

International and European Disability Policy Relating to Stuttering: What you need to know and why

Dear Colleague

Most people involved with stuttering and disability issues are probably aware of the legal situation in their own country. What they often lack is knowledge of the European and international scene.

This brochure provides a brief overview of European and world-wide disability policy. It aims to guide you through the main pieces of legislation, declarations, conventions and treaties that people who stutter can use to help claim their right to equal treatment and non-discrimination. These policy instruments represent strong political commitments and legal rights and as such are powerful tools to ensure further progress.

The European League of Stuttering Associations (ELSA), along with many other European Non-Governmental Organisations, believes that co-operation at all levels, from international to local, is the key to changing perceptions and policies thus opening the door to a tolerant and barrier-free society.

Much has already been achieved in the last 10-15 years. It is therefore essential for people with disabilities, including people who stutter and their support organisations, to be aware of these achievements to ensure future campaigning builds on what has been done.

However, awareness is only a first step.

Through this brochure, ELSA would like to encourage stuttering organisations, their boards, staff, volunteers and interested members to become more familiar with the existing political, legal and policy frameworks and be robust in using them when raising awareness of stuttering and campaigning for improved conditions and equal rights.

Please use this brochure as an aide-mémoire of what is already in place internationally and across Europe to help you and ELSA achieve our goals.

Although this brochure is primarily written for people who stutter and their support organisations, ELSA hopes it will also be a useful reference for others involved in the disability field.

Edwin J. Farr MBE
Chair of the European League of Stuttering Associations (ELSA)

THE EUROPEAN YEAR OF PEOPLE WITH DISABILITIES 2003 is a unique opportunity to raise awareness of the situation of people with disabilities in Europe and the efforts made to allow them to live to their full potential.

The European League of Stuttering Associations, with funding from the European Union, has been working hard to make this Year a success. ELSA is a member of the European Disability Forum (EDF), an umbrella organisation of European Non-Governmental Organisations and National Disability Councils representing the various disability groups and interests in Europe.

Not all people who stutter regard themselves as disabled. However, they are often treated as such by society facing discrimination in many areas of life. Whether it is being faced with impatience and irritation when ordering a drink, being overlooked when interviewed for a job, being bullied at work or even during oral assessment in school, people who stutter, just like most people with disabilities, are confronted with ignorance, lack of awareness and refusal, or inability, to accommodate their needs.

What has been achieved to date?

It is only in the past 10 to 15 years that people with disabilities, including people who stutter, have made progress in changing attitudes and claiming the right to equal treatment and inclusion into society. As a result of their action disability policy throughout Europe has changed direction.

A strong shift towards a rights-based approach is gradually taking hold as seen by the growing number of policy instruments ranging from declarations to non-discrimination legislation. Some of these instruments have been adopted world-wide, others at European or national levels. Some are political commitments, others legal obligations. What they have in common is their focus on an inclusive society where people with disabilities enjoy equal opportunities and no longer rely on charity.

Disability policy has many faces. In addition to local services provided directly by local authorities or disability organisations there is:

- **National** legislation which ranges from laws on disability benefits and allowances to comprehensive non-discrimination legislation;
- **European** legislation on employment discrimination, non-binding declarations on mainstreaming and policy commitments by European institutions;
- A number of **international** conventions and declarations of intent (again non-binding).

These different policy instruments influence each other. National legislation on non-discrimination in the USA, Australia and the UK has been used as a blueprint for legislative proposals at European level. European disability programmes have facilitated exchange of information about the situation of people with disabilities in different countries leading to the development of best practice guidelines and increased awareness of disability policy in general.

ELSA has participated in this exchange of information across Europe since 1990 thus giving a voice to people who stutter at this increasingly important policy level.

What are the main policy instruments?

The Universal Declaration of Human Rights

"All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood."

Article 1

This Declaration was adopted in 1948 as a response to the atrocities committed during the Second World War. It specifically mentions disability in the context of social security. However, more importantly, people with disabilities are covered by the Declaration simply because they are human beings and can therefore claim equal dignity rights as laid down in Article 1 and the right to protection against discrimination in violation of the Declaration in Article 7. The Universal Declaration of Human Rights lays down universally accepted basic human rights. It has been widely used to remind Governments of their obligation to afford the same opportunities to all. <http://www.un.org/Overview/rights.html>

The UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities

"People with disabilities - as citizens of their societies - should have the same rights and obligations as all other citizens"

UN Standard Rules

The General Assembly of the United Nations adopted the UN Standard Rules in 1993. Although they are not legally binding they represent a strong moral and political commitment by Governments to create an inclusive society where people with disabilities are treated as equal and barriers to their participation in society are dismantled. The 22 rules cover all areas of life from education and employment, to family life, legislation and economic policy. They recognise the important role of disability organisations in the planning, implementation and evaluation of measures relevant to people with disabilities. The implementation of these rules is one of the objectives of the European Disability Forum. They are useful argumentative tools that people with disabilities should use in discussions about disability policy with relevant authorities. <http://www.un.org/esa/socdev/enable>

Article 13 of the Amsterdam Treaty

"Without prejudice to the other provisions of this Treaty, and within the limits of the powers conferred by it upon the Community, the Council, acting unanimously on a proposal from the Commission, and after consulting the European Parliament, may take appropriate action to **combat discrimination** based on sex, racial or ethnic origin, religion or belief, **disability**, age or sexual orientation."

Article 13

Article 13 of the Amsterdam Treaty (continued)

The Amsterdam Treaty, adopted in 1997, introduced the aim of an ever closer union between the EU Member States into the Treaties that govern the European Communities. One of its aims was to establish a decision-making system that would enable the Union to cope with the impending entry of ten (and potentially even more) new members. The Amsterdam Treaty, like its predecessors, is an intergovernmental treaty which pools the sovereignty of the Member States in areas where joint action appears to be more effective than action by individual Member States (prime examples are trade and environmental policy). Over the years new areas have been added to the original competences including the recognition of the EU's responsibilities in the area of human rights.

It is in this context that the Amsterdam Treaty is of particular significance for people with disabilities. Whereas discrimination on the grounds of nationality and sex (mainly regarding equal pay for men and women) has long been recognised as an issue within the EU's remit, it took an intensive campaign by disability organisations to extend the principle of non-discrimination to disability. This was a remarkable achievement showing the capacity of disability organisations to campaign simultaneously at national and European levels. Since the adoption of the clause required unanimous agreement from all Member States, disability organisations in each Member State had to run their own campaign to convince their own Government. The European Disability Forum was instrumental in co-ordinating these campaigns and provided national organisations with arguments in favour of the non-discrimination clause. This success illustrates the benefits of joint action at all levels of policy-making. http://www.edf-feph.org/en/policy/nondisc/nond_pol.htm

The Charter of Fundamental Rights of the European Union

Mr Romano Prodi, President of the Commission

"In the eyes of the European Commission, by proclaiming the Charter of Fundamental Rights, the European Union institutions have committed themselves to respecting the Charter in everything they do and in every policy they promote (...). The citizens of Europe can rely on the Commission to ensure that the Charter will be respected (...)".

Nice, 7 December 2000

The Charter was adopted by the European Parliament, the Council of Ministers and the European Commission at the Nice Summit in 2000. It is not a legally binding document but a solemn proclamation that carries great moral and political weight. The Charter consists of six chapters covering "dignity", "freedoms", "equality", "solidarity", "citizens' rights" and "justice". Article 22 explicitly prohibits discrimination on any grounds including disability. Article 26 deals with the integration of people with disabilities recognising their right to benefit from measures designed to ensure their independence as well as their social and occupational integration and their participation in the life of the community. The Charter provisions apply to European legislation only. However, since EU level legislation has to be implemented at the national level they have direct impact on people with disabilities in each of the Member States. <http://www.europarl.eu.int/charter>
<http://european-convention.eu.int/>

The EU Directive establishing a general framework for equal treatment in employment and occupation

“Once properly implemented, the Directive can act as a powerful tool, not only to combat discrimination but also to enhance disabled people's position in the labour market in general.”

European Disability Forum

The non-discrimination clause in Article 13 of the Amsterdam Treaty is not directly applicable, but requires implementing legislation. In 2000, the Article was used for the first time as a basis for non-discrimination legislation covering people with disabilities in employment. The Framework Directive aims to improve the employment opportunities for people with disabilities. It includes an obligation on employers to introduce reasonable measures to ensure that their recruiting procedures and working practices take account of people with disabilities. For instance, employers may be obliged to hold interviews in rooms that can be accessed by people in wheelchairs or they may have to allocate more interview time for a person who stutters. The Directive provides a minimum protection; however, member states which have higher protection levels in place are not allowed to reduce them. Member states should implement the Directive by December 2003; however, there is scope to extend the time limit up to 2006 for the disability provisions.

http://www.edf-feph.org/en/policy/nondisc/nond_pol.htm

The Madrid Declaration

“Non-Discrimination + Positive Action = Social Inclusion”

Madrid Declaration

The Madrid Declaration was adopted by the European Congress of People with Disabilities in March 2002. It provides a framework for the European Year of People with Disabilities 2003 and was supported by disability organisations from 34 countries, the European Disability Forum, the European Commission and the Spanish Presidency of the Council of Ministers. The Declaration provides an impressive snapshot of the current thinking on disability policy and its opportunities for future action. It emphasises the move from a charitable approach to people with disabilities to one of empowerment and equality. It recognises that more needs to be done and demands positive action to achieve an inclusive society where people with disabilities can fulfil their potential. Similar to the UN Rules it is not legally binding but has strong moral force.

<http://www.madriddeclaration.org/>

Glossary:

Charter: A formal written statement describing the rights and responsibilities of a State and its citizens.

Convention: Agreement between States that are less formal than treaties. Also a formal meeting of people.

Declaration: A formal statement intended to create, defend or testify to a right.

Directive: Framework legislation adopted by the EU that is subsequently implemented through the domestic law of Member States.

Legislation: In an EU context, laws adopted on the basis of the EU treaties. The most important type of legislation relating to disability policy are Directives.

Instrument: Legal document.

Treaty: Formally concluded and ratified agreement between States.

What are the priorities for the future?

The European Year of People with Disabilities 2003 - is a major opportunity to raise awareness of the situation of people with disabilities and the need to dismantle barriers in all areas of life. Discrimination continues to be both direct, for example when someone who stutters is refused a job because of prejudice due to their speech and indirect, for example when a person with a hearing impairment misses a train because s/he cannot hear the station announcements advising of a platform change.

The Disability Specific Directive - The European Disability Forum is leading a campaign for a Disability Specific Directive which would introduce non-discrimination legislation across the EU. This would build on the EU's employment directive and experiences in the USA, Australia, the UK and other countries. Comprehensive non-discrimination legislation would cover a broad range of areas from the provision of goods and services to education and leisure time activities. It would not be limited to the minority of people with disabilities in employment. It would allow all people with disabilities to take legal action when faced with discrimination. This is an ambitious goal likely to require legislation both at European and national level. It may therefore take a long time to achieve and will again require a concerted effort from disability organisations in all Member States.

http://www.edf-feph.org/en/policy/nondisc/nond_pol.htm

The European Convention - Disability organisations need to be aware of the ongoing discussions on a written constitution for the European Union. The text prepared by the so-called European Convention aims to replace all previous European treaties – Rome, Maastricht, Amsterdam and Nice – with a comprehensive blueprint for the enlarged Europe. Representatives of national Parliaments, the European Parliament and Governments of all Member States as well as those joining in 2004 are participating in the discussions alongside the European Commission.

<http://european-convention.eu.int>

The New EU Treaty - One of the issues under discussion at the European Convention is the inclusion of the Charter of Fundamental Rights into this new EU Treaty to make its provisions legally binding in all Member States. Such a decision would be a further step to help people with disabilities in their fight against discrimination. It is therefore essential that people with disabilities and their organisations ensure that their voices are heard throughout the process of the finalising of the text for this Treaty.

The United Nations Convention to Protect and Promote the Rights and Dignity of Persons with Disabilities – A process launched in 2001 towards the adoption of a UN Convention on the rights of disabled people is the most relevant UN initiative ever. The UN Ad Hoc Committee decided in June 2003 to start drafting a “*Convention to Protect and Promote the Rights and Dignity of Persons with Disabilities*”. The agreement to allow the participation of Non-Governmental Organisations of persons with disabilities in the working group that will draft the text to be negotiated by the UN Ad Hoc Committee is a major achievement.

<http://www.un.org/esa/socdev/enable/rights/adhocdocs.htm>

What can you do?

- This brochure provides a basic overview of the legislation, declarations and conventions signed by Governments at European and international level that people who stutter can use to claim their rights to equal treatment, non-discrimination and an inclusive society. If you are interested in disability policy and/or involved in campaigning you should pass this information on to colleagues to use in any relevant discussions.
- Raising awareness is a first important step to improving the situation of people who stutter. Whether you are drafting basic information leaflets for your local group or major campaign documents for your national organisation, try to refer to those policy and legal instruments that support your specific objectives.
- Once adopted, European legislation has to be implemented at national level. Whilst it is not possible to change the outline of the legislation at that stage the implementation process allows Governments to adjust the legislation to national requirements. This is your chance to ensure that European legislation is not just copied word by word onto the statute books but takes account of the specific situation of people with disabilities and people who stutter in your country. The most effective way to influence Government at this stage is to join coalitions and network with other disability organisations that are already working on EU issues.
- An effective way to influence European legislation is in the drafting stages. Your organisation may have very limited resources making it difficult to justify involvement at this level. Keeping on top of policy developments at all levels ensures that you can intervene to inform decision-makers of the particular needs of people who stutter. Again, joining cross disability alliances will help you get around potential resource problems. Additionally, keep in touch with the European Disability Forum, who are always aware of the latest policy developments, via their website. <http://www.edf-feph.org/>
- Cross disability alliances are not only important for campaigning purposes. At a more basic level, information exchange will help you to understand the objectives of other disability organisations and foster solidarity.

Finally, you do not need to be an expert on the European Union or international law to make a difference. Whether your involvement focuses on awareness raising measures or extends to drafting responses to Government consultations or European campaign strategies – every contribution is important for the ultimate aim of raising awareness and improving the lives of people who stutter.

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ABOUT STUTTERING

Possibly the first recorded case of stuttering was mentioned in the Old Testament - Exodus Chapter 4, Verse 10, when Moses pleaded, "O Lord, I'm just not a good speaker, I have never been, and I'm not now, even after you have spoken to me, for I have a speech impediment."

Since biblical times many people, other great leaders included, have had the same problem: King George VI, Isaac Newton, Charles Darwin, Somerset Maugham, Lewis Carroll, Marilyn Monroe.

In total, one per cent of the population of the world have the same problem as Moses had. Often incapable of saying what they want to say, there is only a chance that they may say what they can. This lack of fluency leads not only to an inability to communicate effectively, but also a reluctance to communicate at all for fear of failure. In other words, for some people who stutter there can be total isolation.

For an affliction which affects such a large number throughout the world, very few people seem to know, or want to know, about the anguish of people who stutter.

Numerous clinical therapies exist for people who can access them, yet despite decades of research an established cure for stuttering is still not available.

However, practical programmes of self-help can also be successfully used to reduce symptoms of stuttering. Access to information on stuttering and self-help is available through a wide variety of independent support organisations across the globe. For the person who stutters to benefit, this information needs to be constantly developed and made easily available. <http://www.stutteringhomepage.com>

ABOUT ELSA

ELSA is a trans-national, cross-cultural organisation which extends the exchange of information network. It can seek resources only open to multi-national groups. It can represent, and lobby for, people who stutter at a different level. Its main roles are:

- To link together and further the co-operation of Europe's national organisations;
- To provide a forum for exchange of concepts and experiences in stuttering therapy and self-help;
- To help represent, and lobby for, the interests of people who stutter to European and international bodies;
- To put stuttering on to the European agenda to ensure that the needs and challenges faced by people who stutter are considered in a European context;
- To help the personal development of young people who stutter.

ELSA is a founding member of the European Disability Forum and has participated in programmes for people who stutter with the European Commission and the Council of Europe. ELSA co-operates with the International Fluency Association, the International Stuttering Association and has links and dialogue with many other European and International NGO's. ELSA contributes to the International Stuttering Awareness Day on 22 October every year.

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