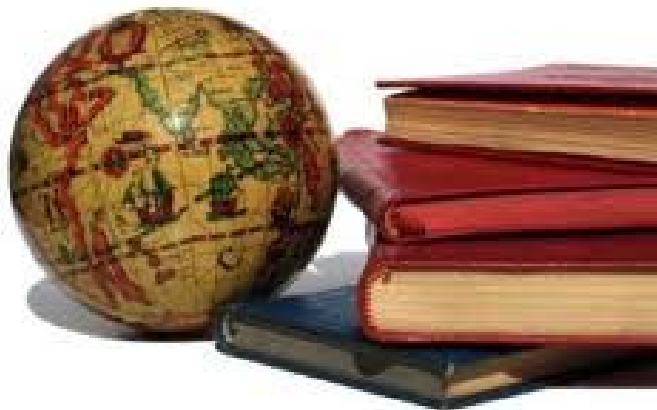


STAND UP FOR EPILEPSY

**Basic principles and Guidance instrument
for
developing, adopting and implementing epilepsy legislation**



HEEMSTEDE, THE NETHERLANDS, MAY 2012

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Foreword

People with epilepsy (PWE) often encounter obstacles in achieving their economic, social and cultural rights. They have unmet needs in the areas of civil rights, transport, education, employment, residential and community services and access to appropriate health care.

The lives of PWE require improvement in many areas. One important way is through policy and plans which lead to better services. To implement such policies and plans, there is a requirement for legislation - that is, laws that place the policies and plans in the context of internationally accepted human rights standards and good practices.

In many countries legislation impacting the lives of PWE is outdated, fails adequately to promote and protect their human rights and, in some cases, even violates these rights. This document aims to assist countries in drafting, adopting and implementing appropriate legislation. It does not prescribe a particular legislative model for countries, but rather highlights the key issues and principles to be incorporated into legislation. In 1997, the International League Against Epilepsy (ILAE), the International Bureau for Epilepsy (IBE) and the World Health Organization (WHO) together organised the Global Campaign Against Epilepsy (GCAE) in an attempt to bring epilepsy “out of the shadows”. This report, developed as part of the ILAE/IBE/WHO “Epilepsy and Legislation Project”, represents a collaborative effort, involving WHO Headquarters, ILAE and IBE chapters/members and experts.

We believe that it will be a very useful guide for professionals working in the area of epilepsy, for lawyers and policy-makers, as well as for advocacy and human rights organizations working in the interests of people with epilepsy at national and regional, as well as international level. The information may also serve to help governments to develop new legislation on epilepsy or to revise and reform existing legislation and regulations related to epilepsy, thus leading to better care and services and improved living conditions for people with epilepsy throughout the world.

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PREFACE

People with hidden disabilities, such as epilepsy, are among the most vulnerable in any society. All chronic diseases affect quality of life but epilepsy has the greatest impact¹. People with epilepsy are vulnerable because of the disorder itself and because of the stigma attached to it. Stigmatisation can lead to discrimination, and both the epilepsy itself and the stigma attached can lead to limitations in economic, civil, political, social and cultural rights².

Accordingly, strategies aimed at promoting the social and professional integration of people with epilepsy, and at rooting out the prejudice they encounter, should be secured and underpinned by legislation. Such legislation provides a legal framework for reinforcing the goals and objectives of policies, plans and programmes, and promotes international human rights standards and best practices³. These should prevent discrimination against people with epilepsy, remove restrictions and barriers to the enjoyment of their human rights and ensure that people are able to exercise their rights on an equal basis with others. Blanket restrictions and barriers automatically generated in response to epilepsy should be prohibited⁴.

Within the framework of the ILAE/IBE/WHO GCAEⁱ, a project on "epilepsy and legislation" was thus developed. The aims of this project include:

- Identification of key human rights issues that need to be addressed at national/regional levels
- Development of an effective reference guide for professionals working in the area of epilepsy, lawyers and policy-makers, as well as advocacy and human rights organisations working in the interests of people with epilepsy at national as well as international levels.

This document has been developed within the GCAE "Epilepsy and Legislation" project in response to a need which has frequently been raised by ILAE chapters and IBE members, other NGOs and interested parties, as well as by experts in the field of epilepsy, when attempting to change existing, or develop new, epilepsy-related legislation. It is inspired by a comparative analysis of epilepsy-related legislation in over 50 countries worldwide, which was conducted under the ILAE/IBE/WHO GCAE as part of the project on Epilepsy and Legislation. The analysis revealed that many laws fail to meet today's international human rights standards in relation to people with epilepsy.



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ⁱ The ILAE/IBE/WHO Global Campaign Against Epilepsy (GCAE) is a partnership of three global organisations, the International League Against Epilepsy (ILAE), representing professionals, the International Bureau for Epilepsy (IBE), on behalf of patients and public, and the World Health Organization (WHO), the specialist health agency within the United Nations system, with the aim of bringing epilepsy "Out of the Shadows".

There are different ways of approaching epilepsy legislation. For example:

- Issues concerning epilepsy may be incorporated in legislation relating to general health, employment, housing, etc.
- Issues concerning epilepsy may be incorporated in one single law
- A combination of the above approaches

This document sets out basic principles and rights that should be considered when drafting legislation related to epilepsy with due respect to given cultures or legal traditions. It does not describe a particular legislative model, but rather highlights the key issues and principles to be incorporated into legislation. Furthermore, it outlines the preliminary steps that may be taken before embarking on the drafting process as well as the steps for adopting and implementing epilepsy-related legislation.

The introduction outlines the international human rights framework for protecting and promoting the rights of people with epilepsy. The document then looks at two overarching areas relevant to the rights of people with epilepsy

1) the right to health

2) the right to live independently and to be included in the community - this second part includes many civil, cultural, economic, political, and social rights required to promote community integration for people with epilepsy

Both of these areas include the following subsections:

- A) Description – this highlights the predominant issues and corresponding international human rights standards relating to people with epilepsy
- B) Key issues for consideration in epilepsy-related legislation – this looks in greater detail at different aspects of the specific rights and what they mean in terms of improving the protection of human rights for people with epilepsy
- C) Suggested actions for consideration in epilepsy-related legislation – this suggests actions to promote aspects of the specific rights/principles

The Guidance Instrument for developing, adopting and implementing epilepsy legislation describes how to write legislation that can help people with epilepsy to overcome the many barriers that impede their right to humane and dignified care and treatment; to enhance their autonomy and liberty; and to improve community integration and promote and protect their human rights more generally.

Both the Basic Principles and the Guidance Instrument contain only guiding principles. The exact legislative process followed in each country will depend on local norms and customs. For example, the reason for developing legislation for one specific disorder (epilepsy) and not for other conditions may need to be justified in some countries and not in others. The question of whether people are best served by specific epilepsy legislation or by common disability-related legislation for a certain issue is not within

the remit of this document. There may be instances or countries where people with epilepsy are better served by joining forces with other groups in the health or disability movement and hence where integration of epilepsy legislation into health, disability and other legislation makes sense, whilst in other countries this may not be the case and specific epilepsy legislation may be required; the decision will depend on each country's circumstances. Furthermore, integrating or reforming epilepsy-related provisions in existing legislation may be in order rather than drafting a specific epilepsy-related law. It is important, however, to bear in mind that, when drafting epilepsy-specific legislation, other laws may need to be amended as well, e.g. legislation on driving, welfare benefits, education and employment.

A summary of the major provisions and related international instruments related to the rights of people with epilepsy has been included at the end of this document (Appendix I)

An important source of information for selecting the components of the basic rights and legal principles were the GCAE-inspired Regional Declarations on Epilepsy (Appendix II).

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**List of respondents (national focal points) to a questionnaire on people with epilepsy,
legislation and human rights**

Country	Name	Country	Name
Albania	H. Aruni	Mozambique	M.L.F. Chaúque Gouveia
Algeria	M. Ait-Kaci-Ahmed	Nepal	J.P. Agrawal
Armenia, Rep. of	G. Melikyan	Netherlands, the	M. Rademaker
Australia	J. Cummins	Norway	S. Strømsø Larsen
Belarus	Y. Lasy	Pakistan	H. Aziz
Belgium	C. van Daele	Pakistan	H.R. Chaudhry
Brazil	J. Taborda	Philippines	J.D. Khonghun
Brazil	F. Cendes	Poland	J. Jedrzejczak
Brazil	L. Guilhoto	Poland	T. Zarebski
Chile	M. Campos	Romania	G. Stanculescu-Topai
China, P.R. of	Shichuo Li	Saudi Arabia	S. Khan
Colombia	F. Fandiño-Franky	Senegal	A.D. Sow
Cuba	S. González Pal	Slovenia	S. Simic
East Timor	E. Somerville	South Africa	M. Clarke
Ethiopia	E. Haddis	South Africa	B. Kies
Fiji Island	O. Chang	Thailand	S. Chiemchanya
France	J. Beaussart	Tunisia	M. Fredj
France	A. Biraben	U.K.	P. Lee
Gambia	P.M. Chiga	U.S.A.	A.K. Finucane
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Greece	KLC Law Firm		
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Honduras	C. Amador		
India	H. Srinivas		
India	V.S. Saxena		
Indonesia	D. Gunawan		
Iran	K. Gharagozli		
Israel	Y. Monnickendam-Givon		
Italy	G. Batista Pesce		
Jamaica	N. Perez		
Japan	Y. Inoue		
Kazakhstan	R. Aldungarova		
Kenya	J. Thurania		
Korea (South)	K. Huh		
Lebanon	M. Mikati		
Lebanon	M. Sawwan		
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The contributions of all those mentioned above and the inputs from many unnamed people have been vital to the publication of this document.

1. INTRODUCTION

More than 650 million people worldwide⁵ (two thirds of whom live in developing countries) have a disability of one form or another, yet most have long been neglected and marginalised by states and society.

People with epilepsy experience wide-ranging human rights violations. Rights are severely impacted by discrimination and stigma against people with epilepsy. Such impairments include restrictions in obtaining or retaining a driving licence, limitations to the right to enter particular occupations and the right to enter into certain legal agreements (in some parts of the world even marriage).

Legislation can represent an important means of addressing these problems and challenges. Well-crafted legislation which is based on internationally accepted human rights standards can prevent violations and discrimination; promote and protect human rights; enhance the autonomy and liberty of people with epilepsy; and improve equity in access to health care services and community integration.

Within the framework of the GCAE a comprehensive study was undertaken to determine the presence or absence, and effectiveness or ineffectiveness, of legislation in promoting and protecting the rights of people with epilepsy. The purpose of the study was to collect information from countries all over the world about existing legislation and regulations related to epilepsy in order to review the comprehensiveness and adequacy of these legal measures in promoting and protecting the rights of people with epilepsy.

The International Human Rights system provides an important framework for protecting the rights of all people, including those with epilepsy. The Universal Declaration of Human Rights, the International Covenant on Economic, Social and Cultural Rights (ICESCR), and the International Covenant on Civil and Political Rights, together with its two Optional Protocols, form what is known as the International Bill of Human Rights. The rights outlined in the International Bill of Human Rights recognise and protect the rights of people with disabilities even if these people are not explicitly mentioned. These rights are to be afforded to everyone, including people with epilepsy. Many of the rights are particularly pertinent to people with epilepsy in light of the discrimination and human rights violations to which they are too often exposed.

The right to health is first and foremost enshrined in the Universal Declaration of Human Rights (adopted and proclaimed by the General Assembly resolution 217A (III) of 10 December 1948), as well as in the UN Convention on the Rights of Persons with Disabilities (CRPD – article 25 [United Nations]) and the UN Covenant on Economic, Social and Cultural Rights (article 12). The right to health or the right to health care is recognized in at least 115 national constitutions; at least six further constitutions set out duties in relation to health, such as the duty of the state to develop health services or to allocate a specific budget to them.

By its resolution 217 A (III) of 10 December 1948, the General Assembly, meeting in Paris, adopted the Universal Declaration of Human Rights with eight nations abstaining from the vote but none dissenting. Hernán Santa Cruz of Chile, a member of the drafting sub-Committee, wrote:

"I perceived clearly that I was participating in a truly significant historic event in which a consensus had been reached as to the supreme value of the human person, a value that did not originate in the decision of a worldly power, but rather in the fact of existing—which gave rise to the inalienable right to live free from want and oppression and to fully develop one's personality. In the Great Hall...there was an atmosphere of genuine solidarity and brotherhood among men and women from all latitudes, the like of which I have not seen again in any international setting."



People with disabilities, including people with epilepsy, face various challenges in their enjoyment of their right to health. Medical practitioners sometimes treat them as objects of treatment rather than as people with rights, and do not always seek their free and informed consent to treatment. This situation is not only degrading, it is a violation of international human rights standards.

The right to health of people with disabilities is closely linked with non-discrimination and other principles of individual autonomy, participation and social inclusion, respect for difference, accessibility, as well as equality of opportunity and respect for the evolving capacities of children. (These and other principles are reflected in article 3 of the CRPD). The right to health is also recognized in several regional instruments, such as the Organization of African Unity's African (Banjul) Charter on Human and Peoples' Rights (1981), and the Organization of American States' additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights, known as the Protocol of San Salvador (1988), and the Council of Europe's European Social Charter (1961, revised in 1996). The American Convention on Human Rights (1969) and the European Convention for the Promotion of Human Rights and Fundamental Freedoms (1950) contain provisions related to health, such as the right to life, the prohibition of torture and other cruel, inhuman or degrading treatment, and the right to family and private life. Furthermore the right to equal treatment is clearly described in law (United Nations Declarations of Human Rights 1948 and the European Union Treaty of Amsterdam, 1997).



UN Secretary General, Kofi Annan, (on the approval of the UN CRPD)

"Today promises to be the dawn of a new era – an era in which disabled people will no longer have to endure the discriminatory practices and attitudes that have been permitted to prevail for all too long. This Convention is a remarkable and forward-looking document."

In 2006 a new Convention (the UN CRPD) came into force looking specifically at the rights of people with disabilities. This Convention aims to put an end to the pervasive human rights violations to which people with disabilities, including people with epilepsy, are exposed in all aspects of their lives. The promotion of the right to health, to living in the community, to self determination, to legal capacity, employment, freedom from discrimination etc. are key features of the Convention. The Convention is the first legally

binding instrument in history to set out the obligations on states to promote, protect and ensure the rights of the millions of people with disabilities across the globe, and to recognise that people with and without disabilities share a common humanity.

The Convention has been signed by 144 countries (April 2010).



July 24, 2009, President Barack Obama signs the order for the United States to become a signatory to the CRPD in the East Room of the White House.

As well as the right to health there are other rights that are equally important.

The right to education is recognised and is understood to include an entitlement to free, compulsory primary education for all children, an obligation to develop secondary education accessible to all children, as well as equitable access to higher education, and a responsibility to provide basic education for individuals who have not completed primary education. In addition to access to education provisions, the right to education also incorporates the obligation to eliminate discrimination at all levels of the educational system, to set minimum standards and to improve quality. Finally, the right to education is enshrined in Article 26 of the Universal Declaration of Human Rights and Article 14 of the ICESCR. The right to education has also been reaffirmed in the 1960 UNESCO Convention against Discrimination in Education and the 1981 Convention on the Elimination of All Forms of Discrimination Against Women⁶.

The right to employment described in Article 27 of the CRPD (amongst other places) recognizes the right of people with disabilities to employment on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and a work environment that is open, inclusive and accessible to persons with disabilities. Countries should safeguard and promote the realisation of the right to work, including for those who acquire a disability during the course of employment, by taking appropriate steps, including through legislation.

Article 6 of the ICESCR also recognises

1. The right to work, which includes the right of everyone to the opportunity to gain a living by work freely chosen or accepted; countries will take appropriate steps to safeguard this right.

2. That the steps to be taken by a State Party to that Covenant to achieve the full realization of this right shall include technical and vocational guidance and training programmes, policies and techniques to achieve steady economic, social and cultural development and full and productive employment under conditions safeguarding fundamental political and economic freedoms to the individual.

Article 7 of the same covenant also emphasises the right of everyone to the enjoyment of just and favourable conditions of work.

The rights to employment are also described in Article 23 of the Universal Declaration of Human Rights.

The rights to social security, privacy, participation and freedom from discrimination are described in article 28 of the CRPD.

Article 29 of the CRPD states, concerning participation in political and public life, that States Parties shall guarantee to people with disabilities political rights and the opportunity to enjoy them on an equal basis with others and thus should ensure that persons with disabilities can effectively and fully participate in political and public life on an equal basis with others, directly or through freely chosen representatives, including the right and opportunity for persons with disabilities to vote and be elected.

Furthermore, regarding equality and discrimination, article 5 of CRPD states that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law.

Finally Article 19 of the CRPD specifically states that people with disabilities have equal rights to live independently and to be included in the community, with choices equal to others, and that States Parties shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community.

It is important to note that International Human Rights instruments are legally binding on governments who are required to put in place legal, policy and other measures to ensure that the rights are respected, protected and fulfilled. It is therefore crucially important to consider these rights when drafting legislation relating to people with epilepsy.

In addition to the human rights instruments, there are also a number of regional declarations specifically on epilepsy which, while not legally binding, represent consensus among countries and can provide important guidance in elaboration of legislation related to epilepsy. These declarations were developed under the aegis of the GCAE of the WHO, ILAE and IBE during a series of regional conferences, and were designed to raise awareness, acceptance and education about epilepsy and the Campaign. The first of these was the European Declaration on Epilepsy in October 1998. In 2000 similar regional declarations, based on the European format, were developed in Africa (in Senegal), Latin America (in Chile), Asia and Oceania (in India) and North America (in the United States). In all, more than 1,200

representatives from WHO, ILAE and IBE, from other non-governmental organisations and UN agencies, from governments, universities and health care providers from well over 130 countries, representing millions of people with epilepsy, have participated in these regional conferences and declarations. All declarations are attached in Appendix II.

2. BASIC PRINCIPLES

2.1 Right to the highest attainable standard of epilepsy care

2.1.1 Description

WHO's Constitution defines health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity". It further states that "the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition".



World Health Organisation, Geneva, Switzerland

The right to health as enshrined in the ICESCR imposes a legal obligation on countries to adopt policies, programmes and legislation to ensure the progressive realisation of the right to health. It is important to note that the right to health is not the right to be healthy but rather the right to health care that is accessible, available, acceptable and of good quality.

The right to health includes:

- the right to prevention, treatment and control of diseases
- access to essential medicines
- equal and timely access to basic health services
- treatment and care which should include non-medical/social aspects of care
- the availability of services and facilities which are accessible, acceptable and of good quality

There is wide disparity in the availability of treatment in different parts of the world. The problem of lack of treatment is universal but is greatest in the developing world where 85% of the minimum 50 million people with active epilepsy live. Three quarters of people with epilepsy in the developing world receive no adequate diagnosis or treatment, and thus are in the so-called treatment gap. This is especially important as epilepsy can be effectively treated with safe and (relatively cheap) treatment – up to 70% of people with epilepsy could be seizure free if properly diagnosed and treated. The reasons for the treatment gap are complex and multifactorial and are affected by both cultural and structural factors. In many developing countries, epilepsy is perceived as a manifestation of supernatural forces. People with epilepsy are often stigmatised, which discourages them from seeking the diagnosis and care they need and deserve. The management of epilepsy is influenced by the levels of education, the communication network and the availability of resources within the health care system. Poor infrastructure, insufficient availability of drugs and scarcity of trained medical personnel are relevant factors for this situation. Other potential causes include the level of health care development, cultural beliefs, economics, distance from health care facilities and supply of

antiepileptic drugs (AEDs), and a lack of prioritisation in national health policies. The mean duration of symptoms before seeking modern medical care can be several years.

2.1.2 Key issues for consideration in epilepsy-related legislation

2.1.2.1 Availability of, and access to, epilepsy care

There is an urgent need for equity in the provision of epilepsy services on a par with other health services. Epilepsy care facilities need to be available in the community close to where people live; improving accessibility of care is an important function of legislation. It involves improving the availability of services, improving financial and geographical accessibility and providing services that are acceptable and of adequate quality. Legislation can promote the introduction of epilepsy care interventions into primary health care settings, thereby increasing access to care for underserved populations and reducing the stigma associated with epilepsy. Supply of antiepileptic medication is a problem in many resource poor countries. Legislation can ensure that antiepileptic medication is at least as available and accessible as medication for other conditions. Comprehensive epilepsy care also involves psychosocial interventions such as counselling, psychotherapy and vocational rehabilitation. Both rehabilitation and aftercare are integral parts of epilepsy care and treatment and therefore it is important that legislation includes provisions for developing such services as part of promoting access to care³.

The right to the availability of, and access to, epilepsy care is supported by a number of international covenants, including the following:

The ICESCR commits its parties to working towards the granting of economic, social, and cultural rights to individuals; these rights include labour rights and rights to health, education, and an adequate standard of living.

The States Parties to the ICESCR recognise the right of everyone to the enjoyment of the highest attainable standard of physical and mental health (article 12). The steps to be taken by the States Parties in order to achieve the full realisation of this right must include the creation of conditions which assure to all medical service and medical attention in the event of sickness, including epilepsy.

Article 25 of the CRPD states that those health services that are needed by people with disabilities because of their disability, including identification and intervention, should be provided.

2.1.2.2 Good quality and acceptable standards of care

Quality has a central role in medical care. The realisation of the rights of people to medical care presupposes good quality medical actions. The meaning of quality goes further than good attention based on scientific evidence and with competent skills. It comprises patient-physician relationships where

professional behaviour is evaluated, based on the fundamental principles of bioethics. These principles sustain the measures to control quality of medical actions, to comply with the rights of patients to have access to good professional care⁷.

The countries of Europe have widely varying structures and systems for the provision of health care. Emphasis differs in the balance between primary and secondary care; the provision of inpatient and outpatient services; the availability of specialised investigations and epilepsy surgery; the quality of training, audit and research; and total expenditure on health. Despite the shared concerns of patients and doctors, the variety of medical systems is likely to produce differences in the quality of care. For this reason, the Commission on European Affairs of the ILAE felt the need to provide guidelines for standards of medical care in 1997⁸ appropriate to the whole of Europe. The guidelines represent an appropriate standard of care. They were essentially a summary of the consensus reached on contemporary expectations concerning evaluation and treatment, regardless of the health-care characteristics and real possibilities for provision in individual countries.

2.1.2.3 The right to informed consent and involvement in decisions affecting care and treatment

According to article 25 of the CRPD, people with disabilities have the right to free and informed consent. Informed consent means consent based on an appreciation and understanding of the facts, implications and future consequences of an action. In cases where an individual is provided with insufficient information to form a reasoned decision, serious ethical issues arise.

People with epilepsy have the right to information concerning the choice of treatment⁵ and to participate in treatment planning and other decisions about their care.

2.1.2.4 The right to doctor-patient confidentiality

Doctor-patient confidentiality stems from the special relationship created when a prospective patient seeks the advice, care, and/or treatment from a physician. It is based on the general principle that individuals seeking medical help or advice should not be hindered or inhibited by fear that their medical concerns or conditions will be disclosed to others. Patients entrust personal knowledge of themselves to their physicians, which creates an uneven relationship in that the vulnerability is one-sided. People seeking medical help or advice should feel confident that their medical concerns or conditions will not be disclosed to others. Physicians will hold that personal information in confidence and use it only for the benefit of the patient. People with epilepsy have the right to confidentiality of information about themselves and their disorder and treatment; such information should not be revealed to third parties without their informed consent.

Confidentiality covers all medical records (including x-rays, lab-reports, etc.) as well as communications between patient and doctor, and it generally includes communications between the patient and other professional staff working with the doctor.

The duty of confidentiality continues after patients stop seeing or being treated by their doctors. Once doctors are under a duty of confidentiality, they cannot divulge any medical information about their patients to third parties without patient consent.

2.1.2.5 The right to access to information

People with epilepsy should have a statutory right to free and full access to their clinical records. This right is protected by general human rights norms, such as article 19 of the United Nations International Covenant on Civil and Political Rights.

Furthermore, each of the Regional Declarations on Epilepsy mentions the importance of information about epilepsy in general to people with epilepsy themselves, their relatives, friends and the general public by educating those affected by epilepsy, their families and the general public about epilepsy as a universal neurological condition, in order to:

- eradicate misconceptions, and empower the affected to seek appropriate treatment and improve their quality of life
- improve public understanding of epilepsy and thereby reduce its stigma
- educate teachers, employers, and the general public about epilepsy, in order to reduce stigma and prejudice and to increase understanding
- eliminate discrimination in all spheres of life, particularly at school and the work place.

The right to health also includes a wide range of factors that can help people to lead healthy lives. The Committee on Economic, Social and Cultural Rights, which is responsible for monitoring the ICESCR, calls these the “underlying determinants of health”. They include adequate nutrition and housing, healthy working and environmental conditions, the provision of health-related education and information⁵.

Information contributes to a person’s knowledge and understanding of his or her own condition. It should be personal to the person receiving it and particular to his or her level of understanding. It is important to be personally involved in one’s own care and treatment, as this can increase the effectiveness of the treatment.

.2.1.3 Suggested actions for consideration in epilepsy-related legislation

Actions suggested to promote the aforementioned principles are to:

- Ensure the availability, affordability and accessibility of optimal diagnosis and treatment; AEDs should be included in the list of essential drugs
- Ensure the availability of trained personnel by improving education and training for health care and other relevant professionals in epilepsy, its prevention (including the formulation of a strategy for the prevention of epilepsy) and its treatment
- Ensure that the person with epilepsy is involved in the consultation, planning and decision making process concerning his or her treatment and the selection of services used. This should include programmes aiming to improve the ability of people with epilepsy to manage their condition, by addressing the impact at each level: medical intervention level (e.g. AED treatment or epilepsy

surgery) as well as non-medical intervention (e.g. counselling, psychosocial assistance and rehabilitation)

- Ensure that informed consent is obtained before any type of intervention is initiated
- Encourage research into epilepsy and its management
- Ensure that people with epilepsy have access to information, including use of technologies such as the internet.

2.2. The right to live independently and be included in the community

2.2.1 Description

People with epilepsy face human rights violations and discrimination in their day to day lives. Human rights violations such as unequal access to health and life insurance, or prejudicial loadings of health insurance provisions, withholding the right to obtain a driving license, limitations to the right to enter particular occupations and the right to enter into certain legal agreements (in some parts of the world even marriage), are severely impacted by the stigma and discrimination of people with epilepsy.

According to article 19 of the CRPD, people have the right to live independently and to be included in the community. In order for people with epilepsy to be able to live independent, integrated and meaningful lives in the community they need to be able to exercise a full range of civil, cultural, economic, political, and social rights.

Furthermore, article 19 states that effective and appropriate measures should be taken to facilitate full enjoyment of this right and full inclusion and participation in the community, including by ensuring that:

- People with disabilities (including people with epilepsy) have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- People with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- Community services and facilities for the general population are available on an equal basis to people with disabilities, and are responsive to their needs.

Furthermore, the right to privacy is a broad concept limiting how far society may intrude into a person's affairs. It includes information privacy, bodily privacy, privacy of communications and territorial privacy. Article 3 of the CRPD states as a general principle that "the fundamental concepts of respect for inherent dignity and autonomy of people with disabilities, non-discrimination, participation, inclusion, equality and accessibility guide interpretation of the Convention's obligations".

Article 22 of the same Convention states that: "People with disabilities have the right to conduct their lives in private and their privacy must be honoured and protected".

Finally, on a different but related note, people with epilepsy should be empowered to live life to their fullest potential with as few restrictions as possible. Sometimes restrictions may be necessary, such as when a person's seizures may endanger the lives of others in a particular situation. However, if that is the case the following conditions should be met:

- Assessment of the risks of having a seizure both for the person and for others
- Limitations of time of restrictions
- Periodical assessment of the need of maintaining any restrictions that are in place
- Prevention of blanket restrictions

2.2.2 Key issues for consideration in epilepsy-related legislation

2.2.2.1 Protection, in law or otherwise, against discrimination in any form because of the condition

People with epilepsy often experience limitations to their enjoyment of economic, social and cultural rights as well as being subject to prejudicial and discriminatory behaviour in many spheres of life and across many cultures⁹. They have many unmet needs in the areas of civil rights, education, employment, residential and community services, and access to appropriate health care¹.

They are also often denied access to justice because of their epilepsy. Access to justice refers to people's ability to use public and private justice systems and services. Equal access to justice means that there must be no restrictions placed on certain categories of individuals or groups. Equal justice also includes the prompt and impartial response of the justice institutions to social demands.

Article 5 of the CRPD states that:

- All people are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law
- All discrimination on the basis of disability must be prohibited, and equal and effective legal protection against discrimination on all grounds must be guaranteed to people with disabilities
- In order to promote equality and eliminate discrimination, all appropriate steps shall be taken to ensure that reasonable accommodation is provided
- Specific measures which are necessary to accelerate or achieve de facto equality of persons with disabilities shall not be considered discrimination under the terms of the present Convention.

Laws that discriminate against people with epilepsy should be repealed. Furthermore, legislation related to epilepsy should include provisions aiming to prevent discriminatory practices and should also put in place positive measures (reasonable accommodation, equal opportunities etc.) to redress discrimination.

Article 13 of the CRPD stipulates that States Parties shall ensure effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages. In order to ensure effective access to justice for persons with disabilities, States Parties shall promote appropriate training for those working in the field of administration of justice, including police and prison staff.

The following articles of the Universal Declaration of Human Rights refer to this issue:

Article 7: All are equal before the law and are entitled without any discrimination to equal protection of the law.

Article 10: Everyone is entitled in full equality to a fair and public hearing by an independent and impartial tribunal.

Article 11.1: Everyone charged with a penal offence has the right to be presumed innocent until proved guilty according to law in a public trial.

2.2.2.2 Social protection and an adequate standard of living

People with epilepsy often lack social protection to ensure an adequate standard of living. This is especially the case in resource poor countries. A questionnaire on Country Resources for Epilepsy, on which the Atlas: Epilepsy Care in the World (2005) is based, included a question about social protection. Of the countries that completed the questionnaire, 157 responded to this question. It was estimated that disability benefits for people with epilepsy were available in only 15% of low-income countries and in 82% of high-income countries. Monetary benefits (82.5%) and rehabilitation and health benefits (55%) are most commonly reported. Legislation needs to ensure that people with epilepsy are included and have access to social service measures such as disability allowance, unemployment benefit, retirement benefits and access to insurance.

Drafting appropriate legislation is vital to enhance the integration of people with epilepsy. Efforts should be made to advocate better provision of benefits for people with epilepsy and secondary handicaps, especially in resource poor countries⁶.

Article 25 of the Universal Declaration of Human Rights recognises that all people have the right to a standard of living adequate for the health and well-being of themselves and of their family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond their control¹⁰.

Furthermore, regarding adequate standards of living and social protection, article 28 of the CRPD states that people with disabilities, including epilepsy, and their families should have:

- Access to food, shelter and drinking water

- Equal access to government social safety nets, e.g. public housing, retirement benefits, social protection and poverty reduction programmes
- When living in poverty, access to assistance from the state with disability-related expenses

People with disabilities have the right to social protection and to the enjoyment of that right without discrimination on the basis of disability.

Disability benefits should be payable from public funds as part of this legal right for people with epilepsy. In many countries, despite the availability of disability benefits for many conditions, people with epilepsy are not eligible. Furthermore, in many countries few people actually receive benefits for epilepsy because of lack of information about eligibility for such benefits and the procedures for claiming them¹¹.

Access to insurance should be guaranteed. Refusal of, and restrictions to obtaining, insurance is reported worldwide. Such discriminatory behaviour is a restriction of the right to make adequate financial protection in guarding against risks for individuals and their families.

2.2.2.3. Respect for home and the family

People with epilepsy are often restricted in terms of their right to marry and to have children on non-justifiable grounds. The chances of getting married can be particularly slim in the developing world as well as in the developed world¹². Stigma and discrimination experienced by people with epilepsy in these areas need to be addressed by governments in order to ensure that people with epilepsy are able to exercise their right to marry on an equal basis with others.

Concerning marriage, article 16 of the Universal Declaration of Human Rights states:

- Men and women of full age (that is, the age at which one attains full personal rights, or majority; - this varies in different parts of the world) without any limitation due to race, nationality or religion, have the right to marry and to start a family

Furthermore, article 23 of the CRPD states that:

- Effective and appropriate measures shall be taken to eliminate discrimination against people with disabilities (including people with epilepsy) in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, to ensure that:
 - The right of all people with disabilities who are of marriageable age to marry and to have a family on the basis of free and full consent of the intending spouses is recognized
 - The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognized, and the means necessary to enable them to exercise these rights are provided
 - People with disabilities, including children, may retain their fertility on an equal basis with others

- The rights and responsibilities of people with disabilities, with regard to guardianship, wardship, trusteeship, adoption of children or similar institutions, where these concepts exist in national legislation, are upheld; in all cases the best interests of the child shall be paramount

2.2.2.4 Right to education

People with epilepsy are often restricted in terms of access to education. Discrimination in access to education is not unusual for people affected by the condition¹³. Obstacles of the educational process to children with epilepsy include the physical and psychosocial effects of seizures, the effects of medication, underlying cognitive difficulties, and an educational system that, all too often, does not provide the necessary support or understanding¹⁴.

As recognised in the Universal Declaration of Human Rights, the ICESCR and the CRPD, people with disabilities have the right to exercise all civil, political, economic, social and cultural rights. These key rights include the right to education: Article 26 of the Universal Declaration of Human Rights states that:

- Everyone has the right to education
- Education shall be directed to the full development of the human personality and to the strengthening of respect for human rights and fundamental freedoms
- Parents have a prior right to choose the kind of education that shall be given to their children

Article 24 of the CRPD states that:

- States Parties recognize the right of persons with disabilities to education
- In realising this right States Parties shall, amongst others, ensure:
 - That persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability
 - That persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live
- In order to help ensure the realisation of this right, States Parties shall take appropriate measures to employ teachers and to train professionals and staff who work at all levels of education
- States Parties shall ensure that persons with disabilities are able to access general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others

Finally, concerning children with disabilities, the CRPD states in article 7 that:

- All necessary measures shall be taken to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.

2.2.2.5. Right to work and employment

Research into the vocational aspects of people with epilepsy shows that people with epilepsy are often advised not to undertake their training of choice because of the suspected consequences of having epilepsy. Worldwide job restrictions are still very common. For instance, severe epilepsy-related job restrictions were found in the records of the Berlin Labour Exchange, which were in sharp contrast to the consistent reports of low accident rates among people with epilepsy¹⁵.

In this respect the following statement (Article 23 of the Universal Declaration of Human Rights) is very important:

- Everyone has the right to work, to free choice of employment, to just and favourable conditions of work and to protection against unemployment
- Everyone, without any discrimination, has the right to equal pay for equal work
- Everyone who works has the right to just and favourable remuneration ensuring for himself and his family an existence worthy of human dignity, and supplemented, if necessary, by other means of social protection
- Everyone has the right to form and to join trade unions for the protection of his/her interests

In the CRPD work and employment are described as follows (article 27): States Parties must promote and realise the right to work and take appropriate steps, including inter alia, to promote employment in the private sector and to ensure that reasonable accommodation is provided in the workplace. States Parties are called upon to employ people with disabilities in the public sector.

The CRPD defines reasonable accommodation as follows: necessary and appropriate modification and adjustments not proposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.

The International Labour Office specifically mentions people with disabilities, stating that: people with disabilities, whatever the origin of their disability, should be provided with full opportunities for rehabilitation, specialised vocational guidance, training and re-training and employment in useful work.

In this respect the Americans with Disabilities Act (1990) is a good example of national legislation. It states (Section 12112) that nobody shall discriminate against a qualified individual with a disability because of the disability of such individual in regard to job application procedures, the hiring, advancement, or discharge of employees, employee compensation, job training, and other terms, conditions, and privileges of employment.

An important issue is whether or not to disclose on a job application or during an interview that a person has epilepsy. This is a difficult topic and there is no right answer for every situation. The presence of legislation on this issue varies across countries. In general, the following factors should be considered:

- whether the presence of seizures affects the person's ability to do the job safely and effectively

- if employers are not aware that an individual has epilepsy and seizures, they cannot provide reasonable accommodation and cannot be blamed for not doing so if appropriate

2.2.2.6 Driving/public transport

The right to drive is a vital component of an acceptable quality of life for many people in many parts of the world and is therefore important for people with epilepsy. Being restricted from driving due to seizures has far-reaching implications for people with epilepsy in many areas of life including working, socializing, and healthcare visits.

Legislation regarding epilepsy and driving exists in most countries in the world. Current legislation in most countries in the world permits people with epilepsy who have controlled seizures to obtain a driving licence. Legislation regarding driving and epilepsy is an attempt to balance the important economic and social value of driving with the risk to public safety from seizure-related road traffic accidents. Various clinical factors are considered in these laws, but the length of the prescribed seizure-free interval is the dominating factor. Restrictions still vary considerably, from country to country and from region to region.

Public transport is important to people who cannot drive. Even when public transport is available it is sometimes not accessible for people with epilepsy, due to unjust and unreasonable restrictions implemented by transport companies not wanting to transport people with epilepsy, who may or may not have a seizure. Laws and policies that discriminate against people with epilepsy in this way must be repealed.

All legislation dealing with these issues must aim first and foremost to promote the capacity of people with epilepsy to exercise their autonomy and their right to live independently and to be included in the community.

2.2.2.7 Right to rehabilitation

Epilepsy is among the disorders which are strongly associated with significant psychological and social consequences for everyday living. Attention to the psychosocial, cognitive, educational and vocational aspects is an important part of comprehensive epilepsy care⁵.

In recent years, evidence has shown that severe epilepsy-related difficulties can be seen in people who have become seizure free, as well as in those with difficult to treat epilepsies. The outcome of rehabilitation programmes would be a better quality of life, improved general social functioning and better functioning in, for example, performance at work and improved social contacts¹⁶.

The right to health includes the right to access rehabilitation services. Beyond health, this also includes the right to access and benefit from a full range of services in the community that enhance autonomy. Thus countries should organise, strengthen and extend comprehensive “habilitation” and rehabilitation services and programmes, particularly in the areas of health, employment, education and training and social services, in such a way that these services and programmes:

a) Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths

b) Support participation and inclusion in the community and all aspects of society, are voluntary, and are available to people with epilepsy as close as possible to their own communities, including in rural areas

Article 26 of the CRPD states that States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive “habilitation” and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services.

2.2.2.8 Integration/inclusion in the community

The right to community integration is an important right that is specifically protected in the International Bill of Rights⁴.

It is well recognised that leisure activities such as going out and joining a club are highly desirable for young people growing up and developing social skills. It also adds to the quality of life for adults¹³.

2.2.3 Suggested actions for consideration in epilepsy-related legislation

Actions which have been suggested to promote the aforementioned principles are to:

- Ensure that all civil, cultural, economic, political, and social rights of people with epilepsy are protected by law
- Draft appropriate legislation for enhanced integration of people with epilepsy
- Advocate better provision of benefits for functionally disabled people with epilepsy, especially in resource poor countries⁶
- Ensure that people with epilepsy are not discriminated against in the location and allocation of housing. Legislation should include provisions to prevent this
- Ensure that legislation does not create barriers for people with epilepsy to enter into marriage or civil partnership
- Ensure that legislation does not create barriers for people with epilepsy to exercise their parental rights
- Ensure that the right to education of children with epilepsy equal to that of other children is included in law
- Ensure that people with epilepsy are protected from discrimination and exploitation in employment
- Ensure that people with epilepsy are not stopped from taking the professional training of their choice
- Ensure that reasonable accommodation is made in the work place to accommodate people with epilepsy
- Ensure that people with epilepsy have equal employment opportunities

- Ensure that employees with epilepsy are protected from dismissal that is solely on account of having epilepsy
- Emphasise in legislation the right of people with epilepsy to access rehabilitation services in the community that enhance maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life

3. GUIDANCE INSTRUMENT FOR DEVELOPING, ADOPTING AND IMPLEMENTING EPILEPSY LEGISLATION

3.1: Compiling background information

Step 1: *Identify key stakeholders for a process of building consensus and negotiating for change¹⁷.*

The involvement of stakeholders in the planning and drafting of legislation on epilepsy or in revising and reforming existing legislation that impacts on the lives of people with epilepsy is crucial for the purpose of ensuring that the legislation meets different stakeholder needs as effectively as possible. It is also essential because the involvement of stakeholders at an early stage will improve the likelihood of effective implementation once the law is passed³.

The stakeholders should include: politicians and parliamentarians, policy makers, government ministries, health and non-health professionals with an interest in epilepsy, people with epilepsy and family members and their organisations, NGOs working in the area of epilepsy, advocacy organisations. In some countries it may also be necessary to include community leaders and traditional healers in the process.

Consensus building and negotiation have an important role to play, not only in drafting the legislation but also in ensuring that legislation is implemented once it is adopted. A broad consensus is also necessary because epilepsy legislation cannot be embraced by any society unless misconceptions, misunderstandings and the fear surrounding the disorder are addressed.

Step 2: *Describe the epilepsy problems in your country and the ways in which they are being managed.*

Information on epilepsy in your country (facts and figures) and the problems that are encountered by people with epilepsy and their family members can help policy makers to understand the existing epilepsy care in the country and its effectiveness and efficiency in dealing with the problems. This should include information about accessibility, availability and affordability of services, the degree to which evidence-based treatments are being provided and details of any human rights violations.

Step 3: Describe the epilepsy services in your country.

Information on the services that are provided in your country can help inform service reform requirements and the potential roles of health professionals and workers in implementing law, for instance regarding doctor-patient confidentiality and informed consent.

Step 4: List legislation impacting epilepsy.

In countries where these exist, specific epilepsy-related laws need to be examined carefully. In addition, components of other laws, as they relate to epilepsy, need to be found and assessed. Legislation that impacts and affects epilepsy is often contained in more than one single law.

It is essential that all relevant legislation is collated and examined before new legislation is drafted. Legislation where epilepsy may feature might be found in the following areas:

- Human rights (eg. constitutional law, civil rights legislation, anti-discrimination legislation, etc.)
- General health, (access to) health care and epilepsy care (including access to diagnostic facilities, AEDs, etc.)
- Health insurance (including public and private insurance)
- Doctor-patient confidentiality
- Education, employment and driving/public transport
- Marriage/Civil Partnership and parental rights
- Social and leisure services
- Housing, planning and consumer protection
- Civil rights, (e.g. right to vote, stand as a candidate)
- Access to insurance and financial services
- Legislation related to the Justice system (eg. affordable access to justice)

Step 5: Identify and describe the gaps in information regarding epilepsy problems.

Once the previous four steps have been carried out, gaps in data and legislation are likely to emerge. Missing information which would be relevant to new legislation or amendments to existing legislation needs to be collected.

Step 6: *Identify the principal barriers and obstacles to good quality epilepsy care in your country.*

It is important to get a clear picture of the barriers and obstacles to good quality epilepsy care in your country and to indicate how legislation may be used to overcome these barriers.

Step 7: *Identify international conventions and standards (identify relevant conventions).*

International human rights standards should guide legislation. Most countries are signatories to various conventions for which implementation is obligatory. Countries that have ratified international human rights instruments have an obligation to respect and fulfil the rights that are enshrined therein through legislation, policy and other measures. (A list of relevant and appropriate conventions is included as an annex to the section on Basic Rights and Legal Principles)

Step 8: *Identify relevant epilepsy legislation on the same issues from other countries.*

Each country is unique and has its own needs, cultures and circumstances, as well as having legislative conventions which may differ. However, by examining laws from different countries there may be a number of significant lessons that can be learned with regard to provisions generally included in legislation. While conducting such a review it is important to remember that many countries still have outdated legislation. The review should focus on countries that have enacted progressive legislation that reflects international human rights standards and current knowledge in the area of epilepsy and epilepsy care. It should also critically examine the effect of legislation in improving the situation for people with epilepsy in these countries.

Reasons for failure may include badly drafted legislation and implementation difficulties resulting from legislative provisions that do not take into account the practical realities in the country. (WHO Resource Book on Mental Health, Human Rights and Legislation).

3 2: Preparing a Proposal for Epilepsy Legislation.

Step 9: *Identify the broad areas to be included in epilepsy legislation or areas which need to be revised and reformed in existing laws which impact on epilepsy.*

Having followed the previous steps regarding the gathering of background information, (e.g. collecting legislation from other countries and examining international human rights standards), decisions need to be made regarding the major objectives of the new legislation and what needs to go into this legislation. If epilepsy-related issues are to be included in more than one law (see step 3) identify the relevant legislation for this incorporation. During a legislative reform process, National Law Reform Commissions are often responsible for ensuring that all relevant laws are identified and revised as appropriate. Where such bodies exist it is important to involve these early in the reform process.

Step 10: *Identify an appropriate group of people to prepare the legislation proposal for submission to the government and legislative body.*

Before legislation can be submitted to the law making body it must be drafted into a format and language common to all laws in a particular country. The drafting of legislation and the process of consultation require a single person or a group to co-ordinate and drive the process. People with sufficient expertise to cover all areas to be included in this legislation must be involved in the entire drafting process, including the initial and later drafts. (See also Step 1)

Step 11: *Consult regarding the reform of epilepsy-related legislation*

Key stakeholders and role-players should be consulted at each stage of preparation of the legislation proposal. This allows potential weaknesses to be removed, conflicts worked through, practical difficulties resolved and for a sense of ownership of the legislation to be developed by the stakeholders.

Ensure that a group of people or a person is identified to co-ordinate the drafting of the final proposal for submission to the appropriate ministries and lobbying process.

Potential stakeholders could include: people with epilepsy and their families, health professionals, NGOs working in the field of epilepsy, experts in the area of legislation and human rights, etc.

3.3: Adopting Epilepsy Legislation

Step 12: *Outline the legislative procedures and lobbying processes.*

An important activity to stimulate the process of adopting epilepsy legislation or revising existing legislation impacting epilepsy is to lobby members of the executive branch of government and the legislature. Members of the legislature need to be informed of the deficiencies in the existing legislation for epilepsy or of the negative implications and consequences of not having epilepsy-related legislation. They need to understand the social needs that prompted the development of the proposed law, the principal ideas on which the draft is based, the probability that the future law will solve existing problems within the field of epilepsy and other issues pertinent to the legislation.

3.4: Implementing Epilepsy Legislation

Step 13: *Identify obstacles and facilitating factors for the implementation phase.*

The analysis of obstacles and facilitating factors for implementation can help build effective strategies to make sure law in paper is law in practice.

Step 14: *Set up an oversight body.*

Once the legislation has been passed into law, its practical implementation must be managed. This often requires an oversight body who will formally monitor and evaluate the implementation, such as commissions, complaint agencies, NGOs etc..In this respect it should be noted that there are two levels of monitoring: the oversight body should provide input to a government oversight body and should also monitor the overall impact of the legislation.

Step 15: *Develop practical support mechanisms/programmes/tools to facilitate the legislation.*

To make legislation operate effectively it is necessary to have support mechanisms to simplify and facilitate implementation. The period after legislation has been passed and prior to enactment is a crucial one. It should be used by NGOs to put procedures in place, to organise training, to develop materials and to make sure that all those involved are ready to implement the legislation once it is enacted.

Step 16: *Educate various groups on the legislation and their roles, rights and responsibilities within it.*

New legislation will affect many people and groups, and all relevant people must have a good knowledge of the contents. Public awareness programmes need to highlight special provisions in legislation providing explanations for their inclusion. It is also necessary to educate people with epilepsy, their family members and advocacy organisations. It is vitally important that they know what the legislation says, and specifically, that they know their rights as provided for in the legislation. Thorough knowledge of epilepsy-related legislation by professionals is extremely important for its implementation. Thus professionals in the field of epilepsy, including all those with an impact on the lives of people with epilepsy (health professionals, social services, relevant people in the judicial system and others), should be made aware of the rights of people with epilepsy. It is therefore necessary to promote special training for these professionals. A guidebook may be developed to provide information important for different role players such as health practitioners, people with epilepsy and their family members.

Step 17: *Mobilise financial and human resources.*

The speed and quality of implementation of the legislation will, in part, depend on the availability of adequate financial and human resources. A strategy should be outlined to ensure that there are sufficient financial and human resources available to implement the legislation. Though much of the financial and resource lobbying may have taken place prior to the passing of the legislation, the statutory obligation imposed by law may assist in mobilising additional resources so that the law can be implemented effectively. In addition, resources promised for implementation may need to be practically harnessed. Funds will be needed for setting up and setting in motion the review body, for the training of professionals in the use of the legislation and for making the necessary changes to the epilepsy services as required by the legislation.

3.5 Overview of the four phases and 17 steps that encompass the guiding principles for developing, adopting and implementing epilepsy legislation

PHASE	STEP
Background	1. Identify key stakeholders for a process of building consensus and negotiating for change.
	2. Describe the epilepsy problems in your country and the ways in which they are being managed.
	3. Describe the epilepsy services in your country.
	4. List legislation impacting epilepsy.
	5. Identify and describe the gaps in information regarding epilepsy problems.
	6. Identify the principal barriers and obstacles to good quality epilepsy care in your country.
	7. Identify international conventions and standards (identify relevant conventions).
	8. Identify relevant epilepsy legislation on the same issues from other countries.
Preparation	9. Identify the broad areas to be included in epilepsy legislation or areas which need to be revised and reformed in existing laws which impact on epilepsy.
	10. Identify an appropriate group of people to prepare the legislation proposal for submission to the government and legislative body.
	11. Consult regarding the reform of epilepsy-related legislation.
Adoption	12. Outline the legislative procedures and lobbying processes.
Implementation	13. Identify obstacles and facilitating factors for the implementation phase.
	14. Set up an oversight body.
	15. Develop practical support mechanisms/programmes/tools to facilitate the legislation.
	16. Educate various groups on the legislation and their roles, rights and responsibilities within it.
	17. Mobilise human and financial resources.

APPENDICES

APPENDIX I: EPILEPSY AND LEGISLATION SURVEY

Introduction

People with hidden disabilities such as epilepsy are among the most vulnerable in any society. While the vulnerability of people living with epilepsy may be partly attributed to the disorder itself, the particular stigma associated with epilepsy brings a susceptibility of its own. Stigmatisation leads to discrimination, and people with epilepsy experience prejudicial and discriminatory behaviour in many spheres of life and across many cultures. People with epilepsy often experience limitations in their enjoyment of economic, social and cultural rights.

Legislation can represent an important means of addressing these problems and challenges. It is known, however, that in many countries, laws impacting the lives of people with epilepsy are outdated, failing adequately to promote and protect their human rights and in some cases actively violating these rights. In other countries, there is a total absence of legislation in this area.

Within the framework of GCAE, a study was undertaken with the following objectives:

- To determine whether legislation exists in each country for addressing discrimination and promoting and protecting the human rights of people with epilepsy
- In situations where legislation exists, to determine the efficacy and effectiveness of legislation in addressing discrimination, and promoting and protecting the human rights of people with epilepsy

Methodology

Study design

The study involved a survey conducted within the framework of ILAE/IBE/WHO GCAE, which was carried out in selected countries. These countries were selected on the basis of recommendations of WHO Regional Offices and GCAE Regional Committees. A minimum of five countries were selected from each of the six WHO regions.

List of countries from different WHO regions which participated in the survey

WPR	EMR	EUR	SEAR	AMR	AFR
Australia	Iran	Armenia	East Timor	Brazil	Algeria
China	Lebanon	Albania	India	Chile	Ethiopia
Fiji	Morocco	Belarus	Indonesia	Colombia	Gambia
Japan	Pakistan	Belgium	Nepal	Cuba	Ghana
Republic of Korea	Saudi Arabia	France	Thailand	Guatemala	Kenya
Malaysia	Tunisia	Georgia		Honduras	Mozambique
Mongolia		Greece		Jamaica	Senegal

Philippines		Israel		Mexico	South Africa
Vietnam		Italy		USA	Zambia
		Kazakhstan			
		Macedonia			
		Netherlands			
		Norway			
		Poland			
		Romania			
		Slovenia			
		UK			

Scope of the survey

The areas or indicators to be covered by the survey were discussed and finalised during the first consultative meeting of the project organised in Geneva on 12-13 December, 2005. These included:

- Health/health care (including health and life insurance)
- Education
- Employment
- Civil rights (driving, marriage, divorce and annulment, sterilisation, adoption, housing etc)
- Criminal responsibility
- Military duties
- Religious duties

Development of the questionnaire and its validation

A checklist covering these areas was developed on the basis of the WHO checklist for mental health legislation and the US check list (based on the UN Resolution on Principles for the Protection of Rights of People with Mental Illness). This checklist was pre-tested in three countries and, based on those responses, the survey questionnaire was developed. The survey questionnaire was validated in at least one country in each of the six WHO regions and, based on the validation findings, the instrument was finalised. A glossary of terms used was prepared in order to ensure that the questions were understood in the same way by different respondents.

Data collection and data analysis

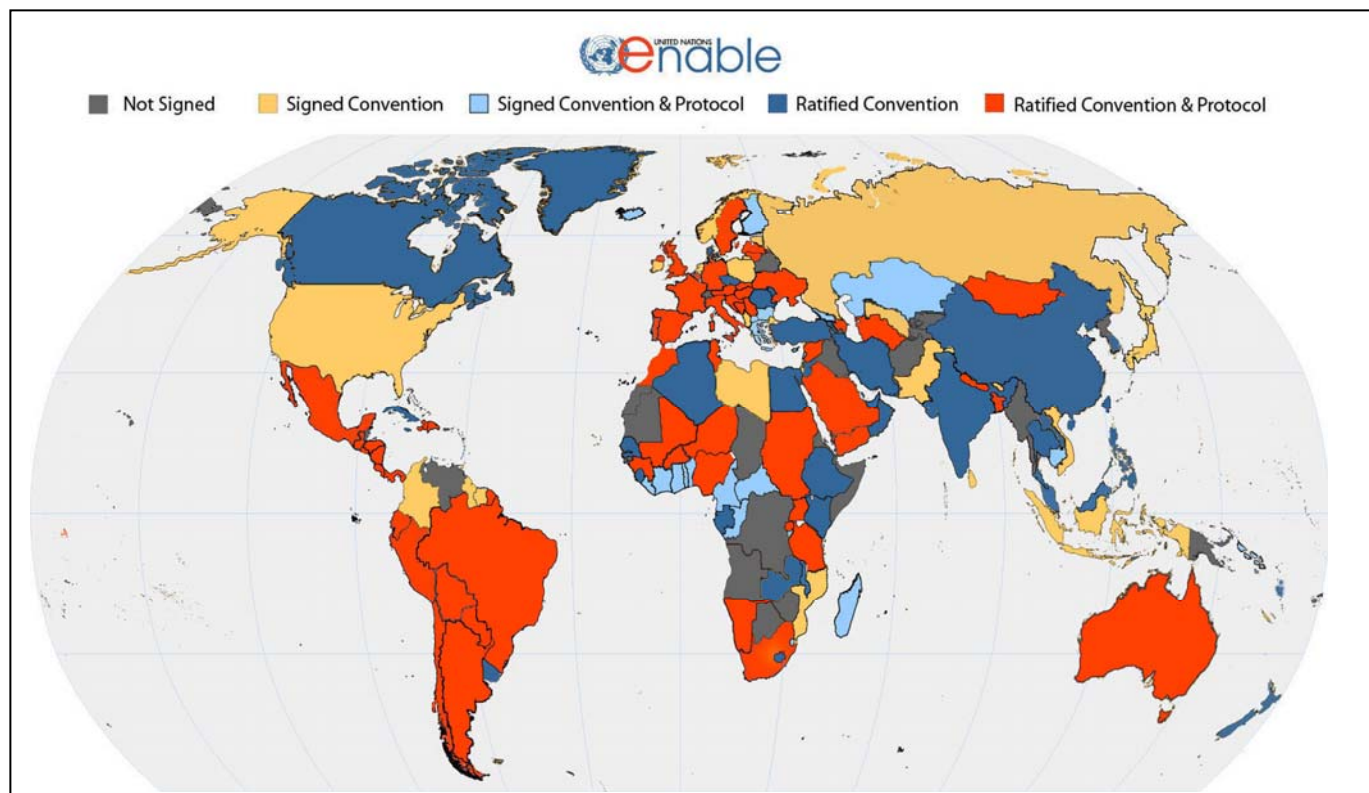
A person who could be the focal point through the ILAE/IBE chapter in the country was identified and the person was asked to liaise with the counterpart in the other organization. The focal point was asked to identify a group of resource people (e.g. a person from the legal profession, education sector, employment sector, insurance sector) and to complete the survey questionnaire based on their best knowledge. All respondents were asked to follow the glossary definitions, in order to maintain uniformity and comparability of information. In the case of incomplete or internally inconsistent information, the

respondents were contacted to provide further information or clarification; where appropriate, documents were requested to support completed questionnaires.

The project was coordinated by SEIN, WHO Collaborating Centre, Netherlands. Any queries related to data collection were dealt by a focal point at SEIN, who was responsible for project's coordination. A database was created and the data analysed.

Survey findings

All the 55 countries were signatories to many international treaties or human rights. These include United Nations Declaration of Human Rights, CRPD, etc..



Ratifications and signatories of the Convention on the Rights of Persons with Disabilities (Source: UN Web Services Section, Department of Public Information and maintained by the Secretariat for the Convention on the Rights of Persons with Disabilities, Department of Economic and Social Affairs © United Nations 2008-2010)

In 45 of 55 countries (82%) which participated in the survey, epilepsy was defined as a medical condition while in the remaining countries, epilepsy was classified as a mental condition. In 35 countries (64%), epilepsy was also defined by the law as disability. Rights afforded to people with epilepsy varied across countries. Disability allowance and welfare benefits for people with epilepsy were available by law in 15/55 (27%) countries surveyed. Free health care for epilepsy through the public health system was available in 16/55 countries. Tax benefits were provided by governments for people with epilepsy in 8/55 countries, although details on the types of benefit was not collected. Frequently these benefits were provided because epilepsy was defined as disability by law. In Zambia, additional rights for people with epilepsy included free education. In Greece, tax benefits are provided in relation to the taxation of inheritance and donations where the tax calculation is based on categories according to the degree of

relationship as follows: Category A (spouse, children, parents, grand-children), Category B (mainly: grand-grand children, grandparents, brothers, uncles etc.) and Category C (cousins, non-relatives etc.). In the case of inheritance tax, disabled persons by at least 67% belonging to the first two categories are entitled to a tax reduction of 2.000 euro. Disabled persons by at least 67% belonging to category C are entitled to a 60% reduction of the tax corresponding to the value of inheritance up to 165.000 euro.

With respect to legislation, in 29 of the countries surveyed, epilepsy was covered under an act related to disability. In some countries, there is no single act related to disability. Legislation concerning people with disability exists in various legislative acts (laws, ministerial decisions etc). In 13/55 countries, epilepsy was covered under mental health law. In countries where epilepsy is covered under mental health law or an act related to disability (n=36), respondent from 30 countries felt that the legislation is protective and positive. However, many of them (27/36) felt that the legislation is not well implemented.

With regard to legislation relating to people with epilepsy in areas outside the health sector, in most cases these are included in general legislation rather than in specific legislation for people with epilepsy. In four countries there is legislation regarding marriage of people with epilepsy and respondents from three of these reported that it is excluding and negative. In India the legislation concerning marriage was repealed in 1999; the Indian Epilepsy Association played an active role in this effort. Two countries reported the existence of legislation regarding property ownership by people with epilepsy. For instance, in the UK the Disability Discrimination Act (1995 and 2005) makes it illegal to discriminate against a person with a disability (which includes epilepsy) in relation to renting or owning property. The majority of the countries (84%) reported that people with epilepsy have the right to maintain parental rights (i.e. to foster and adopt). In three of the countries, there is legislation regarding parental rights. Almost half (25/55) of countries reported the presence of legislation regarding employment of people with epilepsy. In 20% of these, legislation was reported to be excluding and negative but in the majority it was positive and protective. The respondent from the USA reported that, relating to child custody, the standard is the best interest of the child and this is determined on a case-by-case basis. There are no blanket exclusions of people with epilepsy adopting or being foster parents.

Two-thirds of the respondents reported having legislation regarding holding a driving licence for motorcycles, cars, taxis, trucks and buses. The law varies in different countries. Mostly people with epilepsy are not allowed to hold a driving licence for public transport such as buses and taxis. For private transport, the duration of seizure-freedom varies across countries from six months to two years. In most countries when applying for a driving licence all applicants are asked about the presence of possible epilepsy.

There is legislation regarding the education of people with epilepsy in 12 countries and it is usually protective and positive. In Australia education standards under the Disability Discrimination Act Commonwealth (1992) require all educational providers to insure that all the services are equally accessible for all students, including those with any disability. The presence of a legislation affecting health care of people with epilepsy was reported by 17/55 respondents. Forty percent of the countries reported the presence of a government or other statutory body specifically responsible for promoting and

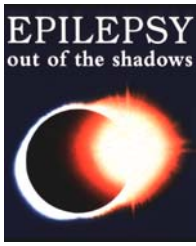
maintaining the quality of health care for people with epilepsy; this was frequently the lay association of people with epilepsy. Only nine countries reported the presence of legislation related to standards of care for people with epilepsy. When respondents were asked for all the factors that, in their opinion, prevented the achievement of a minimum standard of care, lack of accessibility (73%) was the most common cause, followed by lack of money (73%). Other causes included lack of medical expertise (67%), lack of equipment (62%), other priorities (62%) and, finally, the lack of drugs (46%).

Health insurance for people with epilepsy is protected by legislation in 15/55 countries. The issue of informed consent for people with epilepsy is covered specifically by legislation in only six countries. The issue of doctor-patient confidentiality is covered in general for all patients and not specifically for people with epilepsy; 17/55 countries reported the presence of such legislation.

Appendix II	Summary of the major provisions and international instruments relating to the rights of people with epilepsy
Key human rights related to health	Instruments safeguarding the human rights
<p>People with disabilities are entitled to the enjoyment and protection of their fundamental human rights.</p>	<ul style="list-style-type: none"> • International Covenant on Economic, Social and Cultural Rights (ICESCR) http://www.unhcr.org/refworld/docid/3ae6b36c0.html • International Covenant on Civil and Political Rights (ICCPR) http://www.unhcr.org/refworld/docid/3ae6b3aa0.html • Convention on the rights of persons with disabilities (CRPD) http://www2.ohchr.org/English/law/disabilities-convention.htm • UN Declarations of Human Rights http://www.un.org/Overview/rights.html • African Charter on Human and Peoples' Rights http://www1.umn.edu/humanrts/instreet/z1afchar.htm • Convention for the Protection of Human Rights and Fundamental Freedoms http://conventions.coe.int/Treaty/Commun/QueVoulezVous.asp?NT=005&CL=ENG • American Declaration of the Rights and Duties of Man http://www.hrcr.org/docs/OAS_Declaration/oasrights.html • American Convention on Human Rights http://www.hrcr.org/docs/American_Convention/oashr.html • Standard Rules on Equalization of Opportunities for Persons with Disabilities http://www.un.org/esa/socdev/enable/dissre00.htm • Declaration of Caracas http://www.tsj.gov.ve/informacion/eventos/caracasdeclaration.html • Recommendation of the Inter-American Commission on Human Rights for the Promotion and Protection of the Rights of the Mentally Ill http://www.cidh.oas.org/annualrep/2000eng/chap.6e.htm • Americans with Disabilities Act of 1990 http://www.ada.gov/pubs/ada.htm
<p>Right to the highest attainable standard of health care</p>	<ul style="list-style-type: none"> • International Covenant on Economic, Social and Cultural Rights (ICESCR) http://www.unhcr.org/refworld/docid/3ae6b36c0.html • Convention on the rights of persons with disabilities (CRPD) http://www2.ohchr.org/English/law/disabilities-convention.htm • African (Banjul) Charter on Human and Peoples' Rights http://www1.umn.edu/humanrts/instreet/z1afchar.htm • Standard Rules on Equalization of Opportunities for Persons with Disabilities http://www.un.org/esa/socdev/enable/dissre00.htm • European Social Charter http://conventions.coe.int/treaty/en/treaties/html/035.htm • Declaration of Caracas http://www.tsj.gov.ve/informacion/eventos/caracasdeclaration.html • International Convention on the Elimination of All Forms of Racial Discrimination http://www2.ohchr.org/english/law/cerd.htm

	<ul style="list-style-type: none"> • Convention on the Elimination of All Forms of Discrimination Against Women • Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights
Protection against discrimination	<ul style="list-style-type: none"> • International Covenant on Economic, Social and Cultural Rights (ICESCR) • Convention on the rights of persons with disabilities (CRPD) • International Covenant on Civil and Political Rights (ICCPR) • Inter-American Convention on the Elimination of all Forms of Discrimination against Persons with Disabilities • Americans with Disabilities Act of 1990 • Standard Rules on Equalization of Opportunities for Persons with Disabilities • Recommendation of the Inter-American Commission on Human Rights for the Promotion and Protection of the Rights of the Mentally Ill • Convention on the Elimination of All Forms of Discrimination Against Women

Appendix III: Regional Declarations.



African Declaration on Epilepsy DAKAR - 06 May 2000

Under the aegis of the Global Campaign Against Epilepsy of the World Health Organization (WHO), International League against Epilepsy (ILAE) and International Bureau for Epilepsy (IBE), a meeting "Epilepsy: A Healthcare priority in Africa" was held in Dakar, Senegal, Africa on 5 and 6 May 2000. Professionals from Health and Social Sciences sectors and representatives from universities coming from every African Region unanimously agreed to the following Declaration:

CONSIDERING THAT:

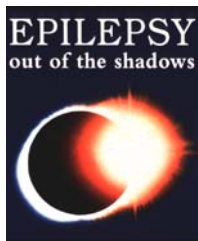
- epilepsy is the most common serious chronic brain disorder, estimated to affect at least 50 million people in the world of whom 10 million live in Africa alone, irrespective of race, religion, sex, age or socio-economic groups,
- epilepsy is not an infectious disease and seizures are not contagious,
- all people with epilepsy can be effectively and inexpensively treated,
- ¾ of people with epilepsy in Africa have no access to healthcare provisions and are not appropriately treated,
- general information about epilepsy, trained expertise, diagnostic facilities, antiepileptic drugs and surgery are not available to - or affordable by - the majority of people with epilepsy, for geographic, financial or cultural reasons,
- beliefs in supernatural causes and traditional treatment of epilepsy in Africa contribute to the under-utilization of the medical health services, to discrimination and social isolation,
- because of these factors, disability and mortality are greater in Africa than elsewhere,
- epilepsy has serious physical, psychological and social consequences for the afflicted and their families,
- the impact of epilepsy is most severe in children and adolescents,
- in Africa preventable causes of epilepsy, including infectious diseases, head trauma, insufficient perinatal care and consanguinity, are more frequent than elsewhere, ,
- epilepsy does not receive adequate attention in existing national health plans,

WE PROCLAIM THE FOLLOWING:

Epilepsy is a healthcare priority in Africa requiring every government to develop a national plan to:

- ⇒ address the needs with respect to epilepsy in terms of access to trained personnel, modern diagnostic equipment, antiepileptic medication and surgical treatment, information communication, prevention and social integration,
- ⇒ educate and train health care and other relevant professionals about epilepsy,

- ⇒ educate those affected by epilepsy and the general public about epilepsy as a universal neurological, non-communicable and treatable condition,
- ⇒ eliminate discrimination in all spheres of life, particularly at school and the work place,
- ⇒ encourage incorporation of prevention and treatment of epilepsy in national plans for other relevant healthcare issues such as maternal and child health, mental health, infections, head trauma, neurovascular diseases and community based rehabilitation programs,
- ⇒ encourage the public and private sectors and NGOs to get involved in the local activities of the Global Campaign against Epilepsy,
- ⇒ promote interaction with traditional health systems,
- ⇒ encourage basic and applied research on epilepsy,
- ⇒ proclaim a National Epilepsy Day,
- ⇒ encourage regional and continental co-operation.



Latin American Declaration on Epilepsy SANTIAGO DE CHILE - 9 September 2000

Under the aegis of the **Global Campaign Against Epilepsy**, the Commissions on Latin American Affairs of the International League against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE), the Pan American Health Organisation/ World Health Organisation (PAHO/ WHO), UNICEF for Latin America and the Caribbean, the Regional Office on Education for Latin America and the Caribbean of UNESCO, the Ministry of Health of Chile, organisations of people with epilepsy and parents of children with epilepsy, and the delegates of the national Leagues against Epilepsy of the Latin American and other countries of the world, on September 9th of 2000, at Santiago de Chile, unanimously declare:

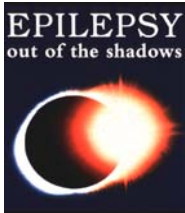
- Epilepsy is a neurological disorder that, if inadequately treated, produces severe physical, psychological, social and economic problems, which are aggravated by poverty in all Latin American countries.
- At least five million people in Latin America, probably more, have epilepsy, and more than three million do not receive treatment.
- Epilepsy may occur at any age, mainly in childhood and adolescence, but is also frequent in the elderly.
- Lack of adequate detection and treatment worsens the prognosis including the social and economic impact.
- Mortality in people with epilepsy is higher than in the general population.
- With appropriate treatment, most people with epilepsy may be relieved of their seizures and enjoy a significantly improved quality of life.
- Direct and indirect costs of epilepsy in Latin America are high and can be reduced by effective treatment.

We call on the Latin American Governments, national and regional, public and private organisations, all health care providers and the general public to join us in taking strong and decisive action to meet the objectives of the Global Campaign Against Epilepsy of the PAHO/WHO-ILAE-IBE “Epilepsy: Out of the Shadows”.

Specifically we urge action to:

- Improve public understanding of epilepsy and thereby reduce its stigma.
- Fight discrimination against people with epilepsy in all social environments, especially in the school and at the workplace.
- Educate people with epilepsy and their families to improve their understanding of their condition and to empower them to seek appropriate treatment and lead fulfilled lives.

- Strengthen primary health care, emphasising prevention, diagnosis and treatment by training the professionals working on this level.
- Ensure availability of modern equipment, trained health personnel, access to the full range of antiepileptic drugs, epilepsy surgery and other forms of treatment.
- Promote research and education in epilepsy.
- Promote close liaison of governments, health and social authorities with ILAE, IBE and PAHO/WHO to develop strategic projects and mobilise resources for the control of epilepsy.
- Develop national plans for epilepsy in all Latin American countries.
- Support publication of a detailed public health assessment on epilepsy in Latin America.
- Promote national and international legislation, which facilitates the implementation of health policies in accord with the initiatives, which are proposed in this declaration.



North American Declaration on Epilepsy LOS ANGELES - 01 December 2000

At a meeting in Los Angeles on December 1, 2000, leaders of North American professional and lay bodies, WHO representatives and health experts from governments and universities unanimously adopted the following declaration:

- ❑ Approximately four million people in North America have epilepsy. In many cases, it is a life-long condition.
- ❑ People with epilepsy have an increased risk of serious injury and death. Their chance of dying is three times higher than people without seizures.
- ❑ Uncontrolled epilepsy can lead to severe adverse social, psychological, and economic consequences.
- ❑ Uncontrolled epilepsy in childhood can lead to permanent brain damage and learning impairment.
- ❑ Seizure disorders are becoming an increasing cause of disability among the elderly.
- ❑ The incidence of epilepsy is increased in socioeconomically disadvantaged groups.
- ❑ The cost of epilepsy, at least 12.5 billion dollars per year in the USA alone, could be reduced substantially with effective action.
- ❑ Epilepsy can be controlled in many people with currently available treatment; however, a large number continue to have seizures despite optimal therapy.
- ❑ Better epilepsy treatment could permit more people to realize their full potential, with economic benefits for the community as well as for themselves.
- ❑ Neuroscience research promises further advances in patient care and, for the first time, offers the possibility of a cure for epilepsy.

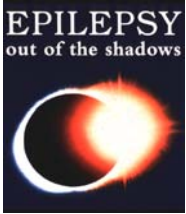
Yet,

- ❑ Too often, patients and health care providers believe that seizures cannot be fully controlled and that patients must 'live with them'.
- ❑ Funding for research on epilepsy is lower on a per capita basis than that devoted to many other less common and less burdensome disorders.
- ❑ People with epilepsy in North America have unequal access to necessary care. Socioeconomically deprived groups such as inhabitants of inner cities, and indigenous peoples are particularly neglected.

We call on governments, private organizations, care providers and other concerned individuals:

- ❑ To provide uniform access to optimal care, including specialized centers and surgery where medically indicated.
- ❑ To improve training in epilepsy for specialists, primary care physicians and other health workers.
- ❑ To ensure that people with epilepsy and their families are fully informed about the disorder.

- ❑ To educate teachers, employers, and the general public about epilepsy, in order to reduce stigma and prejudice.
- ❑ To promote the collection, analysis, and interpretation of data necessary to implement and evaluate public health programs related to epilepsy.
- ❑ To increase basic and clinical research funding for epilepsy.
- ❑ To take advantage of recent advances in neuroscience to prevent, treat, and ultimately cure epilepsy.



Eastern Mediterranean Declaration on Epilepsy

CAIRO - 04 March, 2003

Under the aegis of the Global Campaign Against Epilepsy of the World Health Organization (WHO), International League against Epilepsy (ILAE) and International Bureau for Epilepsy (IBE), a meeting "Epilepsy as A Public Health Concern in the Eastern Mediterranean Region" was held in Cairo, Egypt, on 3 and 4 March 2003. Professionals from Health and Social Sciences sectors and representatives from universities coming from the member states of the Eastern Mediterranean Region unanimously agreed to the following Declaration:

CONSIDERING THAT:

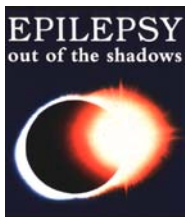
- epilepsy is the most common serious chronic brain disorder, estimated to affect at least 50 million people in the world, of whom at least 4 million live in the Eastern Mediterranean Region,
- contrary to many misconceptions, epilepsy is a brain disorder with natural causes and requiring medical treatment,
- it is often not realised that epilepsy is treatable, and that most people with epilepsy can lead productive lives as a result of relatively inexpensive, cost-effective treatment,
- in parts of the Eastern Mediterranean Region many people, especially in rural areas, have no access to appropriate healthcare provisions and treatment,
- general information about epilepsy, trained expertise, diagnostic facilities, antiepileptic drugs and surgery are not available for or affordable by many people with epilepsy, for geographic, financial, cultural or communication reasons,
- epilepsy has serious physical, psychological and social consequences for the afflicted and their families,
- the impact of epilepsy is most severe in children and adolescents,
- epilepsy does not receive adequate attention in existing national health plans in many countries,

We call on the governments of the member states of the Eastern Mediterranean Region, national and regional, public and private organisations, all health care providers, and the general public to join us in taking strong and decisive action to meet the objectives of the Global Campaign Against Epilepsy of the WHO/ILAE/IBE "Epilepsy: Out of the Shadows".

Specifically we urge action to:

- address the needs with respect to epilepsy in terms of prevention, access to trained personnel, modern diagnostic equipment, antiepileptic medication, surgical treatment where necessary, and social integration,

- include antiepileptic drugs in the list of essential drugs in all countries, and make them constantly available to avoid the serious consequences of treatment interruptions,
- educate and train health care and other relevant professionals and volunteers on all levels of health care about epilepsy,
- educate those affected by epilepsy, their families and the general public about epilepsy as a universal neurological condition, to eradicate misconceptions, and empower the affected to seek appropriate treatment and improve their quality of life,
- eliminate discrimination in all spheres of life, particularly concerning school and employment,
- encourage the public and private sectors and NGOs to get involved in the local activities of the Global Campaign against Epilepsy,
- encourage basic and applied research on epilepsy as an integral part of epilepsy services on all levels,
- proclaim a National Epilepsy Day,
- encourage regional and international co-operation.



European Declaration on Epilepsy

HEIDELBERG - 25 October 1998

At a meeting in Heidelberg, Germany on 25 October 1998, over 100 leaders of European professional and lay bodies, WHO representatives and health experts from governments and universities unanimously agreed the following declaration:

- Six million people in Europe currently have epilepsy. Fifteen million will have epilepsy at some time of their lives.
- Epilepsy has profound physical, psychological, and social consequences
- Children, adolescents and the elderly are especially afflicted by non-detection and under-treatment.
- With appropriate treatment over three quarters of people with epilepsy could lead normal lives free of seizures.
- Epilepsy costs the countries of Europe over 20 billion ECU every year, an amount that could be significantly reduced with effective action.

We call on the governments of Europe, the European Union, and all health care providers to join us in taking strong and decisive action to meet the objectives of the Global Campaign against Epilepsy launched by the WHO, ILAE, and IBE.

Specifically, we urge action:

- to improve public understanding of epilepsy and thereby reduce its stigma
- to remove discrimination against people with epilepsy in the workplace
- to help people with epilepsy to understand their condition and to empower them to seek appropriate treatment and lead fulfilled lives
- to improve the knowledge of health care professionals and other professionals about epilepsy, before and after graduation
- to ensure the availability of modern equipment, facilities, trained personnel and the full range of antiepileptic drugs, so that an accurate diagnosis can be made leading to the most effective treatment
- to encourage research on epilepsy and its management
- to encourage close liaison among governments, health and social authorities and agencies, and the national chapters of the ILAE and IBE

- to support the publication of a "white paper" as a detailed Public Health statement on Epilepsy in Europe
- to provide practical assistance for countries with underdeveloped epilepsy services within and beyond Europe.

Background Note

Epilepsy is the commonest serious brain disorder in every country, and probably the most universal of all medical disorders. It occurs at all ages, especially in childhood and old age, and in all races and social classes. At least 50 million people world-wide have epilepsy. One hundred million people will have epilepsy at some time in their lives.

Epilepsy is widely misunderstood, leading to fear, secrecy, stigmatisation, and the risk of social and legal penalties. In some European countries it is still not recognised as a brain disorder and up to 40% of people with epilepsy may be untreated – the treatment gap. The life span of people with epilepsy is reduced. Indeed, in specific risk groups the mortality may be twice or more that of the general population.

The ILAE has published a document on "Appropriate standards of epilepsy care across Europe". However, professionals treating people with epilepsy often do not have sufficient specialised knowledge about the condition. In some countries, AEDs are not always available or are unaffordable. In a number of European countries diagnostic facilities are lacking or inadequate.

Although WHO and World Bank studies have shown that epilepsy is a considerable economic burden, very few European countries have national plans for epilepsy.

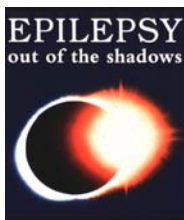
Epilepsy has profound physical, psychological, and social consequences:

- Many children with epilepsy receive inadequate schooling.
- The rate of unemployment is disproportionately high for people with epilepsy mainly due to the ignorance of employers. It is two to three times greater than the general rate, and more than for people with other disabilities.
- Many people hide their condition. This contributes to social isolation, low self esteem, and can lead to helplessness and depression.
- Many people with epilepsy lack knowledge about their condition. Women with epilepsy often have inadequate information about pregnancy and child-bearing.
- The quality of life in elderly people is often impaired due to unrecognised epilepsy.

- Many people with epilepsy have a severe problem with independent mobility.

The objectives of the Global Campaign Against Epilepsy of the World Health Organization, the International League Against Epilepsy, and the International Bureau for Epilepsy are:

- to increase public and professional awareness of epilepsy as a universal, treatable brain disorder
- to raise epilepsy to a new plane of acceptability in the public domain
- to promote public and professional education about epilepsy
- to identify the needs of people with epilepsy on a national and regional basis
- to encourage governments and departments of health to address the needs of people with epilepsy including awareness, education, diagnosis, treatment, care, services, and prevention.



Asian - Oceanan Declaration on Epilepsy NEW DELHI – 13 November, 2000

A meeting "Epilepsy: A Public Health Priority in Asian & Oceanian Region" was held in New Delhi on November 10, 2000. Over 600 professionals from health and social sciences sectors and representatives from many other organisations of the region unanimously agreed on November 13, 2000 to the following declaration:

CONSIDERING THAT IN ASIA/OCEANIA:

- At least 30 million people have the common brain disorder - epilepsy. This compares with approximately 50 million people with epilepsy world-wide.
- Epilepsy can have serious medical, psychological, social and economic consequences for people with epilepsy and their families.
- Epilepsy affects people with epilepsy and their families irrespective of race, religion, gender, age or socioeconomic status.
- Although epilepsy is a brain disorder, it is often mistakenly believed to be a mental illness, or to be caused by supernatural powers.
- It is erroneously, yet widely, believed that epilepsy is an infectious disease and seizures are contagious.
- It is often not realised that epilepsy is treatable, and that most people with epilepsy can lead productive lives as a result of relatively inexpensive, cost-effective treatment.
- The majority of people with epilepsy are treated inadequately and inappropriately because of ignorance, discrimination and limited health resources.
- Good quality standard anti-epileptic drugs are not regularly available in many countries.
- Disability and mortality are greater because epilepsy is inadequately treated.
- Epilepsy impacts most severely on the period of greatest development, namely childhood, adolescence and young adulthood. Yet it is during this time of life that it is most readily and successfully treated.
- The preventable causes of epilepsy such as poor perinatal care, infectious diseases, parasitic infestations, head trauma and consanguineous marriages are particularly prevalent.
- Epilepsy has not been included in most National Health Care plans.

PROCLAMATION

We call on the governments and other health providers of the Asian and Oceanian region, to join us in taking strong and decisive action to meet the objectives of the Global Campaign Against Epilepsy launched by the World Health Organization (WHO), the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE).

Specifically, we urge every government in this region to:

- Educate people with epilepsy, their families and the general public about epilepsy as a wide-spread, non-communicable and treatable chronic brain disorder. Educational means appropriate to all levels of literacy should be used.
- Educate and train health care and other relevant professionals about epilepsy, its prevention and its treatment.
- Provide access to trained personnel, modern diagnostic equipment and appropriate medication and/or surgical treatment for epilepsy.
- Promote and support research in Asia and Oceania into the basic processes, clinical aspects, and psycho-social consequences of epilepsy.
- Promote social integration and eliminate discrimination against people with epilepsy in all spheres of life, especially school, work and marriage.
- Include epilepsy in their national health plans, just as they do maternal and child health, mental health, infections and immunisation.
- Encourage cooperation between modern medical, traditional and other healing systems for the treatment of epilepsy.
- Encourage the public and private sectors, as well as relevant Non-Governmental Organizations to actively support local activities related to the Global Campaign Against Epilepsy.
- Raise public awareness of epilepsy by proclaiming a National Epilepsy Day, and supporting the establishment of a World Epilepsy Day.
- Encourage regional and global cooperation in dealing with epilepsy.



GLOBAL CAMPAIGN AGAINST EPILEPSY

WORLD HEALTH ORGANIZATION

INTERNATIONAL LEAGUE AGAINST EPILEPSY

INTERNATIONAL BUREAU FOR EPILEPSY

A QUESTIONNAIRE ON

PEOPLE WITH EPILEPSY: LEGISLATION AND HUMAN RIGHTS*

Country name

Filled by:

Name

Title

Current position

Connection with epilepsy

Address

Telephone

Fax

E-mail

Filled in:

Date Month Year

***In the context of this questionnaire, *epilepsy* refers to all types of this disorder, epileptic syndromes and related disorders.**

1. Background information

1.1 Is your country a signatory to any international treaties or agreements on human rights?

Yes No

If yes, can you name these (if more than one, list all)?

1.2 How is epilepsy defined by law? (tick all that apply)

- Mental condition Yes No
- Disability Yes No
- Medical condition Yes No
- Insanity Yes No
- Any other (please specify) Yes No

1.3 If epilepsy is defined as disability, what rights are afforded to people with epilepsy? (tick all that apply)

- Disability allowance Yes No
- Welfare benefits Yes No
- Free health care Yes No
- Daily living aids Yes No
- Tax benefits Yes No
- Other Yes No

Please specify

1.4 Is epilepsy covered under the mental health law in the country?

Yes No

Comments

1.5 Is epilepsy covered under the act related to disability in the country?

Yes No

Comments

1.6 If the answer to 1.4 or 1.5 is yes, in your opinion, is this legislation

• Protective and positive Yes No

• Excluding and negative Yes No

• Well applied and implemented Yes No

• Any other Yes No

Please specify

2. Rights and legislation affecting people with epilepsy - outside health sector

In your country:

2.1 Marriage

i. Is there any legislation regarding marriage of people with epilepsy?

Yes No

ii. If yes, give details of the legislation.

iii. In your opinion, is this legislation

- Protective and positive Yes No

- Excluding and negative Yes No

- Well applied and implemented Yes No

- Any other Yes No

Please specify

2.2 Property

i. Is there any legislation regarding owning property by people with epilepsy?

Yes No

ii. If yes, give details of the legislation.

iii. In your opinion, is this legislation

- Protective and positive Yes No

- Excluding and negative Yes No

- Well applied and implemented Yes No

- Any other Yes No

Please specify

2.3 Voting

i. Is there any legislation regarding voting by people with epilepsy?

Yes No

ii. If yes, give details of the legislation.

iii. In your opinion, is this legislation

- Protective and positive Yes No
- Excluding and negative Yes No
- Well applied and implemented Yes No
- Any other Yes No

Please specify

2.4 Parental rights

i. Do people with epilepsy have the right to maintain parental rights (i.e. fostering and adopting)?

Yes No

ii. Is there any legislation regarding parental rights of people with epilepsy?

Yes No

iii. If yes, give details of the legislation.

iv. In your opinion, is this legislation

- Protective and positive Yes No
- Excluding and negative Yes No
- Well applied and implemented Yes No

- Any other Yes No

Please specify

2.5 Employment

i. Is there any legislation regarding employment of people with epilepsy?

- Yes No

ii. If yes, give details of the legislation.

iii. In your opinion, is this legislation

- Protective and positive Yes No
- Excluding and negative Yes No
- Well applied and implemented Yes No
- Any other Yes No

Please specify

2.6 Driving

i. Is there any legislation regarding the right of people with epilepsy to hold a driving license for the following?

- Motor cycles Yes No
- Motor cars Yes No
- Taxis Yes No
- Trucks Yes No

• Buses Yes No

ii. If yes, give details of the legislation.

iii. In your opinion, is this legislation

• Protective and positive Yes No

• Excluding and negative Yes No

• Well applied and implemented Yes No

• Any other Yes No

Please specify

iv. Any additional information

2.7 Education

i. Is there any legislation regarding education of people with epilepsy?

Yes No

ii. If yes, give details of the legislation.

iii. In your opinion, is this legislation

• Protective and positive Yes No

• Excluding and negative Yes No

• Well applied and implemented Yes No

• Any other Yes No

Please specify

iv. Is there a law to ensure minors with epilepsy receive education?

Yes No

v. If yes, give details of the legislation.

2.8 Any additional information

3. Rights and legislation affecting people with epilepsy - within health sector

In your country:

3.1 Health care

i. Is there any legislation affecting health care for people with epilepsy?

Yes No

ii. If yes, give details of the legislation.

iii. In your opinion, is this legislation

• Protective and positive Yes No

• Excluding and negative Yes No

• Well applied and implemented Yes No

• Any other Yes No

Please specify

iv. Is there a government or other statutory body specifically responsible for promoting and maintaining the quality of health care for people with epilepsy?

Yes No

If yes, please specify

3.2 Standard of care

i. Is there any legislation regarding standard of care for people with epilepsy?

Yes No

ii. If yes, give details of the legislation.

iii. In your opinion, is this legislation

- Protective and positive Yes No
- Excluding and negative Yes No
- Well applied and implemented Yes No
- Any other Yes No

Please specify

iv. In your opinion, what prevents the achievement of minimum standard of care (tick all that apply)?

- Lack of medical expertise Yes No
- Lack of money Yes No
- Lack of equipment Yes No

- Lack of drugs Yes No
- Lack of accessibility Yes No
- Other higher priorities Yes No

3.3 Health insurance

i. Is there any legislation regarding health insurance for people with epilepsy?

Yes No

ii. If yes, give details of the legislation.

iii. In your opinion, is this legislation

- Protective and positive Yes No
- Excluding and negative Yes No
- Well applied and implemented Yes No
- Any other Yes No

Please specify

3.4 Informed consent

i. Is there any legislation regarding informed consent for people with epilepsy?

Yes No

ii. If yes, give details of the legislation.

iii. In your opinion, is this legislation

- Protective and positive Yes No

- Excluding and negative Yes No
- Well applied and implemented Yes No
- Any other Yes No

Please specify

3.5 Doctor-patient confidentiality

i. Is there any legislation regarding doctor-patient confidentiality for people with epilepsy?

Yes No

ii. If yes, give details of the legislation.

iii. In your opinion, is this legislation

- Protective and positive Yes No
- Excluding and negative Yes No
- Well applied and implemented Yes No
- Any other Yes No

Please specify

4. Comments

Please return a copy of the filled questionnaire via E-mail, fax or mail to:

SECRETARIAT: Global Campaign Against Epilepsy, P.O. Box 540, 2130 AM Hoofddorp, The Netherlands

E-mail: cmorton@sein.nl; Fax: + 31 23 5588409

GLOSSARY TO THE QUESTIONNAIRE ON PEOPLE WITH EPILEPSY: LEGISLATION AND HUMAN RIGHTS

International treaty	A formal agreement under <u>international law</u> entered into by states and international organizations.
International human rights	Values and guidelines that governments around the world have all agreed are essential for everyone to live with dignity and respect – no matter who they are or where they live. For example, human rights include the right to life and liberty, freedom of thought and expression, and equality before the law.
Law	The body of rules and principles governing the affairs of a community and enforced by a political authority; a legal system
Disabled person	Someone with a physical or mental impairment that has a substantial and long-term impact on their ability to carry out day-to-day activities. This definition includes people with cancer, diabetes, HIV, multiple sclerosis and heart conditions and people who have a hearing or sight impairment (except where the person's sight can be corrected by glasses or contact lenses) or a significant mobility difficulty. It also includes people with hidden disabilities such as diabetes, epilepsy, and dyslexia and people who have mental health conditions or learning difficulties.
Rights of people with epilepsy	Legal or moral <u>entitlement</u> to do or refrain from doing something, or to obtain or refrain from obtaining an action, thing or recognition in <u>civil society</u> . Rights serve as rules of interaction between people, and, as such, they place constraints and obligations upon the actions of individuals or groups. For example, if persons with epilepsy have a right to get married, others do not have the right to stop them or if a person with epilepsy has the right to own property, others can not stop him/her either.
Mental health law	The area of the law that refers specifically to persons with a diagnosis or possible diagnosis of mental illness, and to the people involved in managing or treating others in this situation.
Acts related to disability	Such acts make it illegal to discriminate against a person based on disability in areas such as education, employment and vocational training, job reservation, research and manpower development, creation of barrier-free environment, rehabilitation of people with disability, unemployment allowance for the disabled, special insurance scheme for the disabled employees

and establishment of homes for persons with severe disability, etc.

Maintaining parental rights

Parental rights include the right to foster or adopt children.

A minor

In law, the term minor (also infant or infancy) is used to refer to a person who is under the age in which one legally assumes adulthood and is legally granted rights afforded to adults in society. This age varies from country to country, but is usually marked at either 18 or 21.

Statutory body

A government-appointed body (*an individual, an organization, or an entity given legal recognition*) set up to give advice and be consulted for a specified area.

Informed consent

A legal condition whereby a person agrees to treatment based upon an understanding of the facts and implications of an action. The person needs to be able to make a balanced decision, i.e. should not be mentally ill or with an impairment of judgement at the time of consenting.

Doctor-patient confidentiality

Doctor-patient confidentiality results when a prospective patient seeks the advice, care, and/or treatment of a physician. It is based upon the general principle that people seeking medical help or advice should feel confident that their medical concerns or conditions will not be disclosed to others. There is generally an expectation that physicians will hold that special knowledge in confidence and use it only for the benefit of the patient.

ABBREVIATIONS

AED	anti-epileptic drug
CRPD	Convention on the Rights of Persons with Disabilities
GCAE	Global Campaign Against Epilepsy
IBE	International Bureau for Epilepsy
ICESCR	International Covenant on Economic, Social and Cultural Rights
ILAE	International League Against Epilepsy
NGO	Non-Governmental Organisation
PWE	People with epilepsy
SEIN	Stichting Epilepsie Instellingen Nederland
UN	United Nations
WHO	World Health Organization

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