European Conference
Destigmatisation and Improving the Quality of Care in Psychiatry
Prague, 28 – 29 May 2009

Anti-Stigma Interventions in Germany:
Experiences from the Open the Doors Programme
and the German Alliance for Mental Health

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## Ten Years of Fighting Stigma and Discrimination in Germany: 1999 – 2009

<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
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<tbody>
<tr>
<td>1999</td>
<td>XI WPA World Congress of Psychiatry (Hamburg)</td>
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<tr>
<td>2000</td>
<td>Foundation “Open the doors e.V.”, Germany</td>
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| 2001 | Baseline Evaluation  
Start of Antistigma Interventions |
| 2004 | Foundation „German Alliance for Mental Health“  
Evaluation Follow-Up |
| 2007 | Start-up Congress  
“Education-Prevention-Integration“ |
| 2009 | Joint Conference “Mental Health and Well-being at the Workplace“ together with WHO Europe and EC DG Health & Consumers |
Destigmatisation and Improving Quality of Care: A Comprehensive Approach
Complex Intervention Strategies

**Intervention**

- Overcoming differences: improving treatment, care and integration
- Education and contact
- Protest, social and legal interventions

**Difference**

- Perception of differences
- Development of an attitude towards the difference

**Negative attitude** = Stigma

**Negative Behaviour** = Discrimination

**Positive attitude**

**Positive Behaviour?**

Open the Doors
The WPA Global Programme Against Stigma and Discrimination Because of Schizophrenia

Germany
Austria
Poland
FYROM
Switzerland
Slovakia
Romania
Spain
Italy
Greece
Turkey
Canada
USA
Brasilia
Chile
Morocco
Egypt
India
Japan
China
and more ..
Open the Doors Germany and Associated Projects

Foundation Centers:
- Kiel
- Itzehoe
- Hamburg (Irre Menschlich e.V.)
- Leipzig (Irrsinnig Menschlich e.V.)
- Düsseldorf
- Munich (ASAM)
- Munich (BASTA)
Examples of Anti-Stigma Activities from Open the Doors

- **Interventions towards target groups, e.g.:**
  - School projects
  - Police projects
  - Mental health staff

- **Public activities, e.g.:**
  - Film and theatre events
  - Public discussions

- **Focus on evaluation, e.g.:**
  - Population based (e.g. representative telephone surveys)
  - Target-group based (e.g. attitude questionnaires)
Evaluation of Antistigma Interventions

• Which interventions can influence the components of stigma related to mental illness (experimental evidence)?
  => Efficacy evaluation

• To what extent can real life interventions reduce stigma (field studies)?
  => Effectiveness evaluation

• Which components of an intervention contribute to the effect?
  => Process evaluation
Example I:
Mental Health Staff Project
“Anti-Stigma Competence” – Why and How?

Knowledge
- Psychiatric disorders
- Burden of stigma
- Stigma theories
- Stigma research
- History of psychiatry
- Empowerment
- Recovery
- Self-help groups and user-movement
- Stigmatisation of other social groups
- Human rights and patient rights
- ...

Attitudes
- Awareness for stigmatisation
- Self-respect and reflection of role
- Tolerance & acceptance
- Respect for human dignity and diversity
- Intercultural understanding
- Gender-sensitive attitude
- Empathy
- Maximum non-violence
- Reflection and critical thinking
- ...

Skills
- Communication and active listening
- Trialogical work
- Civil courage
- Multiply information
- Critical thinking and problem-solving
- Conscious conflict transformation
- ...

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Training of Mental Health Staff: Workshop Anti-Stigma Competence

- Target group: staff of psychiatric and psycho-social services
- Interdisciplinary in-house training
- 2 workshop days with 4 blocks:
  - Stigma, discrimination and social inclusion (introduction, self-reflection)
  - Roles, strategies, and challenges in stigma work (group work on own experiences)
  - Perspectives of experts by experience (self-help groups, solution-oriented group work)
  - Together against stigma (transfer to the workplace)
- Co-trainer with a personal history of psychosis
- Evaluation with pre/post/3month-follow-up assessments
Workshop Anti-Stigma Competence: Social Distance pre vs. post

Total (N=38): t-test for dependent samples $p = 0.006$
(3 month-follow-up currently in process)
Methods

Standardized telephone interview (10-15 min.)
First assessment: Spring 2001
Follow Up: Spring 2004
Sampling: “Next Birthday Method”

General Population aged 16 years +

\[ N_{\text{Contacts}} = 9.451 \]
\[ N_{\text{Total}} = 7.206 \text{ (Response Rate: 76 \%)} \]
\[ N_{\text{Follow Up}} = 4.586 \text{ (Follow-Up Rate: 64 \%)} \]

Assessment in Cities with/without Interventions:
• Düsseldorf / Munich (Antistigma Programmes)
• Cologne / Bonn (Awareness Programmes)
• Berlin / Essen (Controls)

Schizophrenia Research 98:184–193
"Would you probably or definitely ..."

- feel disturbed about sharing a room with someone ...
- be unable to maintain a friendship with someone ...
- be disturbed about working on the same job with someone ...
- feel afraid to have a conversation with someone ...
- feel ashamed if people knew someone in your family ...

"... who has schizophrenia" / "... diagnosed with schizophrenia"

N=4586; * Wilcoxon Test p <= 0.01

Gaebel W et al. (2008)
Schizophrenia Research 98:184–193
ANOVA: Time \( p \leq 0.001 \); Group n.s.; Interaction Time X Group \( p = 0.002 \)

Single comparisons: t-test f. dep. samples with Bonferoni-correction (* \( p \leq 0.016 \))

Social Distance 2001/2004

Range: 6 - 24
Std.-Dev.: 2,85

Gaebel W et al. (2008)
Schiz Res 98: 184–193
Respondents who could name causes of schizophrenia, especially according to the multi-factorial model, show lower degrees of social distance.

ANOVA: Time p = 0.004, Causes p = 0.002, Time X Causes n.s.

Persons who know at least one antistigma-project (Open the doors, ASAM, BASTA) show a higher decrease of social distance between 2001 and 2004 (t-test f. indep. samples: p = 0.003)

Implications for Antistigma Projects
Impact on Target Groups?

• Positive evaluations for different target groups in different countries

• BUT:
  • Longterm effects are rarely examined
  • The impact on the real situation of people with a mental illness remains open
Impact on the Public?

Correlations* were found between positive changes of social distance and:

- Locations of antistigma activities
- Knowledge of antistigma projects

BUT:

Effect sizes for both the found positive changes and the correlations are rather small.

There is only indirect evidence for the efficacy of antistigma projects on attitudes and behavior.

More research is needed!
German Alliance for Mental Health
German Alliance for Mental Health

• National alliance with long-term engagement of participating groups and associations

• Confederation of local and nationwide antistigma projects and initiatives together with societal institutions (e.g. politics, church, work, health care, sports …)

• Targeting different mental illnesses

• Active role of service user and caregiver associations (BPE, BApK) in planning and implementation of anti-stigma interventions (“trialogue“)
German Alliance for Mental Health: Structure

Patronage: Federal Health Minister Ms. Ulla Schmidt
Funding: DGPPN and BMG

General Assembly
approx. 50 Member Organisations

Mental health organisations, anti-stigma initiatives, service user and caregiver organisations, health départements (state, regional), psychiatric associations, medical associations etc.

Steering Committee

DGPPN, Open the doors, BMG, BPE, BApK, BÄK, Dt. Alzheimer-Gesellschaft, Aktion Psychisch Kranke, Irrsinnig Menschlich, AG Psychiatrie der AOLG, BASTA, Kompetenznetz Schizophrenie

Workgroups
Public relations, fundraising …
Examples of Activities
The plenum adopted the topic “Active Combat of Stigmatization and Discrimination of People With a Mental Illness” with great majority.

Deriving Tasks:

- Adopting “Stigma of Mental Illness” into medical education curricula
- Lobbying for an equitable mental health care system
- Advocating in cases of structural discrimination
Annual Weeks on Mental Health

2007: First Week of Mental Health in Berlin
Approx. 85 events all over the city
Patronage: Major of Berlin, Klaus Wowereit

October 2008
• In the Sign of Art and Culture
• Approx. 130 events

October 2009
• Mental Health in the family
Member Activities

• **Film festival** “Ausnahme|Zustand” by Irrsinnig Menschlich (October 2008 – December 2009)
  Motto: “Hunger for Life” – focus on younger people
  Approx. 40 participating cities in Germany

• Anti-stigma interventions in **schools** by BASTA, Irrsinnig Menschlich, Irre Menschlich Hamburg, etc.

• Anti-stigma interventions at **police** academies and departments by BASTA
Member Activities

• “Mentally ill at work – what to do?” Anti-stigma project in enterprises by BApK (national caregiver/family self-help association) and BKK (health insurance fund)

• Action group against oblivion of NS euthanasia victims organized by BPE (national users‘ association): Remembrance Day in Berlin (first Saturday in September)
Member Activities

• Against Depression Campaign by German Alliance Against Depression

• Sponsored Anti-Stigma Award by Open the Doors Germany together with DGPPN (German Society of Psychiatry, Psychotherapy and Neurology)

• Photo-Exhibition by Irre Menschlich Hamburg
Joint Conference “Mental Health and Well-Being at the Workplace” (March 2009)

Cooperating Partners:
- Federal Ministry for Health
- World Health Organization, Regional Office for Europe
- European Commission

Topics:
- Prevention of mental health problems at the workplace
- Pathways to integration in today’s regular job market
- Overcoming stigma and discrimination at the workplace
Future Perspectives
Perspectives

• Developing an evidence-based strategy for anti-stigma interventions (ongoing project funded by the Federal Ministry of Health)

• Refining and intensifying public as well as targeted interventions together with improving standards of treatment and care (DGPPN: guidelines, quality indicators)

• Cooperating with international partners, e.g.:
  • WPA Section on Stigma
  • WPA Task Force on Stigma against Psychiatry and the Psychiatrist

• Implementation of the EU Mental Health Action Plan
European Pact for Mental Health and Well-Being
Brussels, June 13, 2008

Call for action in 5 priority areas – activities by the German Alliance for Mental Health:

• Prevention of depression and suicide
  => German Alliance against Depression

• Mental health in youth and education
  => School projects as “Crazy? So what!” from Irrsinnig menschlich e.V.,
    further provider: Irre menschlich e.V., BASTA
  => Deutsche Gesellschaft für Kinder- und Jugendpsychiatrie

• Mental health in workplace settings
  => WHO Joint Conference, Berlin March 2009
  => Symposium in cooperation with the German Medical Association 2009

• Mental health in older people
  => Deutsche Alzheimergesellschaft

• Combating stigma and social exclusion
  => Open the doors
  => Project “Anti-stigma Interventions” (funded by the Federal Health Ministry)
Thank You for Your Attention!