Support service at home are the types of housing provided, with 54% of its own resources, and 46% of public funding.
- 97 service users living in the residential services (residencies and assisted living apartments) and 17 users receiving support service at home.
- The entire organization has the staff of 388 (51% with disability 49% without disability).
- With regards to the residential services, the cost is approximately from 1.500 to 3000 euros per place, and it also depends on the support they need.
- 99,9% of residents have moved to the residence directly from home.
- Various activities are available for residents, such as sports: football, basketball (training and competitions), Zumba; Leisure: theatre, different activities during the weekend in smalls groups, holidays activities.
- Residents have the freedom to express the choice and control in terms of the support they receive, and have full responsibility over the quality of their lives.
- An annual training program for the staff is organized, based on needs and preferences of; 5.885 hours invested in formation and training during 2018.

Additional comments were pointed towards the policies that currently have an inclusive prospective in their design. For example, policies are made that work on uniting people with and without disabilities, or different generations. They also focused on providing awareness policies in relation to inclusion.
Potential solutions of inclusion are seen in awareness campaigns, providing economic aid, and support measures; with spaces are adapted to accommodate all the people and activities designed to include all the population.
Actors involved in the creation of solutions should be, but not limited to, decision-makers on national level, municipalities, society, persons with and without disabilities.

Box 3: Case study 2

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Discussion

With the ageing population, an increasing number of older people with severe disability and in need of a long-term care is to be expected, which will have implications for care provision currently put in place. This will only to be exacerbated with the reduction of availability of informal carers or the ageing of professionals.

The right to independent living has a profound implication for people with disabilities, meaning they can exercise choice and control with respect to their living arrangements, the support and the community services they use, placing them at the center of decisions about their quality of living. It is clear that the needs of older people with disabilities are not well met within the current frameworks of care and support. This report shows that there is still a long way to go before the right to independent living finds its way in the national frameworks and is fully implemented. Limited choices of living arrangements, lack of appropriate and available support services, lack 0f staff's specialist knowledge of the needs of older people with disabilities and barriers in accessing general community services make almost impossible for a person with disabilities to equally participate in the community, as others do. Gathering harmonized, standardized and regular data can be a step in the rights direction, and possibly play a crucial role in informing and developing processes to make independent living a reality for people with disabilities.

As this report shows, community-based services present an alternative to institutional care that enables older disabled people to take the lead in shaping their own care solutions and services. Presented are various different models, such as 'housing-with-care' across Europe, developed over the last two decades, which offer better solutions for older people with care needs in their final years. Many of these models are centered with social inclusion, maintaining sense of self. There is evidence that substantial number of older people have experienced new ways of community living, with reported satisfaction and successful transition from a home environment. It is safe to say that financing care for greater number of older people has not been without problems, however, innovation in housing-with-care is the potential that could lead to cost reduction. Technological innovations also show a step in the right direction, but they need to be adjusted to older people's wishes and requirements, as well as recognized within national frameworks.

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Conclusion

In conclusion, older people with disabilities experience a range of unmet needs within current service and support models. Key services identified include providing support and care for forward planning, community inclusion and availability of more appropriate choices for accommodation in later life. The literature reviewed further demonstrates that there is a lack of robust research evidence concerning the lives of older people with disabilities and a need for more research that directly engages with the alternatives of institutional setting for older people with disabilities.

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Annex: Survey for service providers for adults with disabilities that are ageing

EASPD
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IMPROVING LIVES
European Association of Service providers for Persons with Disabilities

Survey for service providers for adults with disabilities that are ageing

Thank you for agreeing to complete this survey.
Your answers will be used as case study for the Research Paper on the state of play of service provisions for persons with disabilities that are ageing. Your answers will only be seen by the person conducting this evaluation and the EASPD.

The survey is divided into 3 sections. Please take time to get familiarized with the questions and if there is anything unclear, please feel free to contact the EASPD for further clarification. It is also possible to schedule a conference call to further elaborate on the issues in question, if needed.

Section A of this survey covers the information on the organization, people using the services, as well as the requested information on the organizational staff.
Section B and section C cover the question on the social exclusion and social inclusion of people with disabilities that are ageing, and we look forward to hear your opinion with regards to these questions. Please feel free to go in depth with your answers as much as you feel compelled to do so, as well as if you wish to address something that is not covered by this survey. It is greatly appreciated.

Please provide as much information and comment as you wish either in the spaces provided.

All the information provided in this form will only be used for the organizational purposes related to this research and deleted afterwards. EASPD will treat your information with respect and according to our privacy policy: http://www.easpd.eu/en/content/privacy-policy

Section A: about your organization

A.1 Your name and contact details

your details

surname _____ title _____

first name(s) _____

Name of organisation and contact details

_____

email _____

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A.2 Type of organization (public/private/NGO)

A.3 Types of funding sources?

A.4 When was the organization opened?

A.5 Average age of people who use the services (male/female)?

A.6 Number of people residents/people the organization is providing services?

A.7 What is the type of housing provided?

A.8 Details on apartments/housing.

A.9 Philosophy of care? (residential care/ community based care/ short-term rehabilitative care/ long term extended care…)

A.10 Type of community-based service(s) provided?

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A.11 What type of facilities exist within the organization?

A.12 Number of staff?

A.13 Cost per place?

A.14 Admission criteria?

A.15 Discharge criteria (if any)?

A.16 Previous accommodation for your occupants (if known)?

A.17 Number of people served in the past year?

A.18 What kind of support is available from the staff?

A.19 Leisure activities offered?

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A.20. Do the users of the services have an expression of choice and control over the support received or the services/facilities they use and if they do, how is expressed?

A.21 Quality assurance system provision in the functioning of the organization?

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Section B: about elements of *social exclusion*

B.1 How current programs and policies promote social exclusion of adults with disabilities?

B.2 How exclusion impacts people?

B.3. Cost of exclusion?

B.4. Who has the responsibility to address the sources of exclusion?

Section C: about elements of *social inclusion*

C.1 Sources of inclusion?

C.2 How current programs and policies promote inclusion?

C.3 Measures of inclusion?

C.4 Who would need to be involved in the solution?

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C.5 Which processes would need to designed to make the solutions work?

C.6 Desired outcomes of inclusion? (for the individual and for society)

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