

Dementia in Europe Yearbook 2022: Employment and Related Social Protection for People with Dementia and Their Carers

Owen Miller

Alzheimer Europe, Luxembourg, Luxembourg

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Owen Miller

Owen Miller is a public policy professional with more than 10 years of experience working primarily in health and social care policy. In his role as Policy Officer at Alzheimer Europe, a position he has held since August 2018, he focuses on ensuring dementia is recognised as a European priority by supporting the campaigns of Alzheimer Europe and its members, developing policy statements and contributions to ongoing European Commission consultations, presenting the views of Alzheimer Europe to members of European institutions, supporting the activities of the European Alzheimer's Alliance of MEPs, and collaborating on national reports on dementia policies. He previously worked in a similar role at a national level, at Alzheimer Scotland.

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Corresponding author: Owen Miller, Policy Officer, Alzheimer Europe, 14, rue Dicks L-1417, Luxembourg, Luxembourg. E: owen.miller@alzheimer-europe.org

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In an expert interview, Owen Miller, Policy Officer at Alzheimer Europe, Luxembourg, discusses the *Dementia in Europe Yearbook 2022: Employment and Related Social Protection for People with Dementia and their Carers* (henceforth, the Yearbook).¹ The Yearbook is a report that provides an overview of the challenges and opportunities that people with dementia and their caregivers face in Europe. It is published by Alzheimer Europe, a non-profit organization that represents people with dementia and their caregivers at the European level.² The report is based on a survey of national Alzheimer associations from 30 European countries and provides insights into the employment status of people with dementia, their access to social protection, and the support available to their caregivers. It also highlights the significant barriers to employment that people with dementia and their caregivers face and the lack of adequate social protection and support for these groups. The report concludes with recommendations for policymakers, employers and civil society organizations to address these challenges and promote greater social inclusion for people with dementia and their caregivers.

Q. Could you give an overview of the *Dementia in Europe Yearbook 2022* and its overarching goals?

The *Dementia in Europe Yearbook 2022* is a policy resource that focuses on the employment of and related social protection for people with dementia and their carers.¹ It provides an overview of the provisions of the EU Charter of Fundamental Rights,³ the European Pillar of Social Rights,⁴ the United Nations Convention on the Rights of Persons with Disabilities,⁵ and examples of EU legislation and policy initiatives in the area of employment and social protection. In addition, based on the responses of 21 Alzheimer's associations across Europe, Alzheimer Europe collated information on the current policies and legislation from different countries, identifying common strengths and weaknesses of different systems and the extent to which they upheld the rights of people living with dementia and carers.

The Yearbook aims to provide a snapshot of the current situation of people with dementia and their carers across Europe, highlighting the commonalities between approaches, identifying examples of good practice from different countries and sharing the experiences of persons with lived experience. It is intended as a resource for a broad range of stakeholders to inform and contribute to debates around improving the experience of people living with dementia and their carers.

Q. From your findings in the Yearbook, what is the current landscape in relation to the employment of and social protection for people with dementia and their carers across Europe?

The current situation for the employment and social protection of persons with dementia across Europe is varied. On the one hand, in the international and European accords, the rights of persons

with dementia were well articulated (as a disability), although the carers' rights were not acknowledged specifically. By comparison, within the EU, there are notable legislation and programmes that aim to protect against discrimination based on disability and provide some measure of protection for carers.

Employment and social protection systems are incredibly complex and reflect each country's systems and administrative structures. Yet, recurring criticisms of these systems emerged across countries. These included the overly complex nature of these systems, the restrictiveness of the eligibility criteria for benefits and carers' allowances, and the insufficient financial support they provide. For people with dementia, there were only a few examples of social protection systems that recognized the specific nature of dementia as a progressive, incurable and life-limiting condition. For carers, benefits were often assessed according to the level of disability of the cared-for person, not the level of care provided or the needs of the carer themselves.¹

Competency in these matters is split between the EU and its Member States. However, the main challenges identified fall under the purview of the Member States, either at the national, regional or local level.

Q. It was interesting to read that the voice of people living with dementia and their carers had been included in the Yearbook. From these shared experiences, what common themes emerged?

The experiences shared in the Yearbook varied considerably, and the stories they shared were highly personal. For carers, the insufficient support and the difficulty in caring for a person with dementia while having to navigate complex social protection systems came through strongly. There was a feeling that systems should be simpler to navigate and take a more person-centred approach, tailored to different needs and circumstances.

People with dementia provided some excellent examples and some truly awful experiences. Some people disclosed their diagnosis during their working life, and some chose not to do so. However, regardless of disclosure, the prevailing feeling was that support and understanding

from colleagues (usually managers) or employers were crucial. This applies to employers not only understanding their legal obligations but also creating a supportive and understanding environment, showing respect to the individual and their contribution.

People with dementia and carers both agreed that there is still much work to do before their rights are fully respected.

Q. Finally, are there any reflections on the Yearbook, and what questions remain unanswered?

The Yearbook demonstrates that there is a disconnect between high-level agreements and accords, the legislation and policies of different countries, and the implementation and experiences of people whom systems are meant to protect and support. That is not to say that international agreements and frameworks are not important – they are an important benchmark against which we must measure national policies and legislation. However, national governments must recognize and do more to meet their obligations. Ratifying the United Nations Convention on the Rights of Persons with Disabilities or other measures is only the starting point in an on-going process to improve the lives of persons with disabilities (including people with dementia) – it is not an end in itself.

One question we were not able to explore in detail related to the European Work–Life Balance Directive.⁶ The European Work–Life Balance Directive is a legislative measure that was adopted by the EU in 2019 and that aimed to improve work–life balance for parents and carers and promote gender equality in the labour market. The Directive sets out minimum standards for paid-leave entitlements, flexible-working arrangements and other measures to support working parents and caregivers across the EU. We would have liked to understand why this instrument was not referenced more by our members, despite the fact that Member States were required to implement the Directive by August 2022.⁶ For us, questions remain about whether this reflected a lack of implementation or lack of communication by governments, or whether provisions were already in place in several countries. This is something we will continue to monitor in our policy work. □

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