

CONVENTION ON THE RIGHTS OF THE CHILD CRC

WRITTEN SUBMISSION TO THE COMMITTEE ON THE RIGHTS OF THE CHILD IN RELATION TO THE COMBINED FIFTH AND SIXTH PERIODIC REPORTS SUBMITTED BY ITALY

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The **Italian Disability Forum (Forum Italiano sulla Disabilità - FID)** is an Italian not-for-profit DPO, full member of the European Disability Forum (EDF), representing the interests of persons with disabilities in Italy. It is composed exclusively of national organizations of persons with disabilities and their families. Its aims are to fight for the recognition, promotion and protection of the human rights of persons with disabilities, as well as for non-discrimination and equal opportunities. Since its establishment, the Italian Disability Forum has participated in all initiatives and activities carried out by EDF.

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Introduction

By presenting this report, the Italian Disability Forum (hereinafter: "FID") would like to provide the CRC Committee with additional information regarding the rights of children with disabilities in Italy to support the assessment of the State Party's report.

The adoption of the United Nations Convention on the Rights of Persons with disabilities (CRPD) by Italy has triggered the long-awaited process of inclusion of disability in the human rights system. The data collected by the civil society, however, show that the cultural change underlying this new approach is yet to be consolidated in our country. **Issues related to the rights of children with disabilities still cover a marginal position in the political, social and cultural agendas, especially when applied to national and local administrative policies.**

The **International Convention on the Rights of the Child** is the latest among the treaties signed in the 20^{th} century under the international law on human rights and the "most extensively" ratified in the history of relations among countries. It can therefore be stated that the 20^{th} century closed with the recognition of the fundamental human rights, especially those of children. The much hoped-for central role of children and adolescents¹ of either gender shows how important and precious they are in the development of human history and spurs reflection on positive and negative actions towards them.

The CRC includes an article – Article 23 – on children with disability. Nevertheless, according to Part.1, Art. 2, all the rights set forth in the CRC apply to any child, "*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.*". As a consequence, through this written submission we wish to suggest elements for the analysis and the evaluation of the policies for the promotion of all human rights set forth in the CRC from a children-with-disabilities perspective, and at the same time, to suggest a more in depth analysis of some key issues of pivotal role/importance for children with disabilities across the CRC articles.

Some of FID network's organizations contributed to the First, Second and Third Supplementary Reports on the Implementation of the Convention on the Rights of the Child in Italy². It is a strongly felt collaboration which has been established to achieve mainstreaming of disability in all political, civil and social actions.

Our reflections stress the invisibility of children and adolescents with disabilities in government actions, further developing the specific chapters included in the 3^{rd} Supplementary Report made by the Italian NGO Group for the Convention on the Rights of the Child (CRC Group)³.

¹ "Child" refers to any human being aged 0-18 years

² <u>https://tbinternet.ohchr.org/_layouts/treatybodyexternal/SessionDetails1.aspx?SessionID=1226&Lang=en</u>; https://tbinternet.ohchr.org/Treaties/CRC/Shared%20Documents/ITA/INT_CRC_NGO_ITA_31112_E.pdf

³ Ibidem footnote n. 2

CRC Part 1, art. 2, 3 and 4

The Committee on the Rights of the Child's recommendations and observations addressed to Italy regarding children and adolescents with disabilities have not been transposed in official government measures⁴.

There is a lack of adequate funding for the implementation of the national Plan for Children, a lack of a national law defining the minimum standards of educational services for early childhood and early diagnosis and intervention, as well as a lack of adequate tools for assessing the quality and efficiency of the staff qualification and the services provided to children with disabilities in education and healthcare services.

The implementation of the provisions of the Third National Plan of Action referred to in the Government Report, which expired in 2011, were not supported by any specific funding. This made the State-Regions Conference state that "the lack of reference to financial resources and no determination of the minimum standards (as required by Article 117, point m, of the Constitution), does not allow a positive assessment of the Plan and of its concrete operability⁵.

Box 1- Being children in Italy

In its 8th Report Update on the monitoring of the Convention on the Rights of the Child in Italy $(2014 - 2015)^6$ the Italian Group for the CRC⁷ noted that there are many children who suffer from one or more situations of vulnerability. As approximate and only applicable for certain conditions, the following risk factors are estimated: - 1 child in 50 suffers from a condition, congenital or acquired during pregnancy and childbirth, which results in significant disability at the age of entry into the primary school⁸; - 1 in 30 develops specific learning difficulties⁹; - 1 out of 500 live in shelter homes¹⁰; - 1 in 20 is a victim of assisted domestic violence and 1 in 100 of maltreatment¹¹; - 1 out of 7 was born and raised in a family in absolute poverty¹²; - 1 in 20 live in areas at high risk of environmental pollution, resulting in increased risk of mortality¹³; - 4 out of 10 are not breast-fed for at least six months, and only 1 in 14 is exclusively breastfed, as recommended by the WHO and the Ministry of Health¹⁴;

⁴Italian NGO Group for the CRC, *The rights of children and adolescents in Italy.* 8th update report on the monitoring of the Convention on the Rights of the Child in Italy, year 2014-2015, pag 117 www.gruppocrc.net ⁵8th supplementary report to the CRC, pag31 available at www.gruppocrc.net

⁶Ibid,<u>http://www.gruppocrc.net/IMG/pdf/VIIIrapportoCRC.pdf</u>

⁷ The Italian NGO Group for the CRC (II Gruppo di Lavoro per la Convenzione sui Diritti dell'Infanzia e dell'Adolescenza - Gruppo CRC) is a network currently composed by almost 86 NGOs and associations that have been working for a long time for the promotion and protection of children's rights in Italy. The Italian NGO Group for the CRC is coordinated by Save the Children Italy. The Italian NGO Group for the CRC was established in December 2000 with the main aim of drafting a Report on the implementation of the Convention on the Rights of the Child (CRC) in Italy, supplementary to the one presented by the Italian Government, to be submitted to the UN Committee on the Rights of the Child (UN CRC Committee) at the High Commissioner for Human Rights.

⁸ ISTAT, *L'integrazione degli alunni con disabilità nelle scuole primarie e secondarie di primo grado statali e non statali*, a.s. 2013/2014, published on December 19, 2014. Available at: <u>http://www.istat.it/it/archivio/143466</u>

⁹ Lopez, L. et al., I Disturbi Specifici di Apprendimento: inquadramento generale, AID 2014.

¹⁰ Elaboration of the Center for Child Health, based on the latest data provided by the Ministry of Labour and Social Policy on "Foster care placements and community at 31/12/2012", in *Quaderni della ricerca sociale*, n. 31/2015. For further details please see Chapter IV, Section "Minor deprived of a family environment" of this Report.

¹¹ Terres des Hommes and CISMAI, *Maltrattamento sui bambini: quante le vittime in Italia?*, 2013 available at <u>http://www.garanteinfanzia.org/sites/default/files/documenti/dossier-bambini-maltrattati-tdh-cismai.pdf</u>.

 ¹² ISTAT, *La povertà in Italia*, year 2013, published on July 14 2014. Available at <u>http://www.istat.it/it/archivio/128371</u>
¹³Comba, P. et al., "Le aree ad alto rischio ambientale in Italia", in *Ecoscienza*, 2014, n. 1, pp. 58-60; IAvarone, I. Biggeri, A. - Cadum, E. et al., "SENTIERI KIDS: monitorare lo stato di salute infantile nei siti inquinati italiani", in Comba, P. et al. (a cura di), *SENTIERI: mortalità, incidenza oncologica e ricoveri ospedalieri*, Epidemiologia&Prevenzione, 2014.

- 1 out of 8 born in birth centers which are not sufficiently equipped to provide quality perinatal care and the same number are born through inappropriate procedures¹⁵; - More than 8 out of 10 children do not have access to social and educational services in the first three years of life¹⁶ and one of 10 in the age between three and five years¹⁷

The Third Biannual National Action Plan for the protection of the rights and development of children¹⁸ calls for a particular attention to the rights of children with disabilities. Nevertheless, children, and in particular children with disabilities, have not been consulted on the design, implementation and monitoring of the plan, including through their representative organizations.

The monitoring of the implementation of the Action Plan by the National Observatory for Children and Adolescents¹⁹ (referred to L 451/97), highlighted the shortage of systematic measures for screening and early detection of disabilities, excessive discrepancies across regions in the levels of assistance provided to children with disabilities and support to their families, and, as regards education, the high mobility of the teaching staff (and in particular of support teachers), the uncertain professional profile and, in many cases, inadequate for the purpose, undervalued and unmotivated support teachers, curricular teachers without special educational training and, in many cases, unwilling to cooperate with their support peers²⁰ (see also article 24). On July 28, 2015 the draft of the Fourth National Plan on Children was approved. At the time of writing this report, the National Plan is still waiting to be approved by Decree of the President of the Republic.

Data collection

There is a lack of regular studies and data on children and adolescents with disabilities, who are often overlooked in the statistics both in numbers and with respect to the achievement of their rights. Existing data is not updated, and especially do not allow aggregations or international comparisons, based on indicators and methods of different analysis²¹.

There is no information on the incidence of disabilities, the causes of perinatal disabilities or other clinical events that can result in a disability. Moreover, there is no information on the geographical distribution of children with disabilities, their demographic data or the socio-economic indicators of the population aged 0-5²² The official statistics on the number of people with disabilities aged 6 and over living with their families, presented to the CRPD Committee,²³ are out of date (2004) and do not include institutionalised children or those with intellectual and psycho-social disabilities.

Also, in Italy there are no reliable official statistics on the number of children with disabilities in the age range 0-5 years. The only report on the Monitoring of Social Policy, presented in 2005

¹⁷Elaboration of the National Group on nursery and primary of the Ministry of Education – Statistical Service ¹⁸ Adopted with Presidential Decree of 21 January 2011

¹⁴Macaluso, A. - Bettinelli, M.E. et al., "A controlled study on baby-friendly communities in Italy: methods and baseline data", in Breastfeeding Medicine, 2013, n. 8, pp. 198-204.

¹⁵ ISTAT, Gravidanza, parto e allattamento al seno, 2014 and Save the Children, Mamme in arrivo, 2015.

¹⁶ISTAT, L'offerta comunale di asili nido e altri servizi socio-educativi per la prima infanzia, a.s. 2012/2013, published on July 29, 2014 available at http://www.istat.it/it/archivio/129403

¹⁹ Syntheses report on the result s of the monitoring of the Third Biannual Plan for adoptions and protection of the rights and development of children

¹⁹ National Observatory on children and adolescents with the support of the national documentation centre and analysis for children. 2011

²⁰Associazione TreeLLLe, Caritas Italiana e Fondazione Agnelli Gli alunni con disabilità nella scuola italiana: bilancio e proposte, 2011 ²¹<u>http://www.unicef.it/doc/4824/minori-e-disabilita-la-situazione-in-italia.htm</u>

²² http://www.camera.it/temiap/2015/02/25/OCD177-979.pdf.

²³ CRPD/C/ITA/1.

by the Ministry of Welfare²⁴, reports that there are about 42.460 children with disabilities between 0 and 5 years old. The data released by the ministry is only an estimate, obtained by the assumption that there is an incidence at birth of 1% and consequently calculating the trend by which the phenomenon is developed up to 6 years.

All this perpetuates the invisibility of this group of children with disabilities by increasing their vulnerability and their consequent exclusion, with definitive impact in their social and working life.

Notwithstanding this, the official statistics on the number of disabled persons aged 6 years and older and living in the household are dated (2004) and never updated. The same statistics have been used in the National Report to the CRPD Committee. Furthermore, these data exclude persons with disabilities institutionalized and do not include those children and adults with intellectual and psychosocial disabilities as the official survey only includes questions on physical abilities of the person.

CRC Part I, Art.6

Assuming that the principles at the base of article 6 about the right to life, read in connection with art. 2.1, is guaranteed and enforceable by all children, "irrespective of the race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status", it is implied that it cannot be violated on the basis of the presence of a disability. Collection and access to adequate information on disabled live births, stillbirths and abortions are occurring is important in order to compare among the various choices made my mothers and act upon it. For instance, for Down Syndrome, the number of live births is equal to those aborted.

Therefore, the concept according to which the presence of genetic diseases of the embryo/fetus which results in its death after birth may result in a decision to terminate the pregnancy arises serious issues concerning discrimination of approaches in assistance based on a disability.

Article 6 of the Law no. 104 of 4 February 1992, Framework Law for the assistance, social integration and rights of handicapped people indicates the steps to be taken so that the person with disabilities is protected in his right to life: a) in information and health education of the population on the consequences of disability, b) in the prevention during preconception, pregnancy, childbirth, the neonatal period and the various stages of life development, and services that perform these functions, c) in services for the genetic counseling and prenatal and early diagnosis for the prevention of genetic diseases that can cause physical disabilities.

About the assisted fertilization, art. 13. 1c of the Law 40 of 19 February 2004 provided for the prohibition of all forms of selection of embryos and gametes for eugenic purposes [....] and that the detectable condition of disability is not a sufficient for the elimination of the "defective" embryo and/or gamete but rather prohibited it, only to allow the woman, afterwards, to request the termination of pregnancy once a disability is detected.

In these ten years, this law has been the subject of at least 34 Judgments that, in fact, have revolutionized his original structure. These judgments have eliminated especially the ban on heterologous fertilization, on the obligation to implant a maximum of three embryos and all at the same time and on access to technical (and consequently the pre-implantation diagnosis) to fertile couples. In November 2015 Constitutional Court ruling no. 229/2015 vanishes the ban on embryo selection, without exception. Judges have determined that the selection of the embryos is not a crime in cases where it is intended to prevent 'implantation of embryos with serious diseases, or

²⁴<u>http://www.lavoro.gov.it/Strumenti/StudiStatistiche/Documents/Rapportodimonitoraggiosullepolitichesociali.pdf</u>

those provided by law 194 on abortion²⁵ ("when there are verified pathologies, including those relating to significant anomalies or malformations, which constitute a grave danger to the physical or mental health of the woman").

To eliminate any ideological controversy, it would be worthwhile to understand, also through information and data collection, whether the principle of equality in the right to life is guaranteed to persons with disabilities.

Focusing on the moment of birth

At international level, the International Clearinghouse for Birth Defects Surveillance and Research and (ICBDSR), affiliated with the World Health Organization, through worldwide research programs and surveillance, tries to investigate the incidence of malformations and impact their consequences. As for Italy, there are only five regional registries (Campania, Emilia-Romagna, Lombardy, Northeast and Tuscany) and the data is updated only to 2012²⁶. In these registries it is possible to find the total number of annual births, of the live births, of the still births and of the termination of pregnancy for birth defects.

Unfortunately, each of these registers has different origins and methods of collecting and analyzing data. In addition to these registers, there are no epidemiological data available at national level that can detect the high number of disabilities in children after birth and the various diseases responsible for disabilities in the developmental age frame.

As for interventions for the prevention and prenatal and early diagnosis of disability, there is no national data available on services for genetic counseling and early prenatal diagnosis for the prevention of genetic diseases that can cause disability. Not even analysis and checks on their presence in the country and on the evaluation of the effectiveness of these services in terms of efficiency.

Some epidemiological studies indicate prematurity as a cause of disability. According to the publication of the Manifesto of the Premature Child ²⁷, currently it cannot be detected at the national level how the Guidelines on Premature Births are applied and especially if they have generated general strategies and targeted prevention of prematurity and the survival of the premature fetus. It would be useful to know if there are validated data on the causes of prematurity and whether there are studies that investigate the quality of life of preterm survivors.

Statistics, presented in the above-mentioned Manifesto, indicates that rates of Italian neonatal mortality in the ranges of gestational age at greatest risk are among the lowest in the world. This shows the efficiency of the services and the effectiveness of perinatal care.

Unfortunately, still today, perinatal care does not prevent that current rates of severe disability among surviving preterm infants are equal to:

²⁵ <u>http://www.salute.gov.it/imgs/C_17_normativa_845_allegato.pdf</u>

²⁶<u>http://www.icbdsr.org/filebank/documents/ar2005/Report2012.pdf</u> pages 137-149 and 256

²⁷ Promoted by "Associazione Vivere Onlus": National Coordination of Associations in Neonatology with the sponsorship of the World Health Organization, SIGO Italian Society Gynecology and Obstetrics, SIN Italian Society of Neonatology. According to such Manifesto, the incidence of disability in premature infants is as follows: Severe: 0.2 to 0.5% of live births; Moderate 2.4% of live births; Mild 10-15% of live births born, severe in gestational age from 22 to 31 weeks: 8.2%

Weeks of gestation: 23; percentage: 42,9% Weeks of gestation: 24; percentage: 21,4% Weeks of gestation: 25; percentage: 16,3% Weeks of gestation: 26; percentage: 14,1% Weeks of gestation: 27; percentage: 10,3% Weeks of gestation: 28; percentage: 7,1%

Some research suggests that the incidence of disease expected in premature births amounted to 2% while for assisted conception it increases to $9\%^{28}$. It would be useful to know whether there is data on this suggested trend and if the meetings with potential parents who access assisted fecundation discuss the risks associated with these assumptions.

Violations of article 6

The discussion in the country, at all levels, is focused only on the issue of termination of birth and assisted procreation. There is total lack of information concerning the protection throughout the lifecycle.

In Italy there are serious gaps in the legislative system with regard to bioethical events such as living wills, forced feeding, euthanasia. This lack is dangerous for a real protection of life because the parliamentary process remains anchored to the ideologies (pro-life or against life) that clash without bringing any results.

On the national territory are not available data on consultancy services for genetic counseling and prenatal diagnosis for the prevention of genetic diseases that can cause disability.

Recommendations

- Take concrete measures of evaluation of the effects of regulations on the protection of the right to life on children with disabilities
- Develop and apply a survey system on incidence of disability at birth, the perinatal causes of disability, the incidence of birth defects, their consequences, the causes of prematurity and the quality of life of preterm survivors
- Put in place a concrete evaluation system on the quality of consultancy services
- Provide a full information on acquiring informed consensus on genetic counselling and family counselling, including concrete experience of disability coming by experts from DPOs

CRC Part I, art. 9

Another critical element in the data collection is to be related to the number of **children with disabilities who live in services alternative to the family environment**. The information available is to be updated to 31 December 2012^{29} and report the number of 28,449 children in the age group 0-17 who live outside the family of origin and welcomed in foster homes or residential communities.

There is a lack of data regarding the reasons why children are being removed from their families of origin, the time needed to process the requests and the type of host structures chosen. Data is totally

²⁸ Australian study published in The New England Journal of Medicine and led by Michel Davies of the Robinson Institute in Adelaide. Thanks to the registers present in their country have taken into account the more than 300 thousand births and all abortions from 1986 to 2002 out of a population of 1.6 million inhabitants.

²⁹Ministry of Labor and Social Policy on "Foster care placements and community at 31/12/2012", in *Quaderni della ricerca sociale*, n. 31/2015

http://www.lavoro.gov.it/Strumenti/StudiStatistiche/sociale/Documents/Quaderni%20_Ricerca%20_Sociale%20_31%2 0Report%20MFFO%202.pdf

absent for minors in the age group 0-5 years. To know the number of children with disabilities one could refer to the national report on assisted residencies of social and sanitary nature of 2011^{30} , where it is reported a generic 17% (4.836 children) the total of minors living in such residencies that have mental health issues or disabilities. There is a clear incompatibility of data as records kept by the various Ministries do not coincide³¹.

From the data provided by the Department for Juvenile Justice³², it shows that in February 2014 **three hundred disabled children were still waiting to be adopted**. Almost all it has "serious and very serious physical conditions, with handicaps and disabilities, behavioral disorders and cognitive deficits." The average age is ten years old: 62 younger, while 137 are more than 15 years old. The National database of adoptable children, required by law 149/2001, for now only operates in eleven of 29 courts.

CRC Part I, art. 16

In the occurrence and timing of divorce among parents of children with highest level of support needs is higher compared to parents of children without disabilities.

Prejudices and false beliefs contribute to influence legal decisions in separation or divorce proceedings and can lead to forced separation of children with disabilities from their families. Very few families of children with disabilities have access to information, services and the support needed to prevent concealment, abandonment, neglect and segregation. Support to families of children with disabilities is poor and mainly focused on financial support. The burden of support and care of relatives has a negative impact on family life, despite of the constitutional right of family to be supported and protected with economic measures and other facilities.

box 2- The impact of false beliefs on family life of children with autism

Parents of children with Autism Spectrum Disorders (ASD), and in particular mothers, are exposed to blame and prejudices stemming from the disproved "Refrigerator mother" theory, attributing to mothers the responsibility of triggering autism in their children. The persistence of prejudices based on "Refrigerator Mother" theory among general public and legal system professionals have detrimental effect on family life and on legal decisions in separation or divorce proceedings, which may deprive parents legal custody based on the presumption that they are unable to rear their children with ASD.

Support to families of children with disabilities is poor and mainly focused on financial support³³. Starting from 2011, austerity measures have fostered cuts in social services, including further cuts to support measures to families of persons with disabilities. The excessive delegation to families of the care of children with disabilities) entails also a negative impact on social and work life of their families, in particular of mothers.

³⁰<u>http://www.camera.it/temiap/2015/02/25/OCD177-979.pdf</u>

³¹ Ministry of Labor and Social Policies and Department for Juvenile Justice

³²http://www.redattoresociale.it/Notiziario/Articolo/491283/Quei-300-minori-italiani-disabili-che-nessuno-vuoleadottare

³³ISTAT, La disabilità in Italia. Il quadro della statistica ufficiale, 2009

box 3- Impact on families of the assistance and care of relatives with disabilities

In Italy, the full delegation to families of the surveillance ad care of-children with Autism spectrum disorders or intellectual disabilities with high support needs at home is very common. Parents of children with autism spectrum disorders (ASD) spend 17 hours/day on average in surveillance and care of their children at home, The consequent economic burden to the family amounts to 51.000 Euros/year, while the economic burden to assist and care a person with Down Syndrome at home amounts to 44.000 Euros/year³⁴. The assistance and care burden, together with the lack of support, has a relevant impact on work life of parents of children with ASD. 61,3% of families of children or adults with mild autism and 68,3% of families of children or adults with severe autism reported a negative impact on the work life of one at least of parents, compared to 20% of families of children without disabilities. The negative impact of care of relatives with ASD at home on work life affects mainly mothers (62,6%), compared to 25,5% of fathers.³⁵

Violations of article 16

The Italian legislation does not provide for preventing discrimination against children with disabilities in all matters relating to family, parenthood and relationships. National policies in favor of families fail to provide equal and sufficient information, services and the support needed to prevent concealment, abandonment, neglect and segregation of children with disabilities and high support needs, who remain mainly in charge to their families, entailing a disproportionate burden on families and negative impact on family life.

Recommendations

- Combat prejudices and false beliefs on parents of children with disabilities, concerning their capacity to have and take care of their children.
- Adopt policies and measures and allocate adequate funds to provide information, services and the support needed to prevent concealment, abandonment, neglect and segregation of children with disabilities and their families, as well as disproportionate burden on families of children with disabilities with high support needs.

CRC Part I, art. 19 and art. 34

The **ill-treatment and abuse of children** in general is a phenomenon that continues to be underestimated and in Italy. There is no national system able to identify child victims of ill-treatment³⁶, its frequency, its epidemiology, the risk factors and its causes as well as a monitoring mechanism. Although a pilot scheme was introduced by the National Childhood and Adolescence Documentation and Analysis Centre³⁷, this scheme has only been adopted by five regions and experimented within just a few small areas. It is a long way from becoming a "national system". The same goes for the specific area of sexual exploitation, where there is an informative website of

³⁴Censis, 3° numero del «Diario della transizione», 2014

³⁵Censis - Fondazione Serono : La dimensione nascosta delle disabilità. Terzo rapporto di ricerca2012

³⁶ The available surveys on <u>www.osservatoriopedofilia.gov.it</u> are focused on the crimes or on the persons reported and not on the victims.

³⁷<u>http://www.minori.it/centronazionale</u>

the Observatory for the Fight against Pedophilia and Child Pornography³⁸, however its database is still not operational³⁹.

It is important to highlight that the same Observatory confirms that the statistics are based on the detection of the number of crimes committed and of people reported, not the number of children who have been abused.⁴⁰

Attempts to study the phenomenon have been carried on by the civil society, of course. Studies usually refer to specific geographical areas and assessment methods are usually differentiated, nonetheless, they can provide reliable data to help us estimate the incidence of this phenomenon at national level.

Box 4 - Ill-treatment of children: how many victims in Italy?⁴¹

This recent report takes into consideration this phenomenon among children of 49 Italian municipalities. It shows that 1 out of 6 children taken in charge by the social services are victims of ill-treatment and 1 child out of 100 (0.98% of the total resident children) is assisted by social services for reasons of ill-treatment. Given that as of January 1, 2012 the global child population in Italy was 10.574.660, it is **plausible to say that more than 100.000 children are victims of maltreatment**. The study gives a real picture of the extent of the phenomenon and projects it on a national scale, demonstrating that the phenomenon is widespread in our country, and not just 'estimated'.

It is alarming to conclude that in those reports there is no mention to children (girls and boys) with disabilities.

Many questions are to be asked considering the complete indifference of Italian authorities. Where are these children? Are they not victim of violence and ill-treatment? Are they not taken care of by Social Services or, on the contrary, they are but adults have not been able to appropriately interact with them and obtain the necessary information? Are children with intellectual disabilities even taken into consideration when implementing direct interview-based researches? And yet, the incidence of violence suffered by children with disabilities corresponds to significant percentage.

Box 5 - Incidence of abuse on children with disabilities

Researchers⁴² have found that children with disabilities are about 3.7 times more at risk of being subjected to forms of neglect, 3.8 times to be victims of physical or psychological abuse, and 4 times more at risk of being subjected to forms of sexual abuse compared to children without disabilities⁴³.

UNICEF also reports studies conducted from 1990 to 2010 on violence against children with disabilities estimating the percentage of children victim of various forms of violence ranging from 26.7%, to 20.4% of those victim of physical violence and 13.7% victim of sexual violence. **It is estimated that compared to their non-**

³⁸http://www.osservatoriopedofilia.gov.it/

³⁹<u>http://www.gruppocrc.net/IMG/pdf/2_Rapporto_CRC_2010_StC.pdf</u>english abridged version pages 74-75 ⁴⁰<u>http://www.osservatoriopedofilia.gov.it/dpo/resources/cms/documents/1_rel_parl_pedof_2005_2007.pdf</u> ⁴¹ "Maltreatment of children: how many victims in Italy?", published in 2012

http://www.terredeshommes.it/dnload/dossier-bambini-maltrattati-tdh-cismai.pdf. Carried out by CISMAI and Terres des Hommes, two NGOs that are also members of the CRC Group, a civil society network that follows the implementation of the CRC and produces yearly reports, as well as the shadow reports to the CRC committee. ⁴²http://www.acp.it/wp-content/uploads/Quaderni-acp-2014_212_69.pdf

⁴³Jones L et al. Prevalence and risk of violence against children with disabilities: a systematic review and metaanalysis of observational studies. Lancet 2012;380:899-90

disabled peers, children with disabilities are 3.7 times more likely to be victims of various forms of violence and children with intellectual or mental disabilities are 4.6 times more likely to be victims of sexual violence⁴⁴.

Box 6 - The tools available to press charges

August 2011 Italy's written reply to UN Committee on the Rights of the Child (CRC Cttee) says that "Anybody can report violations about children's rights or situations of risk to the Ombudsman, even using the public free phone numbers" (para 67 of CRC Italy's written reply). However we have to underline that the Law establishing the Ombudsman do **not explicitly foresees accessible complaint mechanisms or even accessible information on how to report violations of the rights. For example, the public free phone numbers, mentioned earlier, is not accessible to children with hearing impairments. This type of attitude clearly shows a situation of discrimination on the basis of disability which has been expressly prohibited in Italy, since law no. 67/2006 "Measures for the legal protection of persons with disabilities who are victims of discrimination".**

In the field of prevention of the abuse and ill-treatment of children with intellective disabilities, especially the girls, there are not appropriate training courses for police staffs, judges, lawyers, families, associations on how to identify and recognize the abuse and the violence.

Not ensuring to all children with disabilities the access to diagnosis and early intervention and early educational programs of quality at the nurseries, it determines inequalities that violate the right to education of children with disabilities aged 0-3 years. Not involving children and adolescents in the drafting and monitoring of the Action Plan for Children it is violated their right to freely express their opinions on all issues affecting them

Recommendations

- To define a system of data collection that also includes children with disabilities aged 0-5 in order to identify the number of persons with disability living in Italy.
- Reduce inequalities among regions and local communities; implement the Biannual Program on Childhood Actions concerning children with disabilities, as well as the Concluding Observations of the CRC Committee.
- Initiate and fund systematic measures to ensure access to early detection of disabilities and early intervention evenly throughout the country.
- Establish and adopt minimum standards at national level on the quality of provisions by early education services, on educational staff qualification and training to ensure the application of appropriate educational strategies meeting the special educational needs of children with disabilities, as well as the use of alternative/augmentative modes and methods since babyhood.

⁴⁴http://www.unicef.it/doc/4816/bambini-e-disabilita-il-fenomeno-in-cifre.htm

CRC Part I, art. 24

The lack of official data on the number of children with disabilities (0-6) prevents any implementation of health policies and early intervention from diagnosis to early rehabilitation.

This lack, however, has already been the subject of a specific recommendation to Italy by the UN Committee on the CRC in 2011⁴⁵, but since then, no progress has been achieved by our country in the field.

The "Pact for Health" 2014-2016⁴⁶ has some references to the condition of children with disabilities in terms of attempts to improve the efficiency of health services, against the geographical inequalities in the care process and the inclusion of rehabilitation in the area of neuropsychiatry. However, in the same time there is not any facilitated path for the early rehabilitation care, nor specific skills and methods on disability in hospital wards for minors. Moreover health in childhood does not reach the top of the agenda in the National Prevention Plan 2014-2018⁴⁷, showing a lack of attention to the fact that children's health is the basis for health in adulthood.

A critical element concerns the **persistence of disparities and discrepancies in the quality of care between regions and territories**⁴⁸. It still lacks a coherent plan on taking charge of the child and his/her family, whose paths are characterized by high divergence and fragmentation. The update of the definition of the new Minimum Standards of Assistance⁴⁹ between the Ministry and the State-Regions Conference. Therefore, there is a persistence of violations of the right to early diagnosis, the right to an individualized habilitation treatment, the right to the appropriateness of rehabilitation. The organization of services is lacking therefore families are often left alone to face serious pathological conditions, including genetic ones.

Actions and tools of investigation and monitoring can the extent of the quantity and quality of the health of children with disabilities in our country are scarce. Especially in the age group 0-5 years; there are available only partial information from 6 years. Therefore, **they do not know the extent and characteristics of disability in early childhood**, nor its impact on the population groups that potentially are at greater risk in access and equity of care, such as foreign children.

The lack of information on the presence of communication and/or behavior disorders is relevant. The risk of developing emotional and behavioral problems, for young people with intellectual disabilities, is three to four times higher than that of their non-disabled peers, and communication disorders and language have a frequency greater than 80% in individuals with severe or profound intellectual disabilities⁵⁰.

Having said that, it is not detectable by either the Government or the Action Plan on Disability if there is a definition of habilitation and rehabilitation services for children / adolescents with disabilities and shared and homogeneous both nationally and regionally. If there is a shared and homogeneous list of national and regional requirements and indicators of quality of re-habilitation intended for this age group (0-18) and whether there is a systematic data collection on services and re-habilitation programs, disaggregated by age, representative and uniform among the various

- ⁴⁷<u>http://www.salute.gov.it/imgs/C 17 pubblicazioni 2285 allegato.pdf</u>
- ⁴⁸8th supplementary report to the CRC, pag 117 available at <u>www.gruppocrc.net</u>

⁴⁵ Concluding Observations addressed to Italy by the UN Committee and published October 31, 2011 -CRC/C/ITA/CO/3-4 – point 46

⁴⁶http://www.statoregioni.it/Documenti/DOC_044351_82%20CSR%20PUNTO%20%2016%20ODG.pdf

⁴⁹ Minimum standards of assistance, see footnote7

⁵⁰La Malfa G., <u>Ruggerini</u> C., <u>Castellani</u> A., <u>Manzotti</u> S., <u>Moncheri</u> S., <u>Nardocci</u> F., "La promozione della salute mentale nella disabilità intellettiva. Consenso multidisciplinare e intersocietario"</u>, Erickson, 2010.

regions so as to be comparable and regularly updated on their availability and accessibility, in accordance with point 12 of the CESCR General Comment No. 14⁵¹. Finally, it would be useful to have a data collection on the geographical distribution of re-habilitation services for children and adolescents with disabilities.

CRC Part I. art.27

In Italy, the Citizens with disabilities experience countless daily discrimination. The origin of these discriminations are many and are cause of poverty and impoverishment, low living.

As for the condition of poverty among children with disabilities it is once again stressed that there are no national statistics relating to children with disabilities between 0 and 6 years old. In addition, official data on children poverty does not provide information relating to children with disabilities from 0 to 18 years old.

It is worth, however, referring to the Working Group for Monitoring the CRC⁵² which performed in 2014 a survey on poverty from which it was found that in one year, more than 300.000 children fell into poverty. It happened in Italy between 2011, when they were 723.000 children in poverty, and 2012 when it rose to 1.058.000 children in poverty which amounts to 10.3% of the total number of children. Even in 2013 their number increased up to 1,434,000 equal to the 13.8% of the total child population.

The increasing number of children and teenagers experiencing poverty is in line with the more general increasing number of poor families and individuals. In Italy, according to data reported in 2012⁵³, 3.232.000 families lived in relative poverty (12.7%), for a total of 9.563 million poor individuals the 15.8% of the entire population⁵⁴.

In addition, the ongoing economic crisis has continued to aggravate the disinvestment in actions and policies to combat child poverty in our country, leading to the disparity of social spending (especially that destined to family and motherhood) and the frailty of welfare services, aggravated by policies of strong reduction and fragmentation of resources aimed to social interventions.

Particular attention must be given to the application of the instrument ISEE (Equivalent Economic Situation Indicator)⁵⁵ entering into force through the Prime Ministerial Decree 159/2013. This ISEE Regulations has already been appealed with Sentence of the Administrative Tribunal of Lazio and is waiting for the response of the State Council on some fields of application of the rules. In particular it has been reported unequal treatment for the access to social and health services between adults with disabilities and children with disabilities 56 .

⁵¹ Availability, accessibility (on discrimination, physical accessibility, economic accessibility, information accessibility [acceptability and appropriatedness] ⁵²www.gruppocrc.net

⁵³http://www.istat.it/it/archivio/95778

⁵⁴ ISTAT, La povertà in Italia, 17 luglio 2013. The estimated incidence of relative poverty (ie the percentage of families and poor people) is calculated on the basis of a conventional threshold (poverty line) that identifies the value of consumption expenditure below which, a household is defined as poor in relative terms. The "relative poverty" threshold for a family of two is equal to the average monthly expenditure per person in the country, which in 2012 was of 990,88 euro (-2% on the value of the threshold in 2011). Families composed by two members who have a monthly spending at or below this figure, are classified as poor. For families of different number in members, the value of the line is obtained by applying an equivalence scale, which takes into account the economies of scale as the number of components increases.

⁵⁵ISEE needs to weigh the economic capacity of the applicant of a social benefit.

⁵⁶ The reform stipulates that the legal age for calculating a ISEE staff (or at most household narrower compared to children or spouse), while for children calculate the ISEE whole family registry. Therefore, for a child it is determined

In the same time there is not a specific consideration in the ISEE for facilitated social services in favor of children with disabilities, in respect with other children, as if the disability condition, in the minor age, does not determine the risk of reduced opportunities, if not absolute discrimination, in various social contest.

It was also considered illegal in the ISEE instrument calculate the economic benefits related to disability and, therefore, also for children, the different allowances. The pending appeal to the State Council is creating further inconvenience the citizens, obliged - at present - to calculate the ISEE in a way declared illegal⁵⁷.

The Italian municipalities would have to adapt their rules on accessing and sharing the costs of services according to the ISEE reform introduced with the aforementioned Prime Ministerial Decree 159/2013. The same ANCI (National Association of Italian Municipalities) affirms that this adjustment is largely ignored by municipalities. It means that all the municipal regulations that contained clear violations of regulations pre-reform ISEE will remain in force until the advent of the new criteria, unless they are appealed by the citizens (breaches mainly concerned the involvement of those who are obliged to provide alimony while the rules required that the calculation of costs sharing was based only on the economic status of the disabled person - art. 3.3 Legislative Decree no. 109/1998 and subsequent amendments and additions). It must be stressed that even among the new municipal regulations were found measures which provide that even in the case of ISEE equal to ZERO the recipient of the benefit will pay, even with high rates (up to 35% of the fee) the costs of the service (services falling, often, between the Minimum Standards of Assistance LEA and between the minimum standards of social benefits LIVEAS).

Violations of art.27

The social funds are insufficient to ensure resource policies and consolidated services in the area of competence. Their scarcity, the heavy cutting of financial transfers to the Regions, the strictness of the Stability Pact, a reduction in health expenditure, represent serious and practical limitations to welfare which should be inclusive, universal and showing a logic of investment rather than downgraded to unproductive expenditure.

It is highlighted a tendency to re-institutionalization of dependent persons lacking support of families for which alternative residential options or other forms of support in the community are not provided.

Actions are insufficient, if not absent, to combat poverty and social exclusion of persons with disabilities.

Recommendations

• Enable actions to support persons with disabilities and their families living in poverty, preventing the reduction of services and benefits aimed at children and adults with disabilities.

⁵⁷ Also see ANFFAS press release available here :

ISEE tends higher, which can lead to restricting access to services or extent of such services, if not also in sharing at a higher cost. This is indicative of the erroneous view that children and young people are in any case borne by the family, forcing her to replacement functions for taking over the public, that it should exist to balance, as for the age of majority the disadvantages inherent in condition of disability.

http://www.anffas.net/Page.asp/id=265/N201=18/N101=4280/N2L001=Comunicati%20stampa%20Anffas%20Onlus/se ntenze-tar-lazio-anffas-onlus-illegittimo-il-nuovo-isee and FISH press release of 18 February 2015, available here: http://www.fishonlus.it/2015/02/18/isee-la-fish-chiede-chiarimenti-al-ministero-del-lavoro/

- Introduce active measures to ensure that the social economic benefits reach a minimum enough for an adequate standard of living also developing compensatory measures which could counteract the costs related to the disability condition.
- Strengthen poverty reduction programs
- Monitor the real impact that the new ISEE has on the economic conditions of persons with disabilities, including children with disabilities, and their families

CRC Part I, art. 28

Notwithstanding a legal framework ensuring all pupils and students with disabilities access to mainstream schools and to educational support measures, the qualification of school staff involved in the inclusion of students with disabilities and, as a result, the quality of teaching are often inadequate, resulting in limited access to upper schools and universities and to vocational training. The outcomes in terms of social inclusion and of inclusion at work in the labor market after schooling are unsatisfying, in particular for persons with learning disabilities and for girls and women with disabilities.

Early education

The right of access to mainstream crèches (0-3 years), guaranteed to children with disabilities by Law 104/92, is not enough to guarantee them equal opportunities of development of cognitive, social and communicative. Early childhood is a crucial period for a child's development: some 80% of the upper brain functions develop in the first three years of life⁵⁸. Some research studies show that the most disadvantaged children are those who mostly benefit of early education programmes⁵⁹. This underlines that mainstream crèches should not only include all children with disabilities, in compliance with the national legislation, but also create specific educational interventions aimed at developing cognitive, communication and social skills in young children with disabilities⁶⁰.

The organization of mainstream crèches is for children 0-3 years old are remitted to regional and local rules, including with regard to the allocation of an educator to support classes that includes the allocation of support educators to classes with young children with a disability. The allocated educational support varies from region to region and sometimes from a municipality to another in the same region, on the basis of regional and/or municipal rules and regulations.

The requirements for the access of young children with disabilities vary accordingly from general obligations to disability-based non-exclusion or non-discrimination to positive discrimination policies. Rules and regulations governing crèches do not mention the qualification requirement of educational staff supporting the inclusion of young children with disabilities or the quality of education which is provided for, including the application of appropriate teaching strategies meeting the special educational needs of children with disabilities, as well as the use of alternative/augmentative modes and methods since babyhood.

Notwithstanding the advanced legislative framework and the financial commitment to ensure all students with disabilities access to inclusive education, some exceptions and some challenges remain to be solved.

⁵⁸UNICEF: The state of the world's children 2013. Children with disabilities

⁵⁹United Nations Educational, Scientific and Cultural Organization, 'Inclusion of Children with Disabilities: The early childhood imperative', UNESCO Policy Brief on Early Childhood No. 46, UNESCO, Paris, April-June 2009, <u>http://unesdoc.unesco.org/images/0018/001831/183156e.pdf</u>,31 January 2013.

⁶⁰ Constitutional Court judgment n. 467 / 2002

Exceptions are represented by the Italian schools abroad, which according to their constitution have the possibility, not the obligation to accept pupils with disabilities.

A challenge is represented by a number of schools which do not meet the accessibility criteria for students with disabilities. Data by the Ministry of Education, University and Research (MIUR) concerning school years 2003/2004 and $2009-10^{61}$ show a clear improvement of schools accessibility, although the dismantling of architectural barriers in all school facilities is still to be implemented in 1/3 of school buildings, with substantial differences from region to region.

Another major challenge is the poor quality of education provided to pupils and students with disabilities. Despite of an inclusive education system, several factors contribute to provide a poor quality education to students with disabilities, failing to promote inclusion and participation of adults with disabilities in employment and in society.

Poor and sometimes approximate training of teachers and school staff and in particular of support teachers and communication/ personal assistants supporting the inclusion of students with major learning and communication disabilities on special education and alternative/augmentative communication strategies, on the use of specific aids and of new generation software, challenges learning opportunities for students with major learning and communication disabilities, leading to unsatisfactory results in terms of social and vocational inclusion of persons with disabilities after schooling. The requirements of deaf students who choose sign language as communication tool are not adequately met. During the school year 2011-2012 some 9% of families of students with major learning disabilities and behavioral problems sued their children's schools and public administration to get more support hours to deal with the difficulties met by their children at school.

Moreover the quality of education is challenged by **gaps in the implementation of legislative norms** by schools, by **severe delays** in the **assessment** of functional profiles and timely **individual education planning** for students with disabilities since the beginning of school year, by the **excessive turn-over of support teachers, their** approximate and often **inadequate professional profile, as well as by lack of motivation, of specific competences and collaboration of curricular and support teachers**⁶².

Concerning the continuity of teaching, 14,7% of pupils with disabilities in primary schools and 16,5% of students with disabilities in the first level of secondary school changed their support teachers during the school year 2014-2015, 41,9% of pupils with disabilities in primary school and 36,5% of students with disabilities in first level of secondary school changed their support teachers since the previous school year⁶³.

box 7 - Challenges in the assignment of support places

In 2011 over 300 places for support teachers were been attributed to curricular teachers who lost their place because of the reduction of number of students or teaching hours or because a more entitled colleague arrived from another school. Almost all of them had no qualification to teach students with disabilities. Assigning support places to curricular teachers without qualification is a double mistake. On one hand, because nobody would assign a place for teaching mathematics to a

⁶¹ISTAT: La disabilità in Italia - Il quadro della statistica ufficiale (2009)

http://www3.istat.it/dati/catalogo/20100513 00/arg 09 37 la disabilita in Italia.pdf

⁶²Associazione TreeLLLe, Caritas Italiana e Fondazione Agnelli Gli alunni con disabilità nella scuola italiana: bilancio e proposte, 2011

⁶³ISTAT : L'integrazione degli alunni con disabilità nelle scuole primarie e secondarie di primo grado statali e non statali. Anno scolastico 2014-2015 <u>http://www.istat.it/it/archivio/176952</u>

teacher of Latin. In this respect, the poor consideration of their professions by teachers who choose to teach a subject they are not trained on, instead of moving to another school that is more distant from their home is amazing. On the other hand, - this is the most concerning aspect–the occurrence confirms that support is often considered by school administration (and by the trade unions) as a less important job, that can be assigned to not qualified teachers, thus neglecting the specific needs of students with disabilities in terms of special education competences and strategies, specific training and expertise.⁶⁴

Students with more complex learning and communication disabilities are not only at risk of violation of their right to quality education, but even of **abuse and degrading treatments** at school, offending their dignity and integrity. Several reportages have been published on cases of abuse on pupils with severe intellectual and developmental disabilities **by teachers because of their lack of competences** to deal with their students' challenging behaviors, in violation of articles 15-17 of the CRPD.

box 8 - Some examples of discrimination and abuse towards students with disabilities at school

Trieste, 27.01.09

As reported by the school assistant, the support teacher M.D.F., in order to calm the student with autism who was trusted to her, enacted loosely a dangerous medical manipulation taking him by the neck to compress forcibly the nerves behind the neck. This medical manipulation must be used all the time by experienced doctors in medical settings in order to stop the "paroxysmal tachycardia in children, not for sure in a school setting by a teacher to foster the child's development. According to the Support Journal, the same teacher makes continually and knowingly use of punishments and degrading treatments towards the student with autism, including forcing him to be exposed semi-nude and staled to the school mates view on a mattress. The teacher M.D.F. has recognised not to have any knowledge of autism. Nevertheless, she is convinced that the student has a "normal" cognitive functioning from his glance, and that therefore he is perfectly able to behave his peers, notwithstanding the daily evidence of the opposite.⁶⁵ Students with autism are particularly at risk of such forms of abuse. Following the frequent occurrence of abuses towards their children at school, some parent associations are considering to demand cameras to be installed in school settings.

Vicenza, 8/4/2013

In Vicenza a 14 years old student with autism suffered slaps, insults and illtreatments by the school staff to whom he was trusted. His support teacher and his assistant have been arrested by the police. The student is non-verbal, so that he was not able to report the mistreatments he had to suffer from at school. The two women have been caught in the act of ill-treatment by the police and immediately

⁶⁴Andrea Gavosto, direttore della Fondazione Giovanni Agnelli, La Stampa, 12.9.2011

⁶⁵From the expert opinion Dr. F. N., Child, adolescent and adult psychiatrist, Neurologist, ct 192/2012, to the Trieste Appellate Court, Employment Section, RL 148/2013, concerning the law suit for the re-employment of the support teacher M.D.F

handcuffed because of their abject actions. The advert was made by parents, who acknowledged signs of violence on their child's body, mainly on his head. ⁶⁶

Treviso, 30 /12/ 2014

In a public kindergarten of Mogliano Veneto, the mother of a 5-year-old child with autism was informed by another parent that her child was jerked by the support teacher during the school time. The mother immediately called for an investigation about what happened to the school director and registered a protest. In the meantime, the child refused to go back to school.⁶⁷.

Livorno, 16/6/2015

The parents of a student with severe intellectual and communication disabilities sued the Ministry of Education and the school for disability based discrimination and detrimental behaviour for dignity and liberty of their child by the school staff. The student suffered from discrimination and harassment at school by his support teacher, resulting in offense to his dignity and humiliation based on his disability. Behind recognising these mistreatments, the Court also registered direct forms of discrimination towards the student, as he was excluded from an education travel organised by the school for his class. Moreover, his family was invited not to make him participate in an education event at school. In light of such circumstances both the Ministry of Education and the school have been condemned to refund the non-patrimonial damage in favour of claimers, in consideration of the reiterated and frequent discriminations towards the student.⁶⁸

School leaving of students with disabilities is higher compared to other students, and even higher for students with intellectual and developmental disabilities and for girls with disabilities. As a result, **persons with disabilities have a lower level of education compared to the general population**. Only 17% of persons with disabilities in Italy have middle school diploma, compared to 31% of the general population, 8% of persons with disabilities have higher diploma compared to 28% of the general population.⁶⁹ In 2008-2009 and 2009-2010 girls with disabilities represented 32,6% of pupils with disabilities enrolled in primary schools and 37,3% of students with disabilities enrolled in secondary school. In 2009 16,3% of women with disabilities had no educational qualification, compared to 12,6% of men with disabilities, 25,7% of girls held a diploma or graduated compared 39,6% of boys.

box 9 - Impact of poor quality education on adults with intellectual and developmental disabilities

While 82% of pre-school children with Down syndrome have access to crèches or kindergartens, and up to 97,4% of children aged 6.14 years attend mainstream schools, while the percentage of the adolescents attending mainstream school is reduced to just under half. The same trend occurs among children with autism spectrum disorders (ASD): 93,4% of those under 14, attend mainstream school, compared to 67,1% of adolescents over 14.

 ⁶⁶Gianluca Nicoletti : « Arrestate a scuola: maltrattavano il ragazzo autistico a loro affidato » La stampa, 8/04/2013.
⁶⁷Corriere Del Veneto : « Bimbo Autistico Maltrattato all'asilo. Inchiesta Della Scuola Sulla Maestra », 30 dicembre 2014

⁶⁸N. R.G. 2014/2976 Civil Court of Livorno

⁶⁹Istat 2013, "L'integrazione degli alunni con disabilità nelle scuole primarie e secondarie di primo grado statali e non statali. Anno scolastico 2011-2012

After compulsory schooling, 11,2% only of young people with Down Syndrome have access to vocational training, while 6,7% only of those aged over 20 attend vocational training courses. Their inclusion in the labour market is almost non-existent. 31,4% only of persons with Down syndrome aged over 24 work, of whom the majority (over 60%) does not have any employment contract. More than 70% do not receive any compensation, some receive a minimum salary , lower than the ordinary remuneration for the same job. The situation of persons with ASD is even worst: only 10% of persons over 20 work, including in sheltered work settings.⁷⁰

Ministerial Circular 60/2012 providing for access to home education for students with temporary high level of health needs, excludes from the education system students with disabilities and permanent health needs preventing them to attend school (such as bed ridden or immune-deficient ones). Moreover, the Circular does nor ensure the quality of home education, as it just provides for the assignment of a support teacher at home, while it does not provide for further measures or accommodation needed to develop individually tailored quality education programmes at home.

Violations of art.28

Insufficient and approximate skills of support and curricular teachers on special education strategies and alternative/augmentative communication modes ad methods and the turn-over of support teachers baffle the obligations to ensure children with disabilities the right to education on the basis of equal opportunities. As a consequence, students with disabilities do not enjoy equal opportunities to access higher levels of education, vocational training and inclusion at work. Persons with more complex learning and major communication disabilities are particularly penalized and exposed to the risk of abuse and treatment offending their integrity and dignity, in violation of articles 23 and 37 CRC.

Recommendations

- Design, adopt and use appropriate indicators to monitor the quality of inclusion and education of pupils and students with disabilities in schools and in single classes, including their participation in curricular and extracurricular activities and in terms of access to higher education, vocational training, and inclusion at work after schooling, in conformity with the concluding observation of the CRC Committee. Particular attention must be paid to gender equality issues and to disability-based inequalities towards students with higher educational support needs.
- Enhance the skills of curricular teachers and other school staff on educational needs of students with disabilities through initial and compulsory in service training; establish specific courses on effective special education strategies and alternative/augmentative communication modes and methods which are appropriate to the full range of different education and communication needs of pupils and students with disabilities, as well as specific roles for support teachers; provide the necessary measures to safeguard the educational continuity of teaching for students with disabilities, in compliance with the concluding observations of the CRC and IESCR committees; integrate the draft bill 2444 AC promoted by DPOs in the delegated decree implementing the support reform of the Law 107/2015.
- Include accessibility requirements according to the Universal Design in the requalification of school buildings foreseen in the Law 107/2015, Art.1, 153-155; enhance the access to Universities, including to postgraduate courses, through the uniform provision of services which are appropriate to meet the needs of students with learning and communication

⁷⁰Censis, 3° issue of the «Diario della transizione», 2014

difficulties, namely tutoring, subtitles, sign language interpreters, etc.; promote the enrolment of teachers with disabilities among both the curricular and support school staff.