European
Commission

Feasibility Study for a Child Guarantee

Target Group Discussion Paper on Children with Disabilities

Social Europe

EUROPEAN COMMISSION

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2019

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2019

In 2015, the European Parliament called on the European Commission and the European Union Member States ‘to introduce a Child Guarantee so that every child in poverty can have access to free healthcare, free education, free childcare, decent housing and adequate nutrition, as part of a European integrated plan to combat child poverty’. Following the subsequent request by the Parliament to the Commission to implement a Preparatory Action to explore the potential scope of a Child Guarantee for vulnerable children, the Commission commissioned a study to analyse the feasibility of such a scheme.

The *Feasibility Study for a Child Guarantee (FSCG)* is carried out by a consortium consisting of Applica and the Luxembourg Institute of Socio-Economic Research (LISER), in close collaboration with Eurochild and Save the Children, and with the support of nine thematic experts, 28 country experts and an independent study editor.

For more information on the Feasibility Study for a Child Guarantee, see:
https://ec.europa.eu/social/main.jsp?catId=1428&langId=en.

LEGAL NOTICE

Manuscript completed in 2019

Please cite this publication as: Hunt, Paula (2019). “Target Group Discussion Paper on Children with Disabilities”, Feasibility Study for a Child Guarantee (FSCG), Brussels: European Commission.

Luxembourg: Publications Office of the European Union, 2020

PDF ISBN 978-92-76-20773-3 doi:10.2767/692437 KE-02-20-556-EN-N

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List of official countries' abbreviations and other acronyms

Official countries' abbreviations

EU countries prior to 2004, 2007 and 2013 enlargements (EU-15)		EU countries that joined in 2004, 2007 or 2013	
BE	Belgium	***2004 Enlargement***	
DK	Denmark	**CZ**	Czechia
DE	Germany	**EE**	Estonia
IE	Ireland	**CY**	Cyprus
EL	Greece	**LV**	Latvia
ES	Spain	**LT**	Lithuania
FR	France	**HU**	Hungary
IT	Italy	**MT**	Malta
LU	Luxembourg	**PL**	Poland
NL	The Netherlands	**SI**	Slovenia
AT	Austria	**SK**	Slovakia
PT	Portugal		
FI	Finland	***2007 Enlargement***	
SE	Sweden	**BG**	Bulgaria
UK	United Kingdom	**RO**	Romania
		2013 Enlargement	
		HR	Croatia

Other acronyms

AMIF	Asylum Migration and Integration Fund
CRC	Convention on the Rights of the Child
CRPD	Convention on the Rights of Persons with Disabilities
DPO	Disabled Persons Organizations
EI/EI	Early Identification and Early Intervention
EC	European Commission
ECEC	Early Childhood Education and Care
ECHR	European Convention on Human Rights
EPSR	European Pillar of Social Rights
ERDF	European Regional Development Fund
ESF	European Social Fund
ESC	European Social Chapter
ESPN	European Social Policy Network
FEAD	Fund for European Aid to the Most Deprived
EU-SILC	EU Statistics on Income and Living Conditions
FSCG	Feasibility Study for a Child Guarantee
ICESR	International Covenant on Economic, Social and Cultural Rights

IDA	International Disability Alliance
ILO	International Labour Organization
ISCED	International Standard Classification of Education
LISER	Luxembourg Institute of Socio-Economic Research
PA	Policy Area
SDG	Sustainable Development Goal
SEN	special education needs
SNE	special needs education
TFEU	Treaty on the Functioning of the European Union
TEU	Treaty on the European Union
TG	Target Group
UHC	Universal Health Coverage
UNDHR	United Nations Declaration of Human Rights

Context of the paper, authorship and acknowledgements

Following the call in 2015 from the European Parliament to introduce a Child Guarantee and the subsequent request to the European Commission (EC) in 2017 to implement a Preparatory Action to explore its potential scope, the Commission launched a feasibility study in 2018 that is aimed at examining and making proposals as to how a specific programme could best be developed in order to fight poverty and social exclusion amongst the EU's most disadvantaged children (i.e. children living in precarious family situations, children residing in institutions, children with a migrant background [including refugee children], and children with disabilities) and to ensure their access to the five key policy areas (PAs) identified by the European Parliament, (i.e. free healthcare, free education, free early childhood education and care [ECEC], decent housing, and adequate nutrition).

This *Feasibility Study for a Child Guarantee (FSCG)* has been commissioned as a key part of the Preparatory Action agreed between the EC and the European Parliament. The FSCG is managed by a consortium consisting of Applica and the Luxembourg Institute of Socio-Economic Research (LISER), in collaboration with Eurochild and Save the Children.

The FSCG is a combination of 28 Country Reports, five Policy Papers (one on each of the five PAs identified by the Parliament) and four Target Group Discussion Papers (one on each of the four Target Groups [TGs] identified by the Commission). This work is also being complemented by specific case studies highlighting lessons from international funding programmes, an online consultation with key stakeholders, and focus group consultations with children.

Each TG Discussion Paper examines in detail issues in relation to the access to the five PAs of children in the TG and reviews and assesses the strengths and weaknesses of existing approaches and policies at the national and EU level. It draws heavily on the analysis presented in the FSCG Inception Report[1] that was prepared by the FSCG Core Team, on the findings from the 28 FSCG Country Reports, on the five FSCG Policy Papers and on the results of the FSCG online consultation, as well as on the academic literature and consultation with key experts.

The draft TG Discussion Papers constituted important resources for the four TG fact-finding workshops that were organised in September and October 2019 as part of the FSCG. The papers were then finalised following the workshops. Discussions at these workshops together with the findings of the various FSCG reports will feed into an Intermediate Report, which will provide the basis for discussion at a concluding conference in early 2020. The final outcomes of the study will then be summarised in the Final FSCG Report.

The authors of the four TG Discussion Papers are grateful to Hugh Frazer, Anne-Catherine Guio and Eric Marlier (FSCG Core team), the Country and PA Experts (the list of these experts is provided in the Annex), Eurochild and Save the Children, as well as the fact-finding workshops' participants for their helpful comments and suggestions. All errors remain the authors'. The EC bears no responsibility for the analyses and conclusions, which are solely those of the authors.

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[1] https://ec.europa.eu/social/main.jsp?catId=1428&langId=en

1. Summary

The issues related to children with disabilities have been largely absent from EU policy development and implementation and not much is documented with regards to the lives of children with disabilities and their families.

The FSCG Country and PA Reports describe the life situation of children with disabilities and their families as dire in some countries and unknown in others. Families with children with disabilities tend to be poorer than other families, have less access to good-quality services, more difficulty in securing employment, and fewer opportunities to develop their social networks.

While the EU Member States are signatories of the United Nations Convention on the Rights of the Child (CRC – which is inclusive of children with disabilities), and the EU and its Member States are signatories of the United Nations Convention on the Rights of Persons with Disabilities (CRPD – which is specific to children with disabilities), the European Disability Strategy 2020 is mostly silent on their inherent obligations under both Conventions.

Despite normative frameworks, most children with disabilities in the EU Member States still have very different life experiences from their peers without disabilities:

- they still do not have adequate access to nutrition that fits their needs and is of high quality;
- they still lack opportunities to attend and participate in inclusive Early Childhood Education and Care (ECEC);
- they largely remain separated from their peers without disabilities in education settings, being placed in special schools or in special classes in regular schools;
- they still have difficulty accessing quality healthcare – both primary healthcare and specialised care; and
- they still live in environments that do not adequately respond to their needs.

Even within the group commonly described as *children with disabilities* there are marked differences between children’s experiences, not only due to their own individualities. Preconceived (often erroneous) notions of disability operate in policy and in practice, giving the impression that some children in particular categories (for example, children with intellectual disabilities) are more disabled than others (for example, children with a physical disability); that children with visible disabilities (for example, children who are blind) are more disabled than children with invisible disabilities (for example, children with dyslexia); and that levels of severity are static and impairment-related, rather than fluid, subject to change, and person-specific.

As demonstrated below, the policies aimed at providing and/or regulating services are mostly silent on children with disabilities or envision only the minimum requirements, such as accessibility of public infrastructure or waiving of fees for services. In most countries in the EU, there is a lack of understanding of disability as part of the human condition, of the individuality of each child (with a disability) within the group of children with disabilities, and a lack of understanding of the impact of disability not only on a child but on the entire family.

As recommended below, the first steps in a future Child Guarantee should be to make children with disabilities visible at all policy and action levels, and a dual approach to children with disabilities is envisioned. On the one hand, disability must be mainstreamed throughout policy and implementation, ensuring that all policies and services envision children with disabilities as part of the overall population they aim to serve. On the other hand, it is important to recognise that children with disabilities and their families (like other children from vulnerable populations) may also require specific policies and services in order to be able to realise their rights. Thus, making children with disabilities visible in all EU policy, and ensuring the normative frameworks that already exist are monitored and enforced, should be the primary aim of a future Child Guarantee.

2. Definition of the target group (children with disabilities) and international human rights obligations

2.1 Definition of Target Group – children with disabilities

It is estimated that, in the EU, 80 million citizens have a disability, making this the largest minority group in Europe, with prevalence given to women, the older population and those with a lower education background[2]. However, as detailed in a stock-taking exercise (European Commission, 2017), specific and reliable data and evidence that can detail the life experiences of children with disabilities 'are difficult to collect and, when available, often partial and fragmented' (p.12). According to the European Disability Strategy 2010-2020[3] and the CRPD (Art.1), the definition of disability is rather broad and encompasses an open concept: '**Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others'**.

The description of persons with disabilities proposed in the CRPD results from a progression, over time, of the way in which disability is understood. It reflects the social model of disability (also known as the bio-psycho-social model), in line with the human rights-based approach or the human rights model of conceptualising disability, and is consistent with the World Health Organisation's International Classification of Functioning, Disability and Health[4] (ICF and the ICF-Children and Youth version) that conceptualises a person's level of functioning as a **dynamic interaction** between their **health conditions, environmental factors, and personal factors**. It defines functioning and disability as multidimensional concepts relating to:

- the body functions and structures of people;
- the activities people do and the life areas in which they participate; and
- the factors in people's environment that affect their experiences.

The social model of disability acknowledges the importance of the context and environment in enabling or disabling individuals in terms of participating effectively in society, and provides the *gold standard* for a disability definition. The social model presents a new paradigm for conceptualising disability, a departure from the more traditional ways that relied on descriptions of diseases and illnesses (medical model), and/or portrayed persons with disabilities as recipients of charity, rather than rights holders (charity model).

Up until 2006, each EU Member State accounted for its *disabled population* by counting the number of recipients of disability allowances or benefits, a number often reached by virtue of identification in census questions answered by heads of household. However, in both instances, asking about disability often reflected a biased account, due to a narrow conception of disability (disease or impairment), due to the age-limitation of the census and household surveys (which often start only at the age of lawful employment), or with responses coloured by stigma and fear of retaliation linked to being identified as a person with a disability.

Therefore, after 2006, EU Member States have been encouraged to use a CRPD-compliant definition of disability that would allow for comparable data collection across the EU. However, as detailed below, most EU Member States continue to use a reductive definition of disability that accounts for one or two of the three dimensions it should include: 1) the body functions and structures of people; 2) the activities people do and the life areas in which they participate; and 3) the factors in people's environment that affect their experiences. Many of the 28 Country Reports upon which this paper is based use a variety

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[2] Data from the European Survey on Health and Social Integration of 2012-13.

[3] https://ec.europa.eu/eip/ageing/standards/general/general-documents/european-disability-strategy-2010-2020_en

[4] https://www.who.int/classifications/icf/en/

of definitions of disability. Therefore, while the data reviewed are not comparable across all 28 Member States, an effort is made to provide an overall assessment of the situation of children with disabilities despite the lack of an accurate description of the composition and size of the group.

According to the 2014 report on the implementation of the CRPD by the European Union, 'EU law does not provide for a harmonised definition of disability and persons with disabilities', although it references the definition provided in the CRPD. Further, it advises that 'the concept of disability must be interpreted as including a condition caused by an illness medically diagnosed as curable or incurable, where that illness entails a limitation which results in particular from physical, mental or psychological impairments which in interaction with various barriers may hinder the full and effective participation of the person concerned in professional life on an equal basis with other workers, and the limitation is a long- term one' (paragraph 20). Thus, the definition of disability meant to be used by EU Member States must take into consideration that disability is no longer an intrinsic and individual characteristic, but rather the result of a personal interaction with a specific environment, and the activities persons with disabilities participate in (or do not).

It should be noted that, in some countries, the term 'special needs' is used as a catch-all category that may or may not include (or even be synonymous with) persons with disabilities. The category 'special needs' often lacks accurate definition, and thus masks the specificity of the barriers, and magnitude of the difficulties, encountered by persons with disabilities in realising their rights. In addition, the term 'special needs' is one that many in the disability community object to, arguing that the rights of persons with disabilities should not be qualified as 'special' but rather are the same rights that everyone else is entitled to. In the FSCG, as mentioned in the Inception Report (Feasibility Study for a Child Guarantee (FSCG), 2018), **we will therefore refer to children with disabilities' rather than 'children with disabilities and other children with special needs'** (as originally proposed).

2.2 Legally binding obligations

The EU and its Member States have a dual obligation with regards to children with disabilities. First, all mainstream legislation and policy should be **disability-inclusive** (just as it is gender-inclusive), and applicable to all citizens including those with disabilities. Second, because persons with disabilities often experience exclusion on the basis of barriers that are specific to them, the EU and its Member States are also responsible for developing legislation and policy that are **disability-specific**. Often called a twin-track approach, the aim is to reaffirm that children with disabilities are children first and have the same rights as all other children, but might need differentiated access and adapted means of participating, in order to be able to exercise their rights.

Below are references to some **disability-inclusive** frameworks that are legally binding in the EU and are relevant to this report.

- The right to an adequate standard of living for all children 'including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability' (Art.25) has been promoted since the proclamation of the Universal Declaration of Human Rights (1948).
- In 1989, the CRC again promoted the rights of all children, mentioning children with disabilities specifically in two instances: Article 2 prohibits discrimination on any grounds (including disability); and Article 23 extensively details States Parties' obligations to ensure the fulfilment of all rights by children with disabilities, with an emphasis on the provision of (free) services (mainstream and specific to a disability) leading to self-reliance, full social integration, and individual development.
- The Charter of Fundamental Rights describes 'all the personal, civic, political, economic and social rights that people enjoy within the EU' (p.6), and prohibits discrimination on the grounds of disability (Art.21). Further, it details the right of (any) child to protection and care, to express their views freely, and to maintain a personal relationship with their parents (Art.24) and 'recognises the right of persons with disabilities to benefit

from measures designed to ensure their independence, social and occupational integration and participation in the life of the community' (Art.26).

- The European Pillar of Social Rights (EPSR) expressly address the rights of persons with disabilities to education, training, and life-long learning (Art.1) and income support, services, and a work environment that ensure their lives with dignity (Art.17). It also addresses the right, for all children, to affordable ECEC of good quality, the right to protection from poverty, and the right to specific measures to enhance equal opportunities for children from disadvantaged backgrounds (Art.11).
- Other formative European treaties and declarations, such as the Lisbon Treaty, are disability-inclusive, particularly with regards to: protection from discrimination on the basis of disability; and ensuring social protection mechanisms are inclusive of, and often specific to, persons with disabilities.
- In addition, the newly developed Sustainable Development Goals – in particular SDG 3 (good health and well-being), SDG 4 (quality education), SDG 8 (decent work and economic growth), SDG 10 (reduced inequality), and SDG 16 (peace, justice, and strong institutions) all have implications for children with disabilities.

In addition, there are **disability-specific** legally binding documents, as follows.

- In 2006, the CRPD drew on the CRC text and emphasised the need for States Parties to 'take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with others' (Art.7). By cross-referencing *children* and *disability*, the two Conventions taken together serve as a strong statement of obligation for States Parties, including all the EU members who have signed and ratified both the CRC and the CRPD. In the case of provisions related to the CRPD in which the EU and its members are separate State Parties to the Convention, it is stated that 'all provisions of the agreement falling within EU competence are binding on the EU institutions'.
- The European Disability Strategy 2010-2020 is the framework by which the EU implements the CRPD, and the EU Parliament has provided input to its implementation since 2017. Since 2011 (signature of the CRPD by the EU), its provisions have become part of the EU's legal obligations.
- The European Accessibility Act (provisional at the time of this draft) covers products and services, and aims to ensure the availability of more accessible services and products in the market, at more competitive prices, with fewer barriers in accessing education and the world of work.

In terms of access to the five Policy Areas studied in the FSCG (nutrition, education, ECEC, housing, and healthcare), the legal obligations that are most relevant are a mix of both types: disability-inclusive and disability-specific. With regards to the **right to nutrition**, there are, in addition to those detailed in the above-mentioned documents (and as reported in Bradshaw & Rees, 2019): the Treaty on the European Union (TEU) (Art.2); the Treaty on the Functioning of the European Union (TFEU) (Arts 4, 151 and 153); the Fund for European Aid to the Most Deprived (FEAD); EPSR; and a series of other European-level soft documents. The legal obligations with regards to the **right to education** are, as reported in Nicaise, Vandevoort, & Ünver (2019), the Universal Declaration of Human Rights (UNDHR) (Art.26), the CRC (Art.28), and the CRPD (Art.24). With regards to the **right to healthcare**, legal obligations are those prescribed in UNDHR (Art.25), CRC (Art.24) and CRPD (Art.25). As detailed in Clark-Foulquier and Spinnewijn (2019), legal obligations with regards to the **right to housing** are detailed in: the International Covenant on Economic, Social and Cultural Rights (ICESCR) (Art.11 and GC4); the CRC (Art.27); the European Convention on Human Rights (ECHR) (Arts 3 and 8); and the European Social Chapter (ESC) (Art.16). Of relevance to children with disabilities are obligations detailed in the CRPD that oblige Member States to identify and eliminate barriers to accessibility related to housing (among others) (Art.9) and oblige Member States to 'ensure access by persons with disabilities to public housing programmes' (Art.28, 2d). In addition, and as mentioned in the relevant PA, the UN Special Rapporteur has alerted for violations of the right to housing for persons with disabilities and for the lack of attention 'to hold Governments accountable for failures to address widespread homelessness and inadequate housing among persons with disabilities' (UN Report of the Special Rapporteur on adequate housing as a component of the right to an adequate standard of living, and on the right to non-discrimination in this context, 2017 – p.19). The legal obligations regarding the **right to ECEC** (as indicated in Vandenbroeck, 2019) are those outlined in the UNDHR (Art.26) and the CRC (Art.28) that guarantee a right to free elementary and fundamental education (in particular, General Comment No 7 that specifically addresses ECEC), and in the Sustainable Development Goals (SDG – 4.2).

In summary, EU Member States have the same obligations towards children with disabilities as they do towards all other children. In addition, children with disabilities are awarded specific protections and services, as needed, to ensure their full participation. If implemented fully, with rigorous monitoring and enforced redress, the existing international treaties such as the CRC, CRPD, and other policy guidelines such as the European Disability Strategy and the SDG guidelines, would partially address the situation and policies related to persons with disabilities in the EU; although the CRPD, the European Disability Strategy and the SDGs lack focus on children. Thus, the argument is made for a Child Guarantee that can ensure children with disabilities are at the forefront of policy.

3. Overall situation of children with disabilities in Member States

As mentioned previously, it is estimated that 80 million people in Europe have a disability. The number of persons with disabilities varies widely from country to country due to differences in the definition of disability, in data collection methodologies, and in discrimination faced by persons with disabilities themselves which often prevent them from self-reporting.

Data on barriers to social integration[5] for persons with disabilities aged 15 and over (collected by the EU in 2015) provide an overview of the situation of persons with disabilities in Europe. Persons with disabilities themselves reported barriers related to: mobility (52.9%); transport (31.7%); accessing buildings (37%); education and training (25.6%); employment (38.6%); using the internet (4.6%); social contact (2%); pursuing leisure (60.9%); paying for the essential things in life (22.7%); and perceived discrimination (19.8%). 35.5% of all respondents indicated a barrier in one life area, 28.8% in two or three life areas, and 35.7% in four or more life areas. Of all persons with disabilities, 81.5% reported difficulties with basic activities, 43% reported difficulties with basic care activities, and 53.1% reported difficulties with household care activities.

3.1 Relative size of the group of children with disabilities and overall poverty/social exclusion situation in the Member States

Availability of data

As explained above, identifying and measuring disability according to the social model **goes beyond identifying and measuring an impairment**. It is a description of a person's life situation, including their impairment but also acknowledging the environmental and personal factors that are acting as barriers to (or enablers of) their participation. Therefore, to identify a person with a disability it is necessary to describe the life situation of the person, including **the person's health condition (impairment), their activities and participation restrictions, and the environmental factors that support their participation**, as follows:

> <u>Impairment</u>: significant problems in bodily function (physiological functions) or structure (anatomy) – such as voice and speech functions; structures of the nervous system; and structures related to movement.

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[5] https://ec.europa.eu/eurostat/data/database?node_code=hlth_dsi080

> Activity limitations and participation restrictions: activity limitations are difficulties people have in executing activities, while participation restrictions are the difficulties they face in being involved in a life situation. They are usually described in relation to nine domains: learning and applying knowledge; general tasks and demands; communication; movement; self-care; domestic life areas; interpersonal interactions; major life areas (education, employment, economic life); and community, social; and civic life.
>
> Environmental personal factors: contextual factors that may influence participation – such as assistive technology; natural and man-made environment; support and relationships; attitudes; and services, systems, and policies. Personal factors include gender, age, social/religious background, past and present experiences, ethnic background, and profession.

Only by investigating and studying the relationships between these three sets of determinants can 'disability' be established. To be effective in identifying disability (and providing adequate services) it is important to start as early as possible in the child's life, consider disability determination as a whole-person assessment, and take into consideration the person through the lifecycle. In all cases, gathering information on all three sets of determinants requires that various persons (starting with the most immediate family) provide information related to all aspects of a person's life; and that that information be collected and made available in ways that create one single picture of the person, and be made sense of by those who are the most likely to make a difference in the person's life (starting with the person themself, their family and closest community, and professionals familiar with the person and their services). Only then can functional profiles be developed, always leading to service supports.

These complex data are not collected at EU level.

Furthermore, until 2017, all cross-country comparative surveys gathered data on health conditions starting at age 15 or 16, and relevant information on issues specific to younger children was not gathered[6]. While data on adults with disabilities may be indicative of the overall prevalence of disability in a particular country, they do not replace data on children with disabilities because they do not capture the situation along the lifecycle and in specific domains particular to children.

An ad hoc module on children's health was added to the 2017 EU Statistics on Income and Living Conditions (EU-SILC), gathering information on the general health and limitation in activities due to the health problems of children aged less than 16, as well as information on their unmet needs for dental care, medical examination or treatment (see Section 4 for an analysis of these data). However, as explained above, although the data gathered shed some light on issues related to health and limitations it cannot be understood as equivalent to data on disability. It is also important to note that people living in institutions are not included in the EU-SILC sample. This also means that children with disabilities who live in institutions are not taken into account in the analysis below.

Figure 3.1 provides the proportion of children experiencing limitations in their daily activities in the various EU countries. While the data gathered in the 2017 ad hoc module on children's health are very important and have the potential to shed some light not only on children's access to healthcare but also health-related functional limitations, these data need to be used with caution when determining the size of the population of children with disabilities in a given country because, as indicated above, one's health status does not directly correspond to dis/ability. General health and/or impairment data cannot be used as a proxy for disability. All data related to contextual and personal factors are important when determining disability and functioning. To understand the scope of disability it is important to know how particular health conditions interact with the environment, which are the environmental barriers, and which are potential facilitators; only a complete picture

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[6] One exception is data collected on items related to child material deprivation, which led to the adoption of an EU indicator in 2018: https://www.liser.lu/?type=news&id=1529. For more information on this indicator, see: https://link.springer.com/article/10.1007%2Fs12187-017-9491-6.

can determine the scope of disability. Context will impact the ways in which each person experience disability and persons with the same impairment can experience very different types and levels of disability depending on the environmental and personal factors.

Current situation – children limited in their daily activities in the EU countries

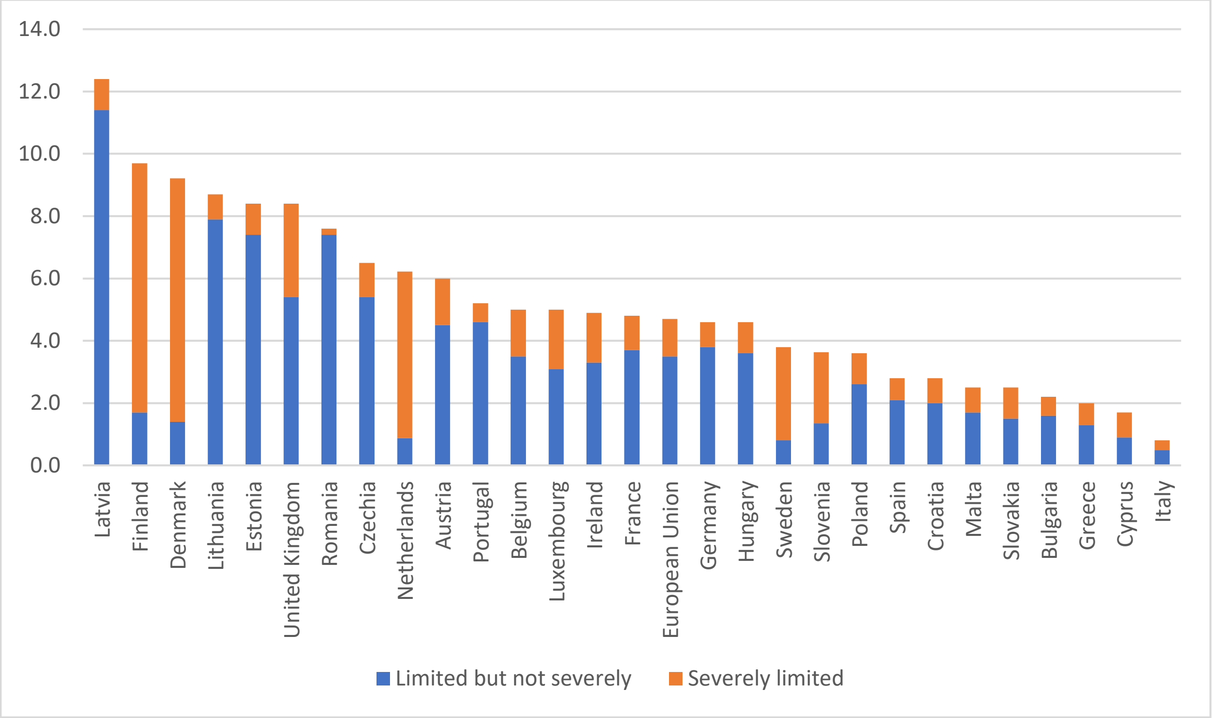
Keeping in mind the above constraints, Figure 3.1 provides the proportion of children 0-15 years old experiencing severe or some (not severe) limitations in their daily activities. The response categories include two levels of limitations, as follows.

- 'Severely limited', which means that performing or accomplishing an activity that can normally be done by a child of the same age cannot be done or only done with extreme difficulty. Persons in this category usually cannot do the activity alone and (would) need help.
- 'Limited but not severely', which means that performing or accomplishing an activity that can normally be done by a child of the same age can be done but only with some difficulties (persons in this category usually do not need help from other persons).

The limitations in daily activities must have started at least six months before the interview and still exist at the moment of the interview. This means that a positive answer ('severely limited' or 'limited but not severely') should be recorded only if the person is currently limited and has been limited in activities for at least the past six months. New limitations which have not yet lasted six months but are expected to continue for more than six months should not be taken into consideration, even if medical knowledge would suggest that the health problem behind a new limitation is very likely to continue for a long time or for the rest of the life of the respondent (such as for type 1 diabetes). The activity limitations of the same health problem may also depend on the individual person and circumstances, and only past experience can provide a safe answer.

Figure 3.1 shows that the proportion of children severely limited or limited (but not severely) in daily activities varies a lot across countries, ranging from less than 2% (Cyprus, Greece, and Italy) to more than 8% (Denmark, Estonia, Finland, Latvia, and Lithuania). In most countries, the proportion of children experiencing *severe* limitations is around 1% of the population aged 0-15 years. The reasons why some countries have a much higher percentage should be further investigated. The comparability of survey questions as between countries, the impact of the mode of data collection, and other data-related issues, must be investigated. This is currently the responsibility of Eurostat.

Figure 3.1: Share of children severely limited or limited (but not severely) in daily activities during the past six months, children 0-15 years old, EU countries, 2017, %



Source: EU-SILC 2017, ad hoc module, table ilc_hch13.

At the country level, administrative data on children with disabilities are also gathered. Despite signing and ratifying the CRPD, most of the 28 EU countries still use a traditional/medical definition of disability. This information is usually captured in multiple databases (based on a specific need/purpose and housed within separate ministries) that often do not allow for triangulation of findings. Thus, in one country, one may find:

- a dataset representing children with an impairment (body part or body function limitation) that often includes chronic illnesses, and should not be used as proxy for disability (usually in the ministry of health);
- a dataset representing children with disabilities who have been officially registered as living with a disability and receive some sort of a benefit/pension/allowance based on the type and severity of the disability (usually from the ministry of social protection or ministry of welfare); and/or
- a dataset representing school-age children with some type of specific education need/support, often designated 'special education needs' (SEN) or 'special needs education' (SNE) – this group of children should include, but should not be restricted to, children with disabilities (it cannot be assumed that all children classified as SEN or in SEN programmes are children with disabilities).

Some Country Reports provide such data.

According to a Joint Statement by the International Labour Organization (ILO) and the International Disability Alliance (IDA) (ILO & IDA, 2019), 'families may restrict participation or even hide children from the rest of the community due to stigma or to protect them, reducing the child's access to support, education and other services. **Children with disabilities are almost four times more likely to experience violence and up to 17 times more likely to enter institutional care than their peers without disabilities, particularly owing to insufficient support for families, a lack of inclusive education and poverty'** (p.3). However, there are also reports of positive developments, such as in the case of Poland (ESPN Synthesis Report, 2017), where there is the provision of a one-off grant to a family who gives birth to a child with a disability.

In addition, one study (Giulio, Philipov, & Jaschinski, 2014) has conducted research in a number of EU countries, gathering information on the prevalence of families with at least one child under the age of 19 who is a child with a disability[7]. The findings indicate that, on average, 1.9% of all families have a child with a disability. In addition, some of the findings of the study are important to mention here, although they do not fit exactly within each of the categories this report focuses on.

Thus, in households with children with disabilities (as compared with households without children with disabilities) there seems to be increased poverty, confirming findings from other parts of the world[8]:

- the percentage of mothers employed is lower (often due to care for the child/family);
- men report lower participation in the labour market;
- fathers are more involved in playtime (60%) than in caring for an ill child (18%);
- a higher percentage of respondents report difficulty in 'making ends meet';
- the perceived health status of fathers and mothers is worse in households with children with disabilities, by as much as 8 times;
- fathers and mothers often report only being close to other families that also have children with disabilities.

According to the online consultation report (FSCG, 2019, p.12), there are a number of barriers to be overcome by children with disabilities (see Table 3.1). All listed barriers were identified in all four policy areas of interest but to different extents. Problems with physical space is a barrier were identified in all four areas, while the non-availability of services was identified as a barrier in three areas: health, ECEC, and housing. Likewise, a lack of adaptation to children's needs was also identified in three types of services: health, education, and ECEC. It is noteworthy that, in health and in education, the greatest barrier is lack of adaptation of services to children's needs, while in ECEC it is non-availability, and in housing it is problems with affordability.

For the remainder of this Section, and as needed for context, the overall situation for children will be provided, to underpin the situation of children with disabilities. While this report is meant to be focused on children with disabilities, it is important to note that, in many cases, the argument for better services for children with disabilities cannot be made without making the argument for better services for all children.

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[7] The question used to identify whether one of the family members had a disability was 'Is any member of your household limited in his/her ability to carry out normal everyday activities because of a physical or mental health problem or a disability? If yes, please put a tick in the "disability" column in the household grid' (p.7).

[8] For more on the links between disability and poverty see, for example, Mitra, Posarac, & Vick (2012).

Table 3.1: Main barriers that need to be overcome by kind of service for children with disabilities (% of respondents)

	Health	Education	ECEC	Housing
Non-availability of services in the area	**50.2**	42.6	**56.4**	**41.9**
Discrimination	19.4	**45.3**	26.9	16.9
Not eligible for support	15.8	15.8	17.8	21.4
Lack of awareness/insufficient information	33.2	30.9	30.7	16.1
Problems of physical access	**46.2**	**52.5**	**44.7**	**49.2**
Problems of cultural access	11.1	19.6	14.8	7.7
Problems of affordability	41.1	22.3	34.1	**52.4**
Services not adapted to children's needs	**51.4**	**54.3**	**51.5**	40.3
Other barriers	4.7	4.5	2.3	3.6
Don't know	11.1	8.7	8.3	9.7
N	253	265	264	248

Note: The number of cases indicates the total number of respondents who identified at least one barrier for each service.
The figures in bold indicate the three barriers identified as most important.

Source: FSCG Online Consultation (2019).

3.2 Overall situation of children with disabilities in terms of adequate nutrition in the Member States

Inadequate nutrition or, according to the World Health Organisation malnutrition, can be expressed as three broad groups of conditions:

- undernutrition, which includes wasting (low weight-for-height), stunting (low height-for-age), and underweight (low weight-for-age);
- micronutrient-related malnutrition, which includes micronutrient deficiencies (a lack of important vitamins and minerals) or micronutrient excess; and
- overweight, obesity, and diet-related non-communicable diseases (such as heart disease, stroke, diabetes, and some cancers).

The Inception Report (FSCG, 2018) and Bradshaw & Rees (2019), both indicate that there are few data on the nutrition status of children with disabilities. Data collected in EU-SILC 2014 on enforced lack of proteins or fruit/vegetables cannot be broken down according to the degree of limitation in daily activity of children, as this latter information was only collected in EU-SILC 2017. For the population of children in general, these data show large variations between countries in the proportion of children living in households lacking (for affordability reasons and not by choice) daily fruit and vegetables or proteins. This proportion varies for fruit/vegetables between less than 1% (in Sweden, Finland, the Netherlands, Austria, Denmark, and Luxembourg) and 40% (Bulgaria). The occurrence of lack of meat, chicken or other vegetarian equivalent for affordability reasons ranges between 0-1% (Sweden, Finland, Denmark, Luxembourg, Portugal, and Slovenia) and 42% (Bulgaria). Income poverty increases the risk of unforced lack of nutrients significantly in almost all countries. This is also true for single parenthood, except in a few countries (Bradshaw & Rees, 2019, p.4).

Most of the Country Reports do not mention children with disabilities regarding nutrition, with Croatia, France, and Lithuania reporting: needs of children with disabilities rarely taken into account (Legros, 2019); the absence of specific data (Zrinščak, 2019); an improper analysis of the needs of children with disabilities (Poviliūnas & Sumskiene, 2019). In addition, the UK Report refers to the known link between disability and poverty, which may heighten the risk of inadequate nutrition (Bradshaw, Rees, Glendinning, & Beresford, 2019).

This shows that lack of data is a barrier to decision-making related to nutrition. Out of 28 countries, only 6 report on the situation of children with disabilities with regards to nutrition, but none has indicated the impact of such provisions on the overall health and well-being of children with disabilities.

Finland reports that, among all TGs and specifically children with disabilities, there are no major problems regarding nutrition. Free meals (breakfast, lunch, and a light meal in the afternoon) are provided in kindergardens and in pre-school settings. Free meals are available for all pupils in schools (Kangas, 2019). Hungary reports that 87% of public institutions provide dietary meals for children with food restriction (OGYÉI: Országos iskolai MENZA körkép, 2018); and Sweden reports that schools are obliged to provide free lunches to all students, with some schools also providing breakfast, and to provide special-diet meals to any student with hypersensitivity or other conditions (Nelson, Palme, & Eneroth, 2019). However, no information is provided about the proportion of children with disabilities who have access to these meals, or its overall impact. Portugal reports that all children with disabilities have access to free-of-charge meals in school canteens (Perista, 2019), and Slovenia mentions that, in institutions for children and young people with special needs, a free snack is provided (Zakon o uveljavljanju pravic iz javnih sredstev, 2010). Romania states that a food allowance of 12 Lei (€2.60) per day for children aged 0 to 3 and 16.60 Lei (€3.60) per day for persons aged 3 to 26 is granted, among others, to children with disabilities, conditional on school attendance (Pop, 2019).

3.3 Overall situation of children with disabilities in terms of problems of access to free education in the Member States

Education, in the context of this study, is understood as compulsory education, which normally includes primary and secondary schooling.

As can be seen in the national situations described below, in almost all cases EU countries are struggling with system-wide difficulties in fulfilling the rights of children with disabilities to education. Not only is there a need to comply with existing normative frameworks, but there is in some cases a complete disregard for the government's obligations towards its citizens. While, according to the online consultation report (FSCG, 2019, p.11), a lack of individualisation of the education plans and services to the student is given as a barrier – closely followed by problems of physical access, discrimination, and non-availability of services – there is also an almost complete disregard of the rights of the child, as envisioned in the CRC, the CRPD, and the EU Charter.

27 out of 28 Country Reports indicated that **education is free**, although the definition and concept of 'free' education differs between countries, with some Country Reports indicating a 'free' education system because tuition is free, and other Country Reports indicating a 'free' education system because other expenses are covered in addition to tuition. Some examples of this variation are: Greece (tuition and transportation are provided free of charge) (Ziomas, Mouriki, Capella, & Konstantinidou, 2019); Hungary (tuition for all students and textbooks are provided free of charge for SEN students) (Albert, 2019); Sweden (tuition and free school transport if needed) (Nelson, Palme, & Eneroth, 2019); Finland (tuition and meals are provided to all at all levels; students in upper secondary education pay for books and transportation) (Kangas, 2019); Poland (tuition is free for all at all levels; textbooks are free in primary school and co-financed for children with disabilities; transportation is free for children with disabilities) (Topińska, 2019); and Slovenia (free education for primary and SEN children; parents pay for textbooks, meals, school trips etc. for all children) (Stropnik, 2019).

Country Reports indicate that **special education in segregated settings** – which can be separate institutions or special schools, and is often offered in parallel with special education in mainstream settings – is provided in 23 countries: Austria (Bildungsdokumentation, 2019), Belgium (Nicaise et al., 2019); Bulgaria (called auxiliary schools) (Bogdanov, 2019); Croatia (Zrinščak, 2019); Czech Republic (Sirovátka, 2019); Cyprus (Koutsampelas et al., 2019); Denmark (special schools, youth schools or day centres) (Danmarks Statistik, 2019a); Estonia (Anniste, 2019); France (Legros, 2019); Finland (Kangas, 2019); Germany (Hanesch, 2019); Greece (Ziomas, Mouriki, Capella, &

Konstantinidou, 2019); Ireland (Department of Education and Skills, 2016); Latvia (Lace, 2019); Lithuania (Poviliūnas & Sumskiene, 2019); Luxembourg (Swinnen, 2019) the Netherlands (van Waveren et al., 2019); Poland (Topińska, 2019); Romania (Pop, 2019); Slovenia (Stropnik, 2019); Slovakia (special schools) (Gerbery, 2019); Spain (Rodríguez Cabrero & Marbán Gallego, 2019); and Sweden (Nelson, Palme, & Eneroth, 2019). It is important to note that special education provided in segregated settings (residential institutions, special schools or special classes within regular schools) constitutes a violation of the right to inclusive education (CRPD Art.24 and GC4).

In Belgium (Flanders), there are a large number of boarding schools, with 142 mainstream boarding schools (which house a minority of 330 children with disabilities) and 19 boarding schools for special education, housing 2,500 children with disabilities. Of these boarding schools for special education, 8 are permanently open, caring for children during weekends (IPO; Beeumen) – a 'hidden' institutionalisation of these children (Nicaise et al., 2019).

The share of children considered to have **'special educational needs'** or a similar denomination, which may or may not include children with disabilities, is: 5.2% for Austria (2016-17) (Bildungsdokumentation, 2019); 4% (Wallonia-Brussels)/3.95% (Flanders) in Belgium, plus 13,752 students receiving individual guidance in mainstream schools (Fédération Wallonie-Bruxelles, 2018; Vlaanderen, 2019; Nicaise et al., 2019); 8.8% (International Standard Classification of Education – ISCED – levels 1 and 2) in the Czech Republic (European Commission, 2018); 4.5% (in primary school, 2017) in Denmark (Kvist, 2019); 7.92% (ISCED 1 and 2) in Estonia (European Commission, 2018); 5.5% in Hungary's public education system in 2011 (KSH, 2011), and 7.32% in ISCED 1 and 2 (European Commission, 2018); 3.7% in Italy (Raitano, 2019); 1.54 % in Luxembourg, at primary and lower secondary schools (European Commission, 2018); 5.5% in Malta (EASIE, 2014); 3% in Poland, in 2016-17 (NIK, 2018); 7.6% in Portugal (ISCED 1 and 2, 2016) (EASIE, 2018); between 17 and 18% for Romania in 2011, with no information being made public since 2012 (Pop, 2019); 8.39% of primary and lower secondary students in Slovenia in 2014-15 (EASIE, 2018); and 2.4% of all non-university students in Spain in 2016-17 (Rodríguez Cabrero & Marbán Gallego, 2019).

All the provided Country Reports included data on the number of children identified as having 'special education needs' (or similar denomination) reported studying in an inclusive setting/mainstream school (summary provided below). Reported data on the percentage of SEN students in mainstream classrooms are calculated taking in consideration the total number of SEN students identified in a population (including those in segregated settings, in home schooling, out of school, etc.). However, as previously discussed, it is highly problematic that, as reported by country experts, there are no data to indicate what proportions of the population of children with 'special education needs' (if any) is specific to children with disabilities. It can be assumed that data-gathering systems (including education management information systems) do not disaggregate the student population to indicate children with disabilities. Thus, after taking into consideration this caveat, the **percentage of children considered to have 'special education needs' (or similar denomination) reported as studying in an inclusive setting/mainstream school** is:

- 64% in Austria, in 2016-17, though being subject to different pedagogical models (Bildungsdokumentation, 2019);
- 54.7% in Croatia, in mainstream education and programmes;
- 81% in Cyprus, for students educated in mainstream schools and classrooms (Koutsampelas et al., 2019);
- 53% for the Czech Republic in 2015 – it is reported that there is a lack of statistics on the enrolment rate of pupils with special educational needs at all levels and types of schools (UNICEF, 2015);
- 53.4% in Denmark (Danmarks Statistik, 2019a);
- 79.7% in France, at the start of 2015 (Legros, 2019);
- 40% in Germany, in 2016-17 (Hanesch, 2019);

- 80.03% in Greece, in 2018-19 (mainstream schools – either in integration classes or in classes with parallel support) (Ziomas, Mouriki, Capella, & Konstantinidou, 2019);
- 68% in Hungary, for the 2016-17 academic year (EASIE, 2016);
- 41.1% in Latvia, in 2016-17 (Lace, 2019);
- 62% in Lithuania – this number may be much lower, see below (Poviliūnas & Sumskiene, 2019);
- 100% in Malta (Vassallo, 2019);
- 87% in Poland, in 2016-17 (NIK, 2018);
- 98% in Portugal (PT CRC report, 2014);
- 75.5% in Slovenia, in 2014-15 (EASIE, 2018); and
- 83.5% in Spain, for the year 2016-17 (MEFP, n.d.).

As for **children with a disability** specifically, it is reported as follows.

- Out of the children identified as having a disability in Cyprus, 11% are educated in special units within mainstream schools and 8% are educated in special schools (Koutsampelas et al., 2019).
- In the Czech Republic, in 2015 (UNICEF, 2015) approximately 47% of children with disabilities were enrolled in special classes.
- In Greece, in the school year 2018-19, 19.97% of children considered to have 'special education needs' attended school units of special education for pupils with disabilities (Ziomas, Mouriki, Capella, & Konstantinidou, 2019).
- In France, 20.3% of children with disabilities were, in the 2015 school year, enrolled in special establishments (Legros, 2019).
- In Latvia, approximately 58.9% of children with disabilities were schooled in special education institutions in the school year 2016-17 (Lace, 2019).
- In Lithuania, 38% of children with a disability study in one of the 74 special schools in the country. This number may, however, be much higher (see below) (Poviliūnas & Sumskiene, 2019).
- In Luxembourg's primary schools, during the school year 2015-16, 918 students with disabilities were educated in separate classes and 767 students were integrated into regular classes (MENJE, 2018).
- In Portugal, the 2% of children with disabilities not in mainstream schooling attend private special schools, subsidised by the State regarding tuition, meals, transportation and therapy (CRC, 2014).
- In Romania, in the 2012-13 school year, only 56% of children with disabilities were enrolled in any form of education (ANPDCA).

Good examples where both policy and practice have resulted in inclusive education systems were reported by Portugal and Malta. In Malta, all children with disabilities are now reported to be in the mainstream educational system, with the former special schools having been transformed into resource centres to aid the provision of inclusive education (Vassallo, 2019). Likewise, in Portugal, as of July 2018, new legislation has been in place (DL 54) that eliminates the need for a 'disability certification' for service provision, making the existing support mechanisms available for all students who require them, be it temporarily or permanently. Additionally, two other Country Reports indicate a high likelihood of inclusive practices: in Finland, children with disabilities have the right to go to the school closest to their home, receiving any support needed free of charge (Kangas, 2019); and in Sweden, if a student is deemed to need special support, an action plan is established, with 14% of students in mainstream schools benefiting from this policy. Special schools and programmes are available for students with several disabilities, with participation being voluntary and having as an alternative attending mainstream school with added support and an action plan. Of the students in special schools, over 10% live in a student home, with travel and accommodation being financed by the state (Nelson, Palme, & Eneroth, 2019).

It is important to note that the number of children with disabilities (or special education needs) in inclusive/mainstream schools is not indicative of the *inclusivity* of the system (for more information on the subject, please refer to Section 4.2), because inclusive education cannot be measured by the number of children with disabilities (or SEN) who are enrolled/attending mainstream classes. While this is an important indication with regards to access to education, a measure of inclusive education can only be taken with regards to the participation and success of learners in the learning process.

The educational system varies widely from country to country, as some of the examples below illustrate.

- In Ireland, education for children with special education needs may be provided in mainstream schools and classes, in special classes within mainstream schools, or in special schools. It is reported that the majority of these students attend mainstream schools with additional supports (Department of Education and Skills, 2016). There are over 140 special schools in the country, which tend to be disability-specific (Daly, 2019).
- In Lithuania, the choice of which school the child attends is left to the parents, with special education being the frequent option, reportedly due to lack of parental awareness, pressure by professionals, and an unadjusted environment in the mainstream schools (Poviliūnas & Sumskiene, 2019).
- In Poland, children with disabilities can start and finish education at a later age than mainstream students, and parents have the option to enrol their children in either mainstream schools or special schools, or provide home schooling. Education in mainstream schools is provided in either 'integration sections (comprising a maximum of 20 pupils, of which up to 5 children with disabilities), or in special sections set up for pupils with 'SEN' (comprised of 4-16 children) (Topińska, 2019, p.22).
- In Slovenia, children with 'special needs' can be enrolled in inclusive education, special classes, or special education institutions. Children with SEN are entitled to free additional hours/lessons of professional aid, a permanent attendant, and additional professional assistance (Stropnik, 2019).
- In Spain, students with 'special educational needs' are considered to receive education in an inclusive setting if they spend at least 80% of the school day in mainstream classes (EASIE, 2016). However, the Country Report indicated an upward trend in the referral of SEN students to special education centres.

Accessibility seems to be a sizeable problem in the following countries.

- In Bulgaria, it is reported that many schools are not accessible, preventing children with disabilities from attending school (Bogdanov, 2019).
- In Estonia, only 20% of schools are reported to be accessible, and a large percentage of parents of children with severe disabilities report difficulties in accessing education (Anniste, 2019).
- In Greece, although Law 3699/2008 foresees that all school units in the country, as well as the relevant educational material, should be accessible to children with disabilities, in practice a large proportion of school buildings do not even meet the minimum standards of physical accessibility (Ziomas, Mouriki, Capella, & Konstantinidou, 2019).
- In France, children with disabilities experience difficulties in accessing school premises and there is lack of support staff (Legros, 2019).

- In Italy, only 32% of schools are physically accessible and resources (both material and staff) are unevenly distributed amongst schools (Raitano, 2019).
- In Latvia, obstacles regarding physical access and content accessibility are still present in the lives of students with disabilities (Lace, 2019).

Children with disabilities are reportedly **denied their right to schooling** in the following countries.

- In Bulgaria, children who cannot access school are given the status of 'student on individual plan' (Bogdanov, 2019), with their education being, thereafter, reliant solely on their household.
- In France it is reported that children with disabilities are occasionally refused access to school (Legros, 2019).
- In Greece it is reported by the Ombudsman that there is an extensive number of cases of violation of existing legislation regarding the enrolment of children with disabilities in formal education, especially for those children who are seeking to enrol in the general public schools (Ziomas, Mouriki, Capella, & Konstantinidou, 2019).
- In Hungary, mainstream schools are not obliged to admit children with special educational needs. Children with severe or multiple disabilities are mostly educated at home or in a residential institution (Albert, 2019).
- In Lithuania, any mainstream school can deny admission to a child on the basis of lack of reasonable accommodation (Poviliūnas & Sumskiene, 2019).
- In the Netherlands, a child may be exempt from attending school by the local school attendance officer if, among others, they are 'physically or cognitively unable to undergo schooling' (p.18), or if the 'parents favour a different outlook on life' (p.18) from the one that the schools of the area provide (van Waveren et al., 2019).

Other specific problems in access that seem to be country-specific are listed below.

- In Latvia, data do not reveal the number of children who are home-schooled, whose numbers seem to be particularly high, although unknown (Izglītības iniciatīvu centrs, 2013).
- In Lithuania, home-schooled children are counted within the list of children in mainstream schooling, which does not allow for an accurate perception of educational distribution (Poviliūnas & Sumskiene, 2019).
- In the Netherlands, special schools are available from primary school age and are divided into clusters depending on the child's disability (van Waveren et al., 2019).
- In Romania, the school segregation of vulnerable children (including children with disabilities) leads to a fast dropout rate from education (Pop, 2019).

3.4 Overall situation of children with disabilities in terms of problems of access to free healthcare in the Member States

The Country Reports document serious shortcomings in healthcare provision and barriers for disadvantaged groups to access them. The systemic issues listed below have an even greater impact on children with disabilities.

Indeed, children with severe limitations in daily activities are at a higher risk than other children of living in a household where a medical examination or treatment is not received when needed, or dental care treatment is not available, in a non-negligible number of countries. Overall, in almost all cases, early detection and early identification of disabilities is not well established, and there is a lack of technical capacity and/or lack of available resources to provide specialised and targeted support to children with disabilities. According to the online consultation report (FSCG, 2019, p.11), 'for children with disabilities, the most frequently cited barrier in respect of access to healthcare is non-adaptation to children's needs (by 51% of respondents), followed closely by the non-availability of services (50%) and problems of physical access (46%) (…). Affordability is also seen in many countries as a major barrier, especially in Bulgaria and Romania (by 56% of respondents)'.

According to the Country Reports, general medical care for children is reportedly **not free of charge/requires co-payments** in 8 countries: Austria – children with disabilities are exempted from prescription fees and daily allowances for in-patient care (Fink & van-Linthoudt, 2019); Belgium – but basic dental care, vaccinations and first mental healthcare consultation are fully reimbursed (Nicaise et al., 2019); the Czech Republic – healthcare is universally guaranteed, but co-payments exist for medical supplies and prescriptions exceeding the reference price, and for a flat payment for emergency care (Alexa et al., 2015); Cyprus – entitlement to free health varies according to annual income; Ireland – there are some free services for children, such as two postnatal family doctor visits, health services for pre-school children, school health services and vaccination (Health Service Executive, 2017; Daly, 2019); Italy – based on an individual's income, but all inpatient treatments are free for children and paediatric care is free for children under 15 (Raitano, 2019); Luxembourg – around 7% healthcare is prepaid by the patient, who then applies for reimbursement of 80-100%, depending on the service (Swinnen, 2018; 2019); and the Netherlands – this cost is covered by the Dutch government for children up to 18, as long as they are included in one of the parents' insurance plans (Kroneman et al., 2016).

Healthcare is **free for all children, including children with disabilities**, according to 17 Country Reports:

- Bulgaria – paediatric and specialised medical care (Bogdanov, 2019);
- Croatia – children and students are exempt from co-payment fees, but payment for medication varies from fully covered to co-payment or to full payment (Zrinščak, 2019);
- Denmark – free for all children, including children with disabilities ; in addition, children have added access to free dental care (Kvist, 2019);
- Estonia – including dental care up to age 19, with small fees for home visits and specialised care, that are waived for children under 2; medication is subject to payment but this can be reimbursed (Habicht et al., 2018);
- Finland – including dental care; long queues and waiting times may exist (Kangas, 2019);
- Germany – children and adolescents are always exempt from co-payments, though the system is insurance-based (Hanesch, 2019);
- Greece – all children have the right to receive free public healthcare services, regardless of their insurance status (Ziomas, Konstantinidou, & Capella, 2018);
- Latvia – exceptions apply to medication that is not generic (Lace, 2019);
- Lithuania – free access to almost all standard services including medicines, dental care, and rehabilitation (Murauskienė & Thomson, 2018);
- Malta – children have additional services such as school medical services, vaccination, specialised services if necessary, and routine check-ups up to the age of 16 (Vassallo, 2019);
- Poland – some out-patient treatment, medicines and therapeutic appliances may be only partially refunded, but medical services are free in public institutions (Topińska, 2019);
- Portugal – exemption from user fees is guaranteed to all children (Perista, 2019);
- Romania – children can access any health service, regardless of the insurance status of their family (Pop, 2019);
- Slovenia – coverage can be extended until age 26, if enrolled in regular schooling (Zakon o zdravstvenem varstvu in zdravstvenem zavarovanju (ZZVZZ), 1992);

- Spain, with universal coverage and legal exemption from pharmaceutical co-payment for the TG – however, this measure is not well integrated (Rodríguez Cabrero & Marbán Gallego, 2019);
- Sweden – with the exception of acute care in hospitals, which is subject to a fee; medicine is free of charge for children (Nelson, Palme, & Eneroth, 2019); and
- the UK, where children are exempt from all charges (Bradshaw, Rees, Glendinning, & Beresford, 2019).

Data from the Inception Report (FSCG, 2018) show that in the majority of European countries children with severe limitations in daily activities also had a higher incidence of living in a household where at least one child did not have medical examinations or treatment when needed, with the same being true for dental care needs.

Policies related to access to healthcare for children with disabilities are reported in 11 Country Reports. Regardless of a policy indicating specific provisions for children with disabilities, 11 out of 28 Country Reports indicated problems for children with disabilities in accessing healthcare, as follows:

- In Croatia, problems arise from a lack of co-ordination between structures, a lack of places (beds) in hospitals and rehabilitation facilities, a lack of training and medical specialisation, difficulties in early detection, and a low rate (40%) of early intervention among children registered in the social welfare centres (Ombudsperson for Persons with Disabilities, 2017).
- In Cyprus, although healthcare is provided free of charge to people experiencing specific chronic illnesses and disabilities and for groups considered vulnerable, many parents of children with disabilities resort to private healthcare services to close the gap between the limited services offered by the public system (mostly through special education schools) and the child's needs. This is especially visible in the age group 0-5, as there is no provision of public rehabilitation services (Stylianou, 2017).
- In the Czech Republic, children with disabilities still face issues relating to the adaptability and acceptability of these services (Sirovátka, 2019).
- In Greece, there is a profound imbalance of healthcare services provision, mainly due to the geographically uneven distribution of healthcare infrastructure and services, especially for children with disabilities (Ziomas, Mouriki, Capella, & Konstantinidou, 2019).
- In France, waiting lists for diagnosis and the beginning of treatment for rare diseases (the cause of 20-35% of child disabilities) are quite long, with over 50% of patients waiting over 18 months (Legros, 2019).
- In Germany, only a small share of medical practices and services have barrier-free access (Hanesch, 2019).
- In Lithuania, most of the healthcare facilities are not accessible to persons with disabilities, with around 68% being partially adjusted (requiring the help of an assistant) (Lithuanian Society of Persons with Disabilities, 2017).
- In Poland, access to specialised care for issues such as mental health, allergies, diabetes or rare diseases is problematic (Topińska, 2019).
- In Romania, there is a lack of support and specialised services; there are weaknesses in systems for early detection of disability; and there is under-diagnosis of many mental health issues (Pop, 2019).
- In Spain, there is a difficulty in responding effectively to the diversity of disabilities, with a reported lack of health protocols related to different disabilities in children (Rodriguez Cabrero & Marban Gallego, 2019).

- In the UK, there are wide local variations in the types of care that are available, with poor co-ordination between services and delays in obtaining referrals affecting many children. In addition, delays can be expected in the provision of, for example, wheelchairs (Bradshaw, Rees, Glendinning, & Beresford, 2019).

On a positive note, processes to facilitate the access to healthcare for children with disabilities were found in 7 Country Reports as follows:

- In Denmark, children are monitored by a family doctor, who can refer them to special treatment/specialised doctors if needed. Children with disabilities have access to a special dental care system, which can be co-paid up to a maximum fee per year (Kvist, 2019).
- In Estonia, medication for chronic illnesses is 90% reimbursed for children between 4 and 16 years of age and for persons with disabilities but a €2.50 co-payment per prescription is charged (Habicht et al., 2018).
- In Hungary, support is granted for medicines and therapeutic equipment for people with disabilities who possess a free medication card, thought this is limited to the items listed in the law (Albert, 2019).
- In Lithuania, after the diagnosis of a disability, persons up to 18 years are prescribed repeated rehabilitation for the first three years after the recognition of disability and supportive rehabilitation is prescribed every year afterwards, according to medical indication (Ministry of Health of the Republic of Lithuania, 2008).
- In Malta, the CDAU Child Development Advisory Unit is an instrument to detect any disability at a very early stage.
- In Poland, children with disabilities are entitled to some additional services such as rehabilitation and co-financing of specialised appliances and of ‘rehabilitation holidays’ (referred to as having the participation of a parent); they are also entitled to receive specialised treatment without queues – that is, in the same day they apply – and without referral from the general practitioner. However, parental stay at the hospital is not free (Topińska, 2019).
- In Slovenia, children with developmental disorders undergo preventive health examinations or, if necessary, ‘intentional examinations’, both of which are adapted to the child’s problems (Stropnik, 2019).

Finally, in Germany there should not, in principle, be any difference in access for children with disabilities; however, the overall experience of both children with disabilities and their parents is that their physical and mental health is somewhat worse than that of the general population (Hanesch, 2019). In Sweden there are no special programmes for children with disabilities, and reportedly no special issues with regard to access to free healthcare (Nelson, Palme, & Eneroth, 2019) – this statement seems to be contradicted by the information provided by the FSCG Inception Report (FSCG, 2018). In Latvia, there is reportedly no research available on the accessibility of healthcare services for children with or without disabilities (Lace, 2019).

3.5 Overall situation of the target group in terms of problems of access to decent housing in the Member States

There are different dimensions as to what constitutes decent housing[9]. According to Clark-Foulquier and Spinnewijn (2019), families of children with disabilities face two types of challenges related to housing: adequacy of existing housing, and cost overburden. First, existing housing is often not adequate to respond to the needs of the family. Second, housing costing overburden is experienced in many countries. According to the online consultation report (FSCG, 2019, p.12), 'In the case of access to housing, problems of affordability (52%), problems of physical access (49%), and non-availability of the services in the area (42%) are the three barriers cited most, though non-adaptation to children's needs (40%) is a close fourth, and the third most cited barrier in many countries'.

As can be seen below, there is little specific information on the situation of children with disabilities with regards to their housing situation. Using the information collected on children's health in EU-SILC 2017 (see above), the EU indicators, usually calculated to assess the housing conditions of the whole population, can be calculated for children with activity limitations. As was the case for access to healthcare, overall, children with (severe) activity limitations are more likely to face severe housing deprivation and overcrowding, have more difficulty in keeping their house warm, and experience housing cost overburden more often than their peers without disabilities (FSCG 2018). These data can be compared with some national information on children with disabilities' access to housing.

Information on Estonia (Clark-Foulquier & Spinnewijn, 2019) shows that although 41% of families with a child with a disability need to adapt their living quarters, financial support is not provided by the state. However, local authorities are required to assist people with disabilities in adapting their dwelling or in obtaining a more suitable dwelling if a person has difficulties moving about, caring for themself or communicating in a dwelling as a result of a disability. In the Netherlands, in spite of the possibility for parents of children with disabilities to apply for financial support to adapt the house to the needs of the children, this target group is referred to as having limited access to decent housing (van Waveren et al., 2019).

In Germany, the municipalities offer special programmes to persons or groups with special housing needs. However, families with children with disabilities reportedly have little chance of finding decent accommodation, especially in metropolitan areas. Like other groups of children, children with disabilities are mentioned as facing massive housing problems (Hanesch, 2019).

In Latvia, there is a reported lack of good-quality housing, with a small social housing stock and limited physical access to housing for children with disabilities (Lace, 2019). In France, it is reported that the situation of children with disabilities is very rarely taken into account (Legros, 2019).

In Lithuania, it is reported that the total number of homes adjusted for people with disabilities (with no mention of how many are children) was 1,402 between 2007 and 2011 (Committee on the Rights of Persons with Disabilities, 2014).

In summary, and as indicated in the FSCG Inception Report (2018) and in Clark-Foulquier and Spinnewijn (2019), there is a marked lack of data related to housing in general, and an even more accentuated lack of information in relation to each of the TGs, including children with disabilities. As indicated in Clark-Foulquier and Spinnewijn (2019), there is a multitude of realities, with vast differences between urban and rural areas. Being poor, living with a disability, living in a single-adult household, having a migrant background or leaving a residential institution increases the risk of severe housing deprivation. But, while Clark-Foulquier and Spinnewijn (2019) acknowledge the likelihood of deprivation being higher for each of the TGs, and a confluence between poverty and disability, it does not explore the exponential likelihood in case where there are multiple deprivation factors, probably due to the lack of reliable and TG-specific data. Therefore, it is important to keep

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[9] For a detailed discussion see Clark-Foulquier and Spinnewijn (2019).

in mind that global research (Banks, Kuper, Polack, & van Wouwe, 2017) indicates that disability and poverty are thought to operate as a cycle, with 81% of studies showing a positive relationship between poverty and disability across all types of disabilities.

3.6 Overall situation of children with disabilities in terms of problems of access to free ECEC in the Member States

ECEC covers all regulated arrangements that provide education and care for children from birth to compulsory primary school age – regardless of the setting, funding, opening hours or programme content – and includes centre and family day care; privately and publicly funded provision; and pre-school and pre-primary provision.

Global evidence points towards the undeniable importance of ECEC for all children and, in particular for children from vulnerable backgrounds and children with disabilities. ECEC is not only essential in maximising the potential of all children, but is crucial in identifying and addressing developmental delays and health conditions that may lead to disabilities later in life.

However, as can be seen below, enrolment rates differ widely between countries (see FSCG, 2018) and **ECEC is free** in only a few countries in the EU, and only conditionally: Austria[10] (oesterreich.gv.at, 2019); Cyprus[11] (Koutsampelas et al., 2019); Germany (Hanesch, 2019); Italy, for children aged 3 to the compulsory school age (Raitano, 2019); Luxembourg, for children aged 1-3, for 20h/week (Swinnen, 2019); Malta (Vassallo, 2019); and Spain, for children aged 3-6 (Rodríguez Cabrero & Marbán Gallego, 2019).

According to the European Commission (2018), data from selected countries indicate that the main reasons for an unmet need for ECEC are (for all children), as shown in Table 3.2.

Table 3.2: Main barriers that need to be overcome by kind of service for children with disabilities

	Financial	Shortage of spaces	Hours not convenient	Distance	Poor quality	Other
Austria	48	16				25
Croatia	57	22				22
Czech Rep	32	24	6	3	2	34
Cyprus	40					
Denmark	11	6	26	6	3	47
Estonia	39	14				
Finland	22	28	14			
Hungary	59					
Latvia	41					
Luxembourg	41	21				

Source: European Commission, 2018.

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[10] The last year of kindergarten is free of charge up to 20 hours per week (Oesterreich.gv.at, 2019).

[11] Only 4% of available nursery schools in Cyprus are public, and thus free, and 31% are partially subsidised by the state (Koutsampelas et al., 2019).

As is the case with free compulsory education (above), and despite normative frameworks for inclusive education that make separate setting unlawful, there are **separate/special ECEC institutions or classes** for children with disabilities in:

- Belgium, in both Flanders[12] (Kind & Gezin, 2017) and Wallonia-Brussels (Office de la Naissance et de l'Enfance, 2017);
- Croatia[13] (Ombudsperson for Persons with Disabilities, 2018);
- Czech Republic (Sirovátka, 2019);
- Greece (Ziomas, Mouriki, Capella, & Konstantinidou, 2019);
- Lithuania[14] (Poviliūnas & Sumskiene, 2019);
- Netherlands[15] (VWS/ CAK, n.d.);
- Poland[16] (Topińska, 2019);
- Slovenia (Statistical Office of the Republic of Slovenia, 2019); and
- Spain (Rodríguez Cabrero & Marbán Gallego, 2019).

Limitations in the access to ECEC for children with disabilities are felt in the following countries.

- In Bulgaria, there are virtually no accessible environments or specialised support, with limitations on the number of staff members and large numbers of children per group (Bogdanov, 2019).
- In Estonia, local governments are often unable to ensure local daycare for all children with disabilities (Anniste, 2019).
- In Greece, there is very limited access to ECEC for children with disabilities, with the available services being provided by non-governmental agencies (National Confederation of Disabled People, 2019) or by the public sector – in Integrated Care Child Centres for those aged between 2½ and 6½, or in Creative Centres irrespective of age. These places are, however, subject to availability and rather limited (Ziomas, Mouriki, Capella, & Konstantinidou, 2019).
- In Latvia, access to ECEC institutions for children with disabilities is reported as a challenge (Lace, 2019).
- In Romania, the access of children with disabilities to ECEC is rather limited as facilities that ‘are able to address these issues’ (p.20) are scarce and unevenly distributed (Pop, 2019).
- In Poland, a study found that only 920 children with disabilities under 3 years old attended ECEC, with the share of enrolment being 1.8% of all children; and that only 38% of facilities were adapted to their needs (GUS, 2018).

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[12] In Flanders, children with disabilities who attend regular childcare centres are not registered (Nicaise et al., 2019).

[13] In 2017, 6,634 children with disabilities attended kindergarten, 628 (9.5%) of whom within special educational groups and 356 (5.4%) in programmes offered by special education institutions (Ombudsperson for Persons with Disabilities, 2018).

[14] In 2015, 79 ECEC centres were open either exclusively for children with ‘SEN’ or had a group specifically for these children. Children with disabilities can attend a mainstream ECEC setting in either an inclusive or special group, or a segregated special education centre (Poviliūnas & Sumskiene, 2019).

[15] In the Netherlands, children with disabilities can access daycare support, offered through the health system (VWS/ CAK, n.d.). There is no mention of whether they have the option of attending the privately owned ECEC institutions in the country.

[16] Children with SEN statements may attend either mainstream kindergartens (in special or integrated sections) or special kindergartens, as decided by their parents (Topińska, 2019).

According to the online consultation report (FSCG, 2019, p.11), ‘non-adaptation to children’s needs (52%) and problems of physical access (45%) are also two of the three of the most often cited barriers to accessing ECEC for children with disabilities. The most frequently cited barrier, however, is the non-availability of services or facilities in the local area (56%). The barriers identified as being most important are much the same across countries, though in countries with a very low level of child deprivation, the three Nordic countries plus Luxembourg, lack of awareness rather than problems of physical access is the third most frequently reported barrier (by 48% of respondents)’.

As **positive examples**, the following countries have strategies to facilitate access to ECEC by children with disabilities:

- Cyprus, where priority in enrolment is being given to children with special education needs, irrespective of age (Koutsampelas et al., 2019);
- Denmark and Finland, where children with disabilities have the same rights to ECEC as other children, and institutions are prohibited from barring them (Kvist, 2019);
- Luxembourg, where ECEC institutions and parents can call upon the support of one of the eight specialised support centres for children with special needs (Swinnen, 2019);
- Malta, where children with disabilities are enrolled in the public ECEC system along with other children, and their development accompanied through the transitions between school levels and with the provision of additional support when needed (Vassallo, 2019);
- Poland, where children with disabilities are given priority and it is expected that parents are provided with clear information on the accessibility of the premises (Topińska, 2019); and
- Sweden, where children with disabilities are given priority for a place in a pre-school setting (Nelson, Palme, & Eneroth, 2019).

A disconnect between the expectations and reality of ECEC for children with disabilities seems to exist in:

- Germany, where children with disabilities have, like all children, access to free ECEC, but they are insufficiently integrated into mainstream services (Hanesch, 2019);
- Slovakia, where the same source mentions that children with disabilities or with chronic illnesses may face problems with access to ECEC, but also that this fact does not limit their participation in ECEC (DIA SK, 2017);
- the UK, where it is expected that children with disabilities will be enrolled in mainstream facilities, but where parents report significant difficulties in finding ECEC for their children (Bradshaw, Rees, Glendinning, & Beresford, 2019); and
- the Czech Republic, where a unique situation is in play, as it is reported that since 2013, no ministry is in charge of nurseries, i.e. ECEC, for children under 2 years old (Sirovátka, 2019).

Data regarding the above-mentioned topics for children with disabilities could not be found in other Country Reports.

Overall, the main barriers for children with disabilities and their families present across the EU are: 1) lack of political will and vision for social inclusion; 2) lack of understanding of what constitutes inclusive policy and programming; 3) lack of coordination across policies and gaps between existing policies and practice; 4) continued vested interests in institutional and segregated services; and 5) inadequacy or lack of community-based services that can provide support to children with disabilities and their families from early identification and intervention and throughout the life cycle.

4. Description and assessment of main policies and programmes in place in the Member States and recommendations for improvements

For the remainder of this section, and as needed for context, an overview of policies that cover all children will be provided (mainstream policies), to underpin or highlight the lack of policies aimed at children with disabilities. While this report is meant to be focused on children with disabilities, it is important to note that, in many cases, the argument for better policies for children with disabilities cannot be made without making the argument for better policies for all children (twin-track).

4.1 Description and assessment of main policies to ensure adequate nutrition and recommendations for improvements

While a lot of information exists (globally and in the EU specifically) about adequate nutrition for the general population including children, few pieces of legislation could be found. The detailed review of the Country Reports shows that most countries indicate a lack of adequate policies related to children, and even fewer related to the TGs. In some cases, policies exist that have not been evaluated for impact.

According to Country Reports, there are a variety of policies which potentially have an impact on children's nutrition. As detailed in Bradshaw & Rees (2019), these are policies that:

1) refer to the extent to which families with children have sufficient means to ensure health nutrition for children;
2) mitigate inadequate income and prevent child malnutrition (health checks, school meals, etc.);
3) encourage breastfeeding;
4) promote healthy eating; and
5) ensure the dietary needs of children with disabilities are met.

Overall, Country Reports were mostly silent on mainstream policies related to breastfeeding and healthy eating (see 3 and 4 above), 2 Country Reports indicated a policy to ensure sufficient means for health nutrition for children (1 above), while the bulk of the existing policies address nutrition (including nutrition for specific populations) through school programmes (2 above).

Policies on nutrition for the mainstream population of children, with the potential to affect nutrition of children with disabilities, could be found in some Country Reports, as follows:

To ensure sufficient means to ensure health nutrition for children (1 above).

- In Germany, **children with special and costly nutritional requirements (due to illness or disability)** can apply for additional benefits, if the household income is not sufficient to cover the cost and if they receive minimum income benefits. These require a recommendation by a doctor, and the percentage increase in the benefit is not defined by law but merely recommended (between 10 and 20%, depending on the condition) (Deutscher Verein (für öffentliche und private Fürsorge), 2014).
- In the Czech Republic, supplementary allowances up to the subsistence level are provided to **people who follow a special diet** (which may or may not be related to a disability) based on the recommendation of a doctor (Sirovátka, 2019).

To **mitigate inadequate income and to prevent child malnutrition** (see 2 above).

- In Belgium, primary schools and schools for special secondary education can receive a subsidy for providing fruit, vegetables and/or milk to their students under the project 'Oog Voor Lekkers' (an eye for a tasteful snack). This project aims to address all children, but schools with a certain percentage of **vulnerable pupils and special education schools** have priority in the selection for participation and receive the subsidy for an extended period (Oog Voor Lekkers, n.d.).

- In Finland, in ECEC/pre-school settings three meals are provided for free, free meals are available in basic schools, and highly subsidised 'student meals' are available in the **second and third grade**, **with special dietary needs** taken into consideration at all levels.
- In the Netherlands, the current National Prevention Agreement (2018-2040) includes, as a specific key activity, the development of a dedicated school intervention **programme for children with special education needs**, to promote a healthier lifestyle. The Healthy School programme prioritises, in its funding, **secondary schools for children with special education needs** (van Waveren, De Vaan, Krop et al., 2018).
- In Slovenia, a free snack and lunch are offered to **students with special needs** in primary school, and a snack in upper secondary school (Zakon o uveljavljanju pravic iz javnih sredstev, 2010). School meals are subsidised. They are free only for children from families with a per capita income below a certain income threshold.
- In Sweden schools are obliged to provide a **special diet** to students with allergies, celiac disease or other hypersensitivities. Pupils in need of a special diet due to other conditions may have individually adapted dietary advice from the healthcare sector, and schools need to engage in dialogue with the caregivers/parents on how to best accommodate such advice. All school meals are provided for free. Children up to age 16 are entitled to receive certain milk, and gluten/soy-free specialty products on prescription (€12 is charged per prescription) (Nelson, Palme, & Eneroth, 2019).

To ensure the dietary needs of children with disabilities' are met (5 above).

- In Bulgaria, policy covers only educational establishments and institutional care – where **children with disabilities'** nutrition is regulated by the Healthy Nutrition Regulations of the Ministry of Health, but seldom followed (Bogdanov, 2019).
- In Romania, children with '**special educational requirements'** receive a daily food allowance up to the age of 26 (if attending any form of education). However, none of the income support is explicitly and transparently based on a nutritional requirement (Pop, 2019).
- In Slovakia, **children with disabilities can apply** for an 'allowance for compensation of increased expenditure for special diet', depending on the health issue (Gerbery, 2019), although the Country Report also recognises that cash measures do not necessarily indicate policy compliance.
- In Portugal, **children with disabilities** are entitled to a fully funded lunch at their school canteen (Perista, 2019).

There are no specific policies regarding the nutrition of children with disabilities in the remaining Country Reports, and no litigation related to nutrition could be found with regards to children with disabilities in the EU.

As reported by Bradshaw and Rees (2019), in most cases the described benefit systems do not address the additional costs associated with providing adequate nutrition to children with disabilities with dietary needs which, as mentioned, 'was identified as an additional risk factor for household poverty' (p.15) in some countries. In addition, 'there was a lack of broader adaptation of systems and services for disabled children with specific nutritional needs. This included availability of quality food; information and training for professionals and parents; and lack of recognition of specific needs of this group of children in national nutritional policies and guidelines.' (p.15).

In addition, the analysis indicates that **mainstream instruments related to nutrition do not sufficiently address** the specific needs of children in general, or the needs of children with disabilities in particular. First, despite ample research on the positive impact of breastfeeding on child development and the need to promote healthy eating, no Country Report indicates this to be considered at the policy level. Second, following up on the obvious links between disability and poverty made in this and other reports, it is concerning that only 2 countries outline a clear policy to address the potential cost and overburden on families when providing adequate nutrition to children requiring a special diet (who may or may not be children with disabilities). Third, while it is promising to see policy related to nutrition in 5 Country Reports, it is concerning that the adequate nutrition of children from vulnerable groups – including children with disabilities – is left up to school policies, taking into consideration the high number of out-of-school children in the EU. If nutrition is only addressed in school policy, children who are not in school (probably those with high levels of service needs) are not covered by any policy, strategy or action on nutrition. Fourth, in almost all cases above where mainstream policies mention children with special needs, allergies, dietary specifications etc., policies are conditional, creating an additional burden on families with children with disabilities.

Existing policies specifically targeting children with disabilities were reported in only 4 Country Reports (Bulgaria, Romania, Slovakia, and Portugal: see above) and none sufficiently addresses the potential needs of children with disabilities with regards to nutrition. In Bulgaria, the policy applies only to children with disabilities in segregated settings, while in Romania and Slovakia the policies are related to cash allowances that may or may not be used as intended. In Portugal, provisions are, once again, related to school provision, leaving out all children with disabilities of school age who do not attend school.

Overall, the right to nutrition has not been, for the most part, clearly outlined in policy with regards to children in general and children with disabilities in particular. While many of the countries above specify policy decisions that were taken to address children with specific health conditions, a health condition is not necessarily indicative of a disability (see Section 2.1 above). Therefore, there are only a few cases where it is possible to argue that children with disabilities have been taken into consideration when designing policy on nutrition. In general, and taking into consideration the fact that many Country Reports did not include information on nutrition related to the TG, the lack of legally binding obligations in most EU countries denies the rights of children with disabilities to adequate nutrition.

In terms of **policy recommendations**, as is the case with all other policy areas, a twin-track approach is required to ensure that nutrition policies (mainstream) adequately address the nutrition needs of children with disabilities, and that additional disability-specific policies exist to provide ‘nutrition-focused support’ (DFID, 2000). The lack of policies on nutrition, both mainstream and specific to children with disabilities, is obvious in the outline above. Even the school-based policies that are aimed at ensuring the adequate nutrition of the entire school population, with a focus on children with disabilities or children with health-related concerns, are not sufficiently broad, because they do not cover all children of school age, but only those who are in school. Where specific policies for children with disabilities exist, they are often conditional and place an additional burden on families, and impact evaluations have not been done to determine their adequacy.

As found in broad literature reviews (Kolset, Nordstrom, Hope, Retterstol, & Iverson, 2018) nutritional policies have not been addressed systematically from a health-promotion perspective in high- or low-income countries. In many cases, issues of nutrition have never been raised or addressed in policy. Lack of research, evidence, and understanding of the links between nutrition and disability is partially to blame for a lack of policy on nutrition, both mainstream and specific policy (Groce, Kerac, Farkas, Schultink, & Bieler, 2013).

The following key priorities in addressing the nutritional needs of children with disabilities (based on those suggested by Bradshaw & Rees, 2019) should be taken into consideration:

- improvements to the benefit systems for the families of children with disabilities, including additional allowances to meet the cost of specific nutritional requirements;
- improvements in the availability of appropriate food to meet different dietary needs in schools and other public services;
- improved levels of services and direct access to services for children with disabilities;
- improved information and training on food and nutrition issues for professionals working with children with disabilities; and
- greater recognition of specific dietary requirements in national policies and guidance.

4.2 Description and assessment of main policies to ensure access to free education and recommendations for improvements

The right of the child to education is, in the EU, enshrined in the CRC, the CRPD, and the EU Charter. Thus, Member States have an obligation to provide free compulsory education in an inclusive education system to all school-age children, without exception. While various interpretations of the **right to inclusive education** are in use in EU Member States, the CRPD in its Article 24 and General Comment #4 (GC4) sets out a framework that must be implemented by EU countries that have ratified the Convention, as well as the EU as a whole. Of particular relevance to this analysis are the provisions and distinctions in terminology the GC4 obliges EU countries to take into consideration, namely the following:

- **Integration** is a process of placing persons with disabilities in existing mainstream educational institutions, as long as the former can adjust to the standardised requirements of such institutions.
- **Inclusion** involves a process of systemic reform embodying changes and modifications in content, teaching methods, approaches, structures, and strategies in education to overcome barriers, with a vision serving to provide all students of the relevant age range with an equitable and participatory learning experience and environment that best corresponds to their requirements and preferences. Placing students with disabilities within mainstream classes without accompanying structural changes to, for example, organisation, curriculum and teaching, and learning strategies, does not constitute inclusion.
- The right to inclusive education is assured without discrimination and on the basis of equality of opportunity. **Discrimination** includes the right not to be segregated and must be understood in the context of the duty to provide accessible learning environments and reasonable accommodation.
- The exclusion of persons with disabilities from the general education system should be prohibited, including any legislative or regulatory provisions that **limit their inclusion** on the basis of their impairment or the degree of that impairment.
- States Parties have a specific and continuing obligation to move as expeditiously and effectively as possible towards the full realisation of Article 24. This is not compatible with sustaining **two systems** of education.

The conceptual and terminological clarifications above serve as the framework for the analysis of the data provided in the Country Reports. The summary and analysis below is based on country reporting on three sets of policies: 1) whether national policy exists that expressly gives the right to free education to all children (with free education taking into consideration tuition as well as most other expenses that may operate as a barrier to access); 2) whether national policy exists that refers to education being provided in an inclusive education system; and 3) whether national policy related to SEN/children with disabilities allows/encourages for education to be provided to children with disabilities in segregated settings – which, as described above, is incompatible with the implementation of inclusive education policy (full segregation, partial segregation or a parallel system).

Table 4.1 (below) summarises the situation (policies and/or practice) in all EU Member States in relation to three sets of policies identified above. In some cases, detail is provided in the table or the narrative below. In other cases, the situation as reported is a legacy of old policies no longer relevant but that continue to be ‘in practice’. In addition, some countries were identified where policies only partially address international obligations. When a box is left blank, it means that no report exists, in any instance.

Table 4.1: countries where policies/practice for free education exist (X), where policies/practice for inclusive education exist (X) and where special/segregated education policies/practice exist (X)

	Free education	Inclusive education	Special/segregated education
Austria		partial	X
Belgium	X (tuition only)	partial	X
Bulgaria	X	X	X
Croatia	X (tuition only)	partial	X
Czech Rep	X (all levels)	X	X
Cyprus	X	partial	X
Denmark	X	X	X
Estonia	X	X	X
France	X	X	X
Finland	X (no books/transport in secondary or tertiary)	X (term is not used)	X
Germany	X (tuition only)	X (differences between lander)	X
Greece	X	partial	X
Hungary	X (tuition and books for SEN students)	X (limited effectiveness)	
Ireland	X	partial	X
Italy	X (tuition only)	X (not enforced)	
Latvia	X	X	X
Lithuania	X	partial	X
Luxembourg	X	X	X
Malta	X (all levels)	X	NO
Netherlands	X		X
Poland	X (no books after primary)	X (integration)	X
Portugal	X	X	
Romania	X	X	X
Slovenia	X (SEN children and primary)	X	X
Slovakia	X	partial	X
Spain	X (differences between regions)	partial	X
Sweden	X	X	X
UK	X	X	

Source: FSCG Country Reports.

In 27 Country Reports there is an indication that **national policy exists that expressly gives the right to free education to all children (including children with disabilities).** In 2 of them, free education extends to all levels of education, beyond compulsory. In another 4 Country Reports, the right to free education is narrowed down to only free tuition, no textbooks or no transportation, in which case families must pay for all additional costs related to school access.

This brief analysis based on Country Reports indicates that although the majority of Country Reports indicate **national policy exists that expressly gives the right to free education to all children**, there is much variation as to what is understood by 'free' education, with some Country Reports indicating that only tuition is free, while others indicate tuition and other expenses are covered by government. This is an important distinction especially considering the existing research on the *hidden costs* of education. Some of the costs of accessing education (such as transportation and accessible textbooks) can be prohibitive for families with children with disabilities.

With regards to **national policies that refer to education being provided in an inclusive education system**, there is wide variation between countries, reflecting the variation in understanding of the concept of inclusive education. 27 Country Reports indicated policies related to inclusive education, although 9 Country Reports indicated partial inclusive education systems, and 3 indicated difficulties in effectiveness, enforcement or outcome. As indicated above, Malta and Portugal seem to have the most developed inclusive education systems. In Malta, 100% of SEN students (including children with disabilities) attend mainstream settings. Numerous pieces of legislation ensure that children with disabilities are included in mainstream education, with support from resource centres and learning support assistants in the classroom, when needed. This process of support continues to the tertiary level (Vassallo, 2019).

23 Country Reports indicated that children with disabilities can be educated in separate settings, even if **efforts to progress towards inclusive education are taking place in parallel with segregated education provisions for children with disabilities**. Some examples are set out below.

- In Austria, the 2012 National Action Plan on Disability announced different measures to implement inclusive education at all levels until 2020 (BMASK, 2012, as cited by Fink & van-Linthoudt, 2019), with one concrete plan being the introduction of three model regions, after which the system would be extended to country level. This plan only encompassed schooling until the ninth year of education, and the model regions were implemented in the 2015-16 school year (Fink & van-Linthoudt, 2019). However, with the 2017 change of government, the maintenance and strengthening of special schools was announced (Regierungsprogramm, 2017). At the time of this report, a Consulting Board has been constituted to decide on a course of action (Fink & van-Linthoudt, 2019). In addition, some allowances are conditional on school enrolment and proving attendance carries a heavy procedural burden.
- In Belgium, a Special Education System, from pre-primary to secondary education, is provided for children with special needs, and a large share of students attend these segregated settings (Nicaise et al., 2019). In the Dutch-speaking community, the adoption of the 'M-decree' was aimed at obliging regular schools to carry out any 'reasonable adaptation' needed to accommodate children with special educational needs. Parents are assisted in making an informed choice between inclusive and special education (Vlaanderen, n.d.). In the French-speaking community, a decree has been adopted to strengthen the integration of students with SEN into mainstream education, with the possibility of four types of integration (European Commission, n.d.).
- In Bulgaria, inclusive education became part of the right to education under the Education Act of 2016, amended in 2017 and 2018. This reform allowed the school to be the centre of support for children, with more teachers and health professionals appointed to schools; a big challenge to full compliance with inclusive education is that many schools are not accessible, forcing those children to 'become students on individual plan', i.e. home-schooled (Bogdanov, 2019).
- In the Czech Republic, legislative measures have been taken to support inclusive education (Act No 561/2004 Coll. On Education) (Sirovátka, 2019); the Inclusive Education Action Plan 2016-2018 (MŠMT/MEYS, 2015a); and the Decree on education of pupils with special educational needs and of gifted learners (Sirovátka, 2019).

Supportive measures, ranging on a five-point scale from light to heavy measures, as well as new diagnostic tools and an increase of teaching assistants, have been some of the changes that allowed for only 3% of pupils to be educated in special classes and 2.4% in schools outside the mainstream system in the 2017-18 school year (Sirovátka, 2019), from 49% in special schools in 2010-11 (MŠMT/MEYS, 2018).

- In Denmark, 'SEN may be provided' (p.17) through in-class support, separate classes or special schools. Children with disabilities may be entitled to free transportation. However, all educational provisions are subject to large variations across municipalities. A new programme has been developed with 'youth with handicap' (p.18) in mind, the specially designed youth education, which is a three-year educational programme aimed at young people who 'cannot finish an ordinary youth education' (p.18) (Kvist, 2019).
- In Estonia, the right to general education is guaranteed and made equally available by the Basic Schools and Upper Secondary Schools Act, regardless of 'special educational needs'. The need to improve the accessibility of education is set out in the Estonian Lifelong Learning Strategy 2020. There is, however, a concern about the suitability and quality of education given to children with disabilities, with low overall accessibility of schools and the need to develop health and support services. Monthly education allowances are available for students with disabilities attending upper secondary schools, vocational schools or higher education, and state-supported places in boarding schools can be provided for basic education if families have difficulties coping. The same legislation states that good-quality general education follows the principles of inclusive education and the principles have been stressed throughout legislation. There is no legislation on special/segregated schools, although these schools still exist in Estonia (Anniste, 2019).
- In France, since 2005, children with disabilities have the right to enrol in the closest school to their home (however, it seems that around 29% of children with a disability are not in school) (Legros, 2019).
- In Germany, special schools provide education for the majority of children with disabilities, and form a separate special school system (Hanesch, 2019).
- In Greece, children with disabilities are entitled to free-of-charge and equal access to public education. In particular, children with disabilities may attend mainstream classes, mainstream classes with parallel support, and integration classes in mainstream schools, or be provided with education in school units of special education, and at home. Vocational secondary schools exclusive to children with disabilities are also available. There have been several legislative efforts to make education more inclusive, but many barriers persist and reliable data are not available (Ziomas, Mouriki, Capella, & Konstantinidou, 2019).
- In Hungary, an inclusive education system is legislated for by the 1997 Act on the Protection of Children, the 2011 Act on National Public Education, and the National Core Curriculum and Guidance on meeting the needs of children with special needs (Ministerial Decree of the Ministry of Human Resources, 32/2012 (X.8.), as cited by Albert, 2019); but this seems not to have had concrete results. As part of the most recent educational reform (2011. CXC. Public education law, in effect from 1 September 2012), compulsory schooling has been reduced from 18 to 16 years of age. Currently, all 1-9 graders receive free textbooks, with the central government selecting two textbooks for each subject. To promote schooling, payment of family allowances is conditional on attendance in education. Based on the Education Act, children with disabilities should participate in 20 lessons per week of development activities or be educated at home (if they cannot take part in state education); in addition, special skills development schools exist in the country, for pupils with moderate intellectual disability (Albert, 2019).
- In Ireland, children with disability have the right to free primary education up to the age of 18. Education for children with 'special needs' may be provided in mainstream classes, special classes in mainstream schools or in special schools. Several educational

policies (such as the Education Act 1998, Education (Welfare) Act 2000, Equal Status Act 2000-2004, Education for Persons with Special Educational Needs Act 2004, and Disability Act 2005) have highlighted the need for inclusive education, though never fully disconnecting from the provision of special education (Daly, 2019).

- In Italy, school attendance is a prerequisite for the attribution of family benefits. The Legislative Decree No 66 of April 2017 requires schools to improve the quality of inclusion of students with disabilities. However, it seems that this decree is largely unenforceable (Raitano, 2019). No information is provided as to policies regulating the cost of education, nor as to how education is delivered to students with disabilities.
- In Latvia, access to education by children with disabilities is limited; children with disabilities are over-represented in special education programmes and institutions, and under-represented in mainstream schools. Under the Law on the Protection of the Rights of the Child, the state guarantees equal rights and possibilities for all children to acquire education appropriate to their abilities; the law on education states that a person with special needs may acquire special education at an educational institution and stipulates that general primary and secondary education institutions may integrate students with special needs (Lace, 2019). The educational policy seems to be one of segregating students with disabilities, with the optional and occasional integration into mainstream schools, with inclusion not being mentioned.
- In Lithuania, the Action Plan for inclusion of children in diverse education 2017-2022 (Lietuvos Respublikos švietimo ir mokslo ministerija, n.d.) sets out measures to improve the inclusion of students with special needs in the general education system. It also aims to reorganise 75% of special schools by 2022, and to develop digital educational programmes, among other measures (Poviliūnas & Sumskiene, 2019).
- In Luxembourg, ‘all children are expected to be served in regular educational settings, except if special (temporary) measures are necessary. The pupils and their parents have the final decision’ (p.20). However, segregated education environments were still a reality according to the 2017 CRPD progress report. In 2018, 8 specialised centres were created to support the inclusion of children with disabilities in mainstream education and to provide training for teachers and educational staff. Subsidies are in place to enable schools to finance reasonable accommodation. Specialised public transport services were established to facilitate the inclusion of all citizens with a disability, enabling many students to reach their school (Swinnen, 2019).
- In the Netherlands, children with special needs attend special education, divided into clusters depending on the child’s impairment (van Waveren et al., 2019).
- In Poland, the Educational Act of 2016 and two further regulations of the Ministry of Education are aimed at adapting the teaching process to children’s capabilities, making education more inclusive (Topińska, 2019).
- In Romania, children with ‘special educational needs’ are given a daily food allowance and an annual allowance (between €73 and €183, in 2017) for clothing, sanitary products, school supplies, and transportation, with the same conditions applying. In spite of several bans on the educational segregation of children, among them children with disabilities, there is no clear monitoring framework to assess their success (Pop, 2019).
- In Slovakia, the segregation of children with disabilities into a special education stream persists, although inclusive education was legally defined for the first time in 2015. Efforts are currently underway to differentiate children with disabilities from those who live in socially disadvantaged backgrounds, and while measures are being made to include the latter in mainstream education, no policies are designed to extend that inclusion to children with disabilities (Gerbery, 2019).
- In Slovenia, the education system for children with ‘special needs’ is multi-track, meaning that children can attend mainstream classes, special classes in mainstream schools, and special education institutions. Primary and secondary education is free of charge in public schools and in special education institutions (Stropnik, 2019).

- In Spain, the majority of students with 'special educational needs' receive education in inclusive settings (see Section 3.3 for the legal definition of inclusive setting), though special education centres remain (Rodríguez Cabrero & Marbán Gallego, 2019), with children with behavioural or mental health disorders being referred to them due to a lack of resources in recent years (Plataforma de Infancia, 2017).
- In the UK, all schools must have systems to identify children needing extra support and to secure that support. School reports must be published on the improvement of accessibility and of further plans to extend it. Nevertheless, children with disabilities may be temporarily or permanently excluded from school, being educated at home with the support of local authorities. This support must be given until the age of 25, and local authorities can be legally challenged if found not to be complying with their duties (Bradshaw, Rees, Glendinning, & Beresford, 2019). There is no mention of what that support may look like for children deemed not able to attend the local school.

In summary, only 1 Country Report did not refer to the existence of national policy on **education being provided in an inclusive education system**, which is mandated by global and EU treaties and norms. However, as reported above, definitions of inclusive education and policies vary greatly among countries.

National policy that refers to education being provided in an inclusive education system **exists in parallel with policy and practice commitments to segregated settings** in the majority of Country Reports. Partial policies on inclusive education exist in 9 out of 28 countries, with an additional number of Country Reports indicating a range of difficulties either in clarity of the policies or the existence of concurrent policies with opposing aims or lack of clarity and commitment at the implementation level (Belgium, Lithuania, Luxembourg, Poland, Slovakia, Slovenia, and Spain), or implementation difficulties in various forms (Austria, Croatia, Romania, and the UK). While various countries reported progress, slowly moving towards less segregated practices (Dutch-speaking and French-speaking communities in Belgium, the Czech Republic, Lithuania, and Poland) there are no reports on the impact of these implementation efforts on the rights of children with disabilities to inclusive education. Likewise, a number of countries (e.g. Greece, Hungary, and Ireland) reported that a range of possible settings are available to children with disabilities (often at parents' discretion). As described at the start of the Section, a range of settings from more to less inclusive is not envisioned in GC4, and does not constitute inclusive education. The existence of policies without adequate and rigorous monitoring and evaluation does not guarantee that the rights of all children are protected and/or fulfilled.

In summary, mainstream instruments related to free and inclusive education do not sufficiently address the specific needs of children in general, or the needs of children with disabilities in particular. Free education is mentioned in 27 Country Reports but there are wide variations among countries; while in some the concept of 'free education' is reduced to free tuition, in others it is extended to all levels of education. 'Free education' is often connected to compulsory education, which also varies greatly among Country Reports.

The situation of children with disabilities vis-à-vis their right to inclusive education in EU Member States is dismal. While the existence of policies is no guarantee of their implementation, in many cases conflicting policies (such as having concurrent inclusive and special/segregated provision) and antiquated views of disability (in policy) have created and are sustaining dual systems of education that are incompatible with normative obligations. Therefore, **specific instruments related to education for children with disabilities do not sufficiently or adequately address the needs** of the TG. Despite normative rules that oblige the EU and each Member State to the contrary, 23 Country Reports indicated that policies exist that allow for children with disabilities to be educated in segregated settings. These range from residential institutions to special schools, special classes within regular schools or home schooling. In some instances Country Reports indicate that these policies exist in parallel with more recent inclusive education policies and that progress towards more inclusive practices is taking place.

Recommendations are provided by policy area but also by highlighting some of the most urgent obligations of some Member States.

First, **free education** should go beyond the concept of free tuition. As mentioned above, while access to education is important, the obligations of EU Member States extend to ensuring participation in inclusive education systems. Therefore, free education must extend to the most basic elements of access and participation: tuition, transportation, textbooks, and meals.

Second, **inclusive education** is an obligation of all EU Member States and its monitoring, evaluation and enforcement should fall within the purview of the EU. Within the FSCG and EU context, countries where inclusive education policy was not reported or was reported to be problematic require the **most urgent intervention** to ensure education-related policies take into consideration the rights of all citizens, including children with disabilities. Where inclusive education policy does not exist or children with disabilities are still educated in segregated settings, **thorough investigation and swift intervention** of the situation are warranted to avoid litigation. The European Court of Human Rights has heard two cases related to accessibility in education, creating a precedent for complaints and redress, in: ‘Stoian v. Romania’ (Application No 289/14) and ‘Gherghina v. Romania’[17]. The European Committee on Social Rights confirmed that inclusive education is a standard applied under the European Social Charter in different cases.[18] There are also domestic examples of litigations which lead to redress, e.g. in Slovakia and in Czech Republic[19].

Third, **technical, human, and financial support** should be extended to all countries that report dual settings, parallel systems of education provisions, and segregated settings still existing despite inclusive education efforts. Within the context of EU funding, an important recommendation concerns the completion of impact studies that can **document the reported progress** of these Member States towards more inclusive practices (obligation of progressive realisation) as well as the practices of each of the settings reported, number of children with disabilities in each setting, their participation, and success in the learning process, etc.

Lastly, the **monitoring** of the situation of children with disabilities in countries where inclusive education policies exist and are implemented (Malta and Portugal) should be periodic, formative, and completed by independent experts.

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[17] https://hudoc.echr.coe.int/eng#{%22itemid%22:[%22001-157408%22]}

[18] European Committee on Social Rights:
Bulgaria: The case concerned a complete denial of education to children with mental disabilities in institutions in Bulgaria, see https://archive.crin.org/en/library/legal-database/mental-disability-advocacy-centre-v-bulgaria.html/ https://www.escr-net.org/caselaw/2015/mental-disability-advocacy-centre-mdac-v-bulgaria-complaint-no-412007
Belgium: The case concerned the denial of inclusive education to children with mental disabilities; either a complete denial of education, or their segregation in special schools. https://validity.ngo/2018/03/30/mass-school-segregation-in-flanders-breaches-rights-of-children-with-mental-disabilities-says-top-european-social-rights-body/

[19] Slovakia: Ella Grebeciova. Case of a girl with disability denied education at her local school. The Constitutional Court of Slovakia found that denial of inclusive education to Ela to amounted to discrimination and confirmed that Ela must be provided with reasonable accommodations at school. http://www.mdac.org/en/news/slovakia-supreme-court-rules-denial-inclusive-education-children-disabilities-can-amount.
Czechia: Jan Hrazdira. Jan is a boy with autism, who was denied education at his local school. Subsequently, he was refused enrollment in 14 other schools and his mother could find no school for him. The local court held the local municipality responsible for not ensuring inclusive education for Jan. It confirmed that the denial of education amounted to discrimination. https://validity.ngo/2014/09/22/why-was-a-boy-with-autism-repeatedly-denied-an-inclusive-education/

With regard to the **affordability** of inclusive education for children with disabilities, 5 countries have instituted policies/regulations that, upon assessment, might prove useful in improving the situation of children with disabilities:

+ in Denmark, despite a full range of options for education settings, from segregated to inclusive, there is free transportation for children with disabilities;

+ in Estonia, cash allowances are provided to children with disabilities in upper secondary education, and state-supported boarding facilities for students from low-income families;

+ in Hungary, family allowances are conditional on school attendance, and textbooks are free to students in grades 1-9;

+ in Luxembourg, subsidies are available to enable schools to provide reasonable accommodation, and specialised public transport exists to help students reach school; and

+ in Romania, social allowances are conditional on school attendance, and children with disabilities are provided with a daily food allowance and an annual allowance for school-related expenses.

4.3 Description and assessment of main policies to ensure access to free healthcare and recommendations for improvements

In this section, health-related policies are reviewed, summarised and analysed in relation to: 1) national policies that, according to Country Reports, include 'free healthcare'; and 2) national policies that include provisions that are specific to children with disabilities (impairment-related). In accordance with international and EU normative frameworks, health policies need to follow a twin-track approach: they need to be disability-inclusive (available to all citizens, including those with disabilities) and they need to be disability-specific to respond to the specific, impairment-related, health needs of persons with disabilities. Children with disabilities often have two types of health-related needs and concerns. On the one hand, children with disabilities have the same health-related needs as all other children, both related to their growth and development and related to preventative and/or primary care. This seems to be envisioned by all EU Member States. On the other hand, children with disabilities often have a second set of health-related needs and concerns, deriving from the impairment that has led to the disability. Although these impairment-related concerns can often be addressed by robust healthcare systems without the need for specific policy, this is not always the case. A lack of impairment-specific healthcare and rehabilitation may lead to difficulties in overcoming obstacles (such as those than can be overcome by means of rehabilitation or assistive technology) or accelerate the deterioration of conditions that could otherwise be prevented.

Table 4.2 below details the countries where policies/practices for free healthcare exist (yes) and where those policies/practices do not exist (no). It also details the countries where provisions specific to the healthcare of children with disabilities exist (yes) and do not exist (no). When a box is left blank, it means that the information was not available.

Table 4.2: Countries where policies/practices for free healthcare exist (yes) and where those policies/practices do not exist (no).

	Free healthcare	Provisions for children with disabilities
Austria	no	yes
Belgium	no	yes
Bulgaria	yes	conditional
Croatia	yes	
Czech Rep	no	
Cyprus	no (yes for children with disabilities)	yes
Denmark	yes	
Estonia	yes	no
France		
Finland	yes	no
Germany	no (yes for children)	
Greece	yes	
Hungary	yes	yes
Ireland	no	yes
Italy	no	
Latvia	yes	yes
Lithuania	yes	yes
Luxembourg	no	
Malta	yes	dental care
Netherlands	conditional	no
Poland	yes	
Portugal	yes	yes
Romania	yes	no
Slovenia	yes	
Slovakia	yes	
Spain	yes	
Sweden	yes	no
UK	yes	yes

Source: FSCG Country Reports.

Some Country Reports indicated that **free healthcare** for children is included in national policy. As with education policy, there are varying ways of interpreting 'free' healthcare; in some instances all health-related expenses are waived for children, and in other instances only certain services are free, as described below.

- In Austria, the public health system is organised according to an insurance-based model, with free-of-charge co-insurance for all children.
- In Bulgaria, the National Programme for the Improvement of Maternal and Child Health 2014-2020 contains the majority of policies in place to implement and improve child healthcare, which do not differentiate between children with and without disabilities. The construction of a children's hospital is currently one of the primary tasks in the field of child health. Medical devices and aids will be provided for children with disabilities by the Ministry of Labour and Social Policy starting at the end of 2019, with a limited range of listed articles whose provision requires multiple visits to different professionals. A major problem for children is that they cannot access items not on the list or items not listed as 'paediatric' (Bogdanov, 2019).
- In Estonia, the current overarching health policy is the National Health Plan 2012-2020. According to the Health Insurance Act of 2002, all minors are excluded from paying in-patient fees.
- In Latvia, the 2017 Healthcare Financing Law made healthcare part of the state social insurance system, creating a two-option system, and has defined groups of the

population for whom health insurance contributions will be made by the state, such as children and people with certain categories of disability (Veselības ministrija, 2017). The Law states that services provided to children are free of charge (including any fees, medication, and medical appliances, with the exception of non-reference medication), and Article 3(2) of the Law on Medical Treatment states that children, pregnant women, and individuals with a potential disability have priority in healthcare provision. The Plan for Improvement of the Health of the Mother and Child for 2018-2020 is another policy in place for the development of healthcare provision.

- In Portugal, the Basic Law of Health (Law 48/90) highlights equality and universal access to healthcare as a legal requirement, and states that special measures for children and adolescents, as well as for people with a disability, should be taken.

Free healthcare provisions for children are **not** included in policy in the following cases.

- In Belgium, only basic dental care, vaccinations, and the first mental healthcare consultation are free or 100% reimbursed for every child (Nicaise et al., 2019).
- In Germany, all citizens are obliged, by the Social Code Book (SCB) V, to take out health insurance, be it statutory or private. Children with disabilities can apply to the health insurance fund under SCB V, to the integration assistance scheme under SCB IX, or for benefits from the long-term care insurance scheme under SCB XI. In addition, SCB IX, as well as several other policies, offer assistance to people with disabilities (Hanesch, 2019).
- In Cyprus (Koutsampelas, et al., 2019).

In the countries below, national policy includes **provisions that are specific to children with disabilities** (impairment-related).

- In Austria, there is an insurance-based model with free-of-charge co-insurance for persons with disability (with no age limit), and no prescription fees and daily allowances for in-patient care are charged for children with disabilities. A 2012 common plan is in place for the co-ordination of child- and youth-specific rehabilitation centres, with an expected increase in beds from 50 to 350. Though the plan has been put in motion, it has not yet come to completion (Fink & van-Linthoudt, 2019).
- In Belgium, children with disabilities, among others, are entitled to increased benefits to improve their access to healthcare (which is not free) (Buffel & Nicaise, 2018; Committee on the Rights of the Child, 2017a). They ‘benefit from a higher compulsory insurance reimbursement rate, a fixed health-care payment under certain conditions, application of the third-party payment system and protection against extra fees in case of hospitalisation’ (Nicaise et al., 2019). A national plan for a new mental health policy for children and adolescents for 2015-2020 was launched in March 2015 (Committee on the Rights of the Child, 2017a).
- In Bulgaria, provisions for children with disabilities are partial and depend on the degree of disability. In practice, there is a lack of suitable support for children with disabilities because treatment is too expensive and above the limit covered by the state or is not accessible/available in the country. Children with disabilities travel to other countries for treatment, which is very expensive and turns them into ‘health migrants’ (Bogdanov, 2019).
- In Cyprus, people with certain chronic illnesses and disabilities are provided, by law, with free access to the healthcare system (Koutsampelas et al., 2019). However, there is no relevant legislation for children with disabilities under the age of 3 (Stylianou, 2017). Legislative frameworks supporting the rights of children to healthcare are the CRC, a Patient’s Rights Law providing a patient rights officer at each hospital, and the CRPD (Koutsampelas et al., 2019). In addition, two plans are currently in existence – the National Strategy on the Rights of the Child on Health (2017-2025), and the associated Strategic Plan (2018-2020) (Ministry of Health, 2017a; Ministry of Health, 2017b).

- In Hungary, the Act on the Protection of Children states 'that children with disabilities are entitled to special care and services promoting their development' (p.30). In 2015, the Decree of the Hungarian Government No 1246-2015 launched an Early Childhood Intervention Programme, to strengthen detection and the co-ordination of services (Albert, 2019).
- In Ireland, under the Disability Act of 2005, children under the age of 5 have the right to apply for an assessment of their health and educational needs arising from a disability. The National Policy for Access to Services for Children and Young People with a Disability or Developmental Delay, from 2016, is aimed at establishing a clear pathway of services for all children according to need, put in place teams working with parents and services users, and ensure that resources are used to the greatest benefit possible (Daly, 2019).
- In Latvia, several laws and normative measures provide that, in the case of disability, children and their families have the right to added support from both local and national government, such as support to obtain medical treatment or social rehabilitation (Lace, 2019).
- In Lithuania the Social Integration Programme for Persons with Disabilities for 2013-2019 (2012) provides an analysis of the situation and needs of children with disabilities. According to it, the most frequent reason for disability in childhood is behavioural and emotional disorders in children. The programme covers access to healthcare, educational, ECEC, social, and housing services, as well as access to the physical environment, transportation, recreation, and sports (Poviliūnas & Sumskiene, 2019).
- In Malta, a special multidisciplinary service, known as the CDAU (Child Development Advisory Service), has been set up; children who are noted to have some difficulty are assessed as early as possible in life and a holistic therapy plan devised (Vassallo, 2019).
- In Portugal, specific policies and programmes in place include: the 'Children and Young People's Health Programme' (implemented in 2013 and with one of the objectives being to identify and support children with special needs, at risk or particularly vulnerable); the 'Health Action for Children and Youngsters and Risk' (created by the Ministry of Health in 2008, aggregating units that support children and youngsters at risk in health centres and hospitals, with the aim of detecting and preventing risk, as well as providing care and referrals for protection); and the 'National System for Early Intervention in Childhood' (created in accordance with the principles in the CRC, it is aimed at ensuring, for children up to age 6 with a disability or at risk of developmental delay, the protection of their rights and the development of their capacities) (Perista, 2019).
- In Slovenia, the Resolution on the National Healthcare Plan 2016-2025, subtitled 'Together for a healthy society', points to the need to improve healthcare for children with special needs; and the Resolution on the National Mental Health Programme 2018-2028, underlines the good practice offered by four advisory centres for children, adolescents, and parents, which provide interdisciplinary support (Stropnik, 2019). Specific to the promotion of healthcare for children with disabilities, the Act Regulating the Integrated Early Treatment of Preschool Children with Special Needs (2017) has just come into effect and is aimed at reorganising the existing development clinics into early intervention centres. At the international level, Slovenia is bound by the following policies: 'Mental Health Declaration for Europe – Facing the Challenges, Building Solutions' – and its Action Plan (2005); and the Green Paper 'Improving the mental health of the populations: Towards a strategy on mental health for the European Union' (2005) (Stropnik, 2019).
- In the UK, children with disabilities should be able to access the care they need through the National Health Service but 'there are wide local variations in the proportions of disabled children and young people who have a Health Action Plan that sets out what they should expect from their health care' (Rigby, 2019, p.18).

No specific policies for children with disabilities exist in the following countries.

- In Estonia there are no specific national policies in place to ensure free healthcare for children with disabilities, as healthcare is free for all children.
- Finland (Kangas, 2019).
- In the Netherlands, the Long-Term Care Act applies to any person, including children, who needs permanent home care (Kroneman et al., 2016). The Dutch healthcare system does not offer specific healthcare programmes for children with disabilities (van Waveren et al., 2019).
- Romania (Pop, 2019).
- In Sweden (Nelson, Palme, & Eneroth, 2019).

An analysis of the information provided in the Country Reports indicates that **mainstream instruments related to health do not sufficiently address** the needs of children in general or children with disabilities in particular. Although most EU Member States have policies that envision **free healthcare for children**, the definition of 'free healthcare' differs greatly between Member States, with some countries reporting that all healthcare-related services for children are free and others indicating that only some services are free. 8 Country Reports indicated the healthcare is not free for any citizens.

Healthcare services specific to children with disabilities are not sufficient in terms of quantity and, in some cases, not adequate in terms of quality. Policies for children with disabilities were reported in only 11 countries, and 5 other Country Reports indicated that policies for children with disabilities do not exist. In 2 Country Reports, provisions for children with disabilities are said not to exist because healthcare is free for all children. However, one may argue that provisions specific to children with disabilities are critical in enabling their inclusion and well-being. In addition, 2 Country Reports indicate that healthcare is placing an emphasis on mental health, while 1 other Country Report indicates that there are no provisions in place for children under 3 years old.

In summary, according to information provided in the Country Reports, healthcare-related policy for children in general, and children with disabilities in particular, does not comply with international norms and EU commitments in most EU Member States. Therefore, it is **recommended** that EU Member States address the health-related needs of children, including children with disabilities, by engaging in policy review and implementation enforcement at two levels: disability-inclusive and disability-specific.

Free healthcare for all children (disability-inclusive provisions)

The EU should monitor, evaluate, and enforce the World Health Organisation's key principle of Universal Health Coverage (UHC)[20] as indicated in Rigby (2019):

> *'Universal health coverage is the goal that all people obtain the health services they need without risking financial hardship from unaffordable out-of-pocket payments. It involves coverage with good health services – from health promotion to prevention, treatment, rehabilitation and palliation – as well as coverage with a form of financial risk protection. A third feature is universality – coverage should be for everyone.'*

As is the case with education, accessing healthcare systems and being healthy carries expenses that go beyond a doctor's visit. Therefore, it is important that the EU ensures that Member States are fulfilling their obligations vis-à-vis the universality of the principle of UHC (above).

Free healthcare for children with disabilities (impairment-specific)

It is most urgent that countries with no specific legislation guaranteeing the rights of children with disabilities to free healthcare, or countries where policies are conditional or

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[20] https://www.who.int/bulletin/volumes/91/8/13-125450/en/

not clearly outlined, **develop laws, norms, and regulations** in line with the CRC, CRPD, UHC, and European Disability Strategy. As detailed above, it is not sufficient to have legislation that is aimed at the entire population (mainstream) and assume that it covers children with disabilities who have specific needs related to body function/structure. The EU should advocate that Member States increase earmarked healthcare spending for children with disabilities, including for the provision of rehabilitation and assistive technology devices, as well as strengthening the dual focus of the health system on both mainstream and disability-specific provision, to ensure a holistic, integrated, and multidisciplinary approach to the work (Rigby, 2019, p.18).

As reported by Bulgaria (but this is probably problematic in other countries as well, although not reported) not all children with disabilities are receiving the means and tools to improve their access to healthcare, despite the existence (to an extent) of such services. Therefore, it is important to **assess the success** of Member States that provide assistive technology and rehabilitation services and **consider expanding/replicating** those programmes and services that prove to be following CRPD guidelines and European Accessibility Act provisional regulations.

It is recommended that EU funds be partially used to conduct **impact studies** in Austria, Cyprus, Ireland, Latvia, and Portugal where specific policies protecting the rights of children with disabilities to free healthcare exist. As with other policy areas, it is important to determine the extent to which existing policies address the rights of children with disabilities.

Only 5 out of 28 Country Reports make mention of the critical services provided in the area of Early Identification and Early Intervention (EI/EI): Hungary, Ireland, Latvia (mother and child), Portugal, and Slovenia (planned). While it is possible that other countries also have partial programmes addressing very young children, it is critical that these include components of screening, prevention, and intervention in the areas of developmental delay or disability. For this, increased human/resource capacity is needed, along with the assurance that professional education provides sufficient core values, knowledge, and skills related to delays and disability. EU funds should be used to **expand EI/EI services** across the EU and **facilitate cross-border** model exchanges and professional capacitation.

4.4 Description and assessment of main policies to ensure decent housing and recommendations for improvements

As indicated in Clark-Foulquier and Spinnewijn (2019), there are very few data upon which to draw conclusions with regards to the fulfilment of the right to housing for all children in EU Member States. However, there are enough data and research to determine that being poor or having a disability increases the chances that a child will be deprived of decent housing, and specific groups of children face additional barriers in accessing decent housing.

In keeping with a twin-track approach, policy related to housing was reviewed, summarised, and analysed in two groups: 1) policy related to housing for all children, including children with disabilities (disability-inclusive); and 2) policy related to ensuring the right of children with disabilities and their families to decent housing (disability-specific).

Policy related to housing for all children, including children with disabilities (disability-inclusive)

- In Ireland, the Equal Status Acts (2000-2015) prohibit discrimination in the provision of housing, including by family status and disability (Daly, 2019). The National Action Plan for Social Inclusion 2007-2016 was aimed at delivering high-quality housing to those who could not afford to meet their housing needs, including people with disabilities and lone parents; but in the updated version of this policy, the Updated National Action Plan for Social Inclusion 2015-2017, the definition of specific groups was no longer included (Department of Social Protection, 2016).
- In Portugal, the 'New Generation of Housing Policies', launched in May 2018, is aimed at re-orienting public policies towards the universal provision of adequate housing, with some of its policy instruments already in place, such as: 'Porta de Entrada', providing urgent accommodation to those who become or are at imminent risk of becoming deprived of housing, with priority being given to households with children and with persons with disabilities, among others; and '1º Direito', aimed at providing a housing solution to those living in poor housing conditions who cannot meet the costs of adequate housing (including the incompatibility of the housing with the specific needs of the person, such as those resulting from a disability). Other policies, such as the 'Programme for Affordable Tenancy' and the 'Chave na Mão' programme, are also in place (Perista, 2019).
- In Spain, the most prominent policies are: the Social Housing Fund (2013), for vulnerable groups who have been evicted, such as households with children or persons in a situation of dependence or with a disability; and Law 1/2013, which suspended evictions for four years and protected persons in situations of exclusion, including families with children and persons with disabilities (Rodríguez Cabrero & Marbán Gallego, 2019).
- In Slovenia, policies and programmes related to ensuring adequate housing for children are split between national and local level. Some of these are: the Rules on the Rental of Non-Profit Apartments (2004), based on the 2003 Housing Act, which prioritise families where a member has a disability (Stropnik, 2019); and the Slovenia Development Strategy 2030, which aims to provide access to suitable housing for all generations (GRS, 2017).

Policy related to ensuring the right of children with disabilities and their families to decent housing (disability-specific)

- In Estonia, specific national policies exist to assure decent housing to families with three or more children, low-income families, and people with disabilities (either by adapting or acquiring a suitable dwelling) (Anniste, 2019).

- In Latvia, normative measures (MK noteikumi No 1170) prescribe support for people with disabilities, including children with disabilities, in the field of housing – with a view to adapting the house in line with the particular needs of the individual (Lace, 2019).
- In Lithuania there is a new Decree of the Ministry of Labour and Social Affairs on increasing social security and adjusting housing to families raising a child with severe disability from 1 July 2018, which stipulates adjustment of living environment to the needs of a child with severe disability.
- In Malta, the Housing Authority runs a special scheme for persons with disability that may be applied to children, involving adaptation works in their residence (Vassallo, 2019).
- In Poland, the State Fund for Rehabilitation of the Disabled provides, upon certification of disability, co-financing for the removal of architectural barriers in the family home and in the neighbouring environment, without income-testing. In the Housing+ programme, families of children with disabilities are one of the groups that should be given priority (Topińska, 2019).
- The UK does have provision/policies for specialised housing for disabled children and their families – they can apply for a 'disabled facility' grant from their local authority (though this is not a right).

For the most part, mainstream instruments related to housing are not sufficiently adapted to take into account the needs of **children with disabilities**, and are rather broad in nature. Only 4 Country Reports make mention of policies that might potentially have an impact on the housing-related needs of children with disabilities and their families. While it is important to include children with disabilities in policies aimed at supporting vulnerable populations, these might not always take into consideration the specific housing needs of families with children with disabilities.

Therefore, **instruments related to housing that are specific to children with disabilities are necessary** in addition to mainstream policies. However, an analysis of available information indicates that these are, in the EU, insufficient and not adequate. 5 out of the 6 Country Reports that provide information indicated that provisions exist to enable the adaptation of infrastructure to the needs of children with disabilities. However, this is a narrow view of housing support for children with disabilities, taking into consideration that only a small percentage of children with disabilities have a mobility limitation that requires adaptations. While these are important, housing policy that addresses the needs of families with children with disabilities has to be flexible and fit-for-purpose and address concerns related to affordability. In addition, while there is evidence of innovative policies to support the housing needs of young adults with disabilities moving out of institutions and into independent living (e.g. Finland and Italy), these do not take into consideration the needs of families with children with disabilities, and may act as incentives for families to place children with disabilities in residential institutions (FRA - European Union Agency for Fundamental Rights, 2018).

Taking into consideration the general nature of the existing information, and the lack of rigorous and specific data at the country level, an analysis of the fulfilment of the right to housing by children in the EU is very difficult. The few recommendations below should be treated with caution, as they are given based on little information. Thus, in relation to both disability-inclusive and disability-specific policies, the most important recommendation is for Member States to gather rigorous and comparable information regarding the fulfilment of the right to housing by all children, including children with disabilities.

As with the previous sections, it is recommended that Member States that do not have policy aimed at protecting children with disabilities and their families with regards to the right to affordable and accessible housing (Bulgaria, Croatia, Greece, Ireland, and Luxemburg) be **urged to do so**, in order to comply with international law and treaties.

Where policy instruments exist but are difficult to access, it is recommended that they be **consolidated and co-ordinated** to ensure that adequate support to children with disabilities and their families is easily accessible and understood.

Countries with either no policies or partial policies should ensure **access to subsidised housing** for families with children with disabilities, helping them to secure accessible and affordable housing. According to Clark-Foulquier and Spinnewijn (2019), on the demand-side, housing allowances should be carefully targeted in order to be effective, focusing inter alia on low-income households with children. Housing allowances should consider specific household needs, such as number of children and children with disabilities. Families should not be penalised for the composition of their household, such as in the case of the two-child limit and benefit cap in the UK.

Lastly, but critical for children with disabilities, EU mechanisms (including funds) should be used to support national and local authorities to develop programmes aimed at **retrofitting and making accessible** the dwellings of families with children with disabilities, whether rented or owned.

4.5 Description and assessment of main policies to ensure access to free early childhood education and care and recommendations for improvements

ECEC is defined and understood differently by different Member States. Despite guidance provided by global and European normative frameworks such as the CRC, the CRPD, and the European Quality Framework, most EU Member States do not provide a legally enforceable right to ECEC. In the cases where ECEC exists, little comparability could be found between countries. In some cases, ECEC starts at birth and continues until compulsory education starts. In some cases, it runs from age 3 until the first year of schooling. In some cases it is provided in formal settings; at other times it is regulated within the parameters of education systems; and in other cases it can be provided in unregulated and non-formal settings.

With regards to **access to ECEC for all children, including children with disabilities**, the most frequently reported barriers were availability and cost. As in the case of other policy areas, children from vulnerable, poor or migrant backgrounds, as well as children with disabilities, are at a disadvantage when trying to secure access to ECEC compared with the average population. Lack of available spaces, geographic disparities, cost of services, lack of quality, and discrimination are some of the barriers identified (Vandenbroeck, 2019).

- In Croatia, under the law, certain families have enrolment precedence for their children (e.g., children with a disability), but these criteria are not applied equally or fully by local governments. There is no national policy in place for ECEC (Zrinščak, 2019).
- In Poland, ECEC for children under 3 follows the provisions of the Act of February 2011, and its amendments, which provided a few measures to make access easier for children with disabilities (such as reducing the maximum number of children per class). For children aged 3-6, ECEC follows the Act on the Education System of 1991 and the Educational Act of 2016. In 2018, some additional legal provisions concerning children with disabilities were added under the Pro-Life Programme, with limited results so far (Topińska, 2019).
- In Portugal, the Decree-Law 54/2018 establishes a new juridical regime for inclusive education that includes pre-primary education, envisaging measures to support learning and inclusion that can be universal, selective or additional (Perista, 2019).

On the basis of the Country Reports where this information is provided, **policies to ensure the free access of children with disabilities to ECEC** differs greatly and the main barriers to access to ECEC differ by country. Barriers to availability were reported in Croatia, Italy, and Luxembourg. Barriers related to accessibility were reported by Estonia and Poland. Barriers related to acceptability were reported by Hungary and Luxembourg. However, on a positive note, some countries (Ireland and Slovenia) highlighted practices in EI/EI that are critical in the prevention, identification, and referral to services of children with disabilities or developmental delays.

There were 6 Country Reports that indicated **specific policy efforts to address the needs of children with disabilities with regards to ECEC** or EI/EI, as follows.

- In Estonia, in 2016, the Social Welfare Act was amended to improve the accessibility of childcare places for children with disabilities (Anniste, 2019).
- In Hungary, the Act on National Public Education enabled parents to use specialised pedagogical services to provide early childhood intervention and prevention, special education, and psychological education and therapy, with these services being free of charge (Albert, 2019) although provided in segregated settings.
- In Ireland, the government's policy document entitled *Better Outcomes, Brighter Futures: The National Policy Framework for Children and Young People 2014-2020* identifies prevention and early intervention as one of its transformational goals, and commits to the inclusion of children with disabilities in mainstream pre-school and early-years settings (Department of Children and Youth Affairs, 2014). The Access and Inclusion Model, introduced in 2016, is a model of supports designed to ensure that children with disabilities can access ECEC programmes (Government of Ireland, 2018).
- In Italy, requirements for the care of children with disabilities vary across regions (Committee on the Rights of the Child, 2017b) and the country has not adopted any national minimum standards relating to ECEC for children with disabilities (Raitano, 2019).
- In Luxembourg, for children with disabilities, ECEC institutions or parents can be supported by one of the eight specialised support centres (Swinnen, 2019).
- In Slovenia, the Act Regulating the Integrated Early Treatment of Preschool Children with Special Needs was adopted in 2017 and became effective on January 2019. The Act provides for the creation of a system of early childhood interventions for children with special needs, from birth until entry to basic schools, as well as support for their families; introduced improved procedures for placing pre-school children in kindergartens that implement the adapted programme of school education; and provides a basis for co-ordination between different structures. There are yet to be developed any executive acts. Other relevant policies are: the Placement of Children with Special Needs Act of 2011; the supplement to the instructions to the curriculum for pre-school daycare centres and additional professional staff for children with special needs or long-term illness, updated in 2016; and the rules on additional professional and physical assistance for children with special needs of 2013 (Stropnik, 2019).

In summary, **mainstream instruments related to ECEC are not sufficiently adapted** to take into consideration children with disabilities. Provision of ECEC to all children, including children with disabilities, is of the utmost importance to the EU and all its Member States, as it contributes to the prosperity and well-being of all citizens, in keeping with relevant international treaties. However, only 3 Country Reports included information on ECEC policies for all children which are also disability-inclusive. Anti-discrimination regulations within each Member State and across EU mechanisms should be enforced in relation to ECEC provisions to address disparities in access related to children's ethnic/cultural, economic or social backgrounds.

In addition, **ECEC instruments specific to children with disabilities are insufficient**. ECEC is important for all children, but of critical importance to children with disabilities because: 1) it provides the necessary services and structures to identify and address developmental delays and disabilities (EI/EI, as reported in the healthcare sub-section above); and 2) it supports children who have been identified as being at risk or with a developmental delays and disability to access the services needed, in health, education, and social protection.

Therefore, with regards to **ECEC policies specific to children with disabilities**, it is recommended that the EU encourages Member States to develop co-ordination mechanisms between service providers, line ministries, and policy-makers that can develop co-ordinated ECEC provisions according to the EU's minimum standards. Therefore, the primary recommendation with regards to ECEC is for Member States to develop **co-ordinating mechanisms between sectors** that can develop multi-sector policies and co-ordinating structures to promote the seamless transition of children with disabilities and their families between services. As can be seen in the Country Reports, only 3 out of 28 countries (Hungary, Ireland, and Slovenia) make mention of EI/EI services for children with disabilities in both the health and ECEC chapters, emphasising a cross-sectoral approach.

In addition, where ECEC policies do not exist, or where policies envision services that are not free, these should be **developed or revised to give priority access for children with disabilities** to ECEC services (including EI/EI), free of charge, and as close to home as possible to ensure that taking advantage of services does not imply family separation.

Lastly, with the support of the EU, Member States could consider developing legislation similar to a Childcare and Education Act, aimed at **consolidating under one legislative umbrella** the provision of a variety of cross-sectoral services for children.

4.6 Extent of integrated, comprehensive and strategic approach and recommendations for improvements

Despite three normative frameworks (CRC, CRPD, and the EU 2013 Recommendation) that oblige the EU and its Member States to ensure that all children's rights must be understood and acted on (inter alia), there are no integrated or comprehensive approaches to the rights of children with disabilities to social protection, education, healthcare, nutrition, affordable housing or ECEC services. Indeed, not only is there a lack of a comprehensive approach but children with disabilities face various and serious obstacles in accessing adequate services in all four areas of interest for this study, obstacles that are quite uniform across most countries included in this study.

According to the online consultation, the top three obstacles (as identified by the respondents) are similar to those identified in Country and Policy Area Reports (see Table 4.3). In **education**, the barriers faced by children with disabilities are non-adaptation of the system (cited by 54% of respondents), non-accessible environment (52%), issues related to discrimination (45%), and non-availability of services (43%). **Healthcare** was deemed non-adaptable by 51% of respondents, not available by 50%, and non-accessible by 46%. Affordability was the most cited (52%) obstacle with regards to **housing**, with non-accessibility cited by 49% of respondents and non-availability by 42%. Non-availability of **ECEC services** was the number one barrier as reported by 56% of respondents, with non-adaptation to children's needs reported by 52%, and a non-accessible environment by 45%.

Table 4.3 – Top three obstacles faced by children with disabilities in each of four policy areas (as reported in the online consultation)

	Availability	Accessibility	Affordability	Adaptability	Acceptability
Education	-	52%	-	54%	45%
Healthcare	50%	46%	-	51%	-
Housing	42%	49%	52%	-	-
ECEC	56%	45%	-	52%	-

Source: FSCG Online Consultation (2019).

As detailed above, an integrated approach across policy areas is essential to ensure that children with disabilities and their families have access to services starting at birth, or at the first indication that a child is at risk of a developmental delay or disability. Because every EU Member State is a signatory of the CRPD, each Member State has a fully or partially developed national law on persons with disabilities and/or an action plan.

Engaging with the national committee of the CRPD that developed and monitors the law/plan, or with the European Disability Forum representative in the country, can be the first step in ensuring the rights of persons with disabilities are taken into consideration when developing policy. However, it is important to ensure that a national law and action plan on disability expressly represents the rights of **children** with disabilities, as these are often quite different (e.g. the right to play and education) from the rights of adults with disabilities (e.g. employment and marriage). This can be done by engaging in co-ordination with the CRC Committee in each country.

4.7 Costs of services (exploratory)

Interest in the cost of including children with disabilities within existing frameworks is a recent development. While it has been theorised that it is more expensive to run separate systems (such as in education) than one single system (OECD, 2000) (UNICEF, 2015) (IDDC, 2016), the arguments for inclusion have focused on the social benefits of inclusion, rather than the financial gains. In some cases it has been easier and more useful to look at the cost of exclusion than the cost of inclusion. However, as posited at the start of this report, there is a documented cyclic relationship between poverty and disability, as well as a relationship between disability and lack of income. A study by the international development organisation CBM (Banks & Polack, n.d.) on the cost of exclusion found that, in a broad review of the literature, in 81% of cases there was a positive relationship between poverty and disability, and in 76% of those the associations were statistically significant.

According to the same source, ‘across 13 LMICs [low-middle income countries], households containing an adult with a disability were 5.0-14.5% more likely to belong to the poorest two quintiles. However, for each additional year of schooling, this probability was reduced by 2-5%, turning the association between disability and poverty from consistently positive and significant to statistically insignificant’ (p.30). Furthermore, ‘In a similar study in the Philippines, increased schooling was associated with higher earnings among people with disabilities, generating an economic rate of return to education of more than 25%’ (p.30).

Educational attainment has been demonstrated to be directly linked to employment and income generation. Similarly, a lack of access to appropriate healthcare, rehabilitation, and assistive technology has an impact on employment. UN Enable (2007) suggests that 80%-90% of persons with disabilities worldwide do not participate in the labour force. The International Labour Organisation (Buckup, 2009) demonstrated that, in Asia, the loss of GDP related to the exclusion of persons with disabilities from the labour market could be estimated at between 3% and 4.6%. It stands to reason that children with disabilities who often do not have access to the same education opportunities as their peers without disabilities also have a much lower rate of success in securing employment and generating income. As a consequence, a lack of education opportunities leads to increased dependency on social protection schemes, expenses that governments are increasingly weary of undertaking.

The exclusion of children with disabilities from national and sectoral policy development, taking into consideration disability-mainstreaming and disability-specific measures, has consequences that go beyond individual sectors or ministries. Co-ordinated and inclusive policies have the potential to lessen the impact of poverty on children with disabilities and reduce the expenses (direct and indirect) of governments.

5. Use of EU Funds

5.1 Extent of use

According to the European Parliament document *Fighting Child Poverty: the Role of EU Funding*, 'In the EU, child poverty has increasingly been understood as a context-specific, multidimensional phenomenon, encompassing not only a lack of money and assets but also other forms of deprivation connected to children's survival, development, protection and participation in decisions that affect their lives. The rights-based approach to child poverty highlights the multiple factors which contribute to a child's well-being, and articulates the rights of children to an adequate standard of living, and to be free from deprivations across crucial aspects of their lives including their health, education, nutrition, care and protection' (p.8).

As detailed elsewhere in this paper, child poverty and disability are thought to be cyclical phenomena. If, as posited in the document above, child poverty has identifiable causes and effects that pose life-long consequences, it stands to reason that it falls within the EU's jurisdiction to address the causes that are 'underpinning broader community and household poverty, linked to economic circumstances, social inequalities and institutional bias in policy and service delivery, among other factors' (Marshall, 2003, p.21). In the EU, as elsewhere, children from the TGs included in this study are more likely to live in poverty, be discriminated against, and face structural inequity. However, as demonstrated in six documented case-studies (Philipov & Jaschinski, 2014), the 'process of the adaptation of EU-level priorities to the national level fails to emphasise the child poverty problem specifically, or to introduce a comprehensive approach to addressing it (…) the process demonstrates fragmented attempts to improve access to services, especially to childcare and education, and in particular for Roma children, children with disabilities and other disadvantaged groups' (p.32). This being the case, it can be assumed that co-ordinated, integrated, and comprehensive policies (and actions) that target poverty alleviation in the EU are more likely to be able to have an impact on the lives of children with disabilities (and their families) in the EU Member States.

The availability of evidence on the extent to which EU Funds are used to support policies and programmes in favour of children at risk of poverty and social exclusion is sketchy, and this is even more the case in relation to the four TGs focused on by the FSCG – including the TG that is the focus of this report, children with disabilities. The limited availability of data and information is a point that is made repeatedly in the Country Reports and the PA Reports prepared for the FSCG, as well as in other recent studies such as that by the ESPN (see Frazer and Marlier, 2017) and a recent report for the European Parliament (see Brozaitis et al., 2018).

According to Bradshaw & Rees (2019), many Country Reports exhibit difficulty in tracing information regarding European Social Fund (ESF) funds used for nutrition, and even fewer links were made with regards to the use of funds for the TGs. FEAD funds were easier to track, with various countries providing examples of their use, although it is difficult to determine to what extent they address the specific needs of the specific TGs (as opposed to children in general). No Asylum Migration and Integration Fund (AMIF) funds were reported to be used for children.

Nicaise et al. (2019) indicate that it is not possible to identify ESF investments spent on children's education, much less those used on children in the TGs. It seems that most funds have been spent on promoting equal access to school and in preventing drop-outs. Similarly, it is difficult to determine from the Country Reports the extent to which ESF funds were spent on the TGs. 3% of European Regional Development Fund (ERDF) funds go to education and vocational training and 6% to social inclusion. Again, the reports are inconclusive as to expenditures on the TGs. FEAD funds (as seen above) were easier to track but without specific links to TGs. No links to the TGs were found in Erasmus+ or in AMIF.

Micklewright (2019) makes no mention of EU funds used in healthcare and with a specific focus on children with disabilities.

Vandenbroeck (2019) provides several examples of how EU funds are used to improve access to ECEC. Some Member States used the funds to increase infrastructure and augment the number of ECEC places (e.g. in Poland), and to increase access for vulnerable children (Bulgaria, Lithuania, Estonia, and Belgium). In Lithuania and Estonia there was a special focus on accessibility for disabled children, and in Lithuania there was also a focus on Roma children.

According to Clark-Foulquier and Spinnewijn (2019), the volume of funds addressing housing issues (ESF, ERDF, FEAD) is currently small and more research is needed to support future decision-making. However, current practices seem promising. Two examples are given specifically of EU funds being used to target persons with disabilities. In Lithuania, social housing for vulnerable populations funded by the ERDF and municipalities is aimed at providing 1,668 housing units, 170 of which are to be adapted for persons with disabilities. In Croatia, most EU funds targeting persons with disabilities have been aimed at supporting deinstitutionalisation efforts. However, so far, there are no evaluations of either project.

5.2 Effectiveness

The various reports alluded to in the previous Section and others such as those by the European Disability Forum (EDF) (Forum 2014) document many weaknesses and limitations in the way EU Funds are currently used that need to be addressed in the future. At the same time they also provide some interesting positive examples of ways in which EU Funds have been used which could be built on in the future.

Findings from EDF (Forum, 2014) show that although Structural Funds are fundamental to persons with disabilities, they have not contributed to their social inclusion. The EDF highlights a few reasons, among them:

- a lack of indicators to ensure equity, non-discrimination, and accessibility;
- a lack of checklists for the indicators in grant proposals, as a means of verification;
- a lack of involvement of civil society and organisations of persons with disabilities (DPOs) in monitoring activities;
- a lack of technical assistance provided to DPOs to access and monitor funds;
- a lack of focus on actions that may have a positive impact on persons with disabilities;
- the use of Structural Funds to reinforce segregation; and
- a lack of attention given to accessibility and non-discrimination when operationalising programmes for 2014-2020.

Overall, there is a lack of knowledge and information within the ESF Committee regarding 'compliance with the ex-ante conditionality on disability, non-discrimination and fight against poverty and social exclusion is ensured in negotiating the operational programmes' (p.3). As demonstrated throughout this report, a lack of information and monitoring by those most directly affected has been reported in almost all cases.

Philipov & Jaschinski (2014) report that EU Funds, by design, do not necessarily address child poverty and that the implementation of other provisions has had limited impact, although they have the potential to 'improve orientation of EU-funded interventions to fight child poverty' (p.10). Their study reports on three types of funds. First, they say that only FEAD funds address child poverty directly and that the funds have been used to address food and material assistance as well as social inclusion activities; they do not make mention specifically of children with disabilities. Second, the ERDF and ESF may be used on a variety of activities focused on education, healthcare, and (some) infrastructure; but they do not address poverty and social exclusion specifically. Third, European Agricultural Fund for Rural Development funds do not tackle child poverty specifically.

Again, it is not possible to look at the specific use of funds for the TG of children with disabilities without looking at the overall use of funds. Several issues are present in fund usage among the five priority areas.

There seems to be an overall difficulty in assessing the use and effectiveness of funds, both in general and with regards to the TGs. Many Country Reports mention a lack of evaluations, a lack of direct targeting of funds at children, and/or a lack of tracking of funds used for the TGs. The effectiveness of EU funds related to housing and as it related to children is 'sub-optimal, despite best practices and a wealth of opportunities' (Clark-Foulquier & Spinnewijn, 2019, p.27). This is also the situation in healthcare, where 'direct focus of EU funds on the delivery of healthcare to the TGs has been minimal – for instance, on adapting healthcare buildings to improve access for those with limited mobility' (Rigby, 2019, p.20). And, it seems to be the same in the area of nutrition where, according to Bradshaw & Rees (2019), countries had difficulty assessing the effectiveness of the funds used. Assessment of FEAD funds was mixed but, again, it was difficult to determine whether the funds targeted children with disabilities.

In education and ECEC the situation is different, with more visibility being given to the use (or misuse) of funds for children with disabilities. There is a mix of reports on funded activities that are not always aimed at inclusive education, social inclusion or the 'best-interest of the child' (CRC, 1985). For example, in ECEC, evidence from Poland (Philipov & Jaschinski, 2014, p.103), suggests that although the situation of children with disabilities is well known, with access to pre-school education made more difficult for children with disabilities and remaining inadequate at '1%-1.3% of all enrolled children' (p.104), the EU funding available did not directly address this issue. While 'Poland is the largest beneficiary of the EU structural funds: ESF funding alone is set at EUR 13.19 billion, and ERDF funding at EUR 40.21 billion' (p.104), funding that targets children with disabilities was used in 2008-09 to improve the communication skills of children with disabilities already in school, rather than address issues related to access.

As indicated by Vandenbroeck (2019), EU funds are often targeting young adults and adults with a view to facilitate entrance into the world of work. Reportedly, there is no information available and/or there is a lack of monitoring with regards to use of funds for children, let alone children in the TGs. On a positive note, his report notes: 'notable advancement has been made in several domains. To give but a few examples, the ESF has led to better targeting of support to the most vulnerable groups in Slovakia. It has enabled the training and financing of Roma assistants in ECEC in Slovenia as well as the training of staff in Luxemburg' (p.24). However, it should be noted that the training in Slovenia is not relevant to children with disabilities.

In education, the ESPN Synthesis Report (2017), provides examples of 19 direct and 7 indirect ways in which EU funds are benefiting children. Of those examples provided, only 4 mention children with disabilities: 'Greece is facilitating access of the disabled and other vulnerable groups of children (Roma etc.) to educational services'; 'Latvia has funded the provision of technologies and adjustments for the inclusive development of children with functional impairment'; 'Latvia is funding work with children with communication difficulties and behavioural disorders'; and 'Slovenia targets children at risk of social exclusion under TO9 (social inclusion), with measures foreseen to promote a greater social inclusion of children belonging to minority ethnic communities and children with disabilities'. In addition, there is no *measure* as to how inclusive the projects are and what the outcomes have been.

Nicaise, Vandevoort, & Ünver (2019) indicate that EU Member States do use EU funding to ensure access to adequate services, especially related to access to pre-school provision and the acquisition of school materials. However, there is a need for evaluations that may lead to more information. Two examples are provided of initiatives that have used funding to initiate/expand inclusive education for children with disabilities (Czech Republic and Estonia) although no evaluations have been completed. In addition, the report also describes the case of Lithuania where, although funds were purportedly provided to renovate schools, they did not take children with disabilities into consideration, putting the use of EU funds into question.

Other projects supposedly focused on children/persons with disabilities are related to musical activities (Usability of Music for Social Inclusion of Children – UMSIC[21]), developing indicators for quality of life (Quality of care and quality of life for people with intellectual and physical disabilities – DIS-QOL[22]) and the promotion of collaborative research in the area of health and disability (Multidisciplinary Research Network on Health and Disability in Europe – MURINET[23]) but none addresses the most pressing needs of children with disabilities in the EU.

5.3 Improvements

The EDF (Forum, 2014) start their recommendations regarding Structural Funds by tasking the EC with collecting good practice examples, developing indicators and checklists, and strengthening enforcement mechanisms. Clarity should be improved at all levels of the process, ensuring accessibility and deinstitutionalisation stand at the core of selection criteria, and partnering with representative bodies of persons with disabilities.

The 2017 EC document *Taking stock of the 2013 Recommendation on 'Investing in children: breaking the cycle of disadvantage'* provides, by way of absence of data, a good example of the need for improvement in all actions (including those related to funding) for children with disabilities. The CRPD is clear in that States Parties must provide both disability-mainstreaming policies and ensure the availability of policies and implementation plans that respond to the specific needs of children with disabilities and their families. Thus, while the findings of the stock-taking are important for all children, and partially relevant to children with disabilities due to their disability-inclusive nature, they lack the strategic focus on children with disabilities that may lead to successful social investment. In all cases, the state of implementation of each of the three pillars upon which the comprehensive integrated approach for the recommendations has been set is silent on issues related to disability. Thus, monitoring progress has been limited and an assessment will require further inquiry with regards to specific measures for children with disabilities.

Similarly, there is an absence of focus on children with disabilities in the ESPN Synthesis Report which provides extensive recommendations for EU fund use for children. In over six pages of detailed recommendations only once are children with disabilities explicitly mentioned – in the case of Estonia, with the recommendation to 'Develop services for and measures aimed at households with disabled children and single-parent households' (p.92). Therefore, **any detailed attention to this particular TG could be considered an improvement**. Likewise, 'the issue of children with a disability should be a key concern in implementing the *European Disability Strategy 2010-2020'* (p.38). In addition, while the report recommends that 'important synergies could be achieved by ensuring close links between the implementation of the Recommendation and other relevant **international level processes**, in particular the United Nations *Sustainable Development Goals* and 2030 Agenda and the *UN Convention on the Rights of the Child*' (Rec.6) it is important to note the absence of any mention of the CRPD, which speaks to the overall lack of attention to children with disabilities as a particularly vulnerable group of children.

All the FSCG Policy Area Reports make recommendations for improvements that can have a direct or indirect impact on children with disabilities. In some cases, the same recommendation is made in slightly different terms but with the same aim. Bradshaw & Rees (2019) indicate that children in the TGs should be given prominence and greater weight in the use of funds, although specific suggestions on how to accomplish this varied and no specific suggestions for children with disabilities were identified (other than those given by Country Reports). Nicaise, Vandevoort, & Ünver (2019) suggest that it is

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[21] https://www.it.lut.fi/project/umsic/

[22] https://www.who.int/mental_health/publications/whoqol/en/

[23] https://www.icf-research-branch.org/other-research-programs-and-projects/multidiscipinary-research-network-on-health-and-disability-in-europe

important to put children at the front of funding, and that funding would be more effective if it was given in a transversal way, with complementarity between programmes. Rigby (2019) supports both notions and provides several improvement suggestions that could specifically make a difference for children with disabilities (see Table 5.1). Clark-Foulquier and Spinnewijn (2019) mention the InvestEU programme 2021-2027 as a promising opportunity, with the caveat that uptake and co-ordination are key. And finally, as summarised in the ECEC Policy Area Report (Vandenbroeck, 2019), the first and most important improvement would be to enhance the access by the TGs to EU funding in general, both funding priorities and monitoring. It is suggested that clear targets and criteria should be focused on children, with coherence as a criterion for funding.

Table 5.1 presents a summary of the most prominent suggestions for improvement included in Policy Area Reports. These were often based on recommendations in the Country Reports and are clearly indicated with the country abbreviation. When recommendations do not include a country abbreviation, they were included in the relevant Policy Area Report.

Table 5.1 Suggested recommendations for EU fund usage

Nutrition	Education	Healthcare	Housing	ECEC
Provide free school meals (BE, CZ)	Provide ESF resources for substantive and organisational changes in education to inclusive education	Develop mental health services (EE, HU, ES)	Develop accessible environments for families with children with disabilities (BG)	Increase ECEC capacity
Develop funding programmes to obtain special foods and supplements for children with special disabilities (BG)	Use ERDF resources to adjust the educational infrastructure	Develop early diagnosis and intervention for child health; screening (EE, RO)	Support actions to upgrade housing conditions so as to adjust to the housing needs of children with disabilities (EL)	Provide resources to working families with young children (such as ECEC fee waiver)
Appoint health professionals (nutritionists, clinical dietitians) for nutritional monitoring of these children (CY)	AMIF resources to integrate refugee children into the same schools	Appoint health assistants for TG children (CZ, RO)	Finance services helping households to keep children with disabilities in their own community (HU)	Support awareness-raising programmes
Increase capacity of social work (CZ)	Use FEAD resources for material support and healthy school meals	Develop paediatric centres in areas of greatest need (IT)	Develop availability of decent housing in the community for children with severe and/or complex disabilities (LT)	
Support research on nutrition and professional training (FR)	Use Erasmus+ resources for the development and exchange of both policy and concrete	Develop disability health services (IT)	Ensure the availability of infrastructure and environment for apartment	

Nutrition	Education	Healthcare	Housing	ECEC
	materials and methodologies		buildings according to the needs of persons with disabilities (LV)	
Support the provision of diverse meals for children on a diet for having digestive disorders and allergies (information campaigns, sharing recipes and training for food catering managers) (HU)		Support locally prioritised community-based development (PT)	Support co-financing of the removal of architectural barriers for people with disabilities (PL)	
Elaborate lists of healthy products/ meals/diets for children with specific disabilities, and provide information to parents; promote healthy food in hospitals and during rehabilitation holidays (PL)		Glasses, prostheses (ES)	Develop accessible environments for families with children with disabilities	
Widen the scope of the FEAD (PT)				
Introduce a transparent updating mechanism for, and unifying, all daily food allowances for all children receiving them (children in residential care, in hospitals, with AIDS, and with SEN) (RO)				

In summary, the key recommendations to improve the use of funds for children with disabilities in the EU are to:

- make children with disabilities visible in all policies and ensure a twin-track approach to policy development (disability-mainstreaming *and* disability-specific);
- give prominence and greater weight to children with disabilities in EU funding use (conditional and "earmarked");
- recognise that deinstitutionalisation is a pre-requisite to social inclusion – invest in social services, inclusive education and child protection measures;
- ensure children with disabilities, their families, and organisations representing them have access to EU funds;
- ensure children with disabilities, their families, and organisations representing them are actively involved in monitoring EU funding uses by developing stronger monitoring and enforcing mechanisms for existing policies – ensure transparency,

the voice of children and independent monitoring aimed at “the best interest of the child”;
- utilise EU Funds to ensure enforcement of the European Disability Strategy 2010-2020, including actions targeting children with disabilities; and
- give priority to EU Funding projects that focus at least partially on providing complementarity between programmes/services (cross-sectoral co-operation).

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Annex: List of Policy Area and Country Experts

List of Policy Area Experts

Name	**PA**
Bradshaw, J. and Rees, G.	Nutrition
Clark-Foulquier, C. and Spinnewijn, F.	Housing
Nicaise, I., Vandevoort, L., and Ünver, Ö.	Education
Rigby, M.	Healthcare
Vandenbroeck, M.	Early Childhood Education and Care (ECEC)

List of Country Experts

Name	**Country**
Fink, M. (with van-Linthoudt, J-M.)	Austria
Nicaise I., Vandevoort L., Juchtmans G., Buffel V., Ünver Ö, Van den Broeck K., and Bircan T.	Belgium
Bogdanov, G.	Bulgaria
Zrinščak, S.	Croatia
Koutsampelas, C., Andreou, S.N., Dimopoulos, K., Chrysostomou, S., Kantaris, M., and Theodorou, M.	Cyprus
Sirovátka, T.	Czech Republic
Kvist, J.	Denmark
Anniste, K.	Estonia
Kangas, O.	Finland
Legros, M.	France
Hanesch, W.	Germany
Ziomas D., Mouriki A., Capella A., and Konstantinidou D.	Greece
Albert, F.	Hungary
Daly, M.	Ireland
Raitano, M.	Italy
Lace, T.	Latvia
Poviliūnas, A. and E. Sumskiene	Lithuania
Swinnen, H.	Luxembourg
Vassallo, M.	Malta
van Waveren, B., Groot, J., Fase, D., Willemijn Smit, W., Dekker, B., and van Bergen, K.	Netherlands
Topińska, I.	Poland
Perista, P.	Portugal
Pop, L.	Romania
Gerbery, D.	Slovakia
Stropnik, N.	Slovenia
Rodríguez Cabrero and Marbán Gallego	Spain
Nelson, K., Palme, J., and Eneroth, M.	Sweden
Bradshaw, J., Rees, G., Glendinning, C., and Beresford, B.	United Kingdom

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