Youth and Disabilities

- EU and CoE policy framework -

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INTRODUCTION

According to the WHO, around 10 per cent of the world's children and young people, some 200 million, have sensory, intellectual or mental health impairment. Estimates suggest that there are between 180 and 220 million youth with disabilities worldwide and nearly 80% of them live in developing countries. The number of youth with disabilities is likely to increase due to youthful age-structures in most developing countries and medical advancements which promote higher survival rates and life expectancy after impairment-causing diseases, health conditions, and injuries. There is a significant dearth of research on the prevalence and consequences of disabilities among youth. The data that does exist shows that young people with disabilities face many more challenges than their non-disabled peers. They often face prejudice and/or negative attitudes which hinder their participation, self-determination and inclusion in the society.

In the EU, presumably, people with disabilities are the largest social minority – about 80 million Europeans have a disabilityⁱⁱ. There is no reliable statistics on the number of youth with disabilities in Europe, partly because youth with disabilities as a group are not quite visible on the policy and research agenda, and partly for the reason that overall disability statistics varies accordingly to the different understanding of a disability across the states.

I. INTERNATIONAL CONTEXT OF DISABILITY POLICIES

1. Policy paradigm shift – from Medical to Social model of disability

Social model understanding of disability has been gradually replacing the commonly accepted medical model since 1970s. Social model emphasizes that solution to the disability problems lies in restructuring the society: it focuses on eliminating the barriers (physical, structural, attitudinal), education to remove prejudice and making sure that laws and policies support the exercise of full participation and non-discrimination. Rather than viewing person with a disability as a problem (as medical model does), it sees barriers and the disabling society as the main problem, and pursues the goal of inclusionⁱⁱⁱ. This understanding of disability underpins the viewing and promotion of *disability as a human rights issue*.

The recent <u>UN Convention on the Rights of Persons with Disabilities</u> (2006) therefore states that disability is "an evolving concept" and the one that "results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others."

2. UN Convention on the Rights of People with Disabilities

The work of the disability movement resulted in the adoption of the UN Convention on the Rights of People with Disabilities (UN CRPD) in 2006. The Convention is the first legally binding international UN instrument on disability, which sets out the minimum standards governments are obliged to meet in order to ensure that persons with disabilities effectively benefit from their civil, political, economic and social rights. While the Convention does not create new rights, it specifically prohibits discrimination against persons with disabilities in all areas of life, including access to justice and the right to education, health services and access to transportation. The Optional Protocol of the UN CRPD establishes a) the individual communications procedure allowing individuals to bring petitions to the Committee claiming breaches of their rights; b) the procedure giving the Committee authority to undertake inquiries of grave or systematic violations of the Convention.

The Convention was negotiated during eight sessions of an Ad Hoc Committee of the General Assembly from 2002 to 2006 and is also the first international treaty that was negotiated with direct participation of its

beneficiaries: persons with disabilities and disability rights groups. Young people with disabilities played a significant role in discussions around the drafting of the CRPD. More than 200 focus group meetings were held with young people with disabilities from 12 countries in order to identify the issues that were of most concern to them^{iv}. Article 3 specifically identifies the principle of "Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities". Principle 8 of the CRPD states "respect for the evolving capacities of disabled children and respect for them to preserve their identities." Article 24 of the UN CRPD highlights the importance of an inclusive education system at all levels, including lifelong learning, vocational training and adult education, with particular emphasis on the provision of reasonable accommodation and support to ensure effective participation in the general education system. However, research has shown that the obligations of the UN CRPD in regard to inclusive education at this point are not fulfilled in Europe, and that they are unlikely to be complied with in the near future.

II. INSTITUTIONAL CONTEXT OF DISABILITY POLICIES AT THE EUROPEAN LEVEL

1. EU disability policy background

During the last decades disability policy at the European level has transformed from a formerly disregarded branch of traditional social policy into a modern policy formation which comprises not only social protection and labour market integration, but also equal rights and non-discrimination^{vi}.

The recent European Union policy on disability is built on an explicit commitment to the social model of disability. Since 1983, the Commission has supported the development of a European disability policy through a succession of Community action programmes (Helios I and Helios II) vii, initially aimed at promoting networking among rehabilitation and education professionals. As a result of active involvement of disability organisations in Helios programmes, European Disability Forum (EDF), the platform for representation of people with disabilities on the EU level, was established in 1997.

The Treaty of Amsterdam which was put into force in 1999 marks a significant shift in both social policy and disability policy; the right to non-discrimination is taken up. From this time on disability is regarded as a civil rights issue and the right to non-discrimination is acknowledged as an integral part of social rights viii. With the specific reference to discrimination on the grounds of disability in the new Article 13 of the Treaty of Amsterdam, and the EU Directive on Equal Treatment in Employment and Occupation, discrimination in the field of employment on the ground of disability is prohibited and reasonable accommodation is encouraged. Article 26 of the EU Charter on Fundamental Rights (2000) recognises and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community. In 2010 the European Commission adopted the European Disability Strategy 2010-2020, which aims to empower people with disabilities so that they can benefit fully from participating in society and in the European economy. In 2011, the European Union has ratified the UN CRPD, becoming the first regional integration organisation to sign on to any human rights treaty^{ix}. All institutions and agents of the EU will have to endorse the values of the Convention in all policies under their competence ensuring the mainstreaming of disability: from transport to employment and from information and communication technologies to development cooperation. Still, research shows prevalence of indirect or direct discrimination: over half of all Europeans consider discrimination on grounds of disability or age to be widespread in the EU^x. The EC has therefore committed to pay attention to the issue as well as the cumulative impact of discrimination that people with disabilities may experience on other grounds, such as nationality, age, race or ethnicity, sex, religion or belief, or sexual orientation.

2. Council of Europe work in the disability field

The European Social Charter (1961) contains explicit provisions on the rights of persons with disabilities to independence, social integration and participation in the life of the community. 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 persons with disabilities in Europe 2006-2015" sets out specific actions to be implemented by member states in areas including participation in political and public life, education, health care, or awareness-raising. In 2011, Recommendation CM/Rec (2011)14 to member states on the participation of

persons with disabilities in political and public life was adopted by the Committee of Ministers. The recommendation recalls the action lines of the Disability Action Plan 2006-2015 and underlines the importance of ensuring equal rights, accessibility, non-discrimination, assistance in decision-making, education in democratic participation and inclusion of people with disabilities in decision-making processes.

III. POLICIES RELEVANT TO YOUTH WITH DISABILITIES

Within the European Union's new strategy for jobs and smart, sustainable and inclusive growth ("Europe 2020"), the "Agenda for new skills and jobs" aiming to raise employment and activity rates, touches on the issue of the extremely low employment and activity rates of persons with disabilities and the 'benefit trap' partly responsible for this. By focusing on transitions from education to employment and on training, the increasing inflow into disability benefits of young people should be counteracted. In this respect, "Youth on the move" programme also offers multiple links with the EU Disability Strategy 2010-2020 by addressing inclusiveness and relevance of education systems, job placement schemes for young people with disabilities, promoting entrepreneurship, and fostering mobility^{xi}.

In 2012 the European Economic and Social Committees drafted the <u>Opinion on young persons with disabilities</u> where inclusive education, reasonable accommodation in employment, incentives for employers to hire young persons with disabilities, accessibility (including accessibility of new technologies and websites) were recognised as crucial to enhance the participation of youngsters with disabilities in Europe. The EU Danish Presidency used the opinion to raise political commitment of the Member States to promote social, political and economic participation of young persons with disabilities.

Youth age of transition has been often left out of policy discussions on disability due to legal distinctions between a child and an adult where anyone above 18 is classified as an adult. There has been a tendency to forget the transition phase between childhood and adulthood, and between education and employment. However, the steps to fill in this policy gap are undertaken. The Social Cohesion and Integration Division of the Council of Europe has come up with the Recommendation on the social inclusion of children and young people with autism spectrum disorders in 2009, where a distinction is made, and children and young people are explicitly mentioned. Another *Recommendation CM/Rec* (2012)6 on the protection and promotion of the rights of women and girls with disabilities that contains an explicit reference to girls with disabilities, was adopted by the Committee of Ministers in 2012.

In the second half of 2012, the Council of Europe Committee of Experts on the Rights of People with Disabilities (CS-RPD) has been working on drafting of the new Committee of Ministers *Recommendation on inclusion of children and young people with disabilities*. It was recognised by the CS-RPD that the phase of transition from education to employment is essential for guaranteeing an inclusive society. Inputs from the Council of Europe Youth Department's Consultative Meeting on "Inclusion of Youth with Disabilities in the Youth Activities of the Council of Europe" are taken into account in drafting of the Recommendation.

IV. PARTICIPATION AND REPRESENTATION OF YOUTH WITH DISABILITIES

Young people with disabilities do not always have option to take part in organisations of youth without disabilities, because of accessibility and/or psychological barriers. Youth with disabilities tend to be organised in disability networks and disability-specific organisations, either as youth NGOs or youth sectors of adult disability organisations (where they may struggle with access to decision-making). On international and regional levels, most active representatives of disability and youth issues include: International Federation of Hard of Hearing Young People, Leonard Cheshire Disability Young Voices, European Union of Deaf Youth, African Youth with Disabilities Network, World Enabled/Pineda Foundation for Youth, World Federation of the Deaf Youth Section. Participation and representation of youth with disabilities on the EU level is enabled through the European Disability Forum Youth Committee. Its role is to mainstream youth in all EDF policies and documents and to raise awareness about the needs of youth with disabilities in EDF and the EU^{xii}. EDF underlines the importance of mainstreaming disability in all areas concerning youth which implies assessment of the implications for disabled people of any planned action, including legislation, policies and programmes, in all areas and at all levels. The Both disability and youth need to be key concerns in formulating any policy.

Owing to the Helios programmes, some positive changes were made in the EU programmes such as Socrates, Youth for Europe, Leonardo da Vinci, Daphne, Phare, Tacis^{xiv} in relation to participation of people with disabilities. The Youth in Action Programme 2007-2013 pays particular attention to increasing the opportunities, in a broad sense, of young people with disabilities; financing specific costs related to disability needs, can be provided. SALTO booklet "No Barriers, No Borders" informs how to run international mixed ability projects for young people with and without a disability^{xv}. Data for Youth in Action Programme in 2010 show that 8% of total granted projects on decentralised level had a primary theme "disability" (271 project); 9% of total granted projects had "disability" as a secondary theme (298 projects); 16% of total granted projects aimed at the inclusion of young disabled and/or directly involving disabled young people (543 projects).

However, as identified by research, access to education alone is a grave problem - not to speak of active participation:

Challenges in the context of youth and disability policies:

- There is limited information regarding the direct impact of (generic) EU policies on people with disabilities xvi, young people with disabilities alone;
- People with disabilities are in some countries absent from discussions on social inequality, exclusion and poverty^{xvii};
- The level of poverty among people with disabilities remains high;
- The current policy measures have not been able to offer to people with disabilities a safety net that would bring them out of the poverty trap and enable them to lead dignified lives^{xviii};
- Limited progress has been made in the area of lifelong learning;
- Women with disabilities are particularly under-represented in recreational activities, culture and sport in terms of participation, leadership, management and media coverage^{xix}. Similarly, children with disabilities face significant barriers to e.g. participation in recreational activities, culture and sport, and remain poorly served by provision of education^{xx};
- Possibilities for accessing mainstream education tend to be unavailable for children with severe disabilities^{xxi}, and segregation is still widespread all over Europe^{xxii} (e.g. in Germany only 15.7 per cent of all children and adolescents with disabilities attend school together with non-disabled pupils)^{xxiii};
- Young people with disabilities are far less likely to attend school or to stay in school than their non-disabled peers^{xxiv}. Even in countries that are close to achieving universal primary education, people with disabilities represent the largest group still out of school^{xxv}. One issue seems to be that families are less likely to prioritise education for children with disabilities, believing they are not capable of learning xxvi.

In order to design effective and efficient policies, greater knowledge of disability issues by decision-makers as well as research on youth with disabilities, are crucial; disability issues should be cross-cutting in youth policy and other policy areas; youth with disabilities shall be directly consulted in decision-making processes in the spirit of the disability rights movement - "nothing about us without us".

 $http://social.un.org/youthyear/docs/Fact\%\,20 sheet\%\,20 youth\%\,20 with\%\,20 disabilities.pdf.$

Youth with Disabilities Fact Sheet,

ii http://www.edf-feph.org/Page_Generale.asp?DocID=12534&id=1&langue=EN – Facts and figures about disability in the EU

Social security and social integration: definitions of disability in Europe, 2006, Shakespeare 1996.

UN Youth Flash, Jan. 2007 Vol. 4, No 1, http://www.un.org/esa/socdev/unyin/documents/flashjanuary07.pdf.

See 'Specific Risks of Discrimination Against Persons in Situation of Major Dependence or with Complex Needs', p. 5.

Anne Waldschmidt, Disability policy of the European Union: The supranational level.

vii Community Social Action Programme on the Social Integration of Handicapped People, 1983-88, (1981); HELIOS I (Second) Community Social Action Programme for Disabled People (1988) OJ L104/38; HELIOS II (Third) Community Action Programme to Assist Disabled People (1993) OJ L56/30.

Anne Waldschmidt, Disability policy of the European Union: The supranational level.

Press-release of the European Disability Forum, January 5, 2011.

- x Special Eurobarometer 317.
- See Commission staff working document accompanying the Communication from the Commission European Disability Strategy 2010-2020: a renewed commitment to a barrier-free Europe
- European Disability Forum Youth Committee webpage, http://www.edf-

feph.org/Page Generale.asp?DocID=28558&id=1&namePage=ourwork&langue=EN

carol Miller and Bill Albert, Mainstreaming disability in development: lessons from gender mainstreaming (March 2005) - www.dfid.gov.uk/r4d/PDF/Outputs/Disability/RedPov_gender.pdf.

European Union Policy Toward People with Disabilities, Disability Studies Quarterly, Fall 2002, Volume 22, No. 4, Teresa Zolkowska.

www.salto-youth.net/rc/inclusion.

Communication on the European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe.

Priestley, M., 'Synthesis report on disability mainstreaming in the 2008-2010 National Strategy Reports for Social

Protection and Social Inclusion (NSRs)', Oct. 2008, Academic Network of European Disability Experts [Online], p. 16.

See Academic Network of European Disability Experts (ANED) (2009), 'The implementation of EU social inclusion and social protection strategies in European countries with reference to equality for people with disabilities', p. 33.

'Study on the situation of women with disabilities in light of the UN Convention for the Rights of Persons with Disabilities', p. 34-135.

'Study on the situation of women with disabilities in light of the UN Convention for the Rights of Persons with Disabilities', p. 135.

'Specific Risks of Discrimination Against Persons in Situation of Major Dependence or with Complex Needs', p. 73.

Specific Risks of Discrimination Against Persons in Situation of Major Dependence or with Complex Needs', p. 74.

See Federal Ministry of Labour and Social Affairs (Germany): 2009 Disability Report.

World Health Organization, World Report on Disability 2011, available at

http://whqlibdoc.who.int/publications/2011/9789240685215_eng.pdf.

UNESCO, Reaching the Marginalised: Education for All Global Monitoring Report 2010 available at: http://unesdoc.unesco.org/images/0018/001866/186606e.pdf.

Groce, N.E. (2004) Adolescents and youth with disability: Issues and Challenges. Asia Pacific Disability Rehabilitation Journal. 15(2): 13-32.

Resources and References:

Youth and Disability in the EU and International Institutions

<u>Disability Intergroup</u> - a cross party group of the Members of the European Parliament from each of the 27 EU Member States supporting the rights of people with disabilities

EU Framework Directive 2000/78/EC on equal treatment in employment

European Disability Strategy 2010-2020

Council of Europe Directorate of Human Rights and Anti-Discrimination, Division "Social Cohesion and Integration", Integration of People with Disabilities Unit

United Nations Convention on the Rights of Persons with Disabilities

European Disability Forum Youth Committee

<u>Human rights of persons with disabilities</u>, overview of the International Human Rights Instruments related to disability, Human Rights Education Associates (HREA)

Overview of International Legal Frameworks for Disability Legislation, UN

Reports and handbooks

World Report on Disability, 2011, WHO

OECD Report "Transforming Disability into Ability: Policies to Promote Work and Income Security for Disabled People", 2003

UN CRPD Handbook for Parliamentarians

Report on equality of educational and training opportunities for young disabled people in European countries, ANED, 2010

Journals

Journal of Disability Policy Studies

Youth and Disability - Facts & Figures

<u>Youth with Disabilities Fact Sheet</u>, UN High Level Meeting on Youth, 2011 Disability and Health Fact sheet N°352, WHO, June 2011

Resources produced or curated by youth with disabilities and their organisations

"Young and Disabled: Daily Challenges for Equality", EDF Youth Committee Publication, published in 2006 and updated in 2009

<u>ExchangeAbility</u> leaflet for coordinators of student exchanges involving youth with disabilities, Erasmus Student Network and EDF Youth Committee, 2009

<u>Youth with Disabilities</u>, youth policy resource page on youth with disabilities, curated by WORLD ENABLED – a collaborative initiative of the Pineda Foundation for Youth

Definition of disability and models of disability

<u>International Classification of Functioning, Disability and Health, WHO Disability Models, International Encyclopedia of the Social Sciences</u>

Disability Research Networks

Academic Network of European Disability Experts (ANED)

Education and Training

<u>SALTO Inclusion</u> home page, includes booklets on inclusion, toolbox on training and youth, training opportunities calendar, links on disability issues

"Role of European trainings, Arts and Participation in Inclusion of Youth with disabilities" (Coyote Magazine, Issue 8-2004) by Karina Chupina

"No Barriers, No Borders" manual on organising and running mixed ability projects, SALTO-YOUTH Inclusion Resource Centre, 2008

Disability youth organizations active on the European level

Network of Blind and Partially Sighted Youth - European Blind Union

International Federation of Hard of Hearing Young People

Leonard Cheshire Disability Young Voices

European Union of Deaf Youth

World Enabled/Pineda Foundation for Youth

World Federation of the Deaf Youth Section

European Disability Forum Youth Committee

Disabled Students Association in Slovenia

Association of Students with Disabilities in Serbia and Montenegro

Norwegian Association of Youth with Disabilities

The Swedish National Association for Disabled Children and Young Persons