

PAVING THE WAY FOR A DISABILITY-INCLUSIVE CHILD GUARANTEE

Assessment of the European Child Guarantee National Action Plans
from the perspective of children with disabilities and their families

JUNE 2023



Paving the way for a disability-inclusive Child Guarantee

Assessment of the European Child Guarantee National Action Plans
from the perspective of children with disabilities and their families

June 2023

“All children with disabilities and their families need access to support services and assistive devices, not only the ones below the poverty line, as the presence of a disability in the family increases the risk of social exclusion.”

For further information, contact Camille Roux, COFACE Senior Policy and Advocacy Officer:
croux@coface-eu.org or Beatrijs Gelders, COFACE Policy and Communication Assistant:
bgelders@coface-eu.org.

Table of Contents

1. Introduction.....	2
2. Children with disabilities as a target group.....	4
3. Access to key services for children with disabilities and their families.....	7
Inclusive education emerges as priority but segregation persists.....	7
Children with disabilities and their families left behind in other key services.....	10
Services for parents and families: The whole-family approach?	12
4. Involvement of children with disabilities and their families	13
5. Conclusion and next steps.....	14
Annex: Children with disabilities and their families in the National Action Plans	16

1. Introduction

More than 18 million children living in the European Union are at risk of poverty or social exclusion. This represents 24.4% or 1 in 4 children in the EU.¹ The **European Pillar of Social Rights Action Plan** puts forward three EU headline targets to be achieved by 2030. One of these targets is to reduce the number of people at risk of poverty or social exclusion by at least 15 million, of which **at least 5 million should be children.**² The European Child Guarantee, established through a Council Recommendation on the 14th of June 2021, is an outcome of Principle 11 of the European Pillar of Social Rights – which provides children’s right to early childhood education and care and to protection against poverty – and complements the Strategy on the Rights of the Child.³

This Council Recommendation calls upon EU Member States to prevent and combat poverty and social exclusion by guaranteeing access to children in need and their families to a set of key services: 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. **Children with disabilities and their families** experience specific barriers when accessing these services and have a more significant risk of poverty and social exclusion.⁴ Children with disabilities are one of the six target groups highlighted within the Child Guarantee.

Although the Child Guarantee is not of a binding nature, there are other normative frameworks that are binding. All the EU Member States, as well as the EU itself, have ratified the **UN Convention on the Rights of Persons with Disabilities (UNCRPD).**⁵ Additionally, all EU Member States have ratified the **UN Convention on the Rights of the Child (UNCRC).**⁶ The Preamble of the Child Guarantee refers to both Conventions.

Article 11(c) of the Council Recommendation establishing a European Child Guarantee asks the EU Member States to submit National Action Plans (NAPs) on how they will implement the Child Guarantee. These should include, if appropriate when considering the national circumstances, targeted measures for children with disabilities. The NAPs were expected to be submitted by the **15th of March 2022.** However, there were many delays in NAP submissions and at the time of

¹ Eurostat, 2021, https://ec.europa.eu/eurostat/statistics-explained/index.php?title=Children_at_risk_of_poverty_or_social_exclusion.

² European Commission, [The European Pillar of Social Rights Action Plan](#), 2021, p.11-12.

³ Council of the European Union, [Council Recommendation \(EU\) 2021/1004 of 14 June 2021 establishing a European Child Guarantee](#); European Commission, [The European Pillar of Social Rights](#), 2017.

⁴ European Disability Forum, [“Increasing cost of living: Persons with disabilities hit harder”](#), 2022; European Disability Forum, [“EDF Resolution - Prioritising persons with disabilities in the action against inflation and energy costs”](#), 2022; European Commission, [“Feasibility study for a child guarantee - Target group discussion paper on children with disabilities”](#), 2020, p.15-16.

⁵ UN General Assembly, [Convention on the Rights of Persons with Disabilities](#), 24 January 2007, A/RES/61/106; Committee on the Rights of Persons with Disabilities, [General comment No. 4](#) on the right to inclusive education, 25 November 2016, CRPD/C/GC/4.

⁶ UN General Assembly, [Convention on the Rights of the Child](#), 20 November 1989, United Nations, Treaty Series, vol. 1577, p. 3.

finalising this assessment, there are still **five NAPs missing**, namely from the following countries: **Austria, Germany, Latvia, Lithuania, and Romania**.⁷

COFACE advocates for a **two-generation approach** in policy and practice, which is based on the interrelated well-being of children and their caregivers, that was put forward in the Child Guarantee and is highlighted in the COFACE Child Compass 2030.⁸ This approach is used to combat child poverty and social exclusion by adopting strong family support policies. COFACE brings this vision to the EU institutions and to key partners like the EU Alliance for Investing in Children, which promotes child-centred, quality and comprehensive policies to tackle child poverty and promotes the well-being of children and their families, by providing expert support in the development of EU and national policies, legislation and funding programmes.⁹ During the Porto Social Forum 2023, the EU Alliance for Investing in Children called on the EU and its Member States to prioritise the adoption of **tangible measures** to eradicate child poverty.¹⁰ Additionally, to support the development and implementation of the Child Guarantee, COFACE and the Association of German Family Organisations (AGF), COFACE member organisation, have jointly organised two expert meetings in Berlin bringing together civil society organisations and family policy-makers.¹¹

Two years after the Council’s unanimous adoption of the Recommendation on the 14th of June 2021, COFACE Families Europe assessed the NAPs (submitted by the 1st of April 2023) from a disability perspective and using a two-generation lens.¹² This includes consideration of the following dimensions: inclusive education and school-based activities, inclusive (digital) educational tools, accessibility of key services, intersections with other policy fields or discrimination forms, involvement of children with disabilities and civil society organisations, and measures to support families of children with disabilities. This assessment starts with an overview of definitions and how children with disabilities are included in the NAPs (section 2). Then it looks more specifically at access to services for children with disabilities and their families (section 3) and the involvement of children with disabilities and their families, as well as their representative organisations in the NAPs process (section 4). Finally, the concluding section provides key messages and priorities for the inclusion of children with disabilities and their families (section 5). The annex highlights key aspects which are essential for making the Child Guarantee disability-inclusive.

⁷ During the drafting process of this assessment, the Slovenian, Slovakian and Hungarian National Action Plans were published. However, only plans published before the 1st of April 2023 have been assessed in this report. *European Commission’s website with the available NAPs*: <https://ec.europa.eu/social/main.jsp?catId=1428&langId=en>.

⁸ COFACE Families Europe, “[Child Compass 2030 - For a Europe which invests in shaping a healthy society, environment and economy fit for children](#)”, 2020.

⁹ EU Alliance for Investing in Children, “[Joint Statement on the belated submission of the Child Guarantee National Action Plans](#)”, 2022; *More information about the Alliance for Investing in Children*: <https://www.alliance4investinginchildren.eu/>.

¹⁰ EU Alliance for Investing in Children, “[Joint Statement: No child should experience poverty and social exclusion in a Social Europe](#)”.

¹¹ COFACE Families Europe, [Berlin Meeting 2022](#): “Stepping up implementation of the EU Child Guarantee – National action plans in the spotlight”; COFACE Families Europe, [Berlin Meeting 2020](#): “The Child Guarantee – A tool to tackle family poverty?”.

¹² See: COFACE Families Europe, “[Child Compass 2030 - For a Europe which invests in shaping a healthy society, environment and economy fit for children](#)”, 2020; COFACE Families Europe, “[S.H.I.F.T. – A guide to shift towards meaningful inclusion of persons with disabilities and their families](#)”, 2019.

2. Children with disabilities as a target group

The recommendations laid down in the Child Guarantee apply to children in need, who are described as *“persons under the age of 18 years who are at risk of poverty or social exclusion”* (**Articles 1 and 3(a)**). Children with disabilities are included in **Article 5(b)** of the Recommendation as one of the six target groups of children in need who experience specific disadvantages. However, it is not always easy to define who falls under this target group. According to the **Strategy for the Rights of Persons with Disabilities 2021-2030**¹³ and the **UN Convention on the Rights of Persons with Disabilities (UNCPRD)**, the definition of disability is rather broad and is based on the social model. This model acknowledges that disability is created by the interaction with barriers in society, not because of an impairment. Nevertheless, many Member States still use an outdated definition of disability reflecting the medical and/or charity models of disability.¹⁴

The lack of a uniform definition in the EU also brings difficulties in **collecting data on children with disabilities**. Nevertheless, children with disabilities and their families must be visible in the statistics so that policies can be drafted in an informed manner. **Article 11(c)** of the Child Guarantee recommends that the NAPs include a national framework for data collection, monitoring, and evaluation of the Recommendation. Furthermore, Member States have an obligation under the UNCPRD Article 31 *“to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention.”*

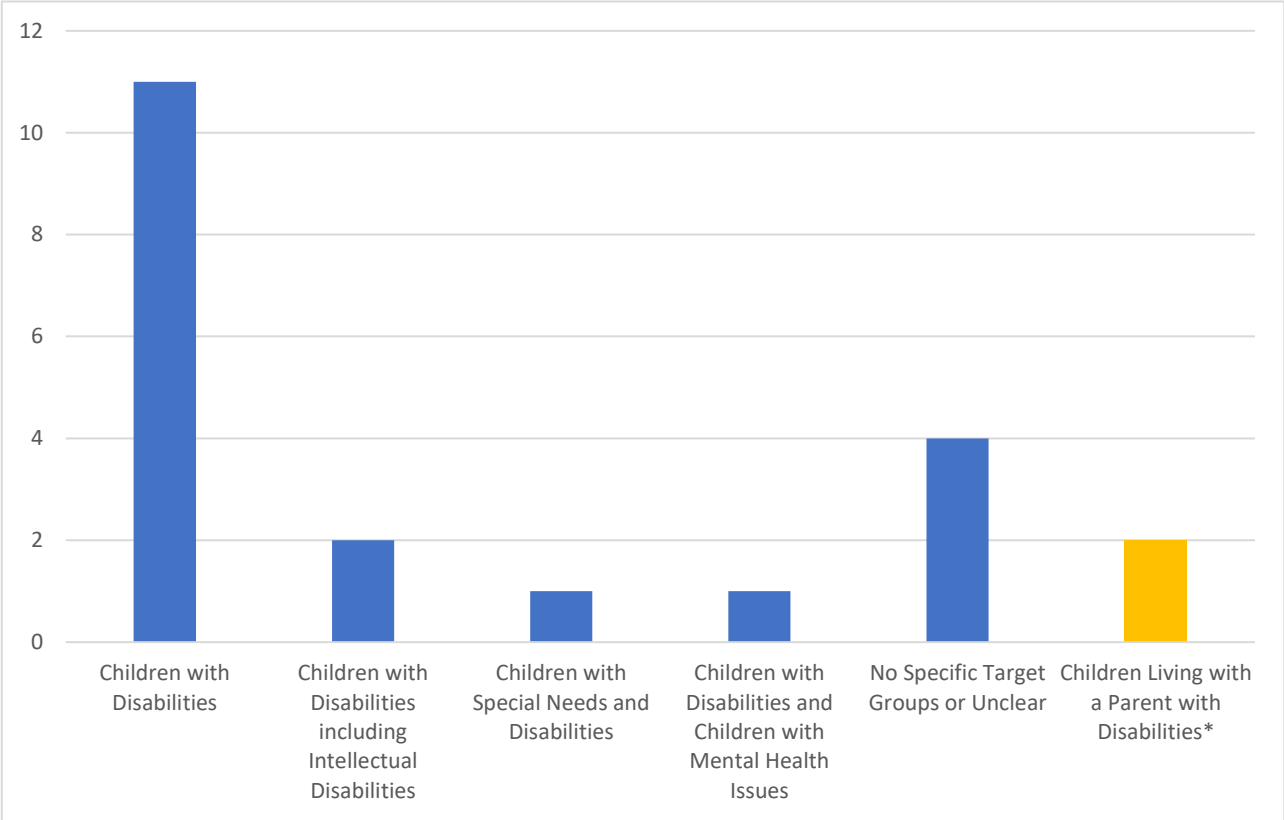
Some NAPs admit the lack of definition and/or data collection. The **Danish** NAP, for example, says that there is no clear definition of who children and young people with disabilities in Denmark are and that there is no central register of persons with disabilities. **Sweden** states that statistics are largely missing on children with a disability. Specifically regarding education, the Swedish NAP mentions that disability data are not collected in school statistics, which makes it impossible to assess how well the Swedish school system functions for pupils with disabilities. Also, the **Belgian** NAP underlines that there is currently very little information available on specific groups of vulnerable children in the federated entities. However, Belgium mentions in its NAP a proposal *“to set up a process, with a view to the next biennial update of the Child Guarantee Plan, to invest in the inventory of available administrative data, its analysis and the development of proposals and initiatives to arrive at harmonised data for Belgium.”* Several other Member States include in their NAPs to improve accurate data collection and use of relevant data. When collecting these data, factors like disability, age, ethnicity, and gender must be considered. The **Spanish** NAP gives an example of this: *“Data will be disaggregated by sex and, where appropriate, by age group. As far as possible, a territorial disaggregation will be made, by population and vulnerability profile, so as to*

¹³ *“This Strategy takes account of the diversity of disability, resulting from the interaction between long-term physical, mental, intellectual or sensory impairments, which are often invisible, with barriers in the environment.”* European Commission, [European Disability Strategy 2021-2030](#).

¹⁴ European Commission, [“Feasibility Study for a Child Guarantee – Final Report”](#), 2020, p.25.

obtain data segmented by origin and ethnic profile, among others.” However, it does not explicitly specify whether under ‘vulnerability profile’ also ‘disability’ will be taken into account.

Figure: Target groups covering disability-related vulnerabilities in the Child Guarantee NAPs



*As an additional target group separate from the children with disabilities target group.

Source: National Action Plans, own calculations.

Most NAPs provide an overview of the situation of children in their country and identify the groups of children in need. The figure above gives an overview of the number of NAPs which mention target groups covering disability-related vulnerabilities. However, four NAPs mention explicitly that they do not adopt measures for specific target groups, or the NAPs are unclear about which target group(s) they focus on. The **Belgian** NAP states that *“In general, the federal government and federated entities have chosen not to take specific measures for particularly vulnerable groups of children. In general, measures are taken for all children in poverty, because the needs are great and apply to all.”* But it says further: *“We see that some measures by the federated entities are nonetheless targeted at particularly vulnerable groups, such as children with disabilities, Roma children or migrant children, etc.”* This is, for example, the case for inclusive education measures and healthy nutrition (see section 3). The **Netherlands** does not list specific target groups, but it refers to certain target groups when explaining the Dutch situation regarding the key services mentioned in the recommendation. **Malta** places specific attention on ‘children living in precarious family situations’, without further dividing this group. However, it refers to certain groups when listing the different actions. Lastly, the **French** NAP does not specifically include any target groups.

In fifteen NAPs, children with disabilities are considered a target group. **Denmark** and the **Czech Republic** specifically mention that this includes intellectual disabilities, and the **Czech Republic** also adds seriously ill children and children in palliative care to this group. The **Bulgarian** NAP combines children with disabilities and children with mental health issues in one target group. Several other NAPs include children with mental health issues as a separate target group. Furthermore, **Estonia** refers to the target group as 'children with special needs and disabilities'. More NAPs mention children with special needs or special educational needs when further explaining their planned or already taken measures considering the Child Guarantee. However, these terms are rather vague, and it is unclear how many children within this group have a disability.

It is important that all children with disabilities are included, not only those below the poverty line, and that NAPs adopt an intersectional approach. Gender, sexual orientation, migration and/or ethnic background intersecting with a disability can result in multiple, intersecting, and aggravated forms of discrimination. An example of intersectional thinking can be found in the **Greek** NAP which foresees an action on the prevention and combating of gender-based violence and abuse of women and girls with disabilities. Another example is the **Polish** NAP which includes specific measures for Ukrainian citizens with disabilities. Additionally, children with disabilities of all ages should be covered, also after compulsory education, up until the age of 18. Examples thereof can be found in the **Greek** and **Polish** NAPs which include measures to support adolescents with disabilities accessing the labour market.

Having a disability can also be seen from the perspective of a parent. **Article 3(c)** of the Child Guarantee refers to **children living with a parent with disabilities** under the recommended target group 'children in precarious family situations'. They are considered a separate target group in the NAP of the **Czech Republic** and **Greece**, and they are mentioned in the **Swedish** NAP and included in some NAPs for monitoring purposes (for example the **Polish** and **Belgian** NAP). Children living with a parent with disabilities often face the risk of social exclusion. It should be noted that when a parent has a disability, this does not mean that the parent is not able to raise their child. Having a disability cannot be used as a ground for the termination of parental rights or family separation. Parents, whether they have a disability or not, have the right to family life and to care for their children (UNCRC Article 23).

3. Access to key services for children with disabilities and their families

Children with disabilities and their families are more at risk of poverty and social exclusion due to various factors and disability-related expenses that are not sufficiently covered by the social protection system.¹⁵ Many NAPs give an overview of the various barriers faced by children with disabilities and their families. While most of the NAPs identify children with disabilities as a target group and acknowledge that they face multiple barriers to accessing key services, it is needed that Member States take measures to remove these barriers. It is not always clear from the NAP whether the actions mentioned are new initiatives or already existing measures.¹⁶ Furthermore, **it should be noted that most NAPs do not differentiate measures separately by target group but by key service.** This section will dive deeper into the measures taken for children with disabilities and their families regarding the key services listed in the Child Guarantee.

Inclusive education emerges as priority but segregation persists

Inclusive systems provide a better quality of education for all children and are instrumental in changing discriminatory attitudes.¹⁷ Schools are a place where children develop social relationships and interactions outside their families. When diverse groups of students learn and socialise together in the same school environment, respect and understanding grow. Many children with disabilities in the EU have no access to education and if they do, they are in many cases still segregated from their peers in special schools or special classes.

Article 7 of the Child Guarantee lists several recommendations to guarantee effective and free access to high-quality early childhood education and care, education and school-based activities and a healthy meal each school day for children in need. Some recommendations relate specifically to children with disabilities. Member States are recommended to *“adapt facilities and educational materials of early childhood education and care and of educational establishments and provide the most appropriate response to the specific needs of children with special educational needs and of children with disabilities, using inclusive teaching and learning methods; for this purpose ensure that qualified teachers and other professionals are available, such as psychologists, speech therapists, rehabilitators, social workers or teaching assistants”* (d). Moreover, it recommends putting in place measures to support inclusive education and avoid segregated classes (e) and to ensure equal and inclusive access to school-based activities (j). According to UNCRPD Article 24 – and its General

¹⁵ European Disability Forum, [“Increasing cost of living: Persons with disabilities hit harder”](#), 2022; European Disability Forum, [“EDF Resolution - Prioritising persons with disabilities in the action against inflation and energy costs”](#), 2022; European Commission, [“Feasibility study for a child guarantee - Target group discussion paper on children with disabilities”](#), 2020, p.15-16.

¹⁶ See also: Association of German Family Organisations (AGF), [“European Child Guarantee: Overview of selected aspects of the National Action Plans”](#), 2022.

¹⁷ COFACE Families Europe, [“Recommendations on inclusive education”](#), 2020.

Comment No.4 – State Parties recognise the right of persons with disabilities to education and shall ensure effective access to an inclusive education system at all levels. Additionally, the right to education for all children is recognised in UNCRC Article 28.

The COFACE Disability Platform published in 2020 recommendations on inclusive education¹⁸ which served as a basis for organising a European expert meeting on inclusive education in Monza (Italy), where it was highlighted that even though there are improvements towards more inclusive education systems, much progress is still needed in this area.¹⁹ On a positive note, many of the NAPs bring forward the will to improve inclusive education for children with disabilities. **Greece** acknowledges that important initiatives have been taken in recent years to promote the principles of inclusive education, but that there are still discrepancies between educational policy and pedagogical practice, due to factors such as the rapid increase in the enrolment of students with disabilities in mainstream school classes or lack of initial training for teachers in inclusive education. The NAP contains several actions to improve inclusive education for children with disabilities. Another example is the **Spanish** NAP which refers to a newly approved law on education which includes the obligation to establish a plan to guarantee an inclusive education for all students with special needs within ten years.

Inclusive education is not only about access to education but also the quality of education. Teachers need to have the right training, teaching assistants and education support personnel must be a fully recognised profession, and learning materials need to be accessible for every child.²⁰ Only then, will children with disabilities be able to fully participate in the learning process and to have successful results. Some countries, for example **Malta** and **Poland**, promote accessible educational tools in their plans, such as books and other materials in accessible formats, and digital educational tools. This is a good way forward; however, these actions are not found in all the plans.

Inclusive education also means inclusive school-based activities, such as school trips and sports, leisure, and cultural activities. One of the actions of the **Croatian** NAP is to encourage the involvement of children with disabilities in pupil-representative bodies, extracurricular activities, and other activities in the school environment. Additionally, children with disabilities should be included in measures regarding healthy school meals. Some children have a disability which restricts their diet, school cafeterias might be inaccessible for children with mobility impairments, and some children require assistance in feeding – these are only a few of the barriers children with disabilities might face. An already existing service in the German-speaking Community of **Belgium** organises school meals taking into account the nutritional needs of children with disabilities.

However, there are still some countries which are promoting **segregated education settings**. The **Dutch** NAP, for instance, promotes both mainstream and special schools for children with disabilities. It states that *“learners who are not able to attend a mainstream school may be referred to a school*

¹⁸ COFACE Families Europe, [“Recommendations on inclusive education”](#), 2020.

¹⁹ COFACE Families Europe, [Monza Meeting 2023](#): “Inclusive Education for an Inclusive Europe”.

²⁰ UNESCO, [“The use of teacher assistants and education support personnel in inclusive education”](#), 2020.

for special education". There are also other plans that still refer to special schools. Special schools are still part of the **Swedish** legislation, and the **Danish** NAP mentions that *"for pupils needing more than nine hours of support per week, special education may be provided either in the form of support in mainstream classes, in special classes, in special schools or in internal schools."* Furthermore, the **Irish** NAP provides that *"the policy is that students with special educational needs should be included **where possible and appropriate** in mainstream placements with additional supports provided."* All children with disabilities have the right to be included in the mainstream educational system and this right is binding in all EU Member States. Special schools further discriminate and isolate children with disabilities. Inclusive education means that all children are in the same schools and in the same classrooms (UNCRPD Article 24).

Education is not only a tool for future inclusion in the labour market, but also a powerful way to develop key soft and hard skills and competences for all areas of life. It can also empower children to develop safe and healthy habits such as self-care, active lifestyles and positive sexuality that can serve them for their lifetime. The latter is especially important as the sexual and reproductive health rights of persons with disabilities, mostly women, are not being upheld in most EU countries. As noted above, there remains a stigma for persons with disabilities who would like to become a parent. Forced sterilisation of persons with disabilities is still a reality in some EU countries.²¹ People with disabilities should have voluntary access to information about sexual and reproductive rights to enable them to make free and informed decisions about their health. The **Italian** plan includes a measure to promote affectivity, sexuality, and gender equality education and refers explicitly to children and young people with disabilities: *"Training and information on the **right to emotion management and sex education of children and young people with disabilities** will also be promoted in order to create awareness and the skills to provide adequate answers."*

It is important that children with disabilities can attend mainstream services starting from an early age. **Early Childhood Education and Care (ECEC)** needs to be accessible for children with disabilities and as within the general education system, ECEC staff needs to be properly trained to support children with disabilities.²² As an example, **Ireland** introduces the 'Access and Inclusion Model (AIM)' which enables the full inclusion and meaningful participation of children with disabilities in ECEC programmes. The **Czech** NAP includes an action to educate caregivers in children's groups and workers in kindergartens, family, and community centres in the field of support for children with special educational needs. Another example is **Croatia** which plans on hiring extra staff within ECEC to provide support to children with disabilities.

²¹ European Disability Forum, "[Forced sterilisation of persons with disabilities in the European Union](#)", 2022.

²² See also: COFACE Families Europe, "[Thematic Note – High-quality Early Childhood Education and Care: Low children-to-staff-ratio as a primary driver for children's well-being and families' engagement](#)", 2023.

Children with disabilities and their families left behind in other key services

The focus of the different NAPs when taking measures to make key services accessible for children with disabilities and their families is mainly on inclusive education only, with little mention of access to healthcare, healthy nutrition, and housing for children with disabilities. An explanation for this can be that the feasibility study for the European Child Guarantee put forward inclusive education as the main priority regarding the target group of children with disabilities.²³ This was, for example, the case for **Belgium**.²⁴ Moreover, when it comes to children's rights, the right to education is usually a focus of public policies, and this is also the case for children with disabilities.²⁵ Nevertheless, to lift children with disabilities and their families out of poverty and social exclusion, inclusive education alone is not enough and every mainstream service should be accessible to everyone.

Children with disabilities in relation to **healthcare** benefit from a special mention in **Article 8(b)** of the Child Guarantee to provide them with targeted rehabilitation and habilitation services. This is also restated as an obligation for Member States under UNCRPD Article 26. Healthcare policies should both be disability-inclusive and disability-specific. It means that these services should be accessible to everyone and inclusive of children with disabilities in the way they communicate and have staff trained on disabilities. Moreover, children with disabilities and their families should be supported in meeting disability-related expenses in healthcare, and some children with disabilities additionally need healthcare services responding to their disability-specific health needs. Several NAPs provide actions to improve healthcare services for children with disabilities. The **Bulgarian** NAP, for example, incorporates a measure to improve access to quality, effective and integrated health, and social services, with a focus on children with disabilities and chronic diseases, and to further improve the qualifications of specialists providing health and social services.

Some NAPs include measures improving the early detection of disabilities, which is a first step for early intervention. COFACE promotes family-centred **Early Childhood Intervention (ECI)** which is a field of services to support young children and their families by identifying, preventing, overcoming, or minimising at-risk situations.²⁶ **Estonia**, without naming it, puts forward some principles of family-centred ECI as part of the reform of its support system for children with special needs. This includes creating opportunities to identify the child's need for help as early as possible and the development of a clear and simple support system for the parent of a child with special needs. **Greece** introduced the 'Reform of the early childhood intervention framework (ECI) for children with disabilities', for which technical assistance of DG REFORM of the European Commission is provided and funded through the Technical Support Instrument *"to assess the impact of the new early intervention model*

²³ The feasibility study was prepared at the request of the European Commission and in which the feasibility, efficiency and overall benefits of a child guarantee recommendation were examined. European Commission, "[Feasibility Study for a Child Guarantee – Final Report](#)", 2020.

²⁴ Child Rights Coalition Flanders, "[Van gunst naar garantie: meer ambitie voor het Belgische Actieplan EU-Kindgarantie](#)", 2023, p.5.

²⁵ COFACE Families Europe, "[Breaking policy silos to better support children with disabilities and their families](#)", 2022.

²⁶ EASPD, "[Position Paper – Family-centred Early Childhood Intervention: The best start in life](#)", 2022, p.4.

in Greece, analyse current legal frameworks on the support of young children with disabilities, analyse the needs of early intervention service providers, elaborate an Action Plan for implementation of high-quality early intervention services, develop a customized plan for the support of children and families, training of the providers' staff etc..” Moreover, **Greece** promotes **person-centred services** through the recent introduction of the Personal Assistant for persons with disabilities above the age of 16 and the implementation of the pilot programme ‘Personal Assistant for Persons with Disabilities’.

Article 9(b) of the Child Guarantee speaks about ‘specific dietary needs’ under **healthy nutrition**, but children with disabilities specifically are mentioned neither in the Child Guarantee Recommendation nor in any of the available NAPs regarding nutrition. However, it could be argued that they would benefit from a special mention since children with certain impairments face barriers to getting, for instance, appropriate nutrition from their food. As noted above, children with disabilities have been considered regarding healthy meals at school in the **Belgian** plan. However, there are still many children with disabilities who do not have the possibility to attend school and healthy nutrition is also important outside school hours.

Children with disabilities are at heightened risk of institutionalisation and family separation. The mention under **adequate housing** of support to independent living in **Article 10(d)** of the Child Guarantee, although in relation to institutional care, does not specify independent living for children with disabilities. Nevertheless, **Article 10(b)** recommends Member States assess and revise housing policies which include further improving accessibility for children with disabilities. Additionally, UNCRPD Article 19 recognises the right of persons with disabilities to live independently and be included in the community, and UNCRPD Article 28 recognises the right of persons with disabilities to an adequate standard of living for themselves and their families, and the right to social protection. There is nowadays a lack of accessible housing for persons with disabilities and adaptations can be costly.²⁷ In general, the situation of children with disabilities and their families is rarely taken into account in housing policies. Nevertheless, there are some exceptions, the **Maltese** NAP, for example, provides “*prioritisation of families with children with disabilities on the waiting list for social accommodation.*” Furthermore, it mentions that “*several housing units which are designed specifically for individuals who suffer from a disability are being built and shall be allocated accordingly.*” Moreover, the **Danish** NAP includes a housing measure safeguarding adequate housing conditions for children with disabilities. The Danish Social Services Act includes several social measures “*which are initially provided to foster opportunities for children and young people with disabilities to continue living with their biological family on an equal footing with other children and young people of the same age who have no impairments.*”

²⁷ OECD, “[A crisis on the horizon: Ensuring affordable, accessible housing for people with disabilities](#)”, 2021.

Services for parents and families: The whole-family approach?

Developing effective measures for children with disabilities requires a two-generation approach. This means that support needs to be provided both to children and their families or kinship carers. Families of children with disabilities are at increased risk of poverty and social exclusion and encounter barriers to finding appropriate care services and support. In many cases, one family member – mostly the mother – has no choice but to step out of the job market or reduce their paid work to become a family carer.²⁸ COFACE believes that family carers should access a set of rights as defined by the COFACE Disability Platform in the European Charter for Family Carers²⁹ and under the objective 4 of the S.H.I.F.T. guide³⁰: Families.

Policies tackling the barriers for children with disabilities will only be efficient when they are accompanied by actions to address the barriers faced by their families and carers. The EU is taking measures to address this and spur reforms in Member States, but the inclusion of 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 carers). However, such measures for family carers are rarely found in the NAPs. to implement the Child Guarantee.

There is a need for access to resources, services, and time arrangements for families of children with disabilities.³¹ In the different NAPs there are some general measures to support parents and families in vulnerable situations, while some NAPs include support services specifically for families of children with disabilities. **Italy**, for example, refers to an action undertaken as part of the pilot phase of the Child Guarantee: peer support for families developed in Family Centres, with a focus on families with children with disabilities. The plan mentions that *“the project aims at enhancing the role of the family and the parental competences of care and nursing, especially through peer support schemes, in which families support, inform and guide each other in dedicated spaces and times.”*

The **Dutch** NAP includes an already undertaken measure aiming to support family members and other informal carers. Through the national ‘*Volwaardig Leven*’ (‘Living the Full Life’) programme, the government invests in person-centred care, accessible care and support for family and other informal carers in organising care for their partner, child or relative. **Denmark’s** Social Services Act covers *“the necessary additional costs incurred by parents of children or young people at home as a result of their child’s significant and permanent physical or mental impairment or severe chronic or long-term illness. Compensation for loss of earnings may also be granted to them for dependent children or young people under the age of 18 at home as a result of a significant and permanent physical or mental impairment or severe chronic or long-term illness, for the loss in income they experience in*

²⁸ COFACE Families Europe, [“Who Cares? Study on the challenges and needs of family carers in Europe”](#), 2017, p.7.

²⁹ COFACE Families Europe, [European Charter for Family Carers](#), 2017.

³⁰ COFACE Families Europe, [“S.H.I.F.T. – A guide to shift towards meaningful inclusion of persons with disabilities and their families”](#), 2019.

³¹ COFACE Families Europe, [“Families on the Edge”](#), 2017.

training or caring for the child or young person.” Additionally, there are some plans, for example, **Greece and Ireland**, that cover financial support for families of children with disabilities.

4. Involvement of children with disabilities and their families

For the development of their NAP, countries should involve children with disabilities and their families as well as representative organisations. Several COFACE members have taken part in the NAP consultation process at the national level, on the contrary, some others raised concerns about the lack of consultations. The right of the child to be heard is protected by UNCRC Article 12, and for children with disabilities it is restated by UNCRPD Article 7.3 which provides that disability and age-appropriate assistance shall be provided to the child.

Many NAPs mention the participation of civil society organisations and children, but mostly without specifying whether organisations working with children with disabilities and their families or children with disabilities and their families themselves participated. Some NAPs, for example **Spain, Portugal, and Ireland**, give an overview of the different stakeholders-organisations involved. Furthermore, the **Italian** NAP mentions the involvement of a Youth Advisory Board (ages 14-21), where young people with disabilities were included. However, it is unclear whether within this group of ‘young people’ also ‘children with disabilities’ (under 18) were included. Additionally, for the preparation of the **Greek** NAP focus groups were organised with children (ages 12-17 years) from vulnerable groups, including children with disabilities. Nevertheless, **children of all ages, also under 12 years, should be able to participate.**

In general, it is unclear whether children with disabilities and their families have been involved in the preparation process or not. It would be essential that as a minimum their representative organisations (civil society organisations advocating professionally and daily for them) are involved in the preparation of the NAP. Moreover, involvement should also happen during the implementation and monitoring of the NAP. Some NAPs include measures to improve child participation. The **French** NAP, for example, calls for a protocol for the participation of the ‘children’s college’ when preparing new measures, monitoring the plan’s measures, and evaluating. It is furthermore important that child participation happens in a meaningful way and includes all children, thus also children with disabilities.

To participate in the process, children with disabilities need to be informed and be able to understand what the Child Guarantee is. The Child Guarantee recommends in **Article 11(d)** that the Member States “*develop effective outreach measures towards children in need and their families.*” The Member States need to reach the different target groups mentioned in their plans. Some countries, for example, **Ireland**, have an outreach and awareness-raising strategy to communicate about the Child Guarantee. Among other things, the Department of Social Protection hosts a Disability Consultative Forum and conducts regular meetings with representatives of community and

voluntary sectors. **Spain** includes several dissemination and awareness-raising actions to inform the population about the Child Guarantee, such as developing a web page and organising conferences. It further mentions that the actions and materials to be developed will be child- and adolescent-friendly ensuring the possibility for children participating in the consultation to follow up on the result of their participation. However, these actions and materials also need to be disability-friendly for children with disabilities to be able to participate.

5. Conclusion and next steps

While many of the National Action Plans include children with disabilities as a target group, specific measures addressing the barriers they face are still too often left out. Additionally, there is often a lack of data which makes it difficult to formulate holistic policies to address the barriers that children with disabilities and their families face. Nevertheless, the Child Guarantee and NAPs are living documents and cover the period up until 2030, which means amendments and reviews are still possible. When drafting policies, it is furthermore important to keep in mind that **there are a variety of disabilities and that having a disability can intersect with other vulnerabilities.**

Education is the main key service targeting children with disabilities for which the NAPs formulate measures, which is a positive development. However, not all these measures take the direction of inclusive education in line with the UNCRPD, and some plans still highlight segregating education measures. Children with disabilities need to be included in mainstream schools and classes, need to have access to facilities and educational materials, but also need to have access to school-based activities and non-formal and sexuality education.

Children with disabilities are entitled to the same rights that everyone else is entitled to. **Disability should not only be mainstreamed in education, but every mainstream service should be accessible from the beginning of the life of a person with disabilities.** Additionally, these key services should respond to the specific needs of children with disabilities and their families. Healthcare, nutrition, and housing are important in everyone's life and play an even more important role in the life of people with disabilities, yet not enough actions are highlighted in these areas concerning children with disabilities. Furthermore, fostering social policy frameworks and measures to support the families of children with disabilities are strong in some NAPs, but completely lacking in other NAPs. Additionally, children identified in the different target groups, including children with disabilities and their families, need to be aware of their rights to key services. Having accessible information is an important element of the effectiveness of the Child Guarantee – children with disabilities, their families and representative organisations need to be involved in the full process from design to implementation.

COFACE Families Europe and the COFACE Disability Platform are pushing for the further implementation of the Child Guarantee and Action Plans, and **expect that the European Commission**

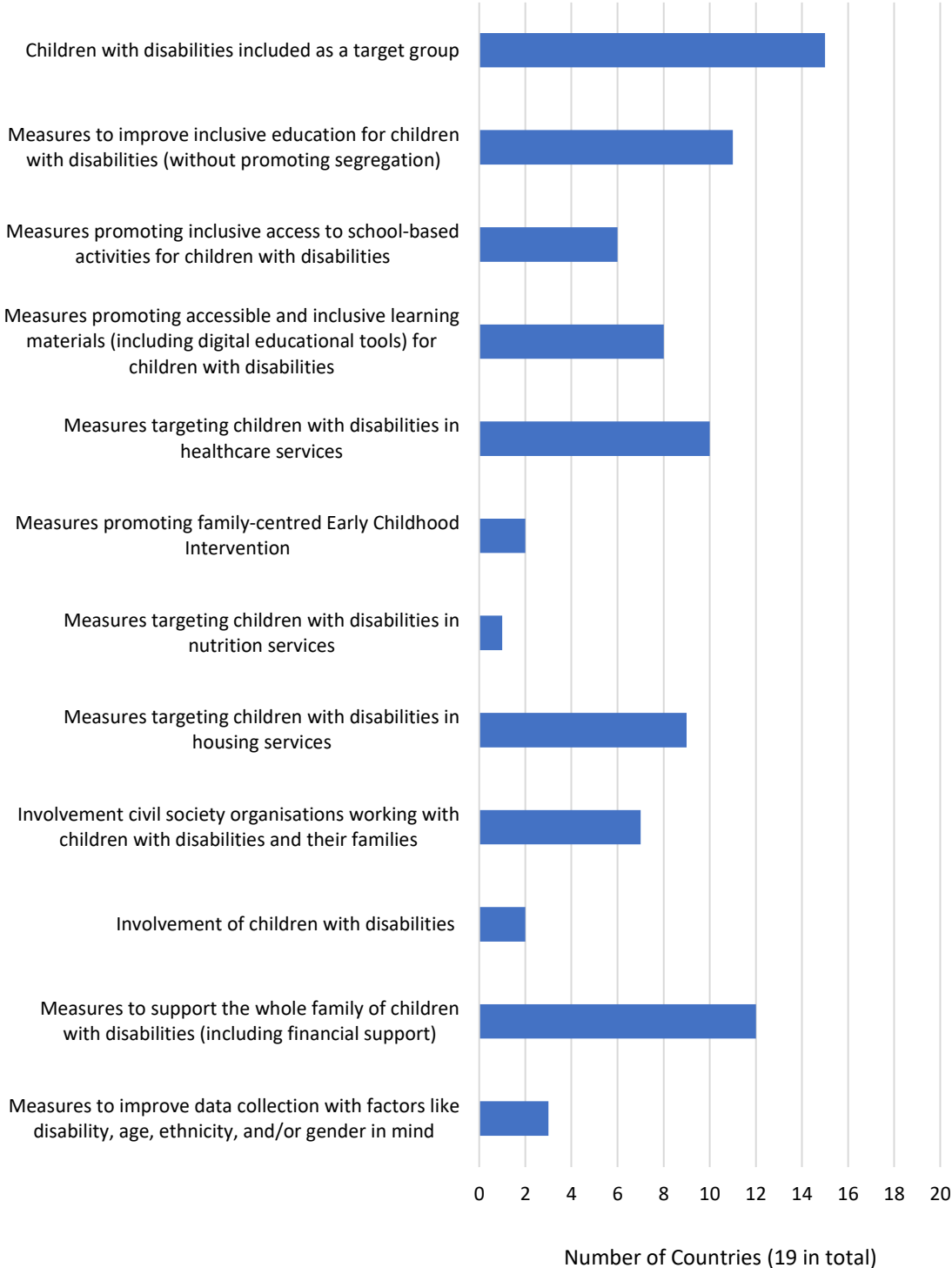
develops a strong European Child Guarantee monitoring framework to measure the implementation of inclusive services for children with disabilities and their families. The implementation of the Child Guarantee must be linked with wider enabling policy frameworks, such as the European Pillar of Social Rights, the Strategy for the Rights of Persons with Disabilities 2021-2030, and the European Care Strategy. Furthermore, Member States should use the available EU funds (such as European Social Fund + and the European Regional Development Fund) to support implementation of their NAP, as well as the Technical Support Instrument of DG REFORM of the European Commission and the full potential of EU Cohesion policy.³² When developing reporting and monitoring frameworks at the national and EU level, the indicators determined should include children with disabilities and their families. The annex includes several aspects to be taken into consideration.

The shift towards inclusion of children with disabilities and their families in all areas of society is yet to become a reality in the European Union. But progress comes slowly, and inclusive systems require changes at all levels of society, including services, the community, and governments.

³² COFACE Families Europe, [“EU Cohesion policy – expected impact on social rights of children and families”](#), 2023; EASPD, [“Assessment of funding models for a successful implementation of the Child Guarantee”](#), 2021.

Annex: Children with disabilities and their families in the National Action Plans

COFACE has identified the following elements when assessing the different EU Child Guarantee National Action Plans. These aspects should be considered when making disability-inclusive policies.



A BETTER SOCIETY FOR ALL FAMILIES



coface-eu.org



@COFACE_EU



@COFACE.EU



Families Europe



Families Europe



COFACE Families Europe



Co-funded by
the European Union

Co-funded by the EaSI strand of the ESF+ programme. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the European Commission. Neither the European Union nor the granting authority can be held responsible for them.