

Schizophrenia: Time to Commit to Policy Change

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The Policy Report

**TIME TO
COMMIT TO
POLICY
CHANGE**

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Schizophrenia

Wolfgang Fleischhacker
Celso Arango
Paul Arteel
Thomas R E Barnes
William Carpenter
Ken Duckworth
Silvana Galderisi
Martin Knapp
Stephen R Marder
Norman Sartorius

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no editorial influence on the content

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

- Professor Wolfgang Fleischhacker, Austria
 - Professor Celso Arango, Spain
 - Mr Paul Arteel, Belgium
 - 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

The Working Group

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- Professor Wolfgang Gaebel, University of Düsseldorf, Germany
- Professor Howard H Goldman, University of Maryland, USA
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- Ms Sigrid Steffen, EUFAMI, Austria
- Ms Deborah Wan, World Federation for Mental Health, Hong Kong
- Professor Peter Woodruff, Royal College of Psychiatrists, UK

The Support Team

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- **Faculty liaison and logistical support**
- MCI Group: Oxford International
 - Bronwyn Friedemann
- **Public policy support**
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 - Katharine Murkett
 - Michael Shaw
 - Nicholas Stilwell (USA)

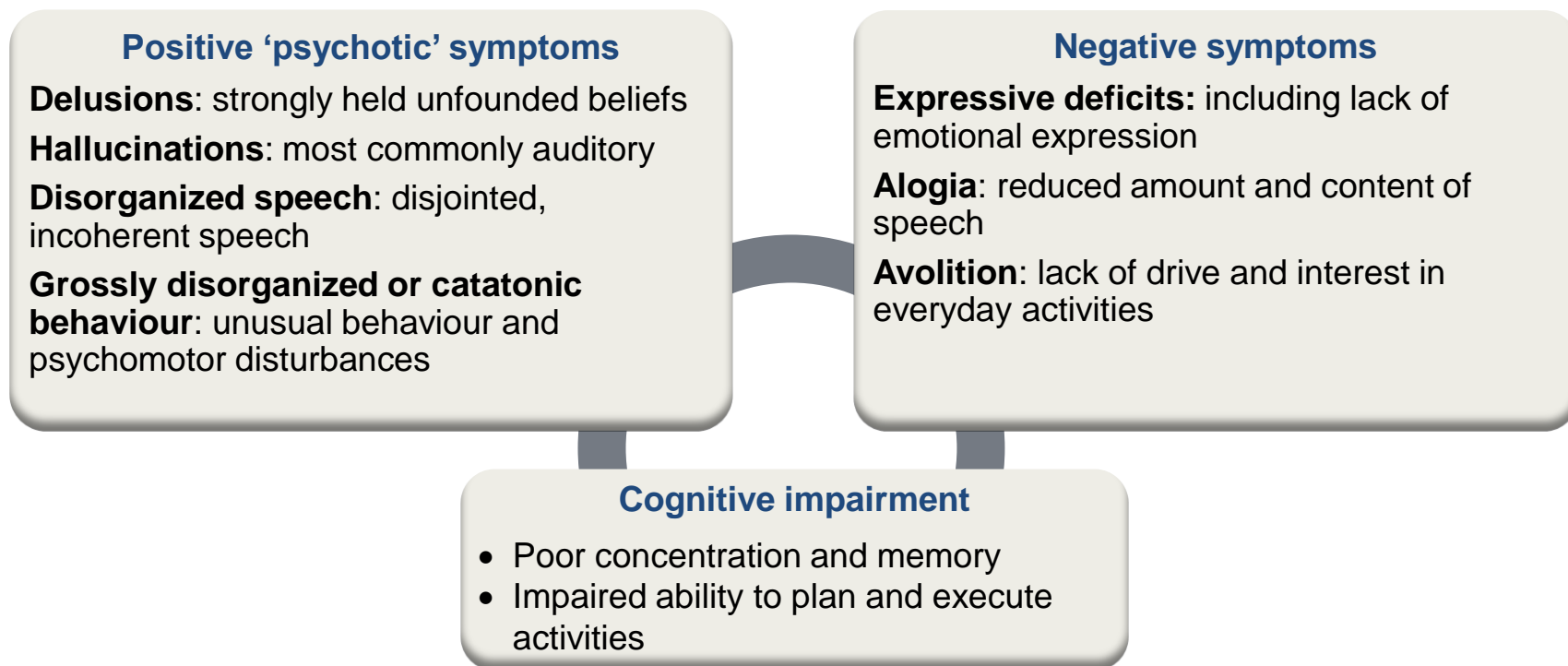
TIME TO COMMIT TO POLICY CHANGE

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- TIME TO
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- # Schizophrenia
- Wolfgang Hertrichner
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 Paul Arnold
 Thomas W. Barnes
 Will Carpenter
 Ken Duckworth
 Sharna Galdens
 Martin Knapp
 Stephen Marder
 Norman Sartorius
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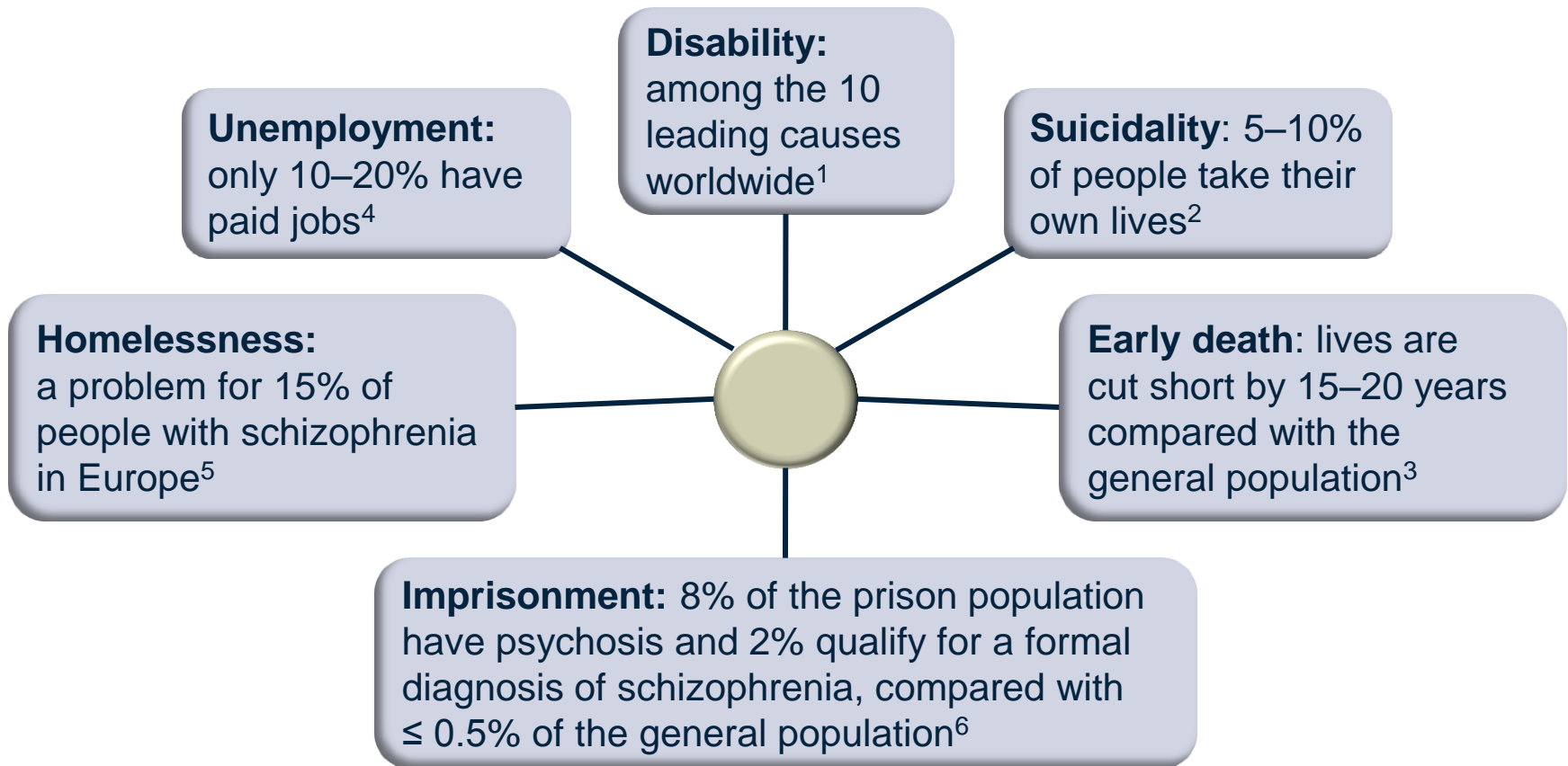
What is schizophrenia?

- 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



Psychosocial consequences

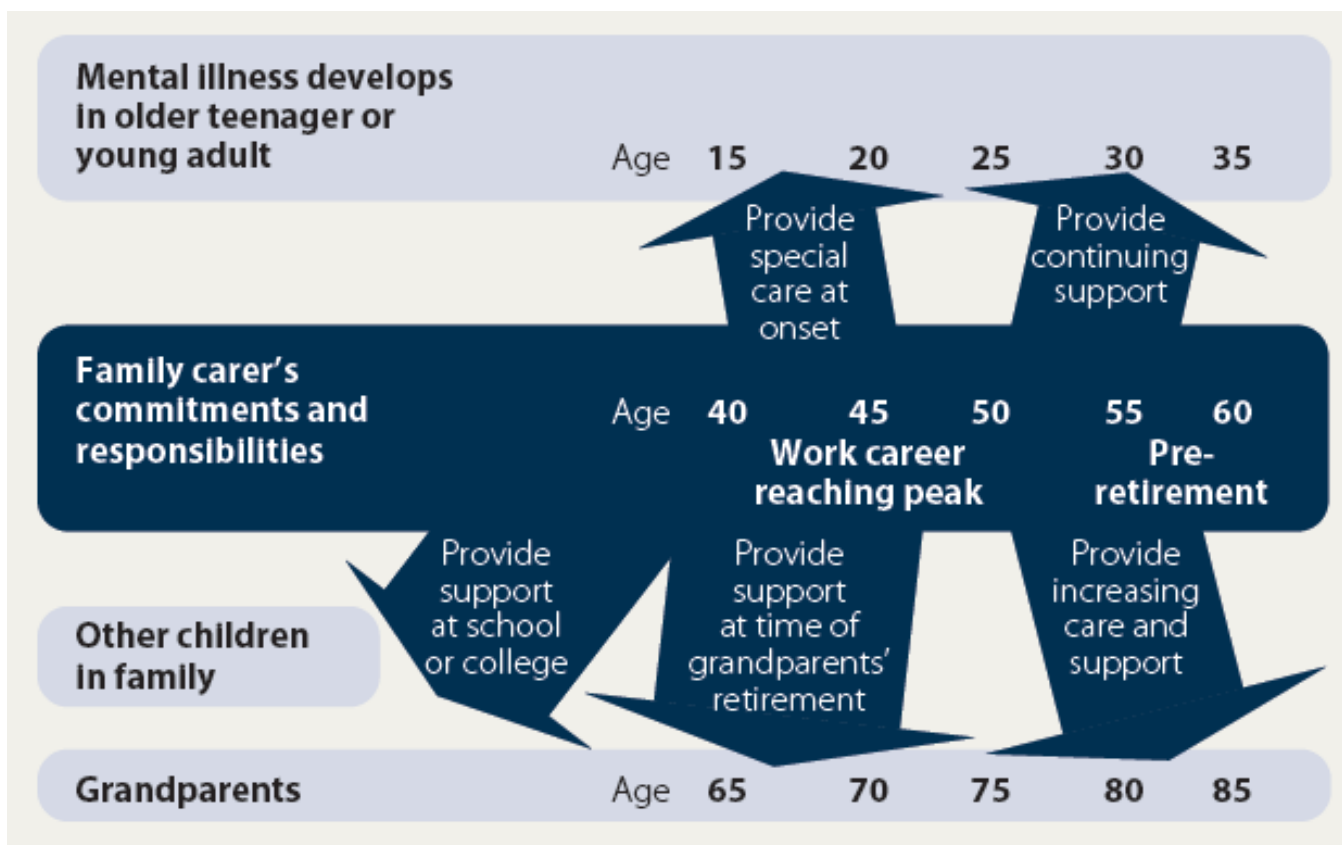
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2. Hor K, Taylor M. *J Psychopharmacol* 2010;24:81–90; 3. Thornicroft G. *Br J Psychiatry* 2011;199:441–2; 4. Organisation for Economic Co-operation and Development. Available from: <http://www.oecd.org/health/theoecdmentalhealthandworkproject.htm>; 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



60s to 90s

90s to 2000s

Present time

Response

Remission

Recovery

**Symptoms control;
relapse prevention**



**Symptoms are
mild or less**

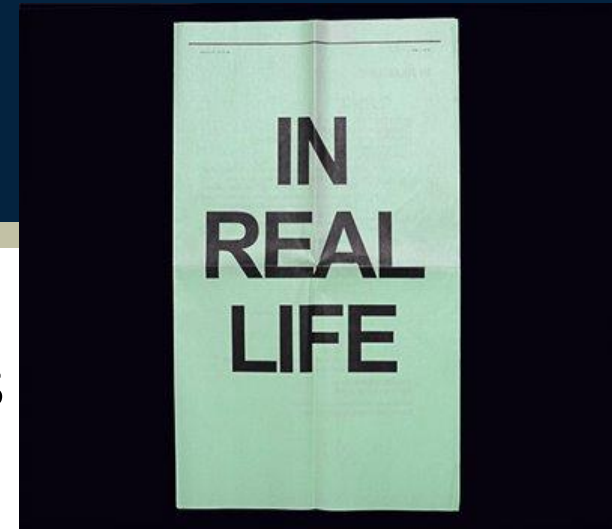


*Functioning in
real life*

RECOVERY



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



The recovery movement

- 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

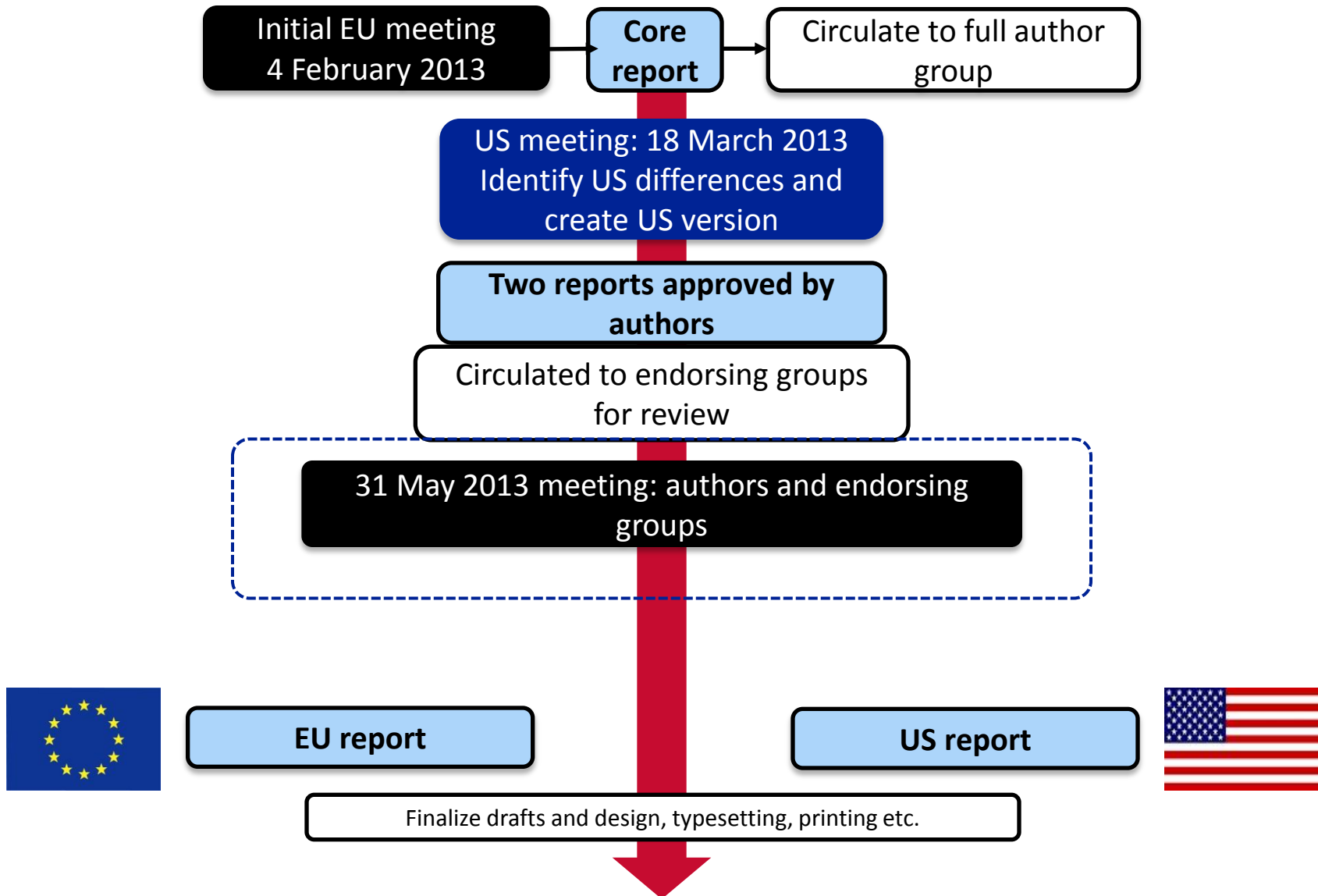
The challenge

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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

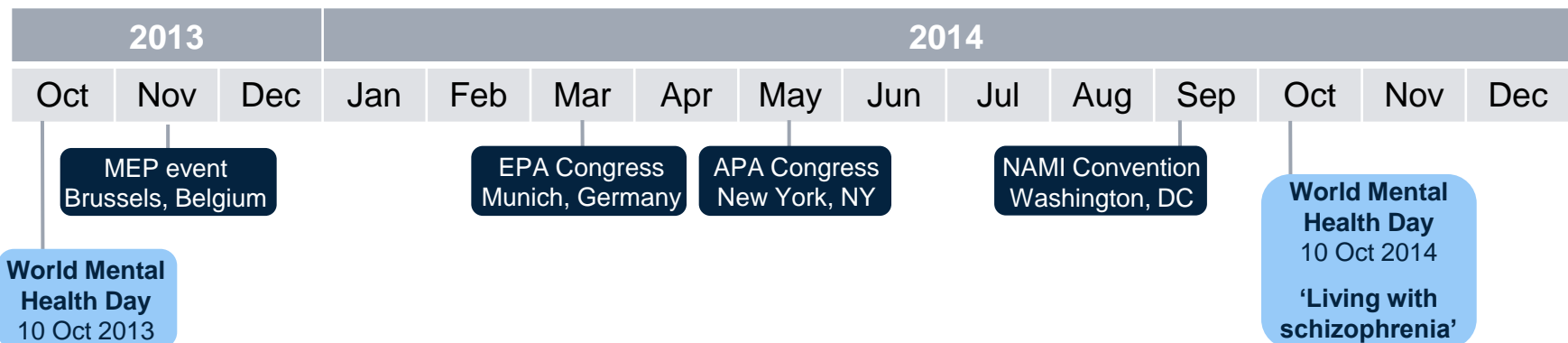
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Wide range of activities

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- 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**

Wolfgang Fleischhacker
Celso Arango
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Ken Duckworth
Silvana Galderisi
Martin Knapp
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Norman Sartorius

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Schizofrenia

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

Wolfgang Fleischhacker
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Paul Arteel
Thomas R E Barnes
William Carpenter
Ken Duckworth
Silvana Galderisi
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Schizophrenia—Time to Commit to Policy Change

W. Wolfgang Fleischhacker^{*,1}, Celso Arango², Paul Arteel³, Thomas R. E. Barnes⁴, William Carpenter⁵, Ken Duckworth⁶, Silvana Galderisi⁷, Lisa Halpern⁸, Martin Knapp⁹, Stephen R. Marder¹⁰, Mary Moller¹¹, Norman Sartorius¹², and Peter Woodruff¹³

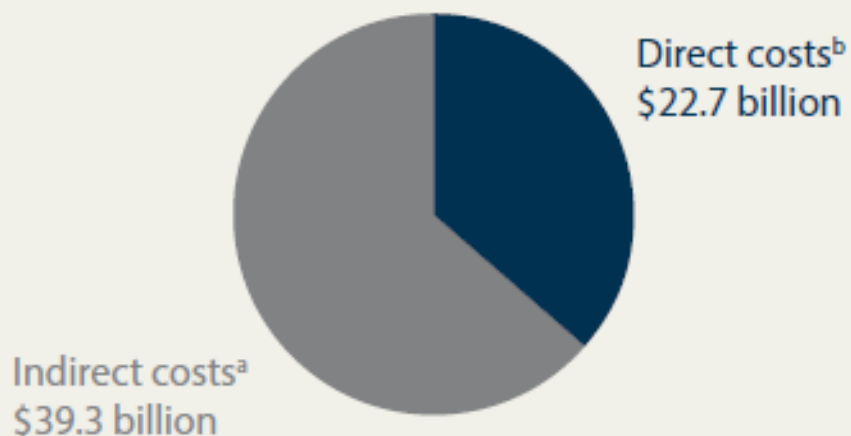
Clinical-political partnership to improve the lives of patients with schizophrenia

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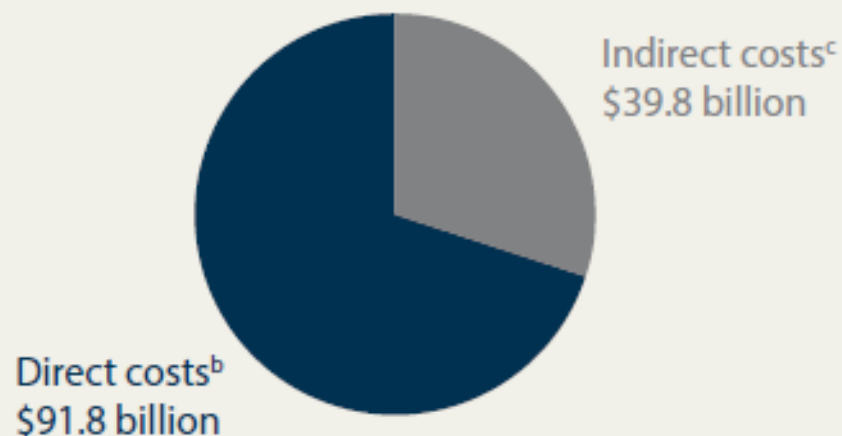
- ▶ Research produces progress in knowledge and enables mental health policies based on evidence
- ▶ Currently, investments in mental health research are scarce and poorly balanced among countries

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* 2003;26:917–32 ¹⁸

Economic burden of mental illness cannot be tackled without research investment

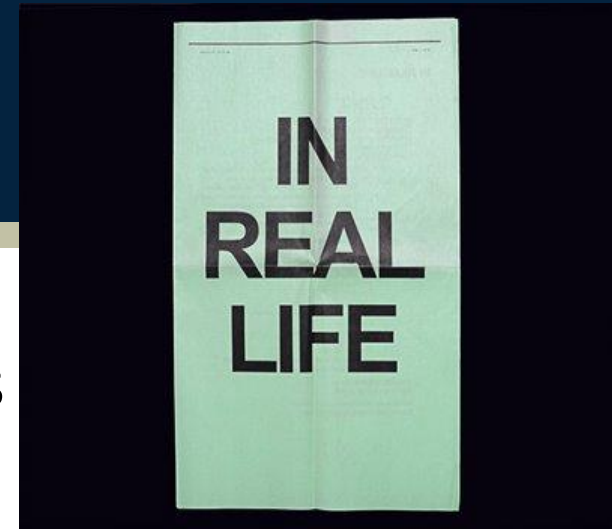
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Data from the National Institute of Mental Health (NIMH) in the USA and Canadian Institute of Health Research (CIHR) suggest that about 7% of research spend is on mental health, while the level of burden is nearer to 15%. The EU has an even lower profile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

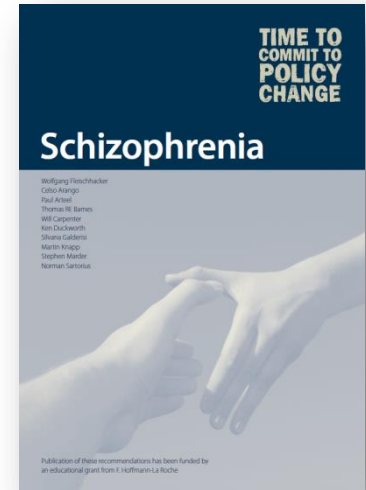
Galderisi et al, World Psychiatry in press

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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!**



Policy recommendations (1)

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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)

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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

Psychosocial interventions

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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

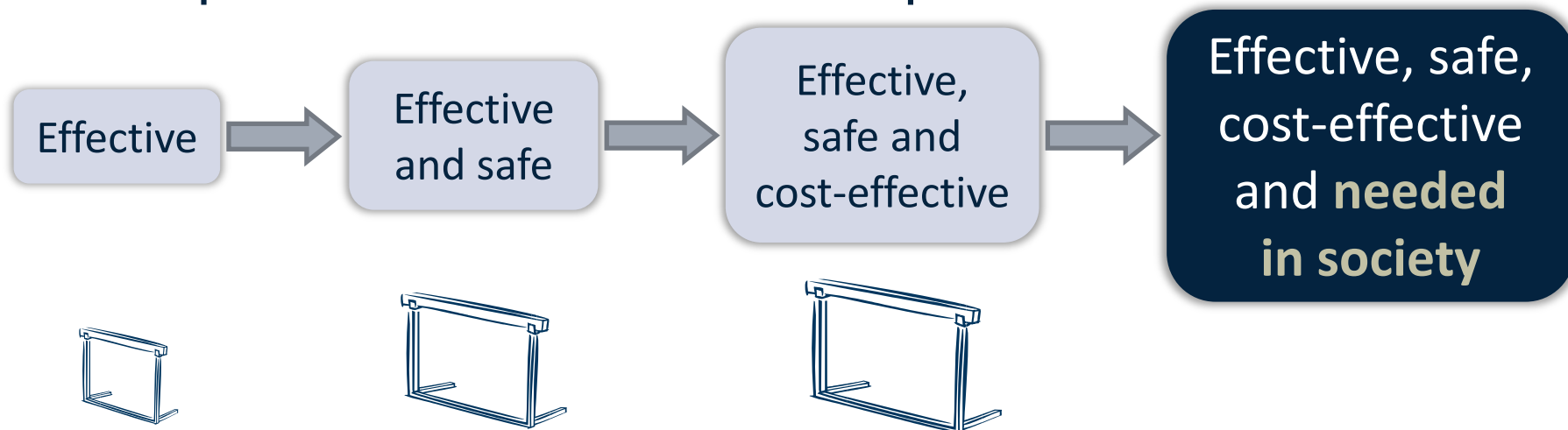


Clinical-political partnership to improve the lives of patients with schizophrenia

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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

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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