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**EDF report on the implementation of the
Disability Action Plan 2006-2015**

**Item 6.2 of the agenda
Evaluation report on the implementation
of the Disability Action Plan 2006-2015**

Document prepared by EDF

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EDF REPORT ON THE IMPLEMENTATION OF THE CoE DAP 2006-2015

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Executive Summary

Persons with disabilities are entitled to enjoy the same human and fundamental rights, and equal opportunities for a life without discrimination in all its dimensions, as anyone else, Nevertheless, they are not recognized as equal citizens with legal and decision-making capacity, live in an inaccessible environment, cannot move around freely, do not have equal access to education, are more likely to leave school early and without qualifications, and are less likely to progress to third level of education.

Persons with disabilities do not have equal access to vote and the opportunity and the support to participate in policy decisions at all levels of governance. The majority of national legislation, policies and practices in Europe deny the recognition of legal capacity of persons with disabilities and maintain guardianship regimens.

Access to cultural, sport and leisure activities remains a challenge for the majority of persons with disabilities in Europe. Accessibility of goods and services, built environment, transport, infrastructure, retail, information and communication, including ICT, is not granted to people with disabilities on equal footing as others..

Notwithstanding a general commitment of many CoE MSs to develop inclusive education systems, equal access to quality education and vocational training in mainstream schools and to life-long education has not been achieved in Europe.

Persons with disabilities are not adequately protected from exploitation, violence, abuse, cruel, inhuman or degrading treatment, in particular against women and girls and in institutional settings. More than 200.000 persons with disabilities in Europe are forced to live in closed institutions deprived of the most fundamental human rights. Few countries adopted legislations and policies providing independent living schemes and access to a range of support services and community-based living options.

There are still important barriers to accessing health care and habilitation/rehabilitation services across Europe: persons with disabilities do not have access to the same variety, quality, and standard of free and affordable health care as other people, to disability-specific services for identification, diagnosis of and intervention, and to a network of suitable (re)habilitation services and programmes which are aimed at achieving independence, inclusion and participation in society.

National legislations and policies did not succeed in helping persons with disabilities to emerge from poverty by supporting their employment and creating job opportunities in the labour market or in sheltered employment as a transitional instrument for disabled workers to enter the mainstream labour market.

The particular gender- based and needs –based discrimination in all the above areas are still not fully recognised, reported and prevented in the CoE MSs. As a consequence, women and girls with disabilities, people with psychosocial or intellectual disabilities and those with complex or intense care needs face increased difficulties in accessing adequate care and support.

The European Disability Forum

The European Disability Forum (EDF) is the umbrella organisation bringing the unified voice of 80 million European citizens with disabilities to European institutions and policy decision makers. EDF is led by persons with disabilities or by parents of persons with disabilities who need intense support to advocate for themselves. The added value of the EDF contribution to European policies and decision making processes is its broad representation of persons with disabilities in Europe through democratic consultation processes of its members, which are European NGOs representing a broad range of diverse disabilities at European level and National Councils on Disability from European Countries, including EU and EEA Member States and other European countries, such as Albania, ex republic of Macedonia, Serbia and Turkey.

Introduction

The Council of Europe recognised disability as a human rights issue, acknowledged persons with disabilities to be one of the most discriminated population of Europe as well as the particular need to protect their rights, and undertook the commitment to contribute to the implementation of the rights of persons with disabilities in Europe through its Disability Action Plan 2006-2015 (DAP)¹.

The DAP 2006-2015 is a policy instrument which endeavours to foster equality of opportunities through concrete responses to the most serious and most common barriers encountered by persons with disabilities in Europe. It is a complementary instrument that can be used as a guide to the progressive implementation of the UN Convention on the Rights of Persons with Disabilities (UN CRPD)², adopted by the United Nations in December 2006 and subsequently ratified by a large majority of the CoE Member States. Nevertheless, the Middle term report on the Implementation of the DAP by member States has shown that the objectives of the DAP have still not been fully implemented.

The European Disability Forum actively participated in achieving the overall objectives of the DAP 2006/2015:

- by participating in :

¹ Recommendation Rec(2006)5 of the Committee of Ministers to member states on the Council of

² The Convention on the Rights of Persons with Disabilities was adopted by consensus by the UN General Assembly in resolution 61/106 on 13 December 2006. The Convention and its Optional Protocol were opened for signature on 30 March 2007 and entered into force on 3 May 2008 following the deposit of the twentieth instrument of ratification. The Optional Protocol also entered into force on the same date, following the deposit of the tenth instrument of ratification.

- the drafting process of the DAP as well as in the monitoring process of its implementation by participating as observer in the CoE European Co-ordination Forum for the DAP 2006-2015 (CAHPAH),
- the Drafting Committee on Evaluation Criteria (CAHPAH-DCEC, 2008-2010)
- the Mid-term Review Report of the DAP 2006-2015³ (September 2010)
- the Committee of Experts on the Rights of People with Disabilities (CS-RPD, since 2012)
- the “*Report on promoting equal opportunities for people with disabilities and their participation in political and public life*” by Mr. Josef Neumann, rapporteur on disability issues to the Current Affairs Committee of the Congress of Local and Regional Authorities of the Council of Europe (2014)
- by drafting and providing to the CS-RPD the “*EDF analysis paper Towards a Disability Action Plan 2016-2020*” (2014)
- by collaborating with European agencies such as the ANED (including through the “*Annotated review of European Union law and policy with reference to disability*”, 2008) and the Fundamental Rights Agency in collecting information on the enjoyment of human rights by persons with disabilities in Europe;
- by supporting its members to achieve the objectives of the DAP through the adoption of the following documents:
 - “*EDF response to the European Commission communication: “Modernising social protection for greater social justice and economic cohesion: taking forward the active inclusion of people furthest from the labour market”*” (2008),
 - “*EDF response to the European Commission communication: “Opportunities, access and solidarity: towards a new social vision for 21st century Europe”*”, (2008),
 - “*EDF observations on the proposal for a Council Directive on implementing the principle of equal treatment between persons irrespective of religion or belief, disability, age or sexual orientation (Article 13 Directive (2008) and the “Toolkit on the National Strategy Reports on Social Protection and Social Inclusion 2008-2010”*” (2007);
 - “*EDF Manifesto on The European Elections 2014*”

Action line No. 1: Participation in political and public life

Some findings⁴ suggest that persons with disabilities are still excluded from participation in political and public life, because of the denial of accessibility provisions, including of voting

³ Mid-term Review Report by Mr Howard LEIGH, Consultant, adopted by the European Co-ordination Forum for the Council of Europe Disability Action Plan 2006-2015 (CAHPAH) at its 4th meeting, Strasbourg, 27-29 September 2010

⁴ FRA, Fundamental Rights Agency: The right to political participation of persons with mental health problems and persons with intellectual disabilities, October 2010

ballots, polling stations and sites, as well as of electoral materials in accessible and in an easy to understand formats. Moreover the denial of the right to vote to persons with intellectual and mental disabilities can be related to restricted legal capacity. The exercise of legal capacity is therefore a key right to political participation by persons with intellectual and psycho-social disabilities. Currently a majority of European countries have capacity-related qualifications for voting, in few countries the rights of persons with intellectual and mental disabilities to vote and to be elected are under constitutional protection.

Participation in public and political life is also about having the right, the means, the space and the opportunity and the support needed to influence policy decisions and measures which affect the lives of people with disabilities. It implies the recognition of the right of persons with disabilities and their representative organizations to be actively and effectively involved in policy and policy related processes at all levels. Involving DPOs in policy decision making is a strategy for making the concerns and experiences of persons with disabilities an integral part of the design, implementation, monitoring and evaluation of policies and programmes so that all disabled persons benefit equally and inequality is not perpetuated. The EDF motto “Nothing about disabled people without disabled people” reflects this strategy with exactitude.

The Council of Europe never recognised EDF, which is the umbrella organisation representing persons with disabilities in Europe, as an equal partner with right to vote in its political bodies and advisory committees, nor supports its participation in policy decision making processes, notwithstanding the particular condition of persons with disabilities and the additional barriers to participation they may experience.

EDF contributed to the implementation of the Action line 1 through the following actions:

- collecting over 1.300.000 signatures in the framework of its Campaign “*One million 4 Disability*” to advocate for the adoption of an EU anti-discrimination directive with a broad scope (2008);
- Participating in the CoE sub-committee on the Participation of people with disabilities in political and public life 8(CAHPAH- PPL) (2011)
- participating in the EU Monitoring Framework of the UN CRPD implementation as equal partner with right to vote (since 2012);
- contributing to draft:
 - the EU anti-discrimination directive, advocating for its adoption towards the EU Institutions and MSs presidencies;
 - the “*Revised Venice Declaration on the Code of Good Practice in Electoral Matters on the Participation of People with Disabilities in Elections*” (2011);
- drafting and adopting:
 - the Resolution on ‘*The future of financial sustainability of civil participation of the movement of persons with disabilities in Europe*’ (May 2011)
 - the position paper “*Equal recognition before the law and equal capacity to act: understanding and implementing article 12 of the UN Convention on the Rights*

- *of Persons with Disabilities”, 2012*
- *the “EDF opinion to the CoE Committee on Equality and Non discrimination of the Parliamentary Assembly on political participation of representative organizations of persons with disabilities at European level” (2014)*
- *The Resolution on the future of financial sustainability of civil participation of the movement of persons with disabilities in Europe /Zagreb, 2014)*
- participating in:
 - *the CoE sub-committee on the Participation of people with disabilities in Political and Public Life (CAHPAH –PPL), (2008)*
 - *the CoE Conference : “Protecting and promoting the rights of persons with disabilities in Europe: towards full participation, inclusion and empowerment”, October 2008.*
 - *the CoE conference “Implementation of the Council of Europe Action Plan to promote the rights and full participation of people with disabilities in society 2006-2015”, Odessa, May 2011*

Action line No. 2: Participation in cultural life

Social inclusion and participation of persons with disabilities in society implies that they should be able to access to sport, leisure and cultural activities, infrastructures, sites, environments and services delivered in public and private places, as well as to relate information. The perspective of the artist/performer/producer with disabilities should be considered too. It is also important that toys and recreational equipment are tailored to the needs of children with disabilities and persons with disabilities in general. This requires that national policies and plans be developed and adopted in order to eliminate barriers which impede full and equal participation of persons with disabilities in leisure, sports and cultural activities as spectators and as active players. This also requires that children with disabilities be included in physical education within the school system “to the fullest extent possible” and enjoy equal access to play, recreation, leisure and sporting activities

EDF contributed to achieving the objectives of the Action Line 2 by participating in the CoE Ad hoc Taskforce on participation in cultural life, March 2013.

Action line No. 3: Information and communication

Persons with disabilities across Europe are still confronted with information and communication barriers preventing them to participate in society on an equal footing with others. Accessibility of information and communication is an essential precondition for persons with disabilities to enjoy and exercise their rights and to reach the objectives of equal participation and social inclusion. All relevant information, including on elections, legal

proceedings, transport, healthcare, (re)habilitation and social services, opportunities for education, training and employment, cultural, sport and leisure activities, as well as information and communications technologies (ICT) and systems such as web, smart phone applications, online services and media services, are not accessible to persons with disabilities. If information and communication are not made accessible, this results in persons with disabilities' inability to perform simple actions everyone else is capable of. For instance, in case of an emergency, a deaf or hard of hearing person will not be able to call the emergency number as any other citizen without video- and text-relay services. The lack of accessible information about healthcare services and entitlements have been identified as major barriers in accessing healthcare by European patients with disabilities⁵, while the lack of adequate information available in accessible formats in public transport systems hinder the mobility of persons with disabilities. Few CoE MSs, if any, have developed and adopted plans with clear objectives for achieving accessibility and/or equal access to information in a reasonable length of time, including:

- the obligation to provide relevant information through the use of augmentative and alternative modes, means and formats of communication , such as sign language, braille and easy-to-understand texts;
- the adoption of specific e-accessibility requirements to make accessible new information and communications technologies (ICT) and systems to persons with disabilities at minimum cost through incentives to ICT developers.

EDF contributed to the achievement of the objectives of the Action line 2 through its campaign for the adoption of an European Accessibility act, including through:

- Drafting and disseminating:
 - The ANEC-EDF “*Joint Position on e-Accessibility*” (2007)
 - The ANEC-EDF “*Joint Position on Web and eAccessibility legislation*” (2008)
 - The AGE-ANEC-EDF joint Response to the European Commission's Communication “*Towards an Accessible Information Society*” (2009)
 - The AGE-ANEC-EDF joint response to the survey on European e-inclusion policy (2009)
 - The AGE-EDF joint “*Position on the Future Digital Agenda*”, (2010)
 - The AGE-ANEC-EBU-EDF joint position paper on web-sites accessibility (2010)
 - The report: “*A Compilation of Resources on the E- and Web-Accessibility Internal Market*” (2012)
 - *the EDF Position Paper Towards a European Accessibility Act* (2013)
 - *the: EDF Position on the Proposal for a Directive on the Accessibility of Public Sector Bodies' Websites (COM (2012) 721 final)* (2013)

⁵ European Union Agency for Fundamental Rights, Inequalities and multiple discrimination in access to and quality of healthcare, 2013, p. 51, available at <http://fra.europa.eu/en/publication/2013/inequalities-discrimination-healthcare>

- the “2nd Position paper on the proposal for a directive on the accessibility of public sector bodies’ websites” (2015)
- the organization of the European conference “An inclusive digital continent” in Jurmala, Latvia, in the frame of the Latvian EU Presidency, February 2015

Action line No. 4: Education

Persons with disabilities and in particular students in need of high level support are often excluded or do not have adequate access to education services in the CoE Member States. The Revised Draft Mid-term Review Report on the implementation of the Council of Europe Disability Action Plan 2006-2015⁶ shows that in some member states there is evidence that special education is still the predominant system for the education of children with disabilities.

The ANED report⁷ concerning the inclusive education of pupils and students with disabilities in Europe shows that the commitment to education for all, and more recently a growing commitment to inclusive education, has increased opportunities in mainstream education in all countries. However, in many countries educational provision includes special schools for specific impairments. Statistical data published in 2011⁸ on school attendance of children and adolescents with disabilities show that

- 19% of youngsters with disabilities are early school leavers,
- 39% of them are pupils with a severe limitation.

Moreover, the concluding observations by the UN CRPD Committee on the European countries’ reports examined up to now have shown that this right is far from granted⁹.

EDF committed to achieve the objectives of the Action Line 4:

- by participating in:
 - the CoE Committee of Experts on the education and integration of children with autism (P-RR-AUT, 2006),

⁶ Council of Europe Disability Action Plan (DAP) 2006-2015, Recommendation Rec(2006)5,. Revised Draft Mid-term Review Report, 2010.

⁷ Academic Network of European Disability experts (ANED) - VT/2007/005: Inclusive education for young disabled people in Europe: trends, issues and challenges. A synthesis of evidence from ANED country reports and additional sources. Serge Ebersold (National Higher Institute for training and research on special needs education, INSHEA) with Marie José Schmitt and Mark Priestley. April 2011.

⁸ European Union Statistics on Income and Living Conditions (EU-SILC) 2011, available at http://epp.eurostat.ec.europa.eu/portal/page/portal/microdata/eu_silc

⁹ Concluding Observation of the UN CRPD Committee on the reports of state Parties, 2014 http://tbinternet.ohchr.org/_layouts/treatybodyexternal/TBSearch.aspx?TreatyID=4&DocTypeID=5

- the CoE Committee on Community living (de-institutionalisation) of children with disabilities (P-RR-CLCD, 2006-2007),
- the 2nd Consultation Meeting on Protecting and Promoting the Right to Quality Education for All,
- the European Parliament of Equal Opportunities for All, workshop on “*Evidence of discrimination in education and social protection*”
- the organisation of a Study Visit for a delegation from the Republic of Moldova to ordinary schools including children with disabilities in Italy, 2014.
- By drafting:
 - the EDF Statement “*Inclusive education: Moving from words to deeds*”, February 2009;
 - the “*Comments on the final draft of the overview study of the Council of Europe “Acquis” on the right to quality education for all*”

Action line No. 5: Employment, vocational guidance and training

Compared to non-disabled persons, people with disabilities are less likely to be in full-time employment; more likely to be unemployed; and significantly more likely to be economically inactive¹⁰. 75% of people with severe disabilities do not have the opportunity to participate in the European labour market¹¹. People with certain types of disability – such as intellectual and psycho-social disabilities face greater difficulties in finding and retaining employment. Disabled women are less likely to have a decent job than either non-disabled women or men with disabilities. The main reasons for such a low participation in the labour market (having as a consequence the untapped labour force hidden in this group) are the remaining discrimination in the employment field as well as the lack of positive actions, support services, inadequate transport, etc.

One of the biggest barriers for ensuring employment opportunities for people with disabilities is the exclusion of people with disabilities from education, in particular from upper education and vocational training programmes. Austerity measures have contributed to higher unemployment and social exclusion of people with disabilities in Europe¹², including in the EU countries, despite of the European Union “Europe 2020” strategy that has made social inclusion one of the three pillars for bringing Europe out the crisis. Due to the impact of the economic crisis, 80 million people in Europe face a higher risk of exclusion and are exposed

¹⁰ Organisation for Economic Co-operation and Development (OECD): *Sickness, disability and work: Breaking the barriers: A synthesis of findings across OECD countries* (Paris, OECD Publishing, 2010).

¹¹ *Employment of disabled people in Europe 2002*” Statistics in Focus Theme 3 – 26/2003 Population and living conditions Eurostat
http://ec.europa.eu/employment_social/health_safety/docs/disabled_%202002_en.pdf

¹² *Assessing the impact of European government’s austerity plans on the rights of persons with disabilities* (European Foundation Centre, 2012)

to the risk of poverty, more than 5 million have lost their job with a 10% increase in the unemployment rates of some EU countries.

According to the “ad hoc module of the Labour Force Survey 2011”¹³, persons with disabilities aged 16-64 were two to three times more likely to be unemployed than non-disabled people. Only 38% of people with disabilities aged 16 - 64 have an earned income, compared to 64% of non-disabled people. The more severe the degree of disability, the lower the participation in the labour force: 78 % of persons with severe disabilities were outside the labour force, compared to 27 % of those without any disability. Only 16% of those who face work restrictions were provided with some assistance to work.

The employment rate of persons with disabilities does not seem significantly improved over the years according to the “ad hoc module of the Labour Force Survey 2011”¹⁴, as the employment rate of persons with a longstanding health problem and/or a basic activity difficulty (LHPAD) is 38.1 %, compared to 70 % of people without limitations¹⁵. Besides placing persons with disabilities at a higher risk of poverty, these patterns combine to bring about significant social and economic losses, estimated at between 3 and 7 per cent of GDP in an ILO¹⁶ pilot study of ten low- and middle-income developing countries¹⁷. The cost of disability benefits alone amounts to up to 4-5 per cent of GDP in some countries¹⁸.

EDF contributed to the acknowledgement and implementation of Action line 5 by drafting and disseminating:

- the “*Analysis of the transposition and implementation of the council directive 2000/78/ec establishing a general framework for equal treatment in employment and occupation*” (2007),
- the “*Common Declaration*” with ETUC (European Trade Union Confederation) (2011),

Action line No. 6: The built environment and Action line No. 7: Transport

The built environment where a person with disability lives, works or just passes through is plenty of obstacles to movement and orientation or to the use of public transport, elements and equipment that are part of their environments. These obstacles appear in both everyday lives and emergency situations; they restrict the autonomy, safety, privacy and dignity of

¹³ European Labour Force Survey ad hoc module on the employment of disabled people (2002)

¹⁴ European Labour Force Survey ad hoc module on the employment of disabled people (2011)

¹⁵ Labour market and Labour force survey (LFS) statistics. Data from April 2014.

¹⁶ ILO 2013 Global Employment Trends for Youth 2013: A generation at risk, Geneva

¹⁷ S. Buckup: The price of exclusion: The economic consequences of excluding people with disabilities from the world of work, Employment Sector Working Paper No. 43 (Geneva, ILO, 2009)

¹⁸ Organisation for Economic Co-operation and Development (OECD): *Sickness, disability and work: Breaking the barriers: A synthesis of findings across OECD countries* (Paris 2010)

persons with disabilities and cause discrimination. Inaccessible buildings, infrastructures and transport compromise the ability of persons with disabilities to function independently and to participate fully in society.

Barriers in school buildings hinder the access of children and young people with disabilities to mainstream education systems. Persons with disabilities often have a poorer health status than persons without disabilities because of the barriers that face to access health care facilities and benefit from quality health services on equal terms with others. Such barriers also impede full and equal participation of persons with disabilities in leisure, sports and cultural activities.. The lack of access to all these services has a direct impact on the quality of life and the expectations of persons with disabilities.

Only a minority of the CoE Member States have accessibility regulations and standards, such as the DALCO standard from the Spanish Association for Standardisation and Certification (AENOR) which are accompanied by a certification scheme. Other Member States have accessibility provisions in their legislation, either in general or anti-discrimination legislation, which is the case in the UK with the Disability Discrimination Act (DDA) or in specific sector legislation, as in France with building regulations¹⁹.

EDF contributed to achieve the objectives of Action lines 6 and 7 by promoting an holistic approach to accessibility in its advocacy action and documents:

- the endorsement of and participation in the Access City Award, launched in 2010, since the early phase of preparation;
- the commitment for the adoption of a binding European Accessibility Act,
- the campaign on Freedom of Movement, launched in 2011
- publishing and disseminating a “*Freedom Guide*”, (2012)
- drafting and adopting:
 - the “*Proposal for a European Mobility Card, 2011*”
 - the “*EDF Position Paper Towards a European Accessibility Act, 2013*”

Action line No. 8: Community living

According to the European Commission funded report “Deinstitutionalisation and Community Living: Outcomes and Costs”²⁰, there were in Europe more than one million children and

¹⁹ Source: Ensuring accessibility and non-discrimination of people with disabilities. European Commission, Directorate-General for Employment, Social Affairs and Equal Opportunities Unit G.3, 2009

²⁰ Mansell J, Knapp M, Beadle-Brown J and Beecham, J (2007) Deinstitutionalisation and community living – outcomes and costs: report of a European Study. Volume 2: Main Report. Canterbury: Tizard Centre, University of Kent

adults with disabilities that live in institutions. While efforts have been undertaken in several European countries to improve the situation, institutionalisation²¹ is still widespread, while alternative living options are not sufficiently being developed, although the situation in the different CoE countries and also within the same country diverges significantly. The permanence of residential segregating facilities depends mainly on the false belief that they are a less expensive solution than community-based services, as well as on the lack of proper interventions fostering the person's independence skills and of support to families. The beliefs that persons with intellectual disabilities and psychosocial disabilities, and in particular those with high level of support needs, cannot be part of the community and that they need to be protected in segregating settings²² are still common assumptions contributing to maintain institutions in our societies.²³ The economic crisis has further exacerbated this situation with reduction in social spending and with the postponement of reform measures and transition plans for replacing institutions with community-based services.²⁴

Women with disabilities have less access to employment and education. Without economic independence, they often depend on their families. Mothers with disabilities have additional problems to live independently. The lack of support for families and careers leads to the separation of children with disabilities from family and institutionalization. Older persons with disabilities also face difficulties to enjoy the right to live in the community and find themselves often excluded or socially isolated.²⁵ People with disabilities belonging to ethnic minorities, such as Roma in Central and Eastern Europe or immigrants with disabilities, are often disproportionately sent to institutions compared to the rest of the population.²⁶

²¹ Mapping exclusion: Institutional and community based services in the mental health field in Europe (Mental Health Europe and the Mental Health Initiative of the Open Society Foundation, November 2013)

²² See for example: Office of the High Commissioner for Human Rights (Europe Regional Office), Getting a Life – Living Independently and Being Included in the Community: Legal Analysis of the Current Use and Future Potential of the EU Structural Funds to Contribute to the Achievement of Article 19 of the UN Convention on the Rights of Persons with Disabilities (April 2012), available at: http://www.europe.ohchr.org/documents/Publications/getting_a_life.pdf (last accessed 03.06.2014).

²³ Inclusive Communities, Stronger Communities: Global report on Article 19, the right to live and be included in community, p. 8 (Inclusion International, October 2012)

²⁴ Assessing the impact of European government's austerity plans on the rights of persons with disabilities (European Foundation Centre, 2012)

²⁵ European Year for Active Ageing and Solidarity between Generations 2012: Everyone has a role to play, p. 7 (AGE Platform, 2011); Getting a life: Living Independently and Being Included in the Community, A Legal Study of the Current Use and Future Potential of the EU Structural Funds to Contribute to the Achievement of Article 19 of the United Nations Convention on the Rights of Persons with Disabilities, p.14 (Office of the United Nations High Commissioner for Human Rights, Regional Office for Europe, April 2012)

²⁶ UN Committee on the Rights of Persons with Disabilities, Concluding observations on Hungary, para. 42 (CRPD/C/HUN/CO/1); Horvath and Kiss v Hungary, European Court of Human Rights,

EDF contributed to achieve the objectives of Action line 8 by:

- establishing a specific Advisory group on Community living,
- Participating in the European Expert Group on the Transition from Institutional to Community based care;
- Participating in the CoE Committee of Experts on Community Living (Deinstitutionalisation) of children with disabilities (P-RR-CLCD)
- Drafting the EDF comments to the Vade mecum on the path followed by a child with disabilities and the support to families with children with disabilities in the frame of the P-RR-CLCD Committee work;
- drafting and adopting the policy paper “*Living in the Community for all People with Disabilities*”, (2014)

Action line No. 9: Health care

People with disabilities develop the same health problems that affect the general population. Some may be more susceptible to developing chronic conditions because of the influence of behavioural factors. People with disabilities are more likely to be overweight than other people (48% compared with 39%), to smoke. (30.5% compared with 21.7%) and to be physically inactive (22.4% compared with 11.9%). Adults with developmental disabilities have a greater rate and earlier onset of chronic health conditions than people without disabilities or with other disabilities

People with disabilities encounter a range of barriers when they attempt to access health care services and therefore have unmet health care needs compared with the general population. Affordability (70.5%)²⁷, lack of services in the area (52.3%), and transportation (20.5%) are the top three barriers²⁸, followed by physical, communication, information, and coordination barriers to using health facilities.

Evidence shows that health promotion interventions such as physical activities seldom target people with disabilities. People with disabilities are generally less likely to receive screening and preventive services. The oral health of many people with disabilities is poor, and access to dental care limited. Adolescents and adults with disabilities are more likely to be excluded from sex education programmes. As a consequence they, and particularly women and girls,

Application no. [11146/11](#), 2013; *Orsus and Others v Croatia*, European Court of Human Rights, Application no. [15766/03](#), 2010

²⁷ Academic Network of European Disability experts (ANED) -The implementation of EU social inclusion and social protection strategies in European countries with reference to equality for disabled people. (2009)

²⁸ World Health Organisation: World report on disability, 2011

are more at risk of abuse, undesired pregnancy or lack of access of contraception tools. Limited access to health promotion has been documented for people with multiple sclerosis, stroke, poliomyelitis, intellectual disabilities and mental health problems. People with mental health conditions, intellectual and developmental disabilities and those with complex or intense care needs face increased difficulties in accessing adequate care and support.²⁹ Because of all these and other factors people with learning disabilities and people with mental health disorders have a lower life expectancy than the general population.

Limited knowledge and understanding of disability among health-care providers may lead to inadequate examinations and uncomfortable or unsafe experiences for people with disabilities, including insensitivity or disrespect, resulting in distrust in health professionals and failure to seek care.

EDf contributed to achieve the objectives of Action line 9 by:

- participating in drafting the WHO European region's declaration "Better health, better lives: children and young people with intellectual disabilities and their families" (2008-2009);
- establishing an Advisory Committee on discrimination in access to health and stereotypes (2011-2013)
- drafting and adopting its paper "*Influence of negative stereotypes on disability in access to health*" (2011)

Action line No. 10: Habilitation and Rehabilitation³⁰

Several countries have good legislation and related policies on rehabilitation, but the implementation of these policies, and the development and delivery of regional and local rehabilitation services, have lagged. Systemic barriers include:

- lack of strategic planning, resulting in an uneven distribution of service capacity and infrastructure³¹;
- lack of resources and infrastructures, particularly in rural and remote communities, reducing access to quality habilitation and rehabilitation services³²;

²⁹ Academic Network of European Disability Experts (ANED): The implementation of EU social inclusion and social protection strategies in European countries with reference to equality for disabled people.. Isilda Shima and Ricardo Rodrigues (European Centre for Social Welfare Policy and Research), May 2009

³⁰ The distinction between habilitation and rehabilitation refers to helping those who are born with or acquire disability early in life to develop maximal functioning, as opposed to assist those who have experienced a loss in function later in life to regain maximal functioning

³¹ Eldar R et al. Rehabilitation medicine in countries of central/eastern Europe. Disability and Rehabilitation, 2008,30:134-141.

- lack of agency responsible to administer, coordinate, and monitor services³³;
- ineffective coordination of responsibilities among providers;
- absence of engagement with representative organisations of persons with disabilities in design, implementation, and evaluation of rehabilitation programmes³⁴.

Unmet rehabilitation needs can delay or prevent autonomy and self-determination, limit activities, restrict participation, cause deterioration in health, increase dependency on others for assistance, and decrease quality of life. These negative outcomes can have broad social and financial implications for individuals, families, and communities.³⁵

Women and girls with disabilities enjoy lower levels of access to habilitation and rehabilitation services and programmes, as a consequence social stereotypes and prejudices assigning lower value to women because they are considered less productive, social roles confining them to the home, housekeeping duties, caring for others and performing tasks which are economically unacknowledged, overprotection by the family and a lack of self-esteem, among other factors,

The paradigmatic shift from a medical model towards a social model of disability does not mean that the health system is exempt from ensuring the right to habilitation or rehabilitation to persons with disabilities. On the contrary, this means that habilitation and rehabilitation should help persons with disabilities to achieve their fullest individual potential by alleviating difficulties which they are confronted with, either stemming from society or from their condition. Habilitation and rehabilitation therefore also include making changes to the individual's environment.

EDF contributed to the achievement of the objectives of Action line 10 by actively participating in drafting the World Health Organisation "*Report on Rehabilitation and Disability*" (2008)

Action line No. 11: Social protection

Exclusion from full participation in social and economic life, education and work opportunities and barriers to accessing health care, social security and adequate support substantially increase the risk of **poverty** of persons with disabilities. The linkage between poverty and

³²Middleton, J. W. et al.: Issues and challenges for development of a sustainable service model for people with spinal cord injury living in rural regions. Archives of Physical Medicine and Rehabilitation, 2008, 89:1941-1947.

³³ Modernizing sickness and disability policy: OECD thematic review on sickness, disability and work issues paper and progress report. Paris, Organisation for Economic Co-operation and Development, 2008.

³⁴ Global survey of government actions on the implementation of the standard rules of the equalisation of opportunities for persons with disabilities., op. cit.

³⁵ World Health Organisation: World report on disability, 2011.

disability is strong and goes in both directions. Poverty causes disability through poor health care, living and working conditions, especially if the proper support and accommodation are not available.

People living in poverty are at higher risk of serious health problems and accidents due to restricted access to health care, poorer working and living conditions and finds himself/herself often denied the opportunities that could help them to escape poverty³⁶. Disability can cause poverty. Poorer educational attainment is a factor in reducing earnings potential and the likelihood of having a job, alongside the other barriers that bring people with disabilities on the top of unemployment rates and to live on significantly lower income.

Income of people with disabilities is for the vast majority dramatically lower compared to the total population and families with a household member with a disability have a lower average level of income. Among people with disabilities, women and elderly people suffer more from poverty and exclusion compared to men and younger people⁹.

The high proportion of people with disabilities who live in jobless households is another contributory factor to the higher incidence of poverty among adults with disabilities or long-term illness. Families with disabled members tend to live in poor conditions as well. In most cases people with disabilities and their families rely on disability benefits. In particular the vast majority of people with intellectual disabilities live below or on the poverty threshold.

Persons with disabilities and their families tend to have a higher burden of financial costs and incur additional costs to achieve a standard of living equivalent to that of non-disabled people. This additional spending may go towards health care services, assistive devices, costlier transportation options, heating, laundry services, special diets, or personal assistance. Austerity measures adopted in many European countries to face the economic crisis have worsened poverty rates and social exclusion of persons with disabilities³⁷.

EDF contribute to achieve the objectives of Action line 11:

- By drafting and disseminating:
 - the Response to the European Commission communications: *“Modernising social protection for greater social justice and economic cohesion: taking forward the active inclusion of people furthest from the labour market”*, (2008)
 - *“Opportunities, access and solidarity: towards a new social vision for 21st century Europe”*, (2008)
 - the *“Toolkit on the national strategy reports on social protection and social inclusion 2008-2010”* Resolution *“A social way out of the economic crisis”* (2011)

³⁶ World Bank, 2005. Disability and Development and the World Bank. A Briefing Summary on February 2, 2005.

³⁷ Assessing the impact of European government's austerity plans on the rights of persons with disabilities (European Foundation Centre, 2012)

- the “*Report on the impact of the crisis on the rights of persons with disabilities*” (2013)
- By establishing an Observatory on the impact of the crisis (2011)
- By raising awareness of the effects of the EU economic policies and of austerity measures on social protection of persons with disabilities towards the EU institutions:
 - at the meetings of the High level group on disability of representatives of MSs
 - at the High Level Meeting with the EU presidents, December 2011

Action line No. 12: Legal protection

Persons with disabilities represent the group whose legal capacity is most commonly denied in legal systems worldwide. The denial of legal capacity to persons with disabilities leads to the deprivation of fundamental rights, including the right to vote, the right to marry and found a family, reproductive rights, parental rights, the right to give consent for intimate relationships and medical treatment, and the right to liberty. All persons with disabilities, can be affected by denial of legal capacity and substitute decision-making. However, persons with cognitive or psychosocial disabilities have been, and still are, disproportionately affected by substitute decision-making regimes and denial of legal capacity.

When a person is considered to have impaired decision-making skills, often because of a cognitive or psychosocial disability, his or her legal capacity to make a particular decision is consequently removed. This is decided simply on the basis of the diagnosis of a disability (status approach), or where a person makes a decision that is considered to have negative consequences (outcome approach), or where a person’s decision-making skills are considered to be deficient (functional approach). In all these approaches, a person’s disability and/or decision-making skills are taken as legitimate grounds for denying his or her legal capacity and lowering his or her status as a person before the law.

Moreover, gender and gender-related aspects are a compounding factor in legal incapacitation processes. For many women and female adolescents with disabilities legal incapacitation is a means to deprive them of their sexual and reproductive rights.

Persons with disabilities are more often than not excluded from participation in the proceedings due to inaccessible justice courts and premises as well as to failure to provide meaningful and accessible communication and information for all people with disabilities³⁸ in simple and accessible language, orally or in writing, and provision of appropriate assistance for persons with hearing and speech impediments.. In addition, inaccessible victim support services are a significant barrier for many victims with disabilities, in particular women with disabilities and persons with intellectual disabilities who cannot benefit from these services.

EDF contributed to achieve the objectives of Action line 12 by drafting and adopting its policy papers:

- “*Equal recognition before the law and equal capacity to act: understanding and implementing Article 12 of the UN Convention on the Rights of Persons with Disabilities*” (2009)
- “*General comment on Article 12 CRPD*” (2014)

Action line No. 13: Protection against violence and abuse

Violence against persons with disabilities is an important phenomenon that has progressively been recognized in a number of OSCE countries' jurisdictions³⁹

People with disabilities in Europe are at higher risk of incidences of torture, violence and abuse in psychiatric hospitals and mental health facilities, general health care hospitals, social care institutions, segregated schools, psychiatric judicial hospitals, and prisons.⁴⁰.. People with disabilities in Europe are at higher risk of incidences of torture, violence and abuse in psychiatric hospitals and mental health facilities, general health care hospitals, social care institutions, segregated schools, psychiatric judicial hospitals, and prisons.⁴¹ Persons with psychosocial disabilities are too often subject to deprivation of liberty without consent due to involuntary treatment and/or placement. In most European countries, compulsory psychiatric detention and/or treatment is legally permitted on grounds of psychosocial disability⁴². The largely negative personal experiences described in European Union Agency for Fundamental Rights report “Involuntary placement and involuntary treatment of persons with mental health problems” underscore the importance of developing legal frameworks which can minimise such outcomes. Furthermore, unequal detention regimes for people with psychosocial disabilities exist as part of the penal system⁴³.

³⁹ “Hate Crimes in the OSCE Region – Incidents and Responses”, Annual Report for 2010, Warsaw, November 2011, p 85; “Hidden in sight, inquiry into disability-related harassment, Equality and human rights commission, p. 5-8

⁴⁰ EDF Manifesto on the rights of women and girls with disabilities in the European Union, 2011, p.17, available at <http://www.edf-feph.org/Page.asp?docid=26614&langue=EN>

⁴¹ EDF Manifesto on the rights of women and girls with disabilities in the European Union, *ibid*

⁴² European Union Agency for Fundamental Rights, Involuntary placement and involuntary treatment of persons with mental health problems, 2012, available online at: <http://fra.europa.eu/en/publication/2012/involuntary-placement-and-involuntary-treatment-persons-mental-health-problems> (last accessed 03.06.2014).

⁴³ European Union Agency for Fundamental Rights, Report on involuntary placement and treatment of people with mental health problems, 2012.

Women and girls with disabilities face additional risks to numerous forms of violence, including forced sterilization, coerced abortion and sexual abuse, as thoroughly documented⁴⁴, including by the former Council of Europe Commissioner for Human Rights.⁴⁵

EDF contributed to the achievement of the objectives of Action Line 13 by participating in the draft report of the Committee on Civil Liberties, Justice and Home Affairs jointly and the Committee on Women's Rights and Gender Equality on the proposal for a directive of the European Parliament and of the Council establishing minimum standards on the rights, support and protection of victims of crime (COM(2011)0275 – C7 0127/2011 – 2011/0129(COD))14 February 2012

Action line No. 14: Research and development

There are very few epidemiological studies on prevalence of disabilities across European countries on which to make appropriated predictions. Surveys and statistics are not performed in cooperation with organisations of people with disabilities. The available studies are infrequent, expensive, problematic and very difficult to compare in a trend time perspective.

The problems arise from three main causes:

1. there is not a common definition of disability across the European countries. Disabilities may be recorded in different ways in case notes and centralized data collections.
2. Diagnostic terms tend to be used in different ways.
3. In epidemiological studies of prevalence, case finding methods vary.

EDF contributed to move forward in the field of research and development on disability by participating as partner in projects, such as:

- *“European Research Agendas for Disability Equality (EuRADE)”*, including through the EDF *“Policy Statement - European Research Agenda's for Disability Equality (EuRADE)”*
- *“DISCIT - Making persons with disabilities full citizens”*, which aims to produce new knowledge enabling European countries to achieve full and effective participation of persons with disabilities in society and the economy;

⁴⁴ Common European Guidelines on the Transition from Institutional to Community based care, European Expert Group on the Transition from Institutional to Community based care, November 2012, p. 43 (available at <http://deinstitutionalisationguide.eu/>)

⁴⁵ Council of Europe Commissioner for Human Rights, The right of people with disabilities to live independently and be included in the community, CommDH/IssuePaper (2012) 3, 12 March 2012, available at: <https://wcd.coe.int/ViewDoc.jsp?id=1917847> (last accessed: 03.06.2014), p. 37

Action line No. 15: Awareness raising

it is increasingly important that the disability awareness is not limited to those CoE and national policy decision makers who have specific competence on that .Equality and non-discrimination for all constitute a basic and general commitment common to the CoE Member States of the European Union – which was founded on the principles of, respect for human rights and fundamental freedoms. Strong and well-organised mainstream campaigns to raise awareness towards all the CoE institutions on the promotion and full implementation of the rights of persons with disabilities in all the above fields of action, and in particular on the need to ensure the participation of representative organisations of persons with disabilities in the decision-making processes affecting their lives, have not been organised so far, few, if any, have been organised at national level.

EDF contributed to achieve the objectives of Action line 15 through:

- participation in the organisation of the European Day of Persons with Disabilities (EDPD) conference together with the EU Commission every year;
- its campaigns:
 - the 1million4disability campaign, which collected more than 1.300.000 signatures of European citizens s in favour of European comprehensive legislative measures to make disability discrimination history (2007);
 - the Freedom of movement campaign (since 2010)
 - the “Inaccessible Websites: Time to Act!” campaign (since 2010)
 - the campaign towards the EP candidates for the promotion of a vision of an inclusive, sustainable and democratic Europe, at the ooccasion of the European elections (2014)

Cross-cutting issues

Women and girls with disabilities

Girls and women with disabilities experience even more discrimination than men with disabilities and women without disabilities. The existence of prejudices and stereotypes distort their image of themselves and their perception of being citizens with full human and civil rights. In this sense, women with disabilities generally lack the effective resources or legal tools to eliminate and correct this discriminatory behaviour.

Women with disabilities constitute 16 percent of the total population of women in Europe, approximately 40 million women and girls with disabilities. Women with disabilities remain in a clearly disadvantageous position within society and face intersectional discrimination in all areas of life in Europe. Girls and women with disabilities are facing the effects of clear and

profound discrimination. This may be seen in the data and through experiences of women and girls with disabilities, that show lack of education, more unemployment, lower salaries, limited access to health and maternity services, limitations to their sexual and reproductive rights, scarce or no access to services or programmes available for woman in general, greater risk to suffer violence and all kind of abuses, limited availability of data broken down by gender and disability, under-representation in DPOs, etc. Women with disabilities are systematically deprived of their equal right to be mother in States whose legal systems allow forced sterilization or forced abortion, or because of prejudices on their capacity to have, and take care of, children.

EDF is committed to achieve the objective of gender equality for girls and women with disabilities across Europe through:

- Participation in the CoE Drafting Committee on protecting and promoting the rights of women and girls with disabilities (CAHPAH-WGD)
- guaranteeing equal opportunities and equal treatment for both sexes and combating all types of gender-based discrimination in its governing bodies and policy work;
- establishing a permanent Gender equality committee;
- drafting, adopting and disseminating:
 - *“EDF Declaration on women with disabilities”* (2008)
 - *“EDF input to the consultation on the roadmap for equality between women and men 2006-2010 and follow-up strategy”* (2009)
 - *“EDF Position on the proposal for a directive concerning the maternal leave (COM(2008) 600/4)”, 2009*
 - *“Gender dimension in the Disability Strategy 2010-2020”* (2010)
 - *“2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union”* (2011)

Children with disabilities

The promotion of children’s rights is an integral part of EU fundamental rights objectives. Yet, the recognition of the specific situation of children with disabilities has largely been declaratory in relevant rather than underpinned by targeted measures addressing their specific needs or monitoring Member States’ respect of EU policies. The situation of children with disabilities in Europe is far from satisfactory, despite European efforts to protect and promote the rights of children. Children with disabilities are not valued the same as other children. As a consequence, they face a higher risk to be subject to unacceptable intervention practices, to be secluded in segregating facilities or to be isolated in unsupported families.

The involvement of families in every relevant decision and intervention programme concerning their children is not ensured across the European countries. Few programmes are

available to empower families to meet their children's with disabilities needs and to defend their rights.

Disability increases children's vulnerability to abuse. Children with disabilities are 3.44 times more likely to be a victim of abuse. Inability to hear, speak, move, dress, toilet, and bath independently increase vulnerability to intrusive personal care and abuse. Challenging behaviors increase vulnerability to abuse: children with intellectual/developmental disabilities, who may not recognize abuses, are 4 to 10 more likely to be victims of abuse. Major communication problems increase vulnerability of affected children as well, because they do not have means to report abuses, so that abuses are possible without being discovered,

Beside the participation to the CoE committees on education of children with ASD and on de-institutionalisation of children, and of its position paper on inclusive education, EDF contributed to promote the rights of children with disabilities by participating in the "State of the World's Children" organised by the UNICEF in 2013.

Persons in need of high level of support

The needs of high level of support are a cross-cutting aspect of disabilities: any person with a disability can have intense support needs, stemming from the severity of its condition as well as from his/her personal circumstances and barriers in the environment. Persons who need high level of support suffer from particular discrimination. They are more likely to be excluded from education, habilitation/rehabilitation programmes and to be secluded in segregating institutions or in exhausted families. . They experience high levels of unrecognised, and when recognised, poorly-managed, secondary medical conditions. As a result, the life expectancy of people with severe intellectual disability is 20 years shorter than the rest of the population⁴⁶.

Because of their difficulties to make their voice heard and express their feelings and will, people who need intense support are particularly exposed to unacceptable practices, adverse treatment or negligence in any setting. They are frequently abused in their every day life from peers and people in positions of power, even in the very services that are supposed to provide care to them. Common types of abuse include neglect of their needs, psychological abuse (such as shaming and belittling), constraints and restrictive practices (such as forced placement in institutions or in restricted settings), legal abuse (restricted access to rights and courts of justice), and physical abuse (physical contention, pushing, etc.).

Lack of self-esteem and self-advocacy skills, lack of understanding of social norms and communication difficulties are strong contributing factors to the high incidence of abuse among this population. Challenging behaviour these people frequently exhibit, including self-

⁴⁶ WHO, 2008

injury, aggression and inappropriate social behaviour, can be the only way of communicating pain, dissatisfaction with a disturbing environment, the lack of opportunities or unsatisfactory living a person who needs high level of support has. Challenging behaviour are also likely to lead to abuse, including serious limitation or deny to access to ordinary community facilities It is therefore crucial that the inherent dignity of these people is fully recognised and strongly defended.

EDF contributed to achieve equal opportunities for people with high level of support needs:

- through its document “*Achieving Equal Opportunities for Persons with Complex Dependency Needs*” (2007)
- by establishing an advisory group on complex dependency needs (2009) and an e-mail expert group (2014)

Conclusions

Where the CoE DAP has been used as a reference document for any new disability-related policies and activities that are adopted, substantial progresses have been reported by member States in the development of policies and plans at national level to promote and deliver on the rights of people with disabilities as equal members of the community.

The Council of Europe, through its Congress of Local and Regional Authorities and its Parliamentary Assembly, via its Social, Health and Family Affairs Committee, were fully involved in contributing towards the achievement of the Council of Europe Disability Action Plan, which was being monitored and promoted by the European Co-ordination Forum for the Disability Action Plan 2006-2015 (CAHPAH). Although the member states of the Council of Europe were responsible for the achievement of the Plan’s objectives, both the Congress and the Parliamentary Assembly could contribute through encouraging European dialogue, deepening the involvement of national Parliaments, sharing of best practice and making suggestions to member states on the implementation of the Plan.

Policies and actions at the CoE institutions and national/regional/local level should be developed to secure the full and effective participation of people with disabilities, through the active involvement as equal partners of their representing organisations in the design, implementation and monitoring of legislations, policies and measures having an impact on their lives. Fair, effective and continuous cooperation with disabilities organisations as well as their involvement in the planning, implementing and monitoring of policies and measures are preconditions to change in the approach of disability from protection to inclusion.

