



**RIGHTS OF CHILDREN WITH DISABILITIES IN THE INTERNATIONAL HUMAN RIGHTS FRAMEWORK AND EUROPEAN UNION POLICY:**

**NORMS, CONCERNS AND OPPORTUNITIES**

*Policy briefing – June 2014*

**ABSTRACT**

This paper<sup>1</sup> summarises the available international and European evidence on the specific situation of children with disabilities and highlights the main opportunities for EU action to guarantee the rights of children with disabilities in the EU. In addition to outlining the general framework that governs the policies on children with disabilities at the EU and UN level, it focuses on five areas particularly relevant to children and young people with disabilities: **participation, family life, freedom from violence and abuse, education and health**. Based on the assessment, the paper presents recommendations to EU policy-makers to realise the rights of children with disabilities in the EU<sup>2</sup> and address their marginalisation.

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<sup>1</sup> This paper was written in the framework of the project Hear Our Voices - promoting and encouraging the participation of children with intellectual disabilities – [www.childrights4all.eu](http://www.childrights4all.eu), co-funded by the EU.

<sup>2</sup> This paper covers the internal dimension of EU policies only and not the external dimension.





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## RECOMMENDATIONS TO THE EUROPEAN COMMISSION

As demonstrated in this paper the European Commission can play a pivotal role in driving change at member state level. The below recommendations outline, for each of the areas analysed, what steps the Commission can take to fulfill the Union's treaty objective of promoting the protection of the rights of the child.

### In the field of participation

- The European Commission should adapt its own Disability Communication Strategy to create accessible information for people with disabilities, including children. Using complex and specialized language should be avoided, as a first basis for equal participation.
- Accessibility: include in the European Accessibility Act provisions on (alternative) communication methods and specific advocacy provisions to ensure that children with severe disabilities and/or complex needs can meaningfully contribute, be heard and understood.
- Build on the findings of the forthcoming mapping study on participation of children in legislation, policy and practice to develop guidance to the Member States on participatory activities, specifically insisting on making these fully inclusive of children with physical, sensory, intellectual and psychosocial disabilities;
- Emphasise participation of children with disabilities in the relevant research projects conducted by the EU Agency for Fundamental Rights;
- Support the implementation of relevant Council of Europe Conventions, notably the 2012 Recommendation on participation of children and young people under the age of 18 and the self-assessment tool<sup>3</sup> that was developed to support its implementation.
- Provide support and financial assistance to projects that aim to meaningfully consult children with disabilities, including those with intellectual disabilities, in matters of importance, using accessible, non-threatening and appropriate communication;

### In the field of the rights with respect to family life

- Identify the extent of the institutionalisation emergency through collection of data on children with disabilities in institutional care, including the reasons for institutionalisation;
- Support the development of national plans for transition from institutional to community-based living that should include a moratorium on new admissions and individual care plans for every child concerned;
- Provide a policy framework and financial support for the development of multidisciplinary teams of professionals (foster carers, social workers, educators, healthcare professionals) able to support care-leavers with disabilities, including those with intellectual disabilities; as well as training for medical professionals involved in ante-natal & maternity services to prevent 'abandonment' or placement in institutions of infants found to have a disability;
- Make sure that the **Common European Guidelines on the Transition from Institutional to Community-based Care** are consistently used to monitor the use of the EU funds to promote family-like alternative care and community-based services for children with disabilities and their families;

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<sup>3</sup> [http://www.coe.int/t/dg3/children/participation/Child\\_participation\\_AssessmentTool\\_en.pdf](http://www.coe.int/t/dg3/children/participation/Child_participation_AssessmentTool_en.pdf)

- Ensure that EU funds are no-longer used to maintain, renovate or support existing institutional models of care and actively co-operate with the 2014 investigation of the EU Ombudsman into respect for fundamental rights in the EU's Cohesion policy in this regard.
- Promote campaigns de-stigmatising disability and informing families, professionals and the general public about the rights of disabled children and the irreversible harm of institutionalisation;
- Ensure that EU legislation and action on parental leave and reconciliation policies are considerate of the needs of parents of disabled children by providing additional support and flexibility in balancing their private, family and professional life

### In the field of protection against violence and abuse

- Mainstream disability in the upcoming EU guidelines on child protection systems, relying on the expertise of a broad range of civil society organisations (including organisations that represent children with intellectual disabilities).
- Use the findings of the forthcoming FRA study on violence towards children with disabilities for formulation of an EU-wide response to the phenomenon, addressing the underlying causes of violence (such as institutionalisation, poverty, social stigma and isolation).
- Ensure that the specific vulnerabilities of children in institutions, those with disabilities and children with intellectual disabilities to violence, abuse and neglect are understood and addressed by all stakeholders.

### In the field of the right to education

- Make sure that the next **Education and Training Monitor**, due to be published in early 2015, includes a section on measures to promote inclusive education for children and young people with disabilities in accordance with the obligations of the EU and its Member States under the CRPD.
- Ensure the upcoming quality framework on ECEC promotes inclusion of children with disabilities by supporting professional training, improving infrastructure and providing individualised support tailored to the needs of pupils with disabilities.
- Earmark funding through the Erasmus+ framework for initiatives, such as exchange of good practices in the field of inclusive education, training of special teaching assistant, promotion of national sign languages
- In the framework of the Erasmus+, create a specific exchange programme between teachers of mainstream schools, which have relevant experience in inclusive education and promote exchange of School Directors/Leaders of inclusive schools.
- Support and promote the work of the **European Agency for Special Needs and Inclusive Education**<sup>4</sup> and rely on it to help identify new common issues where the EU's role must be reinforced;
- Commission and disseminate research on good (national or local) practice in the provision of support for pupils with intellectual disabilities in mainstream schools.

### In the field of the right to health

- Ensure that the accessibility of medicinal products, services and equipment is covered by the forthcoming European Accessibility Act;

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<sup>4</sup> <http://european-agency.org/>

- Facilitate the exchange of good practice, including international practice, in the provision of highly specialised healthcare services;
- Improve data collection on disability and quality of life;
- Consider supporting European Reference Networks and Centres of Excellence that specialise in health issues pertaining to children with disabilities;
- Develop in cooperation guidance for common standards for the treatment of specific health issues by national health authorities to avoid disparities between the Member States;
- Facilitate equal access to healthcare services by children with disabilities through the use of the EU financial instruments, such as the 3rd EU Health Programme and Horizon 2020 Programme; the funded measures should include not only disability-specific healthcare, but also mainstream services, such as dental and eye care, sexual health and preventive services.

In all the above mentioned fields, it is crucial the envisaged actions are accompanied by awareness raising activities and campaigns. By conveying such messages to the wider community, successful implementation is more likely to be achieved.

## INTRODUCTION

The situation of children with disabilities has received much overdue attention lately, particularly in the field of research. Children with disabilities were the focus of the **2013 UNICEF State of the World's Children report**<sup>5</sup> that presented the latest global data on disabled children across the globe. At the European Union level, the **2013 European Parliament study "Member States' Policies for Children with Disabilities"**<sup>6</sup> prepared at the request of its Committee on Civil Liberties, Justice and Home Affairs, is a comparative analysis of 18 national policies for children with disabilities, as well as the European framework.

These reports, reflecting the growing global momentum created by the recent adoption of the UN Convention on the Rights of Persons with Disabilities (CRPD), provide a useful basis for action by the EU. Indeed, a number of recent and on-going policy developments offer opportunities for action by the EU in 2014 – 2015, including:

- The revision of EU disability policy in light of the **initial report of the European Union to the UN Committee on the Rights of Persons with Disabilities**<sup>7</sup> and the mid-term-review of the **European Disability Strategy 2010 – 2020**. These developments call for a critical reflection of the progress made so far and provide an opportunity to step up effort;
- The expiry of the **EU Agenda for the Rights of the Child** expected at the end of 2014. The Agenda should be followed up by a new strategic framework that mainstreams the rights of all children across all relevant areas of the EU's influence;
- The inclusion in the **EU Structural and Investment Funds 2014 – 2020** of obligations to respect the CRPD, to promote deinstitutionalization and community living and to fight social exclusion. The funds available to the Member States have the real potential to make the difference to disabled children on the ground.

<sup>5</sup> ["State of the World's Children 2013: children with Disabilities"](#), UNICEF 2013

<sup>6</sup> Ballesteros M., Jurkiewicz K., Meurens N. ["Member States Policies for Children with Disabilities"](#), European Parliament 2013

<sup>7</sup> Under the terms of the EU's conclusion of the UN Convention on the Rights of Persons with Disabilities, it must submit its first report reviewing the progress in meetings its obligations under the Convention two years after the entry into force of the Convention, and subsequent reports – every four years thereafter.

- The 2014 Investigation of the EU Ombudsman into the compatibility of expenditure of EU Cohesion funds with the EU Declaration of Fundamental Rights will –among other issues– assess if any EU funds have been used to promote or support institutional models of care for people with disabilities.<sup>8</sup>
- Taking stock of progress towards full respect for children’s rights in all 28 EU countries and reaffirm the engagement of the EU using the **25<sup>th</sup> anniversary of the UN Convention on the Rights of the Child** marked in November 2014.

## CHILDREN WITH DISABILITIES IN THE INTERNATIONAL HUMAN RIGHTS FRAMEWORK

Despite the adoption of the **United Nations Convention on the Rights of the Child (CRC)** nearly 25 years ago and its almost universal acceptance by the world’s nation states, the argument that children have inalienable human rights is yet to be won on many fronts. Too often are children seen as ‘mini-humans with mini-rights’ whose need for protection overrides their entitlement to human rights and their freedom to voice their opinions and wishes.

When a child has a disability (particularly, an intellectual disability), the perception of vulnerability increases as the result of the failure to understand the complexities of the disability and to establish two-way communication with the child. Therefore, the realisation of the disabled child’s rights is often left to chance. The **UN Committee on the Rights of the Child** pertinently notes:

*“42. Children with disabilities are more vulnerable to all forms of abuse be it mental, physical or sexual in all settings, including the family, schools, private and public institutions, inter alia alternative care, work environment and community at large. It is often quoted that children with disabilities are five times more likely to be victims of abuse. In the home and in institutions, children with disabilities are often subjected to mental and physical violence and sexual abuse, and they are also particularly vulnerable to neglect and negligent treatment since they often present an extra physical and financial burden on the family. In addition, the lack of access to a functional complaint receiving and monitoring mechanism is conducive to systematic and continuing abuse. School bullying is a particular form of violence that children are exposed to and more often than not, this form of abuse targets children with disabilities<sup>9</sup>.”*

Realisation of the rights of children with disabilities starts with a robust understanding of the **intersection of the young age and disability** and of the specific needs that result from it. Children with disabilities are not a homogenous group: they are unique persons of different ages, genders, educational needs, health and family situations or likes and dislikes. What they have in common are their evolving capacities and human rights that are guaranteed by international law, most importantly the above-mentioned CRC and the **UN Convention on the Rights of Persons with Disabilities (CRPD)**<sup>10</sup>. The CRPD, adopted in 2006, is known for its paradigm shift that empowers disabled adults and children. Both CRC and CRPD **challenge charitable approaches** that regard children with disabilities as passive beneficiaries of care and protection. They state the entitlement of all children to human rights, equality and non-discrimination and to active participation in the life of society.

<sup>8</sup> <http://www.ombudsman.europa.eu/en/cases/correspondence.faces/en/54419/html.bookmark>

<sup>9</sup> General Comment No 9 ‘[The rights of children with disabilities](#)’, UN Committee on the Rights of the Child, 2006.

<sup>10</sup> Other international treaties, such as CERD or CEDAW, are also directly relevant, but will not be covered in this paper.

All articles of the CRC apply to children who have disabilities and all articles of the CRPD apply to persons with disabilities under the age of 18. In addition, both international conventions have dedicated provisions that apply specifically to children with disabilities (CRC Art 23, CRPD Art 7).

There is widespread consensus that the barriers faced by disabled children are not due to the disability itself but as a result of a combination of social, cultural, attitudinal and physical obstacles encountered by children in their daily lives<sup>11</sup>. The elimination of these obstacles is the legal obligation of the nation states that must guarantee that:

- children with disabilities are able to enjoy their human rights on an equal basis with other children and without discrimination on the basis of their disability;
- free participation of children with disabilities in the decisions that affect them is ensured, and assistance is provided to them to express their views;
- measures are taken to eliminate differences that exist in the between and among boys and girls with disabilities;
- the principles of non-discrimination and equality are applied in practice to children with disabilities<sup>12</sup>.

“ 24. The Committee recommends that the State party:

(c) Develop coordinated public policies with sufficient resources to ensure inclusive access to support services that include informed therapeutic, rehabilitation and habilitation services, and care which covers the health, psychosocial and education needs of children with disabilities, in particular during early childhood.”

**CRPD Committee Concluding Observations to Spain, 2011**<sup>13</sup>

In 2010, recognising the particular vulnerability of children with intellectual disabilities to rights’ violations, 53 governments in the WHO Europe region adopted the **“Better Health, Better Lives”**<sup>14</sup> **Declaration** that was also endorsed at the WHO Regional Committee meeting. The Declaration focuses on ten priority action areas that include **de-institutionalisation, protection from abuse, health care of children and their family carers, participation of children with disabilities and data collection**, among others. Drawing inspiration from the binding international conventions, it outlines practical steps for addressing the rights of children and young people with intellectual disabilities.

WHO “Better Health, Better Lives” declaration priorities for action

1. Protect children and young people with intellectual disabilities from harm and abuse
2. Enable children and young people to grow up in a family environment
3. Transfer care from institutions to the community
4. Identify the needs of each child and young person
5. Ensure that good quality mental and physical health care is coordinated and sustained

<sup>11</sup> Supra, nr 6.

<sup>12</sup> [Guidelines on treaty-specific document to be submitted by states parties under article 35, paragraph 1, of the Convention on the Rights of Persons with Disabilities.](#)

<sup>13</sup> [CRPD/C/ESP/CO/1](#), para. 24.

<sup>14</sup> [“Better health, better lives: children and young people with intellectual disabilities and their families”](#). Bucharest, Romania 26-27 November 2010.

6. Safeguard the health and well-being of family carers
7. Empower children and young people with intellectual disabilities to contribute to decision-making about their lives
8. Build workforce capacity and commitment
9. Collect essential information about needs and services and assure service quality
10. Invest to provide equal opportunities and achieve the best outcomes

### **CHILDREN WITH DISABILITIES IN THE EUROPEAN UNION FRAMEWORK**

All EU Member States have become party to the CRC and are thus legally bound to respect, protect and fulfil children’s rights. Most of them have also joined the CRPD<sup>15</sup>. Significantly, **the latter has also been concluded by the EU**, marking the first time that the Union acceded to an international treaty giving rise to individual rights.

“Accession of the European Union to an international human rights treaty giving rise to individual rights is unprecedented in the history of the Union or, indeed, the UN. [...] In addition to the philosophical importance of the ratification, it was also a practical necessity to reflect the transfer of competences to the EU by its Member States to the extent that the implementation of certain Convention rights [*for example those related to transport, free movement or competition*] has become impossible without the leadership and the involvement of the EU.

The Council of the European Union approved of the conclusion by the EU of the UNCRPD by adopting, on 26 November 2009, Decision 2010/48/EC16. The declaration of competences attached to the Decision, outlines the division between the competences of the EU and its Member States in relation to the Convention; it will be regularly updated to take into account the EU legal and policy developments. Following the adoption of the Decision in 2010, the Council adopted the Code of Conduct, specifying the internal arrangements for the implementation of the UNCRPD, including the establishment of joint positions vis-à-vis the United Nations. [...] The Convention entered into force for the EU on 23 January 2011.”

### **Implementation of the UNCRPD in the EU External Relations, European Parliament, 2013<sup>16</sup>**

The conclusion of the CRPD by the EU is an important development for the rights of children with disabilities: given that many of these can only be ensured by the EU and its Member States together, **the joint responsibility of the two parties helps achieve the maximum progress for the rights of disabled children**. For example, the Member States are primarily responsible for the content and teaching methods of special needs education (SEN) within their borders, including the curriculum for training SEN teachers or methodologies for drafting individual educational plans. The EU complements this by putting at the disposal of the Member States resources (through the Structural Funds) for building accessible schools, exchange of best practices on SEN education, staff training or taking measures to eliminate discrimination in vocational training.

Building on the international obligations and the internal EU legal order, the EU has adopted policy packages on the rights of the child and of the persons with disabilities respectively.

<sup>15</sup> As of April 2014, Finland, Ireland and the Netherlands have not yet formally ratified the CRPD, choosing to amend their national legislation before formally signing up to international obligations. The process is ongoing in all three countries.

<sup>16</sup> Arsenjeva J. (2013), [briefing paper](#) “Implementation of the UN Convention on the Rights of Persons with Disabilities in the EU External Relations”, European Parliament, p. 11.

The overall objective of the **European Disability Strategy 2010-2020**<sup>17</sup> is “to empower people with disabilities so that they can enjoy their full rights, and benefit fully from participating in society and in the European economy, notably through the Single market”. The Strategy, adopted in 2010<sup>18</sup>, aims to be the main reference point for the EU policy makers implementing the UNCRPD. As such, it includes actions in eight broad areas: **Accessibility, Participation, Equality, Employment, Education and training, Social protection, Health and External action**. The actions listed in the Strategy cover a wide range of EU policy areas and, wherever appropriate, are coupled with national-level actions. They are underpinned by the horizontal activities of the Commission on (a) raising awareness about disability, (b) providing financial support to the development of disability policies and practice, (c) collect data and statistics, and (d) establishing the governance framework required by the CRPD.

Only two areas of the European Disability Strategy specifically highlight the situation of children with disabilities: ‘**Participation**’ in relation to using EU funds for the development of community-based services for children with disabilities, and ‘**Education**’ in relation to using the Youth on the Move initiative to facilitate inclusive education for children and young people with disabilities<sup>19</sup>. In addition, the Strategy commits to paying particular attention to young people with disabilities in their transition from education to employment (‘**Employment**’). The Strategy’s **Initial List of Actions 2010-2015**<sup>20</sup> outlining the activities to implement the Strategy in its first five years is more specific about the initiatives in each of the action areas. Although it does not specifically mention children with disabilities, many of its actions are directly relevant to disabled children and young people.

In its turn, the **EU Agenda for the Rights of the Child**<sup>21</sup> adopted in 2011 acknowledges that children with disabilities are “more vulnerable” and “deserve special protection” but does not propose any specific actions to this end (although it does cross-reference the European Disability Strategy). Unlike the broader in scope European Disability Strategy, the EU Agenda focuses mainly on actions that are within the remit of the Commission’s Directorate-General Justice (DG JUST), such as child-friendly justice. The Agenda will end in 2014 and it is widely expected and hoped it will be followed by a new forward-looking strategic instrument<sup>22</sup>.

## RIGHTS OF CHILDREN WITH DISABILITIES IN SPECIFIC AREAS

Whereas the harmonious development of the child is conditional upon a multitude of factors, there are certain base elements that are instrumental to the child’s quality of life: **the right to grow up in a family environment and be free from abuse or neglect, the right to receive appropriate quality education, and the right to benefit from accessible healthcare services**. Underpinning these elements is the **right to participate in the society and voice an opinion about the one’s own welfare**. In addition, these are the areas where the EU policies can effectively complement – to some extent – national policies for realisation of children’s rights. Consequently, this overview focuses on this list of areas, while bearing in mind that it is by no means exhaustive.

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<sup>17</sup> [COM\(2010\)636](#).

<sup>18</sup> The European Disability Strategy was preceded by the European Disability Action Plan 2003 – 2010 adopted by the Commission in 2003, the European Year of Disabled People.

<sup>19</sup> [Youth on the Move](#) is a comprehensive package of European policy initiatives on education and employment for young people launched in 2010 as part of Europe 2020 strategy.

<sup>20</sup> [SEC\(2010\)1324](#).

<sup>21</sup> [COM\(2011\)60](#).

<sup>22</sup> Cf Eurochild and UNICEF publication “[Realising the rights of every child everywhere – Moving forward with the EU](#)”, February 2014.

## PARTICIPATION

“[Involving children and adolescents with disabilities in decision-making] is in the States’ interest, for children and young people with disabilities can enrich policymaking and service provision with their daily experiences and are uniquely qualified to provide information on whether their needs are being met and their contributions utilized across the full spectrum of issues and interventions [...]. A child who is able to express herself or himself is a child who is much less likely to be abused or exploited.”

**UNICEF State of the World’s Children report 2013, p 84**

### What are the main issues?

Having a voice that is heard is both a human right and means to defend the child against infringements. Engaging children improves the quality and relevance of policies and serves as an important tool for inclusion and participatory democratic processes<sup>23</sup>. Therefore, any action to guarantee children their rightful role as individual persons with human rights (as opposed to the traditional – and outdated – approach to treat them as silent recipients of care and protection) must be accompanied by measures to ensure that their views are duly heard and taken into consideration at all times.

Participation of children and young people starts with their engagement in daily activities, such as socialising with friends, attending playgroups and clubs, taking part in decisions that concern them, such as medical or schooling questions. These represent important dimensions of every child’s social and personal development. While children learn to communicate opinions, take responsibility and make decisions and to respect authority, they are also learning to become active citizens in a diverse society.

However, for many children with disabilities, participation is challenging if adequate support, taking into account their age, maturity and the context, is not available. Inaccessibility of infrastructure, inadequate means of information and communication, over-reliance on institutionalisation, and segregation in education have made children and young people with disabilities largely invisible. As the result of **deeply rooted preconceived ideas about the abilities of children with intellectual disabilities** to express themselves, they are systematically excluded from participation activities, or their views are not taken seriously.

Yet the failure to understand personal experiences of children and young people with disabilities prior to attempting to address issues that concern them inevitably leads to misplaced, if well-intentioned decisions and reactions. Conversely, as the practice shows, the continuous effort to hear the views of young people enriches policy and adds credibility and legitimacy to the process.

“I had a chance to talk about my dreams, getting a job, friendship, doctors and what is good or bad for me.”

“I think parents should ask us about our opinion, we know what is best for us. To be happy and satisfied we have to give our opinions about our life.”

“Any young person with disabilities has the right and need to have contact with so called ‘ordinary’ people. We are good for each other.”

**Quotes from children and young people with intellectual disabilities, collected in the course of the project “Turning Words into Action” run by Lumos and funded by the EU, in 2011 - 2013<sup>24</sup>**

<sup>23</sup> CRC GC 9, para 32.

<sup>24</sup> [“Listening Together: Examples of Child Participation in Action”](#), Lumos 2013

## What does the international framework say?

The CRC<sup>25</sup> recognises the child's right to freely express her views in all matters that affect him/her, particularly in the judicial and administrative proceedings. In 2009, the CRC Committee adopted **helpful guidance to assist States Parties in practical implementation of their obligation to provide children with participation mechanisms**<sup>26</sup>. The Committee particularly stressed the obligation to ensure the accessibility of the communication modes used to reach out to children with disabilities.

Since 2006, the obligation to involve children with disabilities in a respectful, accessible and non-discriminatory atmosphere has been reinforced by the CRPD framework<sup>27</sup>.

3. States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.

### Article 7, UN Convention on the Rights of Persons with Disabilities

The Convention picks up on the main challenges faced by children with disabilities in expressing their views. As such, the obligation to give "*due weight*" to children with disabilities aims to eliminate attitudinal barriers that portray children with (intellectual) disabilities as less credible than other children; the "*disability- and age-appropriate assistance*" refers to reasonable accommodations, accessible information and communication tools (such as non-verbal communication, pictograms, easy-to-understand language).

In addition, the Convention insists that children with disabilities be actively involved through their representative organisations in making all policies that concerns them<sup>28</sup>.

In Estonia, the Ombudsman for Children formed an [Advisory Committee](#) composed of children and young people, including those with disabilities, whose role focus on assisting the Ombudsman in decision-making process. The members of the Committee are children and young people from various children's and youth organisations, such as Assembly of Student Representations, Estonian Guide Associations and the Union of Estonian School Students' Councils.

## What does the European Union say?

The obligation to actively involve children with disabilities extends to all States Parties to the CRPD, and as such, applies to both the EU and its Member States.

There are processes in the EU to facilitate the participation of EU citizens in the public life of the EU. This participation can happen through taking part in the EU consultation processes, use of the European Citizens' Initiative, petition to the European Parliament Petitions' Committee or a complaint to the European Ombudsman, to name just a few. However, **these channels are only available to adults**, with children and young people left out of the process.

Bearing in mind the EU obligation under the CRPD to actively involve children with disabilities through their representative organisations, the first challenge is to **identify, support and develop**

<sup>25</sup> CRC Article 12.

<sup>26</sup> Committee on the Rights of the Child, General Comment No. 12 (2009), [CRC/C/GC/12](#), paras 21, 100.

<sup>27</sup> CRPD Article 7(3).

<sup>28</sup> CRPD Articles 4(3) and 29.

**such organisations at the local and national levels.** A study commissioned by DG Justice<sup>29</sup> seeks to map children’s participation in practice, policy and legislation across all EU Member States, paying specific attention to participation of groups that normally face more difficulties in being involved, notably children with disabilities.

In parallel, the CRPD obligation to make goods and services accessible to people with disabilities has moved the European Union to adopt a legislative proposal for **accessible public websites**<sup>30</sup> and to prepare the **European Accessibility Act**<sup>31</sup>, regulating the accessibility of goods and services. At the same time, bound by the obligation to make its own communication, information and processes accessible to people with disabilities, the EU must take steps to make sure that its public consultations, websites, materials and public events take into account accessibility to adults and children with all disabilities, including intellectual disabilities.

## RIGHTS WITH RESPECT TO FAMILY LIFE

### What are the main issues?

Every child has the right to know and be cared for by their parents – this is the basic premise universally supported by the international legal norms<sup>32</sup>. The right to grow up in a loving family (or family-like) environment is the natural stepping stone to realising other basic human rights, such as the right to health, education or safety.

Denial of this right through replacing the family-like environment with institutional care and its mass-treatment approach is extremely harmful to a child’s physical and emotional development. It causes long-term and often irreversible effects on their health, particularly if is inflicted in early childhood<sup>33</sup>. UNICEF confirms: *“it has become widely accepted that institutional care for children whose needs cannot be met within their own family is highly detrimental to their well-being and development. Institutionalization often means that children are cut off from their families and the life in their communities”*<sup>34</sup>.

Yet, disability, alongside social exclusion and ethnic origin remains one of the major factors that increases the child’s risk of being placed in an institution<sup>35</sup>. **Limited access to appropriate childcare facilities, absence of alternatives for children with disabilities without parental care, as well as lack of rehabilitation services** for children and **respite services** for parents are among the main reasons for continued institutionalisation of children with disabilities.

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<sup>29</sup> As of June 2014, the study was being finalised.

<sup>30</sup> As of April 2014, the [proposal for a Directive on Accessibility of Public Sector Bodies’ Websites](#) had been reviewed by the European Parliament and waiting for the Council Decision. When adopted, the Directive will regulate the accessibility of public websites, such as those concerning student grants, public libraries or enrolment in higher education or university.

<sup>31</sup> The European Accessibility Act is a forthcoming legislative initiative of the EU that will, when adopted, regulate the accessibility for persons with disabilities of goods and services available on the market. The adoption of the Act is included in the [2014 Commission Work Programme](#).

<sup>32</sup> CRC Article 7, CRPD Article 18(2)

<sup>33</sup> Working Paper [“Deinstitutionalisation and quality alternative care for children in Europe: lessons learned and the way forward”](#), Eurochild and Hope and Homes for Children, 2013, pp. 10 – 11; see also OHCHR Regional Office for Europe, [Forgotten Europeans, Forgotten Rights](#), p 6.

<sup>34</sup> UNICEF, Promoting the rights of children with disabilities, Innocenti Digest n°13, 2007, p 17.

<sup>35</sup> Supra, nr 28, p 12.

A 2011 study found that, in Bulgaria, “the only placement options practically available to disabled children up to three years of age are institutional care and international adoption; domestic adoption does not happen in practice.” The reasons were related to attitudes of professionals from the child protection and health systems, material conditions and lack of additional services made available to foster parents. In Romania, data provided by the General Directorate for Social Assistance and Child Protection indicate that the majority of children with disabilities are in institutional care; only a small number is in foster care.”

**Children under the age of three in formal care in Eastern Europe and Central Asia, UNICEF 2012<sup>36</sup>**

### What does the international framework say?

Recognising the dangerous phenomenon of institutionalisation, the CRPD provides for a set of measures to ensure the respect of the child’s right to be born and to grow up in a safe family environment. Firstly, it imposes on States Parties an obligation to take **preventative measures**, such as “*early and comprehensive information, services and support*” to avoid the separation of children with disabilities from their biological families<sup>37</sup>. The Convention unequivocally states that “*in no case shall a child be separated from parents on account of a disability of either the child or one or both of the parents*” and provides for safeguards to ensure that when a separation is necessary it respects the best interests of the child<sup>38</sup>.

Secondly, it reiterates the right of all persons with disabilities to live in the community and to enjoy access to all necessary **assistance services**<sup>39</sup> thus providing for the necessary support to care leavers and young persons with disabilities who may, in the absence of such support, find themselves without an alternative to an institution.

In addition to the binding provisions of the UN treaties, the **2009 UN Guidelines for the Alternative Care of Children**<sup>40</sup> clarify the obligations in relation to alternative care under the CRC and assist the governments in implementation of their responsibilities.

### What does the European Union say?

Although the EU does not have direct influence over closure of institutions in the Member States, it has at its disposal a number of important tools to influence the national policies on child protection and, as such, protect children with disabilities against the harmful effects of institutional care.

As part of its commitment to community-based care for all persons with disabilities, the **European Disability Strategy** includes an action point to collect age and gender disaggregated data on the number, size and life conditions of residential institutions. This step is welcome, since having concrete data about the size of the problem would help design the targeted solutions for it.

Prevention of separation and abandonment is addressed in the 2013 **Commission Recommendation “Investing in Children”**<sup>41</sup>. It identifies children with disabilities among those facing an increased risk of poverty and social exclusion due to multiple disadvantage. It insists that access to the best available resources and opportunities is not an extralegal privilege granted to the child at the discretion of the state, but the child’s rightful entitlement (reaffirming the so-called ‘*child-rights*

<sup>36</sup> “[Children under the age of three in formal care in Eastern Europe and Central Asia](#)”, UNICEF 2012, p 27.

<sup>37</sup> CRPD Article 23(3).

<sup>38</sup> CRPD Article 23(4).

<sup>39</sup> CRPD Article 19.

<sup>40</sup> [A/HRC/11/L.13](#)

<sup>41</sup> Commission Recommendation «Investing in children : breaking the cycle of disadvantage », [C\(2013\)778](#)

*based approach*' to fighting poverty and social exclusion). The focus of the Recommendation on prevention of family separation (including through anti-poverty programmes), support to families and the call on Member States to stop the expansion of institutional care settings is very welcome.

The EU obligations towards children with disabilities also apply to the distribution of the Union's financial resources that must be spent in compliance with its human rights commitments, such as the ones taken under the CRPD. In 2013, the historic introduction of explicit references to deinstitutionalisation in the **Regulations on the European Social Fund and the European Regional Development Funds 2014 – 2020** is hoped to influence the use of the significant EU resources to end institutional care of children. This will be done through supporting Member States' care system reforms, introduction of prevention programmes and closure of existing institutions, among other measures. Importantly, 20% of the European Social Fund allocations, or some 15 billion euros, will have to be spent on fighting poverty and social exclusion, thus targeting the main cause of institutionalisation of children with disabilities in the EU<sup>42</sup>.

In 2012, the European Expert Group on the Transition from Institutional to Community-based Care published **Common European Guidelines on the Transition from Institutional to Community-based Care**. The Guidelines are based on the European and international best practice and developed in cooperation with the broadest range of civil society organisations, service providers, public servants, and the European Commission. They provide practical support for those planning the transition to community-based care, and should be used by policy and decision-makers with the responsibility for the provision of care and support services for people who are at risk of being institutionalised, including children.

The Guidelines are complemented by the **Toolkit on the Use of European Union Funds for the Transition from Institutional to Community-based Care** that aim to assist public authorities to use the European Funds to improve the quality of family-based and community-based services for persons who need them.<sup>43</sup>

A parallel initiative is the Investigation of the EU Ombudsman into the compatibility of the expenditure of EU Cohesion Funds with fundamental rights. This investigation, being conducted during summer 2014 will investigate if EU funds have been used to support or promote institutional models of care which would be contrary to the EU's obligation to uphold fundamental rights principles. This investigation also asks the European Commission to be more explicit and clarify how it will ensure that EU funding will be spent in line with fundamental rights in the future.<sup>44</sup>

## **FREEDOM FROM VIOLENCE, ABUSE AND NEGLECT**

### **What are the main issues?**

Research commissioned by the World Health Organisation in 2012<sup>45</sup> found that **children with disabilities were almost four times more likely to experience violence than those without disabilities**. WHO reports that globally disabled children are 3.7 times more likely to be victims of physical violence and 2.9 times more likely to be victims of sexual violence, and the ratio goes up

<sup>42</sup> See among other resources, Inclusion Europe - Inclusion International, Poverty and Intellectual Disability in Europe, pp.41-42.

<sup>43</sup> The Guidelines and the Toolkit are available in many European languages at

[www.deinstitutionalisationguide.eu](http://www.deinstitutionalisationguide.eu)

<sup>44</sup> <http://www.ombudsman.europa.eu/en/cases/correspondence.faces/en/54419/html.bookmark>

<sup>45</sup> Jones, L et al. "Prevalence and risk of violence against children with disabilities : a systematic review and meta-analysis of observational studies", 2012

dramatically (4.6 times higher) for children with intellectual or mental disabilities who are more vulnerable to abuse, according to the research. These international findings are corroborated by the EU Fundamental Rights Agency that has identified violence against children as a matter of concern and is currently conducting research on hostility, including violence, towards children with disabilities across the EU<sup>46</sup>.

**Bullying by non-disabled peers** is the violation of rights that most children with disabilities experience with children with intellectual disabilities being particularly susceptible to it. Most bullying case studies reported by families and/or children themselves actually took place within school environments<sup>47</sup>.

Different factors contribute to the staggering numbers of children who experience violence and abuse<sup>48</sup>. **High demands on parents or carers of children with disabilities** and **lack of appropriate support** and **respite services** increase the incidence of violence against children with disabilities at home. **Institutionalisation** is another fertile environment where neglect and physical or sexual abuse of children routinely take place and go unmonitored and unpunished. Structures of power to which children, young people and adults with intellectual disabilities are exposed make it **difficult for them to make use of the support services** available. Often when the existence of abuse is voiced, the credibility of children and young people with intellectual disabilities is questioned and the abuse is often dealt with within the facility (for example by dismissing the perpetrator) rather than being reported – all of which minimises the significance of abuse in the eyes of the society<sup>49</sup>. Communication barriers that often prevent children and young people with disabilities from reporting the abuse have facilitated the abuse, and so have the deeply rooted prejudice and disempowering stereotypes about children with disabilities.

### What does the international framework say?

The CRC imposes obligations on States to protect children with all forms of violence, neglect, exploitation and abuse<sup>50</sup>. The CRPD adds that all protection must be age-, gender- and disability-sensitive<sup>51</sup>. **An authoritative UN study** recognises disability, alongside gender, race, ethnic origin or social status as a factor increasing the child's vulnerability to violence<sup>52</sup>. Recognising the most often children with disabilities experience violence and abuse in family settings, the study calls for the establishment of targeted programmes for families facing especially difficult circumstances<sup>53</sup>.

### What does the European Union say?

The **EU Recommendation "Investing in Children"** echoes the international findings by recognising that **deteriorating social and living environment are factors of violence and abuse of children**. It calls on the Member States to provide children with safe and adequate living environment and

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<sup>46</sup> "[Children with disabilities: targeted violence and hostility](#)", EU Agency for Fundamental Rights. The results of the research are expected to be available in 2014.

<sup>47</sup> Latimier C. and Šiška J. (2011), *Children's rights for all! Implementation of the UN Convention on the Rights of the Child for children with intellectual disabilities*, Brussels, Inclusion Europe, pp.12-13.

<sup>48</sup> UNICEF SOWC 2013, p. 45

<sup>49</sup> Latimier C. and Šiška J. (2011), *Children's rights for all! Implementation of the UN Convention on the Rights of the Child for children with intellectual disabilities*, Brussels, Inclusion Europe, p.9

<sup>50</sup> CRC Article 19.

<sup>51</sup> CRPD Article 16(2).

<sup>52</sup> Report of the independent expert for the United Nations study on violence against children, [A/61/299](#), 2006 p 24.

<sup>53</sup> Idem, Page 28.

support vulnerable families<sup>54</sup>. Such support must be adapted to families with disabled child(ren) and include measures to improve the accessibility of the families' living environment and communication, childcare assistance, rehabilitation and respite services for carers.

In the recent years, the rights of children at risk of abuse have been the focus of the European legislators. Instruments in the fields of trafficking, migration and criminal justice that have been adopted regularly include a child perspective. The 2012 EU **Directive establishing minimum standards on the rights, support and protection of victims of crime**<sup>55</sup> deserves special attention as it provides child victims with a presumption of having '*specific protection needs do to their vulnerability to secondary and repeat victimisation, to intimidation and to retaliation*'<sup>56</sup>. The Directive also recognises that victims with disabilities may need special protection due to their relationship to and the dependence on the offender (for example, when the offender is their carer) or due to the severity of the crime committed. The Directive also makes a special emphasis on the victim's right to understand and to be understood, and on the need to make communication accessible and appropriate to the victim's disability. It also stresses that the right of children to be heard should not be precluded on the basis of their age.

In April 2014, taking stock of the measures undertaken under the EU Agenda for the Rights of the Child, including protection of children in areas such as children's rights in criminal proceedings, free movement within the EU, asylum and trafficking, the Commission announced a public consultation on **guidance for child protection systems** that aim to support Member States' efforts to protect children against violence and clarify areas of EU added value<sup>57</sup>.

## RIGHT TO EDUCATION

### What are the main issues?

Inclusive education is defined as a process that responds to the diversity of needs of all learners through inclusive practices and involves modifications in curriculum, teaching methods and organisational arrangements to accommodate all children within the regular system<sup>58</sup>. **Inclusion of children and youth with special educational needs in mainstream education** and provision them with **reasonable accommodation and assistance** is an indisputable feature of an inclusive education system that is guaranteed to children by the international norm<sup>59</sup>.

Research shows that legislation and policies clearly promote the provision of inclusive education<sup>60</sup>. Figures and information confirm that there is a trend to including children with physical disabilities in mainstream schools. However, the available data on **children with intellectual disabilities** is much less positive, revealing that they are often **denied access to education altogether**. The 2013 EP study<sup>61</sup> reports that Italy is so far the only EU country where almost all children with disabilities

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<sup>54</sup> Supra, nr 36.

<sup>55</sup> <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2012:315:0057:0073:EN:PDF>

<sup>56</sup> Art 22(4).

<sup>57</sup> [Rights of the child: Commission gathers input how to best protect the most vulnerable from violence.](#)

Brussels, 10 April 2014.

<sup>58</sup> UNESCO, 2006, Global Monitoring Report: Literacy for Life.

<sup>59</sup> UNESCO, 1994, The Salamanca Statement and Framework for Action on Special Needs Education.

<sup>60</sup> Latimier C. and Šiška J. (2011), *Children's rights for all! Implementation of the UN Convention on the Rights of the Child for children with intellectual disabilities*, Brussels, Inclusion Europe, p. 17

<sup>61</sup> Supra nr 2, p 101.

(99.6%) attend mainstream schools; whereas countries such as Belgium, Germany or, to a lesser extent, Latvia heavily rely on special schools to educate children with disabilities<sup>62</sup>.

“[In **France**], 90 percent [of children with intellectual disabilities] attend school... The figures of those educated in mainstream schools are rising, but a significant number of these children only attend mainstream school part-time. In addition, it is estimated that between 6,000 and 20,000 of these children do not attend school at all... It often happens that children are refused a place at a school if there are no special needs assistants. In January 2010, ... 4,213 children were waiting for special needs assistants in order to be enrolled at school.

In **Slovakia** and in the **Czech Republic**... the decision to accept or not to accept a child with an intellectual disability [into a mainstream school] remains in the hands of the school principal, who assesses the “*conditions and capacities of the school*” and decides accordingly. In case of refusal, ... the parents have almost no legal means to appeal the decision.

In **Cyprus** the weakness of the system is actually the lack of coordination and of joint action between primary and secondary education... [In addition,] lack of choices and experiences of professions which may match the interests of young people with disabilities is reported [in vocational training]”.

**Children’s Rights for All! Inclusion Europe, 2011**<sup>63</sup>

Lack of accessibility, adapted teaching materials, teacher training, individualised professional support and lack of sufficient resources are named as most serious **obstacles to enjoying the right to inclusive education**. Oftentimes, pupils with disabilities are offered mere insertion in mainstream classes without provision of adequate support from trained pedagogues and assistants. Such scenarios inevitably have detrimental effects on the academic achievements and the social outcomes of all parties, both pupils with and without disabilities. Worryingly, denial of access to inclusive education in the community sometimes causes institutionalisation of children with disabilities.

The **lack of continuity between different levels of education** is another common barrier. The tendency to cut support for attending higher education or vocational training, particularly for young people with intellectual disabilities, results in their lower educational levels, ultimately leading to their lower competitiveness on the labour market and dependence on the welfare systems.

### What does the international framework say?

The CRPD prohibits excluding children with disabilities from free and compulsory primary education, or from secondary education, on the basis of disability<sup>64</sup>. It stresses that the education must be inclusive and accessible, with the provision of reasonable accommodation and individualised support to maximise the person’s development. A truly inclusive education system prohibits segregation of disabled pupils, provides substantive equality of outcomes to all children, regardless of disability, and invests in professional training and building the capacity of professionals to teach inclusive classes<sup>65</sup>.

<sup>62</sup> [WHO World Report on Disability](#), p 211.

<sup>63</sup> Latimier C. and Šiška J. (2011), *Children’s rights for all! Implementation of the UN Convention on the Rights of the Child for children with intellectual disabilities*, Brussels, Inclusion Europe.

<sup>64</sup> Article 24 CRPD.

<sup>65</sup> Thematic study on the right of persons with disabilities to education. Report of the Office of the United Nations High Commissioner for Human Rights. [A/HRC/25/29](#).

The Convention also insists on fostering an attitude of respect for the rights of persons with disabilities through inclusive education, which in practice means the obligation on States to educate non-disabled persons about the human rights model of disability and the benefits of diversity<sup>66</sup>.

“41. The Committee calls upon the State party to allocate sufficient resources for the development of an inclusive education system for children with disabilities. It reiterates that denial of reasonable accommodation constitutes discrimination, and recommends that the State party significantly increase its efforts to: provide reasonable accommodation to children with disabilities based on the student’s individual requirements; provide students with disabilities with the required support within the general education system; and to continue training teachers and all other educational staff to enable them to work in inclusive educational settings.

42. The Committee urges the State party to develop programmes to ensure that Roma children with disabilities are included in mainstream education programmes, without disregarding the provision of reasonable accommodation that might be needed to obtain the desired outcome.”

**CRPD Committee Concluding Observations to Hungary, 2012<sup>67</sup>**

### What does the European Union say?

In the EU, the Member States are responsible for the content of teaching and organisation of school systems at the national level, whereas the EU supports the national work by facilitating the mobility of pupils and students, offering a forum for exchange of best practices and advising on policy reforms. Most support activities of the EU are accompanied by funding to promote learning and education for all age groups.

The **European Disability Strategy** has set for the EU a commitment to promoting inclusive education and lifelong learning for pupils and students with disabilities through **ET 2020**, the strategic framework for European cooperation in education and training<sup>68</sup>. ET 2020 strategic objective 3 “Promoting equity, social cohesion and active citizenship” echoes the European Disability Strategy by committing to “*develop cooperation on learners with special needs: promote inclusive education and personalised learning through timely support, the early identification of special needs and well-coordinated services. Integrate services within mainstream schooling and ensure pathways to further education and training.*” Although not mentioning pupils and students with disabilities explicitly nor referring to the EU obligations under the CRPD, this strategic objective is an important target for the EU and the Member States.

The Commission assesses the progress towards implementing ET 2020 bi-annually on the basis of the country reports and its own evaluation. The findings are then compiled in the **Education and Training Monitors**, the latest of which, published in 2013<sup>69</sup>, does not include any information about the actions taken to advance the inclusive education. In fact, the inequalities and exclusion experienced by children and young people with disabilities and well-reported at different levels, are regrettably not accounted anywhere in the Monitor.

**Erasmus+**, the new EU programme for education, training, youth and sport for 2014 – 2020 that provides a budget of EUR 14.7 billion for transnational opportunities in the field of education for all

<sup>66</sup> CRPD Article 8(2)(b).

<sup>67</sup> [CRPD/C/HUN/CO/1](#).

<sup>68</sup> [OJ C 119/2m 28.5.2009](#). ET2020, initially adopted in 2009, was re-designed in 2012, following the adoption of Europe 2020 – the European Strategy for Growth and Jobs.

<sup>69</sup> [Education and Training Monitor 2013](#).

age groups, specifically stresses *'the need to widen access for members of disadvantaged and vulnerable groups and actively to address the special learning needs of people with disabilities'*<sup>70</sup>. This is an important opportunity to make sure that children and young people with disabilities enjoy accessible quality education on an equal basis with the others.

Last not but least, it is not to be forgotten that the European Union is, jointly with the Member States, responsible for provision of inclusive education in the **European Schools**<sup>71</sup> where around 24 000 children of officials of the EU institutions study.

## RIGHT TO HEALTH

### What are the main issues?

The right to health for children with disabilities means full entitlement to healthcare services that are available to all children and young people, such as immunisation, proper nutrition, dental care, preventive health and wellbeing services, as well as information on mental, and sexual and reproductive health<sup>72</sup>. In addition to **mainstream services**, disabled children are entitled to affordable, accessible and quality **services linked to their disabilities**, including early identification and intervention, and services designed to minimise further disabilities, such as rehabilitation services, physio- or speech therapy, access to medical equipment, such as prostheses, shunts or wheelchairs, etc.

Although children with disabilities have equal rights in accessing healthcare, in practice they often find themselves at a disadvantage. Discrimination is particularly widespread in case of children with intellectual disabilities. The main obstacles on the way to enjoying the right to health are:

- **Lack of awareness** about the rights and needs of children with disabilities by health care professionals. Their inability and/or unwillingness to establish communication with children results in overmedication, forced interventions and harmful practices, particularly in case of children and young people with psychosocial disabilities<sup>73</sup>;
- **Lack of data and statistics** on access to health and rehabilitation services by children with disabilities. This impedes the formulation of effective policies that respond to their actual needs;
- **Community misconceptions** about the quality of life and healthcare needs of disabled children. These lead to encouragement of child abandonment and institutionalisation of disabled children by healthcare professionals, and exclusion of children with disabilities from mainstream health services, such as immunisation, disease prevention or sexual and reproductive health services;
- **Lack of physical accessibility** of hospital building, infrastructures or equipment, as well as **inaccessible information** about health services that is particularly dangerous for children and young people with disabilities who often need to be in touch with the health services more often

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<sup>70</sup> [Regulation \(EU\) No 1288/2013 establishing Erasmus +: the Union programme for education, training, youth and sport](#), recital 7.

<sup>71</sup> [www.eurisc.eu](http://www.eurisc.eu)

<sup>72</sup> Supra nr 1, p 23.

<sup>73</sup> [Submission](#) by the European Network of (Ex-)Users and Survivors of Psychiatry, International Disability Alliance, Mental Disability Advocacy Center and the World Network of Users and Survivors of Psychiatry to the UN Special Rapporteur on Torture on his upcoming thematic paper on torture in the context of healthcare, para 26

than their non-disabled peers. Failure to establish communication with a child with a disability usually results in excluding them from decision-making about their own health and well-being<sup>74</sup>.

The 2013 FRA report on multiple discrimination in relation to access to healthcare<sup>75</sup> confirms that, adding the double burden faced by children with disabilities coming from ethnic or linguistic minorities who, because of inaccessibility of services, often fail to be correctly diagnosed and treated. Additionally, the FRA research showed that children with disabilities from certain minorities are often hidden away from the public eye by their stigma-fearing families and communities, falling off the public health services' radar<sup>76</sup>.

“For most children [with hydrocephalus], the surgical insertion of a shunt (a valve to drain the cerebro-spinal fluid from the brain) makes it possible for the child to have a normal life. In Bulgaria, the average cost of a shunt was 1,500 euro - about five times the average monthly salary. Families who were poor and could not afford the shunt felt they had no option but to put their child in an institution. However, if the child survived 18 years, the cost to the State would be 64,000 euro.”

**Lumos, 2013<sup>77</sup>**

“One of the recurring problems in the area of health is dental care as children with intellectual disabilities do not cooperate easily during dental treatment... Dental services are regarded as a particular problem, since orthodontists consent to treat children with intellectual disabilities only with full anaesthesia, [which] involves major risks.”

**Children's rights for all! Inclusion Europe, 2011<sup>78</sup>**

### What does the international legal framework say?

The CRC recognises the **right of all children to the highest attainable standard of health**, including appropriate treatment and rehabilitation<sup>79</sup>, whereas the CRPD complements it by stating that no discrimination on the basis of disability is permitted in access to healthcare<sup>80</sup>.

The CRC Committee stresses that: “States parties should (a) ensure that health facilities, goods and services are available and accessible to all adolescents with disabilities and that these facilities and services promote their self-reliance and their active participation in the community; (b) ensure that the necessary equipment and personal support are available to enable them to move around, participate and communicate; (c) pay specific attention to the special needs relating to the sexuality of adolescents with disabilities; and (d) remove barriers that hinder adolescents with disabilities in realizing their rights”<sup>81</sup>.

<sup>74</sup> IDA [submission](#) for the General Comment of the Committee on the Rights of the Child on the right of the child to the enjoyment of the highest attainable standard of health.

<sup>75</sup> [Inequalities and multiple discrimination in access to and quality of healthcare](#), EU Agency for Fundamental Rights, 2013.

<sup>76</sup> Ibid, p 48.

<sup>77</sup> [A victory for children with hydrocephalus](#), Lumos, 2013.

<sup>78</sup> Latimier C. and Šiška J. (2011), Children's rights for all! Implementation of the UN Convention on the Rights of the Child for children with intellectual disabilities, Brussels, Inclusion Europe, p. 26.

<sup>79</sup> CRC Article 24.

<sup>80</sup> CRC Article 25(b).

<sup>81</sup> CRC Committee General Comment No. 4 (2003) Adolescent health and development in the context of the Convention on the Rights of the Child. [CRC/GC/2003/4](#), para 35.

The 2010 “**Better Health Better Lives**” Declaration adopted by the European WHO members in cooperation with WHO, UNICEF, EU and Council of Europe demonstrates a strong European consensus that the **right to health of children with intellectual disabilities** is closely linked to all other areas of life and is impossible to guarantee if these areas are neglected. As such, the Declaration calls for concerted efforts in the areas such as de-institutionalisation, protection from violence and abuse, developing and supporting a workforce able to provide high-quality services and ensuring the participation of children with intellectual disabilities<sup>82</sup> in the design and delivery of those services.

### What does the European Union say?

In the EU, the responsibility for provision of healthcare and rehabilitation lies primarily with the Member States, whereas the Commission is competent for taking action to support policy developments related to equal access and quality of healthcare, health inequalities, or promotion of awareness about healthy life choices. In particular, for 2010 – 2015, the **European Disability Strategy** has set the specific objective to “*ensure that people with disabilities have equal access to healthcare, including prevention, and that quality and affordable specific health services are provided.*”

The 2013 Commission **Recommendation on investing in children** reiterates the relationship between disability, poverty and health inequalities. It specifically asks the Member States to devote special attention to children with disabilities or mental health problems when working to improve the responsiveness of health systems<sup>83</sup>.

“Children who enjoy universal access to primary healthcare services that are available, affordable, accessible and of quality are able to attain the best possible level of physical and mental health more easily and are less likely to experience ill-health in the adult life. [...] The Recommendation further urges the Member States to devote special attention to children in vulnerable situations. This may include making sure that health services are accessible to children with disabilities (including those with intellectual or psychosocial disabilities) [...]”

**Eurochild, March 2013**<sup>84</sup>

The EU policy recognises the promotion of mental health in young people as key to their overall wellbeing. The **Mental Health Pact 2008**<sup>85</sup> stresses that it must pass by the early intervention in the educational system, support of parenting skills, integration of socio-emotional learning in schools, anti-bullying programmes and participation of young people in all areas of life.

*The European project 'Hear our Voices!' addressed the priority of promoting children's rights and in particular the rights of children with intellectual disabilities.*

*The main objectives of the project 'Hear our voices' were:*

- *to strengthen and increase the participation of children with intellectual disabilities in all areas of life in the sense of Article 12 CRC*
- *to plan the use of the complaints procedure introduced by the new CRC Optional Protocol after its entry into force*
- *to contribute to a better protection of the rights of children with intellectual disabilities and to reduce the barriers that hinder their participation.*

[www.childrights4all.eu](http://www.childrights4all.eu)

<sup>82</sup> Supra, nr 9.

<sup>83</sup> Supra, nr 36.

<sup>84</sup> [http://www.eurochild.org/fileadmin/ThematicPriorities/ChildPoverty/Eurochild/Eurochild\\_assessment\\_of\\_the\\_Recommendation\\_2013.pdf](http://www.eurochild.org/fileadmin/ThematicPriorities/ChildPoverty/Eurochild/Eurochild_assessment_of_the_Recommendation_2013.pdf), Eurochild 2013, p 5.

<sup>85</sup> [European Pact for Mental Health and Well-being](#), 2008.