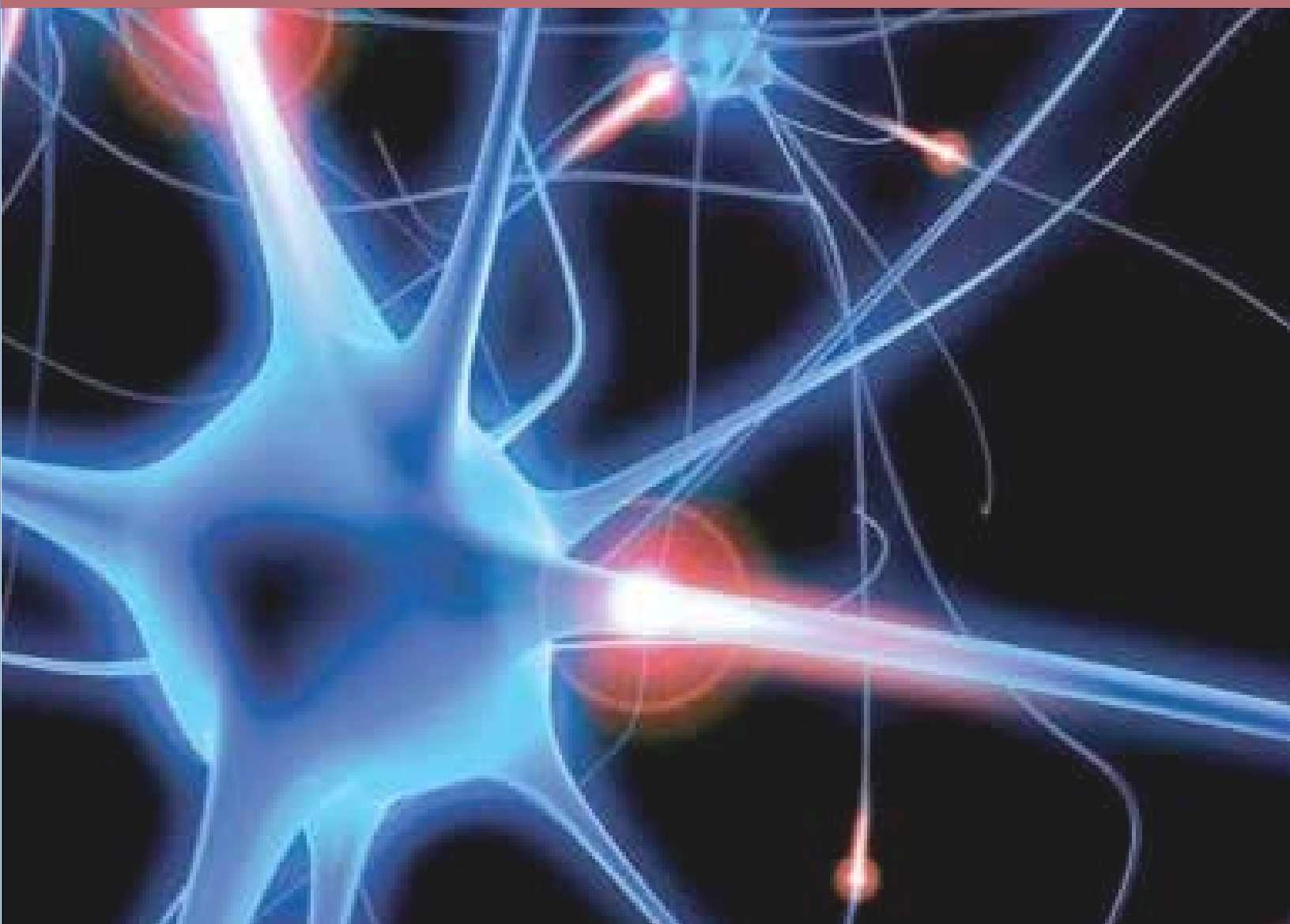


# REPORT ON EPILEPSY IN LATIN AMERICA AND THE CARIBBEAN



**Pan American  
Health  
Organization**



**World Health  
Organization**

REGIONAL OFFICE FOR THE **Americas**



# REPORT ON EPILEPSY IN LATIN AMERICA AND THE CARIBBEAN

Prepared by the Pan American Health Organization (PAHO/WHO) with  
the support of the International League against Epilepsy (ILAE) and the  
International Bureau for Epilepsy (IBE)



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## ABBREVIATIONS

<b>LAC</b>	Latin America and the Caribbean
<b>PHC</b>	Primary health care
<b>EEG</b>	Electroencephalography
<b>CME</b>	Continuing medical education
<b>AED</b>	Antiepileptic drugs
<b>IBE</b>	International Bureau for Epilepsy
<b>ILAE</b>	International League Against Epilepsy
<b>WHO</b>	World Health Organization
<b>NGO</b>	Nongovernmental organization
<b>PAHO</b>	Pan American Health Organization
<b>NMR</b>	Nuclear magnetic resonance
<b>CAT</b>	Computerized axial tomography





# PREFACE

Epilepsy is one of the most common chronic neurological disorders affecting millions of people in our continent as well as globally. It is estimated that in Latin America and the Caribbean (LAC), more than half of these cases are not receiving any form of medical care from health services.

The prognosis for epilepsy depends, to a great extent, on early diagnosis together with an early start on treatment and its continuity. It is encouraging to know that the vast majority of people with epilepsy can live normal lives if they receive appropriate care. It is important to point out that simply providing four basic antiepileptics, particularly at the primary care level, is a crucial measure. These medicines are very effective and inexpensive, if we consider that crises in most cases can be controlled under regimens of monotherapy with these antiepileptics.

However, one of the key challenges in the delivery of services to people with this disease is the problem of identifying, managing, and monitoring cases at the primary care level. Added to this is the fact that in most Latin American and Caribbean countries the secondary or specialized level of care is often nonexistent or highly concentrated in urban centers.

In 2011, the 51st Directing Council of the Pan American Health Organization (PAHO) adopted a Strategy and Plan of Action on Epilepsy. The adopted Resolution explicitly recognized the burden that epilepsy represents and the gap in existing treatment in the countries, and it also emphasized that “we are dealing with an important public health problem.”

In the context of the Directing Council’s mandate and with the support of the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE), we are submitting this report, in which the principal available data for LAC countries on resources, programs, and services for the care of people with epilepsy have been collated and analyzed. This report allows countries to identify their strengths and weaknesses and to set priorities in order to improve the health sector response. The report makes it easier to obtain a more accurate picture of the situation at the regional level, which will, in turn, help to guide technical collaboration in this field.

Allow me to briefly refer to two conclusions of the report that I consider to be especially important. The first is that two-thirds of the countries do not have a health sector program for epilepsy care, while the second is that 80 percent of the LAC countries do not have appropriate legislation related to epilepsy. Consequently, the human and civil rights of people with epilepsy are frequently violated. Furthermore, discriminatory legal regulations with no scientific basis still persist in many countries. Epilepsy continues to be a disease associated with much stigma, due in large measure to a lack of information and education available to the population on this subject.

Finally, we would like to express our gratitude to the teams that have contributed to this work and especially to the authorities of the health ministries that compiled primary data at the country level. This assessment would not have been possible without the support of the ILAE and IBE, as well as the PAHO/WHO Representative Offices in the countries and the advisory services of the Department of Mental Health and Substance Abuse of the World Health Organization. I would also like to acknowledge the important contributions of other actors who played a major role at the national level.

PAHO is fully committed to cooperating with Member States as they work towards improving care for people with epilepsy and this evaluative exercise is an essential step in that process. The challenge, now, is to turn this report into a working tool for planning and implementing new actions to improve the response of health systems. As a fundamental strategic action it will be necessary to strengthen the dialogue and working relationships between the public sector, professional associations, the national chapters of the ILAE and IBE, and the organizations of users and family members. The final objective is to improve the quality of life for people with epilepsy.

Dr. Carissa F. Etienne  
Director

## EXECUTIVE SUMMARY

The 51st Directing Council of the Pan American Health Organization (PAHO) in September 2011 adopted the Strategy and Plan of Action on Epilepsy (CD51/10). The Resolution of the Directing Council (CD51.R8) recognized the burden of epilepsy and the treatment gap existing in countries, and it also stated that “we are dealing with an important public health problem, whose approach in terms of prevention, treatment, and rehabilitation is feasible through concrete measures based on scientific tests.” Based on the foregoing it was resolved “To support the Strategy and approve the Plan of Action on Epilepsy and its application within the framework of the special conditions of each country.”

PAHO with the support of the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE) is submitting this report, which compiles the principal available data at the country level on resources, programs and services related to the care of people with epilepsy in Latin America and the Caribbean (LAC). Information was obtained from 25 of the 33 LAC countries (76%), which responded to the assessment tool during the second semester of 2012.

Approximately, two-thirds of the countries do not have a health sector program or action plan to treat epilepsy, which constitutes a critical problem for planning and being able to undertake organized, coherent and comprehensive interventions with prospects for the short, medium and long term. Some 80% of LAC countries do not have legislation related to epilepsy. Furthermore, discriminatory legal regulations with no scientific basis still persist; for example, 46% of the countries have legal restrictions such that a person with epilepsy can not obtain a driver’s license. This means that the human and civil rights of people with epilepsy are frequently violated.

In general, the association movement for users and family members is weak in the Region; 36% of the surveyed countries do not have this type of civil society organization. Epilepsy continues to be a disease that is perceived by the general population from a discriminatory and stigmatized point-of-view due, to a great extent, to the lack of information and education received in this regard. Some 71% of the countries reported that a stigmatized perception of people with epilepsy predominates.

It is important to point out that in 68% of the countries people with epilepsy, frequently or at least occasionally, seek traditional or alternative type care, particularly with healers. Furthermore, 87% of the countries reported having centers or specialized services devoted specifically to epilepsy or neurology that include epilepsy care. There are 94 surgical services for epilepsy cases located in 16 of the 25 countries analyzed in this report. Lack of these services is concentrated in the English-speaking Caribbean.

The basic four antiepileptic drugs (AED) are included on the list of essential drugs for most of the countries, but this does not mean that they are available throughout the country. Only 62% of the countries reported that these AED are available throughout the year at primary health care (PHC) facilities. With regard to diagnostic tests, 84% of the countries evaluated have equipment for electroencephalography (EEG), 88% for computerized axial tomography (CAT) and 76% for nuclear magnetic resonance (NMR). This does not necessarily mean that within these countries the entire population in need of these technology resources has access to them.

Countries reported that problems with diagnosis (67%) and delays in care (63%) were the most frequent major difficulties with regard to caring for people with epilepsy. In addition, ratios of 1.18 neurologists and 0.78 neurosurgeons per 100,000 population were reported. Only 12 LAC countries reported having

physicians with special training in epilepsy (epileptologists). There are 341 professionals enrolled in neurology residence distributed over 12 countries.

One important conclusion concerns the unequal and inequitable distribution of services and human and technological resources related to epilepsy care. In addition to being insufficient, in many countries these resources are concentrated to a great extent in the capital and large cities. In some countries the coverage that the public sector can provide is limited and private services are extremely expensive and inaccessible to the vast majority of the population. The English-speaking Caribbean exhibits a considerable scarcity or lack of services, specialized professionals, and technology resources for appropriate diagnosis and treatment of epilepsy cases, as well as support for PHC.

Continuing medical education/training (CME) activities were reported in 61% of the countries. The systematic and regular presence of CME/training programs related to epilepsy at health institutions is low. At present, only one-third of the countries reported having some regular CME/training program in epilepsy for PHC. The problem-solving capacity of PHC must be improved in order to achieve early diagnoses and appropriate case management of epilepsy; this is essential to bridging the treatment gap.

Some 36% of the countries do not have basic data on epilepsy compiled by their national health information systems; this is a critical element that needs to be addressed by the national health authorities. Epidemiological research of services and quality is poorly developed in LAC countries; for example, only 40% of the countries reported having some epidemiological study of epilepsy.

An annual average of 5,870 deaths from epilepsy (as primary cause) occurs in LAC countries, which represents a rate of 1.04 per 100,000 population.

# INTRODUCTION

Epilepsy is one of the most common neurological disorders in the world, affecting some 50 million people, of which 5 million live in the Americas. However, it is calculated that in Latin America and the Caribbean (LAC) the treatment gap is higher than 50%, which means that more than half of those with epilepsy are not receiving any type of treatment from health services, either primary health care (PHC) or specialized (1,2).

The incidence ratios and prevalence of epilepsy for the world are not uniform and depend on several factors. The prevalence throughout life in LAC, according to a collection of 32 community-based studies, stands at an average of 17.8 per 1,000 population (range of 6-43. 2). There were no significant differences by sex or age groups (1,2,3,4).

A diagnosis of epilepsy is essentially clinical and can be made in non-specialized contexts—such as at the PHC level—with an adequate history and clinical examination of the patient. The prognosis for epilepsy depends on several factors, such as its etiology, diagnosis and early treatment; it is estimated that up to 70% of people with epilepsy can lead normal lives if they receive appropriate treatment (1,2). However, there are various factors that restrict and hinder treatment, among them lack of information, stigmatization, and limited or lack of access to health services.

The 51st Directing Council of the Pan American Health Organization (PAHO), made up of delegations from Member States, in September 2011 adopted the Strategy and Plan of Action on Epilepsy (CD51/10) (1). This represented a historical milestone, since for the first time all the nations of the Americas discussed the subject of epilepsy, considered it a priority and approved a strategic plan to determine by consensus the way forward for the next ten years.

The Directing Council Resolution CD51.R8 (1) explicitly recognized the burden of epilepsy and the existing treatment gap and also stated that “we are dealing with an important public health problem, whose approach in terms of prevention, treatment, and rehabilitation is feasible through concrete measures based on scientific tests.” Based on the foregoing it was resolved “To support the Strategy and approve the Plan of Action on Epilepsy and its application within the framework of the special conditions of each country.”

This Strategy is the result, to a great extent, of many previous events, which laid the groundwork and improved knowledge of epilepsy and its magnitude in health and social terms, on the part of Governments and civil society. In 2008, PAHO jointly with the International League Against Epilepsy (ILAE) and the International Bureau of Epilepsy (IBE) published the Report on Epilepsy in Latin America (5) that, despite the limitations of the data sources of the time, represented a first effort to show the situation of the LAC countries in this field.

PAHO with the support of the ILAE and the IBE is submitting this report, which compiles the principal available country data on resources, programs, and services related to the care of people with epilepsy in Latin America and the Caribbean. It also describes the information on epilepsy mortality available in the databases of the World Health Organization (WHO) and PAHO.

This report lays out the current situation and facilitates the future measurement of many of the changes and improvements that are expected to be produced in the majority of Latin American and Caribbean nations. Furthermore, this benefits planning at the country level, as it represents an evidence basis for the

action. It may also be useful to international organizations offering technical cooperation in the Region, by identifying problems, strengths, and priorities.

In addition, the report responds to a request from the PAHO Directing Council to prepare a baseline as a fundamental element for evaluating progress and the degree of implementation at the regional level of the Strategy and Plan of Action (September 2011).

# METHODOLOGY

A tool provided by the WHO Department of Mental Health and Substance Abuse (Epilepsy Resource Assessment Tool) was used for data collection, which was modified and adapted for use in LAC; similarly a version in Spanish was translated and prepared. This instrument was sent to all the countries through the Representative Offices of PAHO at that level. The survey was to be officially answered by the Ministries of Health, and it was also suggested that the Ministries seek a consensus on the survey at the national level with other entities interested in the subject, particularly the national chapters of the ILAE and IBE.

The ILAE and IBE asked their respective country representatives to collaborate on the data collection process. The PAHO-ILAE-IBE Regional Working Group, created to support the implementation of the Strategy and Plan of Action, cooperated in the process.

This is a report on the LAC countries, and thus excludes two countries of North America (the United States of America and Canada). Of the 33 PAHO Member States of LAC, information was obtained from 25 countries, which responded during the second semester of 2012. The latter were grouped, for analytical purposes, into three subregions: (1) Mexico, Central America, and Latin Caribbean; (2) South America; and (3) the English-speaking Caribbean.

The countries forming part of the study for the subregion of Mexico, Central America, and Latin Caribbean are: Costa Rica, Cuba, Dominican Republic, El Salvador, Guatemala, Haiti, Honduras, Mexico, and Panama. For the subregion of South America they are: Argentina, Bolivia, Brazil, Chile, Colombia, Ecuador, Peru, Uruguay, and Venezuela. Within the subregion of the English-speaking Caribbean they are: Antigua and Barbuda, Bahamas, Grenada, Jamaica, Saint Kitts and Nevis, Saint Vincent and the Grenadines, and Suriname.

The tool used to measure the availability of resources and services to care for people with epilepsy grouped the different items into six areas of interest: (1) health programs, legislation and human rights; (2) leadership and social participation; (3) cultural perception and traditional or alternative medicine; (4) services and technology; (5) human resources and training; and (6) information and research. The available information was compiled and grouped by countries, subregions, and the LAC total; data were organized into tables and figures for better comprehension.

The number of countries participating in the study represents 75.8% of the total PAHO Member States of LAC and 97.4% of the Latin American and Caribbean population, which means that the report can be considered representative of the reality of the (LAC) subcontinent.

Some limitations should be considered by the reader: (1) the sources of official information are the Ministries of Health, and some countries were able to achieve a consensus with other entities seeking better data quality, but that was not always the case. In some cases the survey was answered by one or two key informants; (2) some items were not answered by some countries, the implication being that no data were available at that time; (3) many questions are formulated such that the response is based on the best estimate of the informant or simply “yes” or “no,” which provides a general appraisal, although the accuracy and depth of the analysis of the indicator remain in question; and d) data quality are not uniform for all countries.

However, and despite the aforementioned limitations, this report represents the most important and comprehensive effort carried out in LAC countries with regard to information on epilepsy, and is endorsed by the Governments of the countries. It also demonstrates a significant collaborative effort at the international level between PAHO, ILAE, and IBE.

# ANALYSIS OF THE RESULTS

## 1. HEALTH PROGRAMS, LEGISLATION AND HUMAN RIGHTS

Having a plan or program to care for people with epilepsy is fundamental to improving their care and level of health. The existence of a program makes health care organization easier, such that it is coherent, comprehensive and in line with the national health policy, and it also facilitates appropriate planning according to present and future needs. This is a priority and strategic point that becomes even more indispensable in countries with few resources.

Having up-to-date legislation related to epilepsy that is in line with technical standards and more current human rights is another essential element for countries. Legal provisions should protect the human rights of people with epilepsy, regulate the delivery of services and ensure comprehensive and quality care, as well as address elements of social protection, especially for people with some degree of disability.

People with epilepsy frequently experience violations and restrictions on their human and civil rights, such as—for example—inequitable access to services, prejudices related to health and life insurance, restrictions on obtaining a vehicular driver's license, limitations on obtaining certain jobs, problems in establishing legal agreements and some countries even reported marriage restrictions. Similarly, there are also regulations that discriminate in terms of access to education (6).

It is important to identify these violations and inequities in order to confront them through available legal means, including amending existing legislation. For purposes of this report three specific aspects were evaluated: employment, driver's license and education.

An essential element in providing appropriate care to people with epilepsy is the presence of antiepileptic drugs (AED) on the country's essential drugs list, especially at the PHC level. This facilitates their regular and effective availability at the first level of care, particularly for the low-income population.

Having a specific budget to care for people with epilepsy within the structure is complex, and public sector administrative machineries at times do not allow it (with funds distributed to several entities). However, knowing the approximate amount of expenditure is necessary to be able to define important needs and plan appropriately. In this regard, it is important to estimate the degree of coverage to which public services extend and what population groups (especially low-income) are left unprotected and without care. Efforts to expand the coverage of public services to include epilepsy care and improve the problem-solving capacity of PHC in this field becomes necessary.



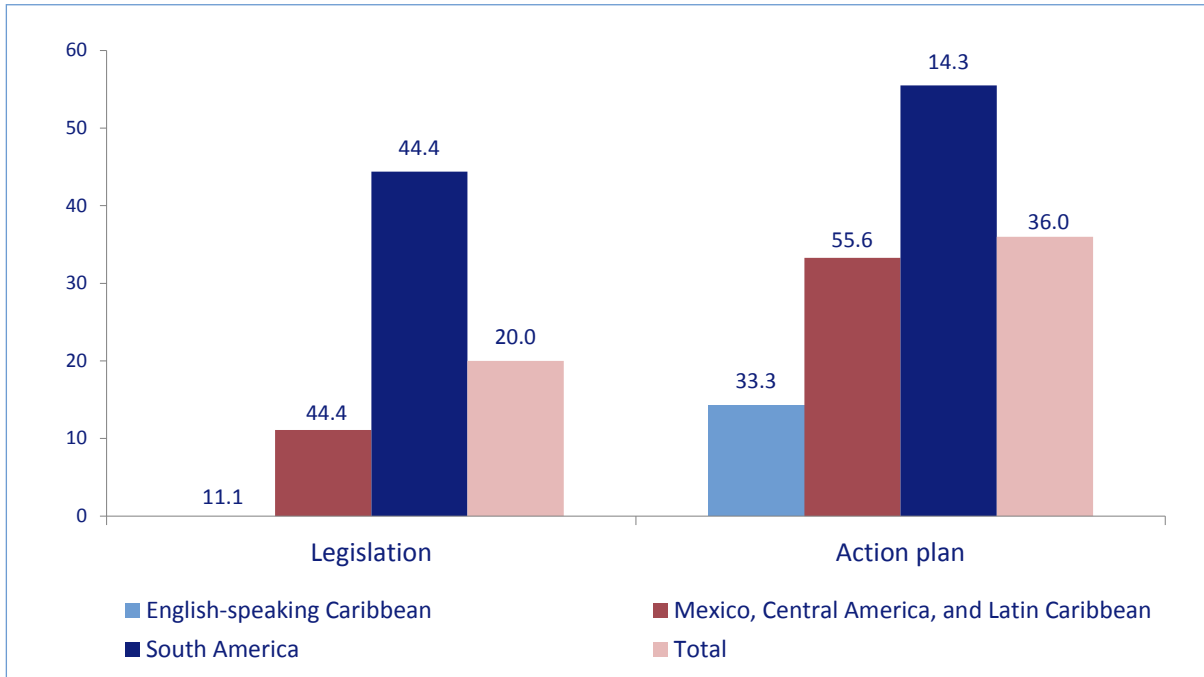
**Table 1 Programs or action plans and legislation for the care of people with epilepsy**

Countries by subregion	Action plan/ program	Year approval/ update	Legislation	Year approval/ update
Costa Rica	No	n/a	No	n/a
Cuba	No	n/a	No	n/a
Dominican Republic	No	n/a	No	n/a
El Salvador	Yes	2011	No	n/a
Guatemala	Yes	1989	No	n/a
Haiti	No	n/a	No	n/a
Honduras	No	n/a	No	n/a
Mexico	Yes	1984	Yes	1984
Panama	No	n/a	No	n/a
<b>Subtotal</b>	<b>9/3: 33.3%</b>		<b>9/1: 11.1%</b>	
Argentina	No	n/a	Yes	2001
Bolivia	Yes	1989	No	n/a
Brazil	Yes	2010	No	n/a
Chile	Yes	2002	Yes	2004
Colombia	Yes	2010	Yes	2012
Ecuador	No	n/a	No	n/a
Peru	No	n/a	No	n/a
Uruguay	No	n/a	No	n/a
Venezuela	Yes	2005	Yes	2009
<b>Subtotal</b>	<b>9/5: 55.6%</b>		<b>9/4: 44.4%</b>	
Antigua and Barbuda	No	n/a	No	n/a
Bahamas	Yes	2012	No	n/a
Grenada	No	n/a	No	n/a
Jamaica	No	n/a	No	n/a
Saint Kitts and Nevis	No	n/a	No	n/a
Saint Vincent and the Grenadines	No	n/a	No	n/a
Suriname	No	n/a	No	n/a
<b>Subtotal</b>	<b>7/1: 14.3%</b>		<b>7/0: 0%</b>	
<b>Total</b>	<b>25/9: 36.0%</b>		<b>25/5: 20.0%</b>	

**Source:** Tool for the assessment of resources devoted to epilepsy (modified version-PAHO/2012).

n/a: not available

**Figure 1 Programs or action plans and legislation for the care of people with epilepsy**



The report shows that only nine of the countries surveyed in LAC (36.0%) have a program/plan of action to care for people with epilepsy. The countries that reported having a plan or national program are the following: Bahamas, Bolivia, Brazil, Chile, Colombia, El Salvador, Guatemala, Mexico, and Venezuela. Of these, six have approved or updated this plan in the last 10 years (after 2002).

The situation in terms of legislation is even more critical; only 20.0% of the surveyed countries have national legislation related to epilepsy. Within the five countries that have this legislation, Chile, Colombia, and Venezuela are the only ones that have updated it since 2002.

**Table 2 Antiepileptic drugs (AED) on the list of essential drugs of the country at the primary health care (PHC) level**

Countries by subregion	Phenobarbital	Phenytoin	Carbamazepine	Valproic acid
Costa Rica	Yes	Yes	Yes	No
Cuba	Yes	Yes	Yes	Yes
Dominican Rep.	Yes	Yes	Yes	Yes
El Salvador	Yes	Yes	No	No
Guatemala	No	No	No	No
Haiti	Yes	No	No	No
Honduras	Yes	Yes	Yes	No
Mexico	Yes	Yes	Yes	Yes
Panama	Yes	Yes	Yes	Yes
<b>Subtotal</b>	<b>9/8: 88.9%</b>	<b>9/7: 77.8%</b>	<b>9/6: 66.7%</b>	<b>9/4: 44.4%</b>
Argentina	Yes	Yes	Yes	Yes
Bolivia	Yes	Yes	Yes	Yes
Brazil	Yes	Yes	Yes	Yes
Chile	Yes	Yes	Yes	Yes
Colombia	No	Yes	Yes	Yes
Ecuador	Yes	Yes	Yes	Yes
Peru	Yes	Yes	Yes	Yes
Uruguay	Yes	Yes	Yes	Yes
Venezuela	Yes	Yes	No	No
<b>Subtotal</b>	<b>9/8: 88.9%</b>	<b>9/9: 100%</b>	<b>9/8: 88.9%</b>	<b>9/8: 88.9%</b>
Antigua and Barbuda	Yes	Yes	No	No
Bahamas	Yes	Yes	Yes	Yes
Grenada	Yes	Yes	Yes	Yes
Jamaica	Yes	Yes	Yes	Yes
Saint Kitts and Nevis	Yes	Yes	Yes	Yes
Saint Vincent and the Grenadines	Yes	Yes	Yes	Yes
Suriname	Yes	Yes	Yes	Yes
<b>Subtotal</b>	<b>7/7: 100%</b>	<b>7/7: 100%</b>	<b>7/6: 85.7%</b>	<b>7/6: 85.7%</b>
<b>Total</b>	<b>25/23: 92.0%</b>	<b>25/23: 92.0%</b>	<b>25/20: 80.0%</b>	<b>25/18: 72.0%</b>

**Source:** Tool for the assessment of resources devoted to epilepsy (modified version-PAHO/2012).

With regard to the inclusion of AED on the list of essential drugs at the PHC level, 92.0% of the countries list phenobarbital, 92.0% list phenytoin, 80.0% list carbamazepine and 72.0% list valproic acid.

Other AED are included on 33.3% of country lists of essential drugs at the PHC level, among them valproic acid, diazepam, and clonazepam are noteworthy.

**Table 3 Regulations or specific legal restrictions for people with epilepsy**

Countries by subregion	Employed	Driver's license	Education
Costa Rica	No	No	No
Cuba	No	No	No
Dominican Rep.	No	No	No
El Salvador	n/r	n/r	n/r
Guatemala	No	No	No
Haiti	Yes	No	Yes
Honduras	No	No	No
Mexico	No	No	No
Panama	No	No	No
<b>Subtotal</b>	<b>8/1: 12.5%</b>	<b>8/0: 0%</b>	<b>8/1: 12.5%</b>
Argentina	Yes	Yes	No
Bolivia	No	No	No
Brazil	No	Yes	No
Chile	No	Yes	No
Colombia	No	No	No
Ecuador	No	No	No
Peru	Yes	Yes	Yes
Uruguay	Yes	Yes	Yes
Venezuela	Yes	Yes	Yes
<b>Subtotal</b>	<b>9/4: 44.4%</b>	<b>9/6: 66.7%</b>	<b>9/3: 33.3%</b>
Antigua and Barbuda	No	Yes	No
Bahamas	No	No	No
Grenada	Yes	Yes	No
Jamaica	No	Yes	Yes
Saint Kitts and Nevis	No	No	No
Saint Vincent and the Grenadines	No	Yes	No
Suriname	No	Yes	No
<b>Subtotal</b>	<b>7/1: 14.3%</b>	<b>7/5: 71.4%</b>	<b>7/1: 14.3%</b>
<b>Total</b>	<b>24/6: 25.0%</b>	<b>24/11 45.8%</b>	<b>24/5: 20.8%</b>

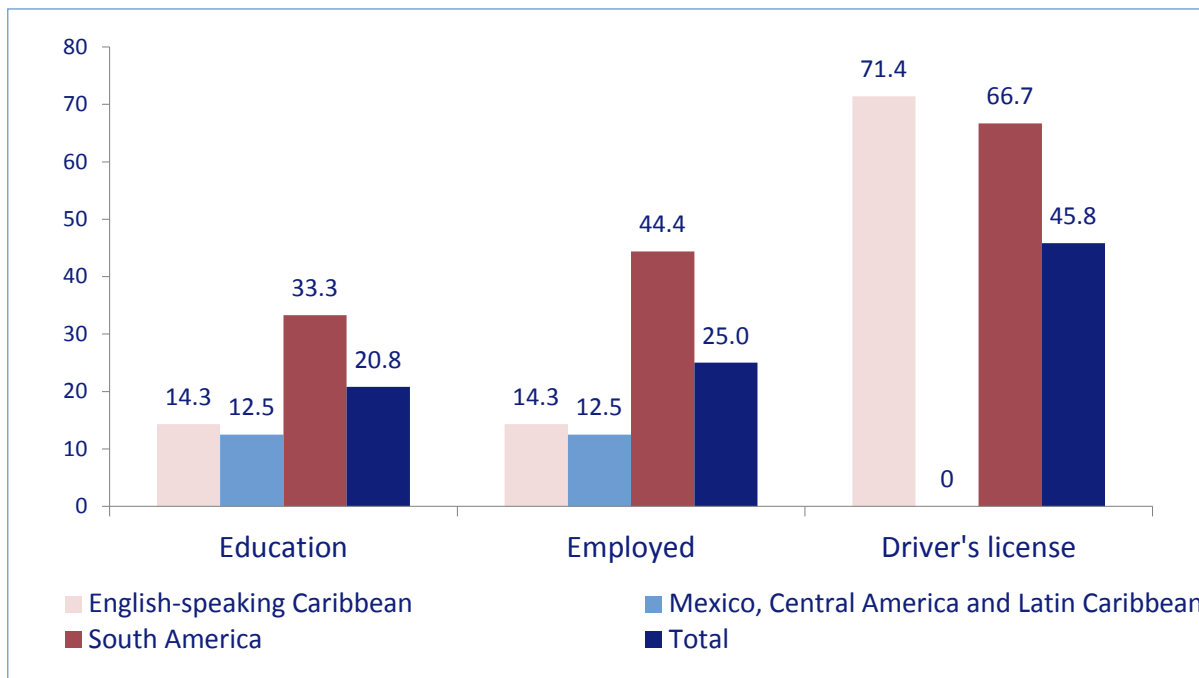
**Source:** Tool for the assessment of resources devoted to epilepsy (modified version-PAHO/2012).

n/a: not available

n/r: not reported

With respect to regulations and/or legal restrictions established by the countries for people with epilepsy, 25.0% of the countries have restrictions on obtaining or maintaining employment, 45.8% have restrictions on obtaining a driver's license and 20.8% have specific regulations related to education.

**Figure 2 Regulations or specific legal restrictions for people with epilepsy**



### Governmental expenditure allocated to epilepsy

The country reports revealed that they lack specific and reliable data concerning the proportion of the governmental health budget allocated to care for people with epilepsy. In the future this analysis should be strengthened and countries should be encouraged to set up mechanisms to identify the structure of governmental expenditure and how much of it is devoted to epilepsy.

## Coverage of care for people with epilepsy, according to public sources of financing

Eleven of the countries evaluated did not offer information in this regard. The remaining fourteen countries offered the following data as estimates of public coverage with regard to care for people with epilepsy:

% Range of public sector coverage	Number of countries	Percent
90%-100%	6	42.9
80%-89%	3	21.4
70%-79%	1	7.1
60%-69%	1	7.1
50%-59%	1	7.1
40%-49%	1	7.1
Less than 40%	1	7.1
<b>Total</b>	<b>14</b>	<b>100.0</b>

Two-thirds of the countries reported that public services cover more than 80% of the population affected by epilepsy.

## International donors for the care and treatment of people with epilepsy

Some 20.0% of the countries receive money from international funds to care for people with epilepsy. Within the subregions, Mexico, Central America, and the Latin Caribbean stand out as the subregion using most of these funds (44.4% of the countries), unlike South America with 12.5% and the English-speaking Caribbean where no country reported international donors.

## 2. LEADERSHIP AND SOCIAL PARTICIPATION

Professional associations in the health field are an important component in efforts to improve the quality of care and well-being of people with epilepsy. The best known and most directly involved in this area are those trained by neurologists, a medical specialty that offers specialized services to people with epilepsy. Professional organizations can and should be involved in education programs for the general population, training, and research, among others. Some countries do have organizations devoted specifically to epilepsy, which usually function as chapters or national associations of the ILAE and IBE.

The presence of organizations of users and/or family members is an important indicator showing the degree of civil society organization and its potential participation in the planning and execution of programs related to epilepsy. People with epilepsy (users of health services) and their family members are the parties most interested in improving care for this health problem, which means their organization and active participation should be encouraged.

**Table 4 Professional associations, neurologists and users/family members related to epilepsy**

Countries by subregion	Professional associations	Number of members	Neurologists association	Number of members	Users and/or family members association	Number of members
Costa Rica	1	8	1	96	1	n/r
Cuba	1	250	1	n/r	No	n/a
Dominican Rep.	1	70	1	85	1	20
El Salvador	No	n/a	No	n/a	No	n/a
Guatemala	3	150	2	60	1	50
Haiti	No	n/a	No	n/a	No	n/a
Honduras	1	20	1	20	1	41
Mexico	1	150	2	1.400	3	n/r
Panama	2	21	1	21	1	80
<b>Subtotal</b>	<b>10: 9/7</b>	<b>669: 7/7</b>	<b>9: 9/7</b>	<b>1.682: 7/6</b>	<b>8: 9/6</b>	<b>191: 6/4</b>
Argentina	1	150	2	n/r	2	n/r
Bolivia	1	25	1	45	1	50
Brazil	1	321	2	n/r	2	n/r
Chile	3	150	3	500	19	250
Colombia	10	100	2	400	6	n/r
Ecuador	2	40	2	40	No	n/a
Peru	1	n/r	1	n/r	No	n/a
Uruguay	1	65	2	145	1	25
Venezuela	1	100	1	283	1	600
<b>Subtotal</b>	<b>21: 9/9</b>	<b>951: 9/8</b>	<b>16: 9/9</b>	<b>1.413: 9/6</b>	<b>32: 9/7</b>	<b>925: 7/4</b>
Antigua and Barbuda	No	n/a	No	n/a	No	n/a
Bahamas	No	n/a	No	n/a	3	n/r
Grenada	No	n/a	No	n/a	No	n/a
Jamaica	1	80	No	n/a	1	35
Saint Kitts and Nevis	No	n/a	No	n/a	No	n/a
Saint Vincent and the Grenadines	No	n/a	No	n/a	No	n/a
Suriname	No	n/a	No	n/a	1	n/r
<b>Subtotal</b>	<b>1: 7/1</b>	<b>80: 1/1</b>	<b>n/a: 7/0</b>	<b>n/a: 0/0</b>	<b>5: 7/3</b>	<b>35: 3/1</b>
<b>Total</b>	<b>32: 25/17</b>	<b>1.700: 17/16</b>	<b>25: 25/16</b>	<b>3.095: 16/12</b>	<b>45: 25/16</b>	<b>1.151: 16/9</b>

**Source:** Tool for the assessment of resources devoted to epilepsy (modified version-PAHO/2012).

n/a: not available

n/r: not reported

Some 32 professional associations related to epilepsy were reported, with 1,700 members, distributed over 17 countries; eight countries (32.0%) have no associations of this type. There are 25 associations of neurologists, with 3,095 members, located in 16 countries. It is noteworthy that the English-speaking Caribbean subregion (with the exception of Jamaica) lacks professional associations related to care for people with epilepsy; this may be so because they are small nations with limited specialized human resources.

Some 45 users and/or family member associations were reported with a total membership of 1,151, distributed over 16 countries. Membership data are underreported since 56% of these countries reported this data as unavailable.

Nine countries (36.0%) have no organizations of users and/or family members. The countries that reported no organizations of this type are: Cuba, El Salvador, Haiti, Ecuador, Peru, Antigua/Barbuda, Grenada, Saint Kitts and Nevis and Saint Vincent and the Grenadines.

### **3. CULTURAL PERCEPTION AND TRADITIONAL OR ALTERNATIVE MEDICINE**

Perception of the disease by professionals and health workers may be different from that of the general population or of some specific groups such as teachers and employers. Once the myths and the stigma surrounding this disorder have been identified, as well as knowledge and existing attitudes, community education becomes an important working tool to use in the psychosocial rehabilitation of people with epilepsy and to improve their living conditions.

Spiritual and cultural beliefs have been identified as among the principal aspects to be considered in ensuring an adequate delivery of services. The role of traditional medicine should be appropriately evaluated and have a place in the care process.



**Table 5 Perception of epilepsy by the general public, teachers, and employers**

Countries by subregion	Discrimination	Stigmatization	Fear	Comprehension	Empathy
Costa Rica	No	Yes	Yes	No	No
Cuba	No	Yes	No	Yes	No
Dominican Rep.	Yes	Yes	Yes	No	No
El Salvador	No	Yes	No	No	No
Guatemala	Yes	Yes	Yes	Yes	Yes
Haiti	Yes	Yes	Yes	No	No
Honduras	No	Yes	Yes	No	No
Mexico	Yes	Yes	Yes	Yes	No
Panama	Yes	Yes	Yes	No	No
<b>Subtotal</b>	<b>9/5: 55.6%</b>	<b>9/9: 100%</b>	<b>9/7: 77.8%</b>	<b>9/3: 33.3%</b>	<b>9/1: 11.1%</b>
Argentina	Yes	Yes	Yes	No	No
Bolivia	Yes	Yes	Yes	No	No
Brazil	Yes	Yes	Yes	Yes	No
Chile	Yes	Yes	Yes	No	No
Colombia	Yes	No	Yes	Yes	No
Ecuador	No	Yes	Yes	No	No
Peru	No	No	Yes	No	No
Uruguay	Yes	Yes	No	No	No
Venezuela	Yes	No	Yes	Yes	No
<b>Subtotal</b>	<b>9/7: 77.8%</b>	<b>9/6: 66.7%</b>	<b>9/8: 88.9%</b>	<b>9/3: 33.3%</b>	<b>9/0: 0%</b>
Antigua and Barbuda	No	No	No	No	No
Bahamas	Yes	Yes	Yes	No	No
Grenada	No	No	Yes	Yes	Yes
Jamaica	No	Yes	No	No	No
Saint Kitts and Nevis	No	No	No	No	No
Saint Vincent and the Grenadines	No	No	No	No	Yes
Suriname	n/r	n/r	n/r	n/r	n/r
<b>Subtotal</b>	<b>6/1: 16.7%</b>	<b>6/2: 33.3%</b>	<b>6/2: 33.3%</b>	<b>6/1: 16.7%</b>	<b>6/2: 33.3%</b>
<b>Total</b>	<b>24/13: 54.2%</b>	<b>24/17: 70.8%</b>	<b>24/17: 70.8%</b>	<b>24/7: 29.2%</b>	<b>24/3: 12.5%</b>

**Source:** Tool for the assessment of resources devoted to epilepsy (modified version-PAHO/2012).

n/r: not reported

Upon surveying key informants of the countries on people's perception of epilepsy (in particular among the general public, teachers and employers), in 54.2% of the countries this disorder is perceived in some

discriminatory manner, 70.8% stated there is stigmatization and 70.8% concluded that epilepsy is perceived with fear. On the other hand, only 29.2% maintained that epilepsy is perceived with comprehension and 12.5% with empathy.

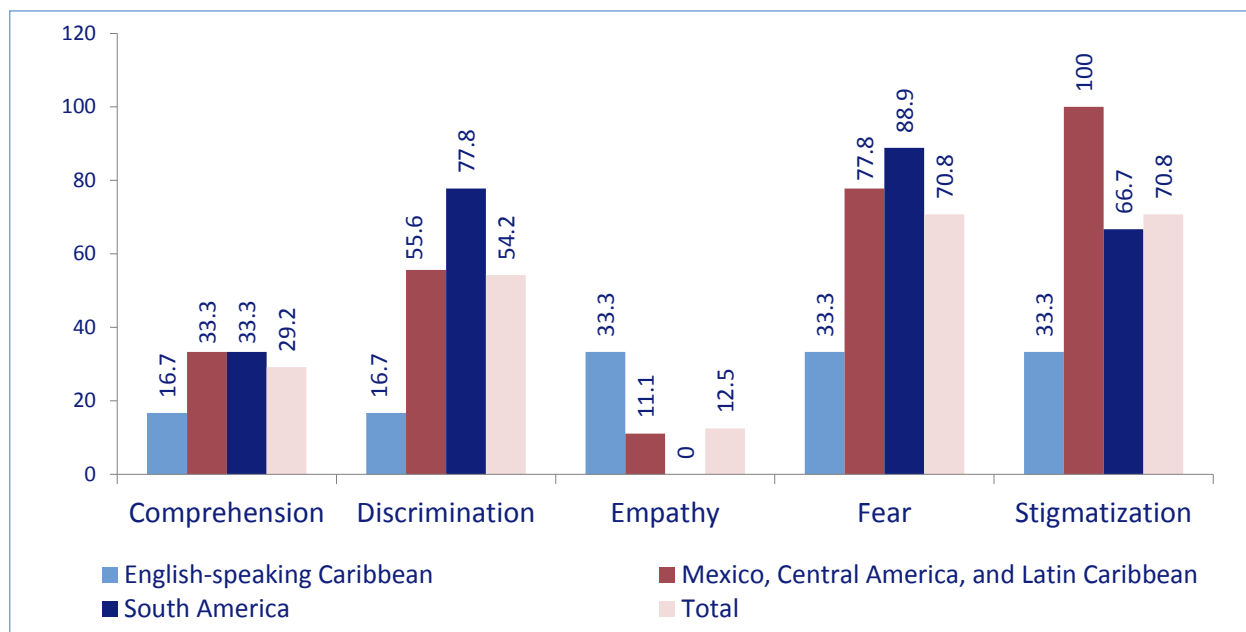
**Table 6 Traditional or alternative medicine and frequency of use of these resources**

Countries by subregion	Frequently	Sometimes	No/almost never
Costa Rica	n/r	n/r	n/r
Cuba	No	Yes	No
Dominican Rep.	Yes	No	No
El Salvador	No	No	Yes
Guatemala	Yes	No	No
Haiti	Yes	No	No
Honduras	No	Yes	No
Mexico	No	Yes	No
Panama	No	Yes	No
<b>Subtotal</b>	<b>8/3: 37.5%</b>	<b>8/4: 50.0%</b>	<b>8/1: 12.5%</b>
Argentina	No	Yes	No
Bolivia	Yes	No	No
Brazil	Yes	No	No
Chile	No	Yes	No
Colombia	No	No	Yes
Ecuador	No	Yes	No
Peru	No	Yes	No
Uruguay	No	Yes	No
Venezuela	No	No	Yes
<b>Subtotal</b>	<b>9/2: 22.2%</b>	<b>9/5: 55.6%</b>	<b>9/2: 22.2%</b>
Antigua and Barbuda	n/r	n/r	n/r
Bahamas	No	Yes	No
Grenada	No	No	Yes
Jamaica	No	No	Yes
Saint Kitts and Nevis	No	No	Yes
Saint Vincent and the Grenadines	No	No	Yes
Suriname	n/r	n/r	n/r
<b>Subtotal</b>	<b>5/0: 0%</b>	<b>5/1: 20.0%</b>	<b>5/4: 80.0%</b>
<b>Total</b>	<b>22/5: 22.7%</b>	<b>22/10: 45.5%</b>	<b>22/7: 31.8%</b>

**Source:** Tool for the assessment of resources devoted to epilepsy (modified version-PAHO/2012).

n/r: not reported

**Figure 3 Perception of epilepsy by the general public, teachers, and employers**



Regarding the use of traditional or alternative medicine (particularly healers) for the treatment of epilepsy, 68.2% of the countries reported the population frequently or at least occasionally uses these resources; on the other hand, in 31.8% of the countries, they were almost never used or not used at all. Three countries did not report data in this regard.

This information reveals a significant use, on the part of the population, of traditional or alternative resources to care for people with epilepsy.

#### 4. SERVICES AND TECHNOLOGY

Lack of access to services has been identified as the greatest barrier to people with epilepsy receiving treatment, especially in middle-income and low-income countries. The principal strategy to confront this problem is to improve their first line of contact with the health system. Training PHC workers to identify cases, their management (including prescribing AED) and referral (in complex cases) seems to be the most effective way to bridge the existing treatment gap.

Specialized services, outpatient and inpatient (neurology, epileptology, neurosurgery, among others), located at the second level of care, are indispensable to PHC support and for the care of complex or complicated cases that require specialized interventions. In many countries these services are limited and concentrated in the capital and large cities.

Effective and regular availability of AED at different levels of the health system is a crucial element for the success of National Programs. PAHO's Regional Strategy urges governments to ensure that at least these four essential AED are available at the PHC level: phenobarbital, carbamazepine, phenytoin, and valproic acid (1).

Epilepsy surgery is an important treatment option for people with drug-resistant epilepsy. The Regional Strategy (1) recommends that the countries have at least one center specialized in this procedure. For better diagnosis and management of cases, for handling of complications and in order to support rehabilitation processes, other services or disciplines such as psychiatry, neuropsychology, psychosocial rehabilitation, special education, among others, are frequently necessary.

Technology is necessary for an appropriate diagnosis and management of epilepsy. Currently electroencephalography (EEG), computerized axial tomography (CAT), and nuclear magnetic resonance (NMR) are available in the majority of countries; the problem lies in their inequitable geographical distribution (concentration in capitals and large cities), and at times they are located in high-cost private centers.

**Table 7 Centers or specialized services for the care of people with epilepsy**

Countries by subregion	Number of centers/services	Centers in the capital	Capital %	Pediatric specialization	Pediatrics %
Costa Rica	4	4	100	1	25.0
Cuba	14	5	35.7	4	28.6
Dominican Rep.	2	2	100	0	n/a
El Salvador	8	4	50.0	1	12.5
Guatemala	9	9	100	3	33.3
Haiti	1	1	100	0	n/a
Honduras	11	11	100	11	100
Mexico	63	15	23.8	13	20.6
Panama	4	3	75.0	1	25.0
<b>Subtotal</b>	<b>116: 9/9</b>	<b>54</b>	<b>46.6%</b>	<b>34: 9/7</b>	<b>29.3%</b>
Argentina	78	22	28.2	29	37.2
Bolivia	1	1	100	0	n/a
Brazil	n/r	n/r	n/r	n/r	n/r
Chile	30	9	30.0	12	40.0
Colombia	45	12	26.7	12	26.7
Ecuador	1	1	100	1	100
Peru	1	1	100	0	n/a
Uruguay	3	3	100	1	33.3
Venezuela	49	14	28.6	3	6.1
<b>Subtotal</b>	<b>208: 8/8</b>	<b>63</b>	<b>30.3%</b>	<b>58: 8/6</b>	<b>27.9%</b>
Antigua and Barbuda	1	1	100	1	100
Bahamas	5	5	100	2	40.0
Grenada	0	n/a	n/a	0	n/a
Jamaica	12	n/r	n/r	2	16.7
Saint Kitts and Nevis	n/r	n/r	n/r	n/r	n/r
Saint Vincent and the Grenadines	0	n/a	n/a	0	n/a
Suriname	0	n/a	n/a	0	n/a
<b>Subtotal</b>	<b>18: 6/3</b>	<b>6</b>	<b>33.3%</b>	<b>5: 6/3</b>	<b>27.8%</b>
<b>Total</b>	<b>342: 23/20</b>	<b>123</b>	<b>36.0%</b>	<b>97: 23/16</b>	<b>28.4%</b>

**Source:** Tool for the assessment of resources devoted to epilepsy (modified version-PAHO/2012).

n/a: not available

n/r: not reported

Regarding the existence of centers or specialized services for the care of people with epilepsy (neurological services or other services devoted to epilepsy), 342 such facilities were reported distributed over 20 countries; two countries did not report this data (Brazil and Saint Kitts and Nevis). Of the total countries reporting, only three do not have this type of service (all in the English-speaking Caribbean). The subregion of South America has the greatest availability of specialized centers (n=208).

Approximately one-third (36.0%) of the centers or services are located in the capitals of the countries; but this regional number is achieved thanks to the larger countries with a federal structure or to those with more developed health systems, where there is less concentration (Cuba, Mexico, Argentina, Chile, Colombia and Venezuela). Unequal distribution is characteristic of the remaining countries, with a high or total concentration of services in the capitals.

There are 97 services (28.4% of the total), distributed over 16 countries, where there are centers or specialized services (neurological or other services devoted to epilepsy) exclusively or partially dedicated to children and adolescents with epilepsy. Two countries did not report this data and seven have no specialized services of this type for children.

**Table 8 Surgery centers or services and number of annual operations**

Countries by subregion	Number of centers/services	Centers in the capital	Capital %	Annual operations
Costa Rica	1	1	100	15
Cuba	1	1	100	n/r
Dominican Rep.	1	1	100	4
El Salvador	2	2	100	4
Guatemala	2	2	100	10
Haiti	0	n/a	n/a	n/a
Honduras	1	1	100	2
Mexico	10	7	70.0	n/r
Panama	0	n/a	n/a	n/a
<b>Subtotal</b>	<b>18: 9/7</b>	<b>15</b>	<b>83.3%</b>	<b>35</b>
Argentina	13	8	61.5	140
Bolivia	1	1	100	n/r
Brazil	25	n/r	n/r	n/r
Chile	6	5	83.3	48
Colombia	4	1	25.0	35
Ecuador	2	1	50.0	10
Peru	1	1	100	n/r
Uruguay	1	1	100	5
Venezuela	23	13	56.5	20
<b>Subtotal</b>	<b>76: 9/9</b>	<b>31</b>	<b>40.8%</b>	<b>258</b>
Antigua and Barbuda	0	n/a	n/a	n/a
Bahamas	0	n/a	n/a	n/a
Grenada	0	n/a	n/a	n/a
Jamaica	0	n/a	n/a	n/a
Saint Kitts and Nevis	0	n/a	n/a	n/a
Saint Vincent and the Grenadines	0	n/a	n/a	n/a
Suriname	0	n/a	n/a	n/a
<b>Subtotal</b>	<b>0: 7/0</b>	<b>n/a</b>	<b>n/a</b>	<b>n/a</b>
<b>Total</b>	<b>94: 25/16</b>	<b>46</b>	<b>48.9%</b>	<b>293</b>

**Source:** Tool for the assessment of resources devoted to epilepsy (modified version-PAHO/2012).

n/a: not available

n/r: not reported

The information obtained with respect to centers or surgical services for people with epilepsy shows there are 94 surgical centers, distributed over 16 countries (64.0%). There are nine countries (36.0%) without this resource. The English-speaking Caribbean has no surgical services whatsoever for epilepsy. The subregion of South America has the greatest quantity, with a total of 76 centers or services.

The total number of people per annum who had surgery for epilepsy is higher in the subregion of South America with 258 cases; Mexico, Central America, and Latin Caribbean had only 35 cases of surgery, and

the English-speaking Caribbean reported no cases of surgery for epilepsy. These are underreported figures since several countries with surgical services for epilepsy did not report the number of such cases (Bolivia, Brazil, Cuba, Mexico, and Peru).

If we exclude Brazil (which did not report the territorial distribution of the surgery centers), it is observed that two-thirds of these services are concentrated in the capital of the countries.

**Table 9 Antiepileptic drugs (AED) available throughout the year in the public services network**

Countries by subregion	Hospitals	Ambulatory centers/ services	AED
Costa Rica	Yes	Yes	Yes
Cuba	Yes	No	No
Dominican Rep.	No	Yes	No
El Salvador	Yes	Yes	Yes
Guatemala	Yes	Yes	No
Haiti	Yes	No	No
Honduras	Yes	Yes	No
Mexico	Yes	Yes	Yes
Panama	n/r	n/r	n/r
<b>Subtotal</b>	<b>8/7: 87.5%</b>	<b>8/6: 75.0%</b>	<b>8/3: 37.5%</b>
Argentina	Yes	Yes	No
Bolivia	Yes	No	No
Brazil	n/r	n/r	n/r
Chile	Yes	Yes	Yes
Colombia	Yes	Yes	Yes
Ecuador	Yes	No	No
Peru	n/r	n/r	n/r
Uruguay	Yes	Yes	Yes
Venezuela	Yes	Yes	Yes
<b>Subtotal</b>	<b>7/7: 100%</b>	<b>7/5: 71.4%</b>	<b>7/4: 57.1%</b>
Antigua and Barbuda	Yes	No	Yes
Bahamas	Yes	Yes	Yes
Grenada	Yes	Yes	Yes
Jamaica	Yes	Yes	Yes
Saint Kitts and Nevis	Yes	Yes	Yes
Saint Vincent and the Grenadines	Yes	Yes	Yes
Suriname	n/r	n/r	n/r
<b>Subtotal</b>	<b>6/6: 100%</b>	<b>6/5: 83.3%</b>	<b>6/6: 100%</b>
<b>Total</b>	<b>21/20: 95.2%</b>	<b>21/16: 76.2%</b>	<b>21/13: 61.9%</b>

**Source:** Tool for the assessment of resources devoted to epilepsy (modified version-PAHO/2012).

n/r: not reported

Some 95.2% of the countries reported having AED available (at least one drug and throughout the year) at hospitals, 76.2% at centers or outpatient services and 61.9% at the PHC level. The reports do not make clear if this availability is achieved throughout the entire country. Four countries did not report this data.

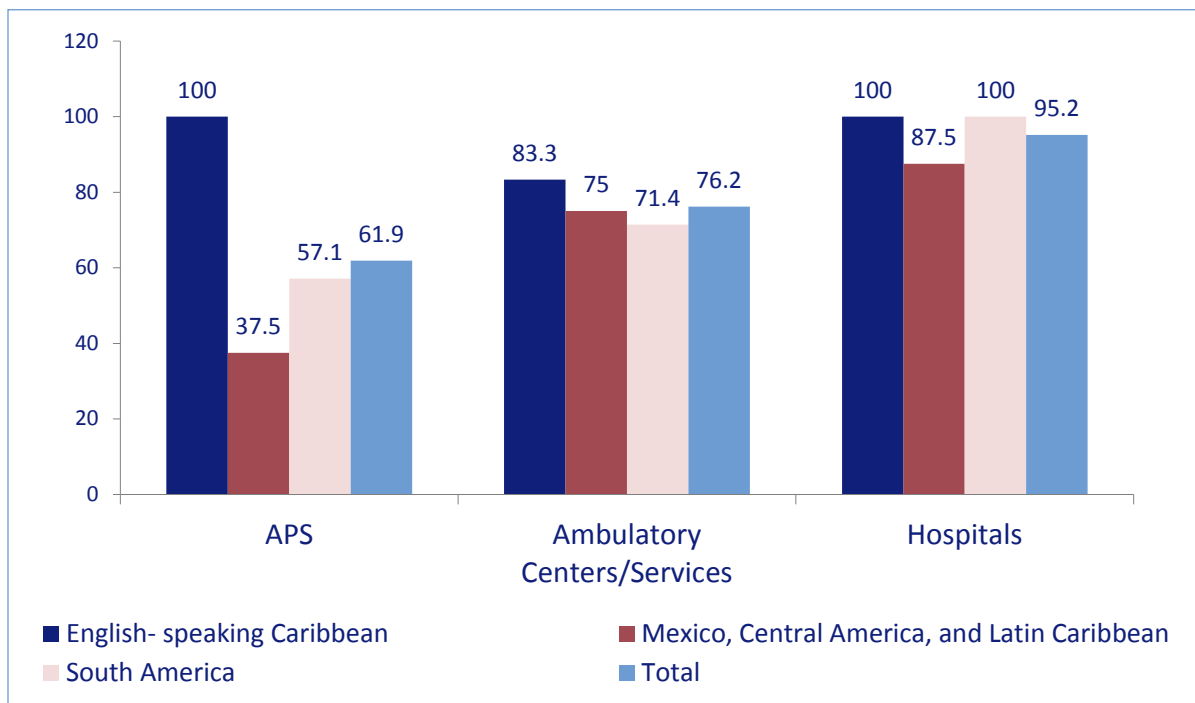
**Table 10 Diagnostic technologies available in the public sector**

Countries by subregion	EEG	TAC	RMN	SPECT	Video EEG	PET	EEG digital
Costa Rica	Yes	Yes	Yes	No	Yes	Yes	Yes
Cuba	Yes	Yes	Yes	Yes	Yes	Yes	No
Dominican Rep..	Yes	Yes	Yes	No	Yes	No	Yes
El Salvador	Yes	Yes	Yes	No	Yes	No	Yes
Guatemala	Yes	Yes	Yes	No	Yes	No	Yes
Haiti	Yes	No	No	No	No	No	Yes
Honduras	Yes	Yes	Yes	No	Yes	No	Yes
Mexico	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Panama	Yes	Yes	Yes	No	Yes	No	Yes
<b>Subtotal</b>	<b>9/9: 100%</b>	<b>9/8: 88.9%</b>	<b>9/8: 88.9%</b>	<b>9/2: 22.2%</b>	<b>9/8: 88.9%</b>	<b>9/3: 33.3%</b>	<b>9/8: 88.9%</b>
Argentina	Yes	Yes	Yes	Yes	Yes	Yes	No
Bolivia	Yes	Yes	No	No	No	No	Yes
Brazil	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Chile	Yes	Yes	Yes	Yes	Yes	No	Yes
Colombia	Yes	Yes	Yes	Yes	Yes	Yes	No
Ecuador	Yes	No	Yes	No	No	No	No
Peru	Yes	Yes	Yes	No	Yes	No	Yes
Uruguay	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Venezuela	Yes	Yes	Yes	No	No	No	Yes
<b>Subtotal</b>	<b>9/9: 100%</b>	<b>9/8: 88.9%</b>	<b>9/8: 88.9%</b>	<b>9/5: 55.6%</b>	<b>9/6: 66.7%</b>	<b>9/4: 44.4%</b>	<b>9/6: 66.7%</b>
Antigua and Barbuda	No	Yes	Yes	No	No	No	Yes
Bahamas	Yes	Yes	No	No	No	No	No
Grenada	No	No	No	No	No	No	No
Jamaica	Yes	Yes	Yes	No	No	No	No
Saint Kitts and Nevis	No	Yes	No	No	No	No	No
Saint Vincent and the Grenadines	No	Yes	No	No	No	No	No
Suriname	Yes	Yes	Yes	No	No	No	No
<b>Subtotal</b>	<b>7/3: 42.9%</b>	<b>7/6: 85.7%</b>	<b>7/3: 42.9%</b>	<b>7/0: 0%</b>	<b>7/0: 0%</b>	<b>7/0: 0%</b>	<b>7/1: 14.3%</b>
<b>Total</b>	<b>25/21: 84.0%</b>	<b>25/22: 88.0%</b>	<b>25/19: 76.0%</b>	<b>25/7: 28.0%</b>	<b>25/14: 56.0%</b>	<b>25/7: 28.0%</b>	<b>25/15: 60.0%</b>

**Source:** Tool for the assessment of resources devoted to epilepsy (modified version-PAHO/2012).

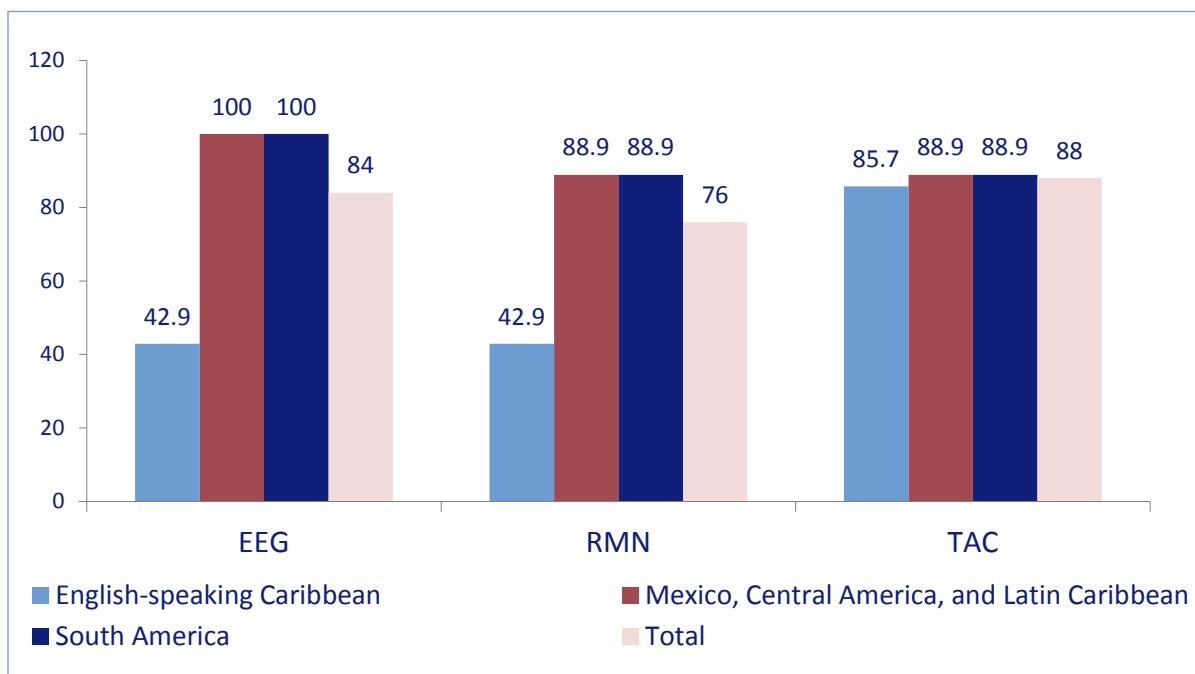


**Figure 4 Antiepileptic drugs (AED) available throughout the year in the public services network**



Some 84.0% of the countries have electroencephalography (EEG) available, 88.0% have computerized axial tomography (CAT), and 76.0% have nuclear magnetic resonance (NMR) available. This does not mean that total coverage of the needs of the people with epilepsy is achieved with these technologies. The most limited technology resources are: SPECT (single-photon emission computed tomography) and PET (positron emission tomography).

**Figure 5 Diagnostic technologies available in the public sector**



The essential problem lies in the concentration of this equipment in country capitals, urban areas and large cities. By way of illustration, the territorial distribution of the EEG in the 17 countries reporting this data can be observed below: (eight did not report). In 11 countries (64.7%) EEG equipment is in the capital, a proportion between 70% and 100%.

% Range of public sector eeg concentration in the capital	Number of countries	Percent
90%-100%	6	35.3
80%-89%	1	5.8
70%-79%	4	23.5
60%-69%	2	11.8
50%-59%	2	11.8
40%-49%	2	11.8
<b>Total</b>	<b>17</b>	<b>100</b>

### **Professionals who in accordance with health standards can diagnose and initiate a treatment for people with epilepsy, including prescribing AED**

In 84.0% of the countries primary care physicians are authorized to diagnose epilepsy and initiate treatment. In the remaining countries the initial diagnosis and beginning of treatment have to be made by a specialized professional.

### **Referral and cross-referral mechanisms for epilepsy care**

Almost all the countries (95.8%) have systems or formal and institutionalized mechanisms for referrals and cross-referrals of people with epilepsy for diagnostic purposes and/or treatment.

**Table 11 Availability of other services for people with epilepsy**

Countries by subregion	Psychiatry	Rehabilitation	Neuropsychology	Other services
Costa Rica	Yes	Yes	Yes	Yes
Cuba	Yes	Yes	Yes	Yes
Dominican Rep.	Yes	Yes	Yes	No
El Salvador	Yes	Yes	No	Yes
Guatemala	Yes	Yes	Yes	No
Haiti	Yes	No	Yes	No
Honduras	Yes	Yes	No	No
Mexico	Yes	Yes	Yes	Yes
Panama	Yes	Yes	No	Yes
<b>Subtotal</b>	<b>9/9: 100%</b>	<b>9/8: 88.9%</b>	<b>9/6: 66.7%</b>	<b>9/5: 55.6%</b>
Argentina	Yes	Yes	Yes	No
Bolivia	Yes	Yes	Yes	No
Brazil	Yes	No	Yes	n/r
Chile	Yes	Yes	Yes	Yes
Colombia	Yes	Yes	Yes	Yes
Ecuador	Yes	Yes	Yes	Yes
Peru	Yes	No	Yes	No
Uruguay	Yes	Yes	Yes	n/r
Venezuela	Yes	Yes	Yes	No
<b>Subtotal</b>	<b>9/9: 100%</b>	<b>9/7: 77.8%</b>	<b>9/9: 100%</b>	<b>7/3: 42.9%</b>
Antigua and Barbuda	Yes	Yes	No	No
Bahamas	Yes	Yes	No	No
Grenada	n/r	n/r	n/r	n/r
Jamaica	Yes	No	Yes	n/r
Saint Kitts and Nevis	Yes	No	No	Yes
Saint Vincent and the Grenadines	Yes	Yes	No	No
Suriname	Yes	Yes	Yes	No
<b>Subtotal</b>	<b>6/6: 100%</b>	<b>6/4: 66.7%</b>	<b>6/2: 33.3%</b>	<b>5/1: 20.0%</b>
<b>Total</b>	<b>24/24: 100%</b>	<b>24/19: 79.2%</b>	<b>24/17: 70.8%</b>	<b>21/9: 42.9%</b>

**Source:** Tool for the assessment of resources devoted to epilepsy (modified version-PAHO/2012).

n/r: not reported

In order to get a better diagnosis, treatment, and rehabilitation, many people with epilepsy require other complementary, associated, or specialized services. The information obtained shows that all the countries reporting this data have psychiatry services available; 79.2% of the countries have rehabilitation services, 70.8% have neuropsychology services and 42.9% have other special services.

**Table 12 Principal problems in caring for people with epilepsy**

Countries by subregion	Problems in diagnosis	Delay in attention	Unhappy patients	Lack of access
Costa Rica	Yes	No	No	No
Cuba	Yes	No	No	No
Dominican Rep.	Yes	No	No	Yes
El Salvador	No	Yes	No	No
Guatemala	Yes	Yes	Yes	Yes
Haiti	Yes	Yes	No	No
Honduras	Yes	Yes	Yes	Yes
Mexico	Yes	Yes	No	No
Panama	No	Yes	No	No
<b>Subtotal</b>	<b>9/7: 77.8%</b>	<b>9/6: 66.7%</b>	<b>9/2: 22.2%</b>	<b>9/3: 33.3%</b>
Argentina	Yes	No	No	Yes
Bolivia	No	No	No	No
Brazil	Yes	Yes	No	No
Chile	Yes	Yes	Yes	No
Colombia	No	Yes	Yes	No
Ecuador	Yes	Yes	Yes	Yes
Peru	Yes	Yes	No	No
Uruguay	Yes	No	No	No
Venezuela	No	Yes	Yes	Yes
<b>Subtotal</b>	<b>9/6: 66.7%</b>	<b>9/6: 66.7%</b>	<b>9/4: 44.4%</b>	<b>9/3: 33.3%</b>
Antigua and Barbuda	No	No	No	No
Bahamas	Yes	Yes	Yes	Yes
Grenada	Yes	No	No	No
Jamaica	No	Yes	No	No
Saint Kitts and Nevis	Yes	No	No	No
Saint Vincent and the Grenadines	No	Yes	No	Yes
Suriname	n/r	n/r	n/r	n/r
<b>Subtotal</b>	<b>6/3: 50.0%</b>	<b>6/3: 50.0%</b>	<b>6/1: 16.7%</b>	<b>6/2: 33.3%</b>
<b>Total</b>	<b>24/16: 66.7%</b>	<b>24/15: 62.5%</b>	<b>24/7: 29.2%</b>	<b>24/8: 33.3%</b>

**Source:** Tool for the assessment of resources devoted to epilepsy (modified version-PAHO/2012).

n/r: not reported

Among the principal problems affecting the treatment and care of people with epilepsy, based on a qualitative analysis of the countries, the following problems are the most noteworthy: 66.7% of the countries reported problems in diagnosing cases, 62.5% stated there are delays in care, 29.2% reported unsatisfied patients, and 33.3% stated there are limitations or lack of access to services where people with epilepsy can receive adequate care.

## **5. HUMAN RESOURCES AND TRAINING**

The report assesses the number of available health professionals (totally or partially) engaged in caring for people with epilepsy, which is a key resource for developing programs and services, including the task of training PHC personnel. This basically refers to the following: neurologists, neurosurgeons, and physicians trained in epilepsy (epileptologists); analyzing the education of neurologists (residence of specialization) is also important. The more highly developed countries should analyze the potential and possibilities of training epileptologists.

Another crucial element in terms of graduate education is the availability of regular and systematic programs for epilepsy training of PHC physicians, linked to health services and to support and supervision mechanisms, which is the best way to improve the problem-solving capacity at the PHC level.

**Table 13 Availability of neurologists and neurosurgeons**

Countries by subregion	Number of neurologists in the country	Neurologists/ 100,000 habitants	Number of neurologists for infants	Number of neurosurgeons	Neurosurgeons/ 100,000 habitants
Costa Rica	40	0.87	4	39	0.85
Cuba	410	3.66	n/r	214	1.91
Dominican Rep.	76	0.77	5	35	0.35
El Salvador	40	0.65	11	55	0.89
Guatemala	50	0.35	15	40	0.28
Haiti	1	0.01	0	4	0.04
Honduras	30	0.38	9	41	0.51
Mexico	1,000	0.89	325	855	0.76
Panama	15	0.44	6	32	0.94
<b>Subtotal</b>	<b>1.662</b>	<b>0.92</b>	<b>375</b>	<b>1.315</b>	<b>0.73</b>
Argentina	n/r	n/r	n/r	200	0.50
Bolivia	35	0.34	12	80	0.77
Brazil	n/r	n/r	n/r	n/r	n/r
Chile	560	3.27	270	120	0.70
Colombia	200	0.44	40	400	0.88
Ecuador	512	3.53	n/r	n/r	n/r
Peru	n/r	n/r	n/r	n/r	n/r
Uruguay	114	3.45	39	34	1.03
Venezuela	487	1.69	194	390	1.35
<b>Subtotal</b>	<b>1.908</b>	<b>1.59</b>	<b>555</b>	<b>1.224</b>	<b>0.84</b>
Antigua and Barbuda	0	n/a	n/r	0	n/a
Bahamas	3	0.85	1	3	0.85
Grenada	0	n/a	0	1	0.89
Jamaica	10	0.37	3	8	0.30
Saint Kitts and Nevis	0	n/a	0	0	n/a
Saint Vincent and the Grenadines	0	n/a	0	0	n/a
Suriname	4	0.80	1	2	0.40
<b>Subtotal</b>	<b>17</b>	<b>0.48</b>	<b>5</b>	<b>14</b>	<b>0.38</b>
<b>Total</b>	<b>3.587</b>	<b>1.18</b>	<b>935</b>	<b>2.553</b>	<b>0.78</b>

**Source:** Tool for the assessment of resources devoted to epilepsy (modified version-PAHO/2012).

n/a: not available

n/r: not reported

Four countries of the English-speaking Caribbean have no neurologists and three South American countries did not report this data (Argentina, Brazil and Peru). The 18 remaining countries reported having 3,587 neurologists, which represents a regional ratio of 1.18 per 100,000 population. It is important to point out that the neurologists are highly concentrated in the capitals of the countries.

The ratio of neurologists per 100,000 population varies widely among countries. Those with the best ratio are: Chile (3.27), Cuba (3.66), Ecuador (3.53), Uruguay (3.45), and Venezuela (1.69). The remaining countries reported less than one neurologist per 100,000 population.

A total of 935 child neurologists were reported, distributed over 15 countries. Six countries did not report this data, and four reported having no professional of this type. South America is the subregion with the highest number of this specialized resource. By contrast, the English-speaking Caribbean reported only five child neurologists.

A total of 2,553 neurosurgeons distributed over 19 countries represents a regional ratio of 0.78 per 100,000 population. Three South American countries did not report this data, and three countries of the English-speaking Caribbean do not have this type of professional. In terms of rates per 100,000 population, the countries in the best position are Cuba (1.91), Venezuela (1.35), and Uruguay (1.03); the remaining LAC countries are below 1.0.

**Table 14 Availability of graduate residents in neurology and epileptologists**

Countries by subregion	Neurology residents	Neuropsychology
Costa Rica	8	n/r
Cuba	72	n/r
Dominican Rep.	20	5
El Salvador	No	No
Guatemala	18	2
Haiti	No	No
Honduras	4	3
Mexico	70	n/r
Panama	No	1
<b>Subtotal</b>	<b>192:</b> <b>9/6</b>	<b>9:</b> <b>6/4</b>
Argentina	50	120
Bolivia	10	No
Brazil	n/r	n/r
Chile	45	50
Colombia	7	12
Ecuador	n/r	n/r
Peru	n/r	n/r
Uruguay	15	9
Venezuela	22	26
<b>Subtotal</b>	<b>149:</b> <b>6/6</b>	<b>217:</b> <b>6/5</b>
Antigua and Barbuda	No	1
Bahamas	No	2
Grenada	No	No
Jamaica	n/r	n/r
Saint Kitts and Nevis	No	No
Saint Vincent and the Grenadines	No	No
Suriname	No	4
<b>Subtotal</b>	<b>0:</b> <b>6/0</b>	<b>9:</b> <b>6/3</b>
<b>Total</b>	<b>341:</b> <b>21/12</b>	<b>235:</b> <b>18/12</b>

**Source:** Tool for the assessment of resources devoted to epilepsy (modified version-PAHO/2012).

n/r: not reported

According to the reported data there are 341 physicians currently enrolled in neurology residence (distributed over 12 countries). There are nine countries that do not have residency programs in this specialty: Antigua/Barbuda, Bahamas, El Salvador, Grenada, Haiti, Panama, Saint Kitts and Nevis, Saint Vincent and the Grenadines, and Suriname. Four countries did not report this data.

Twelve countries reported having 233 epileptologists. Six countries have no professionals with special training in epilepsy, and seven countries did not report this data.



**Table 15 Programs for continuing medical education/training (CME) in epilepsy for professionals**

Countries by subregion	CME programs	Scientific societies/ professionals	Public hospitals	Private hospitals	NGO's
Costa Rica	n/r	n/r	n/r	n/r	n/r
Cuba	Yes	Yes	Yes	No	No
Dominican Rep.	Yes	Yes	No	No	No
El Salvador	No	n/a	n/a	n/a	n/a
Guatemala	Yes	Yes	Yes	Yes	No
Haiti	No	n/a	n/a	n/a	n/a
Honduras	Yes	Yes	Yes	Yes	Yes
Mexico	Yes	Yes	Yes	Yes	No
Panama	Yes	Yes	Yes	No	No
<b>Subtotal</b>	<b>8/6: 75.0%</b>	<b>8/6: 75.0%</b>	<b>8/5: 62.5%</b>	<b>8/3: 37.5%</b>	<b>8/1: 12.5%</b>
Argentina	Yes	No	Yes	No	No
Bolivia	No	n/a	n/a	n/a	n/a
Brazil	Yes	n/r	n/r	n/r	n/r
Chile	Yes	Yes	No	No	Yes
Colombia	Yes	Yes	No	No	Yes
Ecuador	Yes	Yes	No	No	No
Peru	No	n/a	n/a	n/a	n/a
Uruguay	Yes	Yes	Yes	No	Yes
Venezuela	No	n/a	n/a	n/a	n/a
<b>Subtotal</b>	<b>9/6: 66.7%</b>	<b>8/4: 50.0%</b>	<b>8/2: 25.0%</b>	<b>8/0: 0%</b>	<b>8/3: 37.5%</b>
Antigua and Barbuda	No	n/a	n/a	n/a	n/a
Bahamas	Yes	Yes	Yes	No	No
Grenada	No	n/a	n/a	n/a	n/a
Jamaica	Yes	Yes	No	No	No
Saint Kitts and Nevis	No	n/a	n/a	n/a	n/a
Saint Vincent and the Grenadines	No	n/a	n/a	n/a	n/a
Suriname	n/r	n/r	n/r	n/r	n/r
<b>Subtotal</b>	<b>6/2: 33.3%</b>	<b>6/2: 33.3%</b>	<b>6/1: 16.7%</b>	<b>6/0: 0%</b>	<b>6/0: 0%</b>
<b>Total</b>	<b>23/14: 60.9%</b>	<b>22/12: 54.5%</b>	<b>22/8: 36.4%</b>	<b>22/3: 13.6%</b>	<b>22/4: 18.2%</b>

**Source:** Tool for the assessment of resources devoted to epilepsy (modified version-PAHO/2012).

n/a: not available

n/r: not reported

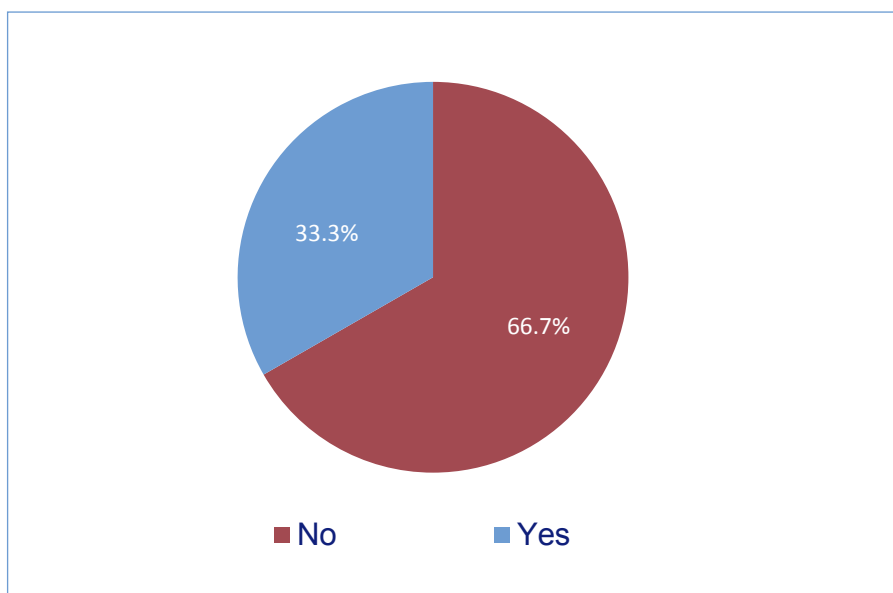
Some 60.9% of the countries have programs in progress for CME/training in epilepsy. In 54.5% of the countries, scientific societies offer courses or programs to improve training; some public hospitals offer programs of this type, which are available and in progress in 36.4% of the countries; in 13.6% of the countries these programs are implemented at private hospitals. Some 18.2% of the countries have nongovernmental organizations (NGOs) with CME/training activities.

Two countries did not report this data: Costa Rica and Suriname. Brazil did not specify in which institutions CME/training activities were given.

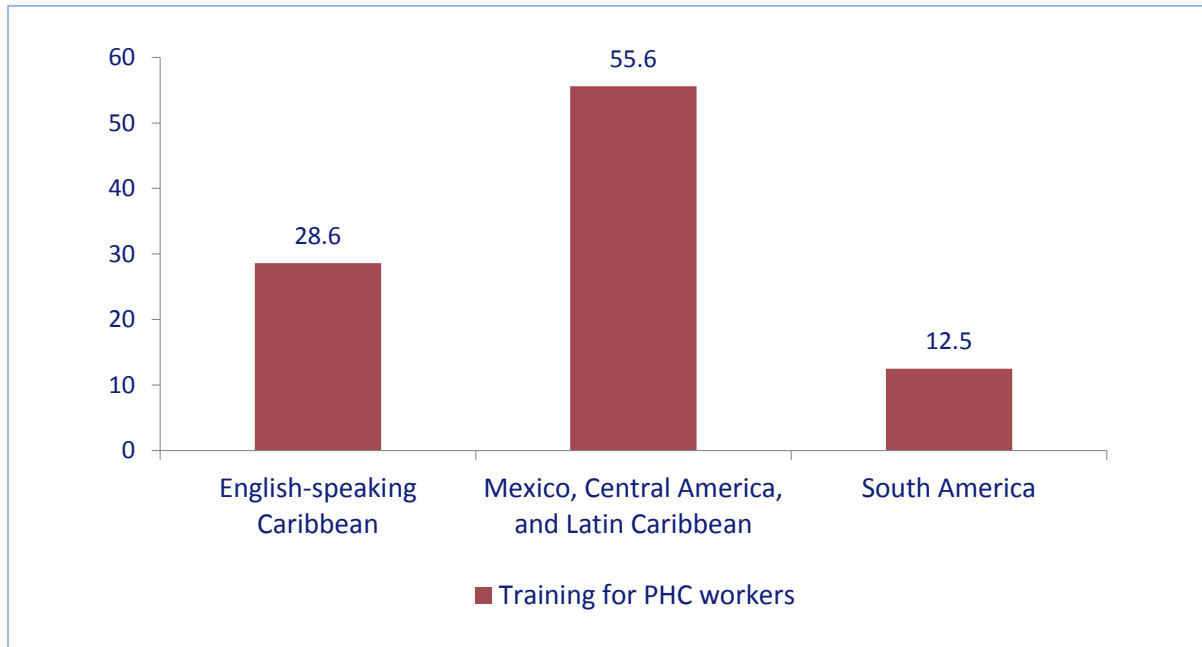
### Training for primary care workers

Only eight countries (32.0%) reported their own regular programs for training PHC professionals. They are: Bahamas, Colombia, El Salvador, Guatemala, Honduras, Jamaica, Mexico, and Panama. In any event, it cannot be stated that these programs cover, at the national level, the entire PHC network.

**Figure 6 Percentage of LAC countries offering PHC training**



**Figure 7 Percentage of countries by subregion offering PHC training**



## 6. INFORMATION AND RESEARCH

A good information system within the Ministries of Health is essential for an accurate analysis of the situation and to provide evidence-based data for planners. In the case of epilepsy it is necessary to define a minimum data set and indicators that should be incorporated into the health information systems.

The countries where studies or epidemiological research on services and their quality are available will be in a better position to advocate on the subject, as well as to set priorities, study trends and evaluate the impact of interventions.

**Table 16 Availability of information from the ministry of health, and from epidemiological studies, of services and of quality**

Countries by subregion	Information on epilepsy min. of health	Epidemiological studies	Service studies	Quality studies
Costa Rica	No	No	No	No
Cuba	Yes	Yes	Yes	Yes
Dominican Rep.	No	No	No	No
El Salvador	Yes	No	No	No
Guatemala	Yes	No	No	No
Haiti	No	No	No	No
Honduras	Yes	Yes	Yes	Yes
Mexico	Yes	Yes	Yes	Yes
Panama	Yes	Yes	No	No
<b>Subtotal</b>	<b>9/6: 66.7%</b>	<b>9/4: 44.4%</b>	<b>9/3: 33.3%</b>	<b>9/3: 33.3%</b>
Argentina	No	Yes	No	No
Bolivia	Yes	Yes	Yes	No
Brazil	Yes	Yes	Yes	Yes
Chile	Yes	No	No	No
Colombia	Yes	Yes	Yes	Yes
Ecuador	Yes	No	No	No
Peru	Yes	No	No	No
Uruguay	Yes	Yes	No	No
Venezuela	Yes	Yes	No	Yes
<b>Subtotal</b>	<b>9/8: 88.9%</b>	<b>9/6: 66.7%</b>	<b>9/3: 33.3%</b>	<b>9/3: 33.3%</b>
Antigua and Barbuda	No	No	No	No
Bahamas	No	No	No	No
Grenada	No	No	No	No
Jamaica	No	No	No	No
Saint Kitts and Nevis	No	No	No	No
Saint Vincent and the Grenadines	Yes	No	No	No
Suriname	Yes	No	No	No
<b>Subtotal</b>	<b>7/2: 28.6%</b>	<b>7/0: 0%</b>	<b>7/0: 0%</b>	<b>7/0: 0%</b>
<b>Total</b>	<b>25/16: 64.0%</b>	<b>25/10: 40.0%</b>	<b>25/6: 24.0%</b>	<b>25/6: 24.0%</b>

*Source:* Tool for the assessment of resources devoted to epilepsy (modified version-PAHO/2012).

Another conclusion of the report is that 64.0% of countries have basic data on epilepsy (minimum information) compiled by the Ministry of Health; 40.0% have epidemiological studies; 24.0% of the countries have reports or studies on the services to care for people with epilepsy and 24.0% also have studies on the quality of care.

## 7. MORTALITY

The annual average for the Region of the Americas is 7,547 deaths from epilepsy (primary cause); of these 1,676 were in North America and 5,871 in LAC. In the analysis according to sex, it is observed that the average mortality is higher for men (62.1% of the total of deaths from epilepsy as the primary cause in LAC).

**Table 17 Average deaths per year in the Americas due to epilepsy as primary cause, by age and sex, 2000-2010**

Region	Age groups					
	Everyone	< 1	1-4	5-19	20-59	60+
<b>Both sexes</b>						
Region of the Americas	7547.0	146.0	289.1	824.1	4568.4	1719.5
North America	1676.4	12.7	29.1	99.2	959.5	575.8
Latin American and the Caribbean	5870.6	133.3	260.0	724.9	3608.8	1143.6
<b>Male</b>						
Region of the Americas	4541.5	83.5	157.2	475.4	2926.2	899.3
North America	894.8	6.3	15.5	54.0	581.5	237.5
Latin American and the Caribbean	3646.6	77.2	141.6	421.4	2344.6	661.8
<b>Female</b>						
Region of the Americas	3004.2	62.5	131.8	348.7	1641.3	819.9
North America	781.5	6.5	13.5	45.2	378.0	338.4
Latin American and the Caribbean	2222.6	56.0	118.3	303.5	1263.3	481.5

**Source:** Mortality Information System / Information and Health Analysis Project. PAHO/WHO.

The regional rate of mortality from epilepsy is 0.84 per 100,000 population; 0.50 in North America and 1.04 in LAC. The LAC mortality rate in men is 1.27 compared with 0.80 in women; by age groups, an increase is observed in the death rate in the older adults group (2.28 for both sexes in LAC).

**Table 18 Annual mortality rate in the Americas due to epilepsy as primary cause per 100,000 population, by age and sex, 2000-2010**

Age groups						
Region	All	< 1	1-4	5-19	20-59	60+
Both sexes						
Region of the Americas	0.84	0.38	0.47	0.36	0.98	1.61
North America	0.50	0.11	0.16	0.15	0.53	1.02
Latin American and the Caribbean	1.04	0.49	0.59	0.45	1.27	2.28
Male						
Region of the Americas	0.99	0.27	0.50	0.41	1.27	1.91
North America	0.53	0.07	0.17	0.16	0.64	0.97
Latin American and the Caribbean	1.27	0.35	0.63	0.52	1.68	2.93
Female						
Region of the Americas	0.68	0.84	0.44	0.31	0.70	1.38
North America	0.47	0.29	0.16	0.14	0.41	1.07
Latin American and the Caribbean	0.80	1.08	0.55	0.38	0.88	1.75

**Source:** Mortality Information System / Information and Health Analysis Project. PAHO/WHO.

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## ANNEX: GLOSSARY OF TERMS

The terms defined below are to be used strictly within the context of this report; the descriptions should not be interpreted as official definitions of the World Health Organization (WHO) and of the Pan American Health Organization (PAHO).

**Association of neurologists:** Nongovernmental professional organizations made up of physicians specialized in neurology (may include neurosurgeons and epileptologists) who include epilepsy as one of their fields of work.

**Professional association:** Nongovernmental organizations of physicians and/or other health professionals who work in the area of caring for people with epilepsy, including research and/or education.

**Association of users and/or family members:** Nongovernmental organizations made up of users and/or relatives of people with epilepsy; they are of three types, that is, of Users, Family Members, or both Users and Family Members. They usually work in the area of advocacy; although they can and also should have an active role in planning and implementation of programs and services for the care of people with epilepsy.

**Continuing medical education/training (CME) in epilepsy:** Educational process aimed at providing knowledge and essential competencies for comprehensive care of people with epilepsy; it includes prevention, diagnosis, treatment, and rehabilitation, as well as referral of complex cases. CME occurs after university or technical education (graduate-level).

**Primary health care (PHC) center:** Facility or health unit that acts as the first point of contact with the health system for the population. PHC Centers usually provide evaluation and treatment of the most common health problems and refer those requiring specialized diagnosis and/or treatment to second level facilities.

**Surgery center or service for epilepsy:** A second- or third-level hospital facility where different types of neurosurgical interventions are performed, whose purpose is to improve the clinical status of epilepsy cases that do not respond appropriately to medicinal treatment.

**Center or specialized service (neurology/epilepsy):** A hospital facility, outpatient or mixed. that specializes in caring for people with neurological disorders (including epilepsy), particularly their clinical and social aspects. This could be a service offered by a general health care facility (hospitals, ambulatory centers, among others) or a center that specializes only in neurology, neurosurgery, or epileptology.

**Center or specialized service (neurology/epilepsy) dedicated exclusively or partially to children and adolescents:** A health facility that meets the definition of a Center or Specialized Service that provides part- or full-time care to children and adolescents with neurological diseases (including epilepsy).

**Epileptologist/specialist in epilepsy:** Physician who has received formal and specific training in the field of epilepsy and is dedicated full- or part-time to providing care to people with epilepsy.



**Antiepileptic drugs (AED):** Drugs used for epilepsy treatment. The report basically refers to those most commonly used and included on the list of essential drugs of each country. The Regional Strategy recommends four essential drugs that should be available at the PHC level: Phenobarbital, Phenytoin, Carbamazepine, and Valproic Acid.

**Legislation related to epilepsy:** Legal provisions related to epilepsy with the force of Law. These provisions usually focus on matters such as: protection of the civil and human rights of people with epilepsy, principles of comprehensive care, including treatment, organization and operation of health services, as well as training and strengthening human resources, in addition to others. It can be a separate body of law dedicated exclusively to epilepsy or be part of a Law that encompasses several matters related to health.

**List of essential drugs:** List of drugs for use in the health system officially approved by the country's health authority; and which usually take the WHO List of Essential Drugs as a reference.

**Traditional or alternative medicine:** Attention to people's health problems based on the wisdom and ancestral tradition of the communities, using different methods (herbs, natural products, spiritual care, among others). May refer to the practices of traditional healers (linked or not linked to health services) or to other types of traditional, complementary or alternative practices, such as acupuncture, for example. It differs from classic western medicine dispensed by physicians and other health workers of formal health services.

**Neurosurgeon:** Graduate in medicine who has successfully completed at least two years of graduate training in neurosurgery (Residence). Such recognition as a specialist is based on the procedures and legal standards of each country.

**Neurologist:** Graduate in medicine who has successfully completed at least two years of graduate training in neurology (Residence). Such recognition as a specialist is based on the procedures and legal standards of each country.

**Child/pediatric neurologist:** Specialized physician (neurologist or pediatrician) with at least one year of training in the subspecialty of child neurology. Such recognition as a specialist is based on the procedures and legal standards of each country.

**Program or national plan of action for the care of people with epilepsy:** Programming document, officially approved by the country's Ministry of Health, which details the strategies and activities to be implemented in order to achieve the objective of providing comprehensive quality care to people with epilepsy. Ideally it should contain goals, indicators, as well as a timetable for implementation and a budget. It can also be part of another Plan, such as one for mental health or non-communicable diseases.

**Regulations or legal restrictions for people with epilepsy:** Legal provisions in laws or regulations that establish restrictions on different aspects of social life; the most frequent ones relate to employment (such as restrictions on obtaining work); total or partial impediment to obtaining a driver's license; and restrictions on being integrated into the country's regular education system (children with epilepsy are sometimes considered intellectual disabled persons requiring special education).

**Special service for people with epilepsy:** Health facilities (services or centers) that complementary to those of Neurology or Epilepsy, whose purpose is to develop interventions that are necessary to determine or expand the diagnosis and improve therapeutic or rehabilitative aspects. The report compiles information on three of these services: psychiatry, rehabilitation, and neuropsychology.

**Neuropsychology service:** Facility where people with psychosocial aspects of epilepsy are evaluated; tests determine strengths and cognitive weaknesses, whether emotional or behavioral, making recommendations possible to the professionals in charge of the case.

**Psychiatry service:** Mental health facility that sees people with psychosocial problems and mental disorders, including epilepsy cases with associated mental illness (comorbidity).

**Rehabilitation service:** Health facility that sees people with epilepsy for the purpose of helping them achieve their optimal functioning level and reduce their disability. They work to improve social skills, facilitating their integration into a working life and the development of an independent life.

**Health information system:** A system or program officially established by the ministries of health to collect, process, and analyze information from the health services. The report surveyed whether basic epilepsy data are incorporated into the system.

**Diagnostic technology:** Equipment to perform tests supporting the diagnosis and management of epilepsy cases. The most common and useful equipment is: electroencephalography (EEG), computerized axial tomography (CAT), and nuclear magnetic resonance (NMR).

**User/patient:** A person with epilepsy that receives care from the health services.





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