

# Children's rights for all!

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



A European Report



**eurochild**  
promoting the welfare and rights  
of children and young people  
pour la promotion du bien-être et  
des droits des enfants et des jeunes



**Inclusion Europe**

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# Acknowledgements

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*We would like to thank all the national experts for the information they have collected in their countries as basis for this European Report. We would also like to thank families and children all over Europe for sharing their personal stories.*

*We would also like to thank Eurochild and Inclusion Europe staff who actively contributed to this project as well as to the realisation of this report.*

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Citation: This report should be cited as 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.

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Photo on the cover: Sophie-Scholl-Schule Gießen, Germany

This publication has been produced with the financial support of the DAPHNE III Programme of the European Commission. The contents of this publication are the sole responsibility of Inclusion Europe and the project partners and can in no way be taken to reflect the views of the European Commission.

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# Executive Summary

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This publication provides an overview of the situation of children with intellectual disabilities in twenty two European countries, with a particular focus on five areas: protection against abuse, family support and (de-)institutionalisation, health, education, and participation of children. It recommends steps to be taken to remove barriers to their inclusion. The publication is based on a series of Country Reports that were prepared by National Experts in Austria, Belgium, Bulgaria, Cyprus, the Czech Republic, Estonia, Finland, France, Greece, Hungary, Ireland, Italy, Latvia, Lithuania, the Netherlands, Poland, Portugal, Romania, Slovakia, Slovenia, Spain and the United Kingdom. These reports with detailed information are available at: <http://www.childrights4all.eu/>. The examples used from the Country Reports in this European Report are illustrative and not exhaustive.

2009 celebrated the 20<sup>th</sup> anniversary of the United Nations Convention on the Rights of the Child (CRC) and the achievements and the continuous fight to enforce children's rights. While the UN Committee on the Rights of the Child repeatedly stresses the vulnerability of children with disabilities and the need to effectively protect and enforce their rights, equal opportunities for children with intellectual disabilities remain poorly addressed. The entry into force of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) has been an opportunity to look again at the inclusion of children with intellectual disabilities.

The Country Reports paint a rather distressing picture of the situation of children with intellectual disabilities. All of them state that there is very limited evidence on how the rights of children with intellectual disabilities are upheld in the researched countries. The results of our survey show that CRC implementation from the perspective of children with intellectual disabilities is far from satisfactory in all five areas. While some attention has been paid to education and health, the European countries should focus also on other areas such as abuse and participation of children with intellectual disabilities. Despite progress and positive developments in the area of education and de-institutionalisation, many children with intellectual disabilities continue to be educated exclusively in segregated settings or are placed in long-term residential institutions.

It has been acknowledged by civil society, governments and experts that children with intellectual disabilities are generally at greater risk of becoming victims of psychological and physical violence, sexual abuse and bullying, especially in institutions or at schools. However, the National Experts underline the extensive lack of information, data and policies in this specific field. A comprehensive assessment is difficult due to the shortage of studies and indicators. The research also shows that a number of necessary measures have been implemented without any consideration for the needs of children with severe disabilities and/or complex support needs. These include support for child victims of abuse, educational measures, prevention schemes and evaluation of the rehabilitation process for victims.

Scant attention is given to the situation of families looking at home after their children with intellectual disabilities. Country Reports identify little support for families, insufficient information to help them in caring for and raising their child with an intellectual disability as well as too few or poor community-based services, especially respite care services. The national experts however confirmed that in many countries, decision-makers are aware that institutionalisation in childhood may lead to institutionalisation in adulthood. Thus considerable attention is given to de-institutionalisation strategies, but the results are still sparse, mainly because of non-inclusive foster care policies and insufficient investment in alternative care.

While progress in favour of inclusive education can be seen in many countries, access to mainstream education for pupils with intellectual disabilities is still rather modest. Significant shortcomings identified in previous researches have been again pointed out, e.g. lack of educational opportunities, inadequacy in the work of support staff and teaching staff, or discrimination based on intellectual disability. In addition, insufficient support in mainstream schools and the lack of trained staff and resources can bring these children back and forth between mainstream and segregated schools. Similarly, restricted access to mainstream education at secondary level and the absence of support in the transition between primary and secondary education are crucial factors which often contribute to disrupted educational paths of children with intellectual disabilities compared to other learners.

While in Europe access to basic health care is ensured for all children, the Country Reports reveal huge disparities among the EU countries. The lack of early intervention services, poor carer and professional awareness, administrative and financial barriers in access to health care or treatment as well as disability-based discrimination are the main issues which need to be addressed to ensure an equal access to health for children with intellectual disabilities.

Finally, children with intellectual disabilities are not provided the opportunity to express their views freely in all matters affecting them. This central obligation enshrined in the CRC Article 12 is often ignored by State Parties. At school there is a distinct lack of self-advocacy and citizenship training for children that would help them to express their views. Yet too often there is a reluctance to recognize the competence of children with intellectual disabilities to contribute to decision-making processes. Huge barriers to promoting the rights of children with intellectual disabilities and encouraging their participation are related to preconceived ideas and prejudices of the society and the community. Case studies collected in this research show that discrimination is still a common occurrence. Both children with intellectual disabilities and their families feel discriminated against. Discriminatory attitudes reduce opportunities for informal learning through the interaction of children with intellectual disabilities with their peers.

The publication ends with recommendations for actions that should be given priority by policy makers at European, national,

regional and local levels to ensure equal opportunities for children with intellectual disabilities.

Based on the findings of this report, Inclusion Europe's and Eurochild's key recommendations are:

- 1) to ratify the Convention on the Rights of the Child by the EU
- 2) to implement the Convention on the Rights of Persons with Disabilities in relation to children with intellectual disabilities
- 3) to take action to enlarge nation-wide quality community based services, necessary to ensure that families with a child with intellectual disabilities can live included in their communities
- 4) to promote living in the community: governments must actively develop alternative family-type setting to stop new

- admissions of children in residential institutions
- 5) to focus on better protection of children with intellectual disabilities against abuse, violence and bullying in all the places they frequent
- 6) to simplify and better coordinate health care, social care and rehabilitation services to facilitate the follow-up by families and professionals who are supporting children with intellectual disabilities
- 7) to remove systemic barriers that hinder progress towards inclusive education. All children must grow up together in one common school system to be accepted by their communities and make real choices for their future lives
- 8) to consult with children with intellectual disabilities and their families throughout all the relevant sectors. Governments and service providers must make efforts to give them opportunities to be heard. ★

## I. Introduction

### A. Background and purpose of the study

The project **"Children's rights for all! Monitoring the implementation of the UN Convention on the Rights of the Child for children with intellectual disabilities"** was financed by the DAPHNE programme of the European Commission. It aims to reinforce the implementation of the UN Convention on the Rights of the Child (hereinafter CRC) from the perspective of children with intellectual disabilities. Because the implementation of the UN Convention on the Rights of Persons with Disabilities (hereinafter CRPD) is being currently discussed in many European Countries and worldwide, it is crucial for the disability movement and community to benefit from the long and fruitful experience of child activists and from the achievements of governments and their civil society partners in the enforcement of children's rights.

While developing its policy strategies for children, Inclusion Europe identified the need for a better understanding and overview of the implementation of the CRC to influence mainstream child policies for children with intellectual disabilities. The need for such research has been also clearly identified by the European Commission in its report entitled *Child poverty and well-being in the EU: Current status and way forward* (DG Employment, Social Affairs and Equal Opportunities, January 2008). Indeed, Recommendation 10 of that report states: *"Better monitoring of the situation of the most vulnerable children is needed. Member States are therefore encouraged to review the different sources of data available from statistical surveys and administrative/register sources to monitor their situation. They should make full use of these data to identify the groups of vulnerable children that need to be specifically monitored"*.

In order to realise this project, expertise on intellectual disability and on children's rights has been combined thanks to the collaboration of two European NGO networks: Eurochild and Inclusion Europe. This European Report and its Country

Reports throw a new light on the CRC and its impact and implementation in the EU Member States.

### B. Methodology

The overall aim of this project was to provide scientific evidence to inform and stimulate policy development in the areas of health, protection against abuse, family support and (de-)institutionalisation, education, and the participation of children. The objectives of the project were to review existing statistical and other quantitative data available in the State Reports to the CRC Committee of the UN and the related NGO alternative report(s). The project assessed the status of implementation of the Convention on the Rights of the Child reported on the issues identified and made recommendations about how governments can take forward this agenda for change.

This European Report is intended to raise the profile of childhood of children with intellectual disabilities and to give impetus to the challenge of ensuring that children with intellectual disabilities are fully included in efforts to promote the human rights of all children.



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The UN CRC considers all children to be “citizens with equal rights”, rather than just dependents of parents or recipients of public interventions. Therefore this report reflects the tripartite research approach using the following resources:

- Official facts and figures (Data analysis).
- Professional opinion (Qualitative assessment): national experts assessed the implementation of the CRC for children with intellectual disabilities in their countries using an evaluation model.
- Voices of children and their parents were heard in the focus groups and interviews.

This methodology combines a quantitative approach and a qualitative approach to obtain structured responses that will support a description of the situation across the countries reported. This report also recognizes that research on children with intellectual disabilities is still at the beginning stage in many European countries. This report aims to combine three basic research resources to assess the implementation of the CRC from the perspective of children with intellectual disabilities.

The research used as far as possible standard definitions of terms and concepts as they are used in other related research and the monitoring of the CRC implementation. In addition, the following definition of the term “institution” as proposed by the European Coalition for Community Living (ECCL) was and is used whenever this term appears in the text:

*“An institution is any place in which people who have been labelled as having a disability are isolated, segregated and/or compelled to live together. An institution is also any place in which people do not have, or are not allowed to exercise control over their lives and their day-to-day decisions. An institution is not defined merely by its size”.*

National experts provided the main input for this thematic report. In addition, gaps in the relevant national research within each of the areas of interest were identified. Moreover, the national experts have identified examples of good practice in the implementation of the Convention on the Rights of the Child from the perspective of children with intellectual disabilities and their families. ★

## II. Statistical data



According to the General Guidelines regarding the form and content of periodic reports submitted by States Parties under the Article 44 of the Convention on the Rights of the Child, States Parties are required to provide information relevant to the implementation of the Convention. State Parties shall provide information with regard to: follow-up, monitoring, resource allocation, statistical data providing e.g. data disaggregated by age, gender, urban/rural area, disability etc. and challenges to implementation. It is clear that countries taking part in the project have some way to go to meet this requirement. At present, comprehensive information is not available for all five areas with regards to intellectual disability.

Most of the countries provide a very limited statistical picture of the lives of children with intellectual disabilities. Most statistical information available usually relates to education, although there is also some in the realm of social security or health care.

The national experts reported various experiences and observations when reviewing the statistical data available in the State or alternative reports. Most often, data on types of disability were scarce because data disaggregation in relation to children with intellectual disabilities is not available. Reliability of statistical data can also often be questioned because there are differences in the terminology surrounding intellectual disability. Even mixing intellectual disability with mental health problems in statistical data was reported from Portugal. In Poland, the Central Statistical Office (GUS) does not usually specify the type of disability in its records. Disabled individuals are classified according to the degree of disability, not its cause. As stated in the Irish Country Report<sup>1</sup> the absence of a common definition of disability in general between the bodies which are involved in various ways shows how the approach to disability based on human rights, as defined by the Convention on the Rights of Persons with Disabilities, is still struggling to permeate the various methodologies used. This means that statistical data are produced that are difficult to compare and open to different interpretations depending on the specific topic.

Fragmentation of care for children in general was also identified as a barrier for collating and analysing relevant statistical data. For example in the Czech Republic and in Latvia the care systems for children remain insufficiently coherent with the following consequences: inconsistent procedures for children at risk, legislative differences between each Ministry,

<sup>1</sup> Country Report always refers to the reports written by national experts in the framework of this project. State Reports or NGO alternative reports to the UN CRC Committee will be specifically mentioned.

inconsistent use of terms, fragmentation in monitoring data about children, sometimes no continuity or flexibility in services provided, as well as time consuming and insufficient communication and cooperation between various ministries.

A justification of the absence of statistical data about children with disabilities and children with intellectual disabilities was included in the Greek State report. According to the Greek Ministry of Health, any intentions of identifying persons with disabilities in the (2001) national census in Greece were abandoned “as a result of reactions on the basis of safeguarding personal data”.

However, some positive trends were reported by the national experts. For example in Spain *the National Strategic Plan for*

*Children and Adolescents* (PENIA) has been a key planning instrument leading to improvements in recent years. The second edition of PENIA (2011-14) should focus in particular on children with intellectual disability. Belgium is planning to set up a “statistical working group” with the aim of developing and introducing a methodology for collating information available currently or in the near future. In the long term, the data should be shared between the authorities in the context of their case management, to obtain reliable data and to adopt appropriate measures. France has made efforts to monitor specifically some areas such as abuse. However, the national expert in France argues that such data have not yet been sufficiently linked up with policies to allow an action strategy with short, medium and long-term goals to be developed. ★

### III. General Assessment of the Implementation of the UN Convention on the Rights of the Child

In this part of the study we were seeking to answer a question about the extent of implementation of the CRC from the perspective of children with intellectual disability in the countries involved in the project. The national experts assessed what the State Parties:

- are planning to do in the specific areas with the aim of improving the situation of children with intellectual disabilities (*approach*)
- are doing to achieve the given goals e.g. in a national plan or by national legislation that have clear outputs and an impact on the life of children with intellectual disabilities (*application*)
- and what State Parties are doing to improve their strategies on the basis of regular and systematic evaluation (statistical data, benchmark strategies, comparative studies etc.) (*improvement*).

The method was informed by assessment methods used in quality management systems by EFQM (European Foundation for Quality Management). In the light of the qualitative nature of the survey, it has not been possible to check in depth the responses; however, efforts have been made to reduce the risk of major errors.

**Figure 1 - Extent of implementation of the CRC according to the five areas**

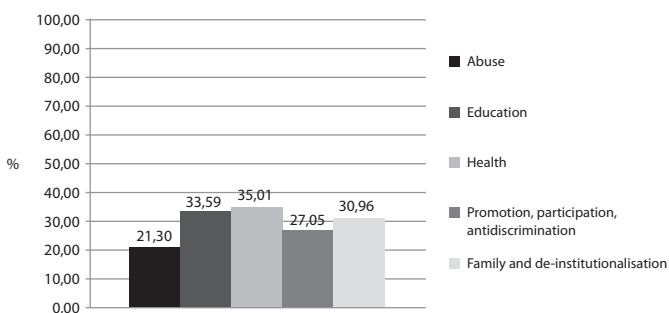


Figure 1 illustrates performance in five areas – abuse, promotion, participation and antidiscrimination, family and de-

institutionalisation, health, education. **The overall assessment of the implementation of the Convention on the Rights of the Child is very low.** Protection against abuse of children with intellectual disabilities was on average assessed by the national experts as the weakest area (21 per cent) followed by promotion, participation, anti-discrimination (27 per cent) and family and de-institutionalisation (31 per cent). Education (34 per cent) and health (35 per cent) were rated by the national experts as areas with relatively high implementation of the CRC. In conclusion, the CRC implementation from the perspective of children with intellectual disabilities is far from satisfactory in all five areas. While some attention has been paid to education and health, the European countries should focus also on other areas such as the abuse and participation of children with intellectual disabilities.

**The assessment has to be made on the basis of a list of benchmarks and indicators divided in 35 questions derived from articles 2, 5, 6, 9, 10, 11, 12, 18, 19, 20, 21, 23, 24, 26, 25, 27, 28, 29, 39 of the CRC.**

1. Assessing the **approach** of the State Party (=what the State Party is doing to fulfil the CRC article): is the approach justified, systematic and connected to listed indicators and benchmarks?

- If there are some plans and legislation at national level but without any connections to practice and the monitoring system, the rating goes from 20-30 points.
- If the legislation and administrative measures are connected with the monitoring system (meaning that the approach is designed to have inputs and outputs with defined procedures), rating goes from 40 to 50 points.
- If this approach is verified and integrated (there is cooperation between the different types of state departments, state institutions and NGOs leading to specific responsibilities for the fulfilment of monitoring requirements) rating goes from 60 to 70 points.

2. Assessing the **application** of the legislation and policies: If there is a monitoring system that collates data from at least



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a quarter of the listed benchmarks and indicators, rating goes from 20 to 30 points. If there is a monitoring system that collates data from at least half of the listed benchmarks and indicators, rating goes from 40 to 50 points. If there is a

monitoring system that collates data from at least three-quarters of the listed benchmarks and indicators, you can rate from 60 to 70 points. If there is a monitoring system that collates data from all listed benchmarks and indicators, rating goes from 80 to 100 points.

3. Assessing **improvements**. If there is a monitoring system that collates data over a period of at least three years so that it is possible to see some improvements through key indicators, rating goes from 40 to 50 points. If there is a systematic and long-term evaluation that shows improvement for most of the indicators, rating goes from 60 to 70 points. If there is a systematic identification of best practices for each indicator and following improvement, rating goes from 80 to 100 points.

**The final rating is the average of the ratings for approach, application and improvement. ★**

## IV. Protection against violence and abuse

### Article 19 CRC

1. States Parties shall take all appropriate legislative, administrative, social and educational measures to protect the child from **all forms** of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse, while in the care of parent(s), legal guardian(s) or any other person who has the care of the child.

2. Such protective measures should, as appropriate, include effective procedures for the establishment of social programmes to provide necessary support for the child and for those who have the care of the child, as well as for other forms of prevention and for identification, reporting, referral, investigation, treatment and follow-up of instances of child maltreatment described heretofore, and, as appropriate, for judicial involvement.

Article 19 of the CRC goes beyond children's rights to protection from "abuse". Article 19 requires children's protection from "*all forms of physical and mental violence*" while in the care of parents or others. The Committee on the Rights of the Child recognised that "*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*"<sup>2</sup>. It also highlighted the following main reasons to explain their particular vulnerability.

- a) "Their inability to hear, move, and dress, toilet, and bath independently increases their vulnerability to intrusive personal care or abuse;

- b) Living in isolation from parents, siblings, extended family and friends increases the likelihood of abuse;
- c) Should they have communication or intellectual impairments, they may be ignored, disbelieved or misunderstood should they complain about abuse;
- d) Parents or others taking care of the child may be under considerable pressure or stress because of physical, financial and emotional issues in caring for their child. Studies indicate that those under stress may be more likely to commit abuse;
- e) Children with disabilities are often wrongly perceived as being non-sexual and not having an understanding of their own bodies and, therefore, they can be targets of abusive people, particularly those who base abuse on sexuality"<sup>3</sup>.

The new General Comment 13 on Article 19<sup>4</sup>, approved by the UN CRC Committee in February 2011 recalls the obligations for State Parties under this article, outlines the measures that State Parties must take and guides them to adopt a holistic approach to implement article 19. Particular attention is given to children with disabilities, including children with intellectual disabilities, recommending State Parties to provide them with disability-specific reasonable accommodation and easy-to-read material for example<sup>5</sup>.

### A. General framework for the prevention of abuse

In all the researched countries, it is clear that there is an absence of **policy or strategy for the prevention of abuse or bullying of children with intellectual disabilities or other disabled children**. The State reports to the CRC Committee often just mention specific projects, including targeting children with intellectual disabilities. Although some projects may be needed

<sup>2</sup> Committee on the Rights of the Child, General Comment n°9, 2006, CRC/C/GC/9, para. 43 available at <http://daccess-dds-ny.un.org/doc/UNDOC/GEN/G07/407/02/PDF/G0740702.pdf?OpenElement>.

<sup>3</sup> Ibidem.

<sup>4</sup> Committee on the Rights of the Child, General Comment n°13, 2011, CRC/C/GC/13 [http://www2.ohchr.org/english/bodies/crc/docs/CRC.C.GC.13\\_en.pdf](http://www2.ohchr.org/english/bodies/crc/docs/CRC.C.GC.13_en.pdf).

<sup>5</sup> Ibidem pages 5 and 19.



and relevant, they do not form an overall strategy and do not guarantee that protection against abuse is ensured. In Finland for example, a number of individual projects exist but there is no systematic response at State level. Finland does not have a special national programme in place for preventing violence against children with intellectual disabilities<sup>6</sup>. In Spain, on the basis of recommendations of the Committee on the Rights of the Child in June 2002, part five (“Abuses and Violence”), the *Third Plan of Action for Persons with Disabilities 2009-2012* provides for a number of measures designed to prevent abuse and acts of violence committed against persons with disabilities, particularly minors, and to facilitate their detection. However, no results were reported after putting plans for action in place.

In addition, in many countries the national experts report **lack of coordination**. Coordination between governmental bodies is often a problem as well as the division of responsibilities which are usually split at federal/national level and at regional level. In Portugal, regardless of the fact that all departments and agencies responsible for child protection against abuse have been identified, the State report shows limited structures for effective coordination between the different programs.

## **B. Identification of the forms of violence against children with intellectual disabilities**

A long history exists of denial by adult society of the extent of violence against children especially against children with intellectual disabilities. The Committee highlighted that it is only through interview studies with children and parents that the States can begin to build up a true picture of the prevalence of all forms of violence against children. It is not possible to measure the progress and the effectiveness of child protection systems without this sort of research<sup>7</sup>.

The national experts reported that **too little is known about forms of abuse suffered by children with intellectual disabilities**. Therefore, often incidents reported are not pursued as there is **insufficient recognition of abuse, especially psychological abuse**.

In Austria, experts estimate that the related prevention policies do not take account of the fact that children with intellectual disabilities are generally at greater risk of becoming victims of psychological and physical violence and sexual abuse, especially in institutions, although there is a lack of verified data<sup>8</sup>. Children and young people with intellectual disabilities are more likely to be victims of sexual and institutional violence<sup>9</sup>. Around 31 per cent of all children with disabilities experience some form of abuse<sup>10</sup>.

In Finland a child victim study was carried out by the country’s Ombudsman for Children in 2008. Amongst others, the Children

Ombudsman recommended conducting the study at regular intervals. The recommendations include the need to examine the violence faced by children with intellectual disabilities and to take into account the situation of this group of children in particular in any such future studies. It is highlighted that it may be difficult to fully appreciate their situation owing to the challenges such as communication. But it is also highlighted that this must not be an obstacle to investigations<sup>11</sup>.

Similarly, because there has been no thorough empirical research into child abuse in the Netherlands, the Government plans to fund research focused on the prevalence and characteristics of child abuse.

*“Structures of power to which children, young people and adults with intellectual disabilities are exposed makes difficult for them to make use of the support services available”<sup>12</sup>*. 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.

In addition, in Finland a study on child protection for chronically sick children and children with intellectual disabilities suggests that it is parental burnout in particular that leads to the families of children with special needs becoming clients of child protection services (Siitari, 2010). The study estimates that 10-30% of families which are clients of child protection services are those with children with special needs<sup>13</sup>.



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<sup>6</sup> See the Country Report from Finland about VERSO, the KiVa project or specifically on children with intellectual disabilities see the Hungarian Country Report “Making life a safe adventure” project.

<sup>7</sup> UNICEF, Implementation Handbook for the Convention on the Rights of the Child, 3rd revised edition, 2007, page 266.

<sup>8</sup> Estimates assume that the rate of abuse of people with disabilities is twice as high as for non-disabled people, Austrian National Council for Disabled Persons (Österreichische Arbeitsgemeinschaft für Rehabilitation – ÖAR) (2010).

<sup>9</sup> Ministry of Labour, Social Protection and Consumer Protection, 2002 (Bundesministerium für Arbeit, Soziales und Konsumentenschutz - BMASK).

<sup>10</sup> Austrian National Council for Disabled Persons (Österreichische Arbeitsgemeinschaft für Rehabilitation – ÖAR) (2010).

<sup>11</sup> Country Report, Finland, page 8.

<sup>12</sup> Country Report, Austria, page 7.

<sup>13</sup> Country Report, Finland, page 8.

## C. Preventing abuse, reporting abuse of children with intellectual disabilities and providing them support

In many of the countries studied, abuse prevention policy lacks comprehensive reporting mechanisms with regard to abuse of children with intellectual disabilities. In Bulgaria, the UN Committee “shares its concerns with the growing number of children subjected to abuse and violence, including emotional, psychological and sexual abuse, of which very few cases reach the courts of justice” (paragraph 41)<sup>14</sup>.

In countries where there is a general strategy or policy for the prevention of abuse and bullying of children, **preventive and reporting measures should apply to all children, including children with intellectual disabilities**. However, the national experts found evidence that would rather go against this affirmation.

In Italy, the measures chosen to acknowledge, identify and report on cases are not accessible to children with intellectual disabilities. Indeed all the mechanisms for “reporting” require an awareness of what can be considered to be abuse and violence, as well as an understanding of how the system of reporting works, the ability to use at least one of the necessary forms of communication (e.g.: phone or internet) and have access to them.

Similarly in Lithuania, two child abuse prevention programmes are in place<sup>15</sup>. However an alternative report developed by the Lithuanian NGOs states that “no measures are implemented to ensure that the most vulnerable groups of children and young persons, such as asylum-seeking children, street children or child victims of trafficking in human beings, receive adequate medical, psychological and social support and get full protection”. The Law also does not provide for any psychosocial intervention and rehabilitation.

In Austria preventive measures include since 2004 legally established, multidisciplinary child protection groups in hospitals, as well as the requirement for education professionals to report any threats to children’s welfare to the youth welfare services since 2007<sup>16</sup>.

In Hungary, a website addressing children exclusively in their own language provides information on how and in which cases (maltreatment and abuse) they can appeal to the Parliamentary Commissioner for Civil Rights, Ombudsman.

As shown by these examples, there is often little evidence that adequate measures and programmes for the prevention of abuse apply to children with intellectual disabilities in the countries studied. While they do not specifically exclude children with intellectual disabilities, they rarely take into

consideration the special conditions and the greater vulnerability of children with intellectual disabilities to violence and abuse.

### GOOD PRACTICE:

In Belgium there is a new important kind of service: consultation teams (e.g. <http://www.senvzw.be/organisation/consulententeam-ampel-cgg-prisma-vzw>) do give new impulses to the care sector by the reinterpretation of “behaviour problems” of certain persons with intellectual disabilities within a framework of mental health. Working within families and residential care they are able ‘to open’ certain cases where there is suspicion of abuse within the family, the neighbourhood or the institutions.

The national experts also reported **inadequate measures for children with intellectual disabilities to express their views and be heard in the context of abuse**. It is often difficult to prove guilt when someone is accused of criminal behaviour, because a child with disabilities is treated as an unreliable witness (they do not believe the child). The UNICEF report *Promoting the right of children with disabilities* confirms this statement: “Impairments often make children with disabilities appear as ‘easy victims, not only because they may have difficulty in defending themselves and reporting the abuse, but also because their accounts are often dismissed. Violence against a child with a disability may be perceived as less serious and the child’s testimony may be regarded as less reliable than that of a person without disabilities”<sup>17</sup>.

In Romania, procedures regarding complaints and protection against abuse are available in specialised services for children with disabilities, child information being provided according to age and type of disability and/or the degree of disability, using alternative formats. It is not known how many services use adapted instruments and the absence of monitoring of cases of abuse on vulnerable groups makes it impossible to know the real situation in regard to the notifications received related to children with intellectual disabilities.

Surveys conducted in France in an attempt to assess the actual number of children at risk reveal that 24 per cent of those surveyed say they experienced abuse during childhood, but only two per cent report that they received support<sup>18</sup>.

The preconceptions professionals have of children with intellectual disabilities and the reality of the disabilities of this group (communication, understanding, representation, difficulties with concentration) cause problems when action is taken by the protection and prevention system. Thus, for example, legal proceedings make no provision for special

<sup>14</sup> Committee on the Rights of the Child, Concluding Observations: Bulgaria, CRC/C/BGR/CO/2, June 2008 available at: <http://nmd.bg/wp-content/uploads/2009/11/CRC48-Concluding-observations-Bulg-EN.pdf>.

<sup>15</sup> National Child Abuse Prevention and Support for the Child Programme and the National Programme against Commercial Sexual Exploitation of Children and Sexual Abuse – for details see Country Report, Lithuania page 4.

<sup>16</sup> Country Report, Austria, pages 5 and 6.

<sup>17</sup> UNICEF, *Promoting the rights of children with disabilities*, Innocenti Digest n°13, 2007, page 19.

<sup>18</sup> GUYAVARCH E., Une estimation du « chiffre noir » de l’enfance en danger par le biais des enquêtes de victimation, Observatoire National de l’Enfance en Danger (ONED), 2008.

arrangements: “The abuser went free... because C. couldn’t find the right words to describe what he did”. In addition, the testimony of the child is not taken seriously enough: “The team thinks that N. is making it up” when she describes the abuse<sup>19</sup>.

However, as noticed in France, more cases of abuse indicate better assessment<sup>20</sup>. The reports submitted to the Committee identify a growth of abuse reported, but this should not be interpreted as a worsening of the problem. However, **the lack of trained staff and unsatisfactory cooperation between professionals** are mentioned in France.

In Cyprus, there is special legislation on abuse in the family and a special agency, which operates within the area of responsibility of the Social Welfare Services. However, this agency is understaffed and requires upgrading in order to respond to the needs as they arise. Also according to the Cypriot State report, data from the police (special unit) indicates that violence in the family and especially psychological violence has doubled between 2001 and 2007<sup>21</sup>.

In Greece it is established that a child, parent, relative or third party with direct knowledge of the violation of the child’s right may lodge a complaint with the Greek Ombudsman. However, the lack of social services at courts and generally in the community, the lack of data on abuse of children with intellectual disabilities, the non-adapted procedures and also the difficulties for the victims to initiate any procedure, render securing protection almost impossible for children with intellectual disabilities<sup>22</sup>.

#### Case study United Kingdom: M. living in alternative care

“Our son M. moved into his residential school 2 years ago. This had taken nearly 2 years of planning and searching for the right school as he has such complex learning needs. It was difficult for M. to settle at this new school but after the first term as far as we could tell all seemed to be going well. As he does not use speech or any other communication system it is always difficult to be sure. His school is 250 miles away from where we live and once he was settled in we noticed that the social worker stopped visiting him or contacting us. We were invited to one review at the school but no-one from our local council (who were paying for this school) came to this review.

Just imagine what it was like for us when after 2 years we had a visit from a social worker first thing one day to tell us that they had been told that there was evidence of systemic sexual abuse going on at M.’s school. The social worker told us that we needed to decide if we wanted to leave him there or bring him home. We were really shocked that she didn’t seem concerned about whether or not M. had been abused.

The school wouldn’t answer any of our questions and just said we had to talk to their lawyers, which was no help at all.

In the end we had to bring M. home and begin the long battle all over again to find another school for him. To this day we still don’t know if he was abused at his school and that’s an awful thing for a parent. We just don’t know what impact this has all had on M. and can’t find anyone to help M. or us”.

## D. Abuse in residential care

**A particular area of concern mentioned in the Country Reports is abuse in residential care.** For example in Belgium, the high number of persons with disabilities living in institutions seems to lead to a higher number of abuse cases<sup>23</sup>. In France, according to a study conducted in 2002 on a partial sample, 38 per cent of abuse reported in residential institutions concerns children and adolescents with intellectual disabilities. A considerable proportion of this abuse is sexual in nature (70 per cent). Sixty per cent of the alleged perpetrators of abuse are co-residents<sup>24</sup>. Abusive attitudes are sometimes observed by parents. Furthermore, verbal abuse is still far too common and often tolerated and psychological abuse is often not recognised at all. Some parents are openly critical of the marginalisation of certain children but others keep quiet for fear of losing their child’s place at the institution.

Problems of abuse have been most seriously and persistently researched and tackled by the Bulgarian Helsinki Committee (BHC) revealing “238 deaths due to neglect, abuse, torture and poor living conditions in institutions” in the period between the year 2000 and 2010. The investigation was performed in cooperation with the Chief Prosecutor’s Office. The Abandoned Children of Bulgaria documentary shown on BBC in 2007 directed public attention to the flaws of institutional care but issues related to family and community care remained out of the public eye<sup>25</sup>.

Similarly in Latvia, government has taken measures to implement the strategy for the prevention of abuse. However, these activities were undertaken only after “Latvian Save the Children” (“Glābiet bērņus”) had informed the community about shocking cases of sexual abuse, physical and emotional violence against children with intellectual disabilities at specialised boarding schools and social assistance centres in 1999-2001<sup>26</sup>.

From the monitoring of the situation of children with disabilities from institutions in Romania, the national expert found that a number of children with intellectual disabilities

<sup>19</sup> DE KEUNYNCK-LEFER M.-C., Le handicap et la justice : une rencontre difficile. La confrontation avec la justice des adolescents déficients victimes d’abus sexuels (mémoire de maîtrise).

<sup>20</sup> Country Report, France, page 6.

<sup>21</sup> Country Report, Cyprus, page 6.

<sup>22</sup> Country Report, Greece page 4.

<sup>23</sup> See <http://www.humo.be/tws/humo-files/20063/pedofilie-in-de-kerk.html>.

<sup>24</sup> Maltraitance envers les personnes handicapées : briser la loi du silence (tome 2, auditions), Rapport de la commission d’enquête sur la maltraitance envers les personnes handicapées accueillies en établissements et services sociaux et médicosociaux et les moyens de la prévenir, 2002.

<sup>25</sup> Country Report, Bulgaria, page 6.

<sup>26</sup> Country Report, Latvia, page 5.

from residential care services were threatened with hospitalization in psychiatric hospitals as a punishment (2006); therefore long-term hospitalization of children is still a practice in these situations<sup>27</sup>.

National experts made references to numerous reports about the major risks of violation of Human Rights of children living in long-stay residential institutions all over Europe and particularly in Central and Eastern Europe. One of the recent report from the Office of the High Commissioner for Europe *Forgotten Europeans Forgotten Rights* states “Numerous reports have noted substandard living conditions, including badly maintained buildings, lack of heating and unhygienic sanitation; poor treatment of residents, including inadequate provision of clothing and food, sometimes leading to malnutrition, physical and sexual abuse, lack of privacy and few or no rehabilitative or therapeutic activities”<sup>28</sup>.

However some positive progress is being made. In Ireland for example, residential services for children with a disability are not subject to independent inspection and statutory standards. Under the Health Information and Quality Authority (HIQA), *Draft National Quality Standards for Registered and/or Inspected Services for Children and Young People* have been drawn up<sup>29</sup> and it is expected that these standards will be implemented in early 2011. These standards will encompass services for children with a disability in addition to other groups of children in State care, who are not under the remit of current legislation, such as children in foster care.

#### Case study Greece: N. living in an institution

The life of N., aged 10 (2007)<sup>30</sup> who has Down’s syndrome, in an institution: “He wakes up at 7.30... bound to the bed by the leg with a strip of white sheet. He is wearing dirty coveralls. At 8.00, two nurses come in... One heads for N. with a bottle of milk. She feeds him as he is, bound to the bed. N. sucks quickly, without taking a breath. Milk rolls down from his mouth to his neck... she is using the same syringe to administer medication to all the children ... then goes to N. Her movements to the child are unceremonious. She abruptly and forcefully pushes her palms at his cheeks. The child opens his mouth with an expression of suffering without fighting her. She empties the medicine in his mouth and leaves...N. lies there, the milk on his clothes... He unzips... tries to take his nappies off. He manages to pull part of it out and tears it to shreds. Puts them in his mouth. Starts to chew on them. His mouth is stuffed. Half an hour later, at 11.30, an orderly comes in. He sees the child and shouts: there we go again, you’ll get us all sent to prison. He squeezes his cheeks so that he can open his mouth and he can clean him up. N. starts crying. At 12.30... the nurse... puts the medication in a spoonful of food and gives it to them.

Using the same spoon for them all... she picks up a dish and starts to feed N. The child stands. He grabs the dish with his hands. He swallows quickly without a break... using a wet T-shirt, she wipes his mouth... at 13.00... she takes his coveralls off. The child is now naked, she changes his nappies... She ties a long strip from torn sheets around his waist to keep the nappies from falling. Then straps him back on the bed... N. lies down and stares at the ceiling. At 16.30 the nurse comes in... N. needs changing again... she pays no attention... At 20.20, the nurse in charge of dinner and medicine administration comes in... same process... She gives all the children a drink of water using the same bottle. The lights in the hallway and in the room are never off. N. and the other children... stay cooped up in the room all night long...”

## E. Bullying – a particular form of abuse

Another area to which national experts draw particular attention is bullying at school. It is a common issue of concern to parents of children with intellectual disabilities whose children often experience discrimination at school by non-disabled children and other people.

The Committee has highlighted bullying in schools in comments to States and has expressed concern about the bullying of children with disabilities: “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>31</sup>.

Most experts drew attention to the underestimation of this phenomena and the lack of relevant prevention programmes.

In Ireland, there is no legislation on bullying. However the “Stay Safe” programme teaches children about recognising an unsafe situation and telling adults when one arises. It is not mandatory in schools and is in about 85 per cent of mainstream schools. No figures are available on special schools and participation of children with disabilities in special classes in mainstream schools. However, the “Stay Safe” website<sup>32</sup> has a specific section on “Personal Safety Skills for Children with Learning Difficulties”, which was designed to assist the teaching of safety skills to children with disabilities. Although targeted at children with a disability in the six-to-thirteen age group, the programme can be used for some older children with disabilities.

It is evident from the case studies that education for children with intellectual disabilities on recognising abuse is not available in the vast majority of mainstream schools, special schools and disability services. Nor is there evidence that parents are provided with information on recognising abuse. Families are concerned that abuse arises in more “everyday”

<sup>27</sup> Country Report, Romania, page 7.

<sup>28</sup> OHCHR, Office for Europe, *Forgotten Europeans-Forgotten Rights*, The Human Rights of persons placed in institutions, 2011, page 6.

<sup>29</sup> Country Report, Ireland, page 4.

<sup>30</sup> Country Report, Greece, page 5. [In Greek] Ch. Asimopoulos, M. Margaritidou, A. Mavromati, M.E. Paraschaki, I. Psara, “Children with disabilities in institutions in Greece: the phenomenon of neglect and abuse in institutions”, *Kinoniki Ergasia*, Issue 94, 2009.

<sup>31</sup> Committee on the Rights of the Child, General Comment n°9, 2006, CRC/C/GC/9, para. 43 available at: <http://daccess-dds-ny.un.org/doc/UNDOC/GEN/G07/407/02/PDF/G0740702.pdf?OpenElement>.

<sup>32</sup> See: [http://www.staysafe.ie/parent\\_sen.htm#The Stay Safe Programme for children with special needs](http://www.staysafe.ie/parent_sen.htm#The%20Stay%20Safe%20Programme%20for%20children%20with%20special%20needs) (Country Report, Ireland).

situations in normal life. For example, they fear that their children will be cheated or deceived whilst shopping or during leisure time or social activities. Paradoxically this leads to a situation of overprotection which tends to reduce the possibility of developing a more autonomous life<sup>33</sup>. Most bullying case studies reported by families and/or children themselves actually took place at schools. The following statement from Greece provides illustration: some parents mention “countless” experiences of physical/psychological violence against their children by peers while playing at the playground or day-care centre but also at school by fellow-students and teachers who either participate or not, or who are indifferent or negative to the children: 1. “the other children mock him or hit him or push him when not accompanied”; 2. “at the general public school, the other children exerted psychological and physical force on him, they wouldn’t play with him, mocked him, hit him; in fact, the teachers mistreated him as well and made it clear that he was unwanted, which also influenced his peers”; 3. “at the special school he has experienced psychological and emotional abuse as teachers consider these children to be objects and speak and act in their presence as if they weren’t there”. Abuse of the minor affects the parents, who then limit the autonomous interactions of the youth with intellectual disability<sup>34</sup>. ★

### Case study from Austria: J. living with his family

At the time of the interview J. was eight years old. From the age of two he attended a private kindergarten which he had to leave because the staff could not cope with his specific needs.

J’s parents report that measures were taken at the kindergarten to prevent sexual abuse. For example, it was explained to the children that they should not approach adults too openly. From the age of three he was able to attend a mainstream local authority kindergarten. At this kindergarten no sexual abuse prevention measures or education were undertaken.

Both in school and at the after-school club there were (physical) violence prevention programmes, but at the same time there was discrimination and structural violence<sup>35</sup> from the staff teaching the integrated class. J’s parents do not know whether preventative work with regard to sexual abuse took place or takes place in the school, but they feel that these measures should be linked and delivered together.

## V. Family support and living in the community

### Article 9

1. States Parties shall ensure that **a child shall not be separated from his or her parents** against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child. (...).

### Article 18

2. (...), States Parties shall render **appropriate assistance to parents** and legal guardians in the performance of their child-rearing responsibilities and **shall ensure the development of institutions, facilities and services for the care of children**.

3. States Parties shall take all appropriate measures to ensure that children of working parents have the right to benefit from **child-care services and facilities** for which they are eligible.

### Article 20

1. A child temporarily or permanently deprived of his or her family environment, or in whose own best interests cannot be allowed to remain in that environment, shall be entitled to special protection and assistance provided by the State.

2. States Parties shall in accordance with their national laws ensure **alternative care** for such a child.

Under the CRC, children, including children with intellectual disabilities, have the right to be cared for by their parents (Article 7 CRC). Article 9 of the Convention on the Rights of the Child enshrines one essential principle of children’s rights: children should not be separated from their parents unless it is necessary for their best interests. It also affirms children’s rights to maintain relations and contact with both parents. Article 23 of the Convention on the Rights of Persons with Disabilities repeats the provisions of Article 9 adding “*In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents*”. To prevent “*concealment, abandonment, neglect and segregation of children with disabilities, States must undertake to provide early and comprehensive information, services and support to children with disabilities and their families*”<sup>36</sup>. Article 18 paragraphs 2 and 3 of the CRC concerning family support from the State are crucial not only for families identified as at risk of breaking down but for all parents. Universal provision of financial and community-based services is an effective form of prevention<sup>37</sup>. Childhood care, pre-school arrangements and after school care are essential to protect the needs of children and by extension, the rights and interests of their parents.

UNICEF reports about 317 000 children with disabilities in public institutional care in 2002 in Central and Eastern European and the Community of Independent States (CEE and CIS)<sup>38</sup>. In addition, a significant number of school-age children with disabilities are living in boarding schools, because of the

<sup>33</sup> Country Report, Spain, page 11.

<sup>34</sup> Country Report, Greece, pages 4,5.

<sup>35</sup> ‘Discrimination’ and ‘structural violence’ as in violence through structures, such as denial of resources and differentiating between children.

<sup>36</sup> Article 23 para. 3 CRPD.

<sup>37</sup> UNICEF, Implementation Handbook for the Convention on the Rights of the Child, 3rd revised edition, 2007, page 240.

<sup>38</sup> UNICEF, *Children and Disability in Transition in CEE/CIS and Baltic States*, Innocenti Insight, 2005, page 16.



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absence of educational opportunities in their communities<sup>39</sup>. Overall this pattern is relatively stable. This, however, does not mean that things are not changing. The UNICEF report on disabled children notes that “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>40</sup>. Research has demonstrated that children experience developmental delays and potentially irreversible psychological damage by growing up in such environments”. Institutionalisation is also particularly harmful for children, because the lack of emotional attachment is very damaging to their development<sup>41</sup>. In addition, children in these settings are denied the important benefit of following the model of other children, which is critical for learning.

The challenge for all countries is to develop the appropriate and adequate community-based services and support to families as well as alternatives to institutional care, such as adoption or fostering.

## A. Services to support families of children with intellectual disabilities

All the national experts report that different types of services (counselling, psychological, pedagogical and/or educational support, rehabilitation, leisure activities), either delivered by NGOs or by the State, exist in the countries reviewed. However, they point out the issue of the **availability of services to families and the unfair and unbalanced geographical distribution of services**. This is the case in countries like Austria or Spain, where regional governments have a very high autonomy, but also in

every country because there are alarming differences between local authorities, even in centralised States, and between rural and urban areas. Support to families depends on where they live in the country. In addition, there is no universal access to services and no balanced network of services.

In Romania, early diagnosis and intervention especially in rural areas are poorly developed. The UN Committee on the Rights of the Child takes note that “many children with disabilities are identified, included in a degree of disability and directed to adequate services only when enrolling in the education system”. The Ministry of Labour, Family and Social Protection therefore carries out a programme to establish and train mobile intervention teams for children with disabilities. In the same way, a major weakness in the UK system of family support is the complexity of the system to access both universal and targeted services. Many families are not aware of what is available in their local area in the UK.

### Case Study Italy: A father

*My wife and I therefore work amazingly hard to manage the various necessities. At times I myself am astonished at how we succeed in managing everything without any help. However, all of this is often the source of great difficulty, suffering and sadness, because we are afraid that we will not be able to give adequate support to A. in terms of knowledge, information and company.*

Project entitled “Human Rights and inclusion: Network action to overcome old and new forms of segregation”, Italy

Respite care (short-break care), is frequently reported to be missing, especially for children with complex needs or severe disabilities. Either the total absence of, or the overall shortage of this service turn the present practice of respite care often into an unreliable and insecure resource for families and make it difficult to plan around available respite. A Mencap survey in the UK points out that 7 out of 10 families have reached breaking point because of a lack of short breaks<sup>42</sup>. In addition, respite care is often problematic: in Ireland for example the location of respite care for children in adult services is a concern. Developments in recent years have also shown that when services receive a cut to the budget they receive from the State, respite care is often the first area to be withdrawn. This has been noticed for example in the Czech Republic and in Ireland recently. The voluntary care by siblings and grandparents to support families is often the only “respite care” available, as the Greek national expert<sup>43</sup> noted.

**Personal assistance and its availability and accessibility**, is a common issue raised in many Country Reports. Personal assistance services for children and young people are not generally available in Austria or in Finland where the decision depends on the local authorities. In Cyprus, disability benefits provide funds to employ a full-time or part-time caregiver for the child. But even in traditional Welfare States, such as Finland it is

<sup>39</sup> Ibidem, page 18.

<sup>40</sup> UNICEF, Promoting the rights of children with disabilities, Innocenti Digest n°13, 2007, page 17.

<sup>41</sup> OHCHR Regional Office for Europe, Forgotten Europeans, Forgotten Rights, page 6.

<sup>42</sup> Breaking 2003, Mencap and Families still need a break, 2006, Mencap.

<sup>43</sup> Country Report, Greece, page 10.

still far from being sufficient and therefore it is common that the mother stays at home to look after their disabled son or daughter. Access to personal assistant services for people with intellectual disabilities who need them has recently begun in Spain through the Act 39/2006 on the Promotion of Personal Autonomy and Care of Persons in Situations of Dependency, but at present it is applied in a greatly restricted fashion and is only available to those with “great dependency” (the maximum level of classification).

Many national experts, such as in Finland, highlight the case of **single-parent families** – whose break-up/divorce was due to a child having disability where sufficient support was not available to deal with the emotional and financial difficulties for families.

**Lack of information** is a common feature reported by families all over Europe. Parents’ associations (self-help groups) are still considered by parents as the best resource to find information: it is the place where parents can find the most relevant and useful information thanks to those who have similar experiences. Parents are concerned about the child’s future and the lack of structures for semi-autonomous/protected living in the community “so he can also exist without us...”<sup>44</sup>. Thus parents’ associations and self-help groups play a crucial role in the life of families with a child with intellectual disabilities.

A father from Bulgaria says: “Even the technical aids are a problem – can you imagine this in 21st century? They offer outdated, useless items and pay companies for them... What D. really needs and what can help her is not in the list of assistive technologies items paid by the government, so we need to buy it and pay out of our pockets”.

**The absence of monitoring the quality** of the existing services delivered to families and children with disabilities is frequently mentioned. In Austria, it was reported that very little has been done for better quality of services and where the gaps are as there is no monitoring. In countries like Portugal, with a strong ideological commitment to family, policies to promote and support families are in place: however no performance indicators or monitoring policies can be found.

Financial support for families and community-based services, including schooling opportunities play a crucial role in **stopping the placement of children with intellectual disabilities in institutions**. The national experts describe the efforts of Governments to support families and prevent placement in institutional care. In France, between 2001 and 2006 the number of places in specialist facilities fell slightly, as there was significant expansion (+48 per cent) of community-based education and health services (*Services d’Education Spéciale et de Soins à Domicile – SESSAD*) – a sign of commitment to the process of care in the community. A third of SESSAD places are for children with intellectual disabilities.

Personal budgets or direct payment schemes are important to children with intellectual disabilities and their families to purchase the support they need and want. Personal budgets however are not always sufficient, as reported by this parent (The Netherlands) with a child living at home funded with a personal budget: “We buy the support she needs from her personal budget. In the last few years, however, we have had to cancel a number of support workers and that’s a great shame. Our daughter’s development has suffered because of this. We are not happy with the support we receive for our daughter. The older she gets, the more hours we have to spend providing special care for our daughter but that’s not shown in the assessment of the Care Assessment Centre”. In addition, there seems to be an assumption that people with complex needs are unable to take advantage of direct payments because of their disability. While in some cases personal budgets may not be sufficient for the specific support needs of a person, in many countries they are de facto reserved for people with lesser disabilities<sup>45</sup>.

Greek parents were discussing, during interviews for the report, the need for radical reform of services and the abolition of segregated provision:

1. “To support me, for one, as to how I should behave towards my child... how to communicate with him. I now improvise to support him better”;
2. To abolish “two parallel worlds, one for healthy individuals and one for persons with intellectual disabilities and their families”;
3. To create “friendly services, aware of his needs, showing respect, not being offensive to his dignity and helping him achieve personal growth and become autonomous in the environment he lives in”<sup>46</sup>.

## **B. Policies for community living and de-institutionalisation**

In many European countries community living and de-institutionalisation remain a challenge. In most countries, the vast majority of children with intellectual disabilities live with their families (e.g.: in Cyprus or in Ireland 97.8% according to 2009 data). However, there are still a large number of institutions in the majority of EU countries. Experts also confirm that in many countries **decision-makers are aware that institutionalisation in childhood may lead to institutionalisation in adulthood**.

In Austria today there are still institutions with over 100 children **without consistent systems to monitor the situation and the quality of life** of children and young people with intellectual disabilities in homes or care facilities<sup>47</sup>. In Hungary, according to the 2001 census data presented in the report, the residential institutions of the special child care system give home to 3405 children, out of which 2549 are children with intellectual disability<sup>48</sup>. Even though, in recent years some modernization has been accomplished in residential institutions, the average number of persons in the same room is still 4, or more.

<sup>44</sup> Country Report, Greece, page 10.

<sup>45</sup> Inclusion Europe, *The Specific Risks of Discrimination Against Persons in Situation of Major Dependence or with Complex Needs*, Report of a European Study, Volume 1: Policy Recommendations, Brussels, 2008, page 11.

<sup>46</sup> Country Report, Greece, page 10.

<sup>47</sup> Country Report, Austria, page 14.

<sup>48</sup> Country Report, Hungary, page 13.

Bulgaria has high number of children in institutional care. However recent efforts leading to community based services are visible. In 2010 a policy document was passed at the highest political level called *Vision on Deinstitutionalisation of Children*<sup>49</sup> with the motto *What's Best for the Children*. This policy document builds a base for de-institutionalisation programmes including prevention work with families at risk, social welfare policy reform and implementation of programmes to support families and foster parents; setting up alternative services and different types of care; promotion of foster care and adoption as alternatives to biological family care; getting society engaged in support of children, and finally endorsing the child- and family centred approach in the performance of all agencies involved. The *Vision of Deinstitutionalisation* includes two crucial indicators: (1) 137 institutions for children should be closed within the next 15 years; (2) any further placement in institutional care of children aged between 0 and 3 is prohibited. Regretfully, the *Vision* fails to specify the authorities responsible for its implementation. The Action Plan again reveals a leading role for the Ministry of Labour and Social Protection and no responsibilities for other ministries or stakeholders are specified<sup>50</sup>.

The Slovak Country Report provides information about positive changes towards de-institutionalisation<sup>51</sup>: in 2004-2006 children in in-patient care and boarding schools were re-located to orphanages. Disabled children have not been accepted into social service facilities anymore since 2008. Since then, they have been accepted into children's home where integrated groups, specialized groups or foster care families have been formed. Substitute in-patient care no longer dominates over other options of alternative care, such as adoption, foster care, substitute personal care and guardianship. The number of children who do not grow up in individual groups in orphanages but in a more natural environment (in foster families) has increased, including for children with intellectual disabilities. Children under the age of 3, including children with severe disabilities, are placed only into foster families.

## C. Foster care and adoption policies

One of the factors identified in the Country Reports that slows down the de-institutionalisation process is the **lack of alternatives for children without parental care**, especially, **foster care policies**. Again in Bulgaria since 2003 foster care develops but slowly and insufficiently – the number of children placed in foster care is growing, but there is no data showing if disabled children are moved from institutional care to foster family care. Similarly in Romania, de-institutionalisation of children with disabilities started in 2001 but very little is done to encourage adoption of children with disabilities. In Greece, although foster care is theoretically available in fact when parents cannot take care of their child, children with intellectual disabilities are still placed in institutions. Usually it means that institutionalisation goes on without re-evaluation of the

situation to the end of their days without enjoying even the legal safeguards which are applied in the cases of involuntary placement and treatment<sup>52</sup>.

A similar situation is reported from Hungary. Very little possibilities for foster care: "*financially not attractive, foster and adoptive parents primarily care for healthy children. Hungary suffers from a special disadvantage in this area, namely that parents raising children with disabilities do not receive an income commensurate with their responsibilities. In short, there are counter-incentives to adopt children with special needs*".

In Lithuania, individuals working with children deprived of parental care are not sufficiently trained. Therefore after a child assessment, children are more likely to be referred to institutional care than to alternative forms of child care.

Other countries are more advanced in creating alternative to institutional care and some data and policy developments have been reported by the experts. In Italy, in 2002 research conducted by the National Observatory for Children shows data broken down by type of disability of children in situations of fostering within another family: the number of children with intellectual disability is 19 out of 369 children; or in situations of fostering with other members of their own family: the number of children with intellectual disabilities is 72 out of 162 children<sup>53</sup>.

In Spain, protection measures have moved on, and the policy of placing unprotected children almost exclusively in institutions is increasingly being sidelined in favour of fostering children with their extended family. However, there has only been a small increase in fostering with other families. It is believed that there could be between 35,000 and 40,000 children in care, of which 25% are under six years old<sup>54</sup>. Of those, it is estimated that  $\frac{3}{4}$  are institutionalised and only  $\frac{1}{4}$  are in foster families. Spanish experts noted that this is the opposite to what is generally found in surrounding countries. They estimated that this situation has not arisen from a lack of potential foster families, including those for children with intellectual disabilities, but because of the many difficulties involved in these processes and a lack of active information and education policies directed at potential families<sup>55</sup>.

In France, in 2005 adoption reform led to improvements in the approval process but further efforts are required to simplify the procedure. There is a large gap between the number of parents wishing to adopt (approximately 25,000) and the number of children adopted (approximately 4,000). A programme was established for children with disabilities, to match them with families seeking to adopt children with special needs – a total of 29 per cent of juvenile wards of the State are not put forward for adoption due to health problems or disability. No evaluation of this programme is contained in the reports to the CRC Committee<sup>56</sup>. ★

<sup>49</sup> The document is available at: <http://sacp.government.bg/detstvo-za-vsichki/viziya-za-deinstitutionalizaciya/>

<sup>50</sup> Country Report, Bulgaria, page 10.

<sup>51</sup> Country Report, Slovakia, page 9.

<sup>52</sup> Country Report, Greece, page 9.

<sup>53</sup> Anfaa [National Association of Adoptive and Foster Families] data available at <http://www.didaweb.net/fuoriregistro/documenti/anfaa.doc>

<sup>54</sup> Country Report, Spain, page 13.

<sup>55</sup> Ibidem.

<sup>56</sup> Country Report, France, page 8.



### Case study Slovenia: A boy living in an institution

A boy with minor intellectual disability living in one of the social care institutions for education, work and care of children and adults with moderate and severe disabilities who was given up by his parents when he was still a baby attends a department for children with Down's Syndrome in a school with an adapted programme, outside the institution. The institution, in cooperation with the Centre for Social Work, placed the boy in a foster family. They started with shorter, one-day visits and then weekend visits. Foster care, unfortunately, was not a success. Since the situation did not work out, the boy was kept under the care of the institution. The problem was in his early upbringing, being in an institution since birth, where he had no proper upbringing and was being raised by many different people. He was not exposed to a proper family model with the roles of father and mother, and so does not know how to function in that kind of family environment.

### Case study United Kingdom: Z. living with his own family

Z. is an 8 year old boy with intellectual disability and complex health needs. His single mother was struggling to care for Z. as well as 2 younger siblings. She approached her local council for support and was assessed as needing a break once a month. For the past year Z. has been spending one weekend a month with a short break (respite) family.

Z. has shown through his "Picture Exchange Communication System" how much he likes going to stay with his short breaks family. He is able to do more in the local community (parks, cinema etc) with his short breaks family than he can with his mother. His mother has found the breaks work out well for her and allow her to spend more time with the other 2 children.

## VI. Education

### Article 28 CRC

States Parties recognize **the right of the child to education** and with a view to achieving this right progressively and **on the basis of equal opportunity**, they shall, in particular:

- (a) Make primary education compulsory and available free to all;
- (b) Encourage the development of different forms of secondary education, including general and vocational education, make them available and accessible to every child, (...);
- (c) Make higher education accessible to all on the basis of capacity by every appropriate means;
- (d) Make educational and vocational information and guidance available and accessible to all children, (...).

Article 28 of the Convention on the Rights of the Child establishes the child's right to education. This must be achieved "on the basis of equal opportunity". The Committee on the Rights of the Child has expressed concern about the realisation of the right to education for children with disabilities. In its examination of State Parties' reports and in its General comment n°9 on "The rights of children with disabilities", the Committee has gone beyond this general concern to emphasize the importance of recognizing the right of children with disabilities to inclusion in regular schools<sup>57</sup>. In addition, the Convention of the Rights of Persons with Disabilities is unequivocal in its support for inclusive education in Article 24, as it states "State Parties shall ensure an inclusive education

system at all levels". In addition, Article 29 of the CRC sets out the aims and goals of education. The importance of this article lies in the recognition of education being *child-centred* and *child-empowering*, therefore responding to the personal needs of every child (the development of the child's personality, talents and mental and physical abilities, the preparation of the child to live in society<sup>58</sup>). This approach allows to evaluate the adequacy and the objective of inclusive education to respond to the different needs of children with intellectual disabilities.

### A. The Right to Inclusive Education

In all European countries, children have a right to education that is guaranteed by law. In addition, national experts reported that **legislation and policies clearly promote and provide to a certain extent provision for inclusive education**. This trend has been noticed by the experts in all the countries researched. For example in the Netherlands, the government policy in recent decades has been mainly geared to keeping as many pupils as possible in mainstream primary education and the number of pupils in special primary schools has fallen. Schools cannot turn away pupils on the ground of their disability. Similarly, in France the *Law No. 11, 2005 on Equal Rights and Opportunities, Participation and Citizenship for Persons with Disabilities* was an important turning point as it states that education in the mainstream system should be a priority. In Bulgaria, legislation imposes an obligation on all types of schools "to create supportive environment for the children with special educational needs" and teach them in one classroom with all other students. Special schools have been kept as a last resort for parents only "after all other options for integrated education have been exhausted". In Hungary, there are no mandatory provisions in the domestic legal system that would

<sup>57</sup> UNICEF, Implementation Handbook for the Convention on the Rights of the Child, 3rd revised edition, 2007, page 335.

<sup>58</sup> Article 29 CRC paras. 1 a) and d).

unambiguously commit to establishing an inclusive educational system.

## B. Access to Inclusive Education

National experts report that turning inclusive policies into practice is far from satisfactory. It appears rather that many countries have made some attempts to make their mainstream education systems more inclusive, but without achieving the necessary level of support to make inclusive education available to all children on their territory<sup>59</sup>.

**Inclusive pre-school opportunities** exist in almost all countries researched. In practice inclusion is significantly more widespread in kindergartens, as reported from the majority of researched countries. However, because pre-school education is not compulsory in most European countries, there is no legal right to a place in an integrated kindergarten, as reported from Austria. In addition, in the UK, parents of children with intellectual disabilities who have additional complex health needs report a real lack of choice of pre-school options.

At **primary school level**, the figures and information given by national experts confirm that there is a trend to including children with disabilities in regular schools. When data are available on children with intellectual disabilities they are however much less positive, sometimes even showing **no access to education at all**.

Attention has to be drawn to the fact that the data available at national level are heterogeneous. While in all countries data is

available about school enrolment rates for different age groups, disaggregated information about the placement of pupils with disabilities is not available in all responding countries, even less for pupils with intellectual disabilities.

Some countries such as United Kingdom, Lithuania and Spain report that the majority of children with intellectual disabilities are included in mainstream primary schools but children with complex needs attend special schools. In Austria, implementation of inclusive educational policies varies: some Landers have virtually abandoned segregated schooling while others are only just beginning to explore integrated education. However, in the Netherlands, the majority of these pupils are still taught in special schools. In Belgium, most children with intellectual disabilities go to special primary schools. Moreover some children do not go to school but to a day care centre for children who do not attend school – most of these children are labelled as having complex and multiple disabilities.

Concerning Greece, the law provides for special educational support in the mainstream school, such as personalised support or integration classes, after an educational/interdisciplinary evaluation of children with disabilities. However, serious deficiencies in terms of funds and staff allocation impede implementation; therefore, children often do not enjoy suitable support. In fact, children with more severe intellectual disabilities or complex disabilities are enrolled in segregated special school units where the services stipulated, such as speech and occupational therapy, adjusted school curricula, books, personalised educational programs and well trained teachers are not provided. A main problem is the way funds are allocated despite the argument of the Ministry that funding is insufficient<sup>60</sup>.

The French Ministry of Education has made significant efforts to double the number of school places available for children with all types of disability. According to the French State Party report<sup>61</sup> on the progress of implementation of the Convention on Rights of the Child, 90 per cent of them attend school. Of these, in 2005, 67 per cent attended facilities run by the Ministry of Education (mainstream classes or special classes in mainstream schools) and 33 per cent were at specialist facilities or in hospital<sup>62</sup>. The figures for 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<sup>63</sup>.

In Romania, the Ministry of Education in its draft National Strategy on the education of persons with special educational needs present the following data<sup>64</sup>: from 53.446 students enrolled in special schools and 1076 in regular schools during the school year 1999-2000 to 27.445 in special schools and 20.728 in regular schools in the school year 2006-2007. However the decrease for students with intellectual disabilities



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<sup>59</sup> Inclusion Europe, Inclusive Education Status Report for Europe, Brussels, 2009, page 8.

<sup>60</sup> Country Report, Greece, pages 6,7.

<sup>61</sup> *Troisième et quatrième rapports périodiques de la France au Comité des Droits de l'Enfant*, 11 September 2007 <http://www.unicef.fr/userfiles/3%20et%204%20emes%20rapports%20periodiques%20de%20la%20France.pdf>

<sup>62</sup> Ibidem.

<sup>63</sup> Country Report, France, page 7.

<sup>64</sup> Country Report, Romania, pages 9 and 10.

is less marked: 24.606 students with intellectual disabilities in special schools in 2003-2004 to 21.575 in regular schools in the school year 2006-2007.

In Hungary, in the school year 2004/2005, 56.2 per cent of the students with physical disabilities attended integrated schools while only 13.3 per cent of children with learning difficulties and a mere 4.5 per cent of students with intellectual disabilities attended integrated schools<sup>65</sup>. The integration efforts have had a positive effect on children with disabilities but children with intellectual disabilities are still at a disadvantage<sup>66</sup>.

The number of children with intellectual disabilities in special schools in Lithuania decreases every year (since 1990 – the number has dropped by 43 per cent). In the school year 2008-2009, children with intellectual disabilities accounted for more than 10 per cent of all Lithuanian schoolchildren. About 90 per cent of them are attending mainstream schools together with their peers, 1 per cent attend special classes and 9 per cent attend special schools<sup>67</sup>. However, the national expert made the comments that in reality, education in the mainstream is accessible only for children with mild intellectual disabilities, whereas children with more severe disabilities are educated in special educational centres<sup>68</sup>.

The Bulgarian national expert reported that there is big discrimination against children with intellectual disabilities placed in institutional care when over 3000 children are not educated at all, as they are excluded from the educational system<sup>69</sup>. MDAC and the Bulgarian Helsinki Committee brought a case to the European Committee on Social Rights challenging the complete lack of education of children in “Homes for Mentally Disabled Children”. The Committee found that Bulgaria had violated its obligations under Article 17 of the *Revised European Social Charter* to provide an education to all children, and found a violation of the right to non-discrimination (Article E)<sup>70</sup>.

Data and information collected by this research does not provide a homogeneous picture of the situation in Europe. Most experts report **achievements in inclusive education for some individual pupils rather than systemic changes**. It appears that many countries have made some attempts to make their mainstream education systems more inclusive. The result is however that only a minority of children with intellectual disabilities are included in regular education with the support they need.

If some achievements have been possible at primary school level, **access to vocational training remains particularly poor. The lack of opportunities for children with intellectual disabilities is obvious**. In Cyprus, lack of choices and experiences of professions which may match the interests of young people with disabilities is reported. Similarly in France, vocational training for young people with intellectual disabilities is largely inadequate



in quality, quantity and variety. In Finland, conventional vocational institutions only rarely implement the principle of inclusion. The vocational education of young people with intellectual disabilities is mainly provided by vocational special needs colleges. The places offered are too few to meet demands. Across the regions in Finland there is an uneven distribution of establishments offering vocational education that also cater for young intellectually disabled people.

### C. Support to families in inclusive education

Almost all Country Reports suggest that parents have to some extent the right to choose mainstream or special education as they want for their children. However, parents interviewed often **described implementation of the “right to choose” as a long and difficult battle**. Families rarely receive enough information on available support, when they choose to enrol their child in mainstream schools.

In Ireland, a key part of the Education for Persons with Special Educational Needs Act 2004 that has been implemented is the establishment of the National Council for Special Education, which aims to plan and co-ordinate education provision to children with disabilities<sup>71</sup>. Special Education Needs Organisers (SENOs) are employed by the NCSE as the liaison point for parents in their area. While SENOs are the local information point for parents, there is an obvious conflict given that the information point on possible education supports is also the individual who decides what supports are to be allocated to an individual child. There are serious concerns raised by parents on the ability of SENOs to provide impartial information given their role in allocating resources. The lack of an independent appeals process is also a major cause for concern<sup>72</sup>.

Similarly in Slovakia and in the Czech Republic parents have the right to choose between mainstream schools, special classes in mainstream schools and special schools in cooperation with

<sup>65</sup> Country Report, Hungary, page 9.

<sup>66</sup> Ibidem.

<sup>67</sup> Lithuanian National Programme of the Integration of the Disabled into the Society 2010-2012 // Official Gazette *Valstybės žinios*, 2002, Nr. 57-2335

<sup>68</sup> Country Report, Lithuania, page 12.

<sup>69</sup> Country Report, Bulgaria, page 7.

<sup>70</sup> European Committee of Social Rights, Mental Disability Advocacy Centre (MDAC) v. Bulgaria, Complaint No. 41/2007, 3 June 2008 available at: [http://www.coe.int/t/dghl/monitoring/socialcharter/complaints/CC41Merits\\_en.pdf](http://www.coe.int/t/dghl/monitoring/socialcharter/complaints/CC41Merits_en.pdf).

<sup>71</sup> Country Report, Ireland, page 6.

<sup>72</sup> Ibidem.



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inclusion possible, and often without resources or support from the education system.

All Country Reports mention that most of the time **pupils in mainstream schools are being taught by support staff rather than by qualified teachers**. The main reasons evoked for this reality is the **lack of training of regular teachers** who “suddenly” have to deal with a large number of students and find it difficult to give individual support when needed and the **lack of financial capacity to include other types of professions in schools** (Portugal). In Lithuania, there is a shortage of specialists in mainstream schools (special pedagogues), trained in disability-related issues, in particular in rural areas. In France, although 86 per cent of primary teachers say that they are prepared to have children with intellectual disabilities, they are held back by the lack of information and training (87 per cent of general teachers and 27 per cent of specialist teachers have not received training on intellectual disabilities)<sup>74</sup>.

In Ireland, the role of Special Needs Assistants (SNA) has caused problems because of the lack of an education role in the official job description. While assisting in the child’s educational development is not technically part of the SNAs role, the role has developed in such a way that parents now see that as being a core part of the job, and when individual SNAs take on that role, parents say it greatly benefits the child’s development. Many parents say their child could not continue in mainstream education without the support of an SNA.

In France, it often happens that children are refused a place at a school if there are no special needs assistants. In January 2010, according to UNAPEI<sup>75</sup>, 4,213 children were waiting for special needs assistants in order to be enrolled at school. At the same time however, special needs assistants do not have adequate training and their contracts are precarious, leading to very high turnover. The specialist services which work in parallel with schools are not able to support education in mainstream schools to a satisfactory degree.

Finally, it is reported from Italy, where special schools were abolished in 1977 that pupils with disabilities are often isolated from the class-group to which they belong and taken to areas reserved for individual activities, thus “re-creating special classes”<sup>76</sup>.

The Italian legislation provides that the Functional Diagnosis, the Dynamic Functional Profile and the Personalised Educational Plan are prepared jointly and with the full involvement of the teaching staff, the local social services, the local Health authorities and the family. However from the NGO monitoring of requests and reports from families, in practice families are merely asked to sign documents already prepared

Special Education Centres, which deliver a pedagogical diagnosis and recommendation that is required when enrolling a pupil at school. However, the decision to accept or not accept a child with an intellectual disability remains in the hands of the school principal, who assesses the “*conditions and capacities of the school*” and decides accordingly. In case of refusal of a child, parents must be informed about the reasons. However the parents have almost no legal means to appeal the decision. The Slovakian report adds that special education centres work closely with special schools. Therefore it is also a matter of concern as there is no independent appeals process if parents do not agree with their recommendation.

Finally, in Greece<sup>73</sup>, children with severe intellectual disabilities who are enrolled in special school units have hardly any chance of becoming integrated in the mainstream. Parents interviewed consider the special school units not as an educational or vocational institution but as “child-sitting”. Therefore many children receive educational support with private lessons paid by the parents.

Limited access to education in rural areas was mentioned in several countries. In Latvia, families in rural areas have to cover large distances to take their children to the educational institution and this often deters poor parents from providing appropriate education for their child. Often these children are forced to live away from their families to acquire an education. In addition, many children have been registered for home schooling – children with severe disabilities and/or in rural areas. These children do not receive appropriate schooling or get no schooling at all!

## D. Resources to support quality education

Where there is success it is usually “ad hoc”, often achieved only by the dedication of a teacher or head teacher to make

<sup>73</sup> The Greek legislation contains provisions which exclude children with severe intellectual or complex disabilities from mainstream schools and promote their segregation in special education school units, social care facilities or agencies for vocational training, which are subsidised by the Ministry of Health and not part of the Educational system. Country Report, Greece, page 8.

<sup>74</sup> *Mise en place d'un Observatoire des perceptions et des besoins des enseignants vis-à-vis du handicap mental en école élémentaire*, Enquête UNAPEI / IPSOS, 2008.

<sup>75</sup> UNAPEI is a French umbrella organisation representing organisations which support people with intellectual disabilities and their families.

<sup>76</sup> The practices mentioned in this paragraph are described thanks to the monitoring work carried out through the Servizio Accoglienza e Informazione (SAI) [Reception and Information Service] and the Sportello Nazionale sull'Inclusione Scolastica Anffas Onlus [Anffas Onlus National Office for Educational Inclusion] [www.anffas.net](http://www.anffas.net), as well as the Osservatorio Nazionale per l'Integrazione Scolastica FISH Onlus [www.fishonlus.it](http://www.fishonlus.it) [National Observatory for Educational Integration] who constantly receive reports and requests for intervention from families, educational workers, associations and their own experts on these matters throughout Italy.

by the school and are not informed of what has been planned. Sometimes, especially for pupils with complex needs or multiple disabilities, no plan has been prepared.

**The most recurrent argument reported by the national experts is that the resources available are allocated predominantly to segregated schooling rather than to support inclusion in the mainstream.** It is the case for example in Bulgaria where the budget per child educated in special school can be up to three times higher than in mainstream schools<sup>77</sup>.

In the Netherlands, parents may choose to send their child to a mainstream school with a personal budget to purchase extra care. Parents however often choose to send their child to special schools, because they are better resourced and there is more support available as the special schools receive more funding than mainstream schools. A mother made the following comments in a roundtable: *“We and a number of other parents are using our personal budgets to pay for a classroom assistant to teach our daughter and a number of other children individually or as a small group. It is going quite well but if the teachers were to take our classroom assistant more seriously it could be much more effective. We have not been happy with the use of the personal budget money for years. Too much money goes to incidental expenses such as travel costs, meetings and other indirect expenses. We think it is very inefficient”*.

In Austria a survey was conducted as part of the research project, *“Quality in special education”*<sup>78</sup>, revealed quality issues in relation to instruction in mainstream secondary schools. In the view of those surveyed, there is a lack of competence in the schools themselves. In addition, they also identified **poor general conditions, questionable resource management** (only partial use of the allocated resources for integration) and **unfavourable conditions in classes in general secondary schools** (with integration classes being used as a repository for all poorly performing pupils in a school).

In Spain, the process towards inclusive education for students with intellectual disabilities is facing **difficulties and setbacks, in particular in the area of secondary education**<sup>79</sup>. The Spanish report concludes that the difficulties and challenges that are observed in ordinary schools are not based on attitudes but on a **lack of resources and “support” of a very different kind** such as continual training and psychopedagogical advice for teachers, education assistants or personal helpers to enable children to live a more autonomous life, better coordination between professionals and between educational and social services, etc.

Finally recent political decisions made as a response to the **financial crisis influenced efforts towards inclusive education**. Evidence can be seen for example in Ireland or Latvia. The Irish

*Education for Persons with Special Educational Needs Act 2004 (EPSEN)* proposes that education of children with disabilities shall take place in an inclusive environment and that people with disabilities shall have the same right to education as their peers. However, full implementation of EPSEN was deferred indefinitely in October 2008 for financial reasons<sup>80</sup>. Key provisions have not been implemented from the Act, most notably Individual Education Plans. In Latvia, while data and comments provided by the Ministries in the State Report from 2005 show an increase in the number of pupils with special needs attending mainstream schools<sup>81</sup>, the crisis has undermined this recent improvement. In the years 2008-2009, there was a rapid fall in the number of schools, pupils and teachers<sup>82</sup>.

## E. Educational paths of children with intellectual disabilities

The alarming issue of incoherent development in education for children with special educational needs was mentioned in several Country Reports. Such incoherence results in **disrupted educational paths of children with intellectual disabilities**. Insufficient support and lack of resources can bring these children back and forth between the mainstream and segregated schools. Similarly, restricted access to mainstream education at secondary level and the absence of support in the transition period are main factors contributing to disrupted educational paths of children with intellectual disabilities compared to other learners.

For example in Austria, the discontinuity of path at schools is illustrated as follows: *“ultimately parents have the right to choose whether the child is educated in a mainstream or in a special school. However, integrated learning is offered in primary schools, general secondary schools and, less often, in academic secondary schools but up to year 8 only. There is no legal provision for continuing the mainstream integration of children with intellectual disabilities in upper secondary schools (after grade 9). Consequently, children with intellectual disabilities must be transferred to special school in order to continue their schooling. There are denied access to upper secondary schooling”*<sup>83</sup>.

Similarly in Lithuania, case studies from families show that often children with intellectual disabilities have been enrolled into mainstream education. However parents were forced to take the child to a special school because of the lack of tolerance shown by non-disabled people, mainly parents of children without disabilities or the inability of teachers to respond to children's needs.

Transition from primary to secondary school is also problematic. In France, 55 per cent of children with intellectual disabilities leave the school system between primary and secondary school (compared with 17 per cent of non-disabled

<sup>77</sup> When individual learning programme is applied, the budget per child is BGN2.475 (€1.230) whereas for a child placed in a special school it varies between BGN 3.353 (€1.670) and BGN 6.116 (€3.050).

<sup>78</sup> Specht, W., Pirchenegger L. G., Seel A. et al. (2006): *Qualität in der Sonderpädagogik. Ein Forschungs- und Entwicklungsprojekt. Forschungsansatz, Ergebnisse, Schlussfolgerungen. Graz. Bifie-Report.*

<sup>79</sup> Red Book of Education by the NGO *Independent Life Forum* <http://www.forovidaaindependiente.org/node/225>.

<sup>80</sup> Country Report, Ireland, page 6.

<sup>81</sup> See the State report on the implementation of the UN CRC of Latvia from 2005: <http://www.lm.gov.lv/text/1318>.

<sup>82</sup> Interviews of Latvian governmental institutions: Ministry of Welfare, Ministry of Health, Educational Content Centre, Central Statistical Bureau.

<sup>83</sup> Country Report, Austria, page 9.

children)<sup>84</sup>. In Cyprus the weakness of the system is actually the lack of coordination and of joint action between primary and secondary education. Also in Ireland, there is no automatic system of transfer of resources from primary to secondary school. Case studies show that there is a major gap when the child leaves primary education and it can be very difficult for children transferring over.

In Greece parents did not have the choice between a general and a special public school. Some children attended the general primary school, after the strenuous efforts of the parents; despite that, the children were then directed to a special secondary school due to the lack of legally mandated personalised support and integration classes in the general secondary school<sup>85</sup>.

As reported by the UK expert, *“Transition is a key issue for parents of children with intellectual disabilities particularly the post-school transition. **The schools are not planning well before the young person is due to leave.** This results in young people not being able to access employment, training or further education that could allow them to take their place as members of the community”*<sup>86</sup>.

While there is a real commitment to advancing towards inclusion in Spain, at the same time significant frustration and growing disillusionment among families of children with intellectual disabilities are reported<sup>87</sup>: *“One of the barriers is the existence of a double network of “ordinary” and “special” schools linked to one another like communicating vessels. The slower the improvement and innovation processes are to help accommodate students with intellectual disabilities, amongst others, in ordinary schools, the less satisfactory the education for families and the students themselves in these schools and the lower the quality of their social relations. In this context, special education schools satisfy these needs in the short term, and alleviate the pressure on ordinary schools. For this same reason, ordinary schools appear in less of a hurry to undertake improvements which would help students with intellectual disabilities to be included. As such, **the school life of many children with intellectual disabilities today is characterised by continual ruptures in their school career caused by changing schools and the associated negative impact this has on their social and personal development”**. ★*

#### **Case study Bulgaria: S. experience from mainstream school** (Group discussion with children from a day-care centre)

Being asked whether he wants to go to school S. – a teenager with multiple disabilities and speech problems – shakes his head affirmatively. His father explains that they take him every day to the mainstream school in the neighbourhood but it is more for social purposes than for learning, and in addition his mother has to be with him all the time since no support or assistance is provided there. That is why S. recently spends more time in the resource centre.

#### **Case Study Poland: The story of N. in the words of A. – a parent**

“My wife chose an inclusive kindergarten. We managed to enroll, but it soon turned out that in terms of development N. (the daughter) was far behind her peers, she was always last in everything, just sitting and watching other kids do something she could not; when everyone is sitting down, she is just standing up. It was a sad experience for her. After that we transferred our daughter to a special pre-school that she attended for quite a while, until my wife ran into a friend who told her that we were in fact harming our child by placing her in special needs education, that she would regress developmentally, etc. So then we found another inclusive kindergarten, on the opposite side of the city. We lived in the Bielany district then, pre-school was in Okęcie. It was completely absurd, driving all the way across town every day. N. could only bear to stay there for 2 months. When she came home after special pre-school she was always smiling, happy, vigorous, everyone loved her there. After inclusive kindergarten, she was apathetic, she kept saying that other children call her “foot, foot”, because N. has no fingers on one hand. Her palm looks like a “paw”. And children called it a “foot”. So she always came back home exhausted, she wouldn’t do anything, didn’t like going there. After two months we started looking for another pre-school. We found one using the Montessori method. And N. attended it for 4 years”.

#### **Case study Finland: Father’s voice**

M. is a seven year old intellectually disabled child who visits a day-centre, where he attends pre-school classes. He speaks, but in his own language, which no one understands. M. also communicates using gestures and pictures. He can dress himself. He cannot as yet express his need to go to the toilet, nor is he inclined to. M. observes his surroundings closely, and especially the other pupils. His father believes, and a statement by a psychologist who knows M. agrees, that learning through models should be a key factor in approaches to his education.

Father applied for a place at the local school for his son. But M. could not start school with children of his own age “due to a lack of space”. Instead he had to continue his pre-school education at the daycentre in the school year 2009-2010. His parents did not even receive a decision in writing concerning the matter.

In the spring and summer of 2010 his father tried all he could to influence M.’s schooling arrangements. He wrote long entreaties to the local educational authorities and experts in the intellectual disability field trying to persuade them of the benefits of inclusive education. A legal advisor for the family care organisation provided support in the form of documentation. His father felt that if his son’s schooling were

<sup>84</sup> *Troisième et quatrième rapports périodiques de la France au Comité des Droits de l’Enfant*, 11 September 2007 <http://www.unicef.fr/userfiles/3%20et%204%20emes%20rapports%20periodiques%20de%20la%20France.pdf>.

<sup>85</sup> Country Report, Greece, page 8.

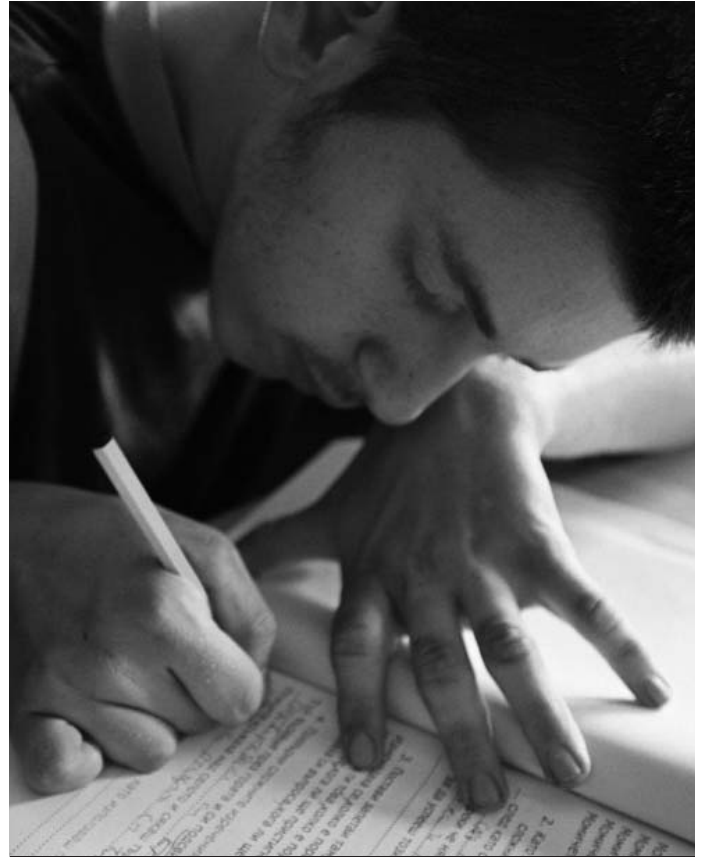
<sup>86</sup> ENABLE, Response to UNCRC Concluding Observations, 2009.

<sup>87</sup> Country Report, Spain, page 12.

provided in special classes for the most seriously disabled children, M. would not benefit from the conventional behavioural and communication models provided by his peers. The psychologist suggested that M. would not need to be placed in a class for the most seriously disabled pupils if suitable communication methods were used in the conventional classroom and if he had his own assistant.

The director of the local educational authority decided against the wishes of M.'s father, who appealed the case with the Regional State Administrative Agency in summer 2010. The Agency rejected the appeal, referring to the Basic Education Act. Section 17(1) and (2) of the Act states that a pupil is entitled to special needs education alongside other teaching and that, **as far as possible**, special needs education is to be organised in conjunction with other education. Because M. needed a lot of support and used pictures to communicate, the view was that his education could not be provided in a conventional classroom.

It would have been possible to appeal the decision of the Regional State Administrative Agency within 14 days. M.'s father tried to obtain another opinion from the psychologist on the benefits to his son of an inclusive education to support his case, but in the July holiday season it was in practice impossible to get an appointment with the psychologist and a statement from him in the allotted time.



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## VII. Healthcare

### Article 23 CRC

2. States Parties recognize **the right of the disabled child to special care** and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is **appropriate to the child's condition and to the circumstances of the parents or others caring for the child**.

### Article 24 CRC

1. States Parties recognize the right of the child to the enjoyment of **the highest attainable standard of health** and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that **no child is deprived of his or her right of access to such health care services**. (...)

Article 24 of the Convention on the Rights of the Child stresses that State Parties must recognize the right of the child to the enjoyment of the highest attainable standard of health and it must strive to ensure that no child is deprived of access to

health care services. Discrimination in the implementation of this article is prohibited. The Committee recalled in many Concluding Observations the need to unify and ensure access to health care with special attention to vulnerable children, including children with disabilities. In its General Comment n°9 on "The Rights of Children with Disabilities", the Committee notes that "children with disabilities are often left out [in relation to their right to health] because of several challenges, including discrimination, inaccessibility because of lack of information and/or financial resources, transportation, geographic distribution and physical access to health care facilities. (...) The importance of community-based assistance and rehabilitation strategies should be emphasized when providing health services to children with disabilities. State Parties must ensure that health professionals working with children with disabilities are trained to the highest standards possible and practice with a child-centred approach"<sup>88</sup>.

### A. Access to health care for children with intellectual disabilities

National legislation in the countries studied ensures that all children have full access to health care services without discrimination. The national experts report that children with intellectual disabilities have in principal the same access to health care as other children, benefit from preventive health

<sup>88</sup> Committee on the Rights of the Child, General Comment n°9, 2006, CRC/C/GC/9, paras 44-45 available at: <http://daccess-dds-ny.un.org/doc/UNDOC/GEN/G07/407/02/PDF/G0740702.pdf?OpenElement>.



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care policies (vaccines and compulsory visits to the doctors, check-ups), and have access to the same general health services covered by the public insurance systems. Children with intellectual disabilities are entitled to health benefits provided under the social security funded universal and free coverage. The UNICEF report on children with disabilities in transition countries also confirms that check-ups are widely and routinely available in the region<sup>89</sup>.

However, health care is also an area with high disparities among the EU countries. Countries, such as Austria or France provide significant health protection measures, including for children with intellectual disabilities. On the other hand, in Bulgaria, getting all children covered by the public health insurance system is an achievement in itself.

Although free universal health care systems exist in all countries, access to health care remains unequal. When universal health coverage is low, health care of children with intellectual disabilities is left to the financial commitment of the parents. Thus costs of health care for children with intellectual disabilities create a risk of poverty for their families. In addition, the national experts report about cases of discrimination on the ground of disability. In Lithuania, due to scarce funding non-disabled children are provided with better quality treatment, whereas the children with intellectual disabilities are most often inappropriately treated. In Romania, the father of a boy with Down's syndrome, with severe intellectual disability and heart congenital malformation, stated that *"during hospitalization, due to the high costs of medical treatment, doctors considered him a lost cause and he could not benefit from complete treatment"*. However, the national expert in Bulgaria reports that access to health care is restricted for all Bulgarians, therefore also for children with intellectual disabilities. This is due to the limited scope of health services paid by the National Health Insurance Fund.

In addition, cases of lack of will of the physicians or lack of competence in public health care to serve children with intellectual disabilities were also reported by families with

children with intellectual disabilities during interviews conducted as part of the study. Such shortcomings in medical care might cause delays in obtaining specific treatments. Thus parents are sometimes forced to use the services of private medical care. In addition, in smaller countries like Cyprus the practice is that children with intellectual disabilities may only be granted access to specialised health services in the private sector or outside Cyprus after a pre-approval by the Ministry of Health.

## B. Prenatal diagnosis

Full prenatal screening is secured in most countries. Only in Romania, parents reported that they did not have the possibility of a prenatal diagnosis.

In Finland, there is a routine uptake of ultrasound screening in particular. But it is not always clear to parents that this particularly focuses on the screening of abnormalities<sup>90</sup>. From 1993 to 2006 roughly half (49.5 per cent) of all Down's Syndrome pregnancies were terminated. The proportion of terminations on the basis of foetal damage compared to all pregnancy terminations has increased from one year to the next<sup>91</sup>.

In Lithuania, almost in all cases when an intellectual disability of a future child is determined, parents choose to terminate the pregnancy (about 90 percent). Ethics in such cases are often disregarded, and scientific achievements are at times misused.

The Spanish Country Report states that in Spain the health care system has achieved high quality, health professionals are however not keeping up-to-date scientifically with respect to the social perspectives on people with disabilities and those with intellectual disabilities in particular. This means that, faced with risky pregnancies or births of children with disabilities, many professionals only see and pass on the strictly medical aspects of the case (for example they analyse Down's Syndrome only as a chromosome disorder)<sup>92</sup>.

In the Greek report it is mentioned that the critical challenge concerning prenatal screening is that it should be secured in practice that health professionals will approach, inform and provide counselling support to the future parents in such a way that the latter can decide without bias<sup>93</sup>.

## C. Early diagnosis and intervention

After-birth and early intervention experienced by parents interviewed vary from one country to another. Nonetheless, parents remain often dissatisfied, if not by the lack of service or its quality, then by the length of time waiting to get access to the medical service itself.

In Italy, in Government reports, there is no mention of any action and/or commitment relating to the right to being taken into care early, continuing into the developmental age, which represents the basic principle of equal access to health care<sup>94</sup>.

<sup>89</sup> UNICEF, *Children and Disability in Transition in CEE/CIS and Baltic States*, Innocenti Insight, 2005, page 35.

<sup>90</sup> H.Pruuk's dissertation, 2007: Who is the patient? A socio-ethical examination of foetal screening practices in Finland.

<sup>91</sup> National Institute for Health and Welfare statistical report 27/2010; and Helsingin Sanomat 30.1.2011.

<sup>92</sup> Country Report, Spain, page 14.

<sup>93</sup> Country Report, Greece, page 11.

<sup>94</sup> "Children who are not treated early tend to have an overall worsening as regards their development" in clarifying Comments on the UCLA Early Intervention Project, August 1997.



In Greece, early diagnosis is often not secured, the child's prospects are described as bleak and this disheartens the parents, there may be no official diagnosis for many years, the child's future development remains an enigma and the parents spend exorbitant amounts of money on doctors in order to pinpoint the problem. To the extent that an after birth diagnosis of disability is possible a procedure should be provided to support the parents and inform them of the consequences of the diagnosis, of the fundamentals of caring for a child with disability and of possible healthcare options, and also, to activate the social agencies and to refer the parents to welfare or education agencies<sup>95</sup>.

In Hungary, in 2007, the number of children in need of early intervention can be estimated at 9.000 -10.000 of which the number of children who actually receive such services is approximately 5.000 – 6.000<sup>96</sup> – better early intervention programmes could prevent further problems.

In Ireland experiences of parents learning of a child's disability post birth often depends on the individual professional they come in contact with, rather than there being a concerted strategy, including counselling and support to parents.

The French reports presented to the CRC Committee in 2007<sup>97</sup> emphasise the importance of the Maternal and Child Health Protection Service (Protection Maternelle et Infantile) in managing the medical care and preventive healthcare measures for children up to the age of six. The PMI works in partnership with social services in situations involving children under the age of six and is also involved in antenatal checks. Parents complain of a lack of information about their child's specific issues and of a bleak picture being painted of the child's future opportunities. However, early intervention centres (Centres d'Action Médico-Social Précoce) provide early detection and diagnosis of developmental problems for children up to the age of six. Once a diagnosis is made, multi-disciplinary teams provide rehabilitative care and support to parents, at the Centre itself or at home. Parents appreciate having such a service. Nevertheless, waiting lists to obtain a consultation are a barrier to accessing early intervention services. Similarly in Cyprus, parents are complaining about long delays in the diagnosis / re-evaluation of the children and about inadequate availability of timely intervention.

In Lithuania, in implementing the National Health Programme for Children with Developmental Disabilities, a network of 40 agencies for early rehabilitation was developed in the country's towns and districts, with the aim of improving access to services for children from rural areas. The programmes cover the following priority areas: mother's and child's health care, social integration of the disabled, protection of the child's rights, mental health care. The services are integrated into primary health care, general health care and a network of community-based social infrastructure<sup>98</sup>.

One of the main concerns from parents' testimonies is the need for specialised and support staff to announce the after birth diagnoses: "had I known, I wouldn't have tried thinking it a lost cause" summarises a Greek mother<sup>99</sup>. One mother from the Czech Republic spoke of her experiences in the period after the birth of her daughter with Down's Syndrome in 2005. "I was six times more likely to have a child with intellectual disabilities... And I refused to have an amniocentesis, because I knew that it could harm the child. Even if I knew 100% that the child had Down's Syndrome, I definitely would not have killed it. After the birth, I knew myself that it was a child with Down's Syndrome. (...) They left me alone and they didn't tell me anything for a long period, not until the next morning. There was a visit, and a doctor stopped by and he asked me about things like how I liked my lunch and so on... Eventually, he asked me drily if I knew that my child had Down's Syndrome. I asked what we could expect. The doctor replied that he did not know much, but that the child would not go to a normal school and that it would not learn anything..." Several weeks after the birth, during visits to healthcare facilities, this mother got the feeling that they were expecting an expression of guilt from her for the birth of a disabled child. "They asked me why I didn't go for an amniocentesis. Every doctor asked me if I knew beforehand during the pregnancy and I was lying to the doctor so that he wouldn't write about me everywhere saying that the mother knew she was giving birth to a child with Down's Syndrome".

## D. Mental health

The national experts commented in particular on the lack of mental health services for children in many countries. In Spain and in Italy, the lack of specialized care in the mental health sector is one notable deficiency in the health care system. Therefore, mental health problems faced by children with intellectual disabilities tend to be considered as an integral part of their disability when it is not the case, and, as a result, they do not receive any treatment for them.



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<sup>95</sup> Country Report, Greece, page 12.

<sup>96</sup> Country Report, Hungary, page 17.

<sup>97</sup> See *Troisième et quatrième rapports périodiques de la France au Comité des Droits de l'Enfant*, 11 September 2007 <http://www.unicef.fr/userfiles/3%20et%204%20emes%20rapports%20periodiques%20de%20la%20France.pdf>.

<sup>98</sup> Country Report, Lithuania, page 8.

<sup>99</sup> Country Report, Greece, page 12.



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Moreover, in Latvia children with intellectual disabilities (with behavioural disorders) are frequently placed in psychiatric clinics although they require totally different treatment (psychologist, psychotherapist...) At boarding schools, orphanages or social care houses children who continue to misbehave may be threatened with such a placement and this can be used to intimidate other children as well.

## E. Dental care

One of the recurrent problems in the area of health is dental care as children with intellectual disabilities do not cooperate easily during dental treatment (e.g.: Hungary, Greece, Austria, Ireland, Bulgaria). Dental services are regarded as a particular problem, since orthodontists consent to treat children with intellectual disabilities only with full anaesthesia.

*"My child has cerebral palsy. You can't imagine how difficult it was to find a dentist for him. No one wants to treat him – they say it is demanding..." (S.'s father from Bulgaria)*

Providing dental care for persons with intellectual disabilities poses the greatest challenge of all. In a petition, under investigation, submitted to the Parliamentary Commissioner for Civil Rights, the Hungarian Association for Persons with Intellectual Disabilities (ÉFOÉSZ) summed up actual cases concerning dental care as follows: *"Discrimination is also based on the fact that healthy people can obtain the same quality health care service free of charge or even if a fee is charged for the care, they can access it at a substantially lower price since there are no special needs that the person who is provided the care must pay for. In the absence of special conditions set out in the financing contract between the state and health care providers, the associated costs must be paid for by the families in every single dental intervention". "In the case of dental treatment, care is frequently provided under anaesthetic, which is simpler for doctors, even if this would not be needed in numerous cases and*

*anaesthetic involves major risks. Furthermore, tooth conservation treatments for persons with intellectual disabilities are rare"*<sup>100</sup>.

## F. Addressing the specific health needs of children with intellectual disabilities

Training for doctors in working with children with intellectual disabilities is often described by families as inadequate. The result is that medical conditions in children with intellectual disabilities are often overlooked or attributed as symptoms of the child's disability and as such remain untreated. The lack of awareness of medical professionals in disability and in interaction and communication with children or young people with disabilities and their parents is often detrimental to access to treatment for children with intellectual disabilities.

The child is not at the centre of the process, in many countries, the assessment process focuses on clinical need rather than inclusive social supports (Ireland). Parents are dependent on mutual self-help initiatives while looking for information. Information on medical care is passed on rather informally between parents or at parent meetings arranged by their organisations. In France and in the Czech Republic, parents talked in the roundtables about having to "make do" and sharing "tips" on finding professionals who are prepared to accept their child and who have a satisfactory approach. Parents made the following comparison in regard to the sharing of information: *"There is a white book of doctors and a black book of doctors"*. Parents concur in stating that the provision of support in the health service for parents of children with intellectual disabilities is practically non-existent. This absence of support is made even more difficult by the fact that doctors show minimal or zero empathy towards parents. When looking for a physiotherapist in France, Françoise had to try seven different practices before she found one willing to take her daughter. Health professionals are sometimes described as being reluctant to provide treatment or may even refuse altogether.

Parents also reported in several countries, such as in Greece, Czech Republic, UK, France and Finland, the lack of available care. There may be shortages of professionals specialised in special care for children with intellectual disabilities, including speech therapists, paediatricians and other professionals specialising in work with children. There is a particular lack of available care for people with complex needs. There is a need for comprehensive medical care for people with complex health problems and needs<sup>101</sup>. The mother of two children with complex needs stated the following: *"Neither doctors nor teachers are able to help us when there are children with complex needs. There are experts on autism, experts on blindness, mental retardation, but what about experts who are able to combine all these disabilities together and create some methodology? That is the problem!"*

A clear message of dissatisfaction, incomprehension and a growing sense of frustration also emerged when parents reported the administrative burden around health care (Poland, Portugal, Spain, Greece, Romania, Czech Republic, the Netherlands). First of all, there are the systemic obstacles to

<sup>100</sup> Country Report, Hungary, page 15.

<sup>101</sup> Country Report, Greece, page 12: refusal of the hospital to perform heart surgery on a 14 year old with intellectual disability due to behavioural problems.

using the health care systems: they reported long waiting lists of several months for a visit to a specialist or in arranging surgery. Therefore, they may choose to pay for private consultation when quick replies or actions are needed. And they also mentioned the lack of financial subsidises for certain medication/treatment (eye health in Portugal for example). The parents are also hugely inconvenienced by the frequent procedures they have to follow with insurance funds to actually get healthcare: *“I have to book an appointment, 20 days in advance, for prescription-writing every month at a hospital, ask for leave of absence from work, stand in line, take a second day to submit the paperwork to the insurance fund to get approval for the medication prescribed, a third day for the refund procedure, a fourth day for a medical appointment every month”*<sup>102</sup> (interviewed parent from Greece). Parents also expressed reservations about the routine of medical check-ups: *“The health service gives you a diagnosis – the child has an incurable lifelong condition. But every two years you still have to prove to social services that the child has not got better and that no miracle has occurred... even though the word incurable is written there”*. Another parent put it this way: *“We have to constantly repeat medical examinations every six months. We go for a psychiatric examination every year. We go for eye check-ups and torment our children. But then they always say ‘incurable’ ”*. The administrative burden imposed by the health care system has a negative and de-motivating impact on parents and creates a lot of frustrations. While they are supporting their child on a daily basis so that it can develop further and improve its skills, the medical professionals who sees the child once in a while merely repeats the same conclusions.

Another challenge is the insufficient collaboration of different medical services around a child with intellectual disabilities. This causes on occasion, in Spain for example, both the unnecessary duplication of rehabilitative care (for example speech therapy) and the failure to access such care, even though it is available, due to a lack of awareness about it. Generally, it is the families, in particular the mothers, who are seen to act as coordinators for the multiple interventions that their children with intellectual disabilities may need<sup>103</sup>. ★

#### Case study Poland: Mother’s experience from hospital

*“After childbirth parents are flooded with information about what should be done, but I wasn’t able to wrap my head around it. I just sat there, listened to people talking and cried. Couldn’t take it in. I was told I had to do such and such tests, but no one told me where to do them, who could help me, where to go... It was from our friends, not doctors at the hospital that we found out about the early intervention center providing early rehabilitation. (...)*

*We had to learn ourselves how to report disability to the ZUS (Social Security Office), doctors couldn’t help us with it.*

*We got most help from an Internet forum for parents of children with Down’s syndrome. It was a treasure-trove of information. The portal is developing on its own, without support from the State or NGOs. (...)*

After that, my J. had heart surgery. The hospital was incredibly hypocritical. Parents were not allowed to sleep in the same room with children. J. was breast-fed back then, she was only 6 months old and I couldn’t really leave her alone. Of course I did sleep with her at night, like all other parents did, but it was all completely improvised. After the head nurse left for home in the evening, we could unroll our sleeping pads and sleeping bags on the floor next to the children’s beds. We had to tidy it all up before the head nurse came for work next morning. As a result, hospital staff could relax, because - other than injections - I was the one doing everything with the baby, I was taking care of her. So it was odd I couldn’t stay there officially, not to mention with more dignified sleeping arrangements”.

#### Case study United-Kingdom: parents’ report from hospital

*“When my nine-year-old daughter D. died, a doctor at the hospital said to me: “It’s almost like losing a child”. What did he think my beautiful daughter was?’ She was the most delightful happy little nine year old. D. tried so hard with this world, she just wanted to please people and to make them smile. But when D. needed help, she was let down. One day, D. went into hospital with a tooth infection. Three weeks later she was dead. During the three weeks D. spent in hospital no proactive plan was put into place to save her life. We spent three weeks in and out of hospital. During these three weeks D. was never treated as though she was seriously ill, and certainly not like her life was in danger. It was horrific. They told us not to worry.’ After D. died, we discovered that staff were fully aware that D.’s life was in danger. They did not try to save her, they just documented her decline. This was not an accident, and it wasn’t the case that they did not realise how ill she was. They told us they had “misjudged her quality of life”.*”



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<sup>102</sup> Country Report, Greece, page 13.

<sup>103</sup> Country Report, Spain, page 14.

# VIII. Promoting Rights, Encouraging Participation and Combatting Discrimination

## Article 2 CRC

1. States Parties shall respect and ensure the rights set forth in the present Convention to each child within their jurisdiction without discrimination of any kind, irrespective of the child's or his or her parent's or legal guardian's race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status.

## Article 12 CRC

1. States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.

2. For this purpose, the child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child, either directly, or through a representative or an appropriate body, in a manner consistent with the procedural rules of national law.

provide for effective remedies in case of violations of the rights of children with disabilities, and ensure that those **remedies are easily accessible to children with disabilities and their parents** and/or others caring for the child and c) to conduct **awareness-raising and educational campaigns targeting the public at large and specific groups of professionals** with a view to preventing and eliminating de facto discrimination against children with disabilities<sup>105</sup>.

Article 12 of the CRC requires State Parties to assure 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: **for the child to be provided the opportunity implies an active obligation on the State Parties to offer the child the opportunity to be heard**<sup>106</sup>. Yet too often there is a reluctance to recognize the competence of children with intellectual disabilities to contribute to decision-making processes. Changing such views so as to encourage child participation in discussion and decision-making concerning their lives is critical and challenging<sup>107</sup>.

Article 2 and Article 12 of the Convention on the Rights of the Child 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. The Committee on the Rights of the Child, even before the adoption of the UN CRDP<sup>104</sup>, emphasised 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. Therefore, the **strategy for promoting their rights is to take the necessary actions to remove these barriers**. The Committee proposes the following measures be taken to prevent and eliminate all forms of discrimination against children with disabilities: a) to include **explicitly disability as a forbidden ground for discrimination** in constitutional provisions on non-discrimination and/or include specific prohibition of discrimination on the ground of disability in specific anti-discrimination laws or legal provisions b) to

## A. Tackling discrimination

General provisions for non-discrimination are usually included in constitutional provisions or anti-discrimination laws<sup>108</sup> in the countries reported but there are not often followed by equality approaches/measures. It mainly stays at the level of a declaration of principles. A number of countries have written constitutions which contain an anti-discrimination rule or an equal treatment provision that explicitly covers persons with disabilities (Germany, Austria, Portugal, Finland, Slovenia)<sup>109</sup>. Most countries have written constitutions which contain more general anti-discrimination rules or equal treatment provisions that cover persons with disabilities by implication. Disability as grounds for discrimination is not explicitly provided for in the Constitution of Belgium, Estonia, France, Greece, Hungary, The Netherlands, Poland or Czech Republic. According to decisions of the respective national courts, discrimination based on disability is also covered by these provisions<sup>110</sup>. Within the framework of EU legislation on non-discrimination<sup>111</sup>, the provisions on non-discrimination on the ground of disability

<sup>104</sup> See CRPD- Art.1 *Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.*

<sup>105</sup> Committee on the Rights of the Child, General Comment n°9, 2006, CRC/C/GC/9, para.9, available at: <http://daccess-dds-ny.un.org/doc/UNDOC/GEN/G07/407/02/PDF/G0740702.pdf?OpenElement>.

<sup>106</sup> UNICEF, *Implementation Handbook for the Convention on the Rights of the Child*, 3<sup>rd</sup> revised edition, 2007, pages 155-156.

<sup>107</sup> UNICEF, *Promoting the rights of children with disabilities*, Innocenti Digest n°13, 2007, page 21.

<sup>108</sup> For an overview of Anti-discrimination legislation and the grounds covered by the related legislation, the reader can go to the thematic publication of the European Network of Legal Experts in the non-discrimination field *Developing anti-discrimination law in Europe: The 27 Member States compared (2009)* available at: [http://ec.europa.eu/justice/discrimination/document/index\\_en.htm#h2-7](http://ec.europa.eu/justice/discrimination/document/index_en.htm#h2-7).

<sup>109</sup> Council of Europe, Prof. Dr. Heinz-Dietrich Steinmeyer, *Legislation to counter discrimination against persons with disabilities*, 2<sup>nd</sup> edition, 2003, Council of Europe Publishing, pages 32-33.

<sup>110</sup> Ibidem, page 34.

<sup>111</sup> EU Directive 2000/78 and Directive 2000/43.

concern only the areas of vocational training, employment and work, yet not education/social protection/insurance/benefits/healthcare treatment. Therefore, in the EU countries where the anti-discrimination acts reproduce more or less the Directives (like Greece<sup>112</sup> and Italy for example or Poland as far as employment is concerned), it is not particularly useful to children, especially, with intellectual disabilities. However, it was shown in several comparative reports<sup>113</sup> that the majority of Member States has gone beyond the requirements of EU anti-discrimination law and have incorporated all the grounds of discrimination of both Directives in their national legislation, thus including more areas in which discrimination on the ground of disability is covered<sup>114</sup>.

As highlighted by the Polish, French and Greek reports: the State reports to the CRC Committee fail to identify strategy and policies for non discrimination against children with intellectual disabilities. Other than references to several declarations (Constitution, laws, policies) there is no mention of any programme aimed at the reduction of discrimination against children with (intellectual) disabilities. However, the Greek State report mentions for example some actions to combat discrimination such as non stereotypical depiction of disabled people in teaching materials<sup>115</sup>.

Although there are relatively few figures available about discrimination against children with intellectual disabilities, case studies collected in this research and in many others, show that discrimination is still a common occurrence. The 2007 UK report to the UN CRC cites for example research that found 55 per cent of children with special education needs felt that they had experienced unfair treatment based on their disability<sup>116</sup>. According to the information given in the Country Report of France<sup>117</sup> almost two fifths of children with intellectual disabilities suffer discrimination at school. Eighty-nine per cent of young people with intellectual disabilities say they have suffered insults and teasing, 44 per cent have been marginalised, 29 per cent have been treated unfairly and five per cent have been refused the enjoyment of a right<sup>118</sup>.

Discrimination not only affects children with intellectual disabilities, but all the families interviewed also feel they suffer discrimination. National experts reported about countless everyday "discrimination". One of the concrete examples given by families from Portugal, for example, was how much the phenotype (associated with Down's Syndrome or visible intellectual disability) immediately conditions how the general population reacts, by preventing children with intellectual disabilities from full participation: for example, when a child sits in a restaurant the waiter will ask the parents what the child wants to eat, ignoring him or her.



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Discrimination often takes place in the community, especially at school, through the behaviour of other parents and children. Opportunities for informal learning through the interaction of children with intellectual disabilities with their peers are frequently denied. These contacts allow them to explore, develop, learn and form opinions in the same way as other children. Unfortunately, policies and programmes addressing the specific requirements of young people with disabilities are rare and usually limited in scope<sup>119</sup>. Children with disabilities lack many of the opportunities open to other children in areas such as learning, recreation, participation in sports clubs and societies. This may be the result of prejudice, inaccessible information or venues or because these children are simply overlooked<sup>120</sup>.

One of the areas where the families and children interviewed feel discriminated against is actually education, as well as sports and leisure activities. It is not rare to find instances of pupils with disabilities who have not been able to take part in educational trips, visits or other cultural activities organized by their schools because of the inaccessibility of the place/means of transport or the shortage of staff, despite the fact that these are integral part of their education. A mother with two disabled children describes her experience in the Czech Republic as follows: *"The school went on a nature trip. All the children went apart from children with combined disabilities or a severe disability, because the teachers didn't dare risk it. Twice it's happened to me that I had two children in the same school, but only one went and the other stayed behind. That hasn't just happened to me, but to several parents who had two children in one school. I know it's not the teacher's obligation, but then it happens even when there are not many children in the class... I interpreted that as discrimination. My daughter lives for school and it was very hard for her to bear"*.

<sup>112</sup> Country Report, Greece, page 13.

<sup>113</sup> See publications of the European networks active in the field of anti-discrimination available at: [http://ec.europa.eu/justice/discrimination/experts/index\\_en.htm](http://ec.europa.eu/justice/discrimination/experts/index_en.htm).

<sup>114</sup> European Network of Legal Experts in the non-discrimination field *Developing anti-discrimination law in Europe: The 27 Member States compared (2009)* available at: [http://ec.europa.eu/justice/discrimination/document/index\\_en.htm#h2-7](http://ec.europa.eu/justice/discrimination/document/index_en.htm#h2-7).

<sup>115</sup> Country Report, Greece, page 13.

<sup>115</sup> Country Report, United-Kingdom, page 14.

<sup>115</sup> Country Report, France, page 15.

<sup>115</sup> Gérard BOUVIER and Xavier NIEL, *Les discriminations liées au handicap et à la santé*, Insee première n°1318, Insee, July 2010.

<sup>115</sup> UNICEF, Promoting the rights of children with disabilities, Innocenti Digest n°13, 2007, page 21.

<sup>115</sup> Ibidem.

Two interesting research studies conducted with children respectively from Latvia and Slovakia are worth mentioning, as they confirm and throw a light on the exclusion and participation of vulnerable children, including children with intellectual disabilities. During the research study<sup>121</sup> on children with special needs, undertaken by “Latvian Save the Children” within the framework of the Children’s Report to the UN (2006), a summary was made of the views of children, their comments and questions, providing the following data: children are of the opinion that they cannot gain any understanding and assistance: in the family - 20 per cent, at school - 37 per cent, from other children - 62 per cent, in the street - 90 per cent. In addition, 18 per cent of the children complain about being ridiculed and suffering physical harassment.

A survey entitled *Newly Emerging Needs of Children in Slovakia* carried out in August 2009<sup>122</sup>, found out that bullying, aggressive behavior and exclusion of those who are different from the majority (Roma children, socially disadvantaged or disabled children, children from failed families and children from orphanages) is a commonplace at schools or in the streets. There are far more cases of violence practiced upon such children as well as cases of child abuse (abuse by either of the parents, aggressive behavior of adults towards children, kidnapping of children). However, there are also positive phenomena: children and their parents can choose schools with innovative teaching methods, the opinions of children are, to some extent, supported and respected – child parliaments and student school boards are formed, the staff working at the ombudsman’s office has increased and more projects where children are responsible for decision-making are being implemented.

The discrimination experienced by children with intellectual or multiple disabilities can also affect other members of the family (*discrimination by association*). One mother from the Czech Republic has described the discriminatory situation experienced by many families with a disabled child: *“How do I understand discrimination? I can collect my son from a preschool at 2 pm or 3 pm, but my daughter finishes her secondary practical school at 12:30 pm. The school could offer some sort of after-school care or some other afternoon care which the school has for the other children”*. Another mother added the following comment: *“My daughter’s classes begin at 8 am and end at 12:30 pm. I also have to spend an hour making my way right across Brno. That’s why I can’t go to any job. I consider that to be discriminatory”*.

The Spanish and Italian reports also mention the new phenomena related to multiple discrimination. Immigration has brought with it the reality of new groups of vulnerable children whose likelihood of discrimination has doubled or tripled. Children with intellectual disabilities from migrant families are a challenge for NGOs of people with disabilities, which should carry out a revision of their approaches and action plans to take into account the needs of these children too.

### Case Study Cyprus: A family with children with autism

A family having many children lives in a village. Two of the children have autistic behaviour. The mother is of European origin and the father is Cypriot and they feel rejected by neighbours and other people in the village, possibly because of the mother’s nationality but also because of the children’s disability. N, 11 years old also has a speech impediment. The other children in the village mock and avoid him. On his birthday, he says with bitterness, none of the village children he had invited actually turned up.

### Voices from children from Greece

The male teenager: *“I didn’t like it last year that our teacher only took my friends to dance... I told her this made me very upset”*. The female teenager in an institution: *“I envy the children who stay at home... They have their own room... All the children here and I, we do the same things and that bores me. We have no freedom...”*.

## B. Promoting the rights and encouraging the Participation of children with intellectual disabilities

Provisions on the rights to participate for children with (intellectual) disabilities are poor or simply nonexistent. Huge barriers arise from preconceived ideas and prejudices in society and the community. Children with intellectual disabilities are seen as less credible and their words are not taken seriously. Preconceived ideas about this group of children are strongly rooted.

In countries where real efforts to enable children to participate have been made, these often overlook children with disabilities, especially children with intellectual disabilities. Only Ireland reported that the Office of the Ombudsman for Children has a Youth Advisory Council, which includes representatives of children with disabilities. In addition, the Comhairle na nÓg, youth councils, were established in 2002 as part of the National Children’s Strategy. Comhairle na nÓg developed best practice in participation, by providing new opportunities for seldom-heard young people to become involved in decision-making structures. They provide a forum for children and young people to discuss local and national issues of relevance to them. Young people with disabilities are members of the Comhairle. Greece also has this year a child with disability in the team of the Youth Advisory Council of the Ombudsman.

Other countries reported none or rather negative experiences with participation of children with intellectual disabilities. There is evidence across the UK of children with intellectual disabilities being excluded from the participation open to other children<sup>123</sup>. Local authorities have failed to consult with disabled children in the development of their children and

<sup>121</sup> Latvian Save the Children – „Glābiet Bērnus”; Report of Latvian NGO Children’s Rights Network to the United Nations on Situation on Protection of the Rights of the Child in Latvia. Rīga, 2006. Available at: <http://www.crin.org/resources/find.asp?orgID=1236>.

<sup>122</sup> Children of Slovakia Foundation, Research Study called Newly Emerging Needs of Children in Slovakia, August 2009 (Prieskumná štúdia Novo vytvárajúce sa potreby detí na Slovensku, Nadácia pre deti Slovenska, august 2009) available at: [http://www.codetipotrebujus.sk/index.php?option=com\\_content&view=article&id=58%3Ainovany-pristup-k-profesionalizacii-prace-s-demi-ii&catid=40&Itemid=58&lang=en](http://www.codetipotrebujus.sk/index.php?option=com_content&view=article&id=58%3Ainovany-pristup-k-profesionalizacii-prace-s-demi-ii&catid=40&Itemid=58&lang=en).

<sup>123</sup> Country Report, United-Kingdom, page 17.

young people's plans as required by the Children Act 2004<sup>124</sup>. Furthermore, the government has not produced consultations in an accessible format. This is despite guidance stating that it is good practice to do so<sup>125</sup>.

#### GOOD PRACTICE:

In Wales Mencap Cymru has delivered a major participation project for young people with intellectual disabilities aged 15-25. This project has demonstrated that it is possible to raise the awareness and engagement of young people with intellectual disabilities in local and national political processes, for example developing and delivering a petition. *Partners In Politics, Mencap Cymru.*

In this study we also looked at how children in general and children with intellectual disabilities participate in decisions which concern them. In 2005 the Office of the Ombudsman for Children was established in Finland. Its work has resulted in a public debate, particularly on a child's right to participate, have a say in his or her own affairs, and be heard. A new framework Act has been proposed to discover the opinions of children and young people in order to promote their well-being. The new Act would oblige the State and local authorities to assess the effects on children of decisions and learn more about the opinion of children and young people (e.g. on educational services, leisure facilities organised locally and services for the disabled provided by the local authorities)<sup>126</sup>. The Finnish Association for Persons with Intellectual Disabilities knows of no local authority where intellectually disabled children and young people are polled and the findings studied before decisions are finally taken<sup>127</sup>.

Similarly in Bulgaria in 2003 a Children's Council was set up with 33 members (including two representatives of DPOs), who must leave the Council when they turn 18. The mission of the Council is to represent children's perspectives on the issues dealt by the State Agency for Child Protection. The Council has two sessions per year. However, because there is no access to the decisions made nor to the minutes of the meetings, it is impossible to evaluate the real participation of children in the decision-making process<sup>128</sup>.

Similarly, in Italy there is no coordination to promote the participation of children and adolescents in decision-making processes<sup>129</sup>. Local administrations have developed good practices with the creation of Children's and Young People Councils. However, there is no evidence that children with disabilities, in particular with intellectual disabilities have been involved. The same can be said in regard to the development of the State or the alternative reports, as children have not been consulted.

Some attempts to realise the right to participation of children are even considered as purely political window-dressing, like in Poland where every year on International Children's Day a session of the Children and Youth Sejm is held in the Lower Chamber of the Polish Parliament. Participating children and adolescents notice the superficial nature of this solution (the alternative report mentions the words "façade, pretense" in this context<sup>130</sup>). In practice, sessions of the Children and Youth Sejm have no impact on the situation of children and adolescents. ★

#### Case Study Poland: J. 5-year-old – in the words of her mum.

"J. attends an integrated pre-school now. But we've had our share of problems. It turned out that our commune did not have an integrated kindergarten. Our district did have an integrated kindergarten, but it was located in the town of L. I was told that since I am not a resident of L. I don't have a chance for enrollment.

So I registered myself and J. as a resident of L. using my friends' address, just to become entitled to apply. I would never think of this myself, that solution was suggested to me in the very kindergarten in L. where I was hoping to apply. The office assistant there told me that some parents resort to that. And J. goes to that kindergarten until today.

The integrated kindergarten only takes care of children until 2 p.m. Healthy children can stay till 6 p.m., disabled children must be picked up at 2 p.m. So I'm hiring a nanny who picks J. up from pre-school and stays with her until I finish work.

Also, at the integrated kindergarten nobody wanted to enroll a disabled 3-year-old. They were only accepting children over 4. I had to intervene with the Mayor to make sure a 3-year-old would be enrolled. My daughter was enrolled after the Mayor's intervention. Healthy 3-year-olds are accepted with no questions asked".



<sup>124</sup> Every Disabled Child Matters, *Off the Radar how local authority plans fail disabled children*, 2007, available at: [http://www.ncb.org.uk/edcm/edcm\\_offtheradar\\_fullreport.pdf](http://www.ncb.org.uk/edcm/edcm_offtheradar_fullreport.pdf).

<sup>125</sup> Gregory W., *Let's make it accessible – Improving government information for disabled people*, Department for Education and Employment, COI Communications; London, 2001.

<sup>126</sup> Yearbook of the Ombudsman for Children, 2010. Office of the Ombudsman for Children publications 2010:2.

<sup>127</sup> Country Report, Finland, page 17.

<sup>128</sup> Country Report, Bulgaria, page 12.

<sup>129</sup> Country Report, Italy, pages 14-15.

<sup>130</sup> Country Report, Poland, page 19.

## IX. Conclusions and Recommendations

Each country has its own particular challenges in promoting and enforcing the rights of children with intellectual disabilities as well as different opportunities for initiating reforms and changes. However, there are similar barriers to realising the rights of children with intellectual disabilities in all countries.

The most significant barrier is the lack of community-based services to support families of children with intellectual disabilities: the lack of early intervention services, the lack of adequate support for attending mainstream schools as well as the lack of free-time and after-school opportunities with peers. Stigma, discrimination and lack of training of health care or educational staff remain often a huge barrier for the inclusion of people with intellectual disabilities. Where positive changes or progress have been made, full inclusion still remains illusory because implementation measures are not properly designed or monitored and resources are inadequate.

Therefore Inclusion Europe and Eurochild recommend that the following actions be given priority by policy makers at both national and European levels:

### ■ **Focusing on the situation of vulnerable children**

The European Union should ratify the Convention on the Rights of the Child in order to enhance the rights of vulnerable children in Europe, including children with intellectual disabilities.

The Committee on the Rights of the Child should better monitor the situation of children with intellectual disabilities by:

- Insisting on States Parties that they have to follow the CRC Committee recommendations and answer the demands for disaggregated data and information about the situation of children with intellectual disabilities.
- Organising a pre-session Thematic Day on children with intellectual disabilities before a meeting of the Committee to discuss the implementation of the Convention on the Rights of the Child.

### ■ **Implementing the Convention on the Rights of Persons with Disabilities**

The ratification of the CRPD by many Member States as well as the EU is providing a new opportunity to implement the CRC in relation to children with intellectual disabilities.

The EU Agenda for the Rights of the Child should be implemented and updated taking into account the requirements of the Convention on the Rights of Persons with Disabilities<sup>131</sup>.

### ■ **Ensuring a comprehensive legal and policy framework at EU and national level for the protection of children with intellectual disabilities by:**

- Including specific provisions on non-discrimination on the ground of disability, as well as discrimination by association with a disabled person.
- Adopting equal opportunity legislation, with a special focus on children with severe disabilities and/or complex needs, who can be excluded from disability services because of the degree of their disability.

- Collecting disaggregated data in every field to formulate concrete policies and monitoring strategies and adjust services and structures in the community.

### ■ **Better protecting children with intellectual disabilities against abuse, violence and bullying**

To enforce this right, it is necessary to:

- **Conduct studies and assess cases** of children with intellectual disabilities abused within the care sector, at school or within their natural/family environment or in large residential care institutions.
- **Train children with intellectual disabilities** on personal relationships and sexuality, relating to adults and what to expect from professionals in their life, for example by including these topics in the curriculum in all mainstream and special schools.
- **Adapt complaints mechanisms** and make reasonable accommodations to allow for children with intellectual disabilities to be heard when they have been victims of violence.
- Take immediate **measures to prevent abuse in residential care institutions** and stop corporal punishments.

In addition, **bullying should be explicitly recognised as a form of abuse** in legislation, and measures taken to ensure that bullying as well as all forms of psychological violence are dealt with in practice at schools and in other places visited by children.

### ■ **Developing and ensuring access to nationwide community-based services, including early diagnosis, early intervention, respite care and personal assistance**

To ensure that families with a child with intellectual disabilities can live included in their communities, it is vital to **increase the opportunities** for children with intellectual disabilities to participate outside school hours in **leisure time activities** with children without disabilities.

It is equally crucial to recognise the importance of personal assistance in supporting children with intellectual disabilities and to make **personal assistance** a universal service and ensure that this service is provided with quality.

### ■ **Promoting Living in the Community:**

The process of de-institutionalisation has begun in all countries and rapid progress has been made in many Central and Eastern European Countries. Governments must actively develop alternative community-based services to stop any new admissions of children into residential institutions, encourage fostering/adoption of children with intellectual disabilities and train staff to support life-long-learning, promote autonomy and foster self-care among children who have lived in institutions. Governments must also establish **standards for alternative family care in the community**, regularly re-evaluating the care provided. These measures are needed to make de-institutionalisation policies successful. Often children with disabilities are still excluded from the necessary support for living in the community leading to family placement or return home without good support services. In too many places, children

<sup>131</sup> See the objective and actions of the EU Agenda for the Child on [http://ec.europa.eu/justice/fundamental-rights/rights-child/eu-agenda/index\\_en.htm](http://ec.europa.eu/justice/fundamental-rights/rights-child/eu-agenda/index_en.htm).



are placed long-term in smaller “family-type” group homes – often with the same staff and no real change in their care regime. This however, does not improve the quality of life of children with intellectual disabilities.

Community based services to support families are also needed to prevent possible violence from exhausted parents or siblings.

#### ■ **Addressing the systemic barriers that hinder further progress towards inclusive education by:**

- Introducing and implementing requirement that all primary and pre-school teachers have a relevant extra training leading to a qualification to educate children with intellectual disabilities.
- Providing qualified professionals, adapted programs, methods, materials and relevant technologies or other special measures to support education of children with intellectual disabilities in mainstream schools.
- Merging special and mainstream schools into a common school system.
- Ensuring that parents of children with a disability who are experts in many aspects of their children’s lives are involved in the inclusive education process.
- Offering good opportunities for vocational training to young people with intellectual disabilities to make sure that can make real choices about their future lives.

In addition, person-centred planning<sup>132</sup> should be used as an instrument to counteract disrupted educational paths for pupils with intellectual disabilities.

#### ■ **Developing services to improve access to health care**

It is necessary to **simplify health care procedures** for children with intellectual disabilities who usually require, throughout their lives, regular personalised special treatments (e.g. occupational therapy, psychological therapy, special training, etc.), medication and frequent medical tests. Therefore, **one stop shops** for the submission of requests, funding and provision of aids and resources should be established.

Governments should also ensure the **full coverage of expenditures** by the health insurance system for medication and specific therapies for children with intellectual disabilities, in order to ensure their equal opportunities and prevent further health complications.

Finally governments should guarantee liaison and coordination between the different health sectors and specialities in order to guarantee **uniform access to health care** throughout the country, including developing mobile teams of specialist and ensuring transportation facilities.

#### ■ **Raising awareness on children with intellectual disabilities by:**

- Involving children with intellectual disabilities and their families in wider efforts to change the beliefs all sectors of the community, including parents, professionals and decision makers about these children.
- Including information on the social model of disability and on communication needs and alternative formats in the training of medical professionals (basic and life-long learning).

- Developing protocols for health care professionals to enable them to communicate properly with the parents and/or children with intellectual disabilities.
- Developing information and education campaigns for families who are not aware of the dangers of abuse towards their children either in public areas or in schools or institutions.

#### ■ **Coordinating services for children with intellectual disabilities and their families**

Previous research identified that the lack of intersectoral (and intrasectoral) cooperation between services can be one of the decisive factors as to why people with severe disabilities are excluded from living a life in normal settings<sup>133</sup>. This research again highlighted the lack of coordination of services as well as the lack of training of relevant professionals, especially in relation to people with multiple disabilities or complex needs. Therefore, governments should **improve the links and communication between health professionals** to facilitate follow-up and coordination of health care, rehabilitation and **social care professionals** who are supporting children with intellectual disabilities (for example, through health passports including information on the disabled child and its support and communication needs). Early intervention should be integrated in the mainstream health care system and be available in the whole territory.

#### ■ **Developing mechanisms to ensure that children with intellectual disabilities and their families are consulted and can influence disability-related policies**

- Work with families at all ages according to their child’s development.
- Mainstream disability issues to ensure that children with intellectual disabilities are included in all programmes and policies throughout all the relevant sectors.
- Include training on self-advocacy and citizenship in the curricula of all schools.
- Support the creation of students school boards and children’s boards in social services, children’s home and other living facilities with children with intellectual disabilities with the aim of monitoring the realisation of rights and of addressing their needs.
- Train key people in communication methods and specific advocacy provisions to ensure that children with severe disabilities and/or complex needs can also be heard and understood.

Finally, Inclusion Europe and Eurochild would like to encourage the cooperation and collaboration of child’s rights NGOs with associations and organisations of parents and children with intellectual disabilities at European, national and local levels. Creating such partnerships and working together for comprehensive implementation of the Convention on the Rights of the Child and the Convention on the Rights of Persons with Disabilities are crucial to ensure that the rights of these “invisible” children will be promoted. The ratification of the CRPD is also providing civil society an opportunity to put pressure on Member States to implement the CRPD and therefore the CRC in relation to children with intellectual disabilities. ★

<sup>132</sup> On person centred planning see for example: Beadle-Brown, J. (2006). Person centered approaches and quality of life, *Learning Disability Review*, 11, 4–13.

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# Inclusion Europe

## The European Association of Societies of Persons with Intellectual Disabilities and their Families

Inclusion Europe is a non-profit organisation. We campaign for the rights and interests of people with intellectual disabilities and their families. Our members are organisations from 39 countries in Europe.

People with intellectual disabilities are citizens of their country. They have an equal right to be included in society, whatever the level of their disability. They want rights, not favours.

Inclusion Europe focuses on three main policy areas:

- Human Rights for people with intellectual disabilities
- Inclusion in society
- Non-discrimination

## Eurochild

Eurochild is the European network of organisations and individuals promoting the rights and welfare of children and young people in Europe.

The network was founded in 2004 and currently has 109 Full and 36 Associate Members in 35 European countries.

Our Vision is a Europe where all children grow up in an environment that nurtures their physical, intellectual, emotional, moral, and spiritual development. A European society in which children's rights, as enshrined in the United Nations Convention on the Rights of the Child (UNCRC), are universally understood and respected by politicians, governments, professionals, parents, guardians and children.

## Charles University in Prague

**The Faculty of Education** is one of 17 faculties associated under the umbrella of the Charles University in Prague. Its primary goal is to train teachers and other pedagogical personnel for all types of schools and school systems. The Faculty provides university-level pre- and in-service teacher education in the field of Humanities, Social Sciences, Art Education, Physical Education, Mathematics and Natural Sciences.

The Faculty is currently training approximately 4200 students in both BA and MA study programmes, plus nearly 10 000 students taught within a wide range of combined forms of study programmes.



With the financial support from the DAPHNE III Programme of the European Commission.



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