



# public health principles and neurological disorders

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**This chapter explains briefly the principles of public health, epidemiology and the burden of disease, and the ways in which health promotion and disease prevention are achieved. It looks at risks to health and prevention strategies, and explains what health policy means. It then describes the goals and functions of health systems and in particular considers service provision for neurological disorders.**

**As many neurological disorders result in considerable morbidity, special attention is paid to disability and rehabilitation. The all-important part played by stigma in neurological disorders is assessed and, finally, education and training in neurology are discussed.**

Many distinctions can be made between the practice of public health and that of clinical neurology. Public health professionals approach neurology more broadly than neurologists by monitoring neurological disorders and related health concerns of entire communities and promoting healthy practices and behaviours among them to ensure that populations stay healthy. Public health specialists focus on health and disease of entire populations rather than on individual patients, whereas neurologists usually

treat one patient at a time for a specific neurological condition. These two approaches could be seen as being almost at the opposite ends of the health-care spectrum. What this chapter aims to do is to help build bridges between these two approaches and serve as a useful guide to the chapter that follows — on the public health aspects of specific neurological disorders.

### PRINCIPLES OF PUBLIC HEALTH

Public health is the science and art of disease prevention, prolonging life and promoting health and well-being through organized community effort for the sanitation of the environment, the control of communicable diseases, the organization of medical and nursing services for the early diagnosis and prevention of disease, the education of the individual in personal health and the development of the social machinery to ensure for everyone a standard of living adequate for the maintenance or improvement of health (1). The goal of public health is to fulfil every society's ambition to create conditions in which all people can be healthy. Public health addresses the health of the population as a whole rather than the treatment of individuals. WHO defines health as "*a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity*" (2). "Healthy people in healthy communities" is the ultimate goal of all public health interventions, which are aimed at promoting physical and mental health and preventing disease, injury and disability (3). Public health is particularly concerned with threats to the overall health of the community. As interventions are aimed primarily at prevention, monitoring the health of the community through surveillance of cases assumes great importance as does the promotion of a healthy lifestyle and healthy behaviour. In many cases, however, treating a disease can be vital to preventing it in other people, such as during an outbreak of a communicable disease. Another way of describing public health is "collective action for sustained population-wide health improvement" (4). This definition highlights the focus on actions and interventions that need collaborative actions, sustainability (i.e. the need to embed policies within supportive systems) and the goals of public health (population-wide health improvement and the reduction of health inequalities).

Since the 1980s, the focus of public health interventions has broadened towards population-level issues such as inequity, poverty and education and has moved away from advocating for change in the behaviour of individuals. The health of people is affected by many elements ranging from genetics to socioeconomic factors such as where they live, their income, education and social relationships. These are the social determinants of health, and they pervade every society in the world. Predictably, poor people have more health problems and worse health than the better-off sections of populations (5). Today public health seeks to correct these inequalities by advocating policies and initiatives that aim to improve the health of populations in an equitable manner.

The extension of life expectancy and the ageing of populations globally are predicted to increase the prevalence of many noncommunicable, chronic, progressive conditions including neurological disorders. The increasing capacity of modern medicine to prevent death has also increased the frequency and severity of impairment attributable to neurological disorders. This has raised the issue of restoring or creating a life of acceptable quality for people who suffer from the sequelae of neurological disorders.

Public health plays an important role in both the developed and developing parts of the world through either the local health systems or the national and international nongovernmental organizations. Though all developed and most developing countries have their own government health agencies such as ministries or departments of health to respond to domestic health issues, a discrepancy exists between governments' public health initiatives and access to health care in the developed and developing world. Many public health infrastructures are non-existent or are being formed in the developing world. Often, trained health workers lack the financial resources to provide even basic medical care and prevent disease. As a result, much of the morbidity and mortality in the developing world results from and contributes to extreme poverty.

Though most governments recognize the importance of public health programmes in reducing disease and disability, public health generally receives much less government funding compared with other areas of medicine. In recent years, large public health initiatives and vaccination programmes have made great progress in eradicating or reducing the incidence of a number of communicable diseases such as smallpox and poliomyelitis. One of the most important public

health issues facing the world nowadays is HIV/AIDS. Tuberculosis is also re-emerging and is a major concern because of the rise of HIV/AIDS-related infections and the development of strains resistant to standard antibiotics.

As the rate of communicable diseases in the developed world decreased throughout the 20th century, public health began to put more focus on chronic diseases such as cancer, heart disease and mental and neurological disorders. Much ill-health is preventable through simple, non-medical methods: for example, improving the quality of roads and enforcing regulations about speed and protective measures such as helmet use help to reduce disability as a result of head injuries.

To increase the awareness of professionals and people in general about the public health aspects of neurological disorders, and to emphasize the need for the prevention of these disorders and the necessity to provide neurological care at all levels including primary health care, WHO launched a number of international public health projects including the Global Initiative on Neurology and Public Health. The outcome of this large collaborative endeavour, which involved many health professionals from all parts the world, clearly indicated that there was a paucity of information about the prevalence and burden of neurological disorders and a lack of policies, programmes and resources for their treatment and management (6–8).

## EPIDEMIOLOGY AND BURDEN

In general, health statistics focus primarily on quantifying the health status of populations and suffer from several limitations that reduce their practical value to policy-makers. The statistical information is partial and fragmented and in many countries even the most basic data (e.g. the annual number of deaths from particular causes) are not available. Further, the simple “head count” approach does not allow policy-makers to compare the relative cost–effectiveness of different interventions, for example the treatment of conditions such as acute stroke versus the long-term care of patients with chronic disorders such as Parkinson’s disease or multiple sclerosis. At a time when people’s expectations of health services are growing and funds are constrained, such information is essential for the rational allocation of resources.

To address these limitations, a large collaborative project called the Global Burden of Disease (GBD) Study was undertaken by WHO, the World Bank and the Harvard School of Public Health (9). The objectives of this unique international undertaking were as follows: to incorporate nonfatal conditions in the assessments of health status; to disentangle epidemiology from advocacy and produce objective, independent and demographically plausible assessments and projections of the burden of health conditions and diseases; and to measure disease and injury burden by developing a novel method that can also be used to assess the cost–effectiveness of interventions, in terms of the cost per unit of disease burden averted. The GBD study developed an internationally standardized and nowadays widely accepted single measurement index: the disability-adjusted life year (DALY). For neurological disorders, perhaps the most important dimension of the GBD study is the attention given to the total morbidity of populations by quantifying the contribution of nonfatal, chronic disorders to the reduction of health status. The GBD study is discussed in detail in Chapter 2, with its methodology and limitations and projected estimates for neurological disorders for 2005, 2015 and 2030.

## HEALTH PROMOTION AND DISEASE PREVENTION

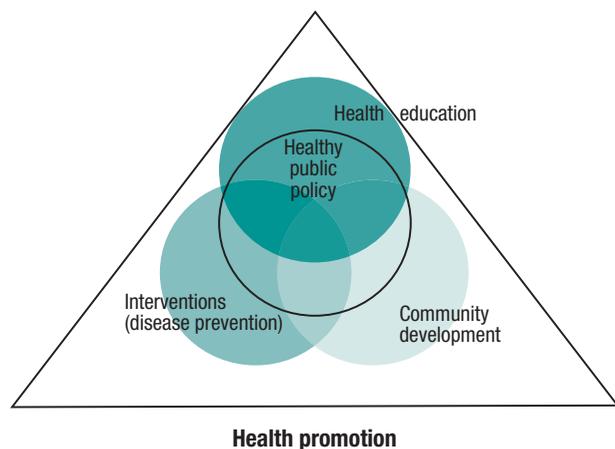
### Health promotion

Historically, the concepts of health promotion and disease prevention have been closely related. According to WHO, health promotion is a process of enabling people to increase control over their health and improve it. It refers to any activity destined to help people to change their lifestyle and move towards a state of optimal health. Health promotion can be facilitated through a combination

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of efforts aimed at raising awareness, changing behaviours, and creating environments that support good health practices, healthy public policies and community development (10). The nature and scope of health promotion is illustrated in Figure 1.1.

Figure 1.1 Nature and scope of health promotion



are included in primary prevention. Universal primary prevention targets the general public or a whole population group without an identified specific risk (e.g. iodine supplementation programmes to prevent neurological and other disorders caused by iodine deficiency). Selective primary prevention targets individuals or subgroups of the population whose risk of developing disease is significantly higher than average, as evidenced by biological, psychological or social risk factors (e.g. prevention of stroke through adequate management of hypertension, diabetes and hypercholesterolemia). *Secondary prevention* aims at decreasing the severity of disease or reducing risk level or halting progression of disease through early detection and treatment of diagnosable cases (e.g. ensuring drug compliance in the treatment of epilepsy). *Tertiary prevention* includes interventions that reduce premature death and disability, enhance rehabilitation and prevent relapses and recurrence of the illness. Rehabilitation may mitigate the effects of disease and thereby prevent it from resulting in impaired social and occupational functioning; it is an important public health intervention that has long been neglected by decision-makers. Moreover, rehabilitation is an essential aspect of any public health strategy for chronic diseases, including a number of neurological disorders and conditions such as multiple sclerosis, Parkinson's disease and the consequences of stroke or traumatic brain injury. Box 1.2 describes some examples illustrating the role of primary, secondary and tertiary preventive strategies for the neurological disorders discussed in this document.

Successful health promotion demands a coordinated action by governments, the health sector and other social and economic sectors, nongovernmental and voluntary organizations, local authorities, industry and the media. A list of required health promotion strategies across sectors and settings is contained in the Bangkok Charter for Health Promotion in a Globalized World (11) (see Box 1.1). For neurological disorders, health promotion is particularly important. In the case of traumatic brain injuries, development of policies in countries to prevent road traffic accidents and legislation to wear helmets are examples of health promotion strategies.

### Disease prevention

The concept of disease prevention is more specific and comprises primary, secondary and tertiary prevention (12). *Primary prevention* is defined as preventing the disease or stopping individuals from becoming at high risk. Universal and selective preventive interventions

## Box 1.1 Bangkok Charter for Health Promotion in a Globalized World

To make advances in implementing health promotion strategies, all sectors and settings must act to:

- *advocate* for health based on human rights and solidarity;
- *invest* in sustainable policies, actions and infrastructure to address the determinants of health;
- *build capacity* for policy development, leadership, health promotion practice, knowledge transfer and research, and health literacy;

- *regulate and legislate* to ensure a high level of protection from harm and enable equal opportunities for health and well-being for all people;
- *establish partnerships and build alliances* with public, private, nongovernmental and international organizations and civil society to create sustainable actions.

Source: (11).

## Health risks

Focusing on risks to health is a key to preventing any disease or injury. Many factors are relevant in prioritizing strategies to reduce risks to health. These include the extent of the threat posed by different risk factors, the availability of cost-effective interventions, and societal values and preferences. Risk assessment and estimates of the burden of disease resulting from different risk factors may be altered by many different strategies (13).

The chain of events leading to an adverse health outcome includes proximal (or direct) causes and distal causes that are further back in the causal chain and act through a number of intermediary causal factors. It is therefore essential that the whole of the causal chain is considered in the assessment of risks to health. Trade-offs also exist between assessments of proximal and distal causes. As one moves further away from the direct causes of disease, there can be a decrease in causal certainty and diagnostic consistency, which is often accompanied by an increase in complexity of treatment. Distal causes, however, are likely to have an amplifying effect in that they can affect many different sets of proximal causes and so can potentially make large differences (14).

## Prevention strategies

Prevention strategies and interventions designed to reduce or prevent a particular disease are of two types. In population or mass approaches, a whole population is asked to be involved in modifying their behaviour in some way (e.g. being immunized against poliomyelitis). In targeted or high-risk approaches, only high-risk individuals are involved, which necessitates some form of screening to identify those who are at high risk (e.g. HIV testing) (13).

The distribution and determinants of risks in a population have major implications for strategies of prevention. A large number of people exposed to a small risk may generate many more cases than a small number exposed to a high risk. Thus, a preventive strategy focusing on high-risk individuals will deal only with the margin of the problem and will not have any impact on the considerable amount of disease occurring in the large proportion of people who are at moderate risk.

## Box 1.2 Examples of preventive strategies for neurological disorders

### PRIMARY PREVENTION

(Measures to prevent the onset of disease or avoid a targeted condition)

- Use of vaccine against poliomyelitis within the Global Polio Eradication Initiative has led to elimination of indigenous polioviruses from all but four countries.
- Measures to control blood pressure, cholesterol levels and diabetes mellitus, to reduce tobacco use, and to promote overall healthy eating patterns and physical activity are advocated for primary prevention of stroke. In Japan, government-led health education campaigns and increased treatment of high blood pressure have reduced blood pressure levels in the populations: stroke rates have fallen by more than 70%.
- Wearing a helmet is the single most effective way to reduce head injuries and fatalities resulting from motorcycle and cycle crashes. For example, wearing a helmet has been shown to decrease the risk and severity of injuries among motorcyclists by about 70%, the likelihood of death by almost 40%, and to substantially reduce the costs of health care associated with such crashes.

### SECONDARY PREVENTION

(Early and accurate diagnosis, appropriate treatment, management of risk factors, compliance)

- Medical treatment of epilepsy with first-line antiepileptic drugs can render up to 70% of patients seizure-free when adequately treated.
- Management of patients with stroke by an organized unit significantly reduces mortality and disability in comparison with standard care on a general medical ward.

### TERTIARY PREVENTION

(Rehabilitation, palliative care, treatment of complications, patient and caregiver education, self-support groups, reduction of stigma and discrimination, social integration)

- Interventions targeting stress and depression among carers of patients with dementia, including training, counselling and support for caregivers, have shown positive results for the management of dementia.
- The strategy of community-based rehabilitation has been implemented in many low-income countries around the world; where it is practised, it has successfully influenced the quality of life and participation of persons with disabilities in their societies.
- Methods to reduce stigma related to epilepsy in an African community successfully changed attitudes to epilepsy: traditional beliefs were weakened, fears were diminished, and community acceptance of people with epilepsy increased.

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In contrast, population-based strategies that seek to shift the whole distribution of risk factors have the potential to control the incidence of a disorder in an entire population (14).

With targeted approaches, efforts are concentrated on those who are most at risk of contracting a disease (e.g. HIV-positive individuals). This has two benefits: first, it avoids the waste of the mass approach and, second, people who are identified as being at high risk are more likely to comply with behaviour change. However, such an approach could increase the costs because of the need to identify the high-risk group of people most likely to benefit. Which prevention approach is the most cost effective in a particular setting will depend on the prevalence of high-risk people in the population and the cost of identifying them compared with the cost of intervention.

Some areas of behavioural change benefit from active government intervention through legislation or financial incentives. For example, road traffic safety is one area where government action can make a big difference in preventing traumatic brain injuries. This can be achieved through control and legislation on alcohol and drug use, better roads, speed control, better motor vehicle design, and requirements to use seatbelts and helmets (see Table 1.1).

Table 1.1 Benefits of wearing a motorcycle helmet

Not wearing a helmet	Wearing a helmet
<ul style="list-style-type: none"><li>• increases the risk of sustaining a head injury</li><li>• increases the severity of head injuries</li><li>• increases the time spent in hospital</li><li>• increases the likelihood of dying from a head injury</li></ul>	<ul style="list-style-type: none"><li>• decreases the risk and severity of injuries by about 72%</li><li>• decreases the likelihood of death by up to 39%, the probability depending on the speed involved</li><li>• decreases the costs of health care associated with a crash</li></ul>

Source: (15).

A different set of interventions can be used to achieve the same goal, and some interventions will reduce the burden associated with multiple risk factors and diseases. For example, interventions to reduce blood pressure, cigarette smoking and cholesterol levels reduce cerebrovascular and cardiovascular diseases and a number of others. The effect of using multiple interventions at the same time might be more than would be expected by summing the benefits of carrying out the interventions singly. Risk reduction strategies are therefore generally based on a combination of interventions. For example, a CVD Risk Management Package has been developed by WHO for managing cardiovascular events (heart attacks and stroke). For cardiovascular disease prevention and control activities to achieve the greatest impact, a paradigm shift is required from the “treatment of risk factors in isolation” to “comprehensive cardiovascular risk management”. The risk management package facilitates this shift. It has been designed primarily for the management of cardiovascular risk in individuals found by opportunistic screening to have hypertension. It could be adapted, however, to be used with diabetes or smoking as entry points. The package is meant to be implemented in a range of health-care facilities in low and medium resource settings, in both developed and developing countries. For this reason it has been designed for three scenarios that reflect the commonly encountered resource availability strata in such settings (16). The minimum conditions that characterize the three scenarios, in terms of the skill level of the health worker, the diagnostic and therapeutic facilities and the health services available, are described in Table 1.2.

### HEALTH POLICY

Health policy usually refers to formal statements or procedures within institutions and governments that define health priorities and actions aimed at improving people’s health. It can have a number of other goals in addition to preventing illness and promoting population health. In choos-

Table 1.2 Characteristics of three scenarios in the WHO CVD Risk Management Package

Resource availability	Scenario one	Scenario two	Scenario three
Human resources	Non physician health worker	Medical doctor or specially trained nurse	Medical doctor with access to full specialist care
Equipment	Stethoscope Blood pressure measurement device Measuring tape or weighing scale Optional: test tubes, holder, burner, solution or test strips for checking urine glucose	Stethoscope Blood pressure measurement device Measuring tape or weighing scale Test tubes, holder, burner, solutions or test strips for checking urine glucose and albumin	Stethoscope Blood pressure measurement device Measuring tape or weighing scale Electrocardiograph Ophthalmoscope Urine analysis: fasting blood, sugar, electrolytes, creatinine, cholesterol and lipoproteins
General drugs	Essential: thiazide diuretics Optional: metformin (for refill)	Thiazide diuretics Beta blockers Angiotensin converting enzyme inhibitors Calcium channel blockers (sustained release formulations) (Reserpine and methyldopa if the above antihypertensives are unavailable) Aspirin Metformin (for refill)	Thiazide diuretics Beta blockers Angiotensin converting enzyme inhibitors Calcium channel blockers (sustained release formulations) (Reserpine and methyldopa if the above antihypertensives are unavailable) Aspirin Insulin Metformin Glibenclamide Statins (if affordable) Angiotensin receptor blocker (if affordable)
Other facilities	Referral facilities Maintenance and calibration of blood pressure measurement devices	Referral facilities Maintenance and calibration of equipment	Access to full specialist care Maintenance and calibration of equipment

Source: (16).

ing appropriate combinations of interventions, governments are also concerned with reducing poverty and other inequalities, with questions of human rights, acceptance by the community and political needs. They must also consider how different types of interventions can be incorporated into the health infrastructure available in the country, or how the infrastructure could be expanded or adapted to accommodate the desired strategies. This section discusses only health policy issues related to health promotion and disease prevention.

A health policy paradox shows that preventive interventions can achieve large overall health gains for whole populations but might offer only small advantages to each individual. This leads to a misperception of the benefits of preventive advice and services by people who are apparently in good health. In general, population-wide interventions have the greatest potential for prevention. For instance, in reducing risks from high blood pressure and cholesterol, shifting the mean values of whole populations will be more cost effective in avoiding future heart attacks and strokes than screening programmes that aim to identify and treat only those people with defined hypertension or raised cholesterol levels. Often both approaches are combined in one successful strategy.

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A critical health policy issue, especially for developing and resource-poor countries, concerns the appropriate balance between primary and secondary prevention and between population and high-risk approaches to primary prevention. If the goal is to increase the proportion of the population at low risk and to ensure that all groups benefit, the strategy with the greatest potential is the one directed at the whole population, not just at people with high levels of risk factors or established disease. The ultimate goal of a health policy is the reduction of population risk; since most of the population in most countries is not at the optimal risk level, it follows that the majority of prevention and control resources should be directed towards the goal of reducing the entire population's risk. For example, policies for prevention of traumatic brain injuries such as wearing of helmets need to be directed at the whole population. Thus, risk reduction through primary prevention is clearly the preferred health policy approach, as it actually lowers future exposures and the incidence of new disease episodes over time.

The choice may well be different, however, for different risks, depending to a large extent on how common and how widely distributed is the risk and the availability and costs of effective interventions. Large gains in health can be achieved through inexpensive treatments when primary prevention measures have not been effective. An example is the treatment of epilepsy with a cheap first-line antiepileptic drug such as phenobarbital.

One risk factor can lead to many outcomes, and one outcome can be caused by many risk factors. When two risks influence the same disease or injury outcomes, then the net effects may be less or more than the sum of their separate effects. The size of these joint effects depends principally on the amount of prevalence overlap and the biological results of joint exposures (13). For example, in the case of neuroinfections such as HIV, one risk factor (i.e. HIV infection) leads to many outcomes, as explained in Chapter 3.5. For some other neurological disorders, one outcome can result from many risk factors: in the case of epilepsy, for example, from factors such as birth injury, head trauma, central nervous system infections and infestations, as explained in Chapter 3.2.

## SERVICE PROVISION AND DELIVERY OF CARE

### Health systems

Health systems comprise all the organizations, institutions and resources that devote their efforts and activities to promote, restore and maintain population health. These activities include formal health care such as the professional delivery of personal medical attention, actions by traditional practitioners, home care and self-care, public health activities such as health promotion and disease prevention, and other health-enhancing interventions such as the improvement of environmental safety.

Beyond the boundaries of this definition, health systems also include activities whose primary purpose is something other than health — education, for example — if they have a secondary, health-enhancing benefit. Hence, while general education falls outside the definition of health systems, health-related education is included. In this sense, every country has a health system, no matter how fragmented or unsystematic it may seem to be.

*The World Health Report 2000* outlines three overall goals of health systems: good health, responsiveness to the expectations of the population, and fairness of financial contribution (17). All three goals matter in every country, and much improvement in how a health system performs with respect to these responsibilities is possible at little cost. Even if we concentrate on the narrow definition of reducing excess mortality and morbidity — the major battleground — the impact will be slight unless activities are undertaken to strengthen health systems for delivery of personal and public health interventions.

Progress towards the above goals depends crucially on how well systems carry out four vital functions: service provision, resource generation, financing and stewardship (17). The provision of

services is the most common function of a health-care system, and in fact the entire health system is often identified and judged by its service delivery.

The provision of health services should be affordable, equitable, accessible, sustainable and of good quality. Failure in any of these objectives adversely affects the care that is delivered. Not much information is forthcoming from countries on these aspects of their health systems, however. Based on available information, serious imbalances appear to exist in many countries in terms of human and physical resources, technology and pharmaceuticals. Many countries have too few qualified health personnel, while others have too many. Staff in health systems in many low income countries are inadequately trained, poorly paid and work in obsolete facilities with chronic shortages of equipment. One result is a “brain drain” of demoralized health professionals who go abroad or move into private practice. The poorer sectors of society are most severely affected by any constraints in the provision of health services.

### Service delivery

Organization of services for delivery of neurological care has an important bearing on their effectiveness. Because of their different social, cultural, political and economic contexts, countries have various forms of service organization and delivery strategies. The differing availability of financial and human resources also affects the organization of services. Certain key issues, however, need to be taken into account for structuring services to provide effective care to people with neurological disorders. Depending upon the health system in the country, there is a variable mix of private and public provision of neurological care.

The three traditional levels of service delivery are primary, secondary and tertiary care. *Primary care* includes treatment and preventive and promotional interventions conducted by primary care professionals. These vary from a general practitioner, nurse, other health-care staff and non-medical staff to primary care workers based in rural areas. Primary care represents the point of entry for most people seeking care and is the logical setting where neurological disorders should begin to be addressed. Many potential benefits exist for providing services through primary care. Users of primary care are more likely to seek early help because of the wide availability of facilities, their easy accessibility, cultural acceptability and reduced cost, thus leading to early detection of neurological disorders and better clinical outcome.

Integration of neurological services into the primary care system needs to be a significant policy objective in both developing and developed countries. Providing neurological care through primary care requires significant investment in training primary care professionals to detect and treat neurological disorders. Such training should meet the specific practical training needs of different groups of primary care professionals such as doctors, nurses and community health workers. Preferably, ongoing training is needed to provide subsequent support for reinforcing new skills. In many countries, this has not been possible and thus suboptimal care is provided (18).

Primary care centres are limited in their ability to adequately diagnose and treat certain neurological disorders. For the management of severe cases and patients requiring access to diagnostic and technological expertise, a *secondary level of care* is necessary. A number of neurological services may be offered in district or regional hospitals that form part of the general health system. Common facilities include inpatient beds in general medicine, specialist beds, emergency departments and outpatient clinics. The various types of services include consultation/liaison services, diagnostic facilities such as electroencephalography (EEG) and computerized tomography (CT), planned outpatient programmes, emergency care, inpatient care, intensive care, respite care, referral facilities for primary care services, multidisciplinary neurological care and rehabilitation programmes. These services require adequate numbers of general as well as specialist professionals who can also provide supervision and training in neurology to primary care staff.

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*Tertiary care* is the most specialized form of neurological diagnosis, treatment and rehabilitation, and is often delivered in teaching hospitals. In some countries, there are also other public or private facilities offering various types of neurological services in inpatient wards and outpatient clinics. These facilities are not expected to deliver primary neurological care but act as secondary and tertiary referral services. They also serve as facilities for clinical research, collection of epidemiological data, and the creation and distribution of health educational materials. Neurological specialist services require a large complement of trained specialist staff. Shortages of such staff are a serious problem in low income countries, as are the lack of financial resources and infrastructure.

Very few countries have an optimal mix of primary, secondary and tertiary care. Even within countries, significant geographical disparities usually exist between regions. Little concerted effort has been made to use primary care as the principal vehicle of delivery of neurological services. Some countries have good examples of intersectoral collaboration between nongovernmental organizations, academic institutions, public sector health services and informal community-based health services. At present, such activities are limited to small populations in urban areas; most rural populations have no access to such services. Even in developed countries, more emphasis is placed on providing specialist services than on approaches to integrate neurological services into primary care.

Many neurological disorders run a chronic, relapsing or remitting course. Such disorders are better managed by services that adopt a continuing care approach, emphasizing the long-term nature of these neurological disorders and the need for ongoing care. The emphasis is on an integrated system of service delivery that attempts to respond to the needs of people with neurological disorders. Integrated and coordinated systems of service delivery need to be developed where services based in primary, secondary and tertiary care complement each other. In order to address the needs of persons with neurological disorders for health care and social support, a clear referral and linkage system needs to be in place. The key principles for organizing such services include accessibility, comprehensiveness, coordination and continuity of care, effectiveness, and equity within the local social, economic and cultural contexts.

## DISABILITY AND REHABILITATION

### Disability

Many neurological disorders and conditions affect an individual's functioning and result in disabilities or limit activities and restrict participation. According to the International Classification of Functioning, Disability and Health (ICF), the medical model views disability as a problem of the person, directly caused by disease, trauma or other health condition that requires medical care provided in the form of individual treatment by professionals (19). Management of the disability is aimed at cure or the individual's adjustment and behaviour change. The social model of disability sees the issue mainly as a socially created problem and a matter related to the full integration of individuals into society. According to the social model, disability is not an attribute of the individual, but rather a complex collection of conditions, many of which are created by the social environment: the approach to disability requires social action and is a responsibility of society.

### Rehabilitation

WHO defines rehabilitation as an active process by which those affected by injury or disease achieve a full recovery or, if a full recovery is not possible, realize their optimal physical, mental and social potential and are integrated into their most appropriate environment (19). Rehabilitation is one of the key components of the primary health-care strategy, along with promotion, prevention and treatment. While promotion and prevention primarily target risk factors of disease and

treatment targets ill-health, rehabilitation targets human functioning. As with other key health strategies, it is of varying importance and is relevant to all other medical specialities and health professions. Though rooted in the health sector, rehabilitation is also relevant to other sectors including education, labour and social affairs. For example, building of ramps and other facilities to improve access by disabled people falls beyond the purview of the health sector but is nevertheless very important for the comprehensive management of a person with a disability.

As a health-care strategy, rehabilitation aims to enable people who experience or are at risk of disability to achieve optimal functioning, autonomy and self-determination in the interaction with the larger physical, social and economic environment. It is based on the integrative model of human functioning, disability and health, which understands human functioning and disability both as an experience in relation to health conditions and impairments and as a result of interaction with the environment.

Rehabilitation involves a coordinated and iterative problem-solving process along the continuum of care from the acute hospital to the community. It is based on four key approaches integrating a wide spectrum of interventions: 1) biomedical and engineering approaches; 2) approaches that build on and strengthen the resources of the person; 3) approaches that provide for a facilitating environment; and 4) approaches that provide guidance across services, sectors and payers. Specific rehabilitation interventions include those related to physical medicine, pharmacology and nutrition, psychology and behaviour, education and counselling, occupational and vocational advice, social and supportive services, architecture and engineering and other interventions.

Rehabilitation services are like a bridge between isolation and exclusion — often the first step towards achieving fundamental rights. Health is a fundamental right, and rehabilitation is a powerful tool to provide personal empowerment.

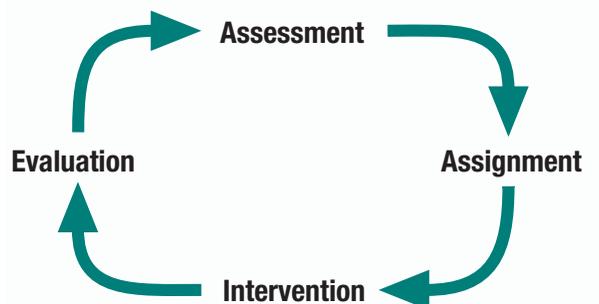
### Rehabilitation strategy

Because of the complexity of rehabilitation based on the above-mentioned integrative model, rehabilitation services and interventions applying the rehabilitation strategy need to be coordinated along the continuum of care across specialized and non-specialized services, sectors and payers. Figure 1.2 illustrates the iterative problem-solving process sometimes called Rehab-CYCLE (20). The Rehab-CYCLE involves four steps: assess, assign, intervene and evaluate. The process is applied on two levels. The first refers to the guidance along the continuum of care and the second to the provision of a specific service.

From the *guidance perspective*, the assessment step includes the identification of the person's problems and needs, the valuation of rehabilitation potential and prognosis and the definition of long-term service and goals of the intervention programme. The assignment step refers to the assignment to a service and an intervention programme. From the guidance perspective, the intervention step is not further specified. The evaluation step refers to service and the achievement of the intervention goal.

From the *service perspective*, the assessment step includes the identification of a person's problems, the review and potential modification of the service or goals of the intervention programme and the definition of the first Rehab-CYCLE goals and intervention targets. The assignment step refers to the assignment of health professionals and interventions to the intervention targets. The intervention step refers to the specification of the intervention techniques, the definition of indicator measures to follow the progress of the intervention, and the definition of target values to be achieved within a

Figure 1.2 The Rehab-CYCLE



predetermined time period. The evaluation step refers to the evaluation of the achievement of the goal with respect to the specified target values of the indicator measures, the Rehab-CYCLE goals and ultimately the goals of the intervention programme. It also includes the decision regarding the need for another intervention cycle based on a reassessment.

### Rehabilitation of neurological disorders

Rehabilitation should start as soon as possible after the diagnosis of a neurological disorder or condition and should focus on the community rehabilitation perspective. The type and provision of services is largely dependent on the individual health-care system. Therefore no generally agreed principles currently exist regarding the provision of rehabilitation and related services.

Rehabilitation is often exclusively associated with well-established and coordinated multi-disciplinary efforts by specialized rehabilitation services. While availability and access to these specialized inpatient or outpatient services are at the core of successful rehabilitation, a need also exists for rehabilitation service provision, from the acute settings through the district hospital and the community, often by health professionals not specialized in rehabilitation but working closely with the rehabilitation professionals. It is important to recognize that rehabilitation efforts in the community can be delivered by professionals outside the health sector, ideally in collaboration with rehabilitation professionals.

Rehabilitation services are limited or nonexistent in many developing countries for people with disabilities attributable to neurological disorders or other causes. This means that many individuals with disabilities will depend totally on other people, usually family members, for help with daily activities, and this situation enhances poverty. Impoverished communities throughout the world are affected by a disproportionate number of disabilities and, in turn, people with disabilities become more vulnerable to poverty because of a lack of access to, or availability of, health care, social care and rehabilitation services. When rehabilitation services are available, the lack of human resources limits considerably the transfer of knowledge from specialized centres to district and community settings.

To address this situation, a community-based rehabilitation strategy has been introduced by WHO as a complement to existing rehabilitation models and to look beyond the medical needs. The strategy of community-based rehabilitation has been implemented in many low income countries around the world and has successfully influenced the quality of life and participation of persons with disabilities in societies where it is in practice.

The philosophy of rehabilitation emphasizes patient education and self-management and is well suited for a number of neurological conditions. The basis for successful neurorehabilitation is the in-depth understanding and sound measurement of functioning and the application of effective interventions, intervention programmes and services. A wide range of rehabilitation interventions, intervention programmes and services has been shown to contribute effectively to the optimal functioning of people with neurological conditions.

Effective neurorehabilitation is based on the involvement of expert and multidisciplinary assessment, realistic and goal-oriented programmes, and evaluation of the impact on the patient's rehabilitation achievements; evaluation using scientifically sound and clinically appropriate out-

### Box 1.3 Case-study: Giovanni

Giovanni is a 20-year-old man who was beaten by a mob two years ago after a football game and suffered traumatic brain injury. He was slow to recover with severe physical limitations, fully conscious but with severe communication problems. He needs an assistive communication device which is not provided by the health system and is not possible for his family to purchase, so his family made a basic communication table he uses to spell out words by point-

ing letter by letter with a finger, the only part of his body he controls partially. Giovanni is totally dependent in all daily activities and needs assistance 24 hours a day. He has a standard wheelchair (though he requires an electrical one); he has no way of leaving his house to access community facilities, he cannot return to his previous job, and he has no relocation option in view.

come measures should also incorporate the patient's and the family's perspectives. There are a number of complexities in the process of neurorehabilitation, as patients can present with diverse sequelae, including the following:

- *Physical functioning limitations* can be evident in many ways — such as paralysis of the left or right side of the body, or both sides — which limit severely the person's capacity for many daily living activities, as well as mobility in the community and, eventually, the capacity to return to work or school. Patients can also present with rigidity, uncoordinated movements, and/or weakness. This is evident in the case-studies of Giovanni and Juan given below in Box 1.3 and Box 1.4, respectively. In developing countries, people with disabilities have very limited access not only to rehabilitation services but also to appropriate assistive technology, such as adequate wheelchairs: persons with head injury who require wheelchairs for adequate positioning and mobility may be severely impaired in their possibility to leave their house and participate in community activities, access educational facilities, or work.
- *Cognitive impairments* can manifest in the form of memory and attention problems, mild to severe intellectual deficiency, lack of perseverance and a limited ability to learn, all of which can make it impossible to return to work, may affect emotional stability, and limit performance at work or at home. All of these problems will affect the person's emotional status, as well as that of the family and friends. It can also mean social isolation in the long term, aggravating depression.
- *Behavioural problems* such as poor impulse control, uncontrolled anger and sexual impulses, lack of insight and perseverance, and the impossibility to learn from past errors are only some of the behavioural sequelae that affect the person's capacity to get involved and be accepted socially, and further limit the possibility of returning to educational or vocational services. Behavioural problems can also become evident when the person affected realizes the severity of his or her limitations, and the fact that they may be permanent.
- *Communication impairments* in the form of speech problems, poor vocalization or stomas, in combination with lack of access to augmentative or alternative communication devices in developing countries, as in Giovanni's case (Box 1.3), are a sure means of social isolation.
- *Basic daily living activities* are affected by functional and cognitive limitations. For a man like Giovanni (Box 1.3), such things as getting dressed or getting a spoonful of food to his mouth can be impossible.
- *Psychosocial limitations*, such as limited access to education, the impossibility to return to vocational status or be relocated vocationally, are consequences of previously mentioned limitations, all of which further impact on the behavioural, physical and cognitive aspects of the person affected by a neurological disorder that causes disability.

### Costs of rehabilitation services

The National Head and Spinal Cord Injury Survey (27) divided costs into direct and indirect. Direct costs were associated with the monetary values of real goods and services that were provided for health care, while indirect costs were the monetary loss incurred by society because of interrupted productivity by the injured person. In 1974, the total cost for all head injuries studied was

### Box 1.4 Case-study: Juan

Juan is a 32-year-old man, a former alcohol and drug addict who sustained a car accident eight years ago. He recovered well from his physical limitations, except for a total paralysis of his right arm and uncoordinated movements of his left arm and legs. He was depressed for years, refusing medical treatment for his former addiction problem. He could not return to his former job as an agricultural labourer

and was supported by his mother, who had to find a job to maintain them both. Finally, on his own, Juan adapted his tools to be able to function as a shoe-shiner in a park. At his last appointment, he was newly wed and attended with his wife and child. He was finally happy with himself and his life, although conscious of his deficits.

US\$ 2384 million, of which 29% was related to the direct costs of care and 71% to indirect costs. The largest annual cost was found to be in the 25–44-year age group, where the loss incurred due to productivity was maximal. Payments for indirect costs are by far the greatest share, and legal charges are only slightly less than the cost for the entire medical, hospital and rehabilitation services provided.

## STIGMA

Stigma has been defined as a deeply discrediting attribute that reduces a person to one who is in some way tainted and can therefore be denigrated. It is a pervasive problem that affects health globally, threatening an individual’s psychological and physical well-being. It prevents individuals from coming forward for diagnosis and impairs their ability to access care or participate in research studies designed to find solutions.

Stigmatization of certain diseases and conditions is a universal phenomenon that can be seen across all countries, societies and populations. It refers to the relation between “the differentness of an individual and the devaluation society places on that particular differentness”. For stigmatization to be consistently effective, however, the stigmatized person must acquiesce to society’s devaluation. When people with “differentness” internalize society’s devaluation, they do not feel empowered to change the situation and the negative stereotypes become an accepted part of their concept of the disorder. The labelling, stereotyping, separation from others and consequent loss of status highlight the role of power relations in the social construction of stigma (22).

People differentiate and label socially important human differences according to certain patterns that include: negative stereotypes, for example that people with epilepsy or other brain disease are a danger to others; and pejorative labelling, including terms such as “crippled”, “disabled” and “epileptic”.

In neurology, stigma primarily refers to a mark or characteristic indicative of a history of neurological disorder or condition and the consequent physical or mental abnormality. For most chronic neurological disorders, the stigma is associated with the disability rather than the disorder per se. Important exceptions are epilepsy and dementia: stigma plays an important role in forming the social prognosis of people with these disorders. The amount of stigma associated with chronic neurological illness is determined by two separate and distinct components: the attribution of responsibility for the stigmatizing illness and the degree to which it creates discomfort in social interactions. An additional perspective is the socially structured one, which indicates that stigma is part of chronic illness because individuals who are chronically ill have less “social value” than healthy individuals. Some additional aspects and dimensions of stigma are given in Box 1.5.

Stigma leads to direct and indirect discriminatory behaviour and factual choices by others that can substantially reduce the opportunities for people who are stigmatized. Whatever the mechanisms involved, stigma is an important public health problem. Stigma increases the toll of illness for many people with brain disorders and their families; it is a cause of disease, as people

### Box 1.5 Dimensions of stigma

<b>Concealability</b>	The extent to which the condition becomes obvious or can be hidden from others.
<b>Course of the mark</b>	The way the condition changes over time and its ultimate outcome.
<b>Disruptiveness</b>	The degree of strain and difficulty stigma adds to interpersonal relationships.
<b>Aesthetics</b>	How much the attribute makes the character repellant or upsetting to others.
<b>Origin</b>	Who was responsible for the acquired stigmatizing condition and how.
<b>Peril</b>	Perceived dangers, both real and symbolic, of the stigmatizing condition to others.

Source: (23).

who are stigmatized have high exposure to health risks and low access to protective factors and treatment.

Sometimes coping with stigma surrounding the disorder is more difficult than living with any limitations imposed by the disorder itself. Stigmatized individuals are often rejected by neighbours and the community, and as a result suffer loneliness and depression. The psychological effect of stigma is a general feeling of unease or of “not fitting in”, loss of confidence, increasing self-doubt leading to depreciated self-esteem, and a general alienation from the society. Moreover, stigmatization is frequently irreversible so that, even when the behaviour or physical attributes disappear, individuals continue to be stigmatized by others and by their own self-perception.

People with some neurological disorders (e.g. epilepsy) and their families may also be subjected to other forms of social sanction, such as being excluded from community activities or from societal opportunities such as education or work. One of the most damaging results of stigmatization is that affected individuals or those responsible for their care may not seek treatment, hoping to avoid the negative social consequences of diagnosis. This leads in turn to delayed or lost opportunities for treatment and recovery. Underreporting of stigmatizing conditions can also reduce efforts to develop appropriate strategies for their prevention and treatment.

Epilepsy carries a particularly severe stigma because of misconceptions, myths and stereotypes related to the illness. In some communities, children who do not receive treatment for this disorder are removed from school. Lacking basic education, they may not be able to support themselves as adults. In some African countries, people believe that saliva can spread epilepsy or that the “epileptic spirit” can be transferred to anyone who witnesses a seizure. These misconceptions cause people to retreat in fear from someone having a seizure, leaving that person unprotected from open fires and other dangers they might encounter in cramped living conditions. Recent research has shown that the stigma people with epilepsy feel contributes to increased rates of psychopathology, fewer social interactions, reduced social capital, and lower quality of life in both developed and developing countries (22).

Efforts are needed to reduce stigma but, more importantly, to tackle the discriminatory attitudes and prejudicial behaviour that give rise to it. Fighting stigma and discrimination requires a multilevel approach involving education of health professionals and public information campaigns to educate and inform the community about neurological disorders in order to avoid common myths and promote positive attitudes. Methods to reduce stigma related to epilepsy in an African community by a parallel operation of public education and comprehensive treatment programmes successfully changed attitudes: traditional beliefs about epilepsy were weakened, fears were diminished, and community acceptance of people with epilepsy increased (24).

The provision of services in the community and the implementation of legislation to protect the rights of the patients are also important issues. Legislation represents an important means of dealing with the problems and challenges caused by stigmatization. Governments can reinforce efforts with laws that protect people with brain disorders and their families from abusive practices and prevent discrimination in education, employment, housing and other opportunities. Legislation can help, but ample evidence exists to show that this alone is not enough.

The emphasis on the issue of prejudice and discrimination also links to another concept where the need is to focus less on the person who is stigmatized and more on those who do the stigmatizing. The role of the media in perpetrating misconceptions also needs to be taken into account. Stigmatization and rejection can be reduced by providing factual information on the causes and treatment of brain disorder; by talking openly and respectfully about the disorder and its effects; and by providing and protecting access to appropriate health care.

## EDUCATION AND TRAINING

Education in neurology contains important aspects of quality assurance and continuing improvement in the delivery of the best care to people with neurological disorders. Training in neurology does not refer only to postgraduate specialization but also the component of training offered to undergraduates, general physicians and primary health-care workers. To reduce the global burden of neurological disorders, an adequate focus is needed on training, especially of primary health workers in countries where neurologists are few or nonexistent.

### Training of primary care providers

As front line caregivers in many resource-poor countries, primary care providers need to receive basic training and regular continuing education in basic diagnostic skills and in treatment and rehabilitation protocols. Such training should cover general skills (such as interviewing the patient and recording the information), diagnosis and management of specific disorders (including the use of medications and monitoring of side-effects) and referral guidelines. Training manuals tailored to the needs of specific countries or regions must be developed. Primary care providers need to be trained to recognize the need for referral to more specialized treatment rather than trying to make a diagnosis.

Training of nurses is particularly important globally. In low income countries, where few physicians exist, nurses may be involved in making diagnostic and treatment decisions. They are also an important source of advice on promoting health and preventing disease, such as providing information on diet and immunization.

### Training of physicians

The points to be taken into consideration in relation to education in neurology for physicians include:

- core curricula (undergraduate, postgraduate and others);
- continuous medical education;
- accreditation of training courses;
- open facilities and international exchange programmes;
- use of innovative teaching methods;
- training in the public health aspects of neurology.

Teaching of neurology at undergraduate level is important because 20–30% of the population are susceptible to neurological disorders (25). The postgraduate period of training is the most active and important for the development of a fully accredited neurologist. The following issues need consideration: mode of entry, core training programmes, evaluation of the training institutions, access to current literature, rotation of trainees between departments, and evaluation of the trainees during training and by a final examination. The central idea is to build both the curriculum and an examination system that ensure the achievement of professional competence and social values and not merely the retention and recall of information.

Neurological curricula vary considerably across countries. This is not necessarily undesirable because the curriculum must take into account local differences in the prevalence of neurological disorders. Some standardization in the core neurological teaching and training curricula and methods of demonstrating competency is desirable, however. The core curriculum should be designed to cover the practical aspects of neurological disorders and the range of educational settings should include all health resources in the community. The core curriculum also needs to reflect national health priorities and the availability of affordable resources.

Continuous medical education is an important way of updating the knowledge of specialists on an ongoing basis and providing specialist courses to primary care physicians. Specialist neurolo-

gists could be involved in training of primary care doctors, especially in those countries where few specialists in neurology exist. Regional and international neurological societies and organizations have an important role to play in providing training programmes: the emphasis should be on active problem-based learning. Guidelines for continuous medical education need to be set up to ensure that educational events and materials meet a high educational standard, remain free of the influence of the pharmaceutical industry and go through a peer review system. Linkage of continuous medical education programmes to promotion or other incentives could be a strategy for increasing the number of people attending such courses.

Neurologists play an increasingly important part in providing advice to government and advocating better resources for people with neurological disorders. Therefore training in public health, service delivery and economic aspects of neurological care need to be stressed in their curricula.

Most postgraduate neurology training programmes, especially those in developed countries, are resource intensive and lengthy — usually taking about six years to complete. Whether adequate specialist training in neurology might be undergone in less time in certain countries or regions would be a useful subject for study. The use of modern technology facilities and strategies such as distance-learning courses and telemedicine could be one way of decreasing the cost of training.

An important issue, as for other human health-care resources, is the “brain drain”, where graduates sent abroad for training do not return to practise in their countries of origin. This public health challenge still needs to be faced with innovative means.

## CONCLUSIONS

Public health is the science and practice of protecting and improving the population’s health through prevention, promotion, health education, control of communicable and noncommunicable diseases and monitoring of environmental hazards. It is a comprehensive approach that is concerned with the health of the community as a whole. Public health is community health: “Health care is vital to all of us some of the time, but public health is vital to all of us all of the time” (3).

The mission of public health is to fulfil society’s interest in assuring conditions in which people can be healthy. The three core public health functions are:

- the assessment and monitoring of the health of communities and populations at risk to identify health problems and priorities;
- the formulation of public policies designed to solve identified local and national health problems and priorities;
- ensuring that all populations have access to appropriate and cost-effective care, including health promotion and disease prevention services, and evaluation of the effectiveness of that care.

Public health comprises many professional disciplines such as medicine, nutrition, social work, environmental sciences, health education, health services administration and the behavioural sciences. In other words, public health activities focus on entire populations rather than on individual patients. Specialist neurologists usually treat individual patients for a specific neurological disorder or condition; public health professionals approach neurology more broadly by monitoring neurological disorders and related health concerns in entire communities and promoting healthy practices and behaviours so as to ensure that populations stay healthy. Although these approaches could be seen as two sides of the same coin, it is hoped that this chapter contributes to the process of building the bridges between public health and neurology and thus serves as a useful guide for the chapters to come.

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