

Care and Disability

Issue Paper

Disability Advisory Committee

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Introduction

Economic Equality is a strategic priority in IHREC's Strategy Statement 2022-2024. As part of IHREC's focus on economic equality, the Commission has highlighted care and care work with the objective of:

'Greater recognition of the economic and social value of care as a form of work, including family and community caring, ensuring that family carers do not suffer financial loss due to their family care work'.¹

In order to achieve this, the Commission envisaged the development of a National Action Plan for Care.

'Seek the development of a National Action Plan for Care, and support this through promoting recognition of care, socially and economically, as a central value in Irish society.'²

Building on this strategic priority, the launch of the European Care Strategy in September 2022 and national developments in this area, the Policy and Research Department is developing a policy statement on care and personal assistance. The policy statement is intended to promote the implementation of the European Care Strategy in Ireland, while also incorporating the critiques raised by disabled people and Disabled Person's Organisations about the classification of services for disabled people as care.

This discussion paper provides an overview of the European Care Strategy, in particular as it relates to disabled people, and the intended areas of focus in IHREC's forthcoming policy statement. It finishes with specific questions for consideration by the DAC. Comments on all aspects of this paper are very welcome.

Overview of the European Care Strategy

The European Care Strategy aims to ensure quality, affordable and accessible care services with better working conditions, gender equality and work-life balance of carers. It will contribute to the

¹ IHREC, [Strategy Statement 2022-2024](#), p.11.

² IHREC, [Strategy Statement 2022-2024](#), p.11.



implementation of the European Pillar of Social Rights and the 2030 targets in the Action Plan on employment, skills and poverty reduction.³ The Strategy consists of:

- Two proposals for Council Recommendations: (1) on the revision of the Barcelona targets on early childhood education and care, and (2) on access to affordable high-quality long-term care.
- A Communication, which sets out a vision for how care is provided in Europe, and provides further supportive actions at European level and calls for action at national level.

Both Recommendations have similar themes in relation to care, predominately focusing on **affordability, availability, accessibility** and **quality**. The Strategy as a whole highlights the gendered nature of care work and the restrictions placed on women's access to the labour market due to caring responsibilities, noting heavily that the Strategy is to facilitate women's labour market participation and ensure that those in need of care can access it.

[Council Recommendations on the revision of the Barcelona targets on early childhood education and care](#)

The Barcelona objectives were adopted by the European Council in 2002 and are targets for high quality and affordable childcare. They set the EU average target of 33% of under 3 year olds in formal childcare structures and of providing 90% of children aged three to school age with high quality and affordable child care. A 2018 report on the objectives showed that a significant number of States did not meet the EU average target of 33%, Ireland among them.⁴ The Objectives also measured the percentage of women (aged 15-64) inactive in the workforce due to personal and family responsibilities. In 2016, Ireland was amongst Member States with the highest percentage of inactive women, with over 15% inactive and more than 10% working part time due to caring responsibilities.⁵ That report also noted a significant gender employment gap in Ireland and notes that the 'gender employment gap is closely related to caring responsibilities'.⁶

The objective of the Council Recommendation on the revision of the Barcelona targets on early childhood education and care ('ECEC') is to 'encourage Member States to increase participation in

³ Questions and Answers: European Care Strategy (7 September 2022) [here](#).

⁴ European Commission, Barcelona Objectives (2018), p.10, [here](#).

⁵ European Commission, Barcelona Objectives (2018), p.6.

⁶ European Commission, Barcelona Objectives (2018), p.5.



early childhood education and care in order to facilitate women’s labour-market participation and enhance the social and cognitive development of children, in particular vulnerable or disadvantaged children’.⁷

The Recommendation states that Member States should ‘encourage’ a time intensity of care that is compatible with meaningful labour-market participation and that the hours of care should increase with age, moving from at least 25 hours for children under 3 to at least 35 hours for those aged 3 and up.⁸ There should be targeted measures to ensure the participation of all children, particularly those at risk of poverty and social exclusion as well as children with disabilities, and to close the gap in participation in early childhood education and care between children at risk of poverty and the overall population.⁹ Early childhood education and care should be:

- of a **high quality** for all children and be in line with national quality frameworks which Member States were encouraged to develop under the 2019 Council Recommendation on High-Quality Early Childhood Education and Care Systems;
- organised adequately **across the territory** to allow accessibility for all;¹⁰
- **limited in expense** for those children who would not qualify for **free early childhood education and care** under the European Child Guarantee;¹¹
- **accessible**, for example solutions for parents with atypical working hours, addressing the needs of single parents and ensuring accessibility for parents and children with disabilities;¹²
- a **legal entitlement to** early childhood education and care should be established;
- **affordable and high-quality after-school** care should be established;
- **awareness raising** efforts should be made to inform parents of their rights to early childhood education and care;
- **fair working conditions** for early childhood education and care staff;

⁷ European Commission, Proposal for a COUNCIL RECOMMENDATION on the Revision of the Barcelona Targets on early childhood education and care COM/2022/442, para 1.

⁸ European Commission, Proposal for a COUNCIL RECOMMENDATION on the Revision of the Barcelona Targets on early childhood education and care COM/2022/442, Article 4&5.

⁹ European Commission, Proposal for a COUNCIL RECOMMENDATION on the Revision of the Barcelona Targets on early childhood education and care COM/2022/442, Article 6.

¹⁰ Article 8.

¹¹ Article 9.

¹² Article 10.



- and Member States should **encourage equal sharing of care for children** through combatting gender stereotypes and promoting family-friendly working conditions.¹³

Proposal for a Council Recommendation on access to affordable high-quality long-term care

In the Recommendation, long-term care is understood as:

‘a range of services and assistance for people who, as a result of mental and/or physical frailty and/or disability over an extended period of time, depend on help with daily living activities and/or are in need of some permanent nursing care’.¹⁴

The rationale for the Recommendation includes that the pool of informal carers is diminishing, as women are increasingly employed and retiring later, along with an increased demand for labour across different sectors decreasing the supply of formal carers as they move to sectors that are more attractive.¹⁵ Additionally, there is a workforce challenge, which includes shortages and non-standard forms of employment in the sector across the EU, and women make up 90% of the workforce making it one of the most gender-segregated sectors.¹⁶ However, informal care represents most care provision, which comes at an expense to both the economy and the individual.

The Recommendation informs that Member States should:

- improve the adequacy of social protection for long-term care by ensuring it is **timely, comprehensive and affordable**;¹⁷
- provide a balanced **mix of long-term care options** by developing and/or improving home care and community-based care; **closing territorial gaps**; roll out **innovative technology**; and ensuring services are **accessible** to people with disabilities;¹⁸
- ensure **high-quality criteria and standards** for long-term care;¹⁹

¹³ Articles 11-18.

¹⁴ Defined in Article 3 of the Explanatory Memorandum of COUNCIL RECOMMENDATION on access to affordable high-quality long-term care COM/2022/441.

¹⁵ COUNCIL RECOMMENDATION on access to affordable high-quality long-term care, p.1.

¹⁶ COUNCIL RECOMMENDATION on access to affordable high-quality long-term care, p.2.

¹⁷ Article 4.

¹⁸ Article 5.

¹⁹ Article 6.



- ensure **fair working conditions**;
- **address skills needs and worker shortages** and establish procedures to identify informal carers and support their care giving through professional support, training and financial support;²⁰
- **ensure policy governance through appointing a national long-term care coordinator** who is properly resourced and with a mandate enabling the effective coordination, monitoring and implementation at a national level, and acting as a contact point at Union level. Additionally, a national framework for data collection and evaluation should be developed and a mechanism for forecasting long-term care needs; strengthen contingency planning, engage in awareness raising efforts; and mobilising and making cost-effective use of adequate and sustainable funding.²¹
- **submit to the Commission, within 12 months of the adoption of the Strategy, a national action plan** to implement the Recommendation.²²

Critiques of the European Care Strategy

The **European Network on Independent Living** ('ENIL') highlighted concerns²³ that the Strategy does not call on Member States to fully implement the UNCRPD and highlights that the use of the word 'care' for people with disabilities is synonymous with the medical model, situating disabled people as passive recipients of care. ENIL would like to see the Strategy clearly state that disabled people have a right to community-based support, in line with the UNCRPD and have articulated that the Strategy does not contain the necessary paradigm shift to support that. ENIL highlights the need for a definition of Personal Assistance and home care services in the Strategy and emphasises that in order to be UNCRPD compliant, disabled people must have autonomy to decide how, when and where services are delivered. They call for the Strategy to state clearly that all forms of institutions should be eliminated and funding redirected into community based support. Finally, ENIL highlight the need for the full involvement of disabled people and their representative bodies.

Social Platform identified issues that include inadequacy in identifying the barriers and intersectional discrimination that marginalised groups face when trying to access care; the need for

²⁰ Article 8 &9.

²¹ Article 10.

²² Article 11.

²³ ENIL, Statement on the European Care Strategy (20 September 2022), [here](#).



a 'Care Platform' which was hoped to be made up of representatives from Member States, CSOs and social partners; and the lack of EU targets and indicators for long-term care.²⁴

ERGO Network, a network of Roma and pro-Roma NGOs, welcomed the pledge to improve access to early childhood education and care for Roma children but highlight that Roma adults were not considered as either long-term caregivers or receivers. Additionally, they echo the concerns of Social Platform by highlighting the gaps in the Strategy in relation to intersectional discrimination and lament that it has not been a core element of the Strategy.²⁵

AGE Platform Europe concerns about the Strategy centred on the lack of mandatory action for Member States, allowing for leeway in implementation and the lack of tangible outcomes particularly in the realm of data collection.²⁶ Furthermore, AGE expressed concern that the Strategy does not go far enough on ending the segregation of care receivers and the rest of society with more emphasis needed on care as enabling the realisation of other rights. They see the Strategy as a starting point for discussing good practice and trying to create a European conversation on long-term care.

The **EU Alliance for Investing in Children** highlighted²⁷ that the Strategy should support more extensively the provision and access to quality family and community-based alternative care and support deinstitutionalisation. Additionally, they highlighted that the Strategy should include a stronger focus on discrimination; that the EU should support and urge Member States to implement the Strategy; there should be a structured implementation plan and funding schemes; and a European Care Platform should be established. In relation to long-term care, they would like to see:

- common EU targets and indicators;
- better recognition of the role of migrants in the provision of care services;
- disabled children and younger persons to be sufficiently covered by the proposal; and

²⁴ Katja Reuter, New momentum for care? Unpacking the new European Care Strategy (29 September 2022), Social Platform Blog Articles, [here](#).

²⁵ Ana Rozanova, European Commission releases the European Care Package – What's in it for Europe's Roma? (29 September 2022) ERGO Network, [here](#).

²⁶ Philippe Seidel, The European Care Strategy has come a long way. What does it change? (16 September 2022), AGE Platform Europe, [here](#).

²⁷ See generally The EU Alliance for Investing in Children, Position paper on the European Care Strategy and upcoming Council recommendations on The revision of the Barcelona targets on early childhood education and care The access to affordable high-quality long-term care (11 October 2022), [here](#).



- the inclusion of Roma adults as care receivers or givers.

IHREC's policy approach

The Policy and Research Department is considering the contents of IHREC's forthcoming policy statement on care, and engaging with stakeholders. The draft statement will be considered by the Commission at Plenary on July 13th, 2023.

Policy and Research acknowledges that early childhood education and care and long-term care are distinct areas of care, and it would be difficult to apply the same approach across both areas. It is also the case that in Ireland, early childhood education and care policy is much more developed than long-term care policy. There has been a massive increase in investment in early childhood education and care in recent years and Ireland is well on its way to achieving the revised Barcelona Targets. We also think that there are distinct differences between the care policies that focus on older people and policies that seek to support disabled people to live independently.

However, we believe there are some 'General Principles' that will apply across the spectrum of care, care work and community support, which are listed below.

General Principles

- Gender equality
- Quality, affordable and accessible care services throughout the life cycle
- Intersectionality
- Community based services
- Personal Assistance

Specific Issues

Further, we consider that there are specific issues regarding disability and disabled people, which are listed below.

- Disabled people as carers, including family carers.
- Differing experiences of care owing to intersectionality of disability and other factors.
- Design of care systems that incorporate intersectionality.
- Deinstitutionalisation.



- Accessible communities and not just accessible services.
- The need to address poverty to ensure people can live well in the community.
- Provision of personal assistance rather than care:
 - Definition of personal assistance.
 - Ability to pick one's own assistants.
 - Awareness raising about PA services.
- Transitions from child to adult and adult to older persons services.
- Ease of access to Health Service Executive Disability Services.
 - Issues with needs assessment process.
 - Sufficient hours to meet demand.
 - The use of 'respite services', whether they are readily available when needed and whether they are appropriate in lieu of calls for deinstitutionalisation.
- Inappropriate placement of disabled people in nursing homes.

Questions for DAC

- What are DAC member's views on the terminology that IHREC could use in this area e.g. care, personal assistance, community support?
- What are DAC member's views on what IHREC could cover in its Policy Statement including the General Principles and the Specific Issues?
- What are DAC member's views on how intersectional issues impact on disabled people's access to or experience of giving or receiving personal assistance and care?
- What are DAC member's views on the provision of personal assistance?
- What are DAC member's understanding/experiences of transitions from child to adult services and from adult to older person's services?
- What are DAC member's understanding/experiences on care for disabled children?