Schizophrenia: Time to Commit to Policy Change

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The Policy Report

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- World-leading clinical insight combined with practical reality of daily living
The Working Group

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    - Nicholas Stilwell (USA)
Goals of this report

- 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!
What is schizophrenia?

- A mental illness characterized by disturbances of thought processes, disrupted perceptions and diminished or exaggerated emotional responses
- ≥ 26 million people affected worldwide\(^1\)
- Can affect an individual’s mood and behaviour and psychosocial functioning

Positive ‘psychotic’ symptoms

- **Delusions**: strongly held unfounded beliefs
- **Hallucinations**: most commonly auditory
- **Disorganized speech**: disjointed, incoherent speech
- **Grossly disorganized or catatonic behaviour**: unusual behaviour and psychomotor disturbances

Negative symptoms

- **Expressive deficits**: including lack of emotional expression
- **Alogia**: reduced amount and content of speech
- **Avolition**: lack of drive and interest in everyday activities

Cognitive impairment

- Poor concentration and memory
- Impaired ability to plan and execute activities

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Psychosocial consequences

Disability: among the 10 leading causes worldwide\(^1\)

Unemployment: only 10–20% have paid jobs\(^4\)

Suicidality: 5–10% of people take their own lives\(^2\)

Early death: lives are cut short by 15–20 years compared with the general population\(^3\)

Homelessness: a problem for 15% of people with schizophrenia in Europe\(^5\)

Imprisonment: 8% of the prison population have psychosis and 2% qualify for a formal diagnosis of schizophrenia, compared with ≤ 0.5% of the general population\(^6\)

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.
Response

Remission

Recovery

Symptoms control; relapse prevention

Symptoms are mild or less

Functioning in real life

60s to 90s

90s to 2000s

Present time

TIME TO COMMIT TO POLICY CHANGE

Present time
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

• 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

Initial EU meeting 4 February 2013

Core report

Circulate to full author group

US meeting: 18 March 2013
Identify US differences and create US version

Two reports approved by authors

Circulated to endorsing groups for review

31 May 2013 meeting: authors and endorsing groups

EU report

US report

Finalize drafts and design, typesetting, printing etc.
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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APA, American Psychiatric Association; EBC, European Brain Council; EPA, European Psychiatric Association; GAMIAN, Global Alliance of Mental Illness Advocacy Networks; MEP, Member of European Parliament; NAMI, National Alliance on Mental Illness
Schizofrenia

Appello all’azione rivolto ai decisori politici

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

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

- 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

Indirect costs comprised absence from work, caregiver burden, premature mortality and reduced productivity at work. Direct costs comprised outpatient care, medication, inpatient care and long-term care. Indirect costs comprised disability, reduced productivity, premature mortality and absence from work.

Economic burden of mental illness cannot be tackled without research investment

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.

Cyhlarova et al, Mental Health Foundation 2010
RECOVERY

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

IN REAL LIFE
Factors influencing recovery

Illness related factors

Personal resources

Social context

Galderisi et al, World Psychiatry in press
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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?

Early recognition and intervention

Integrated programs

Shared decision making
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

- 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
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

**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

Effective, safe, cost-effective and needed in society
Clinical-political partnership to improve the lives of patients with schizophrenia

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

• 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?

Comments, questions and recommendations are highly welcome
The development of a policy report: Main steps

- **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

Olesen et al, European J Neurology, 2011