Policy makers

TIME TO COMMIT TO POLICY CHANGE

Schizophrenia

A call for action for policy makers

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This publication highlights the key recommendations and actions for policy makers contained in the full report, *Schizophrenia – Time to Commit to Policy Change*, which can be found here:

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- European Brain Council
- European College of Neuropsychopharmacology
- European Federation of Associations of Families of People with Mental Illness
- European Federation of Psychiatric Trainees
- Global Alliance of Mental Illness Advocacy Networks-Europe
- National Alliance on Mental Illness
- National Council for Behavioral Health
- Royal College of Psychiatrists
- Schizophrenia International Research Society
- Vinfen
- World Federation for Mental Health

TIME TO COMMIT TO POLICY CHANGE

Recommendations for policy change

Schizophrenia has a profound personal, social and economic impact. Furthermore, public attitudes towards schizophrenia lead to prejudice and discrimination.

We therefore recommend the following policy actions to local, national and regional policy makers.

1. Provide an evidence-based, integrated care package for people with schizophrenia that addresses their mental and physical health needs. This should be underpinned with an integrated approach by their healthcare professionals and supported by the national healthcare system and by educational and research facilities.
2. Provide support for people with schizophrenia to enter and to remain in their community, and develop mechanisms to help guide them through the often complex benefit and employment systems to enhance recovery. Guidelines and educational programmes should be developed and implemented to support the inclusion of people with schizophrenia in their community, workplace or school.
3. Provide concrete support, information and educational programmes to families and carers on how to enhance care for an individual living with schizophrenia in a manner that entails minimal disruption to their own personal lives.
4. Consult with healthcare professionals and other stakeholders directly involved in the management of schizophrenia, including organizations that support people living with schizophrenia, their families and their carers, in order to regularly revise, update and improve policy on the management of schizophrenia.
5. Provide support, which is proportionate to the impact of the disease, for research and development of new treatments that improve the overall outlook for people with schizophrenia, including those that target negative symptoms and cognitive impairment.
6. Establish adequately funded, ongoing and regular awareness-raising campaigns to: increase the understanding of schizophrenia among the general public; emphasize the importance of positive societal attitudes towards mental illnesses; highlight available support for the management of schizophrenia; and deter discriminatory attitudes and actions. Such campaigns should form an integral part of routine plans of action.

Our recommendations are based on research evidence, stakeholder consultation and examples of best practice, worldwide.

Executive summary

This report summarizes the evidence and consensus findings emerging from discussions among a group of international psychiatrists, researchers, advanced practice nurses, patients and carers with expertise and experience in the field of schizophrenia. The group met several times and brought together world-leading insight into the clinical and scientific evidence base for schizophrenia, combined with first-hand insight into the practical reality of living daily with the condition.

Excitingly, this diverse group was united in reaching three clear, evidence-based conclusions.

- The likelihood of a good outcome for people with schizophrenia has improved in recent decades; with appropriate management, many people affected by the condition can now achieve an acceptable quality of life.
- A modern approach to schizophrenia management should aim to move patients along a pathway towards recovery of normal function, as well as to alleviate distressing symptoms.
- Driving further change towards a more positive outlook for schizophrenia requires fundamental policy change.

Improving schizophrenia care – a priority in healthcare policy

The protection and treatment of people with mental disorders is recognized by the United Nations as a human right.[1] Freedom from prejudice, abuse, discrimination and hostility, and a right to the best available treatments, are enshrined in the World Health Organization Global Mental Health Action Plan,[2] which emphasizes the use of evidence-based therapies and the empowerment of people with mental disorders. During the past 20 years, schizophrenia care has improved, but many people with the condition still find it difficult to live a productive life in society; improving the care of people with schizophrenia needs to be a priority in healthcare policy.

What is schizophrenia?

The term schizophrenia describes a mental disorder characterized by abnormal thinking, perceptual disturbances and decreased or increased emotional expression. It affects a person's well-being, cuts life short and is among the top 10 causes of disability globally.[3] At least 26 million people are living with schizophrenia worldwide,[4] and twice as many are indirectly affected by it (e.g. as carers). Importantly, however, with appropriate care and support, people with schizophrenia can recover and live fulfilled lives in the community, with up to 50% of individuals potentially having a good outcome.[5,6]

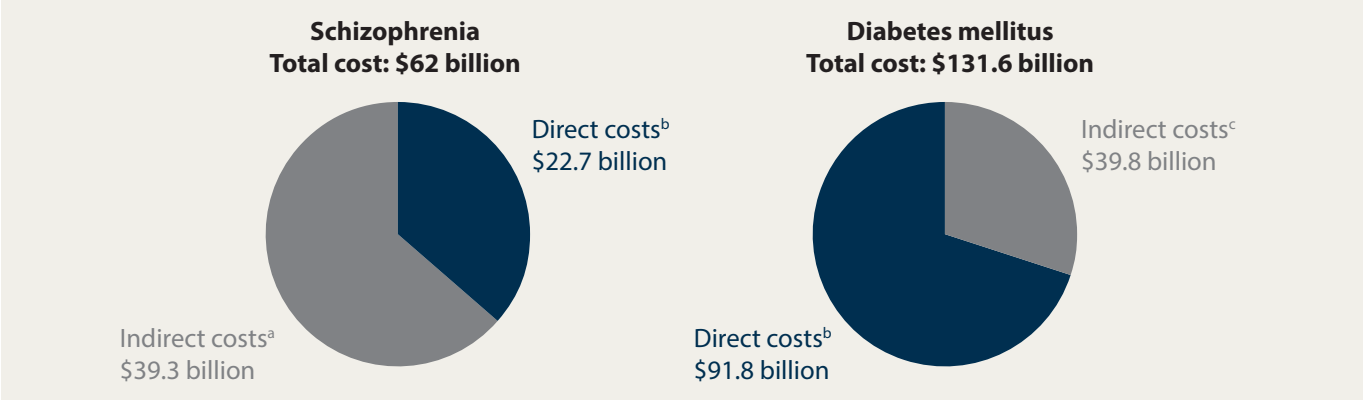

Figure 1. Comparison of indirect and direct costs of schizophrenia[8] and diabetes mellitus[9] in the US in 2002.

[a]Indirect costs comprised absence from work, carer burden, premature mortality and reduced productivity at work. [b]Direct costs comprised outpatient care, medication, inpatient care and long-term care. [c]Indirect costs comprised disability, reduced productivity, premature mortality and absence from work.

How much does schizophrenia cost?

The total cost of schizophrenia to society comprises direct costs of treatment (e.g. medication and hospitalization) and indirect costs (e.g. lost productivity by patients and carers, and reduced earning potential), which are likely to decrease with improved treatment.

In 2012, the estimated total cost in Europe of psychotic disorders such as schizophrenia was €29 billion – equivalent to €5805 per patient per year.[7] However, the cost varies considerably across Europe, and budgets for mental health care are extremely low in many countries.[7] A comparison of the total costs of schizophrenia with those of diabetes mellitus in the US shows that indirect costs account for a higher proportion of the total for schizophrenia[8] than for diabetes mellitus[9] (Figure 1).

Inappropriately managed schizophrenia can have a significant impact on healthcare resources and society. Importantly, spending on direct healthcare costs may result in lower total costs, because productivity of patients and carers increases and associated indirect costs fall. Interventions that reduce the risk of hospitalization may thus produce valuable savings, as well as a better life for the patient. Spending on schizophrenia should not be regarded as a competitor for spending on physical illness, because physical and mental illness often co-exist.

Making *best* practice *standard*: investment is needed

It is imperative that our existing tools are available to all those with schizophrenia who need them. More needs to be done to identify schizophrenia earlier and to initiate treatment as soon as possible. Such aims will require investment in the expansion of existing services, research into the causes and mechanisms of the disorder, and research aimed at improving standards of care.

Integrating current approaches to schizophrenia treatment

Treating schizophrenia with an integrated approach (combining medical and psychosocial therapies, alongside attention to physical health) improves the outcome.

The medical approach

Drugs that treat schizophrenia symptoms (antipsychotics) are effective in reducing positive

symptoms (e.g. hallucinations, delusions and disorganized thoughts and behaviour), but they do not adequately treat negative symptoms (e.g. low motivation and restricted emotion) or cognitive impairment (e.g. problems with memory, decision-making and verbal skills). New therapeutic approaches, aimed at discovering drugs that are effective against negative symptoms and cognitive impairment, are under investigation.[10,11]

Psychosocial therapies

Psychosocial therapies are important in the treatment of schizophrenia. They improve patients' functioning in the community, which can lead to clinical improvements (e.g. reductions in the number of relapses and hospitalizations).[12] Such interventions include cognitive behavioural therapy (a talking therapy that aims to change thought patterns and resulting behaviours) and family therapy/psychoeducation, and they have been shown to be cost-effective.[12–14]

The added impact of physical illness

Schizophrenia is associated with a substantial degree of physical illness: the lives of people with schizophrenia are cut short compared with the life expectancy of the general population (Figure 2).[15,16] This is the result of a number of factors,[17] some of which are discussed below.

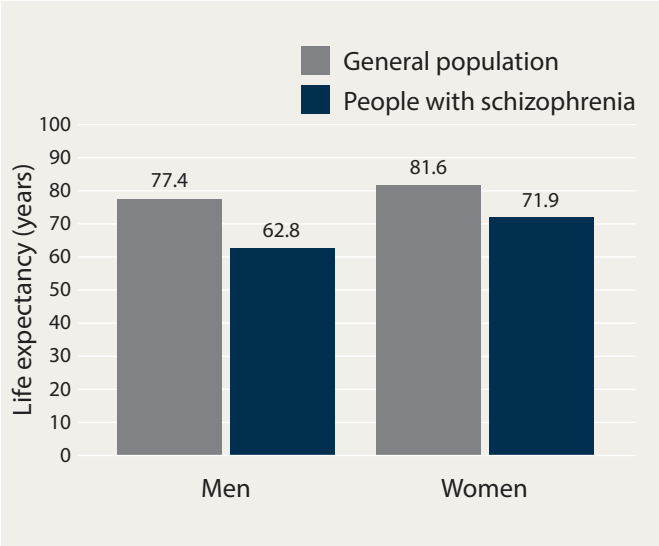

Figure 2. People with schizophrenia die earlier than the general population; the figure shows mean decrease in life expectancy at birth (UK data).[15]

Increased rates of heart disease and smoking compared with the general population are major drivers of early death and ill health among people with schizophrenia.[18,19] Alcohol and substance abuse (especially cannabis abuse) are also common and are associated with increased rates of relapses and hospitalizations, and physical illness.[20]

What can policy makers do?

- Encourage member states to support widespread access to psychosocial therapies. These are often underutilized and are not available to all who could benefit.[21,22] Furthermore, the cost may be prohibitive in countries where these therapies are not available through public health services. Therefore, there are opportunities to increase the uptake, and hence the effectiveness, of psychosocial therapies.
- Prioritize interventions to stop smoking and to reduce substance abuse.
- Support programmes aimed at promoting a healthy lifestyle; such programmes are beneficial[22,23] and should be implemented more widely and integrated into psychiatric care.[24]
- Encourage the review of legislation to help decrease the burden of mental and physical illness; in particular, ensure effective coordination of services and funding, continuity of health and social care, and synchronization with the criminal justice, benefit and employment systems.

Creating a supportive environment that promotes recovery

What are the factors that hinder recovery?

A supportive environment is vital in helping people with schizophrenia to achieve their desired outcomes, but many people face prejudice and discrimination when seeking employment or when trying to form close relationships.[25]

First-person account

"I enrolled in a programme called Work on Track that helps people with mental illness prepare to re-enter the work force….Although Work on Track had helped me to prepare a good résumé, I had a 5-year gap….I was told to say that it was due to a medical condition but that it was now under control and that it would not be a factor in my job … I never got a second interview."

From Scotti P. *Schizophr Bull* 2009;35:844–6.[26]

Unemployment is high among people with schizophrenia; supported employment interventions can produce substantial savings and reduce the risk of hospitalization. Interventions to help young people with schizophrenia to complete their education can also increase their chances of finding competitive employment.[27]

Homelessness is a major barrier to recovery and is common among people with schizophrenia.[28,29] A critical time intervention approach can be effective, in which social workers organize support plans and work intensively with an individual for 6 months to help them to obtain housing.[30]

Contact with the criminal justice system is disproportionately high among people with schizophrenia and increases the economic costs associated with the illness. UK data suggest that about 8% of the prison population have schizophrenia, compared with no more than 0.5% of the general population.[31] Criminal justice diversion programmes have been introduced in some countries, aimed at identifying offenders with mental disorders and linking them to health and social services rather than the criminal justice system.[32] These initiatives have resulted in decreased incarceration, reduced risks of re-offending and decreased alcohol or substance abuse, as well as improved quality of life.[32]

Communication and education about schizophrenia

Psychoeducation campaigns aimed at the general public can be beneficial in increasing awareness of schizophrenia and decreasing negative attitudes towards mental illness.[33] Importantly, they should be a continuing process; single campaigns appear to have a limited effect.[34]

Schizophrenia services are often fragmented, and people with schizophrenia may find it difficult to navigate through the system. People who are affected by schizophrenia can offer powerful and eloquent insights into the condition; as a result, peer-led interventions and advocacy groups have an important role in schizophrenia care. Advocacy groups, such as the Global Alliance of Mental Illness Advocacy Networks (GAMIAN), GAMIAN-Europe and the European Federation of Associations of Families of People with Mental Illness (EUFAMI), speak out in support of those affected by mental disorders, provide information and education, campaign against stigma and discrimination, and much more.

What are the barriers to the creation of a supportive environment?

Inconsistent mental health policy

Even in Europe, where many countries have specific mental health legislation to cover areas such as housing or unemployment, many people with mental disorders may not be adequately protected.

For example, 81% of the population of Europe live in countries that currently have such legislation, but only 38 of 52 countries have dedicated mental health policies (Table 1).[35]

Complicated benefit systems

While social security benefits are essential for people with schizophrenia who are unable to work, the benefit system can make it difficult to find employment.[36] Work can be stressful and, if a person is able to work for only a few hours each week, it may be less lucrative than remaining on benefits. Furthermore, a 'social paradox' exists in some countries, whereby individuals are concerned about losing benefits if they find paid employment.

Information for patients about the support available is often lacking (which can delay benefits being received) or may be difficult to access, especially if literacy is an issue. This is of particular concern among immigrant communities, where cultural differences and language barriers often hinder access to services.[19]

Table 1. Regions of the world with dedicated mental health policy.[35]

Region	Countries with mental health policy	Population coverage, %
Africa	19/45	60.1
Americas	18/32	88.1
Eastern Mediterranean	13/19	84.8
Europe	38/52	90.8
South-East Asia	7/10	31.8
Western Pacific	15/26	94.9
World	110/184	71.5

What can policy makers do?

Improve the benefit system

- Do more to ensure that people with schizophrenia receive the benefits to which they are entitled.
- Promote a better understanding – across cultures and across social insurance systems – of incentives for work and the availability of work opportunities, to help in the provision of employment for people with schizophrenia.

Support education campaigns

- Encourage creative approaches to change public attitudes to schizophrenia and to end the discrimination faced by people when seeking employment or training.
- Develop psychoeducation campaigns (preferably multimedia campaigns, including a social marketing approach) directed towards the general public.
- Commit resources to ensuring that peer-led support and advice are readily accessible, particularly for young people with schizophrenia.

Conclusions

- ***Better lives for people living with schizophrenia:*** this is a reachable goal! We have come a long way towards achieving this in recent years, but much can (and should) still be done. Successful care requires an **integrated team approach**, involving psychiatrists, a range of healthcare professionals, social care providers and other external agencies. It also involves collaboration with people with schizophrenia, their families and other sources of support. For private healthcare systems, such a team approach will require careful alignment of reimbursement mechanisms to support high-quality care.
- A second prerequisite for successful care is **adequate funding** – at least equivalent to that for other medical conditions such as cancer and heart disease – for research, treatment, services and teaching of future mental healthcare professionals. At present, the extent to which effective psychosocial therapies are funded by public healthcare systems varies across countries; hence, many patients are denied treatment. More support is needed for independent studies of potentially beneficial interventions.
- Implementation of the recommendations set out at the front of this report will require **engagement by every stakeholder**. With commitment from all, change can be achieved.

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