

Schizophrenia: Time to Commit to Policy Change

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**TIME TO
COMMIT TO
POLICY
CHANGE**

Schizophrenia

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Psychiatrists, researchers, policy advisers,
nurses, patients, carers and advocacy groups
with expertise in schizophrenia

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 - Professor Thomas R E Barnes, UK
 - Professor William Carpenter, USA
 - Dr Ken Duckworth, USA
 - Professor Silvana Galderisi, Italy
 - Professor Martin Knapp, UK
 - Professor Stephen R Marder, USA
 - Professor Norman Sartorius, Switzerland
-
- World-leading clinical insight combined
with practical reality of daily living

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The Support Team

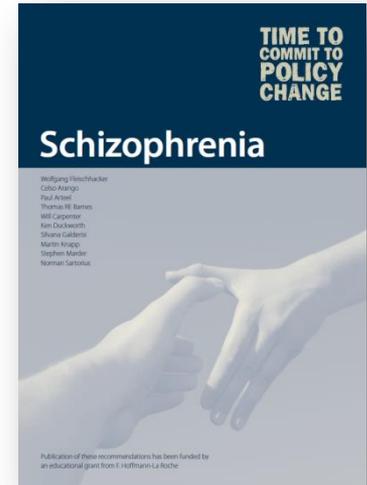
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Goals of this report

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- Highlight the burden of schizophrenia and set out the current needs
 - To policy makers and all relevant stakeholders who influence care quality
- Recommend areas for intervention
- Support the commitment of stakeholders to creating a better future
- Reach a wide audience
- Foster a positive outlook
- Promote 'recovery'
- **Make a difference!**



Schizophrenia: Prevalence and treatment - addressing the fundamental health inequity

Age Group	Number of people
15-24	~10,000
25-34	~15,000
35-44	~20,000
45-54	~25,000
55-64	~30,000
65-74	~35,000
75-84	~40,000
85+	~45,000

Figure 1.1. Costs for individuals with a mental illness can take a toll on the care. The figure shows mean total by care in a year by the 12 National Institute on Mental Health.

- direct costs of treating the condition, which may need to increase in line with the rising burden of patients to be treated in higher patients
- indirect costs, which are likely to increase with increased treatment

Figure 1.2. The estimated total cost of psychiatric disorders, such as schizophrenia, is likely to be between 10% and 15% of the total of care per year. However, when considering the impact of schizophrenia on the wider population, and budgets for mental health care are set to rise in future quarters.

Figure 1.3. In the UK, the total annual cost of schizophrenia has been estimated to be £1.2 billion, an amount which is likely to account for 12.7% of the total of care per year. A comparison of the total cost of schizophrenia with other mental health conditions shows that schizophrenia accounts for a higher proportion of the total of care per year than any other mental health condition. (Figure 2.1.1) However, there is considerable potential for reducing these indirect costs for schizophrenia by

reducing the morbidity (the frequency at which the disease is seen) in the population and hospital and death rates associated with it.

Although there are substantial economic impacts associated with schizophrenia, public spending on interventions to improve mental health care has not risen to the extent that would be expected given the economic burden of the disease. This is due to a number of factors, including the fact that the burden of care is not being met by the current system of care, and the fact that the burden of care is not being met by the current system of care.

Consider the impact of the rise in hospitalization for people with schizophrenia in the UK. In 2010, the total number of hospitalizations for people with schizophrenia in the UK was 10,000. This is a significant increase on the 7,000 hospitalizations in 2000. This increase is due to a number of factors, including the fact that the burden of care is not being met by the current system of care, and the fact that the burden of care is not being met by the current system of care.

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Timeline for family carers: when is the biggest pressure?

At the age of onset of a child's mental illness, the age of family carers (40-60 years) and the possibility of separation or divorce mean that there are a time of great family stress and pressure.

Mental illness develops in a young person

Family carers' responsibilities

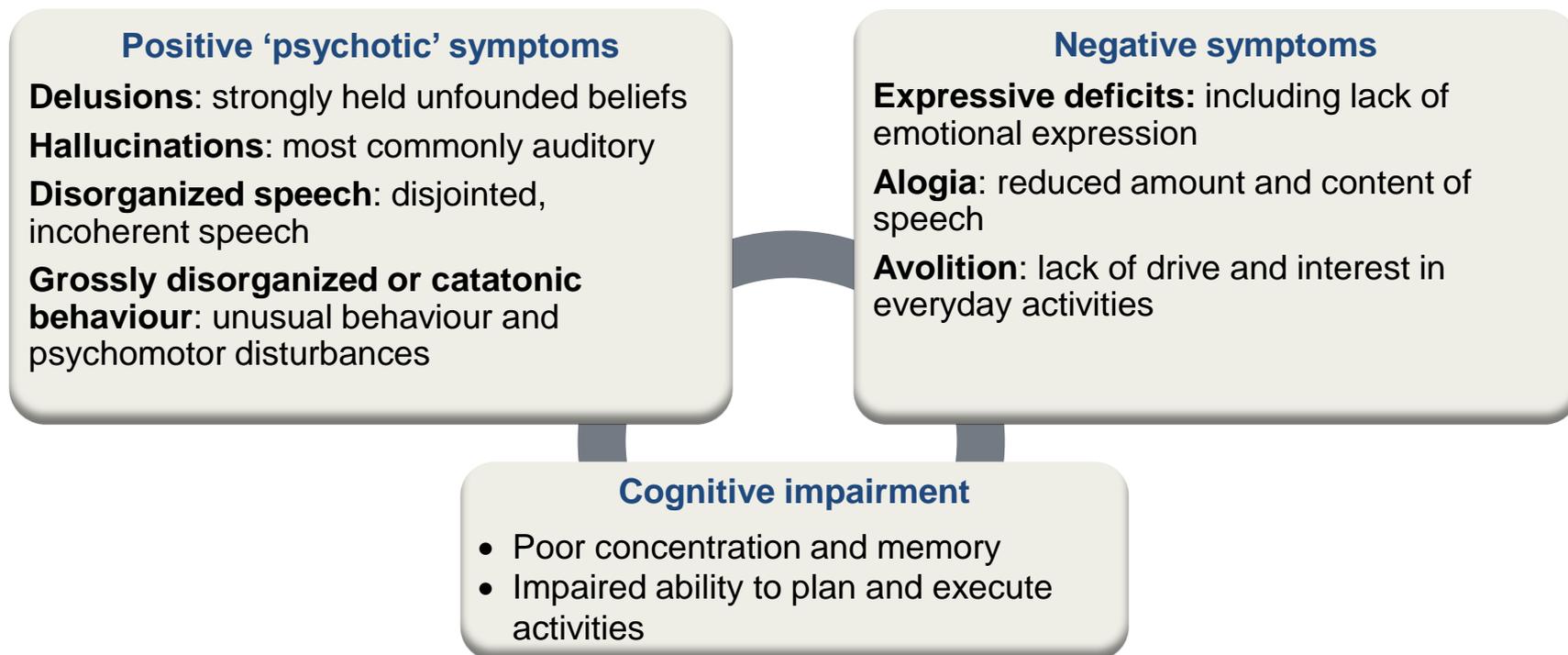
Grandparents

Family member account

Economic consequences of schizophrenia for family

What is schizophrenia?

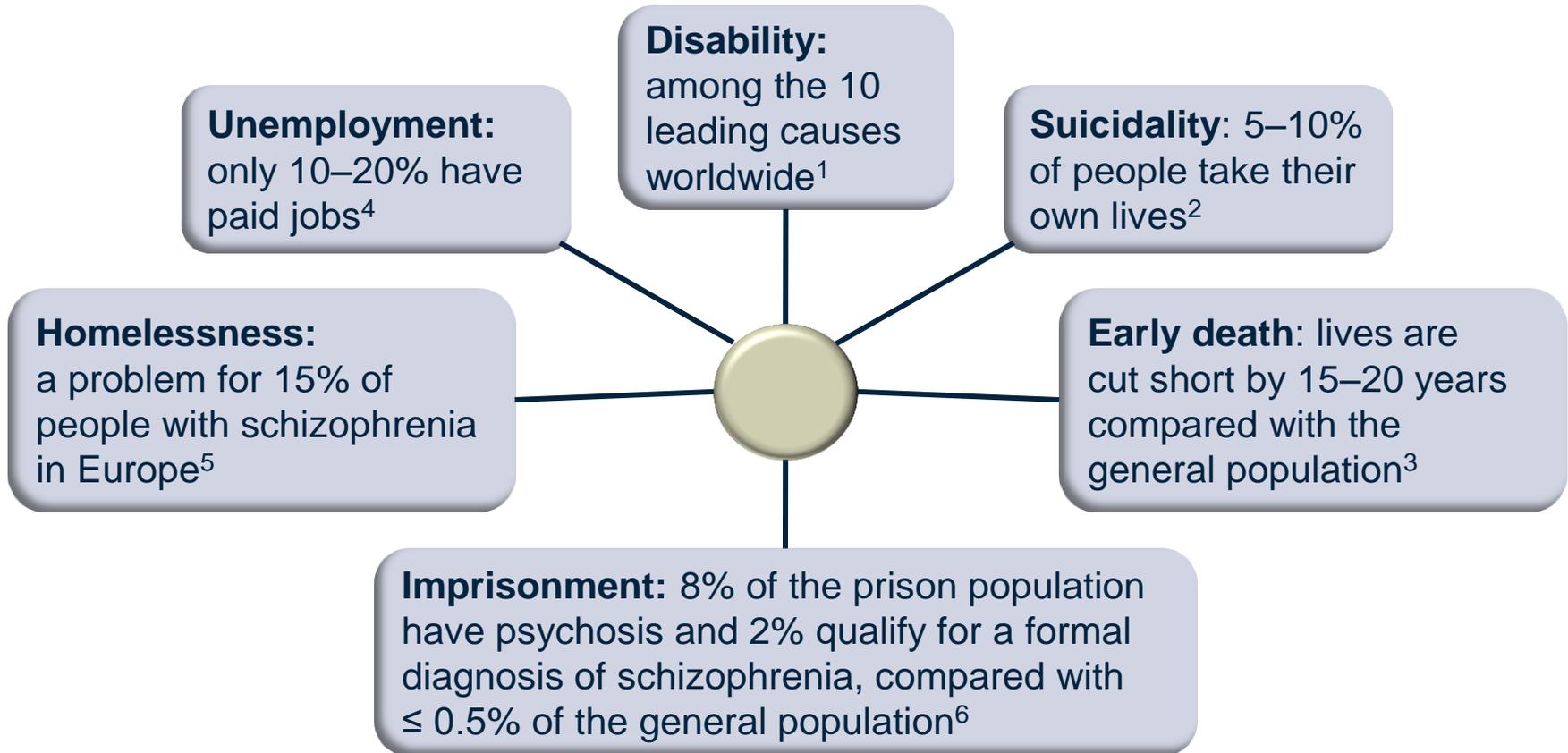
- A mental illness characterized by disturbances of thought processes, disrupted perceptions and diminished or exaggerated emotional responses
- ≥ 26 million people affected worldwide¹
- Can affect an individual's mood and behaviour and psychosocial functioning



1. World Health Organization. Available from: http://www.who.int/healthinfo/global_burden_disease/2004_report_update/en/

Psychosocial consequences

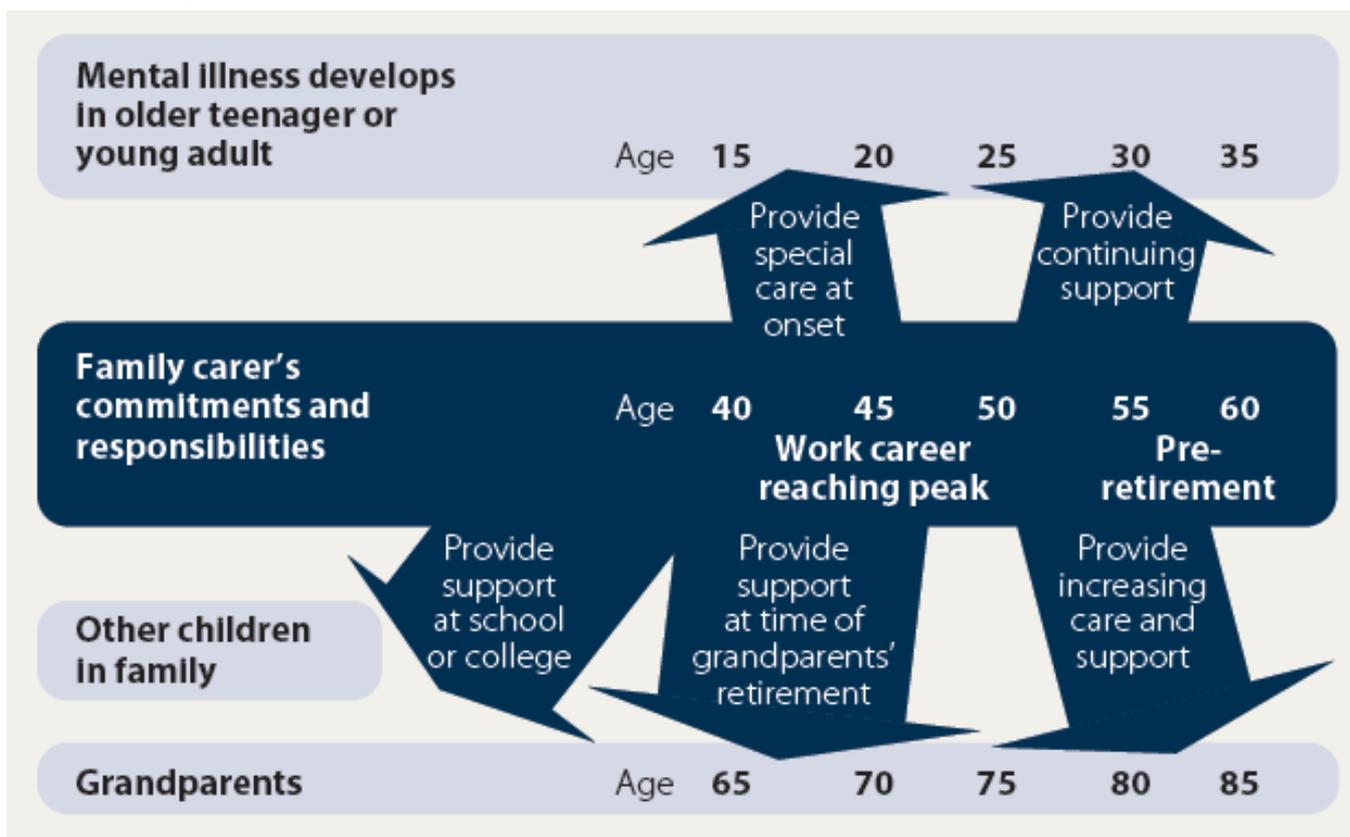
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1. Murray CJL, Lopez AD. Burden of disease. Cambridge, MA: Harvard School of Public Health, on behalf of the World Health Organization and the World Bank, 1996;
2. Hor K, Taylor M. *J Psychopharmacol* 2010;24:81–90; 3. Thornicroft G. *Br J Psychiatry* 2011;199:441–2; 4. Organisation for Economic Co-operation and Development. Available from: <http://www.oecd.org/health/theoecdmentalhealthandworkproject.htm>; 5. Bebbington PE *et al. Soc Psychiatry Psychiatr Epidemiol* 2005;40:707–17;
6. Andrew A *et al.* Available from: <http://www2.lse.ac.uk/LSEHealthAndSocialCare/pdf/LSE-economic-report-FINAL-12-Nov.pdf>

Impact of schizophrenia on family

- At the age of onset of a child's mental illness, a range of commitments and responsibilities can combine to create great family stress



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60s to 90s

90s to 2000s

Present time

Response

Remission

Recovery

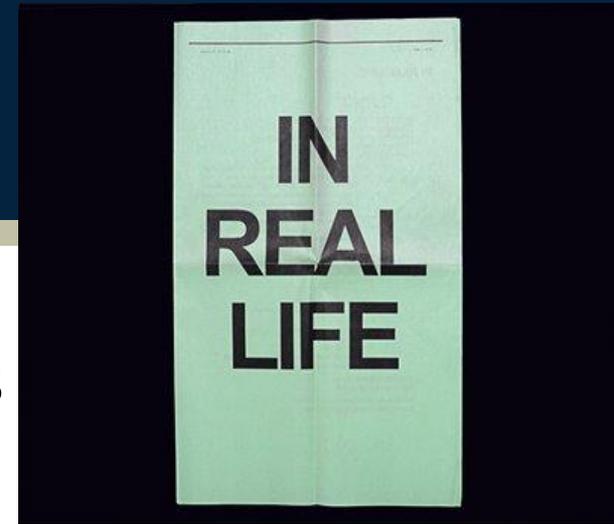
**Symptoms control;
relapse prevention**

**Symptoms are
mild or less**

*Functioning in
real life*

RECOVERY

- Independent living
- Interpersonal relationships
- Leisure activities
- Work/School functioning
- ...



The recovery movement

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- Importantly, the recovery movement has been led by people with schizophrenia
- From their perspective, recovery can be viewed as a process of personal growth despite the presence of mental illness
- Their resilience and empowerment play an important role in recovery: each individual uses their strengths to develop strategies to cope with residual symptoms and to focus on where they want their life to go
- Recovery focuses on progressing beyond the psychological effects of this condition towards a meaningful life in the community

Lieberman JA *et al. Psychiatr Serv* 2008;59:487–96; Mueser KT *et al. Annu Rev Clin Psychol* 2013;9:465–97

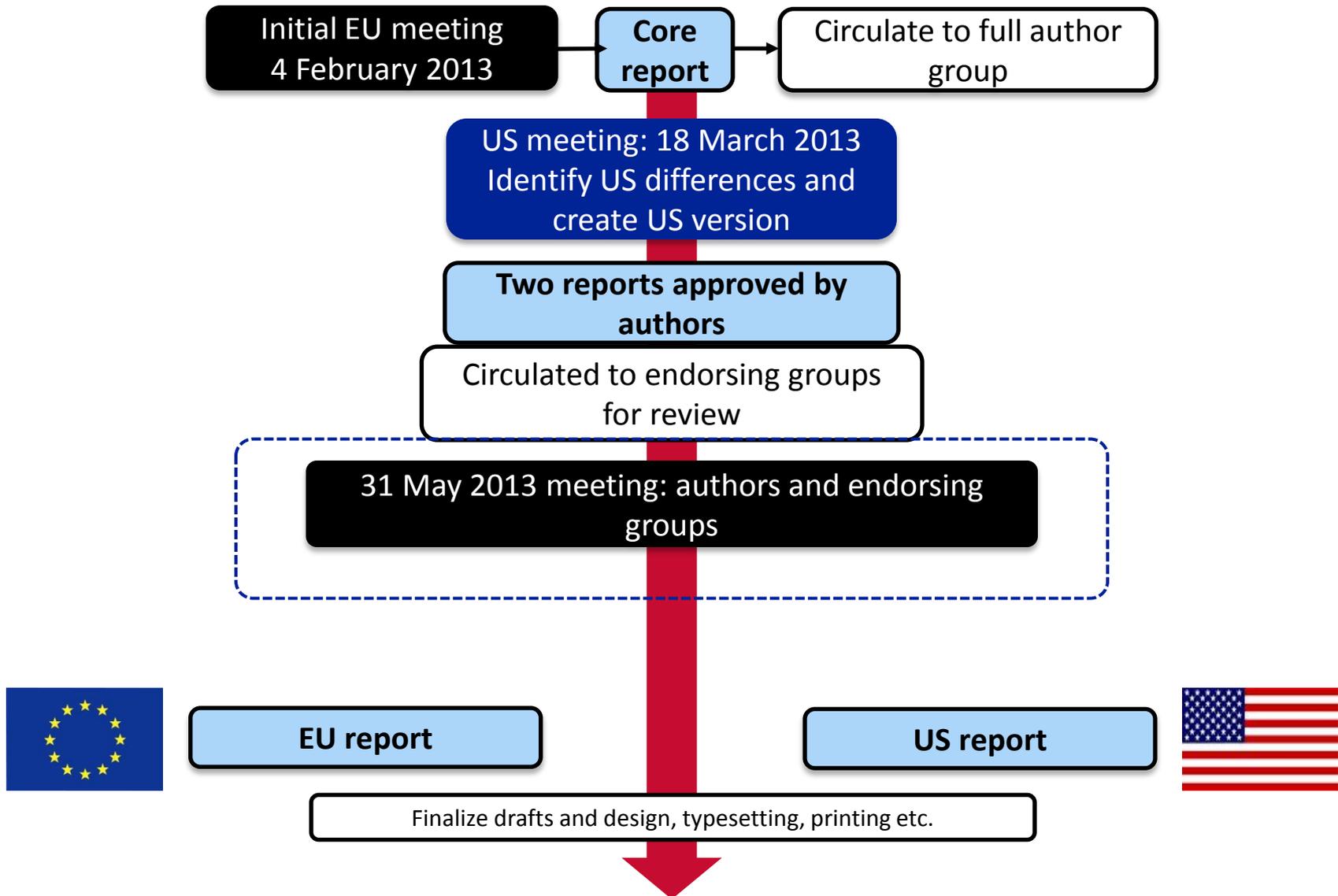
The challenge

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- Medication is just one part of changing the lives of people with schizophrenia
- **Society** as a whole faces these issues ...
 - ... not just people with schizophrenia and their carers
- **Healthcare policy needs to change**

The process

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Wide range of activities

- European Parliament Interest Group on Mental Health
- Short reports for specific audiences
 - Translated into major European languages
- Scientific symposia proposals (EPA, APA)
- Slide kits
- Journal features
- Awareness-raising activities led by advocacy groups (NAMI, GAMIAN, EBC)



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Schizofrenia

**Appello all'azione rivolto ai
decisori politici**

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Schizofrenia

**Sostenere il cambiamento di
politica – Guida per pazienti e
gruppi di advocacy**

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Schizophrenia—Time to Commit to Policy Change

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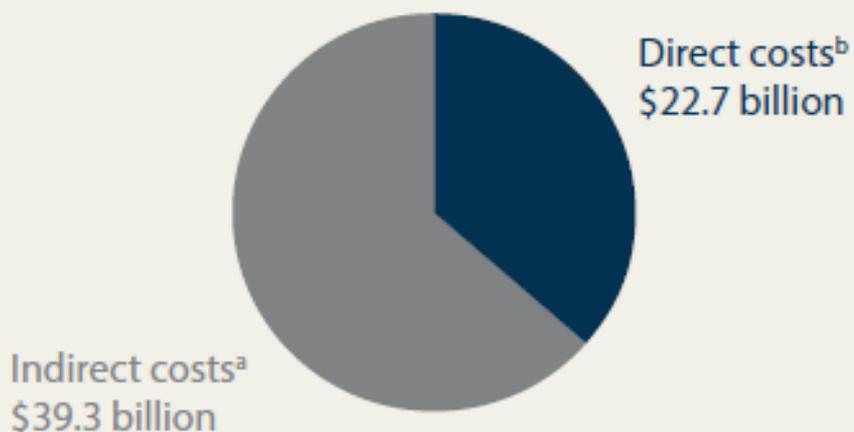
Clinical-political partnership to improve the lives of patients with schizophrenia

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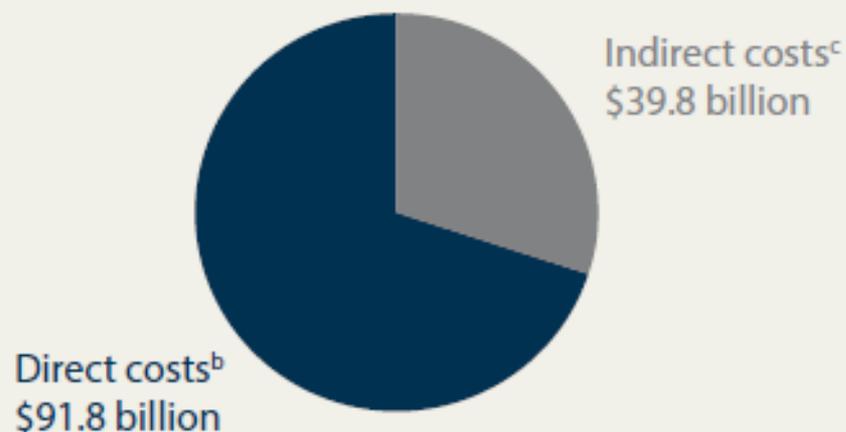
- ▶ Research produces progress in knowledge and enables mental health policies based on evidence
- ▶ Currently, investments in mental health research are scarce and poorly balanced among countries

Indirect and direct costs of schizophrenia compared with those of diabetes mellitus in the US in 2002

Schizophrenia
Total cost: \$62 billion



Diabetes mellitus
Total cost: \$131.6 billion



^aIndirect costs comprised absence from work, caregiver burden, premature mortality and reduced productivity at work. ^bDirect costs comprised outpatient care, medication, inpatient care and long-term care. ^cIndirect costs comprised disability, reduced productivity, premature mortality and absence from work

Wu et al *Journal of clinical psychiatry* 2005;66:1122–9; Hogan et al, *Diabetes care*

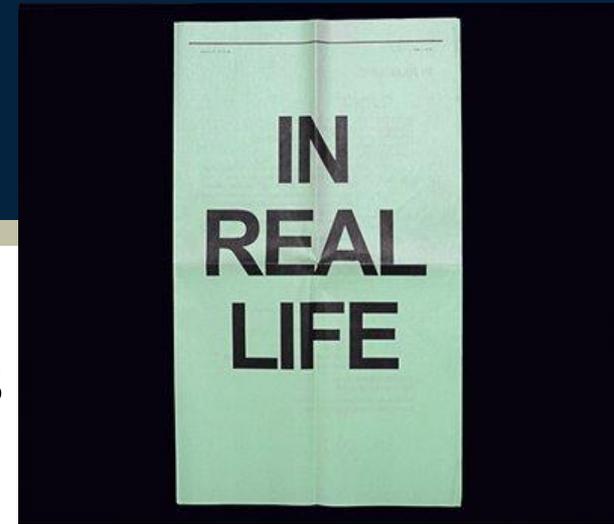
Economic burden of mental illness cannot be tackled without research investment

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Data from the National Institute of Mental Health (NIMH) in the USA and Canadian Institute of Health Research (CIHR) suggest that about 7% of research spend is on mental health, while the level of burden is nearer to 15%. The EU has an even lower profile for mental health research, and in its recent funding rounds has spent less than 2% on mental health research

RECOVERY

- Independent living
- Interpersonal relationships
- Leisure activities
- Work/School functioning
- ...



Factors influencing recovery

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Illness related factors

Personal resources

Social context

Policy recommendations (1)

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**



Make *best practice standard*: investment is needed

- ▶ Make existing tools available to all those with schizophrenia who need them
- ▶ Identify schizophrenia earlier and initiate treatment as soon as possible
- ▶ Invest in the expansion of existing services, research of the causes and mechanisms of the disorder and research aimed at improving standards of care

Illness related factors influencing recovery

What can be done more?

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Early recognition and intervention

Integrated programs

Shared decision making

Policy recommendations (2)

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, in order to **regularly revise, update and improve policy** on the management of schizophrenia



Clinical-political partnership to improve the lives of patients with schizophrenia

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- ▶ Psychosocial therapies are an essential component of treatment programs aimed at improving patients' functioning in the community
- ▶ Research aimed at tailoring treatment programs to individual deficit profiles should be a priority of the European political agenda

Evidence-based approaches

- Assertive community treatment
- Cognitive behavioural therapy for psychosis
- Cognitive remediation
- Family therapy/psychoeducation
- Peer support and self-help strategies
- Social skills training
- Supported employment
- Integrated treatment for coexisting substance abuse disorder

Promising approaches

- Cognitive adaptive therapy
- Healthy lifestyle intervention
- Interventions targeting older individuals
- Prodromal stage intervention
- Social cognition training
- Social rehabilitation

Policy recommendations (3)

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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 and emphasize the importance of positive societal attitudes towards mental illnesses

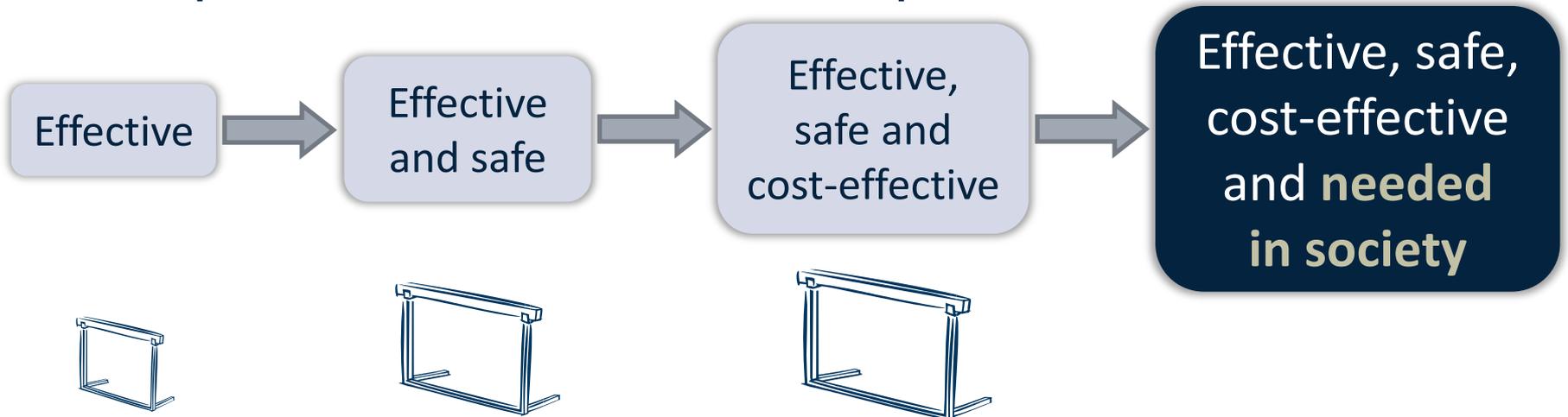


Clinical-political partnership to improve the lives of patients with schizophrenia

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Funding should be made available

- To support research into causes of negative symptoms and cognitive deficits
- To develop more effective pharmacological and psychosocial treatments, thereby facilitating rational implementation of treatment plans



Clinical-political partnership to improve the lives of patients with schizophrenia

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- Funding** should be made available for
- Supported housing and employment

Take-home message

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- **Better lives for people living with schizophrenia are a realistic goal**
- Much is still to be done, but we need:
 - an integrated team approach
 - collaboration with people with schizophrenia, their families and other sources of support
 - adequate funding
 - engagement by every stakeholder: policy makers at every level, clinicians and public agencies
- **With commitment from all, change can be achieved**

Next steps?

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Comments, questions and recommendations
are highly welcome

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The development of a policy report: Main steps

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- **Understand** the spectrum of needs
- **Research** specific disease area and management
- **Seek** an unrestricted grant from pharma
- **Select** experts from diverse backgrounds
 - Clinicians, patients, caregivers, advocacy groups, policy experts, health economists, researchers, nurses ...
- **Find** support for the authors independently of pharma
- **Create** a high-quality 'reference item' with evidence-based policy recommendations
- **Speak** the language of the target audience
- **Adhere** to principles of good publication practice
- **Disseminate** the findings as widely as possible!

The direct and indirect cost of Schizophrenia

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