

### Children's rights for all

# An overview of legal and policy progress in Europe



Ambitions. Rights. Belonging.











#### @InclusionEurope

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Co-funded by the European Union

The European Union bears no responsibility for the contents of the report.

Published in December 2020 Photo on the cover: Sophie-Scholl-Schule Gießen, Germany (reproduction from Children's rights for all, 2011)

#### **Table of contents**

Why this report?	. 4
The situation of children with intellectual disabilities in Europe	. 5
Promoting rights, encouraging participation and combatting discrimination	. 6
European Union	6
Council of Europe	. 8
United Nations	9
Protection from violence and abuse	12
European Union	12
Council of Europe	15
United Nations	16
Family support and living in the community	20
European Union	20
Council of Europe	24
United Nations	26
How to support transition to community-based care	27
Education	28
European Union	28
Council of Europe	30
United Nations	31
Healthcare	33
European Union	33
Council of Europe	35
United Nations	37
Cources	<b>4</b> 0

#### Why this report?

In 2011, together with Eurochild, Inclusion Europe wrote a report focusing on the specific challenges faced by children with intellectual disabilities in Europe.

This report highlighted the situation of children in many European countries.

It showed that many gaps remained in the implementation of both the Convention on the Rights of the Child (CRC) and the Convention on the Rights of Persons with Disabilities (CRPD).

In the last decade, the topic of children with disabilities has considerably evolved at the EU, the Council of Europe and the UN levels.

The increased focus on intersectionality and more particularly, children and girls with disabilities, has led to more cooperation between the disability and child sectors.

This has translated over the past 10 years into more commitment to protect and promote the rights of children with disabilities worldwide through laws and policies as well as case law.

While not all of them are binding for the countries, they constitute a general trend that reaffirms and consolidates the rights of children with disabilities to a family, to live in the community and to inclusive education.

This report gives an overview of the evolution of the legislative framework at the European Union, the Council of Europe and the United Nations levels.

It also provides insights into the work of Inclusion Europe on the matter together with other Disabled People's Organisations (DPOs) and Children's organisations.

This report comes at a time of new children rights initiatives in the EU. It lays out for us – Inclusion Europe, our members and other advocates of the rights of children with intellectual disabilities – the groundwork for further research and advocacy.

## The situation of children with intellectual disabilities in Europe

It is estimated some 93 million children

– or one in 20 of those under 15 years of age –
live with a moderate or severe disability worldwide.<sup>1</sup>

While there is no agreed number of children with disabilities in Europe, according to Eurostat there are 68 million children below the age of 15 in the EU.

About 5% of EU families with children have one or several children with disabilities.<sup>2</sup>

Unicef estimates 5.1 million children with disabilities across Europe and Central Asia.<sup>3</sup>

Furthermore, there are very few statistics available on girls with disabilities at national and international levels, as

generally data are not disaggregated by sex, age and disability. That scarcity of data has contributed to making the pressing human rights issues that affect children with disabilities, and girls in particular, invisible.

# Promoting rights, encouraging participation and combatting discrimination

#### **European Union**

Children's rights have always been one of the priority areas of the EU, based on the legal inspiration from the United Nations Convention on the Rights of the Child 1989 (UNCRC) and the European Convention on Human Rights 1950 (ECHR).

**The treaty on European Union** (TEU) in 1992 inspired by these two conventions clearly highlighted the importance of children's rights.

The Treaty of Lisbon introduced in 2007 amendments that enhanced capacity for children's rights advocacy at EU level with an expansion of EU's social and right-based agenda. The "protection of the rights of the child" was identified as a general stated objective of the EU and an important aspect of external relations policy.<sup>4</sup>

The Treaty on the Functioning of the European Union (TFEU) in 2007 sets out that 'in defining and implementing its policies and activities, the Union shall aim to combat discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation'.<sup>5</sup> It also gives the power to the Council to take appropriate action to combat discri-

mination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation".<sup>6</sup> Therefore, it gives the EU the power to protect the right of children with disabilities.

The EU Charter of Fundamental Rights of 2000 dedicates one article to the "rights of the child" and more particularly the right to protection, to participation and to a family. The Charter also focuses on the "integration of persons with disabilities" in diverse aspects of the community.8

The EU ratified the UNCRPD in 2011. In 2015 the EU received the **Concluding Observations from the UNCRPD Committee** on the situation of children with disabilities in the EU.9 The recommendations targeted specifically the "lack of awareness regarding the rights of boys and girls with disabilities" and the fact that "they are not systematically involved in decisions that affect their lives nor do they have the opportunity to express their opinion on those matters that affect them directly". 10 Moreover, the Committee called for a better consultation from the EU with children with disabilities and their representative organisations.11

In 2012, **Inclusion Europe launched the project "Hear our Voices"** targeting children with intellectual disabilities. The project aimed to show the ways in which children with intellectual disabilities can participate in society. It was based upon the previous project "Children's right for all" that had monitored the implementation of the United Nations Convention on the Rights of the Child for children with intellectual disabilities (UN CRPD) in 22 EU Member States.

**The European Pillar of Social Rights (EPSR)** in 2017 highlighted the importance in its principle 11 on the children's rights to affordable early childhood education and care of good quality. More generally, it reaffirmed the right to protection from poverty and access to equal opportunities. <sup>12</sup> The Pillar was proclaimed by all EU member states.

In parallel of this evolution of the EU legal framework for children and persons with disabilities, more specific strategies, actions, projects were led to specifically target the group of children with disabilities and even more so those with intellectual disabilities.

The EU Disability Strategy 2010-2020 specifically targets children and elderly people in the need to ensure the transition from institutional to community-based care. 13 The text clearly specifies that the EU funds should ensure this goal of community living for people with disabilities. As the current EU Disability Strategy comes to an end, the European Parliament called the European Commission for an ambitious post-2020 strategy that includes a child-sensitive approach. The Parliament also noted that current European policies on the rights of the child do not sufficiently include a comprehensive rights-based strategy for boys and girls with disabilities, nor do they contain safeguards to protect their

rights, and that the disability strategies do not sufficiently address or mainstream them. <sup>14</sup> This strongly resonates with the advocacy work done by Inclusion Europe to ensure a better visibility of children with intellectual disabilities and their families, reaffirmed in 2020. <sup>15</sup> A joint paper from Eurochild and Unicef similarly called for a new EU Child Rights Strategy and to mainstream children rights in EU Disability Strategy. <sup>16</sup>

The European Commission also announced its intention to adopt **Euro**pean Child Guarantee in 2021 which should help ensure that every child at risk of poverty or social exclusion has access to the "most basic of rights like health care and education". In October 2020, Inclusion Europe submitted a contribution on the consultation launched by the EU Commission on the Child Guarantee.<sup>17</sup> The submission highlighted the challenges faced by children with intellectual disabilities in the areas of early childhood education and care, healthcare, quality education, decent housing, nutrition, culture, and leisure activities. The submission also reminds the discrimination faced by children with intellectual disabilities and their families who both face extra costs that reduce their available resources, as well as the limited opportunities they have to secure employment as they need to provide care.

Following Inclusion Europe's petition raising concerns over the rights of persons with intellectual disabilities and their families, the European Parliament recently adopted a resolution on the rights of persons with intellectual disabilities in the COVID-19 crisis. The text recognises that people with intellectual disabilities are more likely

to suffer from the crisis due to the pre-existing barriers they faced.<sup>19</sup> It specifically emphasises on the impact of the closure of schools and other services on them and their families.<sup>20</sup> It finally reminds the importance of closely consulting with people with intellectual disabilities, including children, in all decisions that affect them.<sup>21</sup>

#### **Council of Europe**

The European Convention on Human Rights of 1950 (ECHR) is the most important human rights treaty at the level of the Council of the Europe. While it does not contain any specific reference on children's rights, rights are recognised for all people and do not target one specific age group.

The European Social Charter (ESC) revised of 1996, focusing on social rights, highlights the right of children and young people to protection.<sup>22</sup> It also enshrines the right of persons with disabilities "irrespective of age" and therefore including children.<sup>23</sup>

In 2006, the Committee of Ministers of the Council of Europe adopted a **Disability Action Plan 2006-2015** to promote the rights and full participation of people with disabilities in society: improving the quality of life of people with disabilities.<sup>24</sup> This Action Plan had a specific part on children and young people with disabilities that highlighted some key elements: fight against discrimination, right to participation and active citizenship, access to quality services and family support, and the right of children to grow up in their families.<sup>25</sup>

The more recent **Disability Strategy 2017-2023** does not have a specific part on children, but includes them through many aspects of the document and recognises that they are at risk of multiple/intersectional discrimination.<sup>26</sup>

The Council of Europe Strategy for the Rights of the Child 2016-2021 highlights the importance of reaching out and involve children in vulnerable situation including those with disabilities. It also specifically targets "the participation of children including those with disabilities in the digital environment".<sup>27</sup>

In parallel of the strategies, the Committee of Ministers adopted several recommendations focusing on the right of children and people with disabilities.<sup>28</sup> One specific recommendation adopted in 2013 focused on the "full inclusion of children and young persons with disabilities into society".29 It stressed that children and young people with disabilities should take an active part in social life" while recognising that "the lack of access to appropriate sources and support in development of perspectives often limit the chances of developing their abilities and contribution in social life".30

In 2019, the Council of Europe published a **report on Protecting the child from poverty: the role of rights in the Council of Europe**. It recognises that poverty "pose[s] particular challenges to children with disabilities".<sup>31</sup>

The same year, the Committee of Ministers adopted a **Declaration on addressing child poverty** that encourages "Member States to target and improve child welfare services, taking due account of children in vulnerable situations [...] children with disabilities". <sup>32</sup>

#### **United Nations**

"States should do more for an estimated 93 million children with disabilities who are "among the most likely to be left behind and the least likely to be heard", "Children with disabilities must have a say in all matters that affect the course of their lives...They must be empowered to reach their full potential and enjoy their full human rights – and this requires us to change both attitudes and environmental factors."

UN High Commissioner for Human Rights, Michelle Bachelet, Human Rights Council event, 2019

The Convention on the Rights of the Child (UNCRC) of 1989 is an important human rights Treaty that protects the rights of children with intellectual disabilities and their families. Both its general and specific articles can be used to promote their rights.

Article 2 and Article 12 of the UNCRC include general principles of fundamental importance, relevant to all articles and all aspects of the implementation of the Convention.

Article 2 set outs the fundamental obligations of State Parties to respect and ensure that all the rights enshrined in the Convention apply to all children without any distinction, including children with disabilities. Article 12 of the UNCRC requires State Parties to ensure

that children with disabilities have a right to express their views freely in all matters affecting them, and to have these views given due weight in accordance with the age and maturity of the child. Paragraph 2 of Article 12 refers to a wide range of decisions, from court hearings (including civil proceedings) to formal decisions affecting the child (in education, health, alternative care, employment).

It is important to note the wording of the Convention who targets especially the child who "is capable of forming his or her own view". If this capacity is meant to refer to the age of the child, one could interpret it in the sense of capabilities to exclude children and adults with intellectual disabilities to contribute to decisions.

Article 23 of the UNCRC specifically focuses on children with disabilities and promotes the respect by the States of children's and families' needs. Without using the same terminology as in the UNCRPD, this article highlights the right to equal opportunities for children with disabilities and resonates with the idea of "empowerment".

In 2006, the Committee on the Rights of the Child, even before the adoption of the UNCRDP, emphasised in its General Comment n°9 on children with disabi**lities** that the barrier is not the disability itself but a combination of social, cultural, attitudinal and physical obstacles which children encounter in their daily lives.33 This General Comment develops its interpretation of article 23 and details the right to services, to equal opportunities, the need to collect data, the need to coordinate disability policies through focal points in each "governmental and non-governmental institutions". It reaffirms the right of children to participate in all matters affecting them.

In 2013, the CRC Committee through its **General Comment 14 on the right of** the child to have his or her best interests taken as a primary consideration will further expand on the right to participation. It indicates that "The fact that the child is very young or in a vulnerable situation (e.g. has a disability..) does not deprive him or her of the right to express his or her views, nor reduces the weight given to the child's views in determining his or her best interests".34 The same General Comment also highlights the need to determine the best interest of a child in a vulnerable situation not only vis-à-vis the UNCRC but also "other human rights norms related to these specific situations, such as those covered in the Convention on the Rights of Persons with Disabilities".35

The Committee pointed out in the General Comment n° 17 on the right of the child to rest, leisure, play, recreational activities, cultural life and the **arts** the lack of participation of children with disabilities in recreational activities, cultural life and the arts referring to the article 30 of the UNCRPD.36 The Committee also addressed the lack of opportunities to participate in the community faced by adolescent with disabilities in its General Comment n°20 on the implementation of the rights of the child during adolescence.<sup>37</sup> Specific mention was made of the need to "promote their full inclusion and facilitate effective transitions from adolescence to adulthood".38

The General Comment additionally talks about the importance of the "equal access to digital citizenship through the promotion of accessible formats for adolescents with disabilities".<sup>39</sup> Finally, the Committee expressed in its recent **draft General Comment n°25 on digital environment** the opportunities that represents digital environment for children with disabilities to engage in social relationships, access information and participate in public decision-making processes and the way they should be involved.<sup>40</sup>

More recently, the **CRC Committee** made a statement on the impact of **Covid 19** and called to protect the rights of children. It especially expressed concerns about the lack of services, the struggles for children with disabilities and their families in lockdown and the need ensure accessibility of information for children with disabilities.<sup>41</sup>

It is important to observe the impact of the UNCRPD development on the UNCRC Committee's interpretation of its own convention and how it led to a stronger protection towards children with disabilities over a decade.

In parallel of the evolution of the UNCRC body, the adoption in 2006 of the **Convention on the Rights of Persons** with Disabilities (UNCRPD) implied the birth of a disability-specific international human rights body. The Convention in its **article 7** targets directly children with disabilities with similar notions previously seen in the UNCRC such as full enjoyment of human rights, best interest of the child, and their right to express their views freely. The CRPD also enshrines the right for a child to a family in its article 23 and consequently the obligation of the States Parties to ensure that children with disabilities have equal rights with respect to family life and are not separated from their parents against their will.

The Committee through its General Comments had multiple opportunities to promote the right of children and young people to be included and to participate in the community on an equal basis with others.

The **General Comment n°1 on equality before the law** highlights the importance to respect the "evolving capacities of children with disabilities" and the value given to their views in accordance with their "age and maturity".<sup>42</sup> As the notion of empowerment is a part of the UNCRPD brand, the notion of will and preference of children is introduced to avoid all confusion with an outdated notion of "best interest" for people with disabilities.<sup>43</sup>

While the **General Comment n°3** on women and girls with disabilities mainly focuses on women, the

Committee recognises that girls have "historically been silenced" and disproportionally underrepresented in public decision-making".<sup>44</sup>

The **General Comment n°6 on equality and non-discrimination** acknowledges that "children with disabilities often experience multiple, and intersectional discrimination" and that the States "must prohibit all forms of discrimination on the basis of disability that are specific to children" while raising the awareness "among the public and professionals to prevent and eliminate discrimination". <sup>45</sup> The Committee also reaffirms the need for children with disabilities to be "informed, consulted and have a say in every decision-making process related to their situation". <sup>46</sup>

The **General Comment n°7 on parti**cipation of persons with disabilities acknowledges that "the lack of access to mainstream education or lack of education impede the future participation of children with disabilities as equal citizens in the community".47 It also enshrines a number of recommendations to ensure the participation of children with disabilities such as the need to "allocate specific funds for organisations of children with disabilities" to ensure their participation in policy-making processes.48 The Committee suggests innovative forms of participation to include children with disabilities such as the submission of essays on specific topics.

The Special Rapporteur on the rights of persons with disabilities' report on deprivation of liberty highlighted the need to include children with disabilities on policy reform aiming at ending "all forms of deprivation of liberty based on impairment".<sup>49</sup>

#### Protection from violence and abuse

Children with disabilities are particularly exposed to violence. While many reports urged the authorities to take measures to prevent violence and abuse from occurring, children are still particularly at risk of violence in different environments: institutions, schools, community. It is key to focus on preventive measures, victim support, and child-friendly justice to address the challenges in these areas.

Children with disability are three to four times more likely to experience violence.

Children with mental health conditions or intellectual impairments appear to be among the most vulnerable, with a 4.6 times higher risk of experiencing sexual violence than their non-disabled peers.

WHO Global Disability Action Plan 2014-2021 para 25

#### **European Union**

The **2000 EU Charter of Fundamental Rights** establishes the foundations for the protection of children with disabilities in the EU.<sup>50</sup> The Charter enshrines several articles non child-specific that protect human dignity (article 1), the integrity of the person (article 3), that prohibits torture and inhuman or degrading treatment or punishment (article 4) and protect the right to liberty and security (article 6). The articles more specific to children mention the right to protection and care (article 24) and the prohibition of child labour (article 32).

The **2011 EU agenda for the Rights of the Child** recognises that children with

disabilities are "more vulnerable to the violation of their rights and they require and deserve special protection".<sup>51</sup>

The agenda specifically looks at ensuring a child-friendly justice and targeting EU action to protect children when they are vulnerable.<sup>52</sup>

The same year, two other important directives were adopted: the **Directive on preventing and combating trafficking in human being and protecting its victim**<sup>53</sup> and the **Directive on combating the sexual abuse and sexual exploitation of children and child pornography**. <sup>54</sup>

A year after this text, the **2012 EU Victims' Rights Directive** was adopted and aimed among other things to "assure child victims of crime a set of rights to enable them to be supported, protected and to actively participate in the criminal justice process in line with their needs and taking into account their individual vulnerabilities".

The recently adopted 2020-2025 EU Strategy on victims' rights is including children in it's scope. One of the aspects underlined is the reporting of a crime as "children are often victimised in the family environment, or by persons whom they depend on" and the need to better train professionals working with children. This training also entails "communication with victims in a way that is adapted to victims' specific needs" that "is particularly relevant for victims with disabilities". Finally, the strategy addresses the need for accessible premises for victim with disabilities so they can report crime and participate in criminal proceedings.

In parallel of the EU legislative context on preventing and reporting violence against children, relevant reports have been released to shed light on violence against children with disabilities and child-friendly justice. The EU Fundamental Rights Agency (FRA) released report on violence against children with disabilities: legislation, policies and programmes in the EU in 2015. This report regrets the lack of disaggregated data on children with disabilities. It also recommends that child victims "should be considered and treated as the full bearers of rights [..] and should be entitled to exercise those rights in a manner that takes into account their capacity to form their own views". Based on research, the report also states that victims with disabilities tend to experience a high rate of secondary and repeat victimisation, intimidation and retaliation. Many of the recommendations in this report on professional training, child-friendly justice have been used to draft the aforementioned 2020-2025 EU Strategy on victim's rights.

The 2017 FRA report on child-friendly justice reports that on all children interviewed for the purpose of the study, 35% of children with disabilities were unable to understand proceedings compared to 17% of children without disability.<sup>57</sup>

Inclusion Europe focused on the violence faced by women and girls with intellectual disabilities.<sup>58</sup>

The **Life after violence** report highlights specific figures about violence in the Netherlands:

- · Regarding violence against children with an intellectual disability, Sullivan and Knutson (2000) found a prevalence of 31% (including both physical and sexual abuse).<sup>59</sup>
- · In a Dutch study in which adolescents between 14-19 years old and who lived in a residential institute were interviewed, 26% of the boys and 65% of the girls reported to have been victims of sexual abuse.<sup>60</sup>
- · In another study of adolescents with an intellectual disability, 41% of girls reported sexual intimidation, 38% reported unwanted touching, and 4 % reported to have been forced to touch another person.<sup>61</sup>
- · One Dutch study titled "Prevalentie Seksueel Misbruik in de Nederlandse Jeugdzorg in 2008-2010" (Prevalence of Sexual Abuse in Youth Care) examined the prevalence of sexual abuse among young people in youth care institutions. This study found a prevalence of 9.7 per 1,000 sexual abuse incidents among young people with an intellectual disability. 62
- · A 2005 study from the USA showed that children with an intellectual disability are three to four times more likely to experience violent behaviour against them compared to children without disabilities.<sup>63</sup>
- $\cdot$  Measured in incidents per given year, prevalence of sexual abuse is, according to some studies, between 2,88 per 1,000 people with disabilities up to 0.5% per year.  $^{64}$
- · A longitudinal study showed that over a period of 15 years, 6% of children and adults with intellectual disabilities had been victims of (confirmed, not only self-reported) sexual abuse.<sup>65</sup>

Another **Inclusion Europe project**, **BeSafe** addressed online safety for people with intellectual disabilities. While the project is not child-specific,

it uses materials to prevent cyber-harassment/cyber-bullying and raise the awareness of professionals. Therefore, it is relevant for all age-groups.<sup>66</sup>

#### **Council of Europe**

The European Convention on Human Rights of 1950 (ECHR) prohibits torture, inhuman or degrading treatment or punishment in its article 3. The European Social Charter (ESC) revised of 1996 raises in its article 17 the specific need for protection of children and young people against negligence, violence or exploitation.

Additionally, the Council of Europe adopted in 2005 the Convention on Action against Trafficking in Human Beings, <sup>67</sup> the 'Lanzarote Convention' on the protection of children against sexual exploitation and sexual abuse in 2007 and the 'Istanbul Convention' on preventing and combating violence against women and domestic violence (2011).

The Committee of Ministers adopted a number of important recommendations to complement the adopted conventions. One in 2001 focused on the protection of children against sexual exploitation.<sup>68</sup> In 2005, one resolution specifically highlighted safeguarding of adults and children with disabilities against abuse.69 This resolution provides a definition of abuse as being "any act, or failure to act, which results in a breach of a vulnerable person's human rights, civil liberties, physical and mental integrity, dignity or general well-being, whether intended or through negligence, including sexual relationships or financial transactions to which the person does not or cannot validly consent, or which are deliberately exploitative". The resolution specifically describes the types of violence that can be faced with a "special concern when they take place within a relationship characterised by powerful positions".

In **2009**, the Committee of Ministers' developed **Recommendation and guidelines on the protection of children from violence** that highlights the vulnerability of children with disabilities.<sup>70</sup>

Following the adoption of these key conventions and recommendations, both the disability and children strategies pointed out the need to protect children with disabilities.

A "Building a Europe for and with children" 2009-2011 Strategy enhances the Council of Europe's commitment to children's rights and the eradication of violence against children, with special focus on particularly vulnerable children, without parental care and/or with disabilities.<sup>71</sup>

The aforementioned **Disability Strategy** 2017-2023 recognises that children and those with complex support needs are "at risk of multiple and intersecting types of violence and abuse hate crime and bullying particularly affecting children and young people with disabilities".72 The strategy further elaborates on the need to mainstream disability right into the Convention on the protection of children against sexual exploitation and sexual abuse. The Strategy for the rights of the Child 2016-2021 clearly states the Council of Europe's objective to eliminate "violence against children in all settings and in particular in the fields of education, media, justice, equality, family, migration, alternative care, and children with disabilities".73

In 2016, the Council of Europe published a report on addressing violence in schools through education for democratic citizenship and human rights education.<sup>74</sup> Disability is being described as a major variable in most reports on school violence, with students with disabilities as both victims and perpetrators, based on lack of inclusive practices, prejudicial practices, and victimisation and othering especially of children with learning disabilities.

The Commissioner for Human Rights released a report in 2006 on Children and Corporal Punishment: "The Right Not to Be Hit, Also A Children's Right.

The European Court of Human rights (ECtHR) has an extensive jurisprudence of cases related to violence against children with disabilities. Most ECHR case law concerning violence against children centres on violations of Article 2 (right to life), Article 3 (prohibition of inhuman or degrading treatment) and Article 8 (respect for private and family life). In an old case X & Y v The Netherland **1985,** a girl with "mental handicap" was raped in institution where she lived. The proceedings were not brought against the perpetrator because the girl, traumatised by her experience and deemed unfit to sign an official complaint, had to make the complaint herself.

The ECtHR held that States must ensure that the right procedures are in place to allow children with disabilities to report violence. In Dordevic v. Croatia 2012, the ECtHR condemned Croatia for inaction in a case of harassment of a mother and her son with a disability over four years by a group of children and young people living in the neighbourhood. In the case of **Nencheva and Others** v. Bulgaria 2013, fifteen children and young adults died between December 1996 and March 1997 in a home for "physically and mentally disabled" young people due to coldness and shortages of food, medicines and basic necessities. The staff alerted the authorities, responsible the house funding but nothing was done. The Court recognised that violation by Croatian authorities of their duty to protect the lives of "vulnerable children".<sup>75</sup> In **Valentin Câmpeanu v.** Romania 2014, the Court allowed an NGO to bring a case before it on behalf of a "young mentally disabled man" who died in a psychiatric hospital.<sup>69</sup> In **I.C v** Romania 2016, the court condemned Romania for the inaction for the authorities regarding a girl with a disability's alleged rape. The Romanian court trusted more the abuser and refused to take into account the victim's testimony because of "her young age and physical/ psychological vulnerability".77

#### **United Nations**

The UNCRC targets violence in many of its articles: protection from abuse and neglect (article 19), protection of children without families (article 20), child labour (article 32), sexual exploitation (article

34), sale trafficking and abduction (article 35), other form of exploitation (36) and torture and deprivation of liberty (article 37).

The CRC Committee released in 2011 its **General Comment N°13 on the right of the Child to freedom from all forms of violence**.<sup>71</sup> It highlights the specific types of violence that disproportionally affect children with disabilities, such as abandonment, forced sterilisation, clinical "treatment", deliberate infliction of children to beg in the street.

The Committee calls for a particular vigilance for children with disabilities and recommends the "establishment of specialized units within the police, the judiciary and the prosecutor's office with the possibility of providing accommodations in the judicial process to ensure equal and fair participation of children with disabilities".<sup>79</sup>

The Committee also emphasises the particular situation of children with "communication or intellectual impairments, they may be ignored, disbelieved or misunderstood should they complain about abuse".

The General comment n°24 on children's rights in the child justice system underlines the need for safeguards against discrimination "from the earliest contact with the criminal justice system and throughout the trial, and discrimination against any group of children requires active redress". 80 The text recommends to implement accommodation for children with disabilities such as "support for children with psychosocial disabilities, assistance with communication and the reading of documents, and procedural adjustments for testimony". 81

Finally, the **draft General Comment 25 on digital environment** recognises that "children with disabilities can be more exposed to online risks, including bullying in the digital environment". It further recommends to "address the safety risks faced by children with disabilities, taking steps to ensure that the digital environment is safe for them" with safety information, protective strategies, public information, services and forums relating to the digital environment forums in accessible formats.<sup>82</sup>

A Joint general recommendation of the CRC Committee with the Committee on the Elimination of Discrimination against Women (CEDAW Committee) focuses on harmful practices.<sup>83</sup>

It raises certain practices identified as harmful as they are connected to and reinforce socially constructed gender roles and can reflect negative perceptions of certain disadvantaged group such as individual with disabilities. These practices include: "neglect of girls (linked to the preferential care and treatment of boys), extreme dietary restrictions including during pregnancy (force-feeding, food taboos).<sup>84</sup>

The **UNCRPD** contains a bloc of **articles**, **from 14 to 17**, protecting people with disabilities in general without being specific to children. These articles entail several aspects: liberty and security of person, freedom of torture or cruel, inhuman or degrading treatment or punishment, freedom from exploitation, violence and abuse and the protection of the integrity of the person.

The Committee had the opportunity in its General Comment n°3 on women and girls with disabilities to mention that "children with disabilities are also disproportionately likely not to be registered at birth, which exposes them to exploitation and violence".85 It expresses his specific concerns about the fact that "girls with disabilities are particularly at risk of violence from family members and caregivers". The Committee will keep raising the specific situation of girls with disabilities in its General Comment n°4 on inclusive education. It says that they can "be disproportionately affected by violence and abuse, including physical and humiliating punishments by educational personnel, for example through the use of restraints and seclusion and bullying by others in and en route to school".86

Ms Catalina Devandas Aguilar, as Special Rapporteur on the Rights of Persons with Disabilities pointed out situations of violence faced by children with disabilities in her reports. In a report on the deprivation of liberty of persons with disabilities, the Special Rapporteur points out the overrepresentation of children with disabilities "in juvenile detention facilities and residential institutions for children, such as orphanages, social care settings and small-group homes".87 The Special Rapporteur points out, in a report on the rights of persons with disabilities to the highest attainable standard of physical and mental health, that "children with disabilities are six times as likely as other children to experience violence and abuse".88

"Sterilization of women and girls with disabilities continues to be prevalent, and up to three times higher than the rate for the general population".91

It further specifies that "children with psychosocial or intellectual disabilities have a higher prevalence and risk of violence than children with other disabilities".89 The report also touches upon the issue of "sterilization of women and girls with intellectual and psychosocial disabilities" being prevalent.90 Another report on sexual and reproductive health and rights of girls and young women with disabilities presents studies showing "that the sterilization of women and girls with disabilities continues to be prevalent, and up to three times higher than the rate for the general population".91

The report also highlights the specific experiences of girls and young women with intellectual disabilities who experience aggravated forms of stigma and discrimination such as the view that they "lack the capacity to understand sexuality and their own bodies, as well as the fear of their relatives of being held responsible for allowing their sexual activity, puts those girls and young women under excessive monitoring and control".<sup>92</sup>

To finish, a 2012 **Thematic study of the OHCHR on the issue of violence against women and girls with disabilities** found that persons with disabilities, and in particular those living in institutionalised settings, are the most vulnerable to violence. It also estimates that "1.2 million children and adults with disabilities live in long-stay residential institutions".93 It highlights the particular vulnerability of women and girls with intellectual disabilities who are

"at a particularly high risk of violence, including sexual violence". It targets the evidence-based research on forced sterilisation of women. The report criticises the frequent "reluctance of prosecutors to open cases of violence committed against women and girls with intellectual disabilities, given that they can require more resources owing to the need to investigate the victim's ability to consent and testify".<sup>94</sup>

It also estimates that "1.2 million children and adults with disabilities live in long-stay residential institutions". 93

## Family support and living in the community

"Four decades of work to improve the living conditions of children with disabilities in institutions have taught us one major lesson: there is no such thing as a good institution."

Professor Gunnar Dybwad, founding father of the movement for inclusion, parent advocacy and self-advocacy for persons with disabilities

#### **European Union**

The EU has progressively recognised the importance of the transition from institutions to community-based services. This progressive recognition was accelerated with the adoption in 2006 of the UNCRPD, that clearly stands against institutionalisation, and its subsequent ratification by the EU in 2010.

The **EU Disability Strategy 2010-2020** clearly highlights the promotion of the transition from institutions to community-based care especially for children and elderly people, as one of the goals of the EU Commission to ensure participation of people with disabilities.<sup>95</sup>

The European Pillar for Social Rights in its principle 18 on long-term care emphasises on the importance of the right to affordable long-term care services, in particular home-care and community-based services.

**Inclusion Europe called for EU Disabi**lity Strategy post 2021 to better defend the right to live independently and being included in the community as it is "integral to the realisation of many of the other rights enshrined in the CRPD, including equality and non-discrimination, autonomy and liberty, legal capacity and freedom of movement".96 It also asks the Commission to better promote personal assistance and inclusive services. Finally, as other organisations, it stresses the importance to include deinstitutionalisation as an indicator in the EU social scoreboard to measure how much progress has been made by the countries on the matter.

Another important aspect of EU policies related community living is the implementation part through the **structural funds**. Organisations within the European Expert Group (EEG) on the Transition from Institutional to Community-Based Care have been advocating for years towards stronger mechanisms to ensure that EU funds are spent in community-based services instead of institutions.<sup>97</sup>

In its 2015 Concluding observations on the initial report of the European Union, the CRPD Committee notes that people with disabilities, especially with intellectual or psychosocial disabilities, are still living in institution rather than in their local communities. 98 It also regrets, as many European NGOs, that "despite changes in regulations, the European Structural and Investment Funds continue to be used in different member States for the maintenance of residential institutions rather than for the development of support services for persons with disabilities in local communities". 99

Several important reports on the matter have recently been released to analyse the state of deinstitutionalisation across the EU with a specific focus sometimes on children. The report released by Academic Network of European Disability Experts (ANED) on the right to live independently in 2019 regrets that "in a number of European States, children with disabilities are disproportionately more likely to be placed in institutional care than their non-disabled peers and appear far less likely to benefit from efforts to affect a transition from institutional to family-based care". 100 Moreover, ANED acknowledged that "even in European States in which large-scale institutions were mostly closed several decades ago, such as the United Kingdom, congregate living dominates the living arrangements of those with intellectual disabilities who require support and who are not living with family". 101 The report points out the specificity of children with intellectual disabilities in Bulgaria and Finland according to the national reports sent to ANED.

In Bulgaria by the end of 2015, all institutions for children with intellectual disabilities had been closed. However, six of these turned into institutions for adults as the children who were placed in them turned 18. The implementation of the Updated Plan for De-institutionalisation of Children (2016-2020) is lagging behind as admissions to children's institutions remain open. The share of the institutionalised children that were disabled was nearly 1,4 times higher in 2017 compared to 2010. The deficit of early intervention and prevention of abandonment leads to the fact that 57 % of all admissions in IMSCC in 2017 are disabled babies and children. 102

**In Finland** it is reported that the de-institutionalisation process for children with disabilities has not progressed as well as for adults. The number of children with intellectual disabilities under the age of 18 in institutions has not decreased as planned. In 2017, there were 173 children with disabilities in institutions and it was noted that the process for children had not progressed as well as for adults - in 2015 it was 194. Children living in institutions tended to be children with intellectual disabilities and children on the autism spectrum who showed behaviour described as challenging.103

A year later was released a **report on the transition from institutional care to community-based services in 27 EU Member States, 2020.**<sup>104</sup> According to this report, there are still "at least" 1.438.696 persons living in institutions in the EU while noticing a slight decrease of the number of children in residential care as "they move to live with their families, are being fostered, adopted or are reaching majority and leave residential care for children". <sup>105</sup>

**Luxembourg** There also appear to be some small group home type settings specifically for children with intellectual disability – these are generally between 1 and 5 places (p87).

**Netherlands** the size of residential services for children appear to be small (less than 5 places) although some places for children with intellectual disability and with mental health problems exist in sheltered housing (usually between 11 and 30 places in size). The size of residential care settings for children appears to have decreased although there are still some children in larger settings, in particular those with mental health problems and intellectual disability (p95).

**Portugal**: In 2005 there were 642 places in "Support homes for children" which provide for between 15 and 20 children, 240 places in a large rehabilitation centre for children and young people – all occupied by children with intellectual disability and 120 places in a recuperation centre for children also all occupied by children with intellectual disability.

In parallel of the legislation adopted and the reports requested by the EU institutions, Inclusion Europe has been active on the issue of deinstitutionalisation, including for children with intellectual disabilities.

In a 2019 report on Empowerment of people with complex support needs, Inclusion Europe focuses on how adults and children with intellectual disabilities of this particular group could be supported to live in the community.

The report underlines the importance of interaction of children with complex support needs with other children as key to tackle social perceptions and stereotypes at the youngest age as well as the importance for children to grow up in their families".<sup>106</sup>

The report continues by emphasising on the key role played by families in "preventing institutionalisation and in facilitating social inclusion of their family member – especially when they themselves have the necessary support.

For example, families are especially important during the main transition periods in life – in childhood (such as starting school, going through puberty etc.) and from childhood to adulthood (such as leaving school, going to university, finding employment, starting a family etc). The report highlighted the situation in Spain where a study had been led on families of people with complex support needs.

**Spain**: Families support to their relative can amount to 16 hours a day, there is an estimation of 47.129 euros per year for the cost of the support of a relative by the family (health, human support etc.). The study also finds that 55% of the family carers see experience health problems due their role of carer. Plena Inclusión campaign Todos somos Todos (p26).

In a recent article in 2020 in Apolitical on deinstitutionalisation for children, Inclusion Europe regrets that the improvement on deinstitutionalisation seem not to apply to children. The example of Czechia is given: "public spending on family support represents only 10% of the money going into "mainstream child protection". 108 On the Human Right Day, a coalition of 22 child rights organisations called on the Ukrainian government and the European Union to act about the 1.5% of children living without family in some form of residential institution. They are spread over 700 facilities across the country and constitute one of the highest rate of child institutionalisation in the world. 109

A network called "Opening doors for Europe's children" was created in 2014 and together with other organisations if advocating towards community living of all children.

A 2018 report published by UNICEF calls for EU policymakers to better support the DI transition in the next strategy for the European funds. According to the report, "Europe and Central Asia have by far the highest percentage of children separated from their families worldwide: At present 666 per 100,000 children live in residential care in these two global regions. This is more than five times higher than the average of 120 children per 100,000".<sup>110</sup>

The ongoing covid19 has shed light on the increased vulnerability of people of all ages living institutions. Early figures from 21 countries indicated that persons in "care homes" accounted on average for 46% of Covid-19 deaths.<sup>111</sup>

#### **Council of Europe**

The Council of Europe progressively stood against institutionalisation. While the first fundamental text on social rights: the **European Social Charter (revised)** does not overtly target institutions, it talks about "protection against social exclusion" (preamble, 30) or "social integration and participation in the life of community".<sup>112</sup>

The Committee of Ministers expressed a set of recommendations that paved the way for a stronger legislative framework at the Council of Europe against the institutionalisation of children. A first 1998 recommendation on children's participation in family and social life highlights the need for all children to be included in the community. However, it legitimises back in the day the institutions in the way that it "encourages educational, day care and residential care institutions for children to create possibilities for children to make their opinions heard on matters concerning them and ensures that their views are taken into account in the decision-making processes in these institutions".113

A Recommendation adopted in 2010 on deinstitutionalisation and community living of children with disabilities came to strengthen the position of the Council of Europe on the matter. 114 Greatly inspired by the adoption in 2006 of the UNCRPD and the paradigm shift, this recommendation aims to "promote a human-rights based, anti- discriminatory approach to improving the lives of all people with disabilities, including children and those with enduring and/or complex support needs".

The recommendation recognises the right of children with disabilities to grow up in their own families as it is their

natural well-being. It also describes the need for a deinstitutionalisation process and the importance of a change in the community to better support families and children to truly enable community living for all. It clearly resonates with the aforementioned European NGOs advocacy by saying that "building of new institutions should be discouraged by refusing to approve and fund proposals for this type of project".<sup>115</sup>

A more general **Recommendation in 2011 on children's rights and social services friendly to children and families** will specifically include in its scope "services accommodate the special needs or children with disabilities and their families, for independent living and full participation in everyday life". 116

Finally a **2013** Recommendation on the full inclusion of children and young persons with disabilities into society reaffirms the commitment to deinstitutionalisation, right to independent living and "belonging to community". <sup>108</sup> While it recognises that "many European countries have already committed themselves to deinstitutionalization", it also regrets that "the necessary alternative community-based support services, such as accessible housing and support services, have not always been put into place". <sup>118</sup>

In parallel to these recommendations, the Council of Europe's strategies have all reaffirmed the right to live in the community of people with disabilities. The Strategy for the Rights of the Child (2016-2021) has reaffirmed the intention of the Council of Europe to protection the right of children with disabilities based on the UNCRPD and the previous recommendations adopted by the Committee of Ministers. 119 The Disability Strategy 2017-2023 highlights repeatedly through the whole text the need to move away from institutions, to ensure life and participation in the community and pay particular attention to people with complex support needs who are at higher risk of institutionalisation. 120

The Commissioner for Human Rights wrote reports to promote and advocate for the right of children with disabilities in Europe. A 2010 report of the rights of children strongly declares that "the time has come for de-institutionalisation of children living in institutions, especially in those which are large, obsolete and generally inadequate." The report recommends the need for children to be placed in smaller, family-type establishments or in foster homes. However, it is regrettable that institutionalisation in the report is tolerated as a "last resort solution" in the interest of the child.

In another report in 2012 on the right of people with disabilities to live independently and be included in the community, the Commissioner details recommendations to States on how to ensure community living for all. It especially raises the need to "develop and implement a plan to support families who have a child with a disability to enable the child a full life within family and community and prevent isolation and institutionalisation".<sup>121</sup>

The ECHR has an extensive jurisprudence on case law and European and international organisations have often taken part as third parties in cases related to institutions of people with disabilities. Very important cases like **Stanev** v. Bulgaria in 2013 enabled the disability community to shed light on precarious and life-threatening conditions in institutions and how it is hard for those who are placed there to get out and seek redress.122 However, the limited understanding of the CRPD by the judges had led to disappointing judgements on the right to live independently for people with intellectual disabilities with the recent example of AMV v Findand in 2017.123

Cases on the right to community living for children with disabilities have been brought to the **European Committee** for Social Rights (ECSR) through the collective complaint mechanism. The ECSR recently condemned Czechia for the lack of compliance with its obligation to refrain from institutionalizing children under the age of 3. The Committee considered that the country violated the article 17 of the ESC because of the lack of appropriate protection and care, no adequate measures have been taken towards deinstitutionalisation of the existing system of early childhood care.124

Inclusion Europe together with the European Disability Forum lodged a complaint against France for the lack of access to services for people with disabilities and their families to enable a full inclusion in the community. The collective complaint highlights the extreme situation of 6500 people including 1500 children forced to live in institutions in Belgium, far away from their families. 129

#### **United Nations**

At the UN level, concerns about institutionalisation of children with disabilities have been voiced by different bodies. The UNCRC in its preamble recognises that all children should "grow up in a family environment" for their "full and harmonious development".<sup>127</sup>

The CRC Committee addressed the issue in its **General Comment n°9 on the rights of children with disabilities** and "expressed its concern at the high number of children with disabilities placed in institutions". <sup>128</sup> The Committee also urged States through deinstitutionalisation programmes to "support the ability of such children to live in their family, extended family or foster care". As we have noticed several times, the right to live in the community for children cannot be separated from the right to grow up in their families. <sup>129</sup>

Moving to a disability-specific Convention, the article 19 of the UNCRPD, without being specific to any age category of people with disabilities, enshrines an unequivocal right to live in the community for all.

The CRPD Committee in its 2017 General Comment n°5 on the Right to Live Independently and to be Included in the Community reaffirmed the unconditional right to live in the community regardless of age nor level of support required.<sup>130</sup> The Committee expressed, in the same way as the CRC Committee did 11 years earlier, its concern about the high number of children placed in institutions and call for a better support to families. 131 It clearly states that "[f] or children, the core of the right to be included in the community entails a right to grow up in a family. 132 It condemns "large or small group homes are especially dangerous for children, for whom there is no substitute for the need to grow up with a family". 133 Finally the General Comment emphasises the importance of the support, information and guidance that need to be provided to families to prevent institutionalisation of children with families.134 Inclusion Europe and other organisations advocated for a right to live in the community to be recognised for all, a complete condemnation of institutions and for the key role of families in preventing institutionalisation to be fully recognised and valued.135

The **CRPD Committee's 2017 General Comment n°6 on Equality and Non-Discrimination** reaffirms the need for States to "address violence and institutionalization of children with disabilities, who are denied the right to grow up in their families as a matter of discrimination". <sup>136</sup>

Inclusion Europe together with other organisations repeatedly raised the need for all children to live in the community and grow up in their families.<sup>137</sup>

The Special Rapporteur on the rights of Persons with Disabilities in her 2019 report on deprivation of liberty called for a better harmonisation of UN standard, pointing out the contrast between the UNCRC notion of "suitable institutions" and the higher standards promoted by the UNCRPD.<sup>138</sup>

A general resolution adopted in 2019 by the UN general assembly on promotion and protection of the right of children voices a general concern over the situation of children without parental care and the "potential harm of institutionalization and institutional care to children's growth and development". 139

The general assembly urges States to prioritise "quality alternative care options over institutionalization with the best interests of the child as the primary consideration".<sup>140</sup>

Finally the resolution highlights the needs for a deinstitutionalisation process through the progressive replacement of "institutionalization with quality alternative care, including, inter alia, family and community-based care and, where relevant, redirecting resources to family and community-based care services, with adequate training and support for caregivers". 141

## How to support transition to community-based care

Checklist to ensure EU-funded measures contribute to independent living by developing and ensuring access to family-based and community-based services - Link



#### **Education**

#### **European Union**

At European Union level, there are numerous non-binding statements on children with disabilities' education but no requirement on member countries to have inclusive education.

The **2000 EU Charter of Fundamental Rights** establishes the foundations in the EU for a right to education for in its article 14.<sup>142</sup> The article also includes include the access to vocational and continuing training.

The 2017 European Pilar for Social Rights recognises the importance of education in its first principle on education, training and life-long learning. The principle presents the right to quality and inclusive education as an enabler to a full participation in society and on the labour market. Additionally, the more general principal 3 on equal opportunities mentions among other things the right to education.

In addition to the legislative framework, the EU adopted strategies that specifically mention the right to education. **The European Union (EU) strategic objectives for Education and Training (ET 2020)** also sets goals for 2020 such as the participation of at least 95% of child in early childhood education and less than 15% of 15 years old should be under-skill in reading, mathematics and science.<sup>143</sup>

The **2011 EU agenda for the Rights of the Child** addresses the issue of early

school leavers and echoes the aforementioned Europe ET 2020 Strategy to reduce the share of early school leavers to less than 10%. 144 As highlights the Agenda for the rights of the child, In 2009, more than 6 million young people left education and training, completing lower secondary education or less; 17.4% of them completed only primary education. The agenda also recognises that children growing up in poverty and social exclusion [...] are less likely to do well in school". 145

Education and training is also one of the 8 areas for actions contained in the **EU disability strategy 2010-2020.** <sup>146</sup> The strategy specifically targets EU actions in the field of early identification of specific needs and adequate training and support for professional working at all levels.

A **Digital Education Action Plan 2021-2027** has also been adopted and highlights the need for students with disabilities to have fully accessible online tools to benefit from digital transformation.<sup>147</sup>

The Recommendation of the Council of the European Union on promoting common values, inclusive education, and the European dimension of teaching (2018/C 195/01) emphasises the importance of EU member States to take actions to promote inclusive education.<sup>148</sup>

In the Concluding Observations of the Initial Report of the European Union, the CRPD Committee is concerned by the fact that in several countries of the European Union, children and adults with disabilities cannot access quality and inclusive education.<sup>149</sup> It therefore recommends the EU to take measures towards inclusive education but also to develop disability-specific indicators in the Europe 2020 strategy so progress can be measured.<sup>150</sup>

In parallel of the EU developments, **Inclusion Europe** continued to advocate for the rights of children with intellectual disabilities to be included in schools with other children. Projects led with members and/or other organisations such as **IE+**, and **ICLife** aimed at promoting good practices of inclusive education across Europe.<sup>151</sup>

Inclusion Europe also particularly focused on the situation of pupils with complex support needs who tend to be systematically excluded from mainstream schools and even sometimes deprived of any kind of education.

In its 2018 exploratory study on the inclusion of pupils with complex support needs in mainstream schools, the challenges face by this category and their families are highlighted. 152 All the countries that took part in the study said that there are possibilities for exemptions from the legal obligation to education for children with complex support needs if requested by the parents. 153 The report also acknowledges that "While school systems and achievements are one of the best researched public services, people with complex support needs seem to be still "invisible citizens" and do not appear in any general statistics and studies of the responding countries".154

- · In Flanders (Belgium, ca. 6,4 Million population) about 500 children with complex support needs are "discharged" of the duty to education. In addition, there is the possibility of home education which applies to another 500 children. "We conclude that more than 1.000 children in Flanders are not attending schools because of complex support needs. (p10)
- · In Lithuania there is a general problem with the shortage of teachers: while there were 1.151 mainstream schools in Lithuania in 2016-2017, catering for 331.000 pupils (among them 3.960 with special needs), there were 1.398 teacher's vacancies. This means that mainstream schools have difficulties not only to recruit assistants of teachers, but also teachers themselves (p20)
- · According to a study from Germany combining results from different studies, there would be an estimated less than 3 in every 1000 of pupils in mainstream schools would have complex support needs. (p22)

Inclusion Europe specifically focused on inclusive education in 2020 as a part of its 5E's strategy.

A recent report from Inclusion Europe was released on the impact of Covid 19 on pupils with intellectual disabilities. The report particularly highlights the lack of support received by the families to ensure a continuity of education and how distance e-learning particularly discriminated against children with intellectual disabilities.

#### **Council of Europe**

Education is mentioned within the European Convention on Human Rights (ECHR). Article 2 of the First Protocol states that: "No person shall be denied the right to education. In the exercise of any functions which it assumes in relation to education and to teaching, the State shall respect the right of parents to ensure such education and teaching in conformity with their own religious and philosophical convictions".

The European Social Charter (ESC) contains a positive right to education, in Article 17. States should take "all appropriate and necessary measures" to provide children and young people with "a free primary and secondary education as well as to encourage regular attendance at school".

The Council of Europe Strategy for the Rights of the Child 2016-2021 briefly mentions the access of children with disabilities to inclusive education. The Council of Europe Disability Strategy 2017-2023 includes education and training as one of its cross-cutting themes. It considers that quality education is a prerequisite for persons with disabilities to enjoy human rights on an equal basis with others and that "this also includes early childhood and family support". It also engages the projects funded by the Council of Europe to focus on

inclusive education and children with disabilities.<sup>158</sup> Finally, the importance of professionals training on disability is highlighted.<sup>159</sup>

The **Commissioner for human rights** released in 2017 a position paper about fighting school segregation in **Europe through inclusive education.** 160 The report does not only focuses about the inclusion of children with disabilities but also raises the inclusion of Roma children, children with a migrant background and from other disadvantaged groups. The commissioner expresses concerns about the deprivation of access to schools of "children with disabilities especially those with severe disabilities, those living in institutions and children with psycho-social disabilities such as autism".161 The report highlights the importance of strategic litigation on the matter and the way it led to an extensive jurisprudence.

The European Court of Human Rights and the European Committee on Social Rights have indeed stated in the past two decades on a number of cases related to inclusive education.

The European Court of Human Rights has been criticised by the disability community for the missed opportunities to truly acknowledge and implement the human rights approach in the cases. In the case **Dupin v. France in 2017**, for instance, found that the refusal to admit a child on the autism spectrum to a mainstream school did not constitute a failure of the state obligation to provide education, nor a systematic denial of his right to education on account of disability. 162 Another common issue is that European courts often consider that minimum efforts taken by States are sufficient to comply with the right to education, even if these efforts do not address the needs of the student. This was demonstrated by a recent controverted case, **Ştefan-Moshe Stoian and** Luminița Stoian v. Romania in 2019, strongly criticised by Inclusion Europe alongside other organisations who submitted a third intervention during the case. 163 164 In a recent case **G.L v** Italy, the Court seemed to attach more importance to the lack of reasonable

accommodation in a primary school as it constitutes according to the judges "the foundation of child education and social integration, giving children their first experience of living together in a community.<sup>165</sup>

More efforts of strategic litigation targeted the European Committee of Social Rights. 166 The European Committee of Social Rights, for example, ruled in 2018, Mental Disability Advocacy Center (MDAC) v. Belgium that the systematic denial of inclusive education to thousands of children with disabilities in Flanders, Belgium, is a breach of their fundamental rights. 167 Inclusion Europe lodged in 2017 a complaint against Belgium, Belgium for the systematic discrimination against children with intellectual disabilities who are excluded from mainstream schools in Wallonia.

#### **United Nations**

## A third of out-of-school children worldwide are children with disabilities, according to UNESCO.<sup>168</sup>

The Universal Declaration of Human Rights of 1968 is the first human rights document to recognise the right to education as a human right. Its Article 26 declares that "Everyone has the right to education."

In 1966, the International Covenant on Economic, Social and Cultural Rights (ICESCR) recognises the universal right to education without discrimination of any kind through its Article 13 that primary school must be "compulsory and available free for all."

The **Salamanca Statement (UNESCO 1994)** established inclusive education on an international footing. Children with 'special educational needs must have access to regular schools, and regular schools with an inclusive orientation: "... are the most effective means of combating discriminatory attitudes, creating welcoming communities, building an inclusive society and achieving education for all; moreover, they provide an effective education to the majority of children and improve the efficiency and ultimately the cost effectiveness of the entire education system".

The United Nations Convention on the Rights of the Child (UNCRC) has articles dedicated to education. These articles cover: Article 23 declares that children with disabilities must have effective access to education. **Article 28** enshrines the child's right to education, and the State's duty to ensure that primary education at least is free and compulsory. **Article 29**: "The State's recognition that education should be directed at developing the child's personality and talents, preparing the child for active life as an adult, fostering respect for basic human rights and developing respect for the child's own cultural and national values and those of others".

The CRC Committee further elaborated on the right to education in its general comment N° 20 (2016) on the implementation of the rights of the child during adolescence. It noted its concern about the "numbers of adolescents in marginalized situations who are not given the opportunity to make the transition to secondary education, such

as adolescents with psychosocial, sensory or physical disabilities". Then, the Committee highlighted the "importance of promoting inclusive education for children with disabilities, combating bullying and discriminatory attitudes within the education system".

The Convention on The Elimination of Discrimination Against Women (CEDAW) mentions the need to reduce female students drop out and to organise programmes for girls and women who have left school prematurely. The **CEDAW Committee in its General** recommendation No. 36 on the right of girls and women to education made a number of statements on the right to education for women and girls with disabilities. 169 It recognises the particular discrimination faced by girls with disabilities as a result of intersecting forms of discrimination on the basis of gender and disability.

The Committee acknowledges that while governments actively promote inclusive education, "however, in practice, children with disabilities, especially girls, are either excluded or segregated in special schools. Low attendance rates of children with disabilities, in particular girls, have similar causes globally, namely, lack of physical accessibility, refusal of teachers or school principals to enrol such children, lack of accommodation of their needs in school curricula and teaching materials and, more generally, stigma and lack of awareness among parents and communities, which yield negative attitudes about the learning capacities of women and girls with disabilities. Additionally, the number of teachers trained to address students with special needs is often inadequate."

The Convention on the Rights of Persons with Disabilities (CRPD) reaffirms the right of persons with disabilities to education. **Article 24** "recognize[s] the right of persons with disabilities to education and reaffirms that "all persons with all types of disabilities have the right to education, "without discrimination and on the bases of equal opportunity." The CRPD Committee in its 2016 General Comment n°4 on inclusive education further elaborates its interpretation of article 24.170 It reaffirms the right to everyone to education, including children in foster care or care homes who should be enjoying the right to inclusive education. 171

Moreover, the General Comment highlights the interconnection of between inclusive education and the deinstitutionalisation process which includes access to early childhood interventions.<sup>172</sup> Inclusion Europe, in its submission on the draft general comment n°4, underlined the increase of segregation of students with disabilities in Europe from 2008 (2%) to 2012 (2.25%).173 The submission further elaborates on the fact that mostly students with intellectual disabilities and complex support needs are referred to segregated schools and often deemed too difficult or too expensive to be included in the general education system.<sup>174</sup>

#### Healthcare

#### **European Union**

In the EU, the right to access health services for children with disabilities has not been particularly targeted by directive and legislative text. It is generally raised for all people with disabilities and not specific age-groups within the category of people with disabilities. While the topic of health is primarily a national competence, the EU has the competence to carry out actions to support, coordinate and/or supplement the actions of Member.

States regarding to the protection and improvement of health of European Union citizens The **Directive 2011/24/ EU of the European Parliament and of the Council of 9 March 2011** on the application of patients' rights in cross-border healthcare is an important text. While it does not target children, some mentions are made about the need for accessibility and information of hospitals for persons with disabilities and accessible information about national contact points for cross-border healthcare.<sup>175</sup>

The EU Disability Strategy 2010-2020 targets access to health for people with disabilities. 176 The Strategy recognises the limited access to health services that people with disabilities have and explains how it leads to health inequality that are not related to their disabilities but by the lack of access. It also engages EU to act more on improving awareness of disability in medical schools and in curricula for healthcare professionals. The Strategy also highlights the need to develop early intervention and needs assessment services that are particularly key to enable children with disabilities to reach their full potential and being included in the community.

The **2011 EU Agenda for the Rights of the Child** recognises that children growing up in poverty and social exclusion [...] are less likely to do well in school and enjoy good physical and mental health.<sup>177</sup>

The European Pilar for Social Rights in its principle 16 proclaims that "everyone has the right to timely access to affordable, preventive and curative health care of good quality".

The Concluding Observations from the UNCRPD Committee about EU received in 2015 highlights that discrimination on the ground of disability is not explicitly prohibited in the field of health care while people face obstacles to access health services across the EU.<sup>178</sup> It also recommends to assess the impact of the Directive on patients' rights in cross border health care with regard to gaps in access for persons with disabilities;

A FRA 2013 report Inequalities and multiple discrimination in access to and quality of healthcare, highlighted the difficulty of access to healthcare for children with intellectual disabilities and their families belonging to ethnic minorities.<sup>179</sup> The report points out a lack of awareness of entitlements in relation to access to care and social protection schemes, as migrant families with children who had an intellectual disability appeared to be under-informed about support schemes for which they were eligible. Interviews with healthcare professionals in Sweden and Italy pointed to the complexity of assessing the impairments of children with intellectual disabilities belonging to minority ethnic communities.180

**Austria:** In Austria, the mother of a young Turkish woman and the family of a young man with Down syndrome who has a migrant background, for example, were not informed that they were entitled to receive income support. FRA report 2013<sup>181</sup>

The Academic Network of European Disability Experts (ANED) has published in 2014 a series of Country Reports on the accessibility of healthcare. ANED recommended that "the European Commission (and Eurostat) might usefully play a role in supporting

the design and development of effective systems for monitoring accessibility in healthcare. [...] there is an urgent need for the development of such systems as well as a comparative report highlighted the need for the development of such systems."<sup>182</sup>

A 2018 report from the European Commission on Inequalities in access to healthcare show that people with disabilities are amongst disadvantaged groups who lack access to healthcare services. 183

United Kingdom: A study led by the NHS showed that people with a learning disability have worse physical and mental health than people without a learning disability. The life expectancy of men with a learning disability is 14 years shorter than for men in the general population. On average, the life expectancy of women with a learning disability is 18 years shorter than for women in the general population.

Inclusion Europe released a study in 2017 on equal access to healthcare for people with intellectual disabilities.<sup>173</sup> While this study does not target the specific situation of children with intellectual disabilities, it points out the barriers to access child-specific services such as early identification and intervention. It was noted that significant problems to access these services were reported in Spain, Denmark, France, Bulgaria and the Netherlands.<sup>185</sup>

#### **Council of Europe**

The Council of Europe made very few mentions of the right of children with disabilities to access healthcare services. The European Social Charter (revised) 1996 has an article 11 on the right to protection of health). This article not only engages States to prevent diseases or cause ill-health but also provide advisory and educational facilities for the promotion of health and the encouragement of individual responsibility in matters of health".

The Council of Europe Strategy for the Rights of the Child (2016-2021) notes that children from disadvantaged groups and living in poverty are less likely among other things to "enjoy good health". The Strategy highlights the "devastating" effect of violence on physical and mental health in the short and long term perspective. Violence to which, children with disabilities and particularly those with an intellectual disability are particularly likely to be victims.

The **ECtHR** had the opportunity in Glass v. United Kingdom, 2004, to clarify its position on the need to respect parents' wishes about their child. 188 In this case, the hospital believed the child with complex needs was close to death and gave him powerful medicine which was designed to relieve his pain. The authorities had also placed a "do not resuscitate" on the child's file. All of this was done against the mother's wishes. The Court found the decision of the medical authorities to provide treatment to a severely disabled child against the wish of the mother, and without a court order violated right to respect for his private life and, in particular, his right to physical integrity.

Outside the Council of Europe Framework, the World Health Organisation (WHO) regional office in Europe adopted in 2010 in partnership with UNICEF, the European Commission and the Council of Europe a European Declaration on the Health of Children and Young People with Intellectual Disabilities and their Families.

This initiative aims to ensure that all estimated 5 million European children and young people with intellectual disabilities are fully participating members of society, living with their families, integrated in the community and receiving healthcare and support proportional to their needs. 189 The declaration acknowledges that people with intellectual disabilities are often disadvantaged in their health care from childhood onwards" and that even though they have greater health needs, they encounter major barriers in gaining access to appropriate and effective health promotion and care". 190 The declaration links healthy life to the opportunity to grow up in a family environment and progressively "eliminate institutionalization". 191

The declaration also contains an action plan with 10 priority actions to enable children and young people with intellectual disabilities and their families and live healthy and full lives. The actions are cross-sectoral: grow up in a family environment, protection from abuse, identification of needs, data collection, and preserve the health of family care among other actions.<sup>192</sup>

Better health, better lives: children and young people with intellectual disabilities and their families - Link

Community-based studies suggest that 35– 40% of children and adolescents with intellectual disabilities have a diagnosable mental health disorder, which is five times the rate among children in the general population

While this declaration is now 10 years old, it clearly identified areas to focus on and demonstrated that a healthy life implies transversal policies and a general improvement of life conditions rather than only ensuring the access to health-care services.

#### **United Nations**

The **1989 UNCRC** addresses the topic of equal access to health service for children with disabilities. The **article 23** on children with disabilities states that they should have "effective access to and receive 'education, training, health care service, rehabilitation services". The **article 24** focuses on the right of the child to the enjoyment of the highest attainable standard of health and access to all healthcare services.

One of the first international text to raise the topic of health for children with disabilities is the **1994 UN Standard Rules on Equalization of Opportunities for Persons with Disabilities**. The rule 2.3 says that "States are required to ensure the provision of effective medical care to persons with disabilities. They must also ensure that persons with disabilities, particularly infants and children, are provided with the same level of medical care within the same system as other members of society". This rule paves the way of the notion of equal access to healthcare service.

The CRC Committee adopted in **2013** a general comment n°15 on the right of the child to the enjoyment of the highest attainable standard of health. <sup>193</sup> The General comment specifically targets the need for accessible health facilities as well as accessibility of the information. <sup>194</sup> The Committee also affirms that the decision of putting children and adolescents with psychosocial disabilities in an institution or an

hospital should be made in "accordance with the principle of the best interest of the child with the primary understanding that it is in the best interests of all children with disabilities to be cared for, as far as possible in the community in a family setting and preferably within their own family with the necessary supports made available to the family and the child". The exception to community living and belief that institution or hospital can ensure a better quality of life highlights the difference of standards used by the UNCRPD and the UNCRC in the human rights approach of disability.

The **UNCRPD article 25** focuses, similarly to the article 24 of the UNCRC, on the right to the enjoyment of the highest attainable standard of health. The article highlights firstly the equal access to general health services people with disabilities should be provided with (the same range, quality and standard of free or affordable). <sup>196</sup> It says more specifically that disability-specific services should be provided "including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons". <sup>197</sup>

The CRPD Committee in its general comment n°5 on article 19 on the right to live independently further describes the access to general services as applying to all regardless of the level of support needs.<sup>198</sup>

While very little was said by the CRPD Committee in term of health-related matters, the Special Rapporteur on the Rights of Persons with Disabilities had the opportunity to focus on the topic on its 2018 Report on the rights of persons with disabilities to the highest attainable standard of physical and mental health.<sup>199</sup>

The report highlights studies showing that on average, persons with intellectual disabilities die 15 to 20 years earlier than the general population owing, to a significant extent, to neglect, poor treatment and failure to undertake routine screening, health promotion and prevention activities.

2018 report of the Special Rapporteur

The report regrets that children "often do not receive basic treatment for common childhood illnesses, which may become life threatening if left untreated" and are "often excluded from immunization programmes". <sup>200</sup> The Special Rapporteur also highlights the lack of accessibility of health care: lack of information, communication barriers and ab-

sence of training for service providers in communicating with children and adults with intellectual disabilities".201 The report moreover specifically points out the poor or even lack of transition of many children with disabilities from paediatric to adult health care because of the unavailability of specialists or the reluctance of general practitioners to treat persons with disabilities".202 The "pathologization" and medicalization of the behaviour of children with disabilities" is also strongly criticised and presented as an unacceptable practice that contradict respect of difference.<sup>203</sup> The Special Rapporteur suggests that children should be allowed to "consent to certain medical treatments and interventions without the permission of a parent, caregiver or guardian, such as HIV testing and sexual and reproductive health services".204 Finally, it is says that inclusive health policies should support family of children with disability through "information, education and services, to increase their understanding and capacities to address the health needs of their children without stigma or discrimination".

The Special Rapporteur additionally released a Report on sexual and reproductive health and rights of girls and young women with disabilities. 205 This report makes several mentions of the barriers faced by girls with intellectual disabilities to assert their sexual orientation, to improve their knowledge on sexual and reproductive health.

The University of Tartu in Estonia has provided training for teachers on how to deliver comprehensive sexuality education in plain language so that children with intellectual disabilities can benefit equally from the lessons.

Report of the Special Rapporteur

The **WHO global Disability Action plan 2014-2021** without being specific to children with disabilities make a set of recommendations to States to ensure a better access of people with disabilities to healthcare services.<sup>206</sup>

Finally, the **Special Rapporteur on the Right to Health reflected on the Covid19 pandemic** and its impact.<sup>207</sup> While he reminds of his efforts to stress the need for a paradigm shift in mental health and an end to institutions to protect against covid19, he highlights the urgent need to "address outdated discriminatory laws and attitudes about global mental health and to adopt rights-based approaches to support persons with intellectual, cognitive and psychosocial disabilities".<sup>208</sup>

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#### Children's rights for all, 2011

Implementation of the United Nations Convention on the Rights of the Child for children with intellectual disabilities. Link

