



# Ageing, Disability and Long-Term Care: Recommendations for the European Care Strategy

**European Disability Forum Position Paper**  
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## Introduction

### The European Disability Forum

The European Disability Forum (EDF) is an independent NGO that represents the interests of 100 million Europeans with disabilities. EDF is a unique platform which brings together representative organisations of persons with disabilities from across Europe. EDF is run by persons with disabilities and their families. We are a strong, united voice of persons with disabilities in Europe.

### Disability among older people

There are many commonalities between the barriers faced by older people and those faced by persons with disabilities. One of the main reasons for this is that a considerable percentage of older people do in fact have disabilities themselves in one form or another. According to the United Nations, 46% of persons over 60 globally have a disability<sup>1</sup>. This means that almost half of older people are part of the disabled community.

While many older people might not self-identify as being disabled or even acknowledge that certain barriers they face later in life actually come from having a disability, the reality is that many of the challenges older people face overlap with those we experience in the disabled community. There is therefore a huge amount to be gained by addressing certain issues from the disability and ageing perspective simultaneously.

One of the key overlaps between the requirements of the two communities relates to long-term care. We observe common issues affecting older people, persons with disabilities and, of course, people who fall into both of these categories. The key issues that persist are, among others, unmet support needs, the right to choose, independent living and inclusion in the community, the affordability of support services, support for informal carers - who are more often women, including women with disabilities - and the disproportionate barriers faced by older women and women with disabilities in general.

When talking about care for older people, including older persons with disabilities, we must also acknowledge that the goals and objectives often differ when compared to support for younger people. Whereas for

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<sup>1</sup> <https://www.un.org/development/desa/disabilities/disability-and-ageing.html#:~:text=Currently%20it%20is%20estimated%20that,experience%20moderate%20to%20severe%20disability>

younger people care services are often aimed at a gradual progression towards further autonomy, with a focus on learning new life skills and decreasing dependence on caregivers, care for older people often has the aim of assisting the person to maintain their autonomy to the greatest extent possible and to adjust their way of life in light of the changes caused by ageing.

In 2021 the European Commission announced plans for an EU Care Strategy. This Strategy should be a means for the EU to live up to its commitments in the [EU Pillar of Social Rights](#), particularly Principle 18 on long-term care, and Principle 17 on the inclusion of persons with disabilities. Principle 18, in particular, states that "everyone has the right to affordable long-term care services of good quality, in particular home-care and community-based services", a principle that has been endorsed by all EU Member States.

In this position paper we aim to outline the main overlapping issues faced by older people and persons with disabilities, including women, and to present a series of recommendations for how we feel these should be addressed in the new EU Care Strategy.

## What is “Care”?

Care is not about dependency but autonomy, embedded in a human rights-based approach. The right to be cared for and to care for others requires addressing the needs and the rights of all at different stages of our lives.

From the perspective of disability, care services and provision must be aligned to the UN Convention on the Rights of Persons with Disabilities (CRPD), in particular Article 19 and General Comment 5, to avail support services to live independently and be included in the community framework. The Convention is part and parcel of the policy framework of the EU, not least because it was signed and ratified by both the EU and the Member States.

## Issues in long-term care for persons with disabilities and older people

### **Inclusion in the Community and the right to choose**

When it comes to catering services and long-term care to the requirements of older people and persons with disabilities, including

people who fall into both categories, there are a number of elements that must be taken into account.

First and foremost, in line with [Article 19 of the United Nations Convention on the Rights of Persons with Disabilities \(UN CRPD\)](#), and its [General Comment 5](#), persons with disabilities have the right to live and be fully included in the community, with choices equal to others.

The care or support services a person receives must be ones that they have selected on the basis of informed consent. This requires having information about the different services available to them easily available, and in an easy-to-understand format. This clarity of information is particularly important for certain people who have grown up with disabilities and without any choice over their living arrangements or how they live their lives, and therefore do not have experience of exercising their right to choose.

When it comes to assisted-living and residential services, which arguably have one of the biggest impacts on a person's day-to-day life, it is crucial that each person is able to freely choose their place of residence, where and with whom they want to live, and not be obliged to live in any particular living arrangement.

For many persons with disabilities and older people, the preference is to live independently. People who require a disability later in life in particular might fear having to leave the homes they have spent their lives in, as their need for support increases. For all persons with support needs, there is a risk of being placed in institutional care, a type of care provision that runs counter to the EU Charter of Fundamental Rights and the UN CRPD.

Institutional care, in the definition given by the [European Expert Group on the Transition from Institutional to Community-based Care](#), refers to care settings that display any of the following characteristics:

- A. Residents are isolated from the broader community and/or compelled to live together;**
- B. Residents do not have sufficient control over their lives and over decisions which affect them;**
- C. The requirements of the organisation itself tend to take precedence over the residents' individual needs.**

The risk of placement in institutional settings is made all the greater when there is a lack of personalised and community-based services available, such as in-home support and personal assistance. The probability of being institutionalised is also greatly increased when personalised forms of support are not made affordable, and when the State or local authorities do not help to cover the costs. The risk of institutionalisation can thus be

reduced by increasing the availability and affordability of personalised services that offer a realistic alternative to institutions, such as in-home support and personal assistance, for which the demand currently far outweighs the offer.

It is also important to include a gender perspective as highlighted in General Comment No. 5 of the CRPD, para.72: "Often, women and girls with disabilities are more excluded and isolated, and face more restrictions regarding their place of residence as well as their living arrangements owing to paternalistic stereotyping and patriarchal social patterns that discriminate against women in society." This can also apply to older women with disabilities who are more likely to be institutionalised than older men.

## **Recommendations for the EU Care Strategy**

- An objective of the Strategy should be to **survey the care preferences of persons requiring support** to understand where to focus investment. **Member States and local authorities should keep track of the demands for specific types of services in different areas** (for example, the number of people requesting personal assistance) and the extent to which this outweighs availability.
- The Strategy should **prioritise all types of support that reduce reliance on institutional care settings**, and cases where persons with disabilities and families are forced to turn to institutions due to a lack of other, more appropriate support mechanisms. The Strategy should seek to **increase the investment in in-home support and personal assistance** in particular, through the use of EU, national and local funding. Authorities responsible for the funding of care and support services should also be strongly encouraged to **deliver personal budgets to the individual receiving support** rather than service provider directly.
- The EU Care Strategy **should assess the costs of long-term care to individuals in a regular reporting framework and foster exchange of good practices to reduce it**.
- In order to ensure funding and investment to meet increasing care needs, and to reduce the cost to the service-user, the EU Care Strategy should **encourage Member States to establish long-term care as a branch of social protection**. This will offer a way to provide the funding for long-term care through collective solidarity.

- The strategy should also focus on **the role EU funds can play in improving the affordability of care services** and ensuring that nobody foregoes the support they need because of cost.
- The European Commission should consider setting up a specific **working group to study the support needs of older people and persons with disabilities**, with the aim of lengthening autonomy, understanding how support needs change during different life stages, and avoiding as far as possible displacing people from their usual environment.

## **Unmet needs and the availability of service providers**

A common problem for all persons with support needs, when it comes to the issue of long-term care, is that of un-met support needs and the lack of availability of quality service providers. This is an issue that is further accentuated by the ageing of our societies and the increase in demand for support. According to the Social Protection Committee's 2021 Report on Long-Term Care, the number of people potentially in need of long-term care in the EU is projected to rise from 30.8 million in 2019 to 38.1 million in 2050<sup>2</sup>.

Access to formal support is a pressing issue in Europe. About one in three people in need of formal care and support in the EU are not able to access it, while the care needs of persons with lower incomes are more often even higher<sup>3</sup>. Making person-centred and community-based services available to the people that need them, and ensuring the quality of these services, is dependent to a large extent on attracting people to work in the care sector. This is particularly important in a context where increasing interest is being shown in how to digitalise the care sector and rely less on human contact.

As well as making the profession an attractive one in terms of salary and working conditions, service providers must also be supported to feel confident and well-prepared for the work they do. It is therefore in the

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<sup>2</sup>

<https://ec.europa.eu/social/BlobServlet?docId=24081&langId=en#:~:text=The%202021%20Long-term%20care%20report%2C%20jointly%20prepared%20by,care%20provision%20and%20key%20challenges%20across%20the%20EU.>

<sup>3</sup>

<https://ec.europa.eu/social/BlobServlet?docId=24081&langId=en#:~:text=The%202021%20Long-term%20care%20report%2C%20jointly%20prepared%20by,care%20provision%20and%20key%20challenges%20across%20the%20EU.>

interest of carers and the people they serve that quality training is given on how to offer support in a way that fits around the wants and needs of each service user. This should include training to make all service providers and assistants familiar with the UN CRPD and its General Comments, and what this means for how persons with disabilities and older people should be supported and empowered.

## Recommendations for the EU Care Strategy

- Encourage member States to further professionalise care roles by **improving training for current and future workers in the sector**, including on taking a human rights-based approach to support, **understanding the rights of people with support needs as outlined in the UN CRPD** and learning how to tailor support to the choices of the individual.
- The Strategy should **promote effective social dialogue** in the care sector and at all levels, to increase pay and improve other working conditions for care staff.
- The EU Care Strategy must be clear that the aim of care is to **maintain human contact and social inclusion**. As such, the digitalisation and robotisation of care must not lead to a reduction of quality human contact of persons in need for care and support.

## Why care is also a gender issue

There is a strong gender dimension to long-term care provision for persons with disabilities and older people that we cannot ignore. Firstly, the demand for support among women is significantly greater. When we look specifically at older people with support needs, around 37% of women over 65 report needs for long-term care, versus 23% of men over 65. On average, women live 3.5 years longer than men and spend 12.7 years with a chronic health condition or disability, compared to 9.2 years for men<sup>4</sup>.

Another issue in which women are disproportionately affected is with regards to informal care. Informal carers are mostly women who are not employed or who have left their jobs to care for their child, sibling, partner or parent with support needs, which has a huge impact on their pension rights and thus their own ability to live independently in old age.

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<sup>4</sup>

<https://ec.europa.eu/social/BlobServlet?docId=24081&langId=en#:~:text=The%202020%20Long-term%20care%20report%2C%20jointly%20prepared%20by,care%20provision%20and%20key%20challenges%20across%20the%20EU.>

The EU Care Strategy should offer support to families, and particularly women, including women with disabilities themselves, who too often offer informal care to family members with disabilities without support from the State. While it is true that the EU has taken significant steps to address this by adopting the [Directive on work-life balance for parents and carers](#), which defines informal care in EU legislation and grants four days of leave per year for informal carers, this clearly has its limitations. Some of the main shortcomings of the Directive are:

- Four days per year does not appear to be a sufficient amount away from employment to coordinate health and long-term care services, let alone to provide emotional support
- The Directive does not set out minimum standards for income security or social protection of informal carers
- Being a piece of labour market legislation, the Directive does not include the provision of support services to informal carers

### **Keeping families together through long-term care**

Efforts should also be focused on the types of services available to assist people who grow old alongside a spouse, partner, sibling etc, and who find themselves taking on the role of informal carer as their loved one develops a disability. Many older people inadvertently become carers in such cases, while at the same time having to adjust to the reality of their own ageing. This can take its toll on their own wellbeing and ability to age healthily. It is also the case that persons with disabilities who have always lived with and been supported by their parents, later reverse the care roles and become carers for their parents as they age.

The availability of services on offer to enable couples and/or family members to remain united as they age and/or develop disabilities is extremely significant. Such services are a cornerstone of the realisation of Article 19 of the CRPD and General Comment 5, and a make-or-break element in ensuring that people are not separated from their loved ones due to the insufficient availability or affordability of personalised support.

### **Recommendations for the EU Care Strategy**

- The EU Care Strategy should push for **greater support to informal carers, including financial support** for the service they provide.

- The Strategy should envisage **regular mapping of carers' leave arrangements and the provision of social rights** (especially pension credits) in the EU and **encourage Member States to go beyond the minimum provision in the Work-life Balance Directive**;
- The Strategy should **promote support services for informal carers**: day-care and respite care services; training and peer counselling as well as personalised coaching. This support should take the form of available EU funding and the development of guidelines to Member States for the support of informal carers.

## Document credits

This document was prepared by Haydn Hammersley

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