

Strengthening Participation Rights of Children and Young People with Disabilities in Europe

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“We are what we think. With our thoughts, we make the world”

Buddha

Abstract

This paper deals with an important question: Why children and young people with disabilities are almost absent from the debate about children rights, specially, children participation rights? Figures show that children with disabilities represent, in our society, a minority within another minority, that of “children and young people”.

In order to answer this question, adults should change how to communicate with them and how to reach a major knowledge regarding new means of communication, above all, when new technology is involved. New technologies could facilitate the accessibility to information but also the communication of information and opinions itself. In this way the concept of “reasonable accommodation” should be expanded beyond the employment and occupation areas embracing others domains.

Keywords: children, young people, disability, Europe, participation rights, mean of communication, reasonable accommodation

1. Linking Children Rights and Disability

The subject matter of this research concerns children with disabilities, specifically, the exercise of rights by these children and, in particular, the enjoyment of participation rights. There is significant research and literature that take into consideration, on one hand, children and children rights and, on the other hand, disability and people with disabilities. However, the starting point of both research and literature regarding children rights deals with children with any disability. And the starting point of both research and literature concerning people with disabilities is the “adult’s viewpoint”, that is, children with disabilities are almost absent from both children rights and disability research and literature. The intersection between children rights and disability is in both domains not significant and not properly made, what means in turn that the principle of equal opportunities in the field of children and children rights does not have practical application.

By means of this paper I would like to contribute to the “visibility” of children with disabilities and strengthen the exercise of their rights to participate in our society as other children can or at least could do. First of all, I would address some figures (1.1), whereby we could turn a vision into this social reality; then I attempt to expose the reasons which explain why children with disabilities are, in our society, “still” invisible (1.2). I conclude this section with some observations (1.3).

1.1 Statistics Data

As stated by UNICEF, Innocenti Research Centre, almost 650 M. people worldwide are living with disabilities. 10 % of the world’s children have sensory, intellectual or mental and physical health impairments¹, that is, 200

¹ UN Convention on the Rights of Persons with Disabilities (hereafter as “CRPD”) presents a holistic approach when defining “disability”. Indeed, Art. 1 para.2 sets forth that: “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

M. children, 80% of whom are living in developing countries².

In Europe, the EU Commission has addressed that one of every six persons presents some kind of moderate disability, which means about 80 M. of the total EU population³, most of whom are adults. Due to the lack of births⁴, young people in Europe-27 in 2012 are just 23.4 % of the total population including 2 to 3 % of children with disabilities⁵.

Contrary to common thinking, the rate of children who are born with disabilities is very low because of, on one side, the nowadays good health and living conditions of the parents and, on the other side, the prenatal detection of diseases using new technologies that permits to interrupt the pregnancy. Accordingly, most of the disabilities appear during the course of a person's life due to different factors⁶ and they increase with age. We can find the higher rate (30%) at 65 years old or more⁷.

others". The definition remarks the social model moving away from the medical pattern of disability or, at least, that was the drafters' purpose.

The first definition of disability in Europe was appointed by the European Union Court of Justice (hereafter as "EUCJ") in the *leading case* Sonia Chacón Navas v. Eurest Colectividades, SA (Case C-13/05, 11 July 2006, paras.43-44) in relation to the *Council Directive 2000/78/EC, of 27 November 2000, establishing a general framework for equal treatment in employment and occupation* (OJEU L 180, 19 July 2000). According to this judgment the concept of disability is not defined by the Directive 2000/78 itself. Nor does the Directive refer to the laws of the Member States for the definition of that concept. In the context of the Directive (the Directive aims to combat certain types of discrimination as regards employment and occupation) the concept of "disability" must be understood "as referring to a limitation which results in particular from physical, mental or psychological impairments and which hinders the participation of the person concerned in professional life" (para.43). Disability differs from "sickness". The two concepts cannot be treated as being the same (para.44). Disability is defined by the EUCJ in a medical way rather than in a social fashion [D. Schiek, D., Waddington, L. & Bell, M. (2007). *Non-Discrimination Law*. Oxford / Portland: Hart Publishing, pp. 137-138].

Some EU Member States have included no definition of disability, when implementing the above-mentioned Directive (e.g. Belgium, Bulgaria, Greece, Italy, Poland, Romania, Slovakia). However, this does not mean that there is not a definition of disability at all. Indeed, these countries leave the definition to national social security legislation defining the requirements in order to determine the eligibility for a pension whilst there is no definition of disability in national non-discrimination legislation. Other Member States have chosen to introduce a definition of disability within non-discrimination legislation like Austria, Malta, Portugal, Sweden and UK with a highly medical approach. Czech Republic and Slovenia have borrowed the definition of disability from other legislation, notably, from the social security legislation. On the other side, a number of EU Member States have implemented the disability provisions of the Directive in two different rules: one law concerns non-discrimination whilst the second refers to the reasonable accommodation duty. Such an approach is typically in Germany, France and Hungary. Spain has included a definition of disability in non-discrimination legislation [the legislation of the EU Member States is mentioned by Waddington, L. & Lawson, A. (2009). *Disability and non-discrimination law in the European Union*. European Commission, July, pp. 21-26].

² UNICEF (2007), Innocenti Research Centre, Innocenti Digest13. *Promoting the Rights of Children with Disabilities*.

³ That is approximately 25 % of the EU Population aged 16+; people with some kind of limitations in daily activities. The rate of women, who have a limitation, is higher than that of men [*Communication from the Commission to the European Parliament, the Council, the European economic and social Committee and the Committee of the regions. European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe*, COM(2010) 636 final].

⁴ The number of children that would be born alive in 2011, for EU-27, is just 1.57 per woman (<http://epp.eurostat.ec.europa.eu/tgm/table.do?tab=table&init=1&language=en&pcode=tsdde220&plugin=1>). Retrieved May 2014.

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http://epp.eurostat.ec.europa.eu/statistics_explained/index.php?title=File:Population_age_structure_indicators_2011.png&filetimestamp=20130129113545. Retrieved May 2014.

⁶ Relevant factors for disabilities in adults' lives are: risky lifestyles, poverty and low education, sickness during the course of life and accidents at work or professional diseases [Applica, Cesep & European Centre (2007), *Study of Compilation of Disability Statistical Data from the Administrative Registers of the member States*. Final Report, November, p. 24].

⁷ Grammenos, S. Idee, indicators of disability equality in Europe. ANED 2011 Task 4, Update and extend the piloting of quantitative implementation indicators, *Comparative data on a selection of quantitative implementation indicators*, October, 2011 (ANED 2011 Task 4 – Synthesis Report.doc).

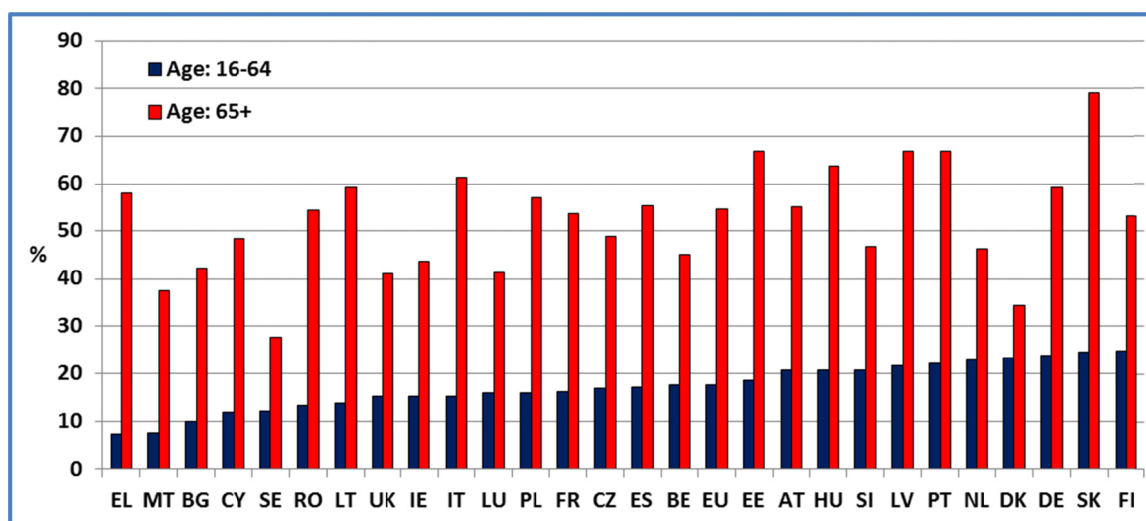


Figure 1. People reporting activity limitations by age group, 2009

As a % of the general population in same age group

Data source: EU-SILC 2009

These figures show that “children with disabilities” represent, in our global society, a minority within another minority, that is, within the minority of “children and young people”⁸. The rate of children with a moderate limitation is higher than the rate of children with a severe impairment⁹. There are, in general, more moderate than severe limitations for daily life activities.

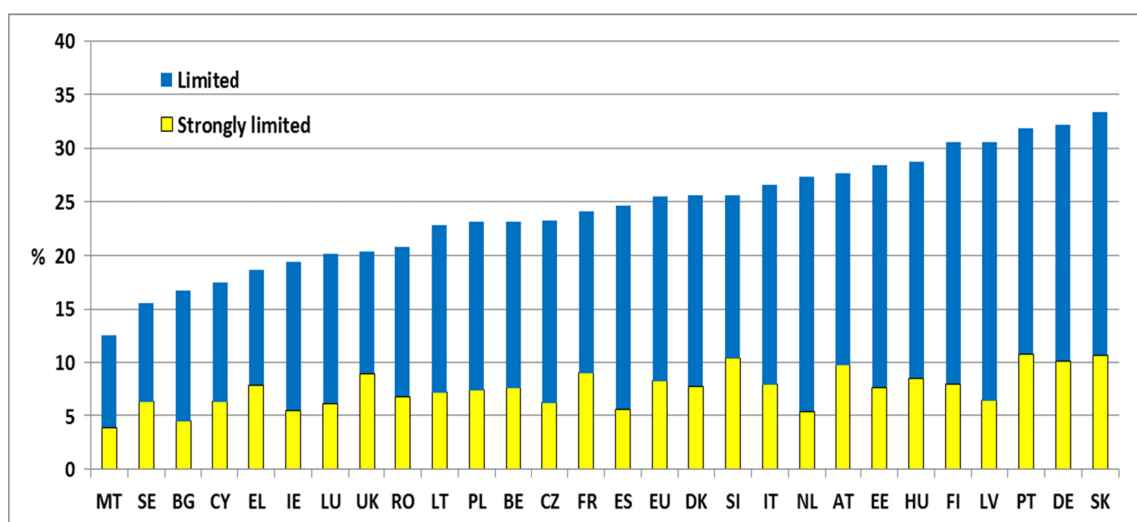


Figure 2. People reporting activity limitations by Member State and degree of limitation; 2009

As a % of the general population; age 16+

Data source: EU-SILC 2009

⁸ In Spain, for instance, there are 3.8 M. people with disabilities, that is, 8.3% of the total population. Among them only 139.000 children have some kind of disabilities, which means 3.6 % of the total of people with disabilities and 0.4 % of the total Spanish population [Colectivo IOÉ (2012). *Discapacidades e inclusión social*. colecc. Estudios sociales, 33. Obra social “La Caixa”, Barcelona].

⁹ Grammenos, S. Idee, indicators of disability equality in Europe. ANED 2011 Task 4, Update and extend the piloting of quantitative implementation indicators, *Comparative data on a selection of quantitative implementation indicators*, October, 2011 (ANED 2011 Task 4 – Synthesis Report.doc).

1.2 The “Still” Invisibility of Children and young People with Disabilities. Why?

Children with disabilities are absent from public debate. Indeed, they are usually not taken into account by psychologists, sociologists, social workers, educators and jurists in the scientific research. As an example, I would highlight the very interesting Feldman, Battin, Shaw & Luckasson’ article, who have selected two well-known and with high-impact developmental journals (*Child Development* and *Development Psychology*) from 1996 to 2010, in order to see how many of the published articles were concerned with the mainstreaming and integration of children with disabilities¹⁰. The results that the authors obtained were astonishing: *the exclusion rate of children with disabilities was 90%, 74 % of the studies did not provide justification for exclusion*. Possible reasons for exclusion are, as the authors point out, that the person with disabilities is seen as a vulnerable human being, as a potential victim of abuse and exploitation, he or she is not able to give consent to the research protocol due to his or her disability or cannot communicate properly¹¹. Particular exclusion is suffered by children and young people with significant mental impairments, who cannot use speech as a mode of communication¹².

All of these reasons show the mental barriers that researchers themselves have, rather than being representative of the persons’ and, especially, the disabled children’s point of view¹³. Accordingly, children with disabilities are defined by what they cannot do, rather than what they can¹⁴.

Parents are also reluctant to permit research with their children because they seek to protect them from abuse, exploitation and stigmatization from society. They see their children not only “different” but as a “deviation” when compared with non-disabled children, although they advocate for children rights. Actually, they advocate more for their rights as parents of disabled children, rather than for the rights of these as active actors involved in the decision-making process¹⁵.

Society and adults (including, parents) view children and young people with disabilities with mixed feelings: on one side, as a stigma and, on the other side, with a “paternalistic” bias. This last approach is not so strange. Indeed, the general pattern of family and that of the child that emerges from the data provided by the OECD and EUROSTAT is a traditional and conservative one, in which the child is seen as depending on an adult (usually, the parents) and needing special care, help and assistance¹⁶. This pattern is self-evident when we handle with children and young people with disabilities, area in which there is, in my opinion, an “exacerbated” paternalism. It could be said that they are facing with a “redouble” and doubtful paternalism: on one hand, as children and, on the other hand, as disabled people.

From the society’s viewpoint, paternalism and paternalistic measures could hide some kind of discrimination. The Council of Europe’s Commissioner for Human Rights, Thomas Hammerberg, in 13th March 2012, has stressed in relation to disabled people in general that:

“Whether due to stigma, inaccessibility of places, technologies, services and social structures, or lack of support within the community, people with disabilities have been isolated and segregated from their communities. People in many countries are confined to institutions, and therefore segregated from the

¹⁰ It is worth to mention that, in the UK, among others, the Social Policy Research Unit of the University of York does current research with children and young people with disabilities; in particular, concerning their participation rights [Franklin, A. & Sloper, P. (2009). Supporting the Participation of Disabled Children and Young People in Decision-making. *Children & Society* 23, pp. 3-15].

¹¹ Feldman, M. A., Battin, S. M., Shaw, O. A. & Luckasson, R. (2012). Inclusion of children with disabilities in mainstream child development research. *Disability & Society*, pp. 1 et seq.

¹² Rabiee, P., Sloper, P. & Beresford, B. (2005). Doing Research with Children and Young People Who Do Not Use Speech for Communication. *Children & Society* 19, pp. 385-396.

¹³ Feldman et al., 2012, (note 11), p. 4, stress, as mental obstacles coming from researchers, overestimation of vulnerability, underestimation of ability, lack of experience and discomfort with disability, research requires sample homogeneity, and lack of foresight and accommodation. The fact that children with disabilities, as I attempted to show above, are a real minority could be another factor as well, in order to exclude them from the arena. They are not representative in general of children and young people.

¹⁴ Rabiee et al., 2005 (note 12), p. 385.

¹⁵ In 2000, in the field of disability, Hahn, H. (2000) spoke about “the hegemony of paternalism” in Accommodation and the ADA: Unreasonable Bias or Biased Reasoning?. *Berkeley Journal of Employment and Labor Law* 21, p. 181.

¹⁶ Navas Navarro, S. (2013). Child’s Life, Step-Family and Decision-Making Process, *Beijing Law Review* 4-2 (www.scirp.org/journal/blr). doi: 10.4236/blr.2013.42008.

community. In institutions, they are at risk of exploitation, violence and abuse. Countless more people with disabilities are physically located in their communities, but barred from meaningful participation in the life of their communities because either services are not available or communities are organised in ways that exclude them from participation”¹⁷.

It should be noted that two years before the Commissioner, as key recommendation on children rights, has stressed that:

“A child-centred approach based on the principle of the child's best interest should govern all decisions regarding children. Children should be viewed as individual subjects and their views should be taken into account, with due regard for their development and maturity”¹⁸.

The intersection between discrimination based on disability and on age is the kind of discrimination that, even in our society today, children and young people with disabilities suffer. Sometimes another ground of discrimination, such as gender or/and race is added. This is the so-called “multiple” or “multi-dimensional” discrimination¹⁹.

In this sense, they must fighting twice: first, against the idea that children are immature and they cannot express their views suitably, although international and domestic legal instruments set forth that children shall be heard; secondly, against the idea that views coming from disabled children and young people have less value than those coming from non-disabled persons.

Children and young people are concerned with their independence and self-determination²⁰. Children and young people with disabilities are not an exception: they wanted to be heard and to have the opportunity to express their views about matters affecting them, such as, health, leaving care, school, needs, education system, leisure activities and preferences. Disabled children should not be seen as requiring special protection and perceived as incapable of participating in normal social processes²¹.

1.3 Outcome

Albeit the CRPD has established a new pattern of disability²², notably, the underpinned “social” model, and sets rules regarding children rights, the paradigm of disability is not changed, when considering participation of children and young people with disabilities in the decision-making process and their involvement in social matters. Indeed, the “medical” model²³ remains very influential in how society, when children and young people are concerned, copes with disability. The participation of disabled children and young people as real social actors

¹⁷ “The right of people with disabilities to live independently and be included in the Community”, Issue paper (2012)3, https://wcd.coe.int/ViewDoc.jsp?id=1917847#P188_14563. Retrieved June 2014.

¹⁸ <https://wcd.coe.int/ViewDoc.jsp?id=1621589>. Retrieved June 2014.

¹⁹ On this topic, see: Degener, T. (2011). Intersection between Disability Race and Gender in Disability Law. in: Schiek, D. & Lawson, A. (2011). *EU Non-discrimination Law and Intersectionality*. Ashgate, Surrey, pp. 29 et seq.; Ellis, E. & Watson (2012). P. *EU Anti-Discrimination Law*. 2on edition, Oxford: Oxford University Press, pp. 156-157.

²⁰ Navas (note 16).

²¹ Cavet, J. & Sloper, P. (2004). Participation of Disabled Children in Individual Decisions About Their Lives and in Public Decisions About Service Development, *Children & Society* 18, p. 281.

²² As it is well-known the “social” model approach states that it is the society which disables people. The limitation to do daily activities is caused by the social organization that takes little account of people who have some kind of impairments, whereby they are excluded from participating in social life and preventing the economics and social benefits for the entire society [Barnes, C., Mercer, G. & Shakespeare, T. (2000). *Exploring Disability. A sociological Introduction*. Cambridge: Polity Press, p. 78]. The “social” paradigm of disability has taken, as known, the human rights approach [Kanter, A. S. (2003). Essay: The Globalization of Disability Rights Law. *Syracuse J. Int’L. & Com.* 30, p. 241; Stein, M. A. (2007). Disability Human Rights. *Cal. L. Rev.* 95, pp. 1 et seq.; Gostin, L. O. & Gable, L. (2009). The Human Rights of Persons with Mental Disabilities: A Global Perspective on the Application of Human Rights Principles to Mental Health. *Wayne State University Law School Legal Studies Research Paper Series*, No. 08-31, may 14, www.ssrn.com/link/Wayne-State-U-LEG.html. Retrieved June 2014; Asis, R. de, Bariffi, F. & Palacios, A. (2007). Principios éticos y fundamentos jurídicos. In Lorenzo, R. de & Pérez Bueno, L. C. (Eds). *Tratado sobre Discapacidad*. Cizur Menor: Thomson, Aranzadi, pp. 83 et seq.].

²³ Historically, disabled people were contemplating as sick people needing medical care. There was a medicalization of the disabled body seeking to “repair” it [Barnes et al., (note 22), pp. 59-60; Asis, R. de et al., (note 22), pp. 83 et seq.].

in the community²⁴ could turn this “medical” paradigm into a “social” one that will allow them to show what they are able to do by themselves. Furthermore, it enhances family and child well-being.

Moreover, as affirmed before, children and young people with disabilities constitute a minority; so, the risk that their human rights are violated is extremely high. Most of them, because of their communication impairments, require another person to act on their behalf. The fact that the said person are not able to take on this role on account of his or her lack of training and education in dealing with disabled children is a barrier to exercise his or her rights and in particular to participation rights.

2. Participation Rights of Children and Young People with Disabilities

Primary, I will set out the European legal framework in relation to the rights of children and young people with disabilities (2.1). Then, I will introduce the two main European strategies supporting and promoting the rights of disabled people and children rights (2.2) and, finally, I will focus on the right of children and young people with disabilities to be heard and to express their views (2.3).

2.1 The European legal framework

The European legal framework, which I take into account, refers to two main institutions: the Council of Europe and the European Union.

The Council of Europe, as it is well-known, has undertaken an important task concerning legal instruments related to human rights²⁵. Notably, from the former *European Convention for the protection of the rights and fundamental freedoms* signed in Rome in 1950 to the *European Convention for the prevention of torture and inhuman or degrading treatment or punishment* of 1987 coming across to the *European Social Charter* signed in Turin in 1961, which was amended in 1996. All these instruments, even though they make references to the rights of persons with disabilities, do not even have any mention to disabled children. We must wait until year 2007 in order to read a legal instrument that makes a single one specific reference to them. It was the *Convention for the protection against sexual exploitation and sexual abuse*, which has enclosed some rules affecting children with disabilities. Unlike other international legal instruments, Art. 2, when states the principle of non-discrimination, lists “disability” as one possible ground of inequality.

Art. 2 – Non-discrimination principle

“The implementation of the provisions of this Convention by the Parties, in particular the enjoyment of measures to protect the rights of victims, shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth, sexual orientation, state of health, *disability* or other status”.

Art. 18 settles that States Parties shall adopt the necessary measures to ensure that the abuse of the child made in a particular vulnerable situation, notably because of a mental or physical disability, is criminalized. Next to it, Art. 28 considers as an aggravating circumstance the fact that the offence was committed against a particular vulnerable victim; thus, a disabled child.

As a result of the activity of the Committee of Ministers of the Council of Europe, it was adopted the 12th December 2007 the Resolution AP (2007) 4 on the *education and social inclusion of children and young people with autism spectrum disorders*.

If we focus, at this moment, on the European Union, we shall address the *Charter of Fundamental Rights*, which was signed in Nice in 2000²⁶. This legal instrument incorporates “disability” as one ground of discrimination.

Art. 21. Non-Discrimination

“1. Any discrimination based on any ground such as sex, race, colour, ethnic or social origin, genetic features, language, religion or belief, political or any other opinion, membership of a national minority, property, birth, disability, age or sexual orientation shall be prohibited”.

Neither Art. 24 EU Charter mentions disability when considering children rights nor Art. 26 refers to children when stressing the right of persons with disabilities to be included in the community²⁷.

²⁴ Badham, B. (2004). Participation – for a Change: Disabled Young People Lead the Way, *Children & Society* 18, pp. 143-154.

²⁵ All of the Treaties and Conventions of the Council of Europe could be consulted at: <http://conventions.coe.int>. Retrieved June 2014.

²⁶ Last draft of the Charter could be consulted at: OJEU C 326/400, 26th October 2012.

In 2007, the EU signed the CRPD. This signature was a milestone because it was the first time that the EU signed a Human Rights Treaty with worldwide application and the first time that one regional organization, as the EU is, could be a signatory²⁷. On 23 December 2010, the European Union ratified the CRPD²⁹. It was ratified just weeks after the European Commission published the European Disability Strategy 2010-2020, that sets out the programme of action to empower people with disabilities that we will refer to later on. Ratification means that the EU is now bound to ensure that the right of children and young people with disabilities are respected, protected and fulfilled³⁰.

Furthermore, the same year, the European Commission attributed to the EU Charter the same legal value as the Community Treaties or the Treaty of the European Union have (Art. 6 para.1 TEU of Lisbon and Art. 52 para.2 EU Charter), which means that the rights and fundamental freedoms stated in it have direct application in all EU member States and that the EUCJ shall enforce them. The application could be made from the child's rights perspective avoiding adult's viewpoint aiding the provisions of the CRPD in interpreting Art. 24 EU Charter. Accordingly, the CRPD will be part of the foundation of the universal right to equality before the law and protection against discrimination in the EU³¹.

"Disability", as one ground of discrimination that allows the EU Council to adopt all measures and take appropriate action to combat discrimination, was introduced in 1997 in Art. 13 of the Treaty of Amsterdam³². This rule has been reproduced by Art. 19 of the Treaty of Lisbon³³. Moreover, the Treaty considers in Art. 10 that one of the EU aims is combating discrimination based on different grounds, one of which is "disability".

Art. 10. "In defining and implementing its policies and activities, the Union shall aim to combat discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation".

Art. 10 of the Lisbon Treaty has been highlighted as clear illustration of the EU strategy of mainstreaming or transversal application of the values set forth in Art. 2³⁴, in which the EU is founded: human dignity, freedom, democracy, equality, respect for human rights, including rights of persons belonging to minorities, pluralism, non-discrimination, tolerance, justice and solidarity.

This presentation of the main European legal instruments allows to draw two conclusions: in the first place, the interest of the European bodies for the protection and support of people with disabilities has really increased after the signature of the CRPD and, secondly, that there is not a clear intersection between children rights and disability, although both the CRPD and the UN Convention on the Rights of the Child³⁵ have considered within its framework the rights of children and young people with disabilities. Indeed, the disability perspective is taken into account by Arts. 3 lit. h, 4 para.3, 7, 8 para.2 lit. b, 13, 16, 18 para.2, 23 para.1 lit. c, 23 para.2, 3,4,5, and 24

²⁷ As a reminder, two important EU legal instruments in the field of disability are: firstly, the *Council Directive 2000/78/EC, of 27 November 2000 establishing a general framework for equal treatment in employment and occupation*, that we have already taken into consideration and secondly, the *Regulation 1107/2006, of the European Parliament and of the Council, of 5 July 2006 concerning the rights of disabled persons and persons with reduced mobility when travelling by air* (OJEU L 204, 26th July 2006). See: Alonso Soto, F. (2007). Tratamiento de la discapacidad en la Unión Europea. In Lorenzo, R. de & Pérez Bueno, L. C. (Eds). *Tratado sobre Discapacidad*. Cizur Menor: Thomson, Aranzadi, pp. 319 et seq.; Clifford, J. (2011). The UN Disability Convention and its Impact on European Equality Law, *The Equal Rights Review VI*, pp. 11 et seq.

²⁸ The signature of the CRPD by the EU is one of the grounds in which the Proposal for a new non-discrimination Directive irrespective of religion or belief, disability, age or sexual orientation in 2008 is drafted [see: Bell, M. (2009). Advancing EU Anti-Discrimination Law: the European Commission's 2008 Proposal for a New Directive, *The Equal Rights Review 3*, pp. 7-18].

²⁹ Regarding the drafting process of the CRPD and the negotiation process with the EU, see De Búrca, G. The EU in the negotiation of the UN Disability Convention, *Fordham Law legal Studies Research Paper No. 1525611* (http://papers.ssrn.com/sol3/papers.cfm?abstract_id=1525611). Retrieved June 2014.

³⁰ Clifford, (note 27), pp. 11 et seq.

³¹ Clifford, (note 27), pp. 11 et seq.

³² By this rule the EU has acquired competence in respect of disability issues. See: Lawson, A. (2005). The EU Rights based Approach to Disability: Strategies for Shaping an Inclusive Society. *International J. of Discrimination and the Law 6*, p. 269.

³³ To be consulted at: <http://register.consilium.europa.eu/pdf/en/08/st06/st06655-re07.en08.pdf>. Retrieved May 2014.

³⁴ Biel Portero, I. (2011). *Los derechos humanos de las personas con discapacidad*. Valencia: Tirant Lo Blanch, p. 271.

³⁵ Hereafter as "CRC".

para. 2 lit. a CRPD and by Art. 23 of the CRC. Furthermore, the Committee on the Rights of the Child has shown its concerns for the situation of children with disabilities and, thus, in 2006, a General Comment was proposed (n.9) relating the rights of children with disabilities aimed to support States in order to reinforce the application of their rights³⁶.

2.2 Two European Strategies: People with Disabilities and Children Rights

An attempt to turn this situation is the European strategy of both the Council of Europe and the European Union regarding people with disabilities and children rights.

The Council of Europe Disability Action Plan 2006-2015 refers to the barriers that children and young people with disabilities face in our society, experiencing in some cases multiple discrimination. Consequently, the *Recommendation Rec(2006)5 of the Committee of Ministers to member states on the Council of Europe Action Plan to promote the rights and full participation of people with disabilities in society: improving the quality of life of people with disabilities in Europe 2006-2015*³⁷ has highlighted in section 4.4 the needs of children with disabilities and their families, meaning that they need structures of support that ensure an appropriate development of the child in order to have an independent adult life. This aim could be only achieved when they can participate in the decision-making process influencing decisions about all aspects that affect them. The voice of children and young people with disabilities should be heard.

In light of these thoughts, the *Council of Europe Strategy for the Rights of the Child (2012-2015)*³⁸ has launched a cross-cutting programme, in which introduces the Council of Europe's role and the actions that should be taken for implementing children rights effectively. This programme will focus on four strategic objectives: objective 3 is about guaranteeing children rights in special vulnerable situations and objective 4 is about promoting participation rights of children. In accordance with these objectives, the Council provides expertise and guidelines to member states to protect the rights of children with disabilities through the implementation of the CRPD and to promote the full participation of disabled children in society, having the right to express their views.

The European Union has stated that one of its objectives is the promotion and protection of the rights of the child on which the Lisbon Treaty has put special emphasis. In the *Communication from the Commission to the European Parliament, the Council, the European economic and social Committee and the Committee of the Regions*³⁹, the European Commission has launched an EU Agenda for the Rights of the Child for the 21st century. Its purpose is to reaffirm the commitment of all EU institutions and of all member States to promoting, protecting and enforcing the rights of children. As established by the Communication, disabled children are more vulnerable to having their rights violated and deserve special protection. Accordingly, the *Commission Communication on a European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe*⁴⁰ has addressed the needs of disabled children and the importance that their rights should be respected. In addition, there is full recognition of children rights in the sense that they should be given the chance to express their opinions and to be involved in all aspects of their life. The starting point for a greater participation of children will be the implementation of actions and policies in order to consult children and listen to them. The EU Commission has justified this Strategy as necessary to implement the CRPD in Europe.

What is surprising to this author is that the EU Strategy on children rights of 2006⁴¹ has stressed the same actions and policies and, after seven years of the last Action Plan, there is still the necessity to renew the commitment to step up efforts in protecting and promoting the rights of children. There is a strong suspicion that the former EU Strategy concerning children participation rights has not been properly implemented. So, even less the participation rights of disabled children.

³⁶ CRC/C/GC/9. To be consulted at: [http://www.unhcr.ch/tbs/doc.nsf/898586b1dc7b4043c1256a450044f331/405ba882cb9eb3a0c12572f100506ac4/\\$FILE/G0740702.pdf](http://www.unhcr.ch/tbs/doc.nsf/898586b1dc7b4043c1256a450044f331/405ba882cb9eb3a0c12572f100506ac4/$FILE/G0740702.pdf). Retrieved June 2014.

³⁷ <http://www.ijic.org/index.php/ijic/article/viewArticle/386/770>. Retrieved June 2014.

³⁸ COM(2011) 171 final, 15th February 2012.

³⁹ COM(2011) 60 final.

⁴⁰ COM(2010) 636 final.

⁴¹ COM(2006) 367 final.

2.3 The Right of Children and Young People with Disabilities to Be Heard and Express Their Views Within and Beyond Their Family

This section encompasses, first of all, the importance attached to the “communication” of views for the free development of the human potentiality for disabled children (2.3.1); secondly, it is concerned with the “means” by which children and young people with disabilities are informed and give their opinions in all matters that affect them, in particular, in respect of their well-being (2.3.2); and, lastly, the concept of “reasonable accommodation” as a key measure to help disabled people to be heard and express their views is stressed (2.3.3).

2.3.1 Communication and Free Development of the Personality

Art. 12 CRC and Art. 24 EU Charter settle the right of the child to be heard and express his or her views in all aspects of his or her life. Scholars set out different levels of children participation in decision-making process: children are informed, children are listened to and express views, children views are taken into consideration, children are involved in decision-making process and children share decisions and responsibility with adults. Those rules refer only to the first three levels of participation. Nevertheless, they should be interpreted in accordance with other prescriptions both of the CRC and of the EU Charter. Hence, Art. 5 CRC sets forth those adults shall support and guarantee the exercise of rights of children by themselves according to their age and maturity, expanding the participation of children to the fourth aforementioned level⁴².

Disabled children cannot be considered as incapable to take and share decisions concerning matters that affect them. Art. 13 CRC establishes that children should be willing to seek, receive and impart information by any means of communication. Importance should be attached to child’s decisions concerning their care, treatment and well-being⁴³.

Children and young people with disabilities have the same right to be involved in the decision-making process as non-disabled children and young people do. In fact, Art. 12 CRC and Art. 24 EU Charter make no distinction between them and Art. 7 para.3 CRPD emphasizes that “*States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right*”.

If we take into account that the CRPD is part of the foundation of the universal right to equality before the law in the EU and protection against discrimination, as I have pointed out, we should stress that Art. 24 EU Charter shall be interpreted in accordance with the provisions of the CRPD and in particular, with the above-mentioned Art. 7 para.3 CRPD.

The expression of children views is a key element for the development of their personality, the strength of human potentiality and their well-being within and beyond the family. It is in their “best interests” (Art. 3 CRC, Art. 24 EU Charter, Art. 7 CRPD). For the exercise of this right, Art. 12 CRPD is of high value. Indeed, this rule provides the recognition of the persons with disabilities to enjoy legal capacity on an equal basis with others in all aspects of life and that States Parties shall take appropriate measures to provide access to the persons with disabilities to the support they may require in exercising their legal capacity. Art. 12 CRPD applies to all people with disabilities regardless of the form of disability. Therefore, in case of severe impairment that difficult the communication of the person, appropriate measures may include third person assistance to support her or him in taking decisions and exercising her or his rights, merely, her or his legal capacity⁴⁴. Both Art 12 and Art. 7 para.3 CRPD go in the same direction, that is, *disabled people, regardless of their age and maturity, have the right to be informed and express their opinions in all aspects of life, on equal basis with non-disabled people, and to be provided with the appropriate assistance in order to enjoy and realize this right*. Age and maturity are just criteria for giving due weight to their opinions⁴⁵.

⁴² Lansdown, G. (2010). The realization of children’s participation rights. In Percy-Smith, B. & Thomas, N. (Eds). *A Handbook of Children and Young People’s Participation*. Oxon: Routledge, p. 13.

⁴³ Cavet & Sloper, (note 21), p. 279.

⁴⁴ Clifford, (note 21), p. 16.

⁴⁵ Regarding these two different criteria representing two main philosophical theories see: Archard, D. (2004). *Children. Rights and Childhood*. 2nd ed., Oxon: Routledge, pp. 53 et seq.

2.3.2 “Means” of Communication

The first aspect to be considered is the way that information is given to disabled children and young people depending on their impairments. Adults usually give information using means of communication from their point of view. They do not seek to modify “*their*” means of communication when children are involved and even less when disabled children are concerned. So, the first question we have to put in public debate is “*how*” adults give information to the children taking into account environmental and psychological circumstances. Adults tend to reject means of communication that are seen different from which they usually use⁴⁶, even though the definition given by Art. 2 CRPD of “communication” includes “*languages, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology*”. Thus, adults (including, parents and other relatives or family members) should change their attitudes and mental barriers when facing the communication with disabled persons.

The second issue to be confronted with relates to the “means” by which children and young people with disabilities can communicate their views, especially when children or young people, who do not use speech as mean of communication, are involved⁴⁷. The right question is not if they can participate, rather *how* they can participate in decisions affecting them. There is a strong trend that children and young people with disabilities express their views mostly through adults, notably their parents, than non-disabled children and young people do⁴⁸. Of course, parents and adults in general are, in this case more than in other cases, really “*facilitators*”. However, instead of giving the chance to children and young people with disabilities to express their opinions by themselves, they substitute them and express views that, supposedly, children and young people would express if they did not have such disabilities, preventing these persons from effectively participating in a free, open and global society and carry out daily activities. There is clearly a barrier that should be removed. The use of a specific “means” of communication gives the perception that disabled children are not capable to express their views and to understand the delivered information. However, just changing the “means” or adapting those means to the impairment, this perception could be totally different.

Art. 13 CRC does not limit the ways that children can express their opinions depending on the situations and on the child⁴⁹. Some studies have suggested that children with specific impairments are not being allowed to exercise their full rights regarding participation in decision-making process (e.g. “ventilator dependent” young people)⁵⁰. Nevertheless, when participation takes place, it is seen as a positive experience by children and young people with disabilities because they gain confidence and could develop new skills⁵¹, that is, it is in their best interests (Art. 3 CRC, Art. 7 CRPD, Art. 24 EU Charter). Indeed, the “best interests of the child” should be contemplated as the adjustment of the community to disabled people removing barriers and thus allowing the free development of their personality, rather than consider that the best interests of children and young people with disabilities is to conform to a non-disabled environment⁵².

⁴⁶ Badham, (note 24), p. 150; Cherney, I. D., Greteman, A. J. & Traves, B. G. (2008). A Cross-Cultural View of Adults’ Perceptions of Children’s Rights, *Soc. Just. Res* 21, pp. 447-448; Bainham, A. (2006). *Children. The Modern Law*. 3th ed. Bristol: Family Law, pp. 98-99; Breen, C. (2002). *The Standard of the Best Interests of the Child. A Western Tradition in International and Comparative Law*. The Hague / London / New York: Martinus Nijhoff Publishers, pp. 67-68; Lansdown, G. (note 42) , p. 15.

⁴⁷ Such people are at high risk of human rights violation. Art. 12 para.4 CRPD provides that States Parties shall ensure that safeguards to prevent abuse in accordance with international human rights law are taken, when disabled persons exercise their legal capacity [Clements, L. & Read, J. (2005). *The Dog that Didn’t Bark: The Issue of Access to Rights under the European Convention on Human Rights by Disabled People*. In Lawson, A. & Gooding, C. *Disability rights in Europe from theory to practice*. Essays in European Law. Oxford: Hart Publishing, pp. 24 et seq.].

⁴⁸ Rabiee et al. (note, 12), p. 385.

⁴⁹ Lansdown (note 42), p. 12.

⁵⁰ Cavet & Sloper (note 21), p. 282.

⁵¹ Franklin & Sloper (note 10), p. 12.

⁵² Lansdown, G. What works? Promoting the rights of disabled children Guidelines for action, http://unipd-centrodirittumani.it/public/docs/31688_rights.pdf. Retrieved June 2014.

2.3.3 Means of Communication as “Parental Duty” and as “Reasonable Accommodation”

In this section, I face two issues: first, the participation rights of disabled children within their family (2.3.3.1) and second, the participation rights within the community (2.3.3.2) from the viewpoint of the “means” of communication.

2.3.3.1 Within the Family

Parents as well as other adults could be entitled to exercise parental responsibilities over the child in his or her best interests⁵³. Nonetheless, this is only possible if they inform the child and allow that he or she could express his or her views. In other words, adults should facilitate that children could communicate their opinions rather than substitute them. In fact, parents (or other adults) should be seen less as legal representatives and more as supporting persons.

When children and young people with disabilities are involved, depending on the form of impairment, the duty of parents (or other adults that take responsibility over these children) is to provide for appropriate and effective means of communication enabling those children to express their opinions in all aspects of life. In this sense, parents, adults and disabled people could profit from new technologies that give new insights of communication. The problem here could be that new technology is not always offered at a minimum cost. Whether parents could or not benefit from an allowance or subsidy for acquiring such technology depends on the national legislations. In any case, the duty of the parents is to do what is reasonable in order to enable disabled children to communicate their views. However, it should not go in detriment of other family members’ interests, who have the same right to express their views and participate in decision-making processes, that is, to exercise and realize their fundamental rights. Therefore, parents should consider a balance-of-interests of all the involved persons. The proportionality test, when fundamental rights of disabled and non-disabled family members are concerned, should be applied (Art.52 para.1 EU Charter).

2.3.3.2 Within the Community

Having the opportunity to be informed and to communicate their own views, on an equal basis with others (Art. 3 lit. e CRPD), enabling children and young people with disabilities to live independently and express freely their opinions in all aspects of life, is the core element of the “*accessibility*” principle stated by Art. 9 CRPD. Hence, in order to promote accessibility States Parties shall take appropriate measures, on one side, to give assistance and support to persons with disabilities to ensure their access to information (Art. 9 para.2 lit. f CRPD), to promote access to new information and communication technologies and systems (Art. 9 para.2 lit. g CRPD) and, on the other side, to promote the design, development, production and distribution of accessible information and communication technologies and systems (Art. 9 para.2 lit. h CRPD)⁵⁴. Furthermore, Art. 23 CRC stresses their right to social integration and active participation in the community.

To achieve this goal and, at the same time, promoting equality eliminating discrimination, States Parties shall take, as settled by Art.5 para.3 CRPD, all appropriate steps to ensure that “reasonable accommodation” is provided. This concept will play a central role in viewing disabled children and young people as social actors.

Pursuant to Art. 2 CRPD “reasonable accommodation” means:

“necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms”.

A similar definition was settled out by Art. 5 of the Council Directive 2000/78/EC, albeit it was applied only within the context of employment and occupation⁵⁵. With the CRPD, States Parties should expand the concept of reasonable accommodation in order to cover other fields beyond employment and occupation. In fact, Art. 14 para.2, Art. 24 para.2 lit. c, Art. 24 para.5 and Art. 27 lit. CRPD apply the definition of reasonable accommodation to the right to liberty and security of the person, the right to education and the rights to work and employment respectively.

Scholars expose three meanings of “reasonable” accommodation regarding European national legislations. Firstly, it is an accommodation that does not result in an excessive cost of difficulty for the person or authority

⁵³ In relation to the legal meaning of parental responsibility in the European jurisdictions, see: Navas (note 16).

⁵⁴ Biel Portero (note 34), pp. 454 et seq.

⁵⁵ The Americans with Disabilities Act of 1990 (ADA) influenced the above-mentioned Council Directive, in particular, the drafting of Art. 5 [see: Waddington & Lawson (note 1), p. 27].

who should take it; secondly, it is effective in meeting the needs of the disabled person and lastly, the term “reasonable” conveys both that the accommodation must be effective and that it must not impose significant cost to the party⁵⁶.

Accommodation is an adaptation of infrastructures or processes in order to allow that people with disabilities could access them and participate in the community. Generally, the reasonable accommodation requirement implies an individual analysis presenting an individual solution assessing whether such an accommodation is reasonable or not.

According to Stein, there is a wide range of individualized reasonable accommodations depending on the field in which adjustments must be made. These accommodations fall into one or both of two categories: accommodations that involve “hard costs” and those that bring only “soft costs”. The first group requires the physical alteration of the place (e. g. a ramping stair); the second type involves only the alteration of the way that activities (e. g. a job) are performed⁵⁷.

If we take into consideration, as I have highlighted, that what is important, is *how* adults display information to children and young people with disabilities and *how* they communicate their views and participate in the decision making-process, we are willing to affirm that, in this context, reasonable accommodations require only the alteration of the way of communication or of the means of communication. Thus, we are mostly concerned with adjustments that involve “soft costs”. Technology could create new means that alters *how* adults and children with disabilities communicate with each other. If we take into account, as I have explained above, that most of the impairments are moderate rather than severe limitations, design, development, production and distribution of information and communication could be accessible at minimum cost. New technologies could facilitate the accessibility to information but also the communication of information and opinions itself. Actually, the exclusion of children and young people with disabilities from consultation says more about adults’ inability to relate and communicate with them than about the limitations on the part of the children⁵⁸. Some adults are unwilling to use new technologies or they do not really have the will to do it.

A “reasonable accommodation” that enables children and young people with disabilities to live independently and participate fully in all aspects of life and in daily activities (Art. 9 CRPD)⁵⁹ probably requires that adults (merely, the parents) learn how these new means of communication work and how to take new technology into consideration.

3. Concluding Remarks. Advocating for Participation Rights of Children and Young People with Disabilities in All Matters Affecting Them

The first conclusion that this study has raised is that parents and other adults (like school staff), who take care of disabled children and young people have a lack of education and training in order to help them to develop their skills, human potential, sense of dignity and self-worth⁶⁰. This education is comprised of not merely how to assist these persons from the viewpoint of their health, but also how to communicate with them and how to reach a major knowledge regarding new means of communication, when new technology is involved. In this sense, I would suggest that local authorities adopt measures in order to ensure that adults, who deal with disabled children and young people, can afford such education or training. My proposal is that, by virtue of Arts. 9 para.2 lit. c and 24 para.4 CRPD, it could be done by means of “positive actions” measures.

The second conclusion concerns the situation in which parents’ interests’ conflict with those of their children and young people with disabilities. In this case, I advocate for a third person that could represent and defend the child’s interests. The appointment of this third person is especially necessary when parents get divorced and decide aspects concerning their lives but the life of their disabled child as well. Then, there is a strong trend to exclude children from the decision-making process on the basis that they are not capable to take part of the

⁵⁶ Waddington, L. (2007). Reasonable Accommodation. In Schiek, D., Waddington, L. & Bell, M. *Non-Discrimination Law*, Oxford / Portland: Hart Publishing, pp. 669-670.

⁵⁷ Stein, M. A. (2003). The Law and Economics of Disability Accommodations. *Duke L.J.* 53, pp. 88-89.

⁵⁸ Rabiee et al., (note 12), p. 387.

⁵⁹ Cavet & Sloper (note 21), p. 284.

⁶⁰ Their “medical” view still contrasts with the “social” model of disability [Davis, J., Watson, N., & Cunningham-Burley, S. (2008). Disabled Children, Ethnography and Unspoken Understandings. In Christensen, P. & James, A. (Eds). *Research with Children. Perspectives and Practices*. 2nd ed. New York / London: Routledge, p. 223].

decisions concerning their well-being⁶¹. Seeing this as the usual parents' attitude when non-disabled children are involved, we should wonder what the parents' attitude is, when they have to deal with disabled children. An intensified paternalism unfairly diminishes the capacity of those children. Hence, their interests would be better guaranteed if they were represented and defended by a third person⁶².

The third conclusion that arises is the necessity to review all European national legislations with a cross-cutting approach in order to effectively ensure the inclusion of children and young people with disabilities in our society. Some important steps have been taken in this direction, but, as the Action Plans of the Council of Europe and that of the EU show, much remains to be done⁶³. In this sense, EU jurisdiction should expand the concept of "reasonable accommodation" beyond the employment and occupation areas. The influence of the CRPD must not be underestimated⁶⁴.

Finally, because of the direct application of the EU Charter (Art. 6 para.1 of Lisbon Treaty⁶⁵ and Art. 52 para.2 of the EU Charter⁶⁶), both the European Union Court of Justice (EUCJ) and national Courts shall directly enforce fundamentals rights and freedoms stated by this European legal instruments. Therefore, it is feasible that the EUCJ directly enforces the rights of children and young people with disabilities adopting their perspective and not just that of the adults that take care of them (Art. 47 EU Charter⁶⁷). This approach of the matter will be in accordance with Art. 13 CRPD, whereby:

"1. States Parties shall ensure effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages.

2. In order to help to ensure effective access to justice for persons with disabilities, States Parties shall promote appropriate training for those working in the field of administration of justice, including police and prison staff".

The CRDP has added an important new dimension for children and young people with disabilities to fight against discrimination in Europe and for the consolidation, in all matters that affect them, of the children rights perspective. It would be expected that the EUCJ takes into account the CRPD when handing down decisions on children and young people with disabilities, notably, Art. 7 para.3.

⁶¹ Regarding the procedural rights of the child embracing the right to apply for the appointment of a special representative, it should be mentioned Arts. 3 to 5 of the *Convention of the Council of Europe on the exercise of children's rights of 25 January 1996* (<http://conventions.coe.int/Treaty/en/Treaties/Html/160.htm>). Retrieved June 2014.

⁶² Bainham (note 46) , pp. 575 et seq.; Cottier, M. (2008). *Verfahrensvertretung des Kindes im Familienrecht der Schweiz: aktuelle Rechtslage und Reformbedarf*. *Fampra.ch*. 9, pp. 125 et seq.; Kaganas, F. & Diduck, A. (2004). *Incomplete Citizens: Changing Images of Post-Separation Children*, *The Modern Law Review* 67 (6), pp. 959-981.

⁶³ As Clifford highlights: "in Europe paternalistic rhetoric still underpins disability law, policy and practice. Consequently, these strategic developments will only lead to effective equality for persons with disabilities in key areas such as education, healthcare, criminal justice and political participation once the initial enthusiasm and goodwill shown to the CRPD is transformed through the difficult task of putting in place practical solutions for the challenges encountered by persons with disabilities" (note 26, p. 22).

⁶⁴ In Spain there is a Strategic National Plan on Childhood and Adolescence 2013-2016 (PENIA_2013-2016.pdf) and in accordance with it the government will present a Proposal of Amendment of the Children's Act that will take into consideration the rights of disabled children and young people adapting such rule to the CRPD [Alonso Parreño, M. J. (2011). *Propuestas de mejora del marco normativa de los menores con discapacidad en España*, Colección Conv. ONU. CERMI. Madrid: Cinca, *in totum*].

⁶⁵ Like Art. 6(1) of Lisbon Treaty sets forth: "The Union recognizes the rights, freedoms and principles set out in the Charter of Fundamental Rights of the European Union of 7 December 2000, as adapted in Strasbourg, on 12 December 2007, which shall have the same legal value as the Treaties".

⁶⁶ Art. 52(2) EU Charter states that "Rights recognized by this Charter which are based on the Community Treaties or the Treaty on European Union shall be exercised under the conditions and within the limits defined by those Treaties".

⁶⁷ By virtue of Art. 47 EU Charter "the fundamental right to effective judicial protection constitutes:

i) General principle of Community Law".

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