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HUMAN RIGHTS AND DISABILITY:

EQUAL RIGHTS FOR ALL

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Commissioner’s Issue Papers

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1. Introduction

It is estimated that 80 to 120 million Europeans are persons with disabilities, that is 10 to 15% of the total population of the Council of Europe member states. For too long policies concerning persons with disabilities have been focused on institutional care, medical rehabilitation and welfare benefits. Such policies build on the premise that persons with disabilities are merely objects of welfare policies, rather than subjects able and entitled to be active citizens. Over the last few decades a shift in thinking has taken place. It is no longer correct to view persons with disabilities as merely objects of concern. They are citizens with equal rights and have an active role to play in our societies.

The challenge is to put this shift in thinking fully into practice. In reality, persons with disabilities are still discriminated against all over Europe and globally. Children with disabilities are denied their educational rights because schools are not equipped to meet their needs. Job opportunities are limited due to discriminatory practices and inaccessible workplaces, making people dependent on social benefits. Flawed systems of guardianship prevent people from making choices and having control over their lives. Several Council of Europe member states still hesitate to close down residential institutions and develop community-based services for persons with disabilities arguing that institutional care is necessary for persons with multiple or “profound” disabilities.

This paper outlines the international human rights framework for the protection of persons with disabilities. It gives a brief description of the situation focusing on key issues for persons with disabilities: the fight against discrimination; the move from institutional care to community living and the right to take decisions about one’s personal affairs. This is followed by an overview of measures to create open and accessible societies, with action plans as the working method, and the importance of involving persons with disabilities in the process. It concludes with a set of recommendations to member states.

2. Human Rights Law

International human rights instruments protect everybody, regardless of disability. The UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities, adopted in 1993, were for a long time the guiding instrument clarifying state human rights obligations in this area. The purpose of the Standard Rules was to ensure that persons with disabilities could exercise their rights and freedoms on an equal footing with others. It put the obligation on states to act, pointing out that persons with disabilities should be partners in the process.

2.1 *The UN Convention on the Rights of Persons with Disabilities*

The 2008 UN Convention on the Rights of Persons with Disabilities adopted (the Convention) codifies this shift in thinking in a legally binding instrument. Non-discrimination, accessibility, inclusion in society and the freedom to make one’s own choices are core principles. The substantive articles set out the basic human rights of persons with disabilities and the requirements on states to ensure full enjoyment of these rights. For example, to guarantee political rights states must ensure that persons with disabilities have the opportunity to participate in the public debate, vote and be elected.

States must make sure that voting procedures, polling stations and ballot papers are accessible and easy to understand. The necessary changes to offices have to be made and equipment has to be provided so that politicians with disabilities can hold public positions.

The UN Convention entered into force on 3 May 2008. So far, among the Council of Europe member states Austria, Croatia, Hungary, San Marino, Slovenia and Spain have ratified the Convention. They have also ratified the Optional Protocol to the Convention which allows individuals and groups to bring complaints before the UN Committee on the Rights of Persons with Disabilities, a new body to monitor the implementation on the Convention. Thirty-four other member states of the Council of Europe have signed the Convention¹ and twenty of those also the Optional Protocol.² All member states should sign and ratify this Convention and the Optional Protocol without delay and develop clear strategies and plans to put the rights into practice.

2.2 The European framework

Specific standard-setting and policy-making activities concerning people with disabilities have been carried out at the intergovernmental level at the Council of Europe since 1959. In 1992, a coherent policy for people with disabilities was adopted. This policy laid down general principles on prevention of disabilities, active participation in community life and independence. It covered areas such as health care, education, employment and accessibility in further detail.³

Article 15 of the Revised Social Charter ensures the right of persons with disabilities to independence, social integration and participation in the life of the community. To this end State parties must guarantee quality education free of charge, promote access to employment and take action to make transport, housing and cultural activities accessible to all. The European Committee of Social Rights has concluded that non-discrimination legislation covering all these areas and effective remedies for victims are minimum requirements. In addition, action should be taken to remove barriers preventing persons with disabilities from entering public buildings, using public transport and enjoying new communication and information technologies.⁴ For those states who have not accepted article 15, the Committee examines persons with disabilities' access to mainstream schooling and work under the articles concerned with the right to education and the right to employment in general.

¹ Andorra, Armenia, Azerbaijan, Belgium, Bulgaria, Cyprus, the Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Iceland, Ireland, Italy, Latvia, Lithuania, Luxembourg, Malta, Moldova, Montenegro, the Netherlands, Norway, Poland, Portugal, Romania, Russian Federation, Serbia, Slovakia, Sweden, The Former Yugoslav Republic of Macedonia, Turkey and the United Kingdom.

² Andorra, Armenia, Azerbaijan, Belgium, Cyprus, the Czech Republic, Finland, France, Germany, Iceland, Italy, Lithuania, Luxembourg, Malta, Montenegro, Portugal, Romania, Serbia, Slovakia and Sweden.

³ Recommendation No. R(92)6 on a coherent policy for the rehabilitation of people with disabilities, adopted by the Committee of Ministers on 9 April 1992 at the 474th meeting of the Ministers' Deputies. Since 1959, some 60 policy recommendations or resolutions have been adopted and about the same amount of reports published. An overview of achievement and activities is given in: Access to social rights for people with disabilities in Europe, Council of Europe Publishing, Strasbourg, November 2003, and in: Thorsten Afflerbach, Council of Europe Disability Policy, Encyclopaedia of Disability, Vol. I, SAGE Publications, 2006, pp. 320-322.

⁴ European Committee of Social Rights, Conclusions 2005, p 187ff. The unrevised European Social Charter (1961) article 15 protect the rights of persons with mental and physical disabilities to vocational training, rehabilitation and social resettlement.

The Council of Europe Action Plan 2006-2015 to promote the rights and full participation of people with disabilities in society⁵ (Council of Europe Disability Action Plan 2006-2015) is another significant instrument in this field. The Action Plan is complementary to the UN Convention in so far as it suggests very specific measures, which would facilitate the ratification and the implementation of the UN Convention. The Action Plan can be used to monitor progress in the implementation of disability-related reforms and subsequently help Council of Europe member states in meeting their obligations toward the UN instrument. States are invited to report regularly on their progress to the European Co-ordination Forum.⁶

The EU Employment Framework Directive (2000/78/EC) establishes a general framework for equal treatment in employment and occupation. It protects against discrimination based on disability and obliges employers to make reasonable adjustments to the workplace to cater for the needs of disabled job-seekers and employees.

The case-law of the European Court of Human Rights protecting the rights of persons with disabilities has so far been rather limited which is partly due to the restrictions in the scope of the European Convention itself. The Court has, however, laid down clear criteria for detention of persons in psychiatric hospitals and similar closed facilities. The Court has stated that no-one should be detained “unless it has been reliably shown that he or she has a true mental disorder of the kind or degree warranting compulsory confinement”.⁷ This means that all such decisions must be based on objective medical expertise. The Court has also laid down a number of procedural requirements. Admission procedures to closed hospitals must be clearly defined in domestic law. Decisions on admission and prolongation must be subject to judicial review, either by giving the individual the right to appeal or by an automatic periodic review. Procedural safeguards including legal representation must be guaranteed, not only formally, but also effectively in practice. In *Malgalhães Pereira v Portugal (44872/98)* a lawyer was appointed to assist a man suffering from schizophrenia during the judicial review of his confinement. However the lawyer did not take part in the proceedings. The Court concluded that merely “assigning counsel does not in itself ensure effective legal assistance” and found a violation of Article 5 § 4 of the Convention. Several cases challenging so called plenary guardianship laws and procedures depriving persons of their basic human rights - such as the right to vote, to marry and make legally binding decisions - are now pending before the Court.⁸

2.3 “Nothing about Us, Without Us”

The motto “Nothing about Us, Without Us” has been used for years by the disability movement to achieve full participation and equality of opportunities for, by and with persons with disabilities. The disability movements have played an important and active

⁵ 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, referred to as the Council of Europe Disability Action Plan 2006-2015.

⁶ The Forum is a committee composed of experts from the member states, representatives from Council of Europe bodies and other international organisations and organisations of persons with disabilities.

⁷ European Court of Human Rights, *Winterwerp v. the Netherlands*, 24 October 1979, para 39.

⁸ See also Chapter 5 – The Right to make decisions.

role in the development of the UN Convention on the Rights of Persons with Disabilities and the Council of Europe Disability Action Plan 2006-2015. Participation of persons with disabilities in all decisions affecting their lives, both at the individual level and through their organisations, is one of the fundamental principles in the Council of Europe's Action Plan. The same principle governs the rights as enshrined in the UN Convention as well as in the provisions concerning the monitoring of national implementation.

3. Discrimination

Discrimination of persons with disabilities persists in many spheres of society and can affect people's lives from an early age. Many children with disabilities are still not accepted in the mainstream school system. One problem is the lack of personal support and technical aids. Inaccessible school buildings are another obstacle. The problem also arises in child-care centres, sometimes forcing parents to choose between leaving their children in institutional care or giving up their job in order to care for their child.

3.1 Education for all

Even though every child's ability to learn is undisputed, there are still children of school age who are considered to be "uneducable" and denied any form of education. Such practices do not only limit children's options to support themselves as adults, but also their possibilities to become independent and participate in society. Persons with disabilities have the right to receive quality education and no-one should be excluded from schools because of his or her disability. The European Committee of Social Rights interpreted the right to education in *International Association Autism-Europe (IAAE) v. France (13/2002)*. The case concerned the French education system which allowed children with disabilities to be mainstreamed into the general school system or to attend specialised institutions. In practice, only a small number of persons with autism went into the general school system. Since the specialised institutions could not cater for the needs of the majority, they did not receive adequate education. The Committee stated that both legal and practical measures had to be taken to give full effect to the rights protected by the Charter. When implementation is complex and expensive, states must take progressive measures to give full effect to these rights, within a reasonable time using the maximum of its available sources.

A recent decision from the European Committee of Social Rights concerns over 3,000 children with moderate to profound intellectual disabilities living in residential centres for children with disabilities.⁹ Less than 3% of the children were integrated in mainstream primary schools, which the Committee noted as extremely low considering that integration should be the norm. In addition, the teachers had not been trained to teach pupils with intellectual disabilities and the teaching materials were inadequate. Around 3.5% of the children attended special classes and the rest participated in activities at the residential centres. The Committee pointed out that the centres were not educational institutions and that participation in these activities did not entitle the children to any diploma attesting completion of primary school. Thus the children were prevented from

⁹ European Committee of Social Rights, *Mental Disability Advocacy Centre (MDAC) v. Bulgaria*, 3 June 2008.

entering secondary education. The Committee concluded that the activities provided by the centres could not be considered a form of education. After comparing the rate of children with intellectual disabilities having access to education with data on primary school attendance in general, the Committee held that the children residing at the centres were discriminated against because of the very low percentage who receive any type of education compared to other children.

3.2 *The labour market*

Employment rates regarding persons with disabilities vary considerably across Europe, but they have one thing in common: the activity rates for people with disabilities are significantly below that of people without disabilities. A recent report from International Labour Organization indicates that whereas the average European between 16 and 64 has a 66 % chance of finding a job, Europeans with “moderate” disabilities only have a 47 % chance. A survey published by the European Commission confirms this status. Close to 80% of the approximately 25,000 respondents from the member states of the European Union feel that with equivalent qualifications, a person with a disability stands less chance when it comes to being employed compared to a person without any disability.¹⁰ Once employed, persons with disabilities commonly earn less than their non-disabled peers. One explanation is the lack of relevant education and personal skills, due to past discrimination. Another contributing factor is negative attitudes among employers. Job-seekers with disabilities are still perceived as less productive and more expensive to employ, considering the adjustments that may be needed. There are, however, surveys indicating that employees with disabilities perform equally or better compared with their non-disabled colleagues. Moreover, only a small percentage require adjustments to the workplace and when adjustments are required, the costs are generally negligible over time.¹¹

3.3 *Multiple discrimination*

There is increased awareness that a person can be discriminated against on multiple grounds. For example, women with disabilities tend to have lower salaries and be less represented in management positions compared with men with disabilities and women without disabilities. Women and girls are especially vulnerable to physical, sexual and other abuse in residential institutions. The opportunities for children and young people with disabilities to play sport or enjoy recreational and cultural activities are often very limited, especially for those living in rural areas. Migrants, Roma and older persons with disabilities are particularly vulnerable to discriminatory practices within the social protection and health care systems. Both the UN Convention and the Council of Europe Disability Action Plan 2006-2015 request states to address such multiple discrimination, and take appropriate action to empower all persons with disabilities.

¹⁰ European Commission, Special Eurobarometer 263, January 2007, page 18.

¹¹ International Labour Organization, Equality at work: Tackling the challenges, Global Report under the follow-up to the ILO Declaration on Fundamental Principles and Rights at Work (2007), page 44ff.

3.4 Combating discrimination

A comprehensive anti-discrimination legislation is the cornerstone of any strategy combating discrimination. A glance at the situation in Europe reveals that only a few countries have legislation covering all relevant areas of society. This may reflect the EU framework directive covering only the labour market. A wider scope of protection against discrimination is being discussed within the European Union.

Disability-based discrimination manifests itself not only through negative attitudes and ignorance. Failure to take reasonable measures to meet a person's needs has the same discriminatory effect. An example of a reasonable measure would be a restaurant owner putting a ramp in the entrance to make it possible for customers using wheelchairs to enter. Another example is a headmaster deciding to adapt the school environment to the needs of blind or deaf children. Effective protection against disability-based discrimination has to include a legal obligation for employers, teachers and other duty-bearers to take such reasonable measures. The legal term for such an obligation is often called "reasonable accommodation".

Enacting relevant legislation is not sufficient. States should establish effective mechanisms to enforce and monitor the legislation to ensure full implementation. The judicial system has to be accessible to victims of discrimination and the legal costs involved affordable. It is also good practice to provide non-judicial mechanisms to assist victims, such as National Human Rights Institutions, Ombudsmen or other equality bodies. These easily accessible bodies should be mandated to receive complaints, act as independent mediators and/or provide legal assistance to the victims of discrimination in court proceedings.

Efforts to raise public awareness are required to fight prejudices and to empower persons with disabilities to claim their rights. In addition, targeted training for teachers, doctors, civil servants, journalists, employers and service providers as well as lawyers and judges is key to prevent discriminatory practices and ensure effective remedies.

4. The right to live in the community

Life in an institution, separating children and adults from their family and their social context, almost inevitably leads to exclusion. Looking at the situation in Europe, countries are at different stages in the process of closing institutions and replacing them with community-based care, education and social services. Where institutions still exist, living conditions and service differ considerably between, and even within countries. Member states have adopted different strategies and approaches to the de-institutionalisation process. The majority prefer community care, while keeping residential institutions, sometimes renovated and/or transformed into smaller units. Only a few countries have managed to close all institutions and replace them with community-based alternatives.

Article 19 of the UN Convention clearly recognizes the right to choose your residence, on an equal footing with others, and to be included in the community. State parties pledge to take action to facilitate full enjoyment of this right and to prevent isolation and segregation.

4.1 De-institutionalisation

To live up to these standards, states need to make sure that parents receive support to enable them to raise their children. Childcare centres and schools should be open to all children and equipped to meet different needs. Social services and health care providers in the community must be accessible and competent to care for persons with different disabilities. Such reforms are challenging and require commitment and re-allocation of resources.

Experts on community living recommend that member states establish timetables to stop new admissions to institutions and establish community alternatives. A recent European study on the outcomes and costs of deinstitutionalisation explores the complex relation between needs, costs and quality of services. It concludes that a good care system usually involves substantial costs, whether provided in the community or in institutional settings. There is no evidence that community-based systems are more costly as such. However, once set up and well-managed, they tend to provide better quality services than institutions.¹² Experience also shows that when states succeed in providing proper services in the community, people prefer this form of service over institutional settings. Closure of institutions is not a goal in itself, but it is a method to ensure independence and inclusion for persons with disabilities.

4.2 Independent monitoring of closed institutions

As long as people are still living in institutions, their human rights must be protected. Such institutions should have decent living conditions, be adequately staffed and promote maximum contact with the outside world.¹³ The European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT) is mandated to visit psychiatric hospitals and institutions across Europe. All too often the Committee reports of poor conditions and low quality care. In some reports, the CPT concluded that this amounted to inhuman and degrading treatment.¹⁴ These reports also describe flawed admission procedures into institutions. Lack of legal provisions, delayed and/or superficial procedures to review the necessity of detention and lack of legal assistance are common problems.

Several NGO reports also highlight violations taking place in such institutions.¹⁵ Malpractices, such as keeping persons in bed all day, over-medication and abuse of restraints must be stopped immediately. In addition, all involuntary placement, whether at institutions or psychiatric hospitals, must be in accordance with national law and

¹² Mansell J, Knapp M, Beattie-Brown J and Beecham J, Deinstitutionalisation and community living – outcomes and costs: report of a European Study, 2007, p 97ff. See also Recommendations and Guidelines to promote community living for children with disabilities and de-institutionalisation as well as to help families to take care of their disabled child at home, adopted by the Council of Europe Committee on Rehabilitation and Integration of People with Disabilities (Partial Agreement) (CD-P-RR) on 31 December 2007.

¹³ For more details, see: Recommendation (2005)5 of the Committee of Ministers on the rights of children living in residential institutions and Committee on the Rights of the Child, General Comment No 9, para 42-46.

¹⁴ See, for example, CPT report to the Government of the former Yugoslav Republic of Macedonia on the visit to the country 15 to 26 May 2006, para 134 and the CPT report to the Bulgarian Government on the visit to Bulgaria from 16 to 23 December 2003, para 33.

¹⁵ Mental Disability Advocacy Centre, *Biennial Report 2005-2006*; Mental Disability Rights International, *Torment not Treatment: Serbia's Segregation and Abuse of Children and Adults with Disabilities*(2007), *Hidden Suffering: Romania's Segregation and Abuse of Infants and Children with Disabilities* (2006) and *Behind Closed Doors: Human Rights Abuses in the Psychiatric Facilities, Orphanages and Rehabilitation Centres in Turkey* (2005).

subject to judicial review. Procedural safeguards as laid down by the European Court of Human Rights must also be guaranteed. The CPT Standards on involuntary placements in psychiatric establishments as well as two recommendations from the Committee of Ministers – Recommendation (2004)10 on the protection of human rights and dignity of persons with mental disorders and Recommendation (2005)5 on the rights of children living in residential institutions – give detailed guidance for evaluating domestic admission and review procedures.¹⁶

As with all closed settings where the liberty of persons is restricted, effective complaints procedures as well as independent monitoring visits are of crucial importance to ensure that human rights are respected. All member states should ratify the Optional Protocol to the UN Convention Against Torture and other Inhuman or Degrading Treatment or Punishment. Under this Protocol, states are required to establish national inspection systems to monitor all places of detention, including mental health and social care institutions.

5. The right to make decisions

The right to decide where we want to reside, how to spend our money, whether and with whom to get married is something many of us take for granted. But for thousands of Europeans placed under guardianship the reality is very different. In several member states, adults are still deprived – on the basis of a medical diagnosis – of their legal capacity to take binding decisions. The result of such procedures is that these persons can no longer make any decisions with legal effect. They can no longer sign a lease to rent an apartment, consent or refuse medical treatment, cast a vote, marry, or even access a court to challenge this legal incapacitation. More developed systems allow only partial deprivation of legal capacity, while providing proper procedural safeguards and thoroughly regulating the power of guardians. Adequate monitoring procedures should also be in place to protect individuals against financial impropriety or other abuse or neglect.

5.1 The European standards

The European Court of Human Rights has acknowledged that the non-recognition of a person's legal capacity severely limits his or her human rights. In a recent case it stated that full deprivation of legal capacity is a very serious interference with the right to private life protected by article 8 of the European Convention on Human Rights. The sole existence of a mental disorder, even a serious one, cannot in itself justify such incapacitation.¹⁷ The case concerned a man in his twenties who was fully deprived of his legal capacity following a request by his mother. The domestic court made its decision without even informing him of the proceedings, violating the right to a fair trial under Article 6 of the ECHR. As a result he was denied the opportunity to act in almost all areas of life. He could, for example, no longer buy or sell, decide where to live, work, travel or marry. He was denied the opportunity to appeal the decision on guardianship. A few days later, he was detained in a psychiatric hospital by the consent of his mother,

¹⁶ See also: Council of Europe Resolution ResAP(2005)1 on safeguarding adults and children with disabilities against abuse, adopted by the Committee of Ministers on 2 February 2005 at the 913th meeting of the Ministers' Deputies.

¹⁷ European Court of Human Rights, *Shtukaturov v. Russia*, 27 March 2008.

who was appointed his guardian. He was unable to challenge that decision. Only his guardian could decide on his release. The European Court of Human Rights concluded that the proceedings had been seriously flawed and the applicant had been arbitrarily detained.

The Council of Europe recommendation on the protection of adults with disabilities who need assistance in making decisions in their personal or economic affairs, enumerate basic principles for interfering with a person's legal capacity.¹⁸ The main principles are maximum preservation of capacity and respect for choices as far as possible. Nobody should be automatically deprived of their right to vote, draw up a will, consent or refuse any medical intervention or take decisions of a personal nature. Any measure restricting legal capacity should be tailored to the needs of the person concerned. Some persons need support to handle their financial affairs. Others need assistance to communicate their decisions. Procedural safeguards to protect against abuse should also be provided, including the right to be heard in person during proceedings, the right to appeal and a periodic review of the decision.

5.2 Supported decision-making

Articles 3 and 12 of the UN Convention clearly state that people with disabilities have the right to equal recognition before the law and the right to make their own choices. State parties are obliged to provide the necessary support these people may require to exercise their rights. The focus is on enabling people to make and communicate their decisions. This approach, often called supported decision-making, is strongly advocated by the disability movement globally. It builds on the sound belief that everyone can make choices and communicate them to others, while recognising that sometimes this requires support. Independence and personal autonomy is not about being able to do everything on your own, but about having control of your life and the possibility to make decisions and have them respected by others.

6. Removing barriers

Persons with disabilities face a number of barriers that prevent their participation in society. Children with physical disabilities cannot play with other children at public playgrounds because the playgrounds have not been designed with them in mind. Television programmes without subtitles exclude persons with hearing impairments. The possibility to be politically active may be circumscribed by legal barriers, inaccessible voting procedures or simply because public information is not provided in an accessible format.

To meet these challenges, we all need to change the way we think and act. More effort should be invested in creating a society fit for all. The challenge is to open up our societies, remove physical, legal and attitudinal barriers and avoid creating new ones. Whilst the majority of European countries have laws and standards regarding public buildings and transport systems, these regulations are not sufficient. They are often limited to new buildings or buildings being reconstructed. Requiring owners to make

¹⁸ Recommendation No (99)4 of the Committee of Ministers on the principles concerning the legal protection of incapable adults, adopted by the Committee of Ministers on 23 February 1999 at the 660th meeting of the Minister's Deputies.

reasonable adjustments to their existing buildings would be a good practice and an effective way of preventing discrimination. There should be appropriate sanctions for those violating the regulations, and remedies for those who are excluded as a consequence of such violations. Moreover, similar standards should be adopted for other areas of society. The needs of persons with disabilities should always be taken into account when designing new products, services, infrastructure and information and communication systems. Both the UN Convention and the Council of Europe Disability Action Plan 2006-2015 build on the premise that systematic and progressive work is necessary to create inclusive and accessible societies. This can be achieved by improving accessibility of existing environments, and also by applying universal design principles to newly created environments and systems. The Council of Europe's Resolution ResAP(2007)3 on achieving full participation through Universal Design provides member states with specific recommendations.

Scarce resources might have an impact on the timetable for this work, but there is no excuse for not making steady progress. Cost of accessible construction is not always high. According to the World Bank reconstructing buildings may be expensive but the cost of making new buildings accessible adds approximately one percent to the total costs.¹⁹ There is also popular support for such action. A recent survey shows that over 90% of EU citizens think that more money should be spent on eliminating physical obstacles that complicate or hinder the daily life of persons with disabilities.²⁰ In fact, accessible solutions benefit us all. Electronic coffee makers, remote controls and automatic door openers were all originally designed to be assistive devices for persons with disabilities. Today most people use them on a daily basis.

7. National Implementation

7.1 Action Plans as the working method

Achieving inclusive societies requires planning and systematic work. It is therefore encouraging that many European states have adopted disability plans and strategies. Every country will need to develop and implement such action plans tailored to its own circumstances inspired by the Council of Europe Disability Action Plan 2006-2015. Experience shows that certain common factors are crucial for success:

- A high level of political support and allocation of adequate budgetary resources.
- A thorough evaluation of existing policies and practices, to identify problematic areas
- Action-oriented national plans and strategies with concrete measures and clear indications on how these measures will improve the existing situation. The plan should designate who is responsible for implementation and indicate time-frames and benchmarks.

¹⁹ World Bank, *Social Analysis and Disability: A Guidance Note Incorporating Disability-Inclusive Development into Bank-Supported Projects* (2007), p 21.

²⁰ European Commission, *Special Eurobarometer "Discrimination in the European Union"* ref 263.

- Involvement of all concerned actors during the entire process. This must include all those who are responsible for the implementation at national or local level, people with disabilities and their representative organisations. The participatory approach will contribute to the legitimacy of the plan, create ownership and make implementation effective.
- Effective evaluation of the process. We need to learn from our mistakes and build on our successes.
- Gathering data in all relevant fields.

The benefits of working systematically on human rights issues, as opposed to a less structured *ad hoc* approach, are numerous. A systematic approach increases the chances of sustainable results. It also makes it possible to foresee and plan costs and to allocate resources where they are most needed.

7.2 Data collection and analysis

The availability of adequate data relating to persons with disabilities is key to effective policy implementation and monitoring progress. Data collection and analysis can provide information not only on the number of persons with different disabilities but, for example, on their level of enrolment in mainstream education, their situation on the labour market, their level of participation in public life and the barriers they face when exercising their rights. States parties to the UN Convention have undertaken to collect the information needed to give full effect to this Convention. The process must comply with data protection standards to ensure confidentiality and respect the privacy of the persons concerned. The Council of Europe Disability Action Plan 2006-2015 also highlights the importance of including the gender perspective in collecting and analysing data.

An issue that needs to be taken seriously is terminology. Countries use different vocabulary and definitions relating to disability and persons with disabilities. To serve as a tool for identifying barriers, developing action plans and measuring progress, data collection and analysis should be based on a human rights model of disability. This model recognises that a disability is not solely a feature of the person caused by illness or other health condition. The interaction between a person with impairments and the barriers he or she faces in society, is also another feature of disability. The WHO International Classification of Functioning, Disability and Health (ICF), published in 2001, has already adopted this approach.

8. Recommendations

In implementing the rights of persons with disabilities member states should:

1. Ratify the Convention on the Rights of Persons with Disabilities including the Optional Protocol and start implementing it. Use the Council of Europe Disability Action Plan 2006-2015 as a tool to make the standards a reality.
2. Consult with and include persons with disabilities and their organisations in the planning and monitoring of law and policies which affect them.

3. Develop action plans to remove physical, legal, social and other barriers that prevent persons with disabilities from participating in society. Collect and analyse the necessary data to monitor the effective implementation of the action plans.
4. Adopt non-discrimination legislation covering all relevant areas of society. Include an obligation for employers, teachers and other duty-bearers to take reasonable measures to accommodate persons with disabilities. Provide effective remedies for persons who have had their rights violated. This includes making the judicial system accessible and the legal costs involved affordable.
5. Raise awareness to fight prejudice against persons with disabilities while empowering people to claim their rights. Provide training for teachers, employers and service providers as well as for lawyers and judges on the rights of persons with disabilities.
6. Set up an independent Ombudsman or other equality body with a view to ensuring that persons with disabilities are able to fully enjoy their rights. Mandate such bodies to receive complaints, act as mediators and provide legal assistance to victims.
7. Develop programs to enable persons with disabilities to live in the community. Cease new admissions to social care institutions and allocate sufficient resources to provide adequate health care, rehabilitation and social services in the community instead.
8. Review the laws and procedures for involuntary hospitalisation to secure that both law and practise comply with international human rights standards.
9. Set up independent mechanisms equipped to make regular, unannounced and effective visits to social care homes and psychiatric hospitals in accordance with the Optional Protocol to the UN Convention against Torture.
10. Review guardianship legislation to ensure that persons with disabilities can effectively exercise their right to make decisions and have them respected. When necessary and asked for, provide support tailored to individual needs to enable persons to exercise this right together with adequate safeguards to protect them against abuse.