

## **COFACE Families Europe response to the Open Consultation on Enhancing the strategy for the rights of persons with disabilities up to 2030**

### **Under point 3 of the EU Strategy: on decent quality of life and living independently: improving quality of life and autonomy.**

#### **➤ Stronger family dimension of the EU Disability Strategy:**

COFACE is pleased that the family dimension was emphasised in the [EU guidance on independent living](#), and that the European Parliament, in its [resolution on the EU strategy for the rights of persons with disabilities post-2024](#), calls for strong supporting measures for the families and carers of persons with disabilities to be integrated in the new phase of the Strategy. We welcome these developments and reiterate our call for the family approach to be decisively reinforced in the next phase of the Strategy, through the following actions:

- **Giving greater attention to the situation of parents with disabilities and their families.** Specific attention to parenthood and disability remains weak at EU and national level. This is also true regarding the family dimension in statistics and reports on disability. COFACE proposes to give decisive attention to this issue through a **dedicated study on the needs of parents with disabilities** in different areas of life, including on work-life balance, and on how the EU could support them. It is crucial, with a broader scope in mind, to adopt measures aimed at **improving the collection of data on family and disability, overall**, (marital status and parental status of persons with disabilities, data at household level, as well as at the individual level, on earnings, employment, expenditures, access to services and benefits, social activities and loneliness, etc.) at the European and national level.
- Moreover, it is important to **strengthen monitoring systems for the implementation of EU policies that cover** family carers of persons with disabilities and parents with disabilities, to make sure that their needs and the support they receive is continuously assessed. Of particular relevance are the monitoring systems for the Work-Life Balance Directive, the Equality Employment Directive, the Council recommendation on the European Child Guarantee, and the Council recommendation on access to affordable high-quality long-term care. Moreover, any initiative concerning the families of persons with disabilities or parents with disabilities should ensure their participation in policy development and monitoring. Regarding the situation of mothers with disabilities, greater coordination and strengthening of the links between the **Gender Equality Strategy and the Disability Strategy** are needed.

- A second way to improve the family dimension of the new phase of the Strategy is to give **greater attention to the support needs of families with children with disabilities and their family carers**, in a context where there have been watershed developments in this area at the UN level, with the Bellini case or the Care [report](#) of the UN special rapporteur Heba Hagrass, as well as at the EU level with the recent [Bervedi case](#). Although aspects on long-term care are covered by the European Care Strategy, it is important for the new phase of the EU strategy on the rights of persons with disabilities to also focus on this issue and ensure that the rights of parents of children with disabilities are respected, that they have effective access to their rights, and **that the specific needs that pertain primarily to disability do not become peripheral within broader policies related to long-term care, or in other areas**. On the contrary, it is necessary to leverage synergies with these policies. It is also crucial **to assist and support Member States through concrete actions and funding** in developing and assessing appropriate supporting measures for family carers of persons with disabilities, such as respite care, training, psychosocial support, community and in-home support services, which must be tailored to take into account specific dimensions related to age, gender and the family structure.
- **To strengthen the family dimension of the new phase of the EU strategy, it should also be possible to include a flagship** aimed at raising awareness and fostering mutual learning opportunities on **integrated family support approaches at local level** – the family centre models, including peer support models – **that foster the protection and social inclusion of families with disabilities**, as well as practices related to the situation that arises when the primary carer of a person with disabilities is no longer there or able to care for them, and on how to prevent institutionalisation in these circumstances, taking the Italian law on “dopo di noi” as a starting point for reflection.

#### **Under point 4 of the Strategy on Equal Access and non-discrimination.**

➤ **Stronger reasonable accommodation measures in employment and education:**

- The Directive on Equal Employment (2000/78/EC) is one of the cornerstones of EU disability law. It is crucial to ensure that it is properly implemented in all Member States. In particular, the recent decision of the European Court of Justice on the [Bervedi case 38/24](#) has made clear that employers are required, in order to ensure compliance with the principle of equal treatment of workers and the prohibition of indirect discrimination referred to in Article 2(2)(b) of the Directive, **to ensure reasonable accommodation for a parent providing primary care to a child with disability**. It is crucial to ensure that this decision is implemented effectively in all Member States. To ensure the proper implementation of the Directive in this and other areas, the European Strategy should build on the 2020 [implementation](#)

report of the Directive, and present concrete actions for this purpose. Moreover, the Commission should update its guidelines on reasonable accommodation, which are part of the Disability Employment Package, to take into account the recent jurisprudence of the CJEU on reasonable accommodation and clearly inform employers and employees on their rights and obligations.

- Collect and analyse the collection of complaints on reasonable accommodation at work for persons with disabilities received by Equality Bodies and **assess the effectiveness of the rights of workers with disabilities and workers who care for a disabled child.**
- **Explore the potential of social dialogue at national and EU level** in promoting a more targeted approach to inclusive labour markets, building on existing relevant framework agreements, to support the dissemination of information to employers and employees about their rights and obligations in regard to reasonable accommodation, in particular for family carers. The framework agreement of European social partners adopted in 2010 (focusing on inclusive labour markets) must be fully implemented and inclusive of workers with disabilities.
- **Strong actions are needed on inclusive education:** In a context where the proposed directive on the principle of equal treatment is stalled in negotiations, the new strategy should propose independent initiatives to promote non-discrimination in all areas of life, and notably in education, through the setting of **guidance on minimal standards for reasonable accommodation in schools**, withing broader and universally designed approaches, to ensure that students with disabilities can participate fully and equitably in educational programs and are not segregated. This could be done through concrete guidance, the sharing of good practices and whenever possible, through an **ambitious new council recommendation** that would complement recommendations currently covering inclusive education.
- The duty for educational authorities to put in place reasonable accommodation measures to enable accessible learning environments for students with disabilities should be applicable to students of all ages, in formal and non-formal education settings. **European minimum standards could include dimensions related to:** training for education professionals in the use of new accessible technologies, to the availability of accessible materials and tools, to the promotion of inclusive curricula, to accessibility in teaching methods, the assessment processes and the school environment.

➤ **A strong Flagship on Early Childhood Intervention (ECI):**

- It is crucial to strengthen supportive measures for Early Childhood Intervention (ECI) in the new European Disability Strategy, in consideration of the positive impact of ECI and the insufficient attention paid to investments in its services across the EU. **COFACE calls for a Council Recommendation on early intervention** to promote the dissemination of good practices among Member States aimed at ensuring that every child and family with disability receives the support they need at the early stage possible to ensure the better developmental outcome possible, with a strong family centred approach. This would also contribute strengthening the implementation of the European Child Guarantee for children with disabilities.

#### **Under point 8 of the Strategy on awareness, governance and monitoring.**

- **Strong coordination and monitoring with other EU strategies:**
  - **Strengthen its coordination with the European Care Strategy and contribute the design and adoption of a European Care Deal for family carers.** Families providing care for persons with disabilities need targeted social protection and support measures, including financial assistance, access to pension rights, enhanced opportunities for work-life balance, and clear information on available services and rights. These measures are crucial to ensure a real shift towards independent living for all, and for preventing adverse health outcomes, poverty, and social exclusion. This flagship should be backed by adequate funds under the current and future EU budget, namely through **explicit targeting of family carers as a “disadvantaged group” under ESF+** initiatives promoting access to social protection and social services.
  - **Ensure that all future flagships and actions under the Union of Skills are inclusive to persons with disabilities** and have a strong disability dimension.
  - **Closely monitor the impact of the European Child Guarantee on children with disabilities** and, where needed, propose appropriate supportive measures to prevent social exclusion and to facilitate their effective access to early childhood education and care, education, healthcare, housing and healthy nutrition.
  - **Closely monitor the impact of the Reinforced Youth Guarantee on young persons with disabilities and young carers** and, where needed, the new strategy could propose appropriate supportive measures to facilitate transitions to adulthood, and their effective inclusion in the open labour market.
  - **Ensure greater coordination and synergies between gender equality policies** and disability policies, especially recognising the specific challenges of mothers with disabilities.

- **Enhanced implementation and coordination of existing initiatives: Strengthening the implementation and monitoring of the Strategy flagship initiatives** previously undertaken to promote the uptake of high-reaching policies across all Member States through a strong European Disability Platform.