

COFACE DISABILITY POLICY BRIEF

Breaking policy silos to better support children with disabilities and their families

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I. Introduction

For the past years, the European Union (EU) has gone through numerous crises. It is still in the midst of difficulties with the energy prices soaring, the war at its borders and the post-COVID economic crisis. Some call the current situation a permacrisis¹, where various crises are happening simultaneously and have become the new normal circumstance. As always in hard times, children are among the first victims. Breaking the cycle of poverty and social exclusion for children and families is a clear objective of the social agenda of the current European Commission, as highlighted in the European Pillar of Social Rights Action Plan, and several policy frameworks aiming to boost implementation of social rights in the EU. At the same time, there is an increased political attention to the topic of social justice, and the notion of intersecting vulnerabilities is more present in the public debate.

Children with disabilities and their families stand at the intersection of several policy fields. As often, silo thinking in policy making puts these children and their families at risk of falling through the cracks. While considerable efforts are being made by the EU institutions to integrate intersectional thinking, children with disabilities are still not sufficiently covered in child focused policies nor in disability policies. They are (or should be) concerned by all the support policies that aim at reducing and preventing vulnerabilities across the EU policy fields. Families of children with disabilities should be further accompanied to offer their children the best environment possible so they can grow up in their family setting with access to appropriate supports to meet their needs. This support can come as direct help for family members in their role of family carers, but also by ensuring that these families can access sufficient resources, time arrangements and community-based inclusive services to support their (grand-)parenting and caring journey. Last, but not least, children with disabilities have access to a set of universal and inalienable, indivisible, interdependent and interrelated rights under several international human rights conventions that have been ratified by all the Member States of the European Union, as well as several EU frameworks which guarantee rights to children and their families.

In this perspective, the COFACE Disability Platform for the rights of persons with disabilities and their families (COFACE Disability), in collaboration with the COFACE secretariat, created a grid for the analysis of EU social policies to assess whether they address the needs of children with disabilities and their families, as these families are at increased risk of poverty and social exclusion. The analysis grid covers specific support measures for children, intersecting vulnerabilities and the need to provide responses that take a whole-family and intergenerational approach. Taking this grid and the findings of the 2020 *Feasibility Study for a Child Guarantee: Target Group Discussion Paper on Children with Disabilities*² as a starting point for COFACE Disability reflection, the aim of this policy brief is double:

- ➔ first to take stock of how children with disabilities are covered in EU social policies;
- ➔ second to launch a broader reflection on how to deepen the interaction between disability and age in policy making.

In this exercise, COFACE Disability has looked at some recently adopted EU frameworks. This paper does not have the ambition of offering a holistic view of all the EU policies and measures that can have

¹ Fabian Zuleeg, Janis A. Emmanouilidis, Ricardo Borges de Castro, EPC, *Europe in the age of permacrisis*, 2021: <https://www.epc.eu/en/Publications/Europe-in-the-age-of-permacrisis~3c8a0c>

² European Commission, Directorate-General for Employment, Social Affairs and Inclusion, Hunt, P., *Feasibility study for a child guarantee : target group discussion paper on children with disabilities*, Publications Office, 2020, <https://data.europa.eu/doi/10.2767/692437>

an impact on children with disabilities and their families, rather **it aims to lay down the foundations for reflection around the development of more inclusive and intersectional policies**, with a specific focus on policies falling under the European Pillar of Social Rights Action Plan:

- ➔ The European Child Guarantee;
- ➔ The European Strategy on the Rights of the Child;
- ➔ The European Strategy for the Rights of Persons with Disabilities 2021-2030;
- ➔ The European Care Strategy.

The policy brief starts with clarifications in section two, describing the whole-family lens of the 2030 COFACE Child Compass as well as key references to children in international and EU human rights law. Then follows in section three the analysis of the selected EU policy frameworks, giving an overview of measures which specifically include or target children with disabilities. This leads into section four on interrelated well-being of children and their families, highlighting the need to consider children with disabilities within their family and community context to ensure two-generation supports are put in place for positive and sustainable outcomes. The concluding section reflects on the results of the analysis and on the steps needed to address gaps at the intersections of EU social policies.

II. Child rights and well-being: the whole-family approach

COFACE defends a multigeneration vision of children and family wellbeing. This **whole family approach** developed in the Child Compass 2030³ explores 5 different fields for coordinated policy action to improve child and family wellbeing while keeping the best interest of the child at the centre. Hence, following this logic, the reflection in this policy brief opens taking children as the starting point aiming to contextualise the way children with disabilities are included in EU social policies. More specifically, it gives an overview of the specific measures which include children with disabilities in recent EU frameworks. Namely looking at indications that children with disabilities and their families are considered in the above-mentioned policies, whether by:



- Including/ mainstreaming disability inclusive actions in frameworks targeting children;
- inversely if children are mentioned in disability-specific frameworks or;
- putting forward disability-specific actions under general social policy frameworks.

In other words, looking for clear indications that policy makers think about disability inclusion and the interaction between disability and age from the outset of the policy making process, addressing intersecting vulnerabilities of their primary target group. This is as well a way to start picturing how different policies under the European Pillar of Social Rights Action Plan refer and respond to each other and where they can be complementary from the point of view of children with disabilities, a target group standing at the intersection of several frameworks.

First, it is important to remember that children with disabilities (based on their age and/or disability status but also through their families) are covered by several binding instruments in the EU and in EU Members States. Indeed, the EU as a supra national organisation, is governed by several binding

³ COFACE Families Europe, *Child Compass 2030: Shaping a healthy society, environment and economy fit for children*, 2020: <https://coface-eu.org/child-compass-2030-shaping-a-healthy-society-environment-and-economy-fit-for-children/>

treaties. On another level, the EU can sign or support international conventions by supranational entities such as the United Nations (UN) for example. By extension the approach of this brief is to consider that even if the EU is not in itself a signatory to certain international conventions and charter, it is bound to respect them if all the Member States have ratified them, without changing anything on the question of the competences (EU or national).

There are two sets of documents to consider here: the ones drafted and adopted by the EU and the ones of a supra national nature (the focus is put on the United Nations and the Council of Europe in this brief)- but that have value of law in the EU or in **ALL** the EU Member States:

- **Treaty on the European Union:**
 - **Article 3.3:** The Union (..) shall combat **social exclusion and discrimination**, and shall promote social justice and protection, equality between women and men, **solidarity between generations** and protection of the **rights of the child**.
- **The European Charter of Fundamental Rights:**
 - **Article 7** *Respect for private and family life*
 - **Article 9** *Right to marry and right to found a family*
 - **Article 14** *Right to education*
 - **Article 21** *Non-discrimination*
 - **Article 24** *The rights of the child*
 - **Article 26** *Integration of persons with disabilities*
 - **Article 33** *Family and professional life*
- **United Nations Convention on the rights of persons with disabilities (UNCRPD):** all articles but especially:
 - **Article 7** *Children with Disabilities*
 - **Article 23** *Respect for Home and Family Life*
- **United Nation Convention on the Rights of the Child (UNCRC):** all articles but especially:
 - **Article 23** *Children with Disabilities*
- **Council of Europe European Social Charter (Revised)** especially:
 - **Article 4** *The right to a fair remuneration*
 - **Article 7** *The right of children and young persons to protection*
 - **Article 9** *The right to vocational guidance*
 - **Article 13** *The right to social and medical assistance*
 - **Article 15** *The right of persons with disabilities to independence, social integration and participation in the life of the community*
 - **Article 16** *The right of the family to social, legal and economic protection*
 - **Article 17** *The right of children and young persons to social, legal and economic protection*
 - **Article 19** *The right of migrant workers and their families to protection and assistance*
 - **Article 27** *The right of workers with family responsibilities to equal opportunities and equal treatment*
 - **Article 30** *The right to protection against poverty and social exclusion*

When examining EU equality rights-based policies more closely, it is important to take a detour by the terminology that can be used to refer to children with disabilities. For example, the use of the terms “children with special needs” is sometimes understood as covering children with disabilities, but without further specification it is not clear if the legislator really has the intention to develop measures to remove the specific barriers faced by children with disabilities. It is interesting to note that this seems to be understood by policy makers since in the policies analysed in this brief, the notion of “special needs” is no longer commonly used. For example, it was an addition to the explicit mention of children with disabilities in the European Care Strategy.

The same applies to the term “inclusive” which covers much broader realities than just the disability field and is even often used in situations that do not cover disability at all. Hence, if coupled with the term “accessible”, it is safer to assume that children with disabilities are among the target groups of the actions. The other way around, some measures taken for persons with disabilities do not mention children, for instance when looking at social benefits or disability allowances, the child is often not the recipient, but their families or legal guardian are. In those cases, given the specificities of children with disabilities, it cannot automatically be assumed that these measures will apply to them. **Therefore, in this brief, the focus is put on clear and unequivocal mention of age and disabilities.** An age limit or definition in the cases mentioned above are not necessarily needed, however there is a need to acknowledge that children with disabilities can be left behind in general measures meant for children and in the measures meant for persons with disabilities.

It is through this lens that the next section examines the impact of EU frameworks on children with disabilities, and four frameworks in particular which are encompassed under the European Pillar of Social Rights Action Plan as the overarching framework linking up the different EU policy initiatives.

III. Children with disabilities in EU social policy frameworks

Children in the European Strategy for the Rights of Persons with Disabilities 2021-2030

The European Strategy for the Rights of Persons with Disabilities (ESRPD) clearly states its aim to promote an intersectional approach. It acknowledges that children with disabilities deserve specific attention as they may face additional barriers due to their age. For example, when looking at the **right to live independently and be included in the community**. This right is often misunderstood for adults with disabilities but is even more source of confusion when it comes to applying this right to children with disabilities. This is however a misconception that the Strategy addresses, **re-affirming this right is applicable to persons with disabilities regardless of their age and their disability**. It is even more important for children, since children with disabilities are at a heightened risk of family separation and institutionalisation. **Institutionalisation is never in the best interest of a child** and the European Commission is calling on EU Member States to *implement good practices of deinstitutionalisation in the area of mental health and in respect of all persons with disabilities, including children, to strengthen the transition from institutional care to services providing support in the community*.⁴

Another important topic under this framework is **inclusive education and inclusive Early Childhood Education and Care (ECEC)**. The right to inclusive education is far from being achieved in the EU, where segregated school settings are still the norm and children with disabilities are still sometimes denied any access to education. The ESRPD goes beyond compulsory school also referring to other education settings for young people. While the term of “young persons” can cover many definitions, in EU documents, the age range covered is likely the one used by Eurostat, which is 15 to 29 years old. This means that part of this target group is legally speaking, children. Hence, the call for inclusive education settings in the Strategy also covers better **access to mainstream vocational education and training**, as well as highlighting the problem of special schools that do not always offer pathways to higher education or to the labour market. Similarly, references in the ESRPD to the special attention to disabilities under the European Youth Guarantee⁵ could benefit children with disabilities as this covers persons below 30. However, there is no mention of further actions in relation with the European Youth Guarantee in the ESRPD initiatives.

The ESRPD also explicitly targets children in the narrative part of the chapter on **Improving access to art and culture, recreation, leisure, sport, and tourism**, mentioning the need to adopt a twin-track approach of disability mainstreaming and disability-specific actions to fulfil UNCRPD Article 30. Additionally, children with disabilities are singled out to be at heightened risk of becoming **victims of violence**, whether in their home environment, in specific institutions or in other settings, such as bullying at school or in an unadapted health care system. Some children with disabilities are referred to in the ESRPD as facing **increased risks such as children with disabilities on the move or homeless children with disabilities**, showing an attention to intersectional vulnerabilities in this section.

⁴ European Commission, Directorate-General for Employment, Social Affairs and Inclusion, *Union of equality : strategy for the rights of persons with disabilities 2021-2030*, Publications Office, 2021, <https://data.europa.eu/doi/10.2767/31633>

⁵ The reinforced Youth Guarantee is a commitment by all Member States to ensure that all young people under the age of 30 receive a good quality offer of employment continued education apprenticeship traineeship within a period of four months of becoming unemployed or leaving education. More information: <https://ec.europa.eu/social/main.jsp?catId=1079&langId=en>

However, if children with disabilities are mentioned in the narrative parts on culture and violence, it is important to note that no specific actions targeting children are put forward under these headings.

Finally, one of the promises under the ESRPD is to act on data collection, which is highly relevant for making children with disabilities more visibility in EU statistics:

- ➔ *develop a strategy for data collection, steer Member States accordingly and provide an analysis of existing data sources and indicators including administrative data;*
- ➔ *develop, at the latest by 2023, new disability indicators with a clear roadmap for implementation. These should include indicators for children and the situation of persons with disabilities in employment, education, social protection, poverty and social exclusion, living conditions, health, use of new communication technologies, supporting the indicators for the EU Social Scoreboard, the European Semester Sustainable Development Goals;*⁶

The Council of the EU did endorse the ESRPD a few months after its adoption by the European Commission. The necessity of **mainstreaming disability** across the policy board remains in the final text with a clear reference to the **European Child Guarantee** and the **European Strategy for the Rights of the Child**. The rights of persons with disabilities to participate in public and political life is defended in the Strategy, but it is interesting to note that the EPSCO Council Conclusions⁷ specifies in Recital 24 that children with disabilities should also participate in the exchanges of views with the EU and EU Member States. Even though the participation is indirect and through their representative organisations, it is encouraging to see this understanding of the added value of including children with disabilities is raised in the final text.

Disability in the European Strategy for the Rights of the Child

The EU Strategy on the Rights of the Child clearly references the UNCRPD in its introduction, recognising by this that children with disabilities are entitled to their rights under this framework in addition to the ones of the UN Convention on the Rights of the Child (UNCRC).

Chapter two of this Strategy contains the most references to children with disabilities. It focuses on **combatting child poverty and fostering equal opportunities, and children with disabilities** are highlighted as having an equal right to live with their families and in the community. The main action under this heading being the adoption of the **European Child Guarantee** (see next section). However, it is important to note that the European Commission makes an important link to the **European Strategy of the Rights of Persons with Disabilities 2021-2030**, notably in order to advance the independent living agenda. The **equal right for children with disabilities to live with their families and in a community** is mentioned in this child rights framework.

The Strategy mentions the importance of **Early Childhood Intervention and family support** as a way to prevent family separation while restating the need to shift to community and family-based care following a life cycle approach (including transition out of care).

⁶ European Commission, Directorate-General for Employment, Social Affairs and Inclusion, *idem*

⁷ Council of the European Union, *Council Conclusions on the Strategy for the Rights of Persons with Disabilities 2021-2030*, 2021: <https://data.consilium.europa.eu/doc/document/ST-9127-2021-INIT/en/pdf>

The specific needs that children with disabilities can have in terms of **mental and physical health** and the necessity for Member States to address them in an appropriate way is also highlighted in the European Commission text. **Inclusive, non-segregated education** is covered under the Strategy as it highlights the very low rate of enrolment in ECEC services for children with disabilities.

Chapter 4 of the Strategy focuses on child-friendly justice. Children with disabilities are mentioned as one of the groups that experiences barriers in **access to justice**, notably making the point that children with disabilities are *exposed to multiple and intersecting forms of discrimination* and raising the issue of the lack of accessible information on their rights and possible remedies as barrier to exercise their rights.

In the Strategy Chapter 5 on the digital world, the Commission recognises the potential of digital **tools to support children with disabilities in learning, connecting, communicating and participating in activities** online while stressing the need to ensure accessibility of such tools and platforms. Moreover, the Commission invites ICT companies *to ensure that children's rights, including privacy, personal data protection, and access to age-appropriate content, are included in digital products and services by design and by default, including for children with disabilities.*

The 2022 Council Conclusions⁸ endorsing this framework were adopted more than one year after the launch by the European Commission and do include in the Recitals a strong mention of the anti-discrimination that extends to the parents and legal guardians of children with disabilities. **Other than the commitment to fight discrimination on the ground of disabilities, children with disabilities are not mentioned in the Council Conclusions.**

Children with disabilities in the European Child Guarantee

The Council Recommendation establishing a European Child Guarantee was adopted by unanimity by all EU Member States on the 14th of June 2021. One of the key actions under this framework was the agreement that all countries would submit national action plans within 9 months after the adoption of the Recommendation. However, none of the EU Member States respected the official deadline and at the time of finalising this brief, only 15 plans have been published.⁹

Children with disabilities are one of the five target groups pre-identified by the European Commission, based on a thorough feasibility study, *as children living in precarious family situations*. It recognises that these children have a more significant risk of poverty and social exclusion, asking Member States to take those groups into account *when appropriate* in their national actions to implement the Child Guarantee. Clear links are made with the **EU Strategy for the Rights of Persons with Disabilities** in the narrative and with the Article 7 of the UNCRPD (children with disabilities) in the text of the Council Recommendation. There are five areas covered by the Child Guarantee: access to free early childhood education and care; free education (including school-based activities and at least one healthy meal each school day); free healthcare; healthy nutrition, and adequate housing. For each area, EU Member States are invited to look at the relevance of developing measures covering children with disabilities.

⁸ Council of the European Union, *Conclusions on the EU Strategy on the rights of the child*, 2022 <https://data.consilium.europa.eu/doc/document/ST-10024-2022-INIT/en/pdf>

⁹ European Child Guarantee web page, last consulted 22/11/2022: <https://ec.europa.eu/social/main.jsp?catId=1428&langId=en>

Emphasis is put on **inclusive education, including in early childhood education and care**, highlighting that segregation still remains a problem for children with disabilities, including in ECEC, pushing for inclusive teaching and learning methods as key areas to develop.

Children with disabilities in relation to **health care** also benefit from a special mention to provide them with **targeted rehabilitation and habilitation care services**. The inclusion of rehabilitation and habilitation is particularly important as these aspects of care are missing from the **European Care Strategy**¹⁰ (developed in the next section) but is crucial for children and a right under the UNCRPD.

The mention, under the adequate housing chapter, of **support to independent living** in relation with institutional care does not however include specifically the objective of independent living for children with disabilities. However here, it is rather safe to assume that the legislator on the drafting and implementing side had and will think this measure as disability inclusive because of the mention of independent living, which is a right under Article 19 of the UNCRPD. Special dietary needs under **healthy nutrition** are also not especially mentioning children with disabilities while it could be argued that they would benefit from a special mention of the barriers that concern children with certain impairments to get appropriate nutrition from their food for instance. It makes nutrition the only chapter of the proposal for Council Recommendation where children with disabilities are not clearly mentioned.

The Council Recommendation on the Child Guarantee kept the reference to the Article 7 of the UNCRPD as above, as well as inclusion of children with disabilities in the list of *children in precarious family situations*. But it is interesting to notice that the Recommendation further specifies the inclusion of children with disabilities in parts where they were not previously singled out in the European Commission proposal, such as **access to social housing and housing assistance policies**.

Children with disabilities in the spotlight: European Care Strategy

The **European Care Strategy** is the most recent package of social measures launched by the European Commission, in September 2022, consisting of a Commission Communication and two Proposals for Council Recommendations: one on Early Childhood Education and Care (ECEC) and one on Long Term Care (LTC). COFACE Families Europe published a media statement presenting a first overall assessment of the Strategy.¹¹ To date, both Recommendations are still under negotiation in the Council of the EU.

In the Commission Communication, children with disabilities are explicitly mentioned. It also points out the need to **improve data collection** that should be disaggregated by age and disabilities notably, which would automatically cover children with disabilities.

Going into the specific proposals for Council Recommendations, there are also some measures covering children with disabilities, most of them being in the ECEC recommendation.

However, it is important to notice the inclusion of **Article 24 of the Charter of Fundamental Rights** in the LTC recommendation, which concerns the rights of the child. Children with disabilities, although being sometimes beneficiaries of long-term care services across their lifetime, are not particularly

¹⁰European Commission, Directorate-General for Employment, Social Affairs and Inclusion, *European care strategy : for carers and care receivers*, Publications Office of the European Union, 2022, <https://data.europa.eu/doi/10.2767/858795>

¹¹ COFACE Families Europe, *Family Organisations welcome the European Care Strategy and call for swift adoption by EU Social Affairs Ministers*, 2022: <https://coface-eu.org/family-organisations-welcome-the-european-care-strategy-and-call-for-swift-adoption-by-eu-social-affairs-ministers/>

singled out in the LTC recommendation which tends to focus especially on ageing, albeit it is integrating the needs of persons with disabilities and measures for family carers.

The ECEC recommendation, contains a specific heading on children with disabilities in the main text of the proposal, calling for more **inclusivity in ECEC services**. The newly suggested **quality indicator of time intensity** that the ECEC Recommendation puts forward is particularly important for children with disabilities who sometimes can only access ECEC services for a few hours a week (if at all). The text contains a strong call for the EU Member States to fulfil the rights of children with disabilities in an equal way to others with a specific reference to the need for more accessibility, including of accessibility of buildings, infrastructure and transport. The text goes further by taking a broad approach to inclusivity that encompasses **training for ECEC staff and the inclusivity and accessibility of the material used such as digital tools**. It also covers the right to **information in an accessible format**, as lack of awareness of the rights can be one of the reasons for the non-take up effect in measures to boost inclusive ECEC enrolment. The call for inclusivity under this proposal is reinforced by the mention of the **European Strategy on the Rights of Persons with Disabilities** that is also calling, as mentioned above, for more inclusive ECEC services. The proposal also covers **out-of-school inclusive activities**, showing an understanding that care is indeed a continuum and that the transition between family and professional care cannot be restricted to school and formal education.

The two Council Recommendations have not been adopted at the time of the finalisation of this brief, but the implementation of the measures of the Care Strategy at national level have the potential to boost the inclusion of children with disabilities in ECEC services and if addressed properly and further developed by the national level to also cover their needs for long term care and/or support.

IV. Interrelated wellbeing of children with disabilities and their families

The needs of children with disabilities must be considered within their family and community context, so that two-generation supports are put in place to ensure positive and sustainable outcomes.

Families and the right to family life is also covered in several documents that have value of law at the EU level (see list in section 2- covering family). While they do not always mention specifically children with disabilities, the word *families* is considered in this brief as being inclusive of families of children with disabilities. The reason here is that following the COFACE multigeneration approach, the measures targeting children with disabilities seen in section three above will benefit their families, hence this section looks more at the broader family dimension. The UN Convention of the Rights of Persons with Disabilities itself presents a strong family dimension, underlying the interrelation between the well-being of persons with disabilities with their families.^{12 13}

Families of children with disabilities are at increased risk of poverty and social exclusion. They encounter barriers to find appropriate care services and support as the lack of accessible, affordable, quality and community-based services for children with disabilities leaves no choice but to have one family member – in most cases the mother - step out of the labour market or reducing their paid working time to become a family carer. In addition, the expenses related to a family member with disabilities and the insufficient social coverage, is part of the explanation why disability within a family is considered as a vulnerability factor for families.

Additionally, not all children with disabilities have the opportunity to grow up in a family environment. As highlighted in the 2019 European network of academic experts in the field of disability (ANED) synthesis report on *The right to live independently and to be included in the community in European States: In a number of European States, children with disabilities are disproportionately more likely to be placed in institutional care than their non-disabled peers and appear far less likely to benefit from efforts to affect a transition from institutional to family-based care.*¹⁴

With this in mind, COFACE Disability believes that **there cannot be truly efficient policies to address the barriers faced by children with disabilities if they are not systematically accompanied by efforts to tackle the barriers faced by the families of these children and by their carers.** This is the whole family vision that the COFACE Disability Platform defends, advocating for the need to take into account children with disabilities and their family environment in policies and measures in order to fully respect the rights of the child while supporting the family to provide an adequate environment for the child to grow and develop at the fullest of their capacity. This interrelated wellbeing of the child and their family takes a whole new significance when looking at children with disabilities because the families and their members are likely to need extra support, whether it is to cope with the expenses that can be necessary for example for home adaptations or equipment, or time arrangements to have

¹² Gerard Quinn, UN Special Rapporteur on the rights of persons with disabilities, COFACE Families Europe, *OPINION: Disability and the Family, 2020*: <https://coface-eu.org/opinion-disability-and-the-family/> .

¹³ COFACE Disability Platform, *The Family Dimension of the United Nations Convention on the Rights of Persons with Disabilities, 2012*: <https://coface-eu.org/the-family-dimension-of-the-united-nations-convention-on-the-rights-of-persons-with-disabilities/>

¹⁴ Neil Crowther On behalf on the European network of academic experts in the field of disability (ANED), *The right to live independently and to be included in the community in European States ANED synthesis report, 2019*: <https://www.disability-europe.net/downloads/1040-task-year-4-2018-19-policy-theme-il-synthesis-report>

time for childcare and support, the appropriate services to ensure that there is a continuum of care between the family and the professional, peer learning and support to learn about rights for example, and the list goes on. This is why family carers should access a set of rights as defined by the COFACE Disability Platform in the European Charter for Family Carers¹⁵ and under the objective 4 (Families) of the COFACE Disability Platform S.H.I.F.T. Guide.¹⁶

However, the inclusion of considerations for family carers in EU policy documents is a rather new trend (e.g. the minimum standards for carers under the **EU Work-Life Balance Directive**, or the recommendations of the **European Care Strategy** to develop measures in support of family and informal carers), which COFACE Families Europe and the COFACE Disability Platform warmly welcome. Other frameworks sometimes mention families without going into the details of family carers, but they are worth highlighting, nonetheless, since parents of children with disabilities deserve to be considered before all as parents and supported in their parenting journey.

The **European Pillar of Social Rights Action Plan** states the objective of preventing children growing up in poor families from becoming adults at risk of poverty but does not further specify at risk categories or specific targeted actions. Parents and persons with special care responsibilities are clearly mentioned under the **Pillar Principle 9 on Work-life balance** but without further distinction. Data collection on children with disabilities is lacking in the EU and the newly introduced disability focused European targets to monitor the implementation of the Pillar of Social Rights do not include children with disabilities and their families since the focus is on the disability employment gap.

In the **European Strategy for the Rights of Persons with Disabilities**, family care and the extra costs linked to disabilities are listed as extra risk factors for poverty and social exclusion of persons with disabilities and their families.

The need to provide support to families and communities is also highlighted in the **EU Strategy on the Rights of the Child** so that they can ensure children's well-being and development. This is reinforced under the heading 2 on socio-economic inclusion, health and education which is the heading under which the main deliverable is the **European Child Guarantee**, which embraces the multigeneration, family support vision of COFACE Disability.¹⁷

The **European Care Strategy** is an interesting framework to look at from the point of view of children with disabilities and their families. The **Commission Communication on the European Care Strategy** says little on specific measures to support children with disabilities and their families that is not further developed in the two proposals for Council Recommendations. However, it does **highlight the lack of support to families, which combined with the lack of appropriate services and personal assistance, constitutes a violation of the right to independent living and being included in the community.**

The **Proposal for the Council Recommendation on ECEC** notes that half of children with disabilities are cared for only by their parents, without any professional care or support. Family and carers' leaves under the **Work-Life Balance Directive** are also cross-referenced here: the inclusion of carers in EU legislation – and not just as primary carer for a child but also for adults - even if restricted to the

¹⁵ COFACE Disability Platform, *European Charter for Family Carers – updated version*, 2017: <https://coface-eu.org/european-charter-for-family-carers/>

¹⁶ COFACE Disability Platform, *S.H.I.F.T. – A guide to shift towards meaningful inclusion of persons with disabilities and their families*, 2019: <https://coface-eu.org/s-h-i-f-t-a-guide-to-shift-towards-meaningful-inclusion-of-persons-with-disabilities-and-their-families/>

¹⁷ COFACE Families Europe, *European Child Guarantee: Putting children and their families at the centre of the COVID-19 recovery plans*, 2019: <https://coface-eu.org/european-child-guarantee-putting-children-and-their-families-at-the-centre-of-the-covid-19-recovery-plans/>

mention in Article 6 of the Work-Life Balance directive (minimum 5 days) is another step to be welcomed on the recognition of families of children with disabilities in EU frameworks. Lastly, the Proposal mentions the extra barriers faced by women with disabilities and mothers of children with disabilities, highlighting the gender aspects of family care.

In the **Proposal for a Council Recommendation on Long Term Care** the recognition of the right to family life is clearly stated. It is interesting to note that the role of family members with caring responsibilities for a dependent child and adult (the sandwich generation) is highlighted, however there is no specific mention of children with disabilities, except in the definition of informal care where it is obvious that the mention of long-term care needs and children implies that the child is with disabilities and will require care and/or support. The need to recognise and support family carers is included in the text for the Council to negotiate and adopt, and therefore there is still a way to include the specific needs of children with disabilities in regard to long-term care in the implementation phase.

In other words, to get a picture (even if incomplete) of the support and care services that should be provided to children with disabilities and their families in the European Care Strategy, it is necessary to pick and mix the provisions under the two Council Recommendation frameworks to ensure a life cycle whole-family approach that would take the needs and challenges of children with disabilities into account.

IV. Conclusion: Time to fill the gaps

In conclusion, the interrelated wellbeing of children and their families is now a well-accepted concept in EU policies as well as the need for policies to cater for the diverse needs of some families in vulnerable situations. However, this recognition is still weak in terms of policy design, integration, implementation and impact assessment, with a number of gaps to address, as highlighted in this brief.

There is still a long way to go to make sure that an integrated way of designing policies for children with disabilities and their families becomes the norm in policy making and for policies not only to recognise, but to fully embrace intersectional thinking in their making. The need for better coordination, stakeholder participation and an end to silo thinking are more important than ever in regard to the EU ambition to lead on files that that will bring structural transformations such as the Green Deal and the Digital transition, but also as the current economic climate is dragging more and more people into situations of poverty and social exclusion, testing the resilience of families and their capacity to absorb different “shocks”.

There is a need to systematise a two-track approach across the policy board/spectrum, checking that all policies do deliver positive outcomes for every child and their family, through clear two-generation family impact assessments of EU policies and laws. The attention paid to intersecting vulnerabilities in recently adopted EU policies and frameworks is welcome as it raises the visibility of persons and families who are usually left behind in policies. Specific mention of intersecting realities comes to strengthen the understanding of the term “inclusive” by policy makers, as it is important to mention that it hides the different realities that it aims to cover. When looking at children with disabilities, **inclusivity requires an understanding that children need specific policy and service responses to match their unique needs**. By putting the focus on policy responses which cater for individual pathways and needs, it is easier to break the silos and to see the interaction of different elements when ensuring that children with disabilities and their families access the resources, services and time arrangements needed for the achievement of their human rights on an equal basis with others. As noted in this brief, the efforts to move away from the generic term of “children with special needs” in the analysed documents is welcome.

The Feasibility study for a child guarantee: target group discussion paper on children with disabilities¹⁸ is a key document to understand why it is crucial to integrate children with disabilities in policy making. One of the striking points made in this document concerns the **data gap** and it is important to reiterate it in this brief. There are 87 million persons in the EU who have some form of disability.¹⁹ The definition of disability presented under the European Strategy for the Rights of the Persons with Disabilities 2021-2030 (ESRPD)²⁰, is in line with the one of the UNCRPD. It puts forward a broad concept of what constitutes disability, bringing to the definition a dynamic aspect compliant with the social model of disabilities, moving away from the medical model. However, this evolution is not reflected in all EU countries, some of which still used an outdated definition of disability, despite the obligation to move

¹⁸ European Commission, Directorate-General for Employment, Social Affairs and Inclusion, Hunt, P., *Feasibility study for a child guarantee : target group discussion paper on children with disabilities*, Publications Office, 2020, <https://data.europa.eu/doi/10.2767/692437>

¹⁹ European Commission, Directorate-General for Employment, Social Affairs and Inclusion, *Factsheet: Strategy for the Rights of Persons with Disabilities 2021-2030*, 2021: <https://ec.europa.eu/social/BlobServlet?docId=23716&langId=en>

²⁰ European Commission, Directorate-General for Employment, Social Affairs and Inclusion, *idem*

towards a UNCRPD compliant model. In addition to the obvious compliance issue it poses, this lack of adequate and common understanding of the social model has a direct effect on the way data are collected. **The lack of a commonly agreed definition of what constitutes disability impedes a collection of comparative data at the EU level.** This is true for children with disabilities as well, as it was highlighted in the feasibility study on the target group of children with disabilities. In other words, there is no accurate data on how many children with disabilities are living in the EU at the moment, each Member State has their own data collection mechanisms, and often they are not adapted to reflect the situation of children with disabilities, even less the diversity that is in this group. The closest Eurostat data set that exists is *Children's health in the EU* that looks at activity limitation faced by children due to health problems.²¹

Children with disabilities and their families have the right to be visible in EU data sets, in order to inform the policies examined above and to monitor their impact. This right is defended by the UNCRPD Article 31 – Statistics and data collection. Although the respect for privacy is a crucial point to take into account, especially when it comes to children, it should not be used to exclude children with disabilities from informed and evidence-based policy making.

COFACE and its COFACE Disability platform stand ready to support the S.H.I.F.T. towards more disability-inclusive and disability-specific policies and programmes for all ages.

²¹ Eurostat, Children's health in the EU in 2017 More than 95% of children in the EU considered to be in good or very good health Under 5% of children face activity limitations due to health problems, 2019
<https://ec.europa.eu/eurostat/documents/2995521/9550240/3-05022019-BP-EN.pdf/f426eec4-bbff-48f0-8084-88d721fa49ef>

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