



Measuring the impact of stigma: what can we learn from INDIGO study?

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G.Thornicroft: What Can We Do Internationally ?



- Establish an evidence base on the nature of:
 1. Ignorance
 2. Prejudice
 3. Discrimination
- Establish evidence on effective interventions for all 3
- Transfer this knowledge to policy makers & practitioners
- Relentlessly advocate for parity of disability rights

What is Stigma?



- Problems of knowledge = Ignorance
- Problems of attitudes = Prejudice
- Problems of behaviour = Discrimination

Anticipated Discrimination

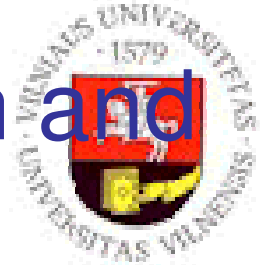


- Similar concepts: self-stigma, self-discrimination
- Avoidance of important actions: eg
 - applying for a job
 - seeking a close relationship
- because of previous failure
or
- in anticipation of failure



Understand Discrimination

International Study of Discrimination and Stigma Outcomes (INDIGO)



Principal Investigators

- Graham Thornicroft, Institute of Psychiatry, King's College London
- Diana Rose, Service User Research Enterprise, IoP, KCL
- Norman Sartorius, WPA Global Programme to Reduce Stigma because of Schizophrenia, Geneva

Study Co-ordinating Team

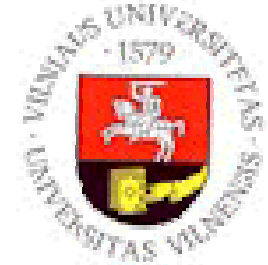
- Elaine Brohan
- Richard Church
- James Fisher
- Ros Furling
- Aliya Kassam
- Ann Law
- Morven Leese
- Mauricio Moreno

Aim of the study



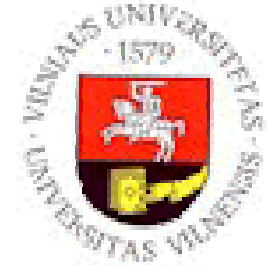
- **To describe the nature, direction, and severity of anticipated and experienced discrimination reported by people with schizophrenia**
- **To evaluate possible limitations of the DISC when assessing stigma impact**

Method of the study



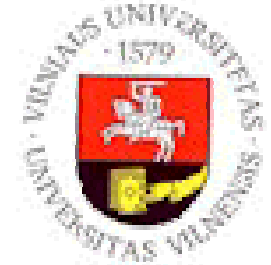
- *Consumer / Service User Study:*
- qualitative and quantitative consumer interviews
- information from people with a diagnosis of schizophrenia of actual experiences of discrimination
- cross-sectional survey in 27 countries, in centres affiliated to the INDIGO Research Network, by
- use of face-to-face interviews with people with schizophrenia. Discrimination was measured with the newly validated discrimination and stigma scale (DISC), which produces three subscores: positive experienced discrimination; negative experienced discrimination; and anticipated discrimination

27 INDIGO Sites



- Austria
- Belgium
- Brazil
- Bulgaria
- Canada
- Cyprus
- Czech Republic
- England
- Finland
- France
- Germany
- Greece
- Hungary
- India
- Italy
- Lithuania
- Malaysia
- Netherlands
- Norway
- Poland
- Portugal
- Romania
- Slovakia
- Slovenia
- Spain
- Switzerland
- Tajikistan
- Turkey
- USA

Site Leads



- Graham Thornicroft (PI)
- Diana Rose (PI)
- Norman Sartorius (PI)
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- Vesna Švab
- Olga Cuenca
- Wulf Roessler
- Alisher Latypov
- Alp Ucok
- Linda B. Cottler
- Dick Warner

Discrimination and Stigma Scale (DISC)



Report by consumers about experiences of discrimination in:

- personal relationships
 - housing
 - education
 - family life
 - work
 - transport and travel
 - financial affairs
 - community life
 - health & social services
 - privacy and safety
 - children
 - avoidance
- 732 people interviewed
- 27 countries

Topic of employment was addressed through the following items



Item 19: Ever treated differently in **finding a job**

- Item 20: Ever treated differently in **getting or keeping a job**
- Item 24: Ever treated differently when **getting welfare benefits/disability pensions**
- Item 42: How much have you stopped yourself from applying for work/training/education
- Item 49: How much have you been denied the social or welfare benefits that you deserve



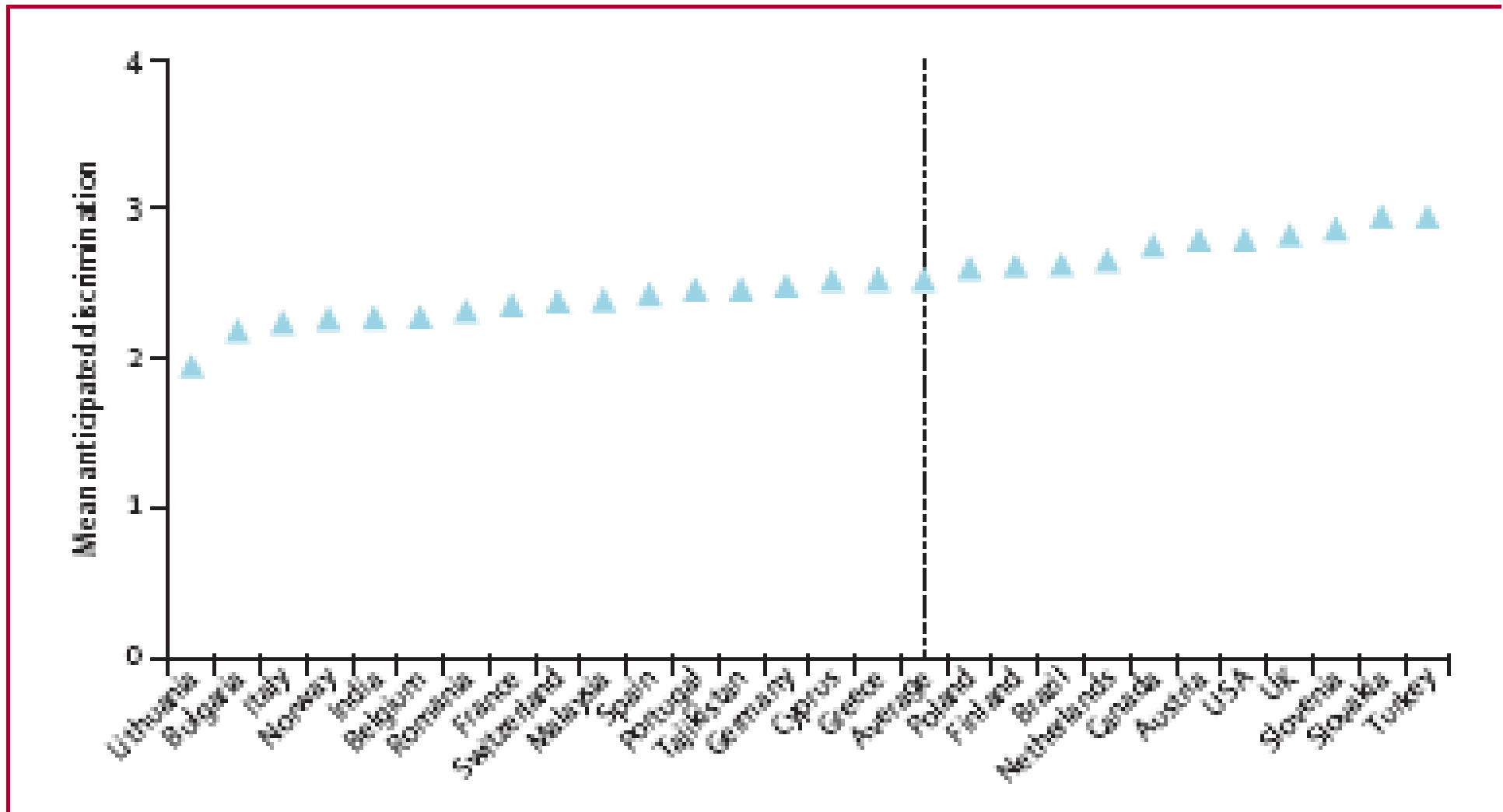
- **Global pattern of experienced and anticipated discrimination against people with schizophrenia: a cross-sectional survey**
- *Graham Thornicroft, Elaine Brohan, Diana Rose, Norman Sartorius, Morven Leese, for the INDIGO Study Group**
- *The Lancet 2009; vol. 373; p. 408-415*

Demographics related to employment

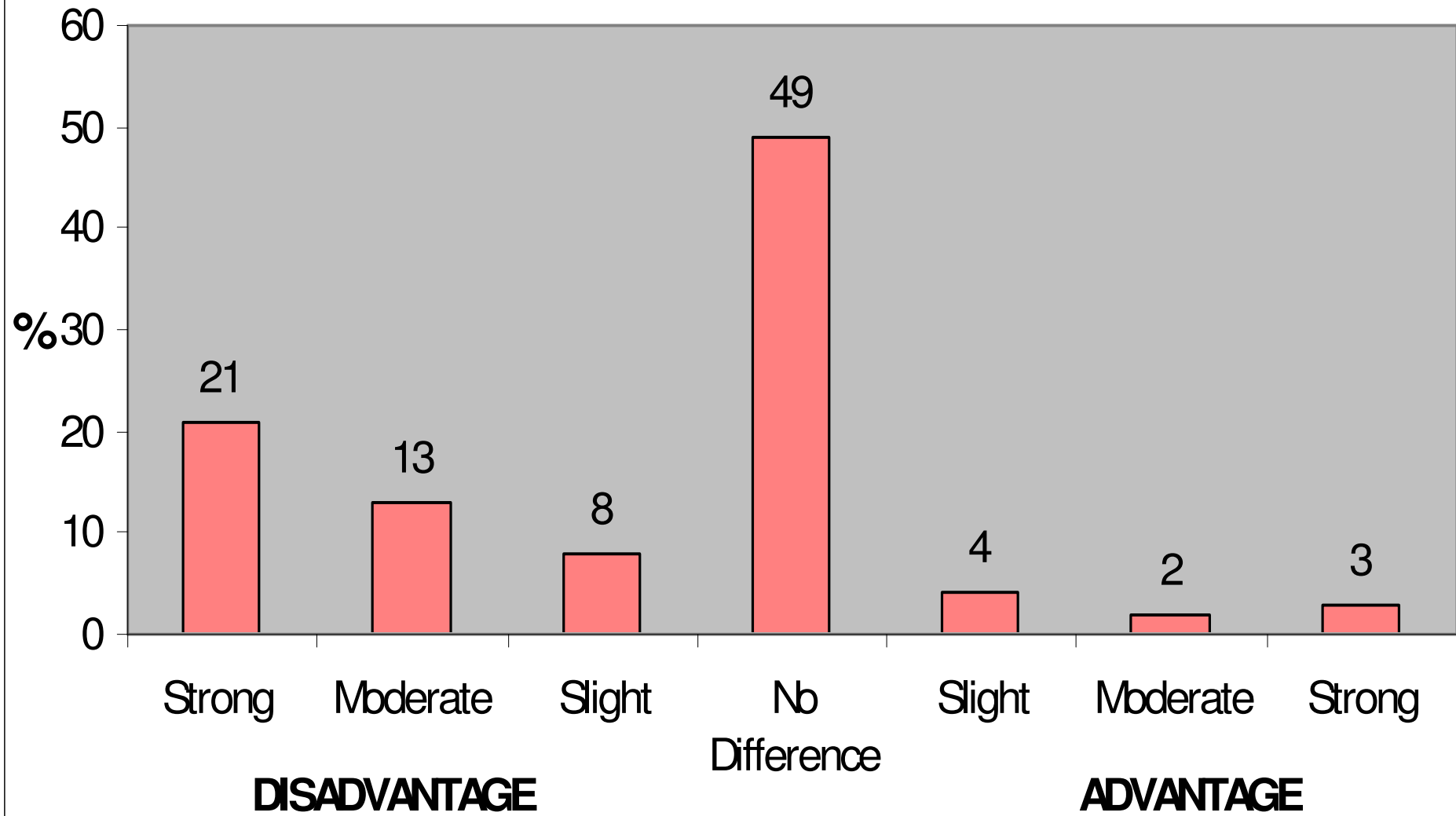


- Mean age: 39.2 (SD=11.32)
- 38% women, 62% men
- Diagnosis: schizophrenia, all clinical forms
- 30% currently in some employment
- Total years in education: mean 12.61 (SD=3.35)
- Time since first contact with MH services:
14.32 (SD=9.65)

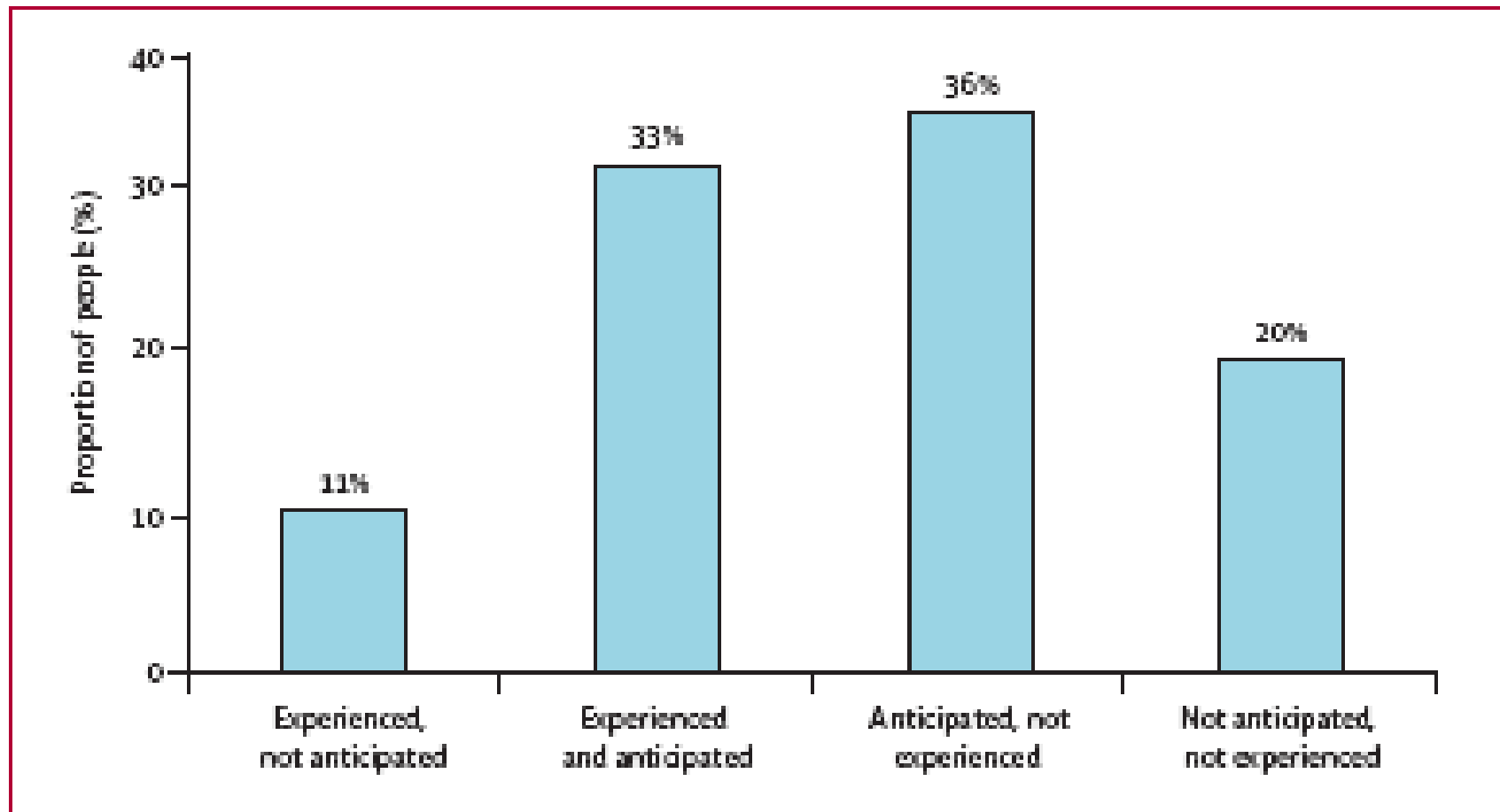
Mean anticipated discrimination subscore by country (0-4)



Item 20: Ever treated differently in keeping a job? (N=518)



Discrimination in finding or keeping work



Limitations of the study results



- Experiences of discrimination were recorded without respect to when such events occurred.
- Other possible reasons for discrimination were not evaluated (gender, race, ethnicity, disability that could lead to inability to work).
- “Work” was difficult to assess, because of variance of cultural traditions across the globe (not paid work, work in household etc.)

INDIGO study conclusions



1. Stigma due to schizophrenia constitute substantial barrier to employment possibilities in about 40% respondents.
2. Only little part of respondents experienced stigma while getting welfare benefits, but practically a large number of others were unaware what benefits they were entitled to.
3. 44% of people with schizophrenia have stopped themselves from applying for job or training/education.

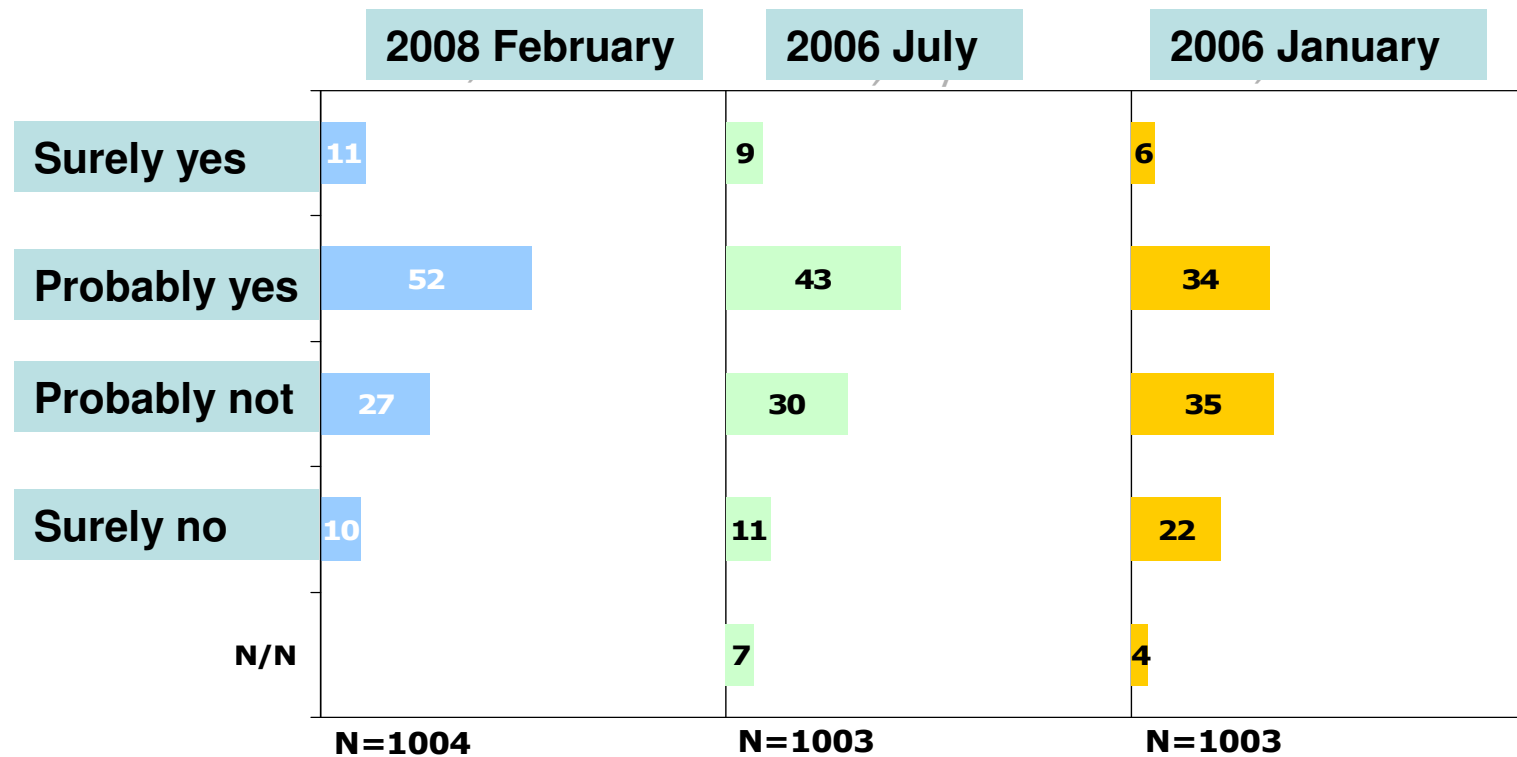


EQUAL project in Lithuania: “Establishing of supported job places for people with mental disability” (2005-2007)

- AntiStigma public education campaign
- as component targeting both general population and employers

Changes of public attitudes towards abilities to work of people with mental disabilities in Lithuania 2006 - 2008

In your opinion, could people with mental disabilities do a job for pay? (%)



Destigmatisation through new projects

- **ASPEN project:** European antistigma network (led by Prof. Graham Thornicroft London Institute of Psychiatry, King's College, UK)
- It will also research applicability of methods of assessment of stigmatisation and discrimination experiences by DISC-12 questionnaire for people with major depression (age 16 – 65)