# THE ASPEN PROJECT

Anti Stigma Programme European Network

# WORK PACKAGE 4: BEST PRACTICE COUNTRY REVIEWS OF EVIDENCE BASE FOR TACKLING STIGMA OF MENTAL ILLNESS

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# ANTI STIGMA PROGRAMME EUROPEAN NETWORK: "BEST PRACTICE"

#### COUNTRY REVIEWS OF EVIDENCE BASE FOR TACKLING STIGMA OF MENTAL ILLNESS

This section contains country reviews of the evidence base for addressing stigma associated with mental health problems - including depression - completed in partnership with all 20 participating sites in 18 EU countries preceded by a review of English-speaking countries.

#### CONTENTS

Introduction to reviews	2
English language countries	3
Belgium	20
Bulgaria	37
Finland	49
France	67
Germany	81
Greece	100
Hungary	106
Italy	116
Netherlands	134
Romania	154
Slovakia	156
Slovenia	164
Spain	177
Turkey	189

#### **INTRODUCTION TO COUNTRY REVIEWS**

The aim of the literature search for ASPEN 'Work Package 4: Best Practice' was to provide a summary of the evidence base and pointers for promising practice for effective interventions to tackle stigma and discrimination associated with depression in the European countries participating in ASPEN. The reviews were led by the ASPEN national partners agency under guidance and support from WP4 researchers who assisted with the parameters and editing of each report. All countries were able to produce reports with the exception of Portugal and Lithuania who found no published or grey literature on stigma and depression. Some country reports introduce data and studies on stigma associated with general (undefined or generic) mental illness or specific mental illnesses other than depression where they had a paucity of studies.

#### Agreeing search terms

It was important that each country undertook a robust review of the evidence base in their country. To support this, a clear briefing note was provided in order that researchers could identify key studies and undertake subsequent citation tracking. The same search terms were provided to each of the individual participating EU countries involved in ASPEN. These terms were agreed by an expert reference group, who included academics, psychiatrists, public health, human rights and mental health NGOs. The terms were:

Depress\* or Dysthymi\* or "Adjustment Disorder\*" or "Mood Disorder\*" or "Affective Disorder" or "Affective Symptoms" AND Stigma, attitudes, Prejudice, Stereotyp\*, Discrimina\*. AND intervention, health education, 'mass media', communication\*, 'multi media", multimedia\*, 'mass communication', 'audiovisual equipment', 'patient information', 'visual information', 'radio', 'television', leaflet\*, posters\*, pamphlet\*, 'print media', printed media', skit\*, 'folk media', broadcast\*, film\*, telecommunication\*

#### A REVIEW OF EVIDENCE ON REDUCING STIGMA AND DISCRIMINATION ASSOCIATED WITH MENTAL HEALTH PROBLEMS, PARTICULARLY DEPRESSION, IN THE UK AND ENGLISH-LANGUAGE COUNTRIES

#### By Lee Knifton, Neil Quinn, Lindsay Siebelt and Tine Van Bortel

#### INTRODUCTION

This section provides an overview of studies and evidence from English-speaking countries including the UK, USA, Canada, Australia and New Zealand. We have also included selected evidence from other countries where it has been published in English language. The aim is to examine both 'what works' and 'promising practice' in tackling stigma and discrimination towards people with mental health problems generally and for people with depression specifically. The reason for selectively broadening our review beyond the participating EU countries is to ensure that wider learning can then help to shape best practice.

#### **METHODOLOGY**

In order to identify key studies, in the first instance, a search of PubMed databases was conducted using the agreed terms. However, since this search covered so many countries, rather than just a single country review, this was then modified to include a more focused set of terms that reflected the main aims of the search. These new terms were as follows:

(depressi\*) AND (stigma\* OR discrimina\* OR attitud\* OR prejudice\*) AND (intervention OR education OR public OR awareness OR programme OR initiative OR resource OR campaign OR workshop OR media)

The search was limited to include papers written in English only. 3520 results were obtained which were then checked individually for relevance to the project, leaving a total of 51 papers. Of these 51 however, several had English abstracts but were written in a foreign language, and a number had limited access; therefore the initial number of papers available for full review was 30. A review of citations on these papers was then undertaken. It was thought to be appropriate to include all 51 papers that had been deemed useful in this citation search because, while 19 of these papers were inaccessible, they were still relevant and it was thought they could provide information on further useful studies. The citation search yielded a further 40 papers which were fully accessible. Finally, a further 11 fully available papers known to the researchers or found through a Google Scholar search (using combinations of the second search terms above) were then added to this, resulting in a total of 81 papers.

An initial review of the studies identified 2 categories: papers could be distinguished by their focus in tackling stigma of depression specifically, or mental health problems as a more general issue (sometimes including depression with varying levels of specificity); They can sometimes be distinguished by a difference in their primary aim of addressing either knowledge, stigma and discrimination however, this was not always distinct or clear.

#### **FINDINGS**

Stigma and mental illness

Stigma can be defined as a combination of ignorance, prejudice and discrimination (Thornicroft et al., 2007). Link and Phelan (2001) describe stigma as the co-occurrence of labelling, separation, stereotyping, discrimination and status loss. They acknowledge that power differences enable discrimination to occur. The inequities that this creates are exacerbated by the fact that stigma and discrimination can operate at a number of levels including family stigma, community or public stigma and institutional discrimination. It can increase the self-stigma or anticipated discrimination of the person affected (Thornicroft et al., 2009). It is one of the main barriers to improving care and inclusion and is a major barrier in preventing those with mental health difficulties from accomplishing their life goals (Corrigan, 2003). It has a strong impact upon people with depression (Priest, 1991).

Reducing stigma and discrimination is context-dependant and therefore institutional and structural changes such as equality legislation, progressive mental health services, community based care and service user / consumer empowerment are important in reducing stigma and discrimination. However, in terms of more specific approaches to reducing public stigma, three main methods of anti-stigma intervention - protest, contact and education - are most often discussed in the literature. Contact has been shown to have the most consistent results in reducing stigma, while protest has more mixed effects (Corrigan et al., 2001; Corrigan and Gelb, 2006).

The need for more research to identify evidence based approaches to reducing mental illness stigma has been identified (Angermeyer, 2002; McNulty, 2004) including for depression (Griffiths et al., 2004) They are supported by Lauber et al. (2005) who criticise the 'common sense' lay approaches currently in use. Yet it is important to acknowledge the difficulties in assessing the effectiveness of anti-stigma strategies, given that the public's attitudes are neither logical nor clear-cut compounded by challenges such as socio-cultural health beliefs, researcher effects, and the many intervening variables in real life social research.

#### Education

This term encompasses a set of approaches that are essentially about giving information such as mental health literacy (Jorm, 2000) and social marketing. Davidson (2002) describes the basis of educational campaigns on mental health stigma as providing 'correct' information about mental health and emphasising the social unacceptability of holding stigmatising views. There is evidence that suggests educational campaigns may increase tolerance and understanding of mental illness (Corrigan et al., 2004) and can reduce stigma amongst school age pupils with negative baseline attitudes (Watson et al., 2004), there is a counter argument that education campaigns are can be ineffective or have only a partial role to play in addressing stigma (Davidson, 2002; McDaid, 2008). The model upon which educational programmes are built is important for example they may over-emphasise the role of individual agency versus structural determinants of stigma, or they may use bio-medical explanations whose effectiveness is uncertain(Mann & Heimlein, 2008; Corrigan & Watson, 2004; Watson et al., 2004).

Educational campaigns appear to be most effective when they target specific anxieties of specific groups rather than mental health generally and wide audiences (Byrne, 2000; Byrne, 2001). There is some support for targeting at community level, for example through a local awareness campaigns in the UK (Evans-Lacko et al., 2010). Such programmes can encourage participation and stimulate interest by preparing educational interventions on subjects familiar

to specific audiences (Tanaka et al., 2003). Interventions should be sensitive to cultural beliefs and literacy levels in lower income countries and communities (Mubbashar & Farooq, 2001). Audience's beliefs, level of understanding and concerns need to be taken in to consideration (Smith, 2002). Multi-level strategies are promoted, including: employment of a social marketing strategy designed to raise awareness and increase positive attitudes (Scheffer, 2003); emotionally involving learners and encouraging them to learn actively rather than be passive recipients of imparted knowledge (Finkelstein et al., 2008); and the use of champions or role models at a young age within schools (Kakuma et al., 2010).

#### Contact

The potential for positive contact, between those with mental health problems and target audiences to reduce stigma shows promise, in a range of contexts ranging from with police officers in the UK (Pinfold et al., 2003a), to schools (Pinfold et al., 2003b) and universities (Mann & Heimlein, 2008), including in lower income countries (Kakuma et al., 2010). Quinn et al. (2010) based upon a national programme of events, go further in espousing the idea that not only should service users and target audiences mix during mental health programmes, service users should be meaningfully involved in all areas of developing and evaluating such events. Contact has been said to be most effective when there is equal status between both parties and when work is on a one-to-one level (Estroff et al., 2004; Mann & Heimlein, 2008;). Estroff et al. (2004) drawing upon evidence from community programmes, argue that not only do contact programmes have benefits for the audience, but also for those presenting with mental health difficulties, as they can empower, heal and contribute to well-being of these individuals.

Further to reduce inequities, target groups should be older people, those on lower incomes and men, given that previous data suggests younger people and women may be easier to reach (Quinn et al., 2010). Young people may be a priority target group for anti-stigma campaigns. Mann and Heimlein (2008) say the classroom is an ideal place for anti-stigma campaigns to take place, and with less cost. It is also important to involve parents, since previous research suggests children and their parents may share similar stigmatising attitudes (Jorm & Wright, 2008).

Overall, an emerging model suggests that in order to be effective, anti-stigma campaigns should be multi-faceted or multi-level in design - a strategy that involves working simultaneously across a number of domains or in a number of directions on initiatives that will support and advise one another (Smith, 2002). Estroff et al. (2004) back this type of approach in saying that no single approach can effectively reduce stigma or suit all participants.

#### Stigma and depression

Many of the approaches and principles described in relation to general mental illness may be similar for depression. However, this cannot be assumed, as there is evidence that commonly held beliefs associated with people with depression differ from those with other conditions (Crisp et al., 2005; Jorm & Griffiths, 2008). Dumesnil and Verger (2009) suggest targeting illnesses separately rather than mental health in general because of the vast differences in illness characteristics. These different beliefs may be more, or less, entrenched in the population and can result in different patterns and severity of discrimination. This is especially so if we encompass all forms of depression.

Generally, researchers highlight a lack of evidence based depression-specific anti-stigma interventions (for example Griffiths et al.,2004). From a public health perspective this is concerning given the extent of morbidity associated with depression at a population level. Possible reasons for this include the fact that the most powerful lobby, psychiatrists, generally focus upon people with long term severe conditions and may prioritise this; it may be that programmes and studies tend to cluster and build upon existing data, therefore a body of work is required to stimulate further activity; or anti-stigma programmes for depression may be seen as difficult to evaluate. Of course it may be that they are nested as aspects of other general 'mental illness' interventions.

A useful starting point is a recent review of public awareness campaigns about depression and stigma by Dumesnil and Verger (2009). Their inclusion criterion included suicide awareness, but excluded programmes in schools and to health professionals. They found only 15 programmes in 8 countries with some form of pre-post or control group. Their overall conclusions were that there was some evidence for programmes having a modest effect on reported knowledge and attitudes. However, there was little evidence of impact upon behaviour, for example help-seeking, nor of sustained longer-term effects. They developed a framework for classifying interventions comprising 4 forms:

Short public awareness media campaigns using television programmes and media publicity. Older programmes identified in the UK (Barker et al., 1993) and Norway (Sogaard & Fonnebo, 1992) had only slight effects on knowledge and attitudes.

Contact and gatekeeper training courses. These include the Australian Depression Awareness Project (Rutter et al., 2005) and Mental Health First Aid (Kitchener & Jorm, 2002). Large studies indicate positive impact upon knowledge, attitudes and confidence to assist someone, sustained at 6 months. They may be less effective with minority ethnic communities.

The largest category of interventions are long term national campaigns. Most combine several strategies for example training and media awareness at the same time for a sustained period. The broad conclusions are that they can achieve modest effects on the public in terms of campaign visibility, knowldge and attitudes. This depends upon resources and indicates that they may have a partial contribution to make. Defeat Depression (UK) was a psychiatrist-led campaign that had low visibility and achieved a modest impact on depression knowledge and attitudes (Wright, 1995; Paykel et al., 1998; Rix et al., 1999). The Changing Minds Campaign which followed correlates with sustained reductions in relation to depression stima (Crisp et al., 2005). Similar small but significant improvements in attitudes were evidences by the Beyond Blue (Hickie, 2002; Jorm et al., 2005; Jorm et al., 2006; Highet et al., 2006) in Australia. Like Mine Like Minds in New Zealand demonstrated stronger impact, although less effective amongst indigenous communities (Vaughan & Hansen, 2004). See Me in Scotland is in its ninth year and has achieved good campaign visibility and correlates with modest improvements in public attitudes including towards depression in the earlier stages of the campaign (Mehta et al., 2009).

The fourth category of intervention is defined as long-term community campaigns. Three stong examples are described. The Defeat Depression campaign was introduced in Western Hong Kong and achieved more than slight improvements in knowledge, attitudes and help-seeking for depression at this locality level (Dumesnil & Verger, 2009). The Compass Programme in

Melbourne, Australia targeted young people using the precede-proceed health promotion model (Wright et al., 2006). By taking account of the local circumstances and using approriate communication channels, they achieved significant improvements in knowledge, attitudes and behaviours. The Nuremberg Alliance Against Depression combined public education, gatekeeper training with empowerment and user-led activity. Evaluations used cities that were not exposed to the programme as controls and there is promising evidence of impact on knowledge and attitudes towards depression (Dietrich et al., 2010).

There is a clear call to focus upon depression specifically in initiatives given its different characteristics and associations. Beyond this though, the nature of these interventions makes it more difficult to draw firm conclusions as most programmes fail to identify clear understanding of the nature of stigma amongst the target populations in advance of studies, and most lack theoretical foundations and fail to use validated scales and instruments. However overall these approaches can have a positive short-term impact on knowledge and reported attitudes and we now expand upon four areas of promising practice.

#### Using multi-level approaches

Overall whilst the range of programmes in relations to depression literacy and stigma remains modest in English-speaking countries, the most promising practice can be seen in programmes that are multi-level, long term and which combine approaches that are known to work more widely in addressing stigma such as contact and education. New media emerges as an important dimension of activity, able to cost effectively transmit information and narratives, and to reach those affected by depression in a confidential way. From a public health perspective, a number of problems emerge that should be addressed. Few programmes are inequalities sensitive or adopt a concerted approach to reaching disadvantaged communities who have the highest need; greater specificity is required about forms and aspects of depression that are being addressed; and there is a need to examine the extent to which consistent knowledge increases result in changes to short term and longer term stigmatising beliefs and discriminatory behaviours at a population level. Importantly, programmes must go beyond the short-term, permanent depression initiatives with a high frequency and broad outreach are needed (Dietrich et al., 2010).

Targeting to different parts of the community and focusing upon local rather then national initiatives

Giving consideration to the target audience is a key factor when designing depression stigma programmes. Based upon their review, Dumesnil and Verger (2009) advocate locally organised programmes which can target limited and more homogenous populations. Large-scale educational campaigns may be ineffective because different sections of the community may hold different stigmatising attitudes (Wang & Lai, 2008). Programmes should consider how depression stigma develops and exists in a cultural context (Peluso & Blay, 2008), therefore allowing relevant targeted programmes to be implemented. For example Norman et al. (2008) recommend that where interventions aim to target marginalisation of those with mental health difficulties, the design adopted should be one built on the social norms of the intended audience, since social norms are predictors of social distance.

In particular, studies have noted a need for culture-specific educational materials relating to depression, particularly relating to larger minority populations within a country. Bhugra & Hicks (2004) argue that there is a lack of such materials available targeting black and minority ethnic communities. The same piloted an educational pamphlet about depression and suicide for British South Asian women and found it to be well accepted, inexpensive to produce, easy to disseminate, effective in increasing willingness to report depression, and potentially useful for reaching emotionally isolated women at risk. Overall, these approaches appear to be less effective amongst ethnic minority and indigenous communities and these groups should be included in further campaigns more effectively in order to avoid increasing inequalities. Studies in Scotland, UK, highlight that existing national campaigns have failed to reach many ethnic minority community members. This relates in part to the fact that national campaigns have not taken into account social context or beliefs about depression. Community research and interventions using culturally sensitive targeted messages, contact methods and cultural approaches have yielded promising results (Knifton et al, 2010).

However, this principle also applies to other social groups who may experience disadvantage for example depression stigma may be higher in rural settings (Griffiths et al., 2009) or lower income communities (Mehta et al., 2009). Therefore programmes should ensure that they effectively target groups that experience disadvantage, who experience higher levels of depression, to avoid increasing the stigma gap and associated inequalities.

#### **Education approaches**

Most interventions in relation to depression focus upon increasing public literacy or knowledge (Griffiths et al., 2008) rather than directly addressing stigmatising attitudes or discriminatory behaviours. There is evidence that short-term knowledge and attitudes towards depression can be improved to some extent through education approaches (Highet et al., 2006; Dumesnil & Verger, 2009). This effect was most strongly demonstrated for longer term teaching (6 sessions) of adolescents in schools where improvements in attitudes towards depression persisted at an 8 month follow up period (Naylor et al., 2009). Education appears to enhance help-seeking for those with depression (Goldney & Fisher, 2008). Suicide prevention programmes in schools such as Signs of Suicide have some impact on knowledge and attitudes towards depression (Aseltine & DeMartino, 2004), as did an awareness programmes with parents (Deitz et al., 2009).

However, education approaches based upon increasing 'illness literacy' are contested with counter-arguments that they may be ineffective or increase social distance towards people with depression (Lauber et al., 2005; Wang & Lai, 2008). Results are often inconclusive. Swartz et al. (2010) in the US found that Adolescent Depression Awareness Programme lessons improved knowledge but not attitudes. Merritt et al (2007) employed a cluster randomised control trial with over 3000 students in UK universities and found that social marketing approaches had no impact on reported attitudes. Didactic teaching sessions with GP's in the UK found that short-term increases in knowledge about depression were not sustained (Kelly, 1998).

Dumesnil and Verger's review identifies the importance of long-term approaches and the value of repeated exposure to messages. They also highlight the value of understanding existing stigma amongst target audiences and the value of theory-led education campaigns – for example the Precede-Proceed Model because of its adaptability to different contexts and disorders worked most effectively and was basically an educational campaign at a locality level

(Wright et al., 2006). The use of the media to share messages has been shown to be a useful means of educating young people about depression (Klimes-Dougan et al., 2009) with relatively large effect sizes.

#### Contact

Dumesnil and Verger's review provides good evidence for the effectiveness of positive contact as a method of reducing depression stigma. For example gatekeeper training and structured contact show particular promise especially at a local level. In a review of depression literacy campaigns, Parslow and Jorm (2002) also found contact to be the most effective strategy to reduce reported stigma. This includes hearing from people about their own personal experiences of depression (Mood Disorders Canada, 2006; Griffiths, et al., 2008). Parslow and Jorm identify the important conditions for positive contact as parties having equal status, when programmes offer real-world rather than contrived interaction opportunities, when contact is sponsored by a well-regarded organisation, and when the person speaking is not 'so exceptional as to be seen as atypical of people who have experienced depression'. This last point is in line with Scheffer (2003) who argues that contact with people who fill "normal" social roles influences attitudes positively.

#### New media

New media and online interventions are an area that has received increasing prominence in tackling stigma and raising awareness about depression (Wright et al., 2006; Finkelstein & Lapshin, 2007; Finkelstein et al., 2007) and mental illnesses more generally. Oh et al. (2008) in a large scale survey indicate that online information is the preferred method for obtaining information about mental health problems. This was endorsed by Leach et al. (2007) although respondents still wanted discussions with health educators especially older citizens. There is good evidence of impact for Australian programmes such as Bluepages (Griffiths et al., 2004; Griffiths & Christensen, 2007) and Moodgym (O'Kearney et al., 2009) although not for those with literacy problems. Ultimate intervention effect sizes may be high even where measured effect sizes are small, when the number of people who access the internet and the cost of delivery is factored in (Griffiths et al., 2004). According to Stjernsward and Ostman (2006) the internet can empower those with depression by providing them with useful information about their diagnosis, and potentially reduce self stigma. The internet is also useful when it comes to providing information as it can be accessed privately and without involving others who may hold stigmatising attitudes (Berger, Wagner & Baker, 2005). Moreover the internet can enable 'proxy contact', through online narratives and stories of experience, in a away that is less fleeting, more flexible and interactive, and less expensive than via traditional media or direct contact methods.

#### **Table 1. Key Depression Stigma Programme Studies**

Campaign Defeat Depression. UK, 1992-96	Description Aimed to reduce depression stigma through the use of newspaper and magazine articles, radio and television programmes, press conferences, leaflets, fact sheets in ethnic minority languages, audiocassettes, a self-help video, and books. A poll conducted at the start showed a lack of knowledge and understanding and informed the campaign (Wright, 1995).	Findings The campaign led to a stigma; a shift to r attitudes; considerable media coverage and a media figures willing to their own depression 1998). White (1998) no result of the campaign positive news about dep media. Rix et al., (199 impact of the campaign moderate.
Depression Awareness Project. Australia, 2001-04	Aimed to raise awareness of depression and reducing stigma through education. Trained 200 educators who led awareness meetings in their communities with 7500 people. Stressed depression is common and treatable.	Over and 1700 attenders depression literacy survey months after the interv enhanced scores at 4 me workshops (Rutter et al., 2
Defeat Depression. Western Hong Kong, 1999- 2002	Aimed to increase depression literacy through distribution of educational materials (translated from UK Defeat Depression Campaign), web, local media, road shows, exhibitions, and a training kit for professionals	Cross-sectional studies exposed and not exp campaign (855 pre and campaign increased kno depression and willingne (see Dumesnil & Verger, 2
Beyondblue. Australia, 2001-05	Has dual aims of increasing community awareness of depression and tackling the stigma, through educational and promotional activities. It involves key partnerships with the media to provide accurate information and publicly convey experiences of those who live with depression (Highet et al, 2006). Promotion of the direct voice of consumers is important (Hickie, 2002).	Before and after cross set using a mental he questionnaire were under and 2004 with approx people from both high an groups. Beyondblue has awareness of depression discrimination (Jorm et positive effects of belie help-seeking (Jorm et al.,
Bluepages. Australia, 2002-03	Allocated 525 individuals with elevated scores of depression to a website detailing information on depression, including biographies of famous individuals who have experienced depression.	Self and perceived stigma before and post inter depression stigma programme improved literacy and reduced p (Griffiths et al., 2004

a reduction in more positive e increase in an increase in to acknowledge (Paykel et al., noted a further was increased epression in the 999) found the with GP's to be

rs sampled using eys pre-post at 4 vention showed nonths after the 2005).

s with those posed to the 913 post). The nowledge about ess to seek care 2009)

sectional surveys nealth literacy lertaken in 1995 oximately 1000 nd low exposure s led to greater on, sensitivity to al, 2006) and liefs about and , 2005).

a were assessed ervention using scales. The d depression personal stigma (Griffiths et al., 2004, Griffiths & Christensen, 2007).

MoodGYM. Evaluated with 157 adolescent females 6 week course designed to help using self-report instruments looking at Australia, people identify and overcome 2009 depression, through information depression literacy and attitudes. No significant effects on knowledge were dissemination. demonstrations. found (O'Kearney et al., 2009). Griffiths questionnaires, and online CBT. It and Christensen (2007) argue it is can be completed with or without health professional involvement unsuitable for those with low general (O'Kearney et al., 2009). literacy skills. Nuremberg This 4-tier community based project The evaluation used pre and 2 post Alliance targeted GPs and public, using the attitudes surveys 10 and 22 months messages: after in the intervention region and in a Against key campaign control region with 1426, 1507 and 1423 Depression. 'Depression can affect everybody' Germany. and 'Depression takes many forms'. respectively. As a result of the 2000-02 Campaign tools included posters, programme, the general public's shortleaflets, brochures, a cinema spot, term awareness and perceptions of website, production of a video, and depression increased significantly - this establishment of close ties with effect was stronger for women (Dietrich local media (Dietrich et al., 2010) et al., 2010). European The Alliance instigated and The model is described by Hegerl & Wittenberg (2009) but evaluations have Alliance evaluated a series of regional Against programmes to address depression taken place at a local level - see Depression, and suicide in 16 countries. Nuremberg Alliance above. EU, 2004-date Signs of School-based suicide prevention Evaluation with 2,100 young people in 5 Suicide. programme. Focuses on recognising high schools through survey at 3 and promoting positive attitudes months, included control groups. The USA, dates towards depression.. Teaching is by programme improved students' video, discussions and includes knowledge and attitudes towards interviews with people affected depression (Aseltine & DeMartino, 2004). Adolescent A high school-based depression The evaluation with 3538 students using Depression curriculum has the primary goal of surveys on knowledge of depression before and after the intervention, Awareness increasing depression literacy and showed positive effects on levels of Programme secondary goals of changing USA, 2001-05 attitudes and levels of stigma depression knowledge, though it was unclear as to whether this led to towards depression, under the message 'Depression is a treatable reduced stigma (Swartz et al., 2010). medical illness' Youth Mental This initiative is aimed at parents as Evaluation with 99 parents randomised caregivers. It comprised a webinto experimental and control groups Health: А based program designed to help using pre and post surveys. Led to Parent's Guide. USA, parents detect signs of depression greater knowledge about youth mental 2007 and anxiety in their children, then health issues and greater self-efficacy facilitate early intervention (Deitz et al., 2009) University social A cluster randomised control trial with Based on marketing techniques, this intervention was 3313 students using attitudinal Social implemented in order to increase questionnaires as used in the Defeat marketing project university students' knowledge Depression campaign found that the UK, 2004 about depression. Posters and postcards with information on depression were distributed throughout university campus location.

DepressionThis education project involvedSeminarsfordidactic teaching and interactiveGP'scase vignettes discussing diagnosticUK, 1998and management problems.

Targeting young people aged 12-25 Compass in Victoria to increase depression Strategy. Australia, literacy, this programme was 2001-03 influenced by the Precede-Proceed Model. It involved promoting messages using cinema, radio, newspapers, magazines, posters, brochures and postcards and online. It included an information phone line, video; training workshops for lay professionals.

Mental health Adolescents' knowledge and school understanding of mental illness was explored, through a programme of 6 programme. UK, mental health lessons to young 1999-2001 people aged 14 and 15 years. Lesson topics included 'stress' and 'depression' and were based on age-appropriate materials. Teaching included discussion, techniques role-playing, internet searching, and the use of video and factsheets.

See Me. National campaign to reduce stigma Scotland, UK, of mental illnesses. Uses social 2002-present marketing techniques including website, billboards, distribution of educational materials, television and radio campaign and media advocates

You in Mind. National television series targeting UK, 1987 prevention of mental illness. Featured seven episodes, topics for which included depression, fears, and expressing feelings

NorwayTo improve understanding ofMental Healthdepression and tackle stigma,Project.through a prime-time nationalNorway, 1992television program and publicity<br/>campaign

intervention failed to increase beliefs that depression can be treated effectively (Merritt et al., 2007).

An evaluation with 88 GPs with pre, post and follow up questionnaires found short-term increase in knowledge that wasn't sustained over time (Kelly, 1998). Evaluation by Wright et al. (2006) with 600 young people from the experimental region and 600 in the control group used telephone interviews.

The programme increased awareness of self-identified depression and the levels of help sought for depression. Website was the most popular method promoted through newspapers, schools, posters and GPs.

Evaluated with pre – post survey 8 months apart. Results included increase in knowledge about mental health; increased empathy in understanding depression; and decreased prejudice and tendency to use pejorative terms regarding those who are mentally ill (Naylor et al., 2009).

Evaluation shows good campaign visibility and correlations with increased public awareness of mental illnesses and decreases in negative attitudes in the early years of the campaign including for depression (Mehta et al., 2009)

The evaluation of the programme found modest improvement in reported attitudes towards depression in a cohort study of over 1000 viewers (Barker at al., 1993).

Results of a cohort study of over 1000 people indicated reduced stigma and greater willingness to seek medical help (Sogaard & Fonnebo, 1992)

Teaches professionals and general	
population how to help those with	increased recognition and knowledge
mental health difficulties including	about mental illnesses and reduction in
depression. Replicated in numerous	stigma including for depression
countries.	(Kitchener & Jorm, 2002).
Campaign with involvement of	Evaluation suggested improved
those with mental health difficulties	knowledge and attitudes and reduced
in training and educating	stigma and discrimination
professionals and the media.	(Vaughan & Hansen, 2004).
Included media campaign, website, and celebrity endorsement	
	population how to help those with mental health difficulties including depression. Replicated in numerous countries. Campaign with involvement of those with mental health difficulties in training and educating professionals and the media. Included media campaign, website,

### Table 2. Key general mental illness stigma programme studies

Campaign Educational intervention with the police. UK, 2001	Description This project used mental health awareness workshops with police officers, and the facilitators included individuals who have themselves experienced mental health difficulties e.g. contact model.	Findings Pre-post survey with 109 police officers demonstrated positive impact on officer's views of people with mental health problems and increased knowledge but less impact on behavioural intentions especially for men (Pinfold et al., 2003a).
Educational intervention with schools. UK, 2001	This project used mental health awareness workshops in secondary schools, and the facilitators included individuals who have themselves experienced	Evaluated in 472 pupils in 5 schools through pre and post questionnaires. Small, positive changes in knowledge and attitudes (Pinfold et al., 2003b). Gender differences in conceptualising
Education about	mental health difficulties e.g. contact model. This programme aimed to combat	mental illness, Contact most important factor in attitude change. Corrigan et al. (2004) tested the effects
stigma programme USA, 2002-3	the stigma of mental illness by challenging myths about mental illness and giving examples of how individuals can have different illness courses and outcomes	of this programme on 161 participants' using attitudinal questionnaires and a control group. Findings showed participants beliefs about dangerousness decreased; they were less likely to endorse social avoidance, and were more willing to help others with mental illness.
Mental health lectures. Japan, 2001-2	A series of lectures on mental health delivered to industrial workers and government employees in 6 sites, by doctors and nurses, with information materials.	Pre-post evaluations using knowledge and attitude questionnaires suggest this type of lecture can improve public understanding and negative attitudes (Tanaka et al., 2003).
Time to Change (Cambridge: Do short-term programmes	Local short campaign. Key messages included 'Mental illness is far more common than you think' through advertising at bus	Evaluation of the study using 410 face to face interviews with people aged 25-45 years, pre-during and post campaign including CAMI scale indicated short

work). England, 2008	stops, local radio and press; city centre street art; and 'talking points' in town where the public could sit and talk to people with experience of mental health problems	term shift towards improved attitudes but not sustained in the longer term. (Evans-Lacko et al., 2010).
National Mental Health Arts and Film Festival. Scotland, 2007- date.	1000 exhibitions, debates, films, documentaries, community events, concerts, gigs, plays, and workshops to 60,000 members of the public – combines education, contact and creative arts or film	In an evaluation of the festival, pre and post scales and qualitative evidence found small but significant improvements in dimensions of stigma, the importance of positive contact, and the potential to worsen attitudes without thoughtful programming (Quinn et al., 2010).
University Stigma Intervention. USA, 2007 The Science of Mental Illness. USA, 2003	Educational and contact method of challenging stigma using 'humanising' first-person 6-hour course with 53 students. School curriculum delivered by teachers in 16 states to over 1500 pupils which promotes the biological basis of mental illness to increase understanding about biological, psychological and social factors	Pre –post evaluation using scales and vignettes and a control group showed significant decrease in stigma (Mann & Heimlein, 2008) Evaluation has shown improvements in knowledge about and attitudes towards mental illnesses particularly amongst those with poorer baseline scores (Watson et al., 2004).

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#### PATTERNS OF MENTAL ILLNESS STIGMA AND ADDRESSING STIGMA IN BELGIUM

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#### **INTRODUCTION**

As part of the Anti-Stigma Programme - European Network (ASPEN) project's Work Package 4 ('Best practice anti-stigma'), Aspen sites were to conduct a literature review on stigma associated with mental health problems and depression in their country. This would include a thorough analysis of all the peer review publications and reports about mental health stigma in their country.

#### This country report is intended to cover two areas:

1) Known patterns of stigma and discrimination associated with mental health, and depression in particular. These can be derived from e.g. public surveys, controlled studies, patterns of stigma and discrimination in key settings, such as schools and workplaces.

2) The evidence base and pointers for promising practice for effective interventions to address stigma and discrimination in relation to mental health problems. These interventionS will be described in terms of the approaches used, the target group, the scale of the study, and the strength of the evidence.

#### METHOD

To perform this literature review, we searched relevant databases and the web, using the range of search terms suggested by the WP4 colleagues. As a first step, peer reviewed articles were searched for in the PubMed scientific database. We performed two searches.

To look for studies describing patterns of stigma and discrimination with regard to mental health in Belgium or Flanders, we used the following combination of search terms:

(Flanders OR Flemish OR Belgium) AND (stigma\* OR attitud\* OR prejudice\* OR stereotype\* OR discrimina\*) AND (mental OR depressi\* OR psychic OR psychiatr\* OR psychological OR schizophreni\*)

In this way, 438 search results were obtained.

To look for studies describing anti-stigma interventions in Belgium or Flanders, we used the following combination of search terms:

(Flanders OR Flemish OR Belgium) AND (stigma\* OR attitud\* OR prejudice\* OR stereotype\* OR discrimina\*) AND (mental OR depressi\* OR psychic OR psychiatr\* OR psychological OR schizophreni\*) AND (stigma\* OR attitud\* OR prejudice\* OR stereotype\* OR discrimina\*) AND (intervention OR "health education" OR "mass media" OR communicati\* OR "multi media" OR multimedia\* OR "mass communication" OR "audiovisual equipment" OR "patient information" OR "visual information" OR radio OR televise\* OR leaflet\* OR poster\* OR pamphlet\* OR "print media" OR "printed media" OR skit\* OR "folk media" OR broadcast\* OR film\* OR telecommunication\*)

This search resulted in 94 search results. Next, all titles and abstracts of search results were checked for relevance. After this process, 17 peer reviewed articles were retained that were relevant to the review.

As a second step, we used the 'snowball' procedure, which includes checking references of the resulting articles and adding other relevant studies that we knew of ourselves. This is particularly a good method to find unpublished, local language or 'grey' literature, such as internal reports. This resulted in an additional 22 relevant local language study reports, presentations at conferences and other unpublished work, including several from our organization, which has conducted a great deal of stigma research in our country.

Finally, we searched the web for any additional studies, using the same search terms as above with Google. This resulted in numerous amounts of hits. However, these mainly lead to websites providing information about mental health and stigma in general, or describing specific activities. Beside 2 unpublished surveys by consultancy firms, no additional (evaluation) studies were found in this way.

So in total, our review resulted in 40 relevant articles, reports and other unpublished material, some of which referred to the same or subparts of one study. All of them are described, grouped by the main study to which they refer, in the results section below.

#### RESULTS

In the first part of the results, we describe studies on patterns of mental health stigma and discrimination in Belgium. The second part summarizes studies on interventions that address stigma and discrimination in relation to mental health problems in Belgium.

#### Part 1: Patterns of mental health stigma and discrimination in Belgium

In this first part, we discern (a) studies on stigma and discrimination as experienced by patients, (b) patterns of stigma and discrimination reported in the general population, (c) in health professionals, and (d) in community professionals.

(A) Patient experiences of stigma and discrimination

ESEMeD and World Mental Health Surveys (Alonso et al 2008; Alonso et al 2009):

The European Study of Epidemiology of Mental Disorders (ESEMeD) is a representative population survey conducted in 6 European countries, including Belgium. The survey in Belgium included n=2419 respondents. While this study primarily investigated epidemiology of mental disorders, 2 questions about perceived stigma were also assessed in people with a mental disorder experiencing significant disability. These questions referred to experienced

embarrassment and discrimination. The data from the ESEMeD study are also part of the World Mental Health Surveys. The results indicated that In Belgium, 48% of people with a mental disorder and significant disability have experienced embarrassment because of mental health problems in the preceding month; 20% experienced discrimination or unfair treatment because of mental health problems; and 16% experienced both. This rate is (near significantly) higher than the mean of other countries in the study.

INDIGO International Study on Discrimination and Stigma Outcomes (Scheerder & Van Audenhove 2006; Thornicroft 2009):

Belgium took part in this international study, led Thornicroft, on perceived stigma and discrimination in people with schizophrenia. A structured interview was held with patients, using the Discrimination and Stigma Scale (DISC), which assessed experiences of being treated (dis)advantageously for several live domains. In Belgium, we interviewed 64 patients in both residential and outpatient settings, and also included patients with depression. In comparison to the other countries in the study, patients in Belgium had a below average level of stigma and discrimination experiences. There was a low level of direct discrimination in society (housing, transport, financial affairs, community life) and in using (mental) health care. A small disadvantage was experienced with regard to finishing education (in patients with schizophrenia) and to keeping a job (in patients with depression). Most stigma was observed in personal relations and with regard to self-stigma. A moderate disadvantage was experienced with regard to self-stigma. A moderate disadvantage was experienced with regard to keeping friends (in both patient groups), marriage and having children (in patients with schizophrenia). More than half of patients in the study displayed self-stigmatizing behaviour, such as avoiding social contact, hiding their diagnosis, and withdrawing from starting personal relationships or from soliciting for a job.

Experiences of stigma in mental health care in Flanders:

In recent years, a PhD study was undertaken to investigate stigma in mental health care in Flanders. It consists of several sub-studies described below.

A first series of studies was conducted in patients using psychosocial rehabilitation services In Flanders (Verhaeghe 2003; Verhaeghe & Bracke 2007; Verhaeghe, Bracke & Bruynooghe 2008). This includes a longitudinal study of experiences of stigmatization and quality of life in n=110 patients in 1 such rehabilitation center, and a cross-sectional study of 595 patients in 47 psychosocial rehabilitation services. In this first study, 57% of patients had experienced some form of social rejection since using the rehabilitation service, in terms of other people avoiding contact, not being at ease or giving disrespectful remarks. Having experienced such rejection was negatively related to the following variables at follow-up: being employed, experiencing social support, and self-esteem. In the second study, it was confirmed that stigmatization is negatively related to self-esteem and peer support positively. However, peer support was only favourable in patients with few stigma experiences. Stigmatization itself impedes the formation of peer relationships, and its associated support. Finally, stigmatization was related to patient characteristics, in particular current mental health status and symptoms, but was related only to a limited amount to organizational features, such as size, patient population and kind of activities provided. A second series of studies was conducted in n=843 patients and n=597 staff at several types of residential and outpatient mental health services, who were surveyed about experiences of and reactions to stigma. Scales used include the Devaluation-Discrimination scale, Social Rejection scale and Self-Rejection scale (Verhaeghe 2007; Verhaeghe 2008; Verhaeghe & Bracke 2008; Verhaeghe, Bracke & Bruynooghe 2007; Verhaeghe, Bracke & Christiaens 2008). Patients in the study indicated a moderate degree of stigma expectation, with 70% agreeing that most people think less of persons receiving mental health care, and 76% that most people take them less seriously. On the other hand, 51% believed that most people would take them seriously. About two thirds of patients experienced some form of social rejection, with for instance 39% agreeing that some people treat them less respectful, and 48% agreeing that some people act as if they are less competent. With regard to self-rejection, 35% of patients felt inferior due to receiving mental health care, and 36% felt ashamed of it. Over 80% of patients preferred active coping with stigma, such as explaining mental health (care) and protest against stigma. Still, more than 60% agreed with passive strategies, such as avoidance and secrecy. A higher degree of selfrejection was strongly related to lower patient satisfaction with care. Life satisfaction was negatively associated with stigma expectations and with social rejection. Stigma expectations and self-rejection were strongly related to self-esteem and self efficacy. Patients with psychosis experienced a higher degree of social rejection, and people in outpatient care experienced a lower degree of both social and self-rejection. A specific analysis of n=366 patients in psychiatric hospitals revealed that less self-rejection was related to more individualized treatment, a positive ward atmosphere, and smaller wards. Finally, patients with no current or past full-time hospitalization reported less social rejection.

Study of experiences of discrimination in using (mental) health care (Van Audenhove 2005):

This study investigated experiences of discrimination in using (mental) health care by patients with a mental illness. Focus group interviews, based upon a previous European study on discrimination and harassment in (mental) health care by Mental Health Europe and LUCAS, were held with 75 patients in Flanders. Overall, 15% of patients reported experiences of discrimination in using somatic health care services and 32% reported experiences of discrimination in using mental health care. This qualitative study provided narrative examples of discrimination that were merged in coherent categories. With regard to somatic health care, these included: physical complaints being regarded as mental problems; treatment and care being refused, postponed or inadequately delivered; being treated disrespectful, patronizing or with neglect, in particular in case of suicidality. With regard to mental health care, these included: not being taken seriously; introducing hopelessness; being regarded disrespectful; misuse of power by using force, isolation, fixation.

Finally, a longitudinal study is currently being conducted by the Flemish Policy Research Centre for Welfare, Health and Family about determinants of care use by people with mental ill-health, including knowledge of care services and perceived stigmatization.

#### (B) Stigma and discrimination in the general population

Our search resulted in several studies on public (stigmatizing) attitudes toward mental health (care). However, these studies were very diverse in type and scale. To take these differences in study design into account, we grouped studies accordingly. Unfortunately, no study so far has conducted a representative general population survey on this topic in Belgium. There are some

international health surveys, in which Belgium participated, that included a part on public attitudes toward mental health (care). And finally, there are some national unpublished and pilot studies or reports on this topic, which are mostly of insufficient quality to make firm conclusions.

National surveys on public attitudes toward mental health (care):

Unlike many other European countries, no representative general population survey on public attitudes toward mental health (care) has been conducted in Belgium so far. However, this is being resolved, as, for the first time, two major such studies are running.

A representative general population survey is currently being conducted in Flanders by LUCAS investigating determinants of suicidal behavior and of seeking professional help for mental problems. These determinants include attitudes toward mental problems, attitudes toward seeking professional help for mental problems, perceived stigma, self-stigma, coping style, and personality characteristics (locus of control). This study involves 4500 adults, aged 18 to 65, that were sent a structured questionnaire, including validated scales on these topics.

Belgium participates in the 'Stigma in global context' international study (lead by Prof. B. Pescosolido). A representative general population survey is currently being conducted specifically about stigma and attitudes toward mental health (care).

International health surveys with a part on attitudes toward mental health:

European Study of Epidemiology of Mental Disorders (ESEMeD) evaluated by ten Have et al (2010) is a representative population survey conducted in 6 European countries, including Belgium. The survey in Belgium included n=2419 respondents. While this study primarily investigated epidemiology of mental disorders, it also included 5 items on attitudes toward help-seeking for mental health problems. Results in Belgium showed that 43% of respondents would not seek professional help in case of serious emotional problems. This is the highest score of the six countries in the survey, the mean for this variable being 29%. Further, 35% would not feel comfortable talking about personal problems with a professional; 19% would feel embarrassed if friends knew about professional help; and 34% believes that professional help is worse than or equal to professional help in terms of effectiveness.

International Health Behaviour in School Children (HBSC study) is also conducted in Flanders ['Studie Jongeren en Gezondheid']. In 2006, this general health survey also included the Depression Stigma Scale (DSS), which was assessed in 16- to 17- year old students (n= about 3500) at secondary schools. IN evaluation undertaken by Hublet & Maes (2007) several items showed stigmatizing attitudes toward depression in Flemish students. For instance, 60% agreed that people with depression could snap out if they wanted to; 38% think they are unpredictable; 32% agrees that depression is not a real medical disease; 23% think that depression is a sign of personal weakness; and 21% would not tell anyone if they had depression. On the other hand, only 5% would not invite people with depression to a party. Overall, boys had higher stigma scores than girls, and girls would be more inclined not to tell if they had depression. There were also significant differences according to education, with boys and girls in professional and technical education showing higher stigma scores than those in general education.

Eurobarometer Mental Well-being (European Commission 2006). The Eurobarometer is a regular opinion poll among the EU-member states population covering various topics. This special edition 248, part of wave 64.4, covered mental well-being, including a section on attitudes toward mental health. In Belgium, this survey was conducted in n=1011 people. In Belgium, 67% agreed that people with psychological problems are unpredictable; 32% that they are a danger to others; 22% that they will never recover; and 11% that they have themselves to blame. These scores for Belgium are very average in comparison to the European mean, for which the report concludes that it constitutes a reasonably tolerant perception of people with psychological problems.

Conseur 4-country consumer survey on suicide: Conseur, an international consumer association, conducted a survey of consumers' beliefs, attitudes and behaviours with regard to suicide in 4 European countries: Belgium, Italy, Portugal and Spain. In Belgium, the survey was conducted by the consumer organization Test-Aankoop in 2002. A postal questionnaire was sent to 25.000 Belgian adults of 18- to 70-years old, including the Suicidal Ideation Questionnaire (SIQ). Although n=2034 people responded, this constituted only an 8% response rate. Common myths about suicide prevail in Belgium too. For instance, 51% agrees that suicide attempts are primarily attention seeking; 45% believes that someone with suicidal ideas will always have them; and 56% agrees that suicide is a flight from life's responsabilities (Jooken & Kupers 2003; Santos et al 2003).

There are also several national unpublished or pilot surveys.

Mental health survey by VVGG (2001). This opinion poll about attitudes toward mental health was ordered from a consultancy firm by the Vlaamse Vereniging voor Geestelijke Gezondheidszorg (VVGG 2001) [Flemish Association for Mental Health]. An interview survey was conducted in Belgian adults (n=903) of 20- to 70-years old, using an ad hoc set of questions. About 80% would not know how to react to people with a mental illness, 70% would be cautious and 64% would be afraid. About half believed that the best way to deal with mental problems is to talk about it with relatives and about 40% by consulting a physician. Specialist mental health care was not mentioned spontaneously, unless for very severe problems. About a quarter indicated ever to have consulted a physician or psychologist for mental problems, and about 10% had thought about doing so, but did not. Further, 'mental willpower' was most often perceived as the best way to stay mentally healthy, followed by 'a good mental hygiene', social contacts and physical activity. Nearly all respondents indicated to have limited knowledge about mental illnesses, their causes, symptoms and treatment. Most often people would like to be informed about depression.

IPSOS opinion poll with regard to schizophrenia: An opinion poll was ordered from the consultancy firm IPSOS about the public's knowledge and attitudes with regard to schizophrenia. A short interview survey was conducted in n=995 adults, 15+ years old, in Belgium in 2005. The results show a very limited knowledge of schizophrenia, with 'do not know' as the most frequent answer to most (multiple choice) questions. For instance, 52% of respondents do not have any idea about the incidence of psychosis; 34% about what schizophrenia is; 41% about what it causes are; 41% about how it can be treated; and 31% about how they would react. Very few respondents believe that people with schizophrenia can function in a normal way. We only found a brief informal Dutch language description (unpublished) of the results of this survey.

Pilot study on public attitudes regarding depression and suicide in Flanders (Scheerder et al 2008): Since almost no data are available on this issue in Flanders, LUCAS undertook a pilot study to prepare a large general population survey, specifically on depression and suicide. Semistructured interviews (n=60) with members of the adult general population were conducted on the following topics: perceived symptoms and causes of depression and suicide ideation, preferred treatment and perceived effectiveness, reactions to people affected, and knowledge of mental health services. Knowledge of depression symptoms was good, but knowledge of mental health services moderate. Attitudes towards suicide appeared to be rather negative and confirmed common myths about suicide. Life events were the predominant explanation for causes of depression, in contrast to biochemical or hereditary factors. Consequently, negative attitudes towards antidepressants prevailed. Almost half of respondents indicated that they would try and solve depression themselves. Professional help would be sought only in severe cases. Comparison of open-ended and closed questions revealed that closed questions more frequently lead to socially desirable answers. Furthermore, there was a notable difference between treatment options people would advice to relatives, in comparison to what they would do themselves. Finally, people's experience with depression or suicide in their personal environment appeared to serve as their framework. These baseline data provide very useful information to set up evidence-based action to increase mental health literacy and to fight stigma.

#### (C) Stigma and discrimination in health professionals

General practitioners (GPs) by Scheerder & Van Audenhove (2005) and Scheerder (2009): In the context of a study investigating GPs' attitude and diagnostic, treatment and referral practices with regard to depression, we assessed GPs' attitude toward depression using the Depression Attitude Questionnaire (DAQ). The survey was sent to all 495 GPs in the region of Waasland, Flanders. GPs generally indicated a positive attitude toward depression, both with regard to dealing with patients and to the malleability of the condition. The large majority of GPs indicated that treating patients with depression is rewarding (86%), albeit 'heavy going' (64%), and about half of GPs (54%) reported to feel comfortable in dealing with the needs of these patients. Most GPs disagreed that depression is not amenable to change (74%), or is a natural part of being old (80%). The number of patients with depression seen in GP practice was related to professional unease in managing depression.

Medical students (Scheerder & Van Audenhove 2010): In a replication of studies by the Institute of Psychiatry in the UK, we investigated the attitude toward mental illness in second year bachelor medical students at the University of Leuven in Flanders (n=202), using the Mental Illness Clinicians Attitude (MICA), the Social Distance Scale (SDS), and 11 items related to stereotypical attributes of people with mental illness. Overall, students showed a relatively positive attitude toward people with a mental illness, with a moderate preference for social distance and a moderate degree of stereotyping. For instance, 87% disagreed that people with a severe mental illness are themselves to blame for their condition; 85% disagreed that they can never sufficiently recover to have a good quality of live; 77% agreed that they can keep a regular job; 67% disagreed that they have a tendency to be dangerous; and 62% disagreed that they are hard to talk to. Less favourable were the scores on self-stigmatization and the low popularity of psychiatry as a field of specialization. For instance, 52% would never admit to have a mental illness to colleagues; and only 5% of students indicate they would be interested in, among others, psychiatry as a specialization. Degree of personal experience with people with a mental

illness appeared to have complex but crucial role. Merely knowing someone with a mental illness is insufficient; only having a close personal contact was related to more positive attitudes, especially with regard to self-stigmatisation.

Nurses in general hospitals (Schaelenbourg et al 2009): As a baseline to an educational programme on depression and suicide, nurses from several departments of two general hospitals in Flanders (n=109) were surveyed on their attitude and current practice with regard to dealing with patients with depression or suicidal ideation. Nurses in this study generally had a relatively positive attitude toward patients with depression. For instance, 96% agreed that anyone can suffer from depression; 90% agreed that it is a real disease; 63% disagreed that it mainly occurs in people with poor stamina; 60% disagreed that it cannot be completely cured; 60% disagreed that it is a normal phenomenon in the elderly; and 55% disagreed that patients with depression are unreliable. On the other hand, 46% agreed that patients with depression put a strain on nurses' work; 30% agreed that they should primarily pull themselves together to get over it; and only 46% agreed that depression is a disease like another. Similar relatively positive attitudes were found with regard to patients with suicidal ideation. For instance, 67% disagreed that talking about suicide can bring people to ideas; 59% disagreed that they do not understand that someone wants to commit suicide; 53% disagreed that people with suicidal ideation cannot be stopped; and 52% agreed that nurses can help to prevent suicide. On the other hand, 66% agreed that patients with suicidal ideation put a strain on nurses' work. Further, nurses generally endorsed a positive attitude toward their potential role in depression care. However, fulfilling this role appeared to be more difficult with patients with depression in comparison with patients with other, physical conditions. For instance, 70% of nurses indicated to have a trusting relationship with patients with physical diseases, compared to only 40% with patients with depression.

#### (D) Stigma and discrimination in community professionals

Pharmacists: Recently, several studies have been conducted in Flanders on the attitudes of pharmacists and pharmacy students regarding mental health, and depression in particular. We discuss the 4 studies separately below.

A random sample of 200 community pharmacists in a region of Flanders was surveyed on their attitude toward depression. A modified version (adapted to the specific context of pharmacists) of the Depression Attitude Questionnaire (DAQ) was used, which covers several aspects of the attitude toward depression. Pharmacists generally endorsed a relatively positive attitude toward depression and patients with depression: 55% of respondents agreed with "depression is a disease like any other", 65% did not agree with "patients with depression are unreliable", 67% did not agree with "patients with depression put a strain on pharmacists", 65% did not agree with "depression real disorder". However, 58% agreed that patients with depression need to pull themselves together, and 44% agreed that such patients do not understand AD medication. Older pharmacists and those with a more pessimistic attitude toward the course of depression endorsed a more negative attitude toward patients with depression (Scheerder et al 2009; Scheerder et al in press).

Using the same sample as in the study above, the second part of the survey investigated pharmacists' attitudes and current practices with regard to the care of patients with depression

in comparison with patients with other, physical conditions (Scheerder et al 2008). Responding pharmacists generally endorsed a very positive attitude toward their potential role in depression care. This willingness was, however, not reflected in current practice, and fulfilling this role appeared to be more difficult with patients with depression in comparison with patients with other, physical conditions (e.g. more difficult to maintain a trusting relationship). A lack of training in mental health issues was the most important barrier reported.

This study was then replicated in all pharmacists of a pharmacy chain in Flanders (n=149) and all 2nd year students of the Master in Pharmaceutical Sciences at the University of Leuven (n=95). The results produced by Foulon et al (2009) were largely similar to those found in the previous study. The attitude of participants in the survey was generally favorable toward patients with depression. On some items a discrepancy between pharmacists and students was observed, which may be due to practice experience. The participating pharmacists also expressed a positive attitude towards their role in the care for patients with depression. This willingness, however, was not reflected in current practice.

Pharmacy student attitudes (Bell et al 2008; Bell et al 2010): A further study assessed data on pharmacy students' attitudes toward people with mental disorders. There were 6 national sites including Belgium, as part of the International Pharmacy Students Health Survey. This survey included six items related to stereotypical attributes of people with schizophrenia or severe depression and the Social Distance Scale (SDS) toward people with schizophrenia. The Flemish sample consisted of n=102 pharmacy students at the University of Leuven. Sub-optimal attitudes toward people with schizophrenia and severe depression were common among pharmacy students in all countries, with students in Belgium scoring near to the average. For instance, 63% resp. 60% believed that people with schizophrenia resp. severe depression are unpredictable; 37% resp. 42% that they are difficult to talk to; 24% that they are a danger to others; and 23% resp. 11% that they will never recover. With regard to social distance from a person previously hospitalized with schizophrenia, more than half of students were unwilling to share a flat with that person, to have that person as a babysitter for their child, to have their child marry that person, or to introduce that person to a friend as a relationship partner. Although the extent to which students held stigmatizing attitudes was similar in each country, the determinants of stigma, however, were different. In Belgium, unpredictability was associated with lower social distance.

Physiotherapy students (Probst & Peuskens 2010): No previous studies have examined the attitudes of physiotherapy students towards mental health. This study investigated the attitudes of physiotherapy students towards psychiatry according to the subject's gender and previous experience with psychiatry. The attitudes towards psychiatry of physiotherapy students (n=219) were compared with those of students without a biomedical background (social sciences, law, theology) (n=112). All students completed an established international questionnaire entitled 'Attitudes Towards Psychiatry'. Attitudes towards psychiatry were moderately positive. There was a small but significant difference between physiotherapy students and non-medical students, the latter ones showing more positive attitudes. Female students had a more positive attitude towards psychiatry than their male peers. Prior experience with mental illness was associated with more positive attitudes.

#### Part 2: Evaluated anti-stigma programmes in Belgium

In this second part, we report on evaluated anti-stigma interventions in Belgium. Such evaluation studies are scarce. Until recently, even anti-stigma activities themselves were scarce. The activities that do exist are small scale, local and temporary ad hoc initiatives, such as open door days, that are poorly elaborated in terms of methods and aims and hardly documented. Not surprisingly, evaluation is very rare, let alone publication of results.

A major recent change has been the development of an umbrella organization: 'Anders Gewoon'. This Consortium coordinates and supports local anti-stigma initiatives, which includes about 50 ad hoc small-scale activities each year throughout Flanders. Nearly all anti-stigma activity in Flanders is involved within this Consortium. It can be regarded as a 'programme' at this level, and is more documented in terms of common aims and methods. Our institute is involved in this Consortium to provide scientific support. This has resulted in some evaluation efforts with regard to anti-stigma action, which were almost non-existent before in Flanders. We have conducted a process evaluation of activities of the Consortium as a whole (participants' characteristics), and a process evaluation of a 3 selected initiatives that are described below.

Before the set up of the Anders Gewoon Consortium, we know of only one larger scale and documented initiative that can be considered as a programme: 'Hoe anders is anders (HAIA)' ['How different is different']. This programme has now stopped, but in fact it was the predecessor of the Consortium, since it was being conducted by the main organization ('Vlaamse Vereniging voor Geestelijke Gezondheidszorg (VVGG)' ['Flemish Association for Mental Health'] behind the Consortium. This programme has not been evaluated. What is available is a report with a description of activities, examples of methods and information materials used as an inspiration for future actions. The same is available for the Anders Gewoon programme. But these reports do not add in terms of strength of evidence (VVGG 2000; VVGG 2009).

Finally, there has recently been for the first time a national public campaign about mental health in Flanders, organized by the government ('10 steps for positive mental health', based on a campaign in UK some years ago). This campaign was about depression and aimed to provide information and stimulate self-help. The focus was on mental health promotion and positive mental health. Decreasing stigmatization was one of the sub-aims. This campaign was not evaluated.

In the evaluated programmes described below, we discern interventions aimed at a) the general population and b) at health and community professionals.

#### (A) Programmes aimed at the general population

Anti-stigma programme 'Anders Gewoon' ['Differently Normal']: The Anders Gewoon Consortium is lead by the Vlaamse Vereniging voor Geestelijke Gezondheidszorg (VVGG) ['Flemish Association for Mental Health'] and Zorgnet Vlaanderen ['Care Network Flanders']. Numerous and varying local partners (mostly mental health care institutions) are involved in local delivery of the activities. Our organization (LUCAS) is involved in the steering group of the Anders Gewoon Consortium to provide scientific advice. In terms of approaches used, Anders Gewoon aims to decrease mental health (care) stigma. It does by increasing contact and mental health literacy of the general population with regard to mental health (care). Therefore, most local activities use contact and information strategies, such as open door days of psychiatric care institutions, lectures and testimonies about psychiatric disorders and their treatment, arts or

theatre play by users, etc. Most activities are informative and experiential and open to anyone interested. It broadly aims at the general population, although the numerous local projects may target specific groups, including young people. Approximately 50 programmes are delivered each year reaching between 1000-5000 people annually. No effect evaluation of the programme as a whole has been conducted, so the evidence is rather weak in terms of effectiveness. The only evaluation available is a process evaluation of activities of the Consortium, with the aim to investigate who the participants to the local Anders Gewoon activities are, how they heard of the initiative, and what they (dis)liked about it. We used a questionnaire to be filled out by participants to the local Anders Gewoon activities (n=2669 participants to 45 initiatives), investigating participants' characteristics, recruitment channels, and appreciation of selected aspects. The results showed that local anti-stigma activities in Flanders tend to reach mainly those people with more time, interest or affiliation with mental health care. Only 18% of participants do not have any experience with mental health (care), and about half are inactive (retired, not working, student). Most participants were recruited via specific notification of the organizing mental health service; only 30% of participants heard of the initiative via media advertisement or word of mouth. This is important, since the latter had less experience with mental health (care). Overall, participants had a very positive appreciation of the Anders Gewoon initiatives, with a mean score of 90% for initiatives being important, well organized and interesting, and a mean total appreciation score of 81%. There was a mean score of 70% for the degree to which the initiative had changed participants' view of mental health (care). However, there were important differences according to participants' characteristics. The less experience participants have with mental health (care), the more they indicate that their views on mental health had changed. Participants particularly liked experiential (interaction with users) and personally relevant methods (answers to questions). We conclude that, to optimize their impact, recruitment of local anti-stigma activities should focus on societal sectors outside health or social care (Scheerder & Van Audenhove 2009).

Theatre play 'Bruggenbouwers' ['Building Bridges']: Theatre play organized by a mental health care institute (Hestia Tienen) and LUCAS, in collaboration with service users from the institute. This project aims to decrease stigma by improving knowledge and attitudes of the general population, and students in particular, with regard to mental illness. It does so by using the contact strategy, i.e. a theatre play by service users. A secondary aim was to increase well-being and recovery of the residents who performed. The theatre play was open to anyone and announced in the region. Students at schools were specifically invited and 200 attended. The investigate the impact of the theatre play on knowledge and attitudes of the students with regard to mental illness, and on the well-being and recovery of the residents who performed, a pre and post assessment of knowledge and attitudes was used, including the CAMI scale and an ad hoc developed instrument to assess knowledge. We also conducted two focus groups with the residents. The results showed that the attitudes of the students, as measured by the CAMI scales, did not significantly change after the intervention. Their knowledge score even decreased. Some socio-demographic characteristics had an influence on the attitude and knowledge scores. The residents' well-being and recovery process seems to be positively affected by their participation in the play.

We may conclude that it is not self-evident that beautiful and interesting actions such as a theatre play have the desired effects on attitudes and knowledge. It may be that the public has other motives to be involved in the intervention than mere interest in mental health care. In this study, the presence of the students at the play was mandatory and this may thus have distorted the measurement. The intervention was, however, helpful for the residents' well-being and

recovery process. It seems necessary to conduct more planned anti-stigma actions for target groups who are aware of the problematic issues (Tambuyzer et al 2008; Tambuyzer et al 2009).

Information day 'Jeugd: Geestelijk gezond?' in Nieuwpoort ['Youth: mentally healthy?']: This information day for youth about mental health, depression and suicide was organized by the 'Vlaamse Vereniging voor Geestelijke Gezondheidszorg (VVGG)' ['Flemish Association for Mental Health'], a user group on depression, the local government and LUCAS. This event specifically aimed to increase mental health literacy and decrease stigma with regard to mental health (care) in general, and depression and suicide specifically, in adolescents. The event consisted of three parts: an information market where local actors in mental health (professionals, users and carer groups) described their work; a discussion panel, where care providers at several levels (crisis hotline, primary care, community care, residential care) answered questions with regard to their experience in dealing with depression and suicide; and a testimony by someone bereaved by suicide. The event was open to anyone and announced in the region, but the main target group were adolescents, who were specifically invited through schools in the region, and 200 attended. The aim of the evaluation was to investigate participants' satisfaction with the programme and 76 participants' were asked to fill out a questionnaire that assessed satisfaction with the programme approach and subparts. Overall satisfaction scores were only moderate to low. The 'mandatory' participating adolescents of schools are less motivated and more critical than the participants 'out of free will', who were interested adults or professionals, but who belong to an 'already converted inner circle' that is knowledgeable of mental health. It is therefore essential to use a specific approach that is adapted to the needs and interests of young people. Interventions elements need to incorporate experiential (testimonies, user participation, contact) and personally relevant methods (interaction). Only a brief informal (unpublished) Dutch language report has been written about the results of this evaluation.

Improve the image of mental health care in the region of Sint-Niklaas (De Rick et al 2003; Van Audenhove et al 2005): This anti-stigma project was organized by LUCAS and local mental health care institutions. This project aimed to decrease stigma and increase mental health literacy of the general population and of home care providers. The strategies used were information and contact (open door event). The intervention consisted of 2 parts of 3 hours each. The first was a lecture and discussion to inform about the care for severe mental illness. The focus was on a positive but realistic message, hope and recovery. In the second part, service users presented their experiences and participants could actively experience the care facilities. This project broadly aimed at the general population. The open door event was open to anyone interested and announced in the region. Home care providers were a specific target specific group, for whom participation was part of their continuous education. 2 programmes were delivered to 200 people. Only the event for the target group of home care providers was evaluated. The aim was to investigate the impact of the intervention on the attitude toward mental illness of home care providers (n=106), using the CAMI scales. After the intervention, there was a significant improvement in three scales of the CAMI: authoritarianism, social restrictiveness, and community mental health ideology. We conclude that anti-stigma projects can be effective in changing attitudes.

Psycho-education about suicide for young people (Portzky & van Heeringen 2006): This study examined the effectiveness of psycho-education in a controlled study, by assessing the effect on knowledge and attitudes. Therefore, the Suicide Information Test and Attitudes Toward Suicide were assessed before and after the program. The programme engaged 172 students aged 14- to

18-year-old at secondary school. A positive effect of the programme on knowledge could be identified and an interaction effect of the program with gender and pre-test scores on attitudes was also found. A negative impact of the program could not be found. The findings from this study suggest that psycho-educational programs in schools may influence knowledge about suicide and attitudes towards suicidal persons.

(B) Programmes aimed at health and community professionals

Nurses: Currently, an evaluation study is running regarding an educational programme on depression and suicide for nurses in general hospitals. Its effectiveness will be evaluated in terms of changes in knowledge and attitude with regard to dealing with patients with depression or suicidal ideation, but no data is available at present.

Pharmacists (Scheerder et al 2006): A training programme was developed to increase community pharmacists' capacity to provide care for people with depression or suicidal ideation. It consisted of 3 x 2 hour sessions and included theory, groups discussion and training psychosocial skills. It was delivered at 2 locations of Flanders, reaching 80 pharmacists. The evaluation of the programme included a before and after assessment of knowledge, attitudes and skills with regard to depression and suicide. Although baseline attitudes were already quite favourable, further significant improvements in participating pharmacists' attitude toward depression and suicide were observed after the training programme. For instance, more pharmacists disagreed that depression mainly occurs in people with poor stamina (48% before to 80% after); that people with depression should primarily pull themselves together to get over it (32% to 57%); that depression cannot be completely cured (65% to 90%); that people with suicidal ideation cannot be stopped (55% to 95%); and that those who talk about suicide will not commit it (35% to 80%).

Psychiatric rehabilitation course for physiotherapy students in Flanders: No previous studies have examined the impact of a specific course on attitudes of physiotherapy students towards mental health. The effect of a 65-hour course on psychiatric rehabilitation on 219 physiotherapy student attitudes was evaluated, using the 'Attitudes Towards Psychiatry' questionnaire. In comparison with baseline scores, reported positive attitudes increased after completion of a psychiatry course (Probst & Peuskens 2010).

#### CONCLUSIONS

Overall, there are rather limited research efforts with regard to stigma and discrimination in Flanders. Although there are a number of mostly small-scale or pilot studies, there is not a culture of evaluation and few resources are devoted to it. In recent years, however, efforts have increased, and finally a national representative general population survey on attitudes toward mental health (care) is being conducted. Another promising point is the research on attitudes of non-traditional professional groups in this regard, such as pharmacists and physiotherapists.

Given the diverse nature, settings, methods and scope of the studies, it is very hard to draw systematic conclusions on common findings. Nevertheless, the available evidence provides some indications. These are largely in line with findings from studies in other western countries. For instance, there are indications that mental health literacy is rather limited in our country and that stigmatizing attitudes with regard to mental illness are present among the public, but

also in health and community professionals. This is not only evident from surveys in these populations, but also from studies of patient experiences. A majority of them perceive public stigma or have experienced discrimination in some regard. In particular, rates of self-stigma tend to be elevated.

With regard to anti-stigma interventions, even fewer evaluation studies are available. Based upon the few studies that do exist, we can conclude that they also provide some evidence that stigmatizing attitudes can be changed, especially when experiential and personally relevant methods are being used. This is in line with the evidence from other anti-stigma studies, which for instance point to the importance of the contact strategy. In this regard, we refer to a review we made on behalf of the Anders Gewoon project on best practice aspects of anti-stigma interventions. As a particular point, we may add that it is important to consider the recruitment of the target population. If the aim is to change public attitudes, then participant recruitment efforts should be actively focused outside the traditional 'in crowd'. But on the other hand, methods need to be tailored to the characteristics of non-traditional target groups.

Finally, we explicitly want to mention the Anders Gewoon project. The creation of this Consortium has had important benefits for anti-stigma action in our country, such as increased number of initiatives, increased internal dynamics (exchange of ideas), increased external visibility and media coverage, increased coordination and coherence of actions, and increased evaluation of actions. The Consortium can therefore be recommended as a model of good practice with regard to anti-stigma activity (Scheerder & Van Audenhove 2007; Scheerder et al 2008).

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# EVIDENCE AND BEST PRACTICE IN TACKLING STIGMA ASSOCIATED WITH MENTAL HEALTH PROBLEMS IN BULGARIA

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### INTRODUCTION

The report includes several sections. First of all, a method of identification of programmes and data collection is described. Next, the findings are presented briefly. A discussion of the findings follows. Some conclusions are offered. At the end there is a list of references.

### METHOD

Information about research and social action on how the issue of the stigma of depression is discussed in Bulgaria was sought in specialized scientific and professional journals (the list is presented below), specialised and mass media Bulgarian websites, policy documents and through consultations with colleagues in the mental health field. There was no available electronic database on the issue in Bulgaria. The list of scientific journals was made on the basis of consultations with professionals in the field, Internet searches and referrals to the journals themselves. The list of contents of each volume was then reviewed and articles on stigma and/or depression were identified. We read through these articles in order to find out any possible discussion of issue of the stigma of depression. Specialised and mass media Bulgarian websites were sought through using as the key word the Bulgarian translation of "stigma" (we decided that using of a key word "depression" would reveals too much sites, having nothing to do with the issues of stigma).

### **FINDINGS**

### **Books and Journals**

The search for specialized scientific and professional journals in the field of psychology and psychiatry yielded 9 journals and 1 book in this area. Full details can be found in appendix 1.

Only 2 of these journals had any articles at all on stigma. "Neurology and Psychiatry" had one article, a report of an interview with Professor Heintz Kachnig on the historical roots of the concept of schizophrenia that have contributed to stigmatizing of this disorder. The only other journal giving significant coverage to stigma was "The Bulletin of the Bulgarian Psychiatric Association" which had 8 articles (each are listed in the references section in English):

One article reports how a conference on stigma and discrimination related to mental illness One addresses Bulgarian mental health policy (it had been quite recently accepted) as a tool for overcoming psychiatric stigma

One reports on the result of research on needs and attitudes related to psychiatric illness in the situation of reforms that had been recently finished

Two article outline how Bulgarian legislation had been treated the issue of the psychiatric stigma over decades, since the beginning of 20th Century, and the latest developments in the field (the Law on Protection against Discrimination)

One is a psychodynamic analysis of psychiatric stigma and societies in transition Two articles are translated from English

In addition, one book was found: "Stigma and Personal Biography" by Professor Donch Gradev, Iztok-Zapad Publishing House, Sofia 2010. It is a review of existing social psychology theories on stigma of various groups (like certain ethnic and racial groups, people with physical disabilities and obesity, mentally ill people, people with non-traditional sexual orientation, poor people, addicted, etc.). Mechanisms and motives of the whole process are reviewed. The whole book is based on the preference of the author of the biographical approach.

# Websites

The search for specialised and mass media Bulgarian websites yielded more than 50 results. The criteria being publishing materials connected to psychological or social stigma (as opposite to "stigmata"). The full list can be found in Appendix 2. However non have high quality evidence of the problem of depression and stigma, nor evaluations of the impact of interventions.

## **Policy documents**

Several local and state policy documents were identified that had implications for stigma, for example:

National Program for Mental Health of the Citizens of the Republic of Bulgaria 2001-2005. Mental Health Policy (MHP) of the Republic of Bulgaria (year 2004 – 2012) National Action Plan for Implementation of the Mental Health Policy of the Republic of Bulgaria Towards Community Based Mental Health Care in Bulgaria. Master Plan

Some more mental health strategies of different regions of Bulgaria also refer to stigma. Stigma is mentioned in all these national policy documents, for example "Stigma and discrimination due to mental illness" is one of the principles of the Mental Health Policy. However, stigma is mentioned as an argument or as a target to be addressed but without any specific information on the problems or specific actions on how it will be addressed.

### Programmes to address stigma

Given the lack of studies and evaluations in the literature on stigma and mental health problems we We consulted with colleagues from various organizations across Bulgaria to identify programmes that had been developed, the organisations included:

Global Initiative on Psychiatry – Sofia (<u>http://www.gip-global.org/p/13/109/-/c25/ms6-31/gip-sofia</u>, <u>http://mh-center.info</u>, and <u>http://www.mh-community.org/</u>)

Public Health Association (<u>http://www.phabul.eu/</u>)

Mental Health Centre "Adaptacia" (<u>http://www.adaptacia.info/</u>)

Association of the Relatives of Mental Health Users "Adaptation Society" (www.psihichnozdrave.com)

Dinamika Centre for Psychotherapy, Counseling and Psychiatric Consultations (<u>www.dinamika-sofia.com/</u>)

Association for the Development of Psycho-social Rehabilitation in Bulgaria

Center "Bulgarian Institute for Human Relations", New Bulgarian University

Association "Chovekolubie" (http://chovekolubie.org)

They provided us information on a wide range of initiatives that have been developed against stigma. These projects have not been evaluated and therefore we cannot assess their effectiveness. However, we have listed 13 key projects, which use different approaches such as the arts, positive contact methods, lectures, coalition-building, to act as a resource to inform future research and action in this field:

Adaptation through Art - User Art club (2002 - 2003). The project consisted of 3 components the piloting of a user art club, a Bulgarian user tour and an International user tour. The user art club started was entirely managed by the user organization "The Children of Kubrat". In collaboration with the users' NGO "The Children of Kubrat" the GIP-Sofia organized a 7-day user tour in Bulgaria in April 2003. The tour started with a big public event in Sofia - promotion of the book of poetry "Philosophy of Madness", with poems and paintings by users. More than 130 people – politicians, mental health professionals, users, artists and citizens were present at the event. Ten users from "The Children of Kubrat", a psychiatrist and a social worker from "Adaptacia" community mental health service, 2 students of psychology – volunteers and the 3 Sofia office staff members continued the tour in 2 other cities of Bulgaria, where public promotions of the book and the paintings were organized. Three psychiatric hospitals were also visited and meetings with the staff and the patients were made. The International tour (June 2003), was a continuation of the Bulgarian User Tour project. The GIP-Sofia bus, with 4 users from "The Children of Kubrat", a psychiatrist from "Adaptacia" and the 3 Sofia office members started the tour from Sofia. They continued to Bucharest, Romania, where 2 other participants joined. The tour went through Hungary, where the participants had a meeting with users and professionals from 3 professional and user organizations. The tour continued to Slovakia, where 2 more participants joined and a meeting was made in a community mental health centre in Bratislava with more than 50 participants. The next stop was in Brno, the Czech Republic, at the community mental health centre there. Meetings were organized with the staff of the centre and its clients. The tour ended in the Tepla monastery with a conference on User and Relatives' Involvement organized by GIP - Hilversum. During the first stage of the project a contact was established with a German producer, working with users from Mihalovce (the Slovak Republic). He had trained the users from a Slovak organization to work with a camera and film their initiatives and experiences. After several meetings with The Children of Kubrat and e-mails exchanged with the team from Mihalovce, the idea emerged that it would be good to train two of the users from Kubrat to work with a video camera and film the user tour. Therefore 2 members of the user organization participated in the third film workshop, held between 10th and 14th March in Mihalovce and later on were able to film parts of the tour

Media for Mental Health – Training Modules (September – December 2003). The Media for Mental Health project, funded by the OSF-Bulgaria, focused mainly on work and developing collaborative relations with the Bulgarian national media (radios, TVs and newspapers). The project task was to inform and to create an attitude of understanding and sensitivity towards the problems of the mentally ill people in Bulgaria. The project objective was to create a positive attitude towards the mentally ill people in the journalists and to attract them as allies for the mental health cause. An effective way of carrying out such a task is the use of personal experience in building relations with mental health service users themselves and with mental health professionals. The project consisted of 4 educational modules – seminars. The topics of the 4 modules were as follows: "Psychiatric stigma", "The rights of people with mental illness", "Bulgarian national program for reform in psychiatry" and "European mental health standards". During each seminar, after a 45 minute lecture covering the main module topic, followed by

discussion aiming to focus the minds of the participants, they visited a mental health service/institution. This gave the journalists an opportunity to touch upon a concrete human story and to learn about the difficulties and problems of the users as well as of the service providers. Their consultants during the visits were the representatives of the user organization "The Children of Kubrat" and the mental health professionals. At a Christmas event in December 2003, awards were given to 8 journalists from national media, for creating non-stigmatizing media messages and the event was in the evening news of one of the biggest national TVs. The most ambitions goal of the Media for Mental Health project was to set the foundations of a Coalition for mental health.

Posters Pandora - User run anti-stigma campaign (2004). With the support of GIP-Sofia the user organization "The Children of Kubra" implemented an anti-stigma segment from the GIP campaign for changing the public attitudes towards people with mental health problems. The message of the Dutch NGO Pandora "Ever met a normal person? ... Did you like it?" was used for a campaign in 2 cities of the country and in the national media.

Anti-stigma coalition (2004 - 2005). The anti-stigma coalition is an alliance of experts working in the field of mental health, representatives of government administration, non-governmental organizations of users, their families, etc. Members of the Coalition are representatives from the Ministry of Labour and Social Affairs, a division of the Ministry of Health – the National Centre for Public Health, the WHO Task Force on Stigma and Discrimination, the NGO "Bulgarian Advocates for Human Rights", the "Bulgarian Institute for Human Relations", the "Bulgarian Association of Social Workers", 2 user organizations - "The Children of Kubrat" and "Mental Health Advocates", as well as "Geneva Initiative on Psychiatry" as a coordinator of the coalition. Partners of the coalition are the group psychiatric practices Adaptacia, Dinamika, Analytica, the Sofia City Psychiatric dispensary, the parents' NGO "Adaptacia Society" and others. The main goal of the Coalition is to concentrate, streamline and offer resources and support to the initiatives aiming to change the public attitudes towards people with mental disorders and mental disabilities. The anti-stigma coalition coordinated and publicly announced a number of events organized by partner NGOs, connected with the October 10, World Mental Health Day, and devoted to better integration of people with mental health problems into society. A press conference of the coalition was held on 6th October, where the mission and goals, as well as the major activities of the partners were presented to the media. The first task that the members of the Coalition agreed upon was to develop in 2005 a Guidebook of the available mental health and social services in Sofia that contains comprehensive information on the state of mental health and social services, types of services offered and their geographical distribution, number as well as qualification of the professionals who work in them. This guide is intended for use by users, professionals, and other interested institutions and organizations.

Anthology of User Art from SEE (2005). One of the purposes behind the development of the anthology was to promote SEE user art, aiming to present to the general public in the region and beyond, the creative side of mental health service users. We offer a quote from a user-painter from Slovenia, whose works are in the anthology, who says: "I believe art has saved or rescued a lot of people with problems in mental health, who find themselves again and begin believing again that they are able to move on. Since I am active in art I have had no serous mental health problems, I do not take any medications but the fact is that for this luxurious state you need to maintain your life in balance, not only by art. Love, basic material background, support and sensible work can be the key for it." Igor Spreizer, Slovenia.

National Chess Tournament for People with Mental Health Problems 2007 The Project goals' were promotion of sports among people with mental health problems; creating opportunities for sports performance of people with mental health problems and making the national chess tournament for people with mental health problems through a traditional sustained funding; fighting stigma against mental illness by demonstrating the intellectual capabilities of people with psychiatric diagnoses; nurture moral and intellectual qualities volitional in people with mental health problems - critical and creative thinking, strengthen mental health interest to sports activities. The target group of the project were people with mental health problems, which are 230,000 in the country. To participate in the national tournament expecting 35 people - 20 of 15 of the country and Pazardzhik.

Program "Finding Job", 2005. The project envisaged the creation of a new program to serve customers of the Center for Social Rehabilitation and Integration. Project goals were: Social integration through the Employment of people with chronic psychiatric problems; improving quality of life of people with chronic psychiatric problems by raising income and increasing their self-assessment; fighting social stigma against people with chronic psychiatric problems. The target group consisted of people with disabilities, in particular people with psychiatric diagnoses. Beneficiaries of social service program "Finding a job were 32 people with mental health problems - customers CSRI, and people with mental problems who need this service without our customers. The project was implemented for 7 months - from 01.06.2005 to 31.12.2005

Anti-Stigma Campaign of the Public Health Association (PHA). A TV clip and six billboards were produced with the following slogans: For some grief is only a stop, but for the other it is a way without; 365 days without sun; 100 years of solitude; Speak to me, speak to me...; People with mental disorders need all us; We all care. The clip was broadcasted via national TV network; the photographs was situated in many places in the center of the city of Sofia.

Dinamika Centre for Psychotherapy, Counseling and Psychiatric Consultations established in the first half of 2005 a small group for GPs. It met twice a week and had 8 - 12 participants on average. As a work method the Balint group approach was used, including processes of transference and countertransference. This meant exploration of the relationship doctor - patient: discussion of feelings, causing the patient and physician behave the way they behaved. The goal is to become a more sensitive doctor with awareness of the unconscious needs of the patient and to deal more effectively with psychosocial problems. The group continued working until 2007

In 2005 the "Association for the Development of Psycho-social Rehabilitation in Bulgaria" implemented a project "Transitional employment program as a way to ensure employment for people with chronic mental disorder". The major task of the project was to persuade a number of prospective employers to establish transitional job places to let people with severe mental disorder to have some work experience on their way to open market employment. There are more than 40 prospective employers contacted. During the project implementation 10 transitional job places were opened. Ten clients in total started at these transitional job places. Two more clients started working on integrated job places with the support of the team of the project.

On request of Technical University, Sofia, the "Association for the Development of Psycho-social Rehabilitation in Bulgaria" prepared a Position Paper of possibilities of people with mental disabilities to get University educational degree (bachelor or master level). The Position Paper defended for ideas of Supported Education and necessity to adapt some educational procedures to needs and possibilities of people with mental disabilities – in order to give them a real chance to get a better education. The Position Paper was submitted to the Dean of the Technical University in November 2005.

Association of the Relatives of Mental Health Users "Adaptation Society" established in 2005 a "Bulgarian Mental Health Portal Website" (<u>www.psihichnozdrave.com</u>). A mission of the site is

to increase availability of mental health services by providing information on existing psychiatric resources (services and care programs) and to let people make an informed choice; to deliver information on citizens' rights of people, receiving mental health services; to increase mental health and mental disorders connected competence of general population; to let people express their opinions freely and to have a discussion on issues how to find and receive psychiatric help, ensuring in that way a participation of citizens in regulation of quality of the services and in maintaining of good standards of service delivery. After end of the period, funded by OSI, the project received additional funding by pharmaceutical company Janssen-Cilag to keep functioning.

Association of the Relatives of Mental Health Users "Adaptation Society": "Living with Serious Mental Illness: Our History, Our Present" (2007 – 2008). Some photos of people with severe mental illness and their relatives were taken. The photographer sought situations that were as typical as it was possible; the other criterion was a readiness of people to let some pictures to be made of them. 16 people were photographed; most of them have severe mental illness, and some are relatives. The photographs were taken in the homes of the people, churches, shops, on the streets, in the day care centre of "Adaptatsia", etc. 27 colour and 28 black and white pictures were chosen. Besides that, personal life stories of people with severe mental illness and their relatives were collected. A number of photos and stories on the website of the Association. The visitors of the website were involved in the process of selection giving feedback to uploaded stories and pictures. Finally, "A Travelling Exhibition" was arranged – presenting the stories and the photographs in governmental, media and community organizations (to attract attention to the needs and achievements of the target group). The "Travelling Exhibition" was arranged in several sites.

### DISCUSSION AND CONCLUSIONS

From this review a number of key points emerge.

There are several organizations active in the field of psychiatric stigma reduction and they are mainly NGO's. They publish a bulk of materials on the issue but our search found no evidence of scientific research of stigma of the depression in Bulgaria.

We found no evidence of scientific research of stigma of the depression in Bulgaria from academics, mental health groups, psychiatrists, psychologists or social scientists. All materials we found were either political (a part of the arguments to follow some political course of action) or educational (giving more or less specific information on stigma or some possible explanation of the phenomenon). But we found no single article on specifics of this phenomenon in Bulgaria. There are a number of activities implemented in order to reduce stigmatizing attitudes. It is impossible, though, to evaluate the effectiveness of these programs. There are no evaluation mechanisms imbedded in the programs; no outside experts have been invited to make an evaluation; we have no information how these were accepted.

On the other side, there is no starting point for the implementation of such programs – nobody really knows how strong is stigma in Bulgaria (it hasn't been measured).

The concept of stigma entered political documents too; there are some repetitive sentences and slogans that can be found in them.

The stigma of schizophrenia and, to smaller extent that of HIV/AIDS, are mostly discussed. The stigma of depression receives much less attention. It is unclear how this choice is made: whether it is based on needs assessment and a following conclusion about severity of the stigma of schizophrenia and HIV/AIDS and, as a consequence, on the emergency of taking some measures in this field. Or whether some other kind of reasons play some role.

It can be speculated that one of the signs of the stigma of depression in Bulgaria is complete lack of real scientific activities in the field. Overall, stigma is seen as a clinical, social or political phenomenon in Bulgaria, but not yet as a subject of possible scientific interest. All users, members of their families, mental health professionals and many interested in the field journalists and politicians know that there is a stigma of mental illness; all agree that the stigma is strong; it seems enough for now.

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### **APPENDIX 1.**

Journals related to mental health and stigma in Bulgaria "Clinical and Counselling Psychology" by Steno Publishing <u>www.stenobooks.com/spisaniq/Clinical\_Psychology/1-2009/index.html</u> "Psychiatry" by Steno Publishing <u>www.stenobooks.com/spisaniq/psihiatriya/index.html</u> "Psychology" - psychologyjournalbg.com

"<u>Psychological</u> Investigations" published by the Institute of Psychology at the Bulgarian Academy of Sciences <u>philosophy.log.bg</u>

"Psychology Journal

"Receptor. Bulgarian Journal of Psychiatry" published by the Association "Private Psychiatry" www.receptor-bg.org

"Neurology and Psychiatry" published by the Publishing House "Prolidiabet" www.imessa.net/polidiabet\_website/nevrologia.html

"Social Medicine" a quarterly edition of the society "Scientific society of social medicine, informatics and healthcare management" <u>www.nchi.government.bg/publications/13.html</u> "The Bulletin of the Bulgarian Psychiatric Association" is the official periodical of the Bulgarian Psychiatric Association (BPA) and a main means for communication among the psychiatrists in the country. The Publication Programme of the BPA succeeded in translation, editing, and publishing some 4-5 books yearly, usually basic, internationally recognized manuals for mental health professionals, including nurses, social workers, and psychologists. www.bpabg.com/?q=en/home

# **APPENDIX 2**

Websites providing mental health or stigma information in Bulgaria

A range of websites provide information about mental health in Bulgaria and they are organized below by themes.

State health care institutions:

http://dpb-lovech.org (State Psychiatric Hospital in Lovech) http://ncphp.government.bg (State Psychiatric Hospital in Tzerova Koria) http://rcz.sliven.info (Regional commission on healthcare) http://www.rcz-yambol.org (Regional commission on healthcare) http://www.sriokoz.com (Capital City Regional Department on Public Health Promotion and Control) http://www.psihologia.net (students, teachers and alumnae of Sofia University)

Municipality structures:

http://www.kpzgo.com (community mental health agency)

International organizations:

http://www.unaids-bulgaria.org (UNAIDS, the Joint United Nations Programme on HIV/AIDS in Bulgaria)

http://www.mhe-sme.org/ (Mental Health Europe)

Bulgarian non-governmental organizations:

http://www.bghelsinki.org (Bulgarian Helsinki Committee)

http://www.psihichnozdrave.com (Association "Adaptation Society" – Association of relatives of mental health users )

http://mh-center.info (Foundation "Global Initiative on Psychiatry - Sofia")

http://hepactive.org (Association for Struggle with Hepatitis "Hepactive")

http://www.nursing-bg.com/ms.html (Bulgarian Association of Health Care Professionals)

http://www.bgpsychology.com (Online counseling agency)

http://www.krasytherapy.eu

<u>http://bg-bg.facebook.com</u> (Center for Emotional and Psychosocial Research and Therapy) <u>http://www.bphu.eu/</u> (Bulgarian Pharmaceutical Alliance)

# RESEARCH ON STIGMA RELATED TO MENTAL DISORDERS IN FINLAND: A SYSTEMATIC LITERATURE REVIEW

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### **EXECUTIVE SUMMARY**

A systematic literature review was performed to map Finnish research on stigma related to mental disorders. Searches of nine electronic databases resulted in a wide variety of research, from psycho-historical studies to ongoing population surveys of population attitudes.

A set of studies have measured experience of stigma and discrimination among people with mental disorders. Qualitative research among service users highlights the important role that mental health professionals and their classification systems have in creating identities, feelings of otherness and even self-stigmatisation among service users. Quantitative data indicate that more about one in three persons with a mental disorder experience stigma due to their disorder, and international comparisons indicate that stigma of people with schizophrenia is at least not less common in Finland than in other developed countries. Fortunately, institutionalised discrimination in public services seems to be uncommon in Finland.

Another extensive set of studies, ranging over more than 50 years, have measured attitudes towards people with mental disorders among the general population. Attitudes of older people have been more negative than attitudes of younger people, which has been interpreted as a generational effect. In earlier studies women had more negative attitudes, but nowadays men have more negative attitudes. Education has consistently been linked to more favourable attitudes. The overall picture given by a repeated population survey, implemented since 2005, indicates that in this short perspective general population attitudes in Finland are rather stable, but there are some signs of a positive development. In the recent years, social acceptance seems to have increased somewhat, and more people tend to believe that you can live a full life despite having a mental disorder. A European general population opinion poll and results from a student survey indicate that attitudes in Finland may be less stigmatising than in many other countries.

A third line of research has analysed attitudes towards people with mental disorders among special groups of interest, such as students or health care staff. A qualitative study of students' attitudes indicates that it may be advisable to avoid clinical categories and language and, instead, to use descriptions in terms of concrete problems and behaviours to describe mental disorders. Problems of mental health should be portrayed as common, reversible and located within the variation of normality. Attitudes of medical students and health care staff have in general been found to be positive, but a study shows rather surprisingly that access to psychiatric consultation among general health care staff was associated with less favourable attitudes.

Taken together, research and opinion polls provide a multifaceted picture of mental health stigma in the Finnish society. Stigma is prevalent, but the situation may be better in Finland than in many of the other European countries. Younger generations tend to have more favourable attitudes. Interestingly, some of the research results point towards an aggravating role of mental health professionals. Diagnostic procedures and clinical language seem to increase stigma. There are grounds for a critical and open discussion about the stigmatising effect of psychiatric diagnoses, which are increasingly used also outside of psychiatric services.

### **INTRODUCTION**

As part of the ASPEN (Anti-Stigma Programme - European Network) project's Work Package 4 ('Best practice anti-stigma'), Aspen sites were to conduct a literature review on stigma research in their country. This would include a thorough analysis of all the peer review publications and reports about mental health stigma in their country. The present paper is the Finnish report to ASPEN.

#### METHOD

#### Data sources

The authors searched nine relevant databases. Three of the searched databases contain publications from Finland only (ARTO, FENNICA, Medic) and four databases have an international coverage but are probably biased towards publications in English (Cinahl, Medline, PsycInfo, SocIndex). In addition, two local library databases were searched (Linda, THLIB).

ARTO is a reference database of Finnish articles, consisting of articles from approx. 600 Finnish journals from 1990 onwards. ARTO contains journal article references and occasionally references to articles in monographs.

FENNICA (the Finnish National Bibliography) contains information about monographs, serials, maps, audiovisual materials and electronic publications printed or produced in Finland. FENNICA also includes materials published outside of Finland that relate to Finland or are written by a Finnish author.

Medic is a Finnish health science database established in 1978. The database is produced by Helsinki University Library, The Meilahti Campus Library Terkko.

Medic contains references to Finnish medical and health science literature: articles, books, dissertations and reports published in Finland and not included in international databases.

Linda is a joint catalogue of Finnish university libraries, which contains the Finnish National Bibliography as well as references to the books, journals, publication series, maps, visual materials, archives and electronic materials in the databases of university libraries, the Library of Parliament, the National Repository Library and the Library of Statistics.

THLIB is the library catalogue of the National Institute for Health and Welfare, Finland

### Search terms

The search terms were as follows:

Fennica: (mielenterv? OR psyyk? OR psyk? OR mental?)[in Word Search/Free text/Keyword] AND (syrji? OR eriarv? OR diskri? OR discri? OR stigma?)

Arto: (mielenterv? psyyk? psyk? mental?)[ in Any Word ]AND(syrji? ennakkoluul? eriarv? diskri? discri? stigma?)

Medic: (mielenterv\*, mental\*, psyk\*, psyyk\*) AND (syrji\*, stigma\*, eriarv\*, ennakkoluul\*, leima\*, prejudice\*, diskrim\*, discrim\*)

Linda: (mielenterv? psyyk? psyk? mental?)[ in Any Word ]AND(syrji? ennakkoluul? eriarv? diskri? discri? stigma?)

THLib: (mielenterv\* tai psyk\* tai psyyk\* tai masen\*) AND (syrji\* tai diskrim\* tai eriarvoi\* tai stigma\*)

Cinahl: (mental disorders or psychiatric patients or depression or mental health services or mentally ill or mood disorders) AND (attitude to mental illness or social worker attitudes or stigma\* or stereotyping or discrimination) AND (Finland or Finnish or nordic)

Medline: 1. Finland.mp.
2. (finland or finnish).ti,ab.
3. exp Mental Disorders/
4. stereotyping/ or stereotyped behavior/
5. exp "Discrimination (Psychology)"/
6. Prejudice/ or stigma.mp.

- 7. exp Depressive Disorder, Major/ or exp Mentally III Persons/
- 8. exp Mood Disorders/
- 9. 1 or 2
- 10. 3 or 7 or 8
- 11. 4 or 5 or 6
- 12.9 and 10 and 11

Psycinfo: 1. exp mental disorders/ 2. exp major depression/ 3. exp Adjustment Disorders/ 4. exp Stigma/ 5. stereotyped attitudes/ or discrimination/ or prejudice/ or social discrimination/ 6.Finland.mp. 7. (finland or finnish).ti,ab. 8. or/1-3 9. or/4-5 10. or/6-7

11. 8 and 9 and 10

Socinfo: (mentally ill or mental disorders or pychiatric patients or depressive disorders) AND (stereotyp\* or stigma\* or discrim\*) AND Finland or finnish or Nordic

### LITERATURE ANALYSIS

## 1. Psycho-historical studies

Finnish research on stigma and discrimination in relation to mental disorders includes historical overviews and analyses. The historian Jari Eilola has published widely on intolerance and discrimination in a historical context, focusing on beliefs of witchcraft and social stigmatisation in the 17th century.1 Toivo Nygård has analysed the situation of marginalised groups in Finland in the 19th and early 20th century2. He writes about the function of hospital institution for mentally ill and also about different forms of remedies on those days.

## 2. Service users' experience of stigma

## (a) Qualitative studies

One of the main research areas in Finland has been the subjective experience of stigma and discrimination. The dissertation of Anna Kulmala is following the research tradition of social constructivism and is based on life course narratives of people with mental disorders3. The first data set consists of texts submitted to the writing contest "When Wings Carry" organised by the Finnish Mental Health Association. The second data set consists of personal interviews with 14 men living in a shelter for homeless people. The interviews show that the construction of own identity of the interviewees was strongly permeated by professional definitions and concepts concerning the interviewees as service users. The concepts and definitions used by professional staff about their clients had been transposed to the self-images of the respondents. The interviewees conveyed a situation in which they were objects who had been defined based on their problems, and this led them to narratives about marginalisation, otherness and outsiderness. Stigmatisation by the professional staff led to a negative social identity, a sense of otherness and self-stigmatisation. Categorisation by staff was followed by self-classification by the clients. A main conclusion of the study is the need to increase awareness of the impact of classification and categorisation of clients, especially as the categories and diagnoses used in work with vulnerable often are negative and problem-oriented. Thinking of the persons categorised, the phenomenon of categorisation is particularly hurtful if the categories are negative, like they tend to be in mental health care. The results of the research project by Anna Kulmala have been further explored in five articles.4-8 This work highlights the important role that mental health professionals and their classification systems have in creating identities, feelings of otherness and even self-stigmatisation among service users.

# (b) Quantitative studies

The user-led Sateenkaaritalo (Rainbow House) in Vaasa, Finland, took part in the international INDIGO study on perceived stigma and discrimination in people with schizophrenia.9 A structured interview using the Discrimination and Stigma Scale (DISC), which assesses experiences of being treated (dis)advantageously for several live domains, was performed with people diagnosed with schizophrenia. In Finland, 26 people participated in the INDIGO study. The results confirmed that people with severe mental disorders are confronted with stigmatisation and discrimination in several domains of life.

The major source of discrimination were personal relationships –two of three respondents reported having been discriminated in making or keeping friends and almost one in two had experienced being treated differently by their family. In Finland, institutionalised discrimination was seldom observed. On the other hand, only a few respondents reported that having a mental disorder diagnosis had provided some advantage to them.

Discrimination leads to self-discrimination, and a majority of the responders had stopped themselves from applying for a job or education due to their diagnosis. Most of the responders perceived a need to conceal or hide their mental illness diagnosis from other people.

International comparisons are bias-prone and should be interpreted with caution, but it should be noted that among people with schizophrenia, participants in only three countries of the 27 countries participating in the INDIGO study, experienced more negative discrimination than the respondents in Finland.

Compared to people with schizophrenia in other participating countries, people residing in Finland had two times more often experienced threats to their personal security. This can partly be explained by the socio-cultural context in Finland, where violence and violent crimes are more common than in many other countries.

Outside of the peer reviewed literature, the opinion poll "Mielenterveysbarometri" (Mental Health Barometer), initiated by the user organisation Finnish Central Association for Mental Health, has since 2005 measured experience of stigma among a random sample of their membership. 10-14 The sample size has varied between 200 and 300 people. Over the years, about one in three of the responders have reported being subject to stigma due to their disorder.

Responders were also asked to estimate the position of people with mental disorders in the Finnish society. On a scale from 1 (totally excluded) to 10 (full members of society), the mean score in the years 2005-2009 has ranged between 5,60 and 5,99.

# 3. Occurrence and measurement of stigmatisation

# (a) General population

The first published study reporting attitudes towards mental illness of the general population is from 1973.15 This study was performed in two rural communities in Finland, one of them mainly agricultural and the other industrialized. The sample consisted of 200 individuals, the response rate was 94 %, and personal interviews were performed using a Likert-type attitude scale created for the purpose. The main hypothesis of the study, introduced on both sociological and psychiatric grounds, was that attitudes in the agricultural community would be more negative than in the industrialized community, but the results failed to confirm the hypothesis. Men's attitudes were found to be more positive than those of women in both communities. A positive association between attitudes and educational level was observed in both communities.

Publication of the abovementioned small scale study was followed by the breakthrough epidemiological UKKI study. The UKKI study was performed in a random population of 1,000 subjects aged 15-64 living in southern Finland (Uusikaupunki) and in northern Finland (Kemijärvi) in the end of the 1960s.16 The stratified sampling included 600 people living in urban areas and 400 people living in rural areas. Attitudes were measured using a Likert-type attitude scale consisting of 20 items, identical to the instrument used in the previous smaller study.15 Each item was scored from 1 to 5, positive attitudes were scored higher. Altogether 941 people were interviewed in person (response rate 94 %).

In this study, attitudes were highly correlated with age, as older people had more negative attitudes. Women expressed more negative attitudes towards mental disorders than men. Education and socio-economic status group were distinctly correlated: the higher the socio-economic status or the better education, the more positive the attitudes. In rural areas, attitudes tended to be more negative than among urban residents. In a multivariable analysis, age and educational level seemed to be the most important predictors of attitudes.

Subjects suffering from psychological disturbances manifested at psychiatric interviews and by other means, and who were assessed as being in need of psychiatric treatment, displayed more negative attitudes towards mental illness than those who were mentally healthy. Particularly negative attitudes were observed in subjects suffering from neuroses. On the other hand it could be established that positive attitudes towards mental illness correlated with subjective need of treatment and willingness to utilize psychiatric treatment.17

A third study18 of general population attitudes towards people with mental disorders was made in the beginning of 1990s, using the same instrument as in the previous studies. 514 persons from different parts of Finland filled in the questionnaire. The attitudes were generally positive, although, as in the previous studies, the attitudes of those older and less educated were more negative compared with the other groups. This result was interpreted as a generational effect, which will vanish as the educational level of the population increases. The questionnaire also included questions about the attitudes and behaviour of 'other people'. The attitudes of 'other people' were thought to be very negative compared with one's own attitudes.

Recent methodological studies have analysed new Finnish instruments aiming at measuring public knowledge and attitudes as well as stigma. These studies originate in the repeated general population survey which has been implemented in the Ostrobothnia region to a randomly selected sample of 10,000 persons aged 15-80 years.19;20 A basic explorative analysis showed that a clear majority (86%) of the Finnish population believed that depression is a real disorder21. A majority (60%) of respondents shared the idea that depression can be considered as a shameful and stigmatizing disease and as many believed that depressed persons should pull themselves together. A lot of negative consequences were connected with mental illness in social relationships, health care system and working environment. It seemed to be difficult for people to figure out the positive and adverse effects of medicine care. Many also believed that one may not get proper mental health services on primary health care level.

A principal component analysis of the instrument identified four main attitudinal components: (1) depression is a matter of will, (2) mental problems have negative consequences, (3) one should be careful with antidepressants and (4) you never recover from mental problems.22 Especially the first component which measures the personal belief that people with depression are responsible for their illness and their recovery seemed to be valid enough to be used as a scale in future analysis.

The same data were used to examine how well a combination of variables predicts stigmatizing attitudes and discrimination in a general population.23 Attitudes were measured using a scale consisting of negative stereotypes about people with depression and stereotypical beliefs connected with mental problems, while discrimination was measured by a social distance scale. Predictors included demographic variables, mental health resources, familiarity with mental problems and stereotypical beliefs. Social discrimination was significantly associated with

respondents' age, gender, language, sense of mastery, depression, stereotypical beliefs and familiarity with mental problems (Table 1). The results suggested that among men, older people and those without familiarity with mental problems the need for anti-stigma intervention is highest. The connection between sense of mastery and discrimination suggested that when planning interventions to counter negative stereotypes, one potential target group could be those with a low sense of life control and poor social networks.

Table 1. Hierarchical linear regression analyses predicting social distance with (1) sociodemographic attributes, (2) mental health resources (3) exposure to mental problem (4) beliefs about depression (Depression is a matter of will -scale) and negative stereotypes of mental problems

	Model 1	Model 2	Model 3	Model 4				
Socio-demographic								
Age	- 0.316***	- 0.321***	- 0.292***	- 0.268***				
Gender	0.042**	0.048***	0.070***	0.120***				
Language	0.034*	0.034*	0.037**	0.037**				
Basic education	- 0.026	- 0.023	- 0.020	- 0.018				
Vocational training	- 0.035*	- 0.041*	- 0.021	0.000				
Mental health resources								
Sense of Mastery	0.056***	0.001	0.039*					
How many people are so close	e to							
you that you can count on them if								
you have serious personal pro	blems?	- 0.040**	- 0.045**	- 0.017				
Exposure to mental problem								
Depression symptoms (CIDI-S		- 0.076***						
Psychological distress (GHQ-1	2) - 0.018	- 0.021						
Familiarity with someone suffering								
from mental problem 0.149*** 0.107***								
Beliefs about depression and negative stereotypes of mental problems								
Depression is a matter of will -scale								
0.135***								
If one tells about her mental problems, all friends will leave her								
0.036*								
If the employer finds out that the employee is suffering of mental illness, the employment will								
be in								
jeopardy								
0.049**								
The professionals in health care do not take mental problems seriously								
- 0.019								

Depression can be considered as a shameful and stigmatizing disease 0.002

It is difficult to talk with a person who suffers from mental illness  $0.140^{***}$ 

Patients suffering from mental illnesses are unpredictable 0.116\*\*\*

Total R20.1130.1170.1480.236R2 change0.113\*\*\*0.003\*\*\*0.032\*\*\*0.088\*\*\*

\*Significant on the P < 0.05 level

\*\*significant on the P < 0.01 level

\*\*\*significant on the P < 0.001 level (one-tailed tests)

Finland has also participated in the Special Eurobarometer wave 64.4 on mental wellbeing24. The Eurobarometer data was collected in December 2005 and January 2006 by telephone interviews of a general population sample. Participants had to be at least 15 years of age. One section of the survey dealt with attitudes towards people with mental disorders. Participants were presented with a set of statements regarding "people with psychological or emotional health problems". Overall, the survey found that Europeans have a reasonable tolerant view of people with mental disorders. In general, opinions were more positive among residents in the northern and western Europe, including the Scandinavian countries, the Netherlands, UK, Ireland and Spain. An exception from the geographical pattern was perceived dangerousness, where some of these countries (Sweden and UK) scored higher than the EU average. In the EU overall, men, elderly, and those with low education tended to have more negative attitudes. Europeans who had received psychological treatment tended to have marginally less negative attitudes.

The results from Finland indicated less stigmatizing attitudes as compared to the average general opinion among Europeans. 55% of Finns agreed that people with psychological or emotional health problems are unpredictable. Among the EU population, the corresponding figure was 63%. 31% of Finns agreed that people with psychological or emotional health problems constitute a danger to others, and only 10% agreed that people with psychological or emotional health problems never recover. The corresponding EU-wide figures are 37% and 21%, respectively.

### b. University students

Hannu Räty has aimed at an qualitative-descriptive analysis of beliefs concerning mental illness and their attitudinal organization25. Empirically, his study was based on the interviews of a group of 30 university students, mostly female, average age 21, supposed to represent people with liberal and educated stands towards various minorities. The interview was semi-structured and consisted of four topics: (1) the study of the implicit theory of psychopathology based on a card sorting task dealing with the relation between attitudes and the way psychiatric symptoms are categorized and evaluated; (2) in studying the social representations of mental illness the answers were analysed in terms of "shared understanding", i.e. not the individual differences but the common frame was focused on; (3) the subject's perspective was investigated as a selfdescription of her attitude, e.g., in regard to the dimensions by which positive self-evaluation is achieved, the ways dissonance is treated, and the kind of values and personal experience used in depicting her views; (4) the nature of argumentation was analysed by presenting statements about mental illness and asking the subjects to state and support their opinion.

Pessimistic beliefs could be grouped into three assumptions, which portrayed mental illness as a basically unknown, incurable and dangerous condition. The representational logic is "naturalistic": mental illness is seen as a category of sinister behaviour obeying some unknown and irresistible laws; its attitude is fatalistic and rejective; it represents society's perspective, where being mentally ill is seen as a form of inactivity and unproductiveness, and thus a negatively evaluated deviance. In contrast a positive approach based on the "criticism of civilization" also existed: mental illness has a symbolic role in representing the victims of society and its disharmony. There was a general tendency among the subjects to avoid explicit psychiatric attributions because their use was regarded as "negative labelling". Individual differences were also found that supported the expected distinction between the active (optimistic) and passive (pessimistic) attitude. Based on the locus of causal attribution and the way in which one's own negative beliefs are treated, two clusters of orientation could be extracted. The first one - a notion of object responsibility - was typical of the pessimistic attitude. The second cluster - a notion of co-responsibility - was typical of the optimistic attitude. Attitude-related differences were also seen in the judgment of deviant behaviour: a subject with a pessimistic attitude attributed more pathology to behaviour descriptions and evaluated them more negatively than one with an optimistic attitude. There appeared to be two quite independent determinants of the mental illness attitude: one's behavioural history and one's values. A subject's own behavioural history - or more precisely, her retrospective account of it – correlated strongly with her attitude: the more negative the experience concerning the mentally ill, the more rejective the attitude. Expressed values also correlated with attitudes: a person with an optimistic view emphasized democracy, morality and "soft values" such as a humane, anti-bureaucratic and ecologically-sound society. Based on a detailed analysis of accounts the following features appeared typical of a consistently positive attitude: (a) a tendency to minimize and counter-balance the negative characteristics of mental illness, (b) a questioning of taken-for-granted thinking, (c) a tendency to consider mental illness rather a social problem than a form of pathology, and (d) symbolic "we-categorization", i.e. the mentally ill person is a victim of unjust conditions and deserves our sympathy.

In his discussion author claims that there is no easy way of changing people's conception of mental illness; it is neither simple "like any other illness" nor "just a myth". He also optimistically claims that there is probably no any active discrimination against mental patients. It seems likely that people are willing to behave in more a positive way if they know how. It seems advisable to avoid clinical categories and language and, instead, to use descriptions in terms of concrete problems and behaviours. Problems of mental health should be portrayed as common, reversible and located within the variation of normality. The finding that the pessimistic view is tied to the value of self-reliance is problematic, since it may prevent a person from getting help for his difficulties.

### (b) Mental health nurses

A international questionnaire survey analysed attitudes of 810 registered nurses working in 72 inpatient wards and units and five community facilities in Finland, Lithuania, Ireland, Italy and Portugal.26 The data were collected using The Community Attitudes towards the Mentally III (CAMI) scale, which is a 40-item self-report questionnaire.27

Nurses' attitudes were mainly positive. Attitudes differed across countries, with Portuguese nurses' attitudes being significantly more positive and Lithuanian nurses' attitudes being significantly more negative than others'. Positive attitudes were associated with being female and having a senior position.

## © ER staff

A series of studies examined attitudes of the emergency staff towards suicide attempters. The first study explained the attitudes of a general hospital emergency personnel (n=184) towards patients who had attempted suicide by comparing the attitudes of the staff in the emergency room (n=64), emergency ward (n=47) and intensive care unit (n=73).28 The attitudes were most negative among emergency room staff, where all attempters are first treated. The intensive care staff, who treats the most serious cases, evidenced the most positive attitudes.

In another study the aim was to compare the attitudes towards patients who have attempted suicide of emergency room staff between two general hospitals, one with psychiatric consultation available and the other without. The Understanding Suicidal Patients (USP) Questionnaire was given to all the staff in the emergency rooms of these two hospitals (n=115). Female gender, older age and working in hospital without routine psychiatric consultation were associated with more positive attitudes. Surprisingly, working in hospital with routine psychiatric consultation was associated with more negative attitudes29.

Next study examined the association between emergency room staff members' psychological distress and the attitudes towards suicide attempters. The Understanding Suicidal Patients (USP) Questionnaire and the 12-item version of General Health Questionnaire (GHQ-12) were given to all staff in the emergency rooms of a general hospital and a psychiatric hospital (n=151). There was a general tendency among emergency room staff to view attempted suicide patients positively and sympathetically. However, there were clear differences in staff attitudes between the two hospitals: those working in the general hospital expressed more negative attitudes than those in the psychiatric hospital. No evidence emerged of association between staff members' own psychological distress and negative attitudes towards suicide attempters30.

In the fourth study the aim was to compare the attitudes of emergency room staff in a general hospital towards suicide attempters before and after establishment of a psychiatric consultation service. Attitudes were measured with the USP questionnaire (n=100). The result was that general understanding and willingness to nurse patients who attempted suicide did not increase during the first year of the consultation implementation, but in general, the emergency room staff were content with the opportunity for psychiatric consultation31.

Taken together, the studies indicate that possibilities for psychiatric consultations do not alter attitudes of ER staff favourably.

# (d) Pharmacy students

A recent international comparison study analysed mental health stigma and its determinants among pharmacy students in Finland, Australia, Belgium, Estonia, India and Latvia.32 In this study, data were collected as part of the International Pharmacy Students Health Survey, a census survey of third-year pharmacy students studying at eight universities in six countries. Response rates varied by country between 70 and 98 %. Respondents (n = 642) indicated how

strongly they endorsed six stigmatising statements about patients with schizophrenia and severe depression and completed a seven-item social distance scale.

The results (Table 2) indicate that among young people, some stigmatising beliefs are less common in Finland than in the comparison countries. In Finland 8% (95% CI 3-12%) of pharmacy students agreed that a patient with severe depression is a danger to others, in the other participating countries the corresponding percentage ranged from 13% in Australia to 39% in India. Of the Finnish students 24% agreed that people with severe depression are unpredictable. In the other countries, the share of agreeing students varied from 36% in Australia to 61% in India. On the other hand, the largest share (44%) of students in Finland agreed that people with severe depression have themselves to blame, indicating differing views on the determinants of depression across countries.

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Table 2. Percentage of respondents	Estonia	India	Belgium	Australia	Finland
who strongly agreed or agreed in	& Latvia	(n =	(n = 102)	(n = 241)	(n =
relation to a patient with severe	(n = 70)	106)			130)
depression (95% CI)32					
A danger to others	37.7	39.0	23.8	13.3	7.7
	(26.3–	(29.7–	(15.5–	(9–17.6)	(3.1–
	49.1)	48.3)	32.1)		12.3)
Are unpredictable	57.1	60.6	59.8	36.4	23.8
	(45.5–	(51.2–	(50.3–	(30.3–	(16.5–
	68.7)	70.0)	69.3)	42.5)	31.1)
Are difficult to talk to	72.9	45.2	42.2	36.4	37.7
	(62.5–	(35.7–	(32.6–	(30.3–	(29.4–
	83.3)	54.7)	51.8)	42.5)	46.0)
Have themselves to	26.1	31.1	9.8	11.7	43.8
blame	(15.7–	(22.3–	(4.0–	(7.6–	(35.3–
	36.5)	39.9)	15.6)	15.8)	52.3)
Not improve without	72.9	55.8	58.4	39.2	86.7
treatment	(62.5–	(46.3–	(48.8–	(33–45.4)	(80.8–
	83.3)	65.3)	68.0)		92.6)
Will never recover	21.4	2.8	10.8	5.0	14.6
	(11.8–	(0.0-	(4.8–	(2.2–7.8)	(8.5–
	31.0)	6.0)	16.8)		20.7)

A further analysis of the survey indicated that there were no significant differences in social distance to people with mental disorders as expressed by the students in the participating countries.33 In Finland, social distance among pharmacy students was linked to perceived dangerousness.

Much contemporary research has indicated that women tend to have more favourable attitudes towards people with mental disorders, and thus comparability of results is hampered by differing gender distributions in the student samples. The Finnish sample had the highest share of female students, and no standardisation for sex was performed by the authors. Any

conclusions are thus preliminary, but this study hints that stigmatising beliefs regarding depression may be more common in low and middle income countries than in high income countries like Finland.

Stigmatising attitudes towards people with schizophrenia and severe depression were common among pharmacy students in all countries. The authors conclude that new models of pharmacy education are required to address the attitudes and misconceptions among pharmacy students.

### (e) Medical students

In this prospective study of attitudes of medical students data were collected twice during their studies and once after graduation.34 Respondents' own explicit attitudes and their perception of others' attitudes towards psychiatric patients, disorders and health care were evaluated by a questionnaire. Throughout the follow-up period the medical students and new doctors had positive attitudes towards psychiatric issues. There were, however, significant negative and positive attitude changes in many individual statements, mainly after the fourth year of study. Most of the changes could be explained with the increase of knowledge and the experience of real patients, but some negative changes indicated increasing cynicism. The ratings of other people's supposed attitudes changed significantly in a positive direction, mostly between the first and fourth year of study. Interpreting respondents' perception of others' attitudes as a projection of respondents' own attitudes, this study suggests that the education had changed unconscious attitudes of medical students in a positive direction.

## 4. Grey literature

One sign of the heightened interest is an increasing number of master theses on the subject; many of them dealing with stigma of people with schizophrenia35-37 or the self-concept of stigma.38-40 A interesting master thesis analysed experiences of 12 non-psychotic patients with depression during their first hospitalisation for a depressive disorder.41 The patients interviewed had searched help for an acute crisis and expected the hospitalisation to result in improved mental health, but most of them were not aware of treatment options and content of in-hospital treatment. The patients expressed fear, stigmatisation and shame. Having a mental disorder and being a psychiatric in-patient were shameful experiences. They feared being stigmatised, and avoided telling others about their hospitalisation, with the exception of telling close friends. They were afraid of being stigmatised upon return to work, but the patients in general felt that close friends had reacted positively when being told about the hospitalisation. The author concludes that hospital staff need to openly discuss feelings of shame and fear of stigmatisation, to reduce the negative consequences of such hidden fears, to provide information and to reduce false beliefs.

Of special interest is the yearly opinion poll and attitude measurement "Mielenterveysbarometri" [Mental Health Barometer] initiated by the user organisation Finnish Central Association for Mental Health. The poll has been performed every year since 2005.10-14 The responder sample has consisted of general population (aged 15-70 years), mental health service users and their families, and since 2006 also psychiatrists and psychologists. The results originating from the service users have been presented in section 2b.

In 2005, a population sample of 639 persons were surveyed. Results indicated that 8% of the population agreed that a person with mental health problems should blame himself. 65% believed that full recovery is possible after a mental disorder. Almost one in three (30 %) would

not like a person with a mental disorder as a neighbour. According to the survey, only drug addicts, alcoholics and criminals were less popular as potential neighbours than people with mental disorders. On the other hand, 52% said that more social and health care resources should be devoted to people with mental disorders. On a scale from 0 to 10 (0 designates total exclusion and 10 designates full inclusion), the position of people with mental disorders in the Finnish society was estimated to be on average 5.47.

In 2006, the general population sample was almost 1300 people. The attitudes of the general population were similar to the previous year: 32% would not like to have a person with a mental disorder as a neighbour, 9% thought that people with mental disorders have to blame themselves, and 58% would like to invest more in health and social services for people with mental disorders. The position of people with mental disorders in the Finnish society was estimated to be on average 5.42.

In 2007, the general population sample consisted of almost 1300 people. Comparing with the two previous surveys, a trend towards slight improvement in attitudes begins to appear: 29% would not like to have a person with a mental disorder as a neighbour and 9 % thought that people with mental disorders have to blame themselves. On a scale from 0 to 10, the position of people with mental disorders in the Finnish society was estimated to be on average 5.24.

In 2008, the general population sample consisted of 628 respondents. The positive trend was maintained, and 28% of respondents reported that they would not like to have a person with a mental disorder as a neighbour and 8% thought that people with mental disorders have to blame themselves. 61% would like to invest more in health and social services for people with mental disorders. On a scale from 0 to 10, the position of people with mental disorders in the Finnish society was estimated to be on average 5.24.

In 2009, the representative population sample was 611 respondents. The positive trend was strengthened. 27% of respondents reported that they would not like to have a person with a mental disorder as a neighbour and 8% thought that people with mental disorders have to blame themselves. 56% would like to invest more in health and social services for people with mental disorders. On a scale from 0 to 10, the position of people with mental disorders in the Finnish society was estimated to be on average 5.24.

The overall picture given by the repeated surveys indicates that in Finland general population attitudes have been rather stable, but there are some signs of a positive development since 2005. The social acceptance seems to have increased somewhat, a more people believe that you can live a full life despite having a mental disorder. It also seems that respondents are more aware of the stigmatisation of people with mental disorders, as the estimate of the social position of people with mental disorders seems to have deteriorated over time. Across the years since 2005, men have evidenced less positive attitudes towards people with mental disorders than Finnish women.

### DISCUSSION

Our review highlights that in Finland there is a long tradition in measuring attitudes towards mental illness and patients in the general population. The literature review indicates that stigma of mental disorders occurred as an issue in the late 1960s, when questions about attitudes

towards mental disorders were included in the UKKI epidemiological study. The issue was further raised in the 1970s in a report from the national Social Security Institution 42. In those early works the researchers developed their own attitude scale and interpreted results to show quite positive attitudes15;42. They also optimistically thought that new generations with better education and knowledge about mental problems would carry more positive attitudes. A follow-up study showed that the direction of change was although only slightly positive between 1970-198518. It is interesting to note that already in those days there was an interest about the effects of attitudes on utilization of psychiatric treatment17. The researchers were also well aware of the problems connected with attitude surveys and critically reminded that attitudes do not predict behaviour well18.

Although the history of stigma research is 50 years old in Finland it has started to flourish in the late 1990s and in the 21st century. There seems to have been little research activity in this field in the 1980s and 1990s. Scarcity of research is indicated by a Finnish review on stigma and diseases, published in 2001, which did not include a single reference to stigma research conducted in Finland.43 However, international activities such as the Zero stigma project led by European Federation of Associations of Families of People with Mental Illness (EUFAMI)44, led to an increase in interest and awareness about stigma related to mental disorders and may have contributed to the recent revisits of Finnish researchers to the field of mental health stigma research. In addition to the scientific literature reviewed above, many opinion papers and papers targeting the general audience have been published on the topic of mental health stigma during the last ten years (e.g.45).

Lately, the Mental Health Barometer Surveys have highlighted discriminatory attitudes in the general population and stigma perceived by the users10-14. On the other hand, the polls have indicated widespread support for investments and improvements in mental health services. The overall picture indicates that in this short perspective general population attitudes in Finland are rather stable, but there are some signs of a positive development. In the recent years, social acceptance seems to have increased somewhat, and more people tend to believe that you can live a full life despite having a mental disorder.

Attitudes of older people have been more negative than attitudes of younger people, which has been interpreted as a generational effect. In earlier studies women had more negative attitudes, but nowadays men have more negative attitudes. Education has consistently been linked to more favourable attitudes.

The voice of service users was first listened to as late as 1996 in the Finnish research, in the form of a thesis on experiences of first-time hospitalised patients from a psychiatric ward40. After that, in the 21st century a series of important qualitative research studies highlight the important role that mental health professionals and their classification systems have in creating identities, feelings of otherness and even self-stigmatization among service users3;7;8. Quantitative data from the Indigo study showed that people with serious mental disorders confronted a lot of stigma and discrimination especially in relationships with friends and relatives but very little on an institutional level9.

The studies concentrated on stigma among special student and professional groups in health care have been a third line in the Finnish stigma research. Attitudes of medical students and health care staff have in general been found to be positive, but one study shows rather

surprisingly that access to psychiatric consultation among general health care staff was associated with less favourable attitudes31. One possible explanation may come from another qualitative study of university students' attitudes where the author advices to avoid clinical categories and language and, instead, to use descriptions in terms of concrete problems and behaviours to describe mental disorders25. It might be that mental health professionals with best intentions use stigmatizing language in consultation.

One important body of research is missing in Finnish stigma research; namely experimental research, i.e. evaluations of anti-stigma interventions. We found no trial reports. Some researchers have made suggestions about possible target groups for interventions, such as people with no familiarity with mental disorders or those with low sense of control and poor social networks23, but actual intervention research is lacking. This may be due to early researchers' disbelief in simple education interventions. More extensive information is recommended to be given in a form enabling its gradual integration with the personality and so that also unconscious factors are taken into consideration15;16. However, it has also been concluded from qualitative research that it seems likely that young people are willing to behave in more a positive way if they would know how25.

Taken together, research and opinion polls provide a multifaceted picture of mental health stigma in the Finnish society. Stigma is prevalent, but the situation may be better in Finland than in many of the other European countries. Interestingly, some of the research results point towards an aggravating role of mental health professionals. Diagnostic procedures and clinical language seem to increase stigma, as pointed out by the qualitative studies3;25 and corroborated by a study of the effect of access to psychiatric consultations on general health care staff31. There are grounds for a critical and open discussion about the stigmatising effect of psychiatric diagnoses, which are increasingly used also outside of psychiatric services.

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### **STIGMA AND MENTAL HEALTH PROBLEMS IN FRANCE**

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#### **INTRODUCTION**

The general objective of the Anti Stigma Programme: European Network (ASPEN) is to make an important contribution to the reduction of stigma and discrimination against people with depression in the 27 EU member states. The methods and means to be used to achieve this will be: (i) produce scales to assess stigma and discrimination with people with depression; (ii) interview 500 people with depression in 20 sites; (iii) collate best-practice to reduce stigma and discrimination; (iv) assess if anti-discrimination policies are applied in practice; (v) recommend how to include people with mental illness for policy formation; and (vi) for generic disability discrimination laws.

The programme of work as a whole will be separated into the following seven work packages:

- WP 1. Coordination of the project
- WP 2. Dissemination of the results
- WP 3. Evaluation of the project
- WP 4. Best practice toolkits
- WP 5. Stigma /discrimination scale development
- WP 6. Stigma & discrimination survey
- WP 7. Analysis of mental health policy and legislation

The main objective of Work Package 4 is to create and use Anti-Stigma Best-Practice Toolkit. Develop, finalise and widely disseminate a pragmatic Anti Stigma Toolkit to describe and assess EU-wide anti-stigma projects and to collate information on best practice, to be summarised in one paper and one web publications relating to adults and to and young people by the end of month 36. Best practice is understood here to mean a technique or methodology that, through experience and research, has proven to reliably lead to a desired result. A commitment to using the best practices in any field is a commitment to using all the knowledge and technology at one's disposal to ensure success.

This national report is divided in two parts.

The first one aims at presenting the known patterns of stigma and discrimination associated with mental health and depression in particular. It includes international studies in which France participated and French studies at local or national level.

The second one is about the evidence base and pointers for promising practice for effective interventions to address stigma and discrimination in relation to mental health problems, and depression in particular. The objective here is to focus on evaluated actions.

#### METHOD

To perform this literature review, as a first step, we searched relevant databases (Science Direct, Psycarticles) and the web, using the range of search terms suggested by the WP4 colleagues. In

addition, we used the electronic library of the WHO Collaborating Center for research and prevention in mental health (Lille, France), which regularly check the ongoing anti-stigma projects in France.

As a second stage, we also contacted directly stakeholders and key contacts. There were several objectives in this approach:

One main objective in the ASPEN study is to develop a concrete network at the international level, but this is also a good opportunity to enhance or strengthen this network at the national and local levels

Information about the ASPEN study has been relayed to a number of new contacts, what leaded to enable new actions or considerations about mental health stigma

Many anti-stigma actions do not come to publication

Anti-stigma work have to involve users, families and representatives

## RESULTS

In the first part of the results, we describe studies on patterns of mental health stigma and discrimination in France. The second part summarizes studies on interventions that address stigma and discrimination in relation to mental health problems in France.

## Patterns of mental health stigma and discrimination in France

## Users experiences of stigma and discrimination

ESEMeD and World Mental Health Surveys (Alonso et al 2008; Alonso et al 2009)

The questionnaire was divided in two parts. Part 1, administered to all respondents, included screening questions on psychopathology and additional questions for the assessment of some mood and anxiety disorders as well as health status and main demographic characteristics. France : N= 2894. All respondents who presented a number of symptoms of specific mood or anxiety disorders and a probability subsample of other part 1 respondents were administered the second part. Part 2 of the interview included questions on chronic conditions and disability and two questions concerning perceived stigma. Selection probabilities for part 2 of the interview were incorporated into sample analysis weights so that survey estimates provide unbiased estimates for the populations surveyed. France : N= 1436

The European Study of Epidemiology of Mental Disorders (ESEMeD) is a representative population survey conducted in 6 European countries, including France.

The survey in France included n= 2894 respondents. While this study primarily investigated epidemiology of mental disorders, 2 questions about perceived stigma were also assessed in people with a mental disorder experiencing significant disability (n= 1436). These questions referred to experienced embarrassment and discrimination. The data from the ESEMeD study are also part of the World Mental Health Surveys.

Results: In France, 78,3 % of people with a mental disorder and significant disability have experienced embarrassment because of mental health problems in the preceding month; 16,7 % experienced discrimination or unfair treatment because of mental health problems; and 16,5 % experienced both. Although the entire questionnaire was cross-culturally adapted using state-

of-the-art methods, there is inevitably some uncertainty about the cross-cultural equivalence of the items used to assess stigma. We did a blind, independent back-translation of the embarrassment item and found high equivalence with the original version in all countries except France, where there was some ambiguity in meaning. This may explain the relatively high prevalence of embarrassment in that country (while the prevalence of perceived stigma in France was intermediate). Finally, there was a non-significant higher probability of perceiving stigma in France and Belgium, especially in comparison to Germany, Spain and the Netherlands."

INDIGO - International Study on Discrimination and Stigma Outcomes (Thornicroft et al 2009; Daumerie et al in press)

France took part in this international study, lead by Porfessor Thornicroft, on perceived stigma and discrimination in people with schizophrenia. A structured interview was held with patients (N=25), using the Discrimination and Stigma Scale (DISC), which assessed experiences of being treated (dis)advantageously for several live domains. A second study addressing depression and using the Discrimination and Stigma Scale has been conducted (N=223).

Results : French interviews lead to some interesting conclusions. First, expressed disadvantages are high for several items (all relations, work and training, housing). In addition, we wish to highlight three specific points: almost half of the participants (46%) suffer from not being respected because of contacts with services, 88% of them felt rejected by people who know their diagnosis and 76% hide/conceal their diagnosis.

Participants with depression (N=223) answered to the DISC items with the same experimental setting, and results was compared. The main finding is that, more than the type of diagnosis, the occurrence of hospitalization(s) would lead to stigma and discrimination. No significant differences were found when considering the type of diagnosis. Conclusions, limits and side effects of the study are discussed."

# 1.2. Stigma and discrimination in the general population

ESEMeD - European Study of Epidemiology of Mental Disorders (ten Have 2010)

The European Study of Epidemiology of Mental Disorders (ESEMeD) is a representative population survey conducted in 6 European countries, including France. The survey in France included n= 1436 respondents. While this study primarily investigated epidemiology of mental disorders, it also included 5 items on attitudes toward help-seeking for mental health problems.

Results: In France, 40% of respondents would not seek professional help in case of serious emotional problems, 38% would not feel comfortable talking about personal problems with a professional; 21% would feel embarrassed if friends knew about professional help; and 39% believe that professional help is worse than or equal to professional help in terms of effectiveness. The belief that respondents would seek help when faced with a serious emotional problem was less often reported by those living in France (compared to the "average" European). They also believed professional help to be less effective in dealing with emotional problems.

Eurobarometer Mental Well-being (European Commission 2006)

The Eurobarometer is a regular opinion poll among the EU-member states population covering various topics. This special edition 248, part of wave 64.4, covered mental well-being, including a section on attitudes toward mental health. In France, this survey was conducted in n=1031 people.

Results: In France, 73% agreed that people with psychological or emotional health problems are unpredictable; 33% that they constitute a danger to others; 17% that they never recover; and 9% that they have themselves to blame. These scores for France are average in comparison to the European mean, for which the report concludes: "These results can be seen to portray that most Europeans have a reasonably tolerant way of perceiving their fellow citizens who have psychological or emotional health problems."

Mental well-being. Special Eurobarometer 248.

Mental Heath in the General Population (MHGP): Perceptions and Realities - An international action-survey to fight stigmatisation and discrimination. Mental health is a public health issue, however, access to relevant treatment often does not meet the population needs. Patients, their relatives, as well as mental health professionals are still victims of stigma. Whatever the countries and the cultural settings, public beliefs and attitudes towards mental illness play a major role in the ranking of priorities given to mental health national prevention and care policies. The research-action 'Mental Health in General Population: perceptions and realities' (MHGP) was carried out by the World Health Organisation Collaborative Centre (Lille, France) and the Direction of research, studies, assessment and statistics (Drees) of the French Ministry of Health, in a sample of 36,000 French subjects over 18 years old, between 1999 and 2003. It was also run in 10 foreign countries. The MHGP Survey is an international multisite study aimed at:

Describing, in the general population, the perceptions attached to insanity, mental illness and depression, and the related care

Assessing the prevalence of major psychiatric disorders in the general population Rising awareness about mental health issues among various social groups: social workers, local elected, care professionals, by including them in the research-action procedure Promoting the development of community psychiatry, following WHO main Guidelines

About 900 individuals were recruited in 47 centres in metropolitan France between 1999 and 2003 in order to reach a representative sample. Subjects were selected by quota sampling stratified by age, gender, educational and occupational level with the general population of the general population of the centre as sampling frame. The quotas were defined on the basis of the 1999 national population census. The assessment included a specially developed questionnaire enabling description of perceptions of insane, mentally ill and depressed individuals; the Mini International Neuro-psychiatric Interview (Sheehan and Lecrubier); a specific questionnaire on care consumption in case of positive MINI diagnosis and a socio-demographic questionnaire. MHGP research-action remains the first study of this scale on the topic of Mental Health in France, combining perceptions, public beliefs and prevalence descriptions. It allowed the development of anti-stigma actions at a national and local level.

In terms of results, over 75% of respondents associated the words "insane" and "mentally ill" with violent and dangerous behaviours and "depressive" with sadness, isolation and suicide. The more dangerous an act is viewed to be, the more likely it is to be viewed as abnormal and attributed by respondents to a person who is insane or mentally ill.

"make a suicide attempt", "cry often or be sad" and the fact "of being lonely and remaining alone" are associated by a majority of the population with "depression" (respectively 79,5%, 86,2%, 61,9%). People consider these behaviours as "abnormal" (62%, 38,1%, 44,6%) and dangerousness is only mentioned in relation to suicide attempts (60,9%). 74.9% think that someone with depression can be cured. The risk of exclusion for people with depression is perceived at the workplace (36.4%), in society (23.7%) and in the family (20%). 96.8% think someone with depression suffers, and also the family (94.8%). Having a mental disorder affected the results slightly. Youth, higher education and income more frequently associated dangerous behaviours with mental illness rather than with insanity. Full detail in Roelandt et al (2000); Defromont & Roelandt (2003); Bellamy et al (2005a); Bellamy et al (2005b); Caria et al (2010); Quidu & Escaffre (2010); Roelandt et al (2010) and Tassone-Monchicourt et al (2010).

FondaMental Study : Representations about mental disorders (Etude IPSOS pour Fondamental 2009) :

People with mental health problems must face negative representations, sometimes widespread in the French population. Moreover, real expectations about diagnoses, treatments and research exist. In this study, 916 participants were asked about their representations with respect to schizophrenia, bipolar disorders and autism. The survey included items about representations, treatment, social distance or research. In terms of findings, 47% of the people interviewed (N=916) associated negative terms to mental disorders (nutty, insane, lunatic, alienated ...). 74 % think people with schizophrenia are dangerous for themselves (bipolar disorders: 71%, autism: 22%) and 65% think they are dangerous for others (bp: 29%, a: 7%). 25% think that people with schizophrenia must be isolated and should not live in the community (bp: 6%, a: 7%), are unable to work or to live with someone. 30% would not agree to work with someone with schizophrenia (bp: 12%, a: 6%), 31% would not let their children with a child with schizophrenia in the same classroom (bp: 15%, a: 3%), 24% would not accept to live with a relative with schizophrenia in the same house (bp: 11%, a: 6%). A lack of information seems to maintain doubts about treatment and research effectiveness. More than a third think treatment and psychotherapy are not effective and 70% that diagnoses are made too late. 51% think research is not effective but 90% think it must be a public heath priority. Two-thirds think they are not informed enough about mental health.

### 2. Anti-stigma programmes and initiatives in France

In the first part we describe what we may call "classical" actions and programmes with methods, results and evaluations lack of evaluation. Then, we introduce some different actions, often implemented at the national level, and that tackle stigma and discrimination, as either a primary or secondary effect.

### 2.1. Anti-stigma programmes

France Dépression Association actions (www.france-depression.org)

Anti-stigma work is present from the start in the statutory objectives of the association: "enhance the comprehension of the general public of the depression and to fight prejudice about mental disease". The most significant project carried out in this field is the advert/spot about information and prevention conceived and carried out by the association in 2007.

The Information and Prevention television spot: France-Depression was the first to take the initiative to diffuse a message on the depression on French television thus constituting an historical event in the French audiovisual landscape. Several talks at the beginning of the year with France-Televisions were organized, leading to an agreement for a cost free diffusion of the spot. The project has been realized with the help of a subsidy of the INPES. The aim was to raise public awareness about depressive disease and to announce the 4th European Depression Day (EDD) in October 2007. The message was very simple and aimed at tackling stigma: anyone may be concerned, treatments and solutions exist, "do not hesitate to consult your doctor". The spot is updated each year in order to announce the EDD. It has also been broadcasted on the parliament channel, in more than 1800 dispensaries, and in the main hospitals around the city of Marseille. The same project is under development for the city of Paris. There is no direct evaluation of this action. But according to members of the association, the feedback was very positive, with numerous phone calls and e-mails and a real recognition of the testimony. The next step will be the development of a new spot about bipolar disorders.

The actions of the association France Dépression also include: working with the media and users testimonies (TV, radio, newspapers, website) - following the example of other associations in Europe and in the United States, the association want to implement a media watch in order to "sanction" and "to inform" the journalists writing a too sensational way; training interventions; work with governmental bodies and NGO; theatre projects with debates following the play

### **INPES** Depression programme

The INPES programme is part of the Psychiatry and Mental Health National Plan that aims to enhance the general public's knowledge about psychiatric disorders, their causes, symptoms and treatments, in order to improve the public representations and the follow-up of users. The main objective of the campaign was to promote tools of information (booklet and Internet site). The secondary objective was to inform the general public on the symptoms and the treatments of the depression in order to facilitate, if necessary, the dialogue with the entourage and the health professionals, to improve knowledge, to change attitudes and behaviours with respect to depression and in time to contribute to the improvement of the access to care. They used a number of techniques including: General public campaign across 3 media forms with a television spot from October 29 to November 18, radio with 4 spots from November 3 to November 21, and Internet with banners from October 29 to January 8). The campaign defined depression as a disease that can affect anyone. It presented the main symptoms by the means of an animation spot (TV) or testimonies (radio) and encouraged people wishing more information on depression to order a free booklet of information by the means of a phone number or an internet site.

The evaluation was based on 4 investigations: 2 post-tests (one with the general public, the other with the health professionals), an investigation of the internet campaign and an evaluation of the impact of the booklet. This evaluation is based on an investigation before/after reception of the booklet with 1503 people who ordered the depression booklet. These people were questioned a few days before the reception of the booklet (1st wave) and then 3 months

after the first interview (2nd wave). The same questions were asked during the two interviews in order to compare the evolution of their answers after the reading of the booklet. The aim was to assess in what extent does the booklet help to 1) Improve knowledge about depression symptoms, about professionals (in particular differences between psychiatrist and psychologist), treatments and types of care, places and care structures, and 2) Change attitudes towards depression, people with depression (stigma), the perceived risk of speaking about its depression, health professionals, perceived effectiveness of treatments, intention of recourse to care in the event of a depressive state. The results indicate that the booklet helped to : improve knowledge about professionals and structures lower stigmatization of people with depression

reduce the perceived risk to talk about depression with the family

improve the image of the psychologists and psychiatrists

improve the perceived effectiveness of psychotherapies.

Other items such as knowledge about symptoms, differences between psychiatrist and psychologist, perception of the risk of talking about depression at work or with friends, or the intention to access care (although positive) showed no significant change.

Finally some items, even if they were the object of improvements, either because of the booklet (such as the image of the "psys") or because of other elements (such as the effectiveness of antidepressants), could still significantly change. Thus the people who had a negative image of the "psys" or did not believe in the effectiveness of antidepressants moved in the desired direction but did not change the valence of their opinion. In the same way, if global knowledge significantly increased, the average score in the 2nd wave represents less than one fifth of the knowledge presented in the booklet.

For the delivery of health professionals campaign, several approaches were used one month before the general public campaign including mailings (1 booklet and leaflets), information in the medical press and presentation of the campaign at the national launch. The evaluation was based on computer-assisted telephone interviews of 622 health professionals (GP's, psychiatrists, psychologists) who received the booklet and assessed 1) Interest for the booklet depression: rate and reading level 2) Attitudes towards the booklet and the campaign 3) Use of the booklet 4) Impact of the campaign on the professional practices. In terms of findings: 78% of the professionals interviewed at least read it quickly and 34% read it with attention, entirely or partly; 83% globally agreed with the content of the booklet; 79% estimated that the campaign is useful; 63% found the tone right, 10% found it harmful and 14% demoralizing; Concerning the booklet, 45% put it in free consultation and 20% directly transmitted it to patients; 11% declared that it encouraged (a little or fairly) people to consult them and 32% declared that it encouraged patients to ask them questions about the depression; 31% of GP declared "an evolution of their practice" following the campaign. Two profiles among the professionals were identified. Those who were conducive to the campaign (40 years and less and women), and those averse to the campaign (51 years and more and "private" psychiatrists).

About the information booklet:

First booklet of information on adult depression for the general public. Co-written by health professionals, representatives of patients and public health actors. Includes useful addresses and phone numbers.

Dissemination:

500.000 booklets (more than 100.000 given by health professionals and prevention networks the booklet can be consulted, downloaded or ordered for free on Internet or by phone. 70.500 phone calls, 341 264 visits on the site and 3.034 7510 pages seen

255 398 booklets ordered (June 2008): 219.790 by the general population and 35.608 by professionals

- 233.000 leaflets ordered by Internet (69%), telephone (26,1%) and mails (4.9%)

For full details see Anguis et al (2001), Morvan et al (2005) and Anadep (2006) or www.inpes.sante.fr or www.info-depression.fr

"National information week on Mental Health" / Semaine d'information sur la santé mentale

This annual campaign was launched 22 years ago by an Association of Psychiatrists and is now organised by a group of 14 organisations1, gathering National Users' Groups Federation (FNAPSY), National Family Groups Union (UNAFAM), and professionals organisations in the field of Psychiatry and Mental Health. It takes place each year the 3rd week of March and is coordinated by the World Health Organisation collaborating centre – WHO-CC (Lille). It aims to: Open the dialogue on Mental Health issues with non-expert audience (general population); enhance the partnership between users, carers, health and social professionals and local elected, at national, regional and local level (new alliance); and increase the knowledge about access to care, support and information. It uses several methods. The National Coordination Committee of 14 partners decides the theme of the year, and produce and dispatch some communication tools (press release, announcement). Any people/body interested then organise an event (debate, conference, informal meeting, exhibition, open doors, movie...). All events are listed by the National Family Groups Union (UNAFAM) web site. No financial support is provided at national level. Every organizer looks for its own budget. An evaluation undertaken has a number of indications: the impact of the week is assessed through a media digest (national, regional and local) and the list of registered event with around 350 events listed in 2010; the local coordination of the actions is improving with more committees for the week emerging at a regional, local or municipal level; the week is used as a tool by users/ family groups and professionals, to raise awareness of stakeholders and local elected politicians; it has helped the development of new partnerships (users, families, professionals and elected) at local, regional and national level; finally it has played a role in the recognition of stigma in the field of mental health (Botbol 2009) and for details see www.unafam.org and www.psycom75.org

"Accepting differences, it's important also for psychiatric disorders" - First French Communication Campaign on Mental Health

This campaign is organised together with National Users' Groups Federation (FNAPSY), National Family Groups Union (UNAFAM), French Municipalities Federation (AMF), and WHO CC (Lille). It

<sup>&</sup>lt;sup>1</sup> Association Française de Psychiatrie (AFP) • Association Française de Psychologie Communautaire (AFPC) • Centre Collaborateur de l'Organisation Mondiale de la Santé pour la recherche et la formation en santé mentale (CCOMS, Lille, France) • Centre National Audiovisuel en Santé Mentale (CNASM) • Fédération d'Aide à la Santé Mentale Croix-Marine (FASM Croix-Marine) • Fédération Française des Psychologues et de Psychologie (FFPP) • Fédération Française de Psychiatrie (FFP) • Fédération Nationale des Associations d'usagers de la Psychiatrie (Fnapsy) • Société Médicale Balint • Union Nationale des Amis et Familles de Malades Psychiques (UNAFAM) • Union Régionale de la Mutualité Francilienne (URMF)

aims at 1) opening the dialogue about mental health issues, and try to change the image of mental health, for a better tolerance and 2) Enhancing the partnership between users, carers, health and social professionals and local elected, at national, regional and local level (new alliance). The core message is that mental illness issues cannot be tackled without referring to exclusion and taboos. The methods have developed between 2006-2009. In 2005-2006, 200 000 posters were dispatched over the French regions, through local relays. In 2006 it used the label 'Campaign of General Interest'. In 2007 it added adverts / spot TV and the creation of the web site <u>www.accepterlesdifferences.com</u>. In 2009, 200 000 booklets were distributed to the French regions through the local relays. There has not been an evaluation of global impact. Local impact assessment suggests the campaign is used as a tool by users/ family groups and professionals to raise awareness of stakeholders and local elected during Mental Health Week; it has helped the development of new partnerships (users, families, professionals and elected) at local, regional and national level; it has played a role in the recognition of stigmatisation in the field of mental health; and the topic is now discussed in many places and has been included into the National Mental Health Plan (2005-2010) (Ketterer 2008; Rhenter, 2010).

## Psycom75: Information to fight stigma in mental health

This public organisation was created 18 years ago by 5 psychiatric hospitals in order to improve the information level of GPs, users and general population about mental health issues. It gathers a board of mental health professionals, users representatives and local elected officials and aims to 1) Spread a message of tolerance, in order to reduce stigmatisation, discrimination and social exclusion and 2) Increase the global level of knowledge about well-being, psychiatric disorders, treatment, good practices, and access to care. It employs 3 broad methods: 1) Editorial activities: 17 information brochures on mental health, 25 leaflets on psychotropic drugs, and guides; Documents are developed by health professionals and users (see www.psycom75.org) and distributed to users, carers, psychiatric services, GPs, school nurses, municipalities, police officers etc. 2) Organisation of symposia and debates each year during the National Mental Health Week including in 2010 co-organising 10 public debates together with carers' organisations and municipalities. 3) Communication including financial support to the national campaign 'accepting differences' and lessons on stigma to health professionals, medicine, psychology, management and nursing students. In terms of output between 2005-2010 there were 500 000 brochures, 70 000 leaflets and 20 000 guides distributed; 40 requests for documents per month and 88 000 visitors on the web site. A study of impact in 2010 with GPs, psychiatrists, users and carers shown that the Psycom75 was perceived as a independent voice, and 91% of professionals and 76% of users regarded the documents as being of high quality and useful.

### Anti-stigma initiatives

### Programme National Médiateur de santé – Pair (National Peer – support program)

This program, funded by the French Ministry of Health, was defined by a board including services users and professionals. It aims to pilot a project hiring peer support workers in mental health teams and in community associations in France. Two project managers, one service user and one professional manage the program. In a first stage, teams will be trained in 3 areas (Lille, Paris and Marseille). In the second stage, 30 peer workers will be hired and will follow continuing training one year long. The program is planned for 3 years (2010-2013). Individual

and group supervision are including during the whole program. A randomised controlled trial will assess benefits and precautions and it will inform evidence-based guidelines. In terms of background, stakeholders' awareness to peer support practice was raised by a conference including the testimony of the Canadian experience in Québec in 2008. Users and professionals knowledge has been developed through two training courses in 2007 and 2008. See Girard et al (2006), Le Cardinal and Peltier (2007), Le Cardinal et al (2007), Le Cardinal and Roelandt (2008).

EMILIA - Empowerment of mental Illness: Lifelong learning, integration and action project

The EMILIA project started in 2005 and finished in 2010. The main aim of the EMILIA project is to facilitate social inclusion and empowerment of its mental health service user

participants through lifelong learning and employment opportunities. The project had eight demonstration sites in eight European countries (Athens, Barcelona, Bodo, London, Paris, Sarajevo, Stroestrum, and Warsaw). Examples of good practice in the promotion of empowerment included facilitating service user's active involvement in high level decision making meetings at a university and various European mental health services; service users being employed to design and deliver training to other service users (paid at competitive rates of pay); formation of service user groups (which fight for the rights of service users and seek out and develop learning, employment and social opportunities for service users); the setting up of a paid service user research assistant post; employing service users in directly teaching mental health professionals (paid at competitive rates of pay); employing service users to provide advice and support for other mental health service users (paid at competitive rates of pay); the formation of community enterprises to promote a wide range of service user opportunities; helping to facilitate service users to submit their own mental health related funding bids with national organizations; creating opportunities for a variety of unpaid significant activities such as involvement in mental health charities and work as mental health researchers; the creation of opportunities for further training, e.g. a specifically designed teaching skills module; the involvement of service users in work to create networks between healthy professions, users and families; involving service users in efforts to reduce stigma in mental health settings and in changing the attitudes of mental health professionals; and providing opportunities for service users to make decisions about their lives e.g. in training sessions to help service users discover, develop and achieve their goals.

The EMILIA project impacted positively on empowerment at various levels (Greacen and Jouet 2008, 2009 and 2010). For example, it allowed mental health service users to rediscover and use skills and knowledge that they had not used for long periods of time. It also enabled service users to increase their control and responsibility in actions which have consequences for their lives. This was both at an individual level through increased self determination, autonomy, self esteem and the development of capacities and resources, and at a socio-political level through greater involvement and influence on decision making processes which affect their lives. The project has enabled the removal of barriers to education and employment through the creation of training and employment which takes into account the needs of service users and which valued the knowledge and experience of mental health service users. The project has also helped transformed power relations by providing service users in decision making processes. For many of the institutions involved in EMILIA it is now seen as essential for mental health service users to be active partners in decision-making processes. At a health service level EMILIA has

facilitated a greater belief in the value of the contribution of service users to health services and a greater belief in the value of networking with service user organizations. The project's quantitative analysis revealed increased rates of service user competitive employment, net income and increases in a measure of coping and adaption. Furthermore, the qualitative analysis revealed improvements in hope, dignity, connection with life, sense of coherence, confidence, social support, meaningfulness, optimism, and self-efficacy. All of which can be important factors in an individual's empowerment.

Conseils locaux de santé mentale – Local Mental Health Councils (LMHC)

The LMHC are networks/platforms aimed at facilitating coordination and implementing projects linked to mental health and care at a local community level. There are 53 in the 68 municipalities. Local elected officials and their technical services, mental health services, health professionals, users and families associations, social services, associations and professionals of housing, employment, justice and police and culture are involved. The general objectives of LMHC, with the leadership of local elected, are to find solutions in: Helping stakeholders to get to know and to appreciate each other; Facilitating access to mental health care, continuity of care; Adapting and restructuring care provision to local needs; Prevention; Social inclusion of users as citizens; Integrated care, coordination between different actors. Concrete impacts have already been noticed (Rhenter 2010) including: the creation of new care settings; development of new interdisciplinary training courses; new action-research activities; new communication and information campaigns; and new cultural and sport projects

#### Project Alice – Alice in wonderland project

Three psychiatric hospitals (Rouffach, France; Emmendingen, Germany; Bâle, Switzerland) created a theater play (from the Lewis Caroll book) beyond borders and languages in order to tackle mental health stigma in Europe. Users and professionals contributed together to the play, which aimed to encourage people to think about care management. The project was founded by public and private local actors and in each hospital in 2008, workshops including users and professionals were set up and animated by professional artists. Each site worked on a specific part of the play (singing, dance, acting) and 60 actors from the 3 countries took part in the play which was presented 6 times. The project was evaluated by 2 sociologists from France and Germany and the impact on users, artists, hospitals organization was assessed. The results indicated: positive impact on users empowerment; changes in user/professional relationship; 1800 people have seen the play; improvement of hospitals image and the development of a cultural network (Stoessel 2009; Lachat 2010). Details at www.ch-rouffach.fr, www.europe-alsace.eu/projets-transfrontaliers-interregIV-rhin-superieur.html and www.espaces-transfrontaliers.org

#### **CONCLUSION**

Evaluated anti stigma programmes are scarce in France. Moreover, many actions are still not evaluated. Though anti-stigma actions are, at least at the local level, numerous, diversified and initiated by many different stakeholders. This is well illustrated by the National information week on Mental Health at the national level or the Local Mental Health Councils at a local level. There is an increasing awareness of the need to promote mental health care, to tackle stigma and discrimination and to link this with public health issues. There is also a real dynamism in

terms of actions, implementations and actors involved. We have to stress the raising involvement, during the last years, of local elected officials concern about mental health and well-being issues.

Additional approaches are to be considered in order to improve the visibility and the effectiveness of these kind of actions:

To develop networks, facilitate cooperation and coordination of the actions with associations, professionals and politic bodies

To work on the programmes' design (which disorders ? who is targeted ? what kind of message ?) Research here is still necessary.

To involve users at each stage of development and implementation of actions.

To conclude, we need to improve our research to ensure that our communicating projects to reduce stigma are effective. We should not forget that fighting against stigma also implies a change of paradigm inside mental health services. Indeed, communication programmes will remain weak tools if good practices, respecting of human rights, are not strongly promoted, implemented and evaluated.

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#### LITERATURE REVIEW OF PATTERNS OF MENTAL ILLNESS STIGMA IN GERMANY

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#### INTRODUCTION

This literature review is part of the ASPEN (Anti-Stigma-Programme: European Network) Work Package 4 (Best Practice Anti-Stigma). It covers two areas:

Patterns of stigma and discrimination in the sector of mental health, with special focus on depression

Evidence for promising practice for effective interventions to tackle stigma and discrimination in relation to mental health problems

#### METHOD

#### a) Patterns of stigma and discrimination

A PUBMED database search was performed to identify relevant peer-reviewed papers. The following search strategy was used:

Keywords: (Germany OR German) AND (stigma OR discrimination OR attitude) AND (psychiatry OR mental illness OR schizophrenia OR depression) AND (survey).

This query resulted in a PUBMED search with the following computed term: (("germany"[MeSH Terms] OR "germany"[All Fields]) OR German[All Fields]) AND (stigma[All Fields] OR ("discrimination (psychology)"[MeSH Terms] OR ("discrimination"[All Fields] AND "(psychology)"[All Fields]) OR "discrimination (psychology)"[All Fields]) OR "discrimination (psychology)"[All Fields] OR "discrimination"[All Fields]) OR ("attitude"[MeSH Terms] OR "attitude"[All Fields])) AND (("psychiatry"[MeSH Terms] OR "psychiatry"[All Fields]) OR ("mental disorders"[MeSH Terms] OR ("mental"[All Fields] AND "disorders"[All Fields]) OR "mental disorders"[All Fields] OR ("mental"[All Fields] AND "disorders"[All Fields]) OR "mental disorders"[All Fields] OR ("mental"[All Fields] AND "illness"[All Fields]) OR "mental illness"[All Fields]) OR ("schizophrenia"[MeSH Terms] OR "schizophrenia"[All Fields]) OR ("depressive disorder"[MeSH Terms] OR ("depressive"[All Fields]) AND "disorder"[All Fields]) OR "depressive disorder"[All Fields] OR "depression"[All Fields] OR "depression"[All Fields]] OR "depression"[All

Reference date was the 14.7.2010. This query resulted in 531 hits which were screened for the title and if necessary for the abstract. 103 papers were identified to be appropriate for a closer examination. These papers were downloaded or ordered via interlibrary loan. In a second step, an in-depth search was conducted. It included also papers known to the authors having a 10-year expertise in the field of stigma research and practice. Furthermore, materials of particular surveys (EUROBAROMETER, ESEMeD and World Mental Health Surveys) were searched for results appropriate for this report. Query results from earlier than 1980 were not included. The paper retrieval was finalized at 5th August 2010. Finally, 87 papers were chosen to be reported or cited in this section of the review. Due to the vast material, the section is a "structured bibliography".

# b) Evidence for promising practice for effective interventions to tackle stigma and discrimination in relation to mental health problems

The second section is based on the research undertaken to identify best practice examples for a preliminary report within ASPEN Work Package 4 in 2009. For this, results of a systematic review were adopted from a research project of the German Alliance for Mental Health funded by the German Ministry of Health (Gaebel et al. 2010).

The review comprised the databases BIOSIS Previews, EMBASE, SciSearch, MEDLINE, Social SciSearch, and PsycINFO. Search strategy key words were (stigma OR antistigma OR stigmatizing OR discrimination) AND (mental illness OR mental health OR psychiatry OR depression OR professionals OR psychologist OR family burden OR caregiver) AND (intervention OR education OR project OR programme OR program OR reduction OR awareness OR campaign). Furthermore, antistigma projects and interventions were identified and contacted via the German Alliance members' network (more than 60 associations from the field of mental health).

Furthermore, an in-depth search was made revisiting the literature known to the authors. Finally, current or running antistigma projects known to the authors were included in this report. Gaebel W, Ahrens W, Schlamann P (2010). Conception and implementation of interventions to destigmatize mental illness: recommendations and results of research and practice. [Konzeption und Umsetzung von Interventionen zur Entstigmatisierung psychischer Erkrankungen: Empfehlungen und Ergebnisse aus Forschung und Praxis.] Strategy Paper, German Alliance for Mental Health funded by the German Ministry of Health.

### FINDINGS

# Part 1: Patterns of stigma and discrimination in the sector of mental health, with special focus on depression

Contents:

- 1.1 Population surveys
- 1.1.1 European surveys (6)
- 1.1.2 Surveys conducted as baselines for evaluation of anti-stigma programmes (2)
- 1.1.3 Surveys from the work group MC Angermeyer (43)
- 1.1.4 Further surveys (10)
- 1.2 Patients' Perspective (12)
- 1.3 Relatives' Perspective (7)
- 1.4 Mental Health Professionals' Perspective (7)

1.1.1 European surveys: Germany is part of several European surveys about mental health issues, e.g. the EUROBAROMETER, European Study of Epidemiology of Mental Disorders (ESEMeD), the WHO Mental Health Survey and the European Values Survey.

### EUROBAROMETER

European Commission. Special Eurobarometer 248 / Wave 64.4 – TNS Opinion & Social. Mental Well-being. EC, May 2006

# [http://ec.europa.eu/health/ph\_information/documents/ebs\_248\_en.pdf] ESEMed/MHEDEA 2000

ten Have M, de Graaf R, Ormel J, Vilagut G, Kovess V, Alonso J; ESEMeD/MHEDEA 2000 Investigators. Are attitudes towards mental health help-seeking associated with service use? Results from the European Study of Epidemiology of Mental Disorders. Soc Psychiatry Psychiatr Epidemiol. 2010 Feb;45(2):153-63.

Alonso J, Buron A, Rojas-Farreras S, de Graaf R, Haro JM, de Girolamo G, Bruffaerts R, Kovess V, Matschinger H, Vilagut G; ESEMeD/MHEDEA 2000 Investigators. Perceived stigma among individuals with common mental disorders. J Affect Disord. 2009 Nov;118(1-3):180-6.

Nutt DJ, Kessler RC, Alonso J, Benbow A, Lecrubier Y, Lépine JP, Mechanic D, Tylee A. Consensus statement on the benefit to the community of ESEMeD (European Study of the Epidemiology of Mental Disorders) survey data on depression and anxiety. J Clin Psychiatry. 2007;68 Suppl 2:42-8.

## WHO Mental Health Survey

Wang PS, Angermeyer M, Borges G, Bruffaerts R, Tat Chiu W, DE Girolamo G, Fayyad J, Gureje O, Haro JM, Huang Y, Kessler RC, Kovess V, Levinson D, Nakane Y, Oakley Brown MA, Ormel JH, Posada-Villa J, Aguilar-Gaxiola S, Alonso J, Lee S, Heeringa S, Pennell BE, Chatterji S, Ustün TB. Delay and failure in treatment seeking after first onset of mental disorders in the World Health Organization's World Mental Health Survey Initiative. World Psychiatry. 2007 Oct;6(3):177-85.

## European Values Survey:

Beck M, Angermeyer MC, Brähler E. [Is there a connection between right-wing extremism and social distancing from mentally ill people? Results from a representative survey among the adult German population]. Psychiatr Prax. 2005 Mar;32(2):68-72.

1.1.2 Surveys conducted as baselines for evaluation of anti-stigma programmes: Evaluation studies are discussed in the second part of this review. Studies presenting data from before the start of anti-stigma campaigns are listed here. The second programme (Open the Doors) was primarily directed at schizophrenia.

German Alliance against Depression evaluation baseline: As a baseline for the German Alliance for Depression Program, opinions and attitudes towards symptoms, causes and treatment options were assessed in 2000 in 2 Bavarian cities (Nuremberg and Würzburg; telephone interviews, N=1426; results were weighted regarding age and gender). Concerning attitudes the study reports agreement rates for the statements "Depression is not an illness at all" (8.7%); "People with Depression are self to blame" (5.1%); "One has to pull oneself together to get rid of a depression" (15.6%); "One needs help from others" (57.7%); "Depression is a normal illness like Asthma or Diabetes" (77.0%). Concerning treatment options, psychotherapy was favored by 77.1% and drug treatment (anti-depressants) were favored by 31.5% (cf. Benkert et al. 1997).

Althaus D, Stefanek J, Hasford J, Hegerl U. [Knowledge and attitude of the general public regarding symptoms, etiology and possible treatments of depressive illnesses]. Nervenarzt. 2002 Jul;73(7):659-64.

German Open the Doors evaluation baseline: The German Open the Doors evaluation baseline was assessed in the framework of the German Competence Network Schizophrenia (Wölwer et

al. 2003) as representative telephone survey (N=7246) in 6 selected German cities. Open the Doors initiatives were located in two cities (Düsseldorf and Munich), awareness projects (also conducted in the framework of the Competence Network Schizophrenia) to promote early recognition of schizophrenia in two further cities (Bonn and Cologne). The other two cities (Berlin and Essen) had none of such interventions in the projected time period between 2001 and 2004. Assessed variables were among others Social Distance and Recommendations how to improve the situation of people with schizophrenia.

Gaebel W, Baumann A, Witte M. [Public attitudes towards people with schizophrenia in six large German cities]. Nervenarzt. 2002; 73: 665-670.

Wölwer W, Buchkremer G, Häfner H, Klosterkötter J, Maier W, Möller HJ, Gaebel W. German research network on schizophrenia. Bridging the gap between research and care. Eur Arch Psychiatry Clin Neurosci 2003; 253: 321-329 [This reference is not part of the actual bibliography but serves as annotation to the explanatory remarks]

1.1.3 Surveys from the work group MC Angermeyer: The workgroup of MC Angermeyer is dedicated to stigma research since the 1980s (at least). Several population surveys were conducted (1990, 1993, 2001, 2004, 2007), most of them with case vignettes of depression and schizophrenia and an N ranging from 1012 up to 5025. Assessed topics belong to mental health literacy (e.g., beliefs about causes, pathways to care, treatment) and attitudes (e.g., social distance, willingness to seek help, attitude towards treatment). Studies focusing only schizophrenia are only listed here if they deal with a specific topic. Some papers of the workgroup are integrated in the passages below (studies about attitudes of mental health professionals, about patients' and relatives' experiences). Alongside the papers about the population surveys, some special topics have been covered: The particular situation in Eastern Germany after the German reunification, international comparisons, and the unique historical context of two assassination attempts on two German politicians and its effect on attitudes towards people with mental illness in the early 1990s. Hence the Workgroup has published also a review and a paper on time trends in Germany between 1990 and 2001.

Focus on Eastern Germany

Angermeyer MC, Matschinger H. Lay beliefs about mental disorders: a comparison between the western and the eastern parts of Germany. Soc Psychiatry Psychiatr Epidemiol. 1999 May;34(5):275-81.

Angermeyer MC, Matschinger H, Holzinger A. [Acceptance of community psychiatry reform in the population. Results of a representative study in new German federal lands]. Psychiatr Prax. 1999 Jan;26(1):16-21.

International comparisons with surveys in Novosibirsk, Bratislava and Mongolia

Schomerus G, Matschinger H, Kenzin D, Breier P, Angermeyer MC. Public attitudes towards mental patients: a comparison between Novosibirsk, Bratislava and German cities. Eur Psychiatry. 2006 Oct;21(7):436-41.

Angermeyer MC, Breier P, Dietrich S, Kenzine D, Matschinger H. Public attitudes toward psychiatric treatment. An international comparison. Soc Psychiatry Psychiatr Epidemiol. 2005 Nov;40(11):855-64.

Dietrich S, Beck M, Bujantugs B, Kenzine D, Matschinger H, Angermeyer MC. The relationship between public causal beliefs and social distance toward mentally ill people. Aust N Z J Psychiatry. 2004 May;38(5):348-54; discussion 355-7.

Assassination attempts

Angermeyer MC, Matschinger H. The effect of violent attacks by schizophrenic persons on the attitude of the public towards the mentally ill. Soc Sci Med. 1996 Dec;43(12):1721-8.

Angermeyer MC, Matschinger H. Violent attacks on public figures by persons suffering from psychiatric disorders. Their effect on the social distance towards the mentally ill. Eur Arch Psychiatry Clin Neurosci. 1995;245(3):159-64.

Angermeyer MC, Siara CS. Effect of assassination attempts on Lafontaine and Schäuble on public opinion about psychiatric patients. Part 1: 1990 development. Nervenarzt. 1994 Jan;65(1):41-8.

Angermeyer MC, Siara CS. Effects on assassination attempts on Lafontaine and Schäuble on public opinion about psychiatric patients. Part 2: 1991 development. Nervenarzt. 1994 Jan;65(1):49-56.

Reviews / Time trends

Angermeyer MC, Dietrich S. Public beliefs about and attitudes towards people with mental illness: a review of population studies. Acta Psychiatr Scand. 2006 Mar;113(3):163-79.

Angermeyer MC, Matschinger H. Have there been any changes in the public's attitudes towards psychiatric treatment? Results from representative population surveys in Germany in the years 1990 and 2001. Acta Psychiatr Scand. 2005 Jan;111(1):68-73.

Population surveys

Schomerus G, Matschinger H, Angermeyer MC. Attitudes that determine willingness to seek psychiatric help for depression: a representative population survey applying the Theory of Planned Behaviour. Psychol Med. 2009 Nov;39(11):1855-65.

Angermeyer MC, Holzinger A, Matschinger H. Mental health literacy and attitude towards people with mental illness: a trend analysis based on population surveys in the eastern part of Germany. Eur Psychiatry. 2009 May;24(4):225-32.

Schomerus G, Matschinger H, Angermeyer MC. The stigma of psychiatric treatment and helpseeking intentions for depression. Eur Arch Psychiatry Clin Neurosci. 2009 Aug;259(5):298-306.

Schomerus G, Angermeyer MC, Matschinger H, Riedel-Heller SG. Public attitudes towards prevention of depression. J Affect Disord. 2008 Mar;106(3):257-63.

Schomerus G, Matschinger H, Angermeyer MC. Familiarity with mental illness and approval of structural discrimination against psychiatric patients in Germany. J Nerv Ment Dis. 2007 Jan;195(1):89-92.

Schomerus G, Matschinger H, Angermeyer MC. Public beliefs about the causes of mental disorders revisited. Psychiatry Res. 2006 Nov 15;144(2-3):233-6.

Schomerus G, Borsche J, Matschinger H, Angermeyer MC. Public knowledge about causes and treatment for schizophrenia: a representative population study. J Nerv Ment Dis. 2006 Aug;194(8):622-4.

Dietrich S, Matschinger H, Angermeyer MC. The relationship between biogenetic causal explanations and social distance toward people with mental disorders: results from a population survey in Germany. Int J Soc Psychiatry. 2006 Mar;52(2):166-74.

Schomerus G, Matschinger H, Angermeyer MC. Preferences of the public regarding cutbacks in expenditure for patient care: are there indications of discrimination against those with mental disorders? Soc Psychiatry Psychiatr Epidemiol. 2006 May;41(5):369-77.

Angermeyer MC, Matschinger H. The stigma of mental illness in Germany: a trend analysis. Int J Soc Psychiatry. 2005 Sep;51(3):276-84.

Schomerus G, Matschinger H, Angermeyer MC. Alcoholism: Illness beliefs and resource allocation preferences of the public. Drug Alcohol Depend. 2006 May 20;82(3):204-10.

Angermeyer MC, Matschinger H. The stereotype of schizophrenia and its impact on discrimination against people with schizophrenia: results from a representative survey in Germany. Schizophr Bull. 2004;30(4):1049-61.

Angermeyer MC, Dietrich S, Pott D, Matschinger H. Media consumption and desire for social distance towards people with schizophrenia. Eur Psychiatry. 2005 May;20(3):246-50.

Angermeyer MC, Matschinger H. Labeling--stereotype--discrimination. An investigation of the stigma process. Soc Psychiatry Psychiatr Epidemiol. 2005 May;40(5):391-5.

Riedel-Heller SG, Matschinger H, Angermeyer MC. Mental disorders--who and what might help? Help-seeking and treatment preferences of the lay public. Soc Psychiatry Psychiatr Epidemiol. 2005 Feb;40(2):167-74.

Matschinger H, Angermeyer MC. The public's preferences concerning the allocation of financial resources to health care: results from a representative population survey in Germany. Eur Psychiatry. 2004 Dec;19(8):478-82.

Angermeyer MC, Matschinger H. Public attitudes to people with depression: have there been any changes over the last decade? J Affect Disord. 2004 Dec;83(2-3):177-82.

Angermeyer MC, Matschinger H, Corrigan PW. Familiarity with mental illness and social distance from people with schizophrenia and major depression: testing a model using data from a representative population survey. Schizophr Res. 2004 Aug 1;69(2-3):175-82.

Angermeyer MC, Matschinger H. Public attitudes towards psychotropic drugs: have there been any changes in recent years? Pharmacopsychiatry. 2004 Jul;37(4):152-6.

Beck M, Dietrich S, Matschinger H, Angermeyer MC. Alcoholism: low standing with the public? Attitudes towards spending financial resources on medical care and research on alcoholism. Alcohol Alcohol. 2003 Nov-Dec;38(6):602-5.

Angermeyer MC, Matschinger H. Public beliefs about schizophrenia and depression: similarities and differences. Soc Psychiatry Psychiatr Epidemiol. 2003 Sep;38(9):526-34.

Angermeyer MC, Matschinger H. The stigma of mental illness: effects of labelling on public attitudes towards people with mental disorder. Acta Psychiatr Scand. 2003 Oct;108(4):304-9.

Angermeyer MC, Matschinger H, Holzinger A. Gender and attitudes towards people with schizophrenia. Results of a representative survey in the Federal Republic of Germany. Int J Soc Psychiatry. 1998 Summer;44(2):107-16.

Angermeyer MC, Matschinger H. Social distance towards the mentally ill: results of representative surveys in the Federal Republic of Germany. Psychol Med. 1997 Jan;27(1):131-41. Angermeyer MC, Matschinger H. Public attitude towards psychiatric treatment. Acta Psychiatr Scand. 1996 Nov;94(5):326-36.

Matschinger H, Angermeyer MC. Lay beliefs about the causes of mental disorders: a new methodological approach. Soc Psychiatry Psychiatr Epidemiol. 1996 Nov;31(6):309-15.

Angermeyer MC, Matschinger H. Lay beliefs about schizophrenic disorder: the results of a population survey in Germany. Acta Psychiatr Scand Suppl. 1994;382:39-45.

Angermeyer MC, Held T, Görtler D. [Pro and contra: psychotherapy and psychopharmacotherapy attitude of the public]. Psychother Psychosom Med Psychol. 1993 Aug;43(8):286-92.

Angermeyer MC, Däumer R, Matschinger H. Benefits and risks of psychotropic medication in the eyes of the general public: results of a survey in the Federal Republic of Germany. Pharmacopsychiatry. 1993 Jul;26(4):114-20.

Angermeyer MC, Matschinger H. [Mentally ill patients: viewed from 2 perspectives. A methodological contribution on attitudinal research in psychiatry]. Soz Praventivmed. 1992;37(2):96-102.

Angermeyer MC. Das Bild der Psychiatrie in der Öffentlichkeit. Tropon-Symposium. Bd IX, Versorgungsstrukturen in der Psychiatrie. Hrsg. F. Reimer. Springer-Verlag Berlin Heidelberg 1994.

Angermeyer MC, Matschinger H. Soziale Distanz der Bevölkerung gegenüber psychisch Kranken. Gesundheitswesen. 1996; 58(Sonderheft 1):18-24.

1.1.4 Further surveys: This paragraph comprises surveys dealing with miscellaneous issues of stigma, e.g., attitudes of specific target groups as secondary school children or attitudes towards coercive measures in psychiatry.

Attitude survey in 5 European countries: Comparison of attitudes and beliefs about mental illness and varied components of stereotypes of schizophrenia between a few European countries (Poland, Switzerland, Germany, Croatia and Spain).

Jackowska E. [Stigma and discrimination towards people with schizophrenia—a survey of studies and psychological mechanisms]. Psychiatr Pol. 2009 Nov-Dec;43(6):655-70.

Survey in vocational colleges and technical secondary schools: Vignette study: Assessment of social distance, emotional and cognitive reactions on vignettes of cases of depressive episode (N=96) or manic episode (N=92). The sample reflects attitudes of young males. No scores are reported but item-wise percentages. In some items, differences were found between the vignettes: emotional reaction: "pity" higher agreement for depression; "lack of understanding" higher agreement for manic episode; cognitive reactions: dangerousness (lacking of self-control, unpredictable, dangerous, aggressive): all 4 items had a higher agreement for manic episode; helpless: higher agreement for depression. 3 of 7 social distance items showed a higher acceptance for depression.

Wolkenstein L, Meyer TD. What factors influence attitudes towards people with current depression and current mania? Int J Soc Psychiatry. 2009 Mar;55(2):124-40.

Survey in secondary schools

Schulze B, Angermeyer MC. What is schizophrenia? Secondary school students' associations with the word and sources of information about the illness. Am J Orthopsychiatry. 2005 Apr;75(2):316-23.

Survey in Turkish immigrants and Germans: Survey in German (N=164) and Turkish (N=139) adolescents (17-25 years) about attitudes towards psychotherapy: Especially Turkish migrants whose cultural orientation is Turkish (vs. German acculturated) show more negative attitudes towards psychotherapy than German natives.

Calliess IT, Schmid-Ott G, Akguel G, Jaeger B, Ziegenbein M. [Attitudes towards psychotherapy of young second-generation Turkish immigrants living in Germany]. Psychiatr Prax. 2007 Oct;34(7):343-8.

Survey on treatment: "Mainz study" (1992; N=2176, representative survey, face-to-face interviews) about views on appropriate treatment of depression (Drugs: 4%, Psychotherapy 64%, Treatment is pointless 5%, Nature cure 8%, No treatment required 15%, No statement 4%) and other (13) diseases. Together with Mania, the opinion that no treatment is required was most frequent for Depression. The opinion that Drugs were the appropriate treatment was least frequent for Depression together with Mania and Social phobia.

Benkert O, Graf-Morgenstern M, Hillert A, Sandmann J, Ehmig SC, Weissbecker H,Kepplinger HM, Sobota K. Public opinion on psychotropic drugs: an analysis of the factors influencing acceptance or rejection. J Nerv Ment Dis. 1997 Mar;185(3):151-8.

CAMI postal survey: The German version of the "Community Attitude Towards the Mentally III"-Scale (Wolff et al. 1996) is validated in this paper (postal survey; N=832).

Angermeyer MC, Heiss S, Kirschenhofer S, Ladinser E, Löffler W, Schulze B, Swiridoff M. [The German version of the Community-Attitudes-Toward-the-Mentally-III (CAMI) inventory]. Psychiatr Prax. 2003 May;30(4):202-6.

<u>Wolff G, Pathare S, Craig T, Leff J</u>. Community attitudes to mental illness. <u>Br J Psychiatry</u>. 1996 Feb;168(2):183-90. [This reference is not part of the actual bibliography but serves as annotation to the explanatory remarks] Studies about compulsory admissions and treatment (general population and mental health professionals): Review (Lauber et al. 2007): Studies on public opinions and perspectives of professionals about coercive admissions are discussed. Only few studies exist. The only German study is focused on schizophrenia (Steinert et al. 2003; 2005; Lepping et al. 2004) and compares recommendations concerning compulsory admissions in different target groups (i.e., Psychiatrists, Psychologists, Social workers, Nurses, Laypeople) in different countries (Germany, England and furthermore Hungary and Switzerland; total N=1737). Three different scenarios (schizophrenia) were presented and people were asked whether they would agree with compulsory admission and treatment, respectively. Overall, a majority agreed with treatment and admission (between 59 and 87% of the participants). Strongest support for compulsory measures was found in Hungary, followed by England, Germany and Switzerland.

Lauber C, Rössler W. [Involuntary admission and the attitude of the general population, and mental health professionals]. Psychiatr Prax. 2007 Apr;34 Suppl 2:S181-5.

Lepping P, Steinert T, Gebhardt RP, Röttgers HR. Attitudes of mental health professionals and lay-people towards involuntary admission and treatment in England and Germany--a questionnaire analysis. Eur Psychiatry. 2004 Apr;19(2):91-95.

Steinert T. Lepping P, Baranyai R, Hoffmann M, Leherr H. Compulsory admission and treatment in schizophrenia. a study on theical attitudes in four European countries. Soc Psychiatry Psychiatr Epidemiol 2005; 40:635-641

Steinert T, Lepping P, Gebhardt RP. Entscheidungen zur Zwangseinweisung und Zwangsmedikation schizophrener Patienten bei Psychiatern in Deutschland und England – Ergebnisse einer vergleichenden Befragung. Psychiat Prax 2003;30:379-383

1.2 Patients' Perspective: The patients' perspective on mental illness and its stigma has been neglected in Germany for a time. Most papers are dated at the second half of the 2000's. Some studies focus on topics as treatment satisfaction and self-stigma. Other studies have diagnose-specific samples (eating disorders, obsessive compulsive disorders, schizophrenia), while two studies compare experiences of patients with depression with patients with schizophrenia. A particular topic is the patients' perspective on coercion in psychiatry. A Scale (Coercion Experience Scale) has been developed to assess the patients' experience of coercion during psychiatric coercive measures. Further studies investigate the experiences related with compulsory treatment and involuntary admissions.

Treatment satisfaction and influencing factors: Comparison between Italy and Germany

Giupponi G, Hensel S, Müller P, Soelva M, Schweigkofler H, Steiner E, Pycha R, Möller-Leimkühler AM. [The patient's satisfaction in relation with the treatment in hospital psychiatry: a comparison between Italy and Germany]. Fortschr Neurol Psychiatr. 2009 Jun;77(6):346-52. Self-Stigma

Rüsch N, Hölzer A, Hermann C, Schramm E, Jacob GA, Bohus M, Lieb K, Corrigan PW. Self-stigma in women with borderline personality disorder and women with social phobia. J Nerv Ment Dis. 2006 Oct;194(10):766-73.

Rüsch N, Lieb K, Bohus M, Corrigan PW. Self-stigma, empowerment, and perceived legitimacy of discrimination among women with mental illness. Psychiatr Serv. 2006 Mar;57(3):399-402. Eating DIsorders

Nedoschill J, Leiberich P, Popp C, Loew T. [www.hungrig-online.de: results from an online survey in the largest German-speaking Internet self help community for eating disorders]. Prax Kinderpsychol Kinderpsychiatr. 2005 Nov;54(9):728-41.

**Obsessive Compulsive Disorders** 

Stengler-Wenzke K, Beck M, Holzinger A, Angermeyer MC. [Stigma experiences of patients with obsessive compulsive disorders]. Fortschr Neurol Psychiatr. 2004 Jan;72(1):7-13.

Schizophrenia: Focus group study (Patients, Relatives, MH Professionals)

Schulze B, Angermeyer MC. Subjective experiences of stigma. A focus group study of schizophrenic patients, their relatives and mental health professionals. Soc Sci Med. 2003 Jan;56(2):299-312.

Patients with Depression / Comparison with other Diagnoses

Stengler-Wenzke K, Angermeyer MC, Matschinger H. [Depression and stigma]. Psychiatr Prax. 2000 Oct;27(7):330-5.

Angermeyer MC, Beck M, Dietrich S, Holzinger A. The stigma of mental illness: patients' anticipations and experiences. Int J Soc Psychiatry. 2004 Jun;50(2):153-62.

## Subtopic: Patients' Perspective on Coercion

Coercion Experience Scale (CES): The Coercion Experience Scale (CES) has been developed to provide a validated instrument to assess the patients' experience of coercion during psychiatric coercive measures. 102 patients were interviewed in the framework of a clinical trial. They had the primary diagnosis F2, F3, or F6 and had experienced a coercive intervention (being secluded or mechanically restrained) before. The scale yields 6 subscales ("Humiliation", "Physical adverse effects", "Separation", "Negative environment", "Fear", and "Coercion"). The CES was developed in German. Items are also translated into English, with a high congruence after retranslation. The CES is intended to screen patients after coercive treatments to identify patients who need support to prevent consequences from traumatic experiences.

Bergk J, Flammer E, Steinert T. "Coercion Experience Scale" (CES)—validation of a questionnaire on coercive measures. BMC Psychiatry. 2010 Jan 14;10:5.

Compulsory Treatment and the patients' perspective

Längle G, Bayer W. [Compulsory psychiatric treatment and the patients' perspective]. Psychiatr Prax. 2007 Apr;34 Suppl 2:S203-7.

Naber D, Kircher T, Hessel K. Schizophrenic patients' retrospective attitudes regarding involuntary psychopharmacological treatment and restraint. Eur Psychiatry. 1996;11(1):7-11.

Post hoc interviews with adolescents after voluntary and involuntary psychiatric admission

Kühnapfel B, Schepker R. [Post hoc interviews with adolescents after voluntary and involuntary psychiatric admission]. Prax Kinderpsychol Kinderpsychiatr. 2006;55(10):767-82.

1.3 Relatives' Perspective: Several papers have been published about the situation of relatives of people with mental illness in Germany. It might be mentioned that in Germany, a well-organized association for relatives ("Family Self-help Psychiatry") is active at the Federal State level as well as at the Federal level (c.f. Brand U, 2001).

Kallert TW, Nitsche I. Assessing the opinions of relatives on the causes and social consequences of different mental disorders: are instruments cross-culturally valid? Psychiatry Res. 2008 Apr 15;158(3):344-55.

Nitsche I, Kallert TW. [Do relatives of patients with different mental disorders also differ in their attitudes towards these disorders?]. Nervenarzt. 2006 Jul;77(7):791-9.

Stengler-Wenzke K, Trosbach J, Dietrich S, Angermeyer MC. Experience of stigmatization by relatives of patients with obsessive compulsive disorder. Arch Psychiatr Nurs. 2004 Jun;18(3):88-96.

Jungbauer J, Wittmund B, Dietrich S, Angermeyer MC. Subjective burden over 12 months in parents of patients with schizophrenia. Arch Psychiatr Nurs. 2003 Jun;17(3):126-34.

Brand U. Mental health care in Germany: carers' perspectives. Acta Psychiatr Scand Suppl. 2001;(410):35-40.

Angermeyer MC, Matschinger H. [Attitude of family to neuroleptics]. Psychiatr Prax. 1999 Jul;26(4):171-4.

Angermeyer MC, Matschinger H, Holzinger A. [Burden of relatives of chronic psychiatric patients]. Psychiatr Prax. 1997 Sep;24(5):215-20.

1.4 Mental Health Professionals' Perspective: As Australian studies have shown, attitudes of people working in psychiatric professions may be as stigmatizing as those of "laypeople". Since this target group is of high relevance for anti-stigma interventions, some corresponding studies have been published in Germany. Among psychiatric professions, medical students are a special target group. One peculiar study shall be highlighted due to its unique methodological approach: a comparison of experienced community acceptance in health practitioners in 6 countries about 20 disabilities.

Kaduszkiewicz H, Wiese B, van den Bussche H. Self-reported competence, attitude and approach of physicians towards patients with dementia in ambulatory care: results of a postal survey. BMC Health Serv Res. 2008 Mar 6;8:54.

Zwerenz R, Barthel Y, Leuzinger-Bohleber M, Gieler U, Rudolf G, Schwarz R, Vogel J, Beutel ME. [Attitudes of medical students towards psychotherapeutic treatment and training]. Z Psychosom Med Psychother. 2007;53(3):258-72.

Kuhnigk O, Strebel B, Schilauske J, Jueptner M. Attitudes of medical students towards psychiatry : effects of training, courses in psychiatry, psychiatric experience and gender. Adv Health Sci Educ Theory Pract. 2007 Feb;12(1):87-101.

Rosta J. Is alcoholism a self-induced disease? A survey among doctors in Aarhus, Denmark and in Mainz, Germany. Nord J Psychiatry. 2004;58(3):219-22.

Angermeyer MC, Link BG, Majcher-Angermeyer A. Stigma perceived by patients attending modern treatment settings. Some unanticipated effects of community psychiatry reforms. J Nerv Ment Dis. 1987 Jan;175(1):4-11.

Medical students

Hillert A, Sandmann J, Angermeyer MC, Däumer R. [Attitude of medical students to treatment with psychotropic drugs. 2: Change in attitude in the course of medical education]. Psychiatr Prax. 1994 Mar;21(2):64-9.

Comparison between 6 countries and 20 disabilities (health practitioners): experienced community acceptance: Assessment of experienced community acceptance (social distance) by health practitioners in 6 different cultures / countries (Anglo-Australian, German, Italian, Arabic, Greek, Chinese; N=665): Community acceptance of 20 different disabilities including "alcoholism" and "psychiatric illness". Psychiatric Illness (3) and alcoholism (5) had had a very low overall acceptance (behind AIDS (1) and Mental retardation (2) and Cerebral palsy (4), respectively). The rankings were similar in all countries. In comparison to the other countries, Germany had the highest average acceptance ratings.

Westbrook MT, Legge V, Pennay M. Attitudes towards disabilities in a multicultural society. Soc Sci Med. 1993 Mar;36(5):615-23.

# Part 2: Evidence for promising practice for effective interventions to tackle stigma and discrimination in relation to mental health problems

Overview. Six initiatives, associations or campaigns were identified having published peerreviewed papers of evaluation studies or of presentations of their activities to fight the stigma of mental illness. Since 1999/2000, a variety of associations and projects have been initiated in Germany with the aim to reduce the stigma of mental illness or the stigma of depression, respectively. The projects described below are those where persons with academic background are active (mostly in responsible positions), hence they are visible in professional circles through peer-reviewed publications. Further local anti-stigma interventions exist in Germany; and many local health care providers are active in local open days, weeks of mental health or other public activities. Before this background, it is not possible to survey all these activities comprehensively. At least, the "Psychose-Seminare" [psychosis seminars] or "Psychose-Foren" [psychosis forums] shall be mentioned here. In more than 100 German towns, people with psychosis, their relatives, and mental health experts and caregivers regularly meet to discuss on equal terms ["trialogic principle"] topics of their own interest. The seminars promote mutual comprehension and are an instrument for empowering people with mental health problems (which is in fact also a strategy to tackle the stigma of mental illness).

Despite the action against stigma taking place in Germany, the situation for people suffering from mental health problems is still not satisfactory. In particular, the situation at the workplaces needs to be improved in the close future. This challenge will be targeted within a new project initiated by the German Alliance for Mental Health in the next two years. Other current developments in Germany are a training workshop addressing "Anti-stigma Competence" for mental health professionals which has been piloted successfully in the framework of the Competence Network Schizophrenia (a peer-reviewed paper is in preparation). Finally, the Federal Ministry of Education and Research has accepted to fund a new multi-center-project in the framework of health services research to implement and evaluate a group therapy module for stigma coping and empowerment strategies for persons with mental health problems.

Weblinks: www.psychiatrie.de/hilfenetz/psychoseseminare

### German Alliance for Mental Health

The German Alliance for Mental Health (GAMH) was initiated by the German Association for Psychiatry and Psychotherapy (DGPPN) and the German anti-stigma society "Open the doors". It cooperates with the German Federal Ministry of Health and unites about 65 membership organisations, among them organizations of physicians (both psychiatrists and general medicine), psychologists, service users and their relatives, self-help groups, and research networks as well as local anti-stigma initiatives.

The GAMH understands itself as a network for interdisciplinary exchange for the promotion of mental health and anti-stigma action. It organizes conferences (opening conference "Education – Prevention – Integration" Berlin October 2007; Joint Conference by the World Health Organization and the German Alliance for Mental Health; co-organized by the European Commission and supported by the German Federal Ministry of Health "Mental Health and Well-Being at the Workplace: Protection and inclusion in challenging times" Berlin March 2009) and annual Weeks on Mental Health in Berlin (since 2007; with an increasing number of events (2007: 85; 2008: 130; 2009: 150)) and supports other cities in organizing such weeks (2010: 20 cities). In this context, the GAMH acts as a network for the local action groups and facilitator for the public perception of these groups and their activities.

Furthermore, the GAMH co-organized together with the German Medical Association a symposium about "People with mental illness at the workplace" (Berlin September 2009). The GAMH is member of the action group to remember the T4 victims (victims of the hereditarily

health laws of the National Socialism) which was initiated by the Federal User's Association (BPE). A memorial day for T4 victims is organised every September in Berlin.

A further focus of action is the scientific substantiation of anti-stigma interventions. The GAMH has recently published a report with recommendations and results from research and practice for anti-stigma interventions (funded by the German Federal Ministry of Health, online resources see below; an English summary is currently being translated). On the basis of this report an anti-stigma intervention is being developed to be implemented in 2011 with the aim to reduce the stigma of mental illness at workplace settings.

Weblinks: www.seelischegesundheit.net; http://aktionswoche.seelischegesundheit.net

Aktionsbündnis Seelische Gesundheit (2010): Konzeption und Umsetzung von Interventionen zur Entstigmatisierung seelischer Erkrankungen: Empfehlungen und Ergebnisse aus Forschung und Praxis. Research Report, available online www.seelischegesundheit.net/images/stories/ Aktionsbuendnis\_Studie\_Konzeption\_Umsetzung\_Interventionen\_2010.pdf

Gaebel W, Zäske H, Baumann A (2004): Stigmatisierung und Diskriminierung psychisch Erkrankter als Herausforderung für die Gesundheitsversorgung in Deutschland. Deutsches Ärzteblatt 101: A 3253-3255, Heft 48

Open the Doors e. V.

The German Open the Doors project as part of the World Psychiatric Association (WPA) global anti-stigma programme (WPA 1998, 2003) was initiated by seven founding centres on the WPA XI World Psychiatric Congress 1999 in Hamburg (Gaebel et al. 2003, 2005). All centers (which are located in six different cities) implemented local anti-stigma projects with the aim to reduce stigma and discrimination because of schizophrenia and mental illness in general; and to educate the public about the illness and increase contacts between people with and without schizophrenia. Soon it became apparent that focusing on a single mental disorder (schizophrenia) might not fully meet the needs in Germany whereas an overarching anti-stigma-approach involving other diagnoses was considered to be more effective and therefore became common practice.

Different target groups were addressed, e.g., general population, pupils, police officers, journalists, mental health staff, politicians. Overall, various activities have been conducted in the different centres (for detailed information of some of these centres, please see below for BASTA, "Irre menschlich" and "Irrsinnig menschlich"). Examples for the different activities are:

Cultural programmes: cinema shows, theatre events, art exhibitions, concerts and subsequent discussions with patients, relatives and professionals;

Educational trainings with journalists and media representatives, mental health staff, politicians, police officers, the interested public;

Psychosis seminars for the interested public, service users, their relatives and mental health professionals;

Annual workshop with media representatives to sensitise them for the impact of media depiction of people with mental illness for public attitudes;

Open days in psychiatric hospitals;

School-projects providing both information about mental illness and contact with a consumer; Anti-Stigma trainings with mental health staff;

Annually advertising of an award for anti-stigma interventions.

The German Open the Doors projects have been twofoldly subject to evaluation: first, selected single interventions were evaluated with pre-post questionnaires with respect to short-term attitude changes in the participants. An exemplary study (Baumann et al. 2003) about the evaluation of a cinema event with subsequent panel discussion did not show the expected

effects (N=113): Hence, in the audience social distance towards people with schizophrenia increased. The effect was attributed to the movie that was made from the first-person perspective with rather realistic sound effects (acoustic hallucinations) and featured realistic conflicts between the protagonists. Nevertheless, short-term effects of anti-stigma interventions and long-term effects may differ from each other, since long-term effects reflect more and other influencing factors, e.g. the mass media representation of mental illnesses. In a long-term and population-based evaluation study with a representative sample (N=4622) conducted in the framework of the German Competence Network Schizophrenia (Baumann et al. 2007, Gaebel et al. 2008), social distance decreased significantly between 2001 (marking the start of the Open the Doors activities in Germany) and 2004. Regression analyses showed that the reduction of social distance was significantly associated with the location of anti-stigma projects in the residence of the interviewed person (Düsseldorf and Munich vs. other cities) and with knowledge about the existence of anti-stigma projects.

The German association "Open the Doors" association is currently in a transformation process. It is intended to install the association as supporting association for the GAMH which took over the function of networking anti-stigma interventions in Germany.

Baumann A, Zäske H, Decker P, Klosterkötter J, Maier W, Möller HJ, Gaebel W. Veränderungen in der sozialen Distanz der Bevölkerung gegenüber schizophren Erkrankten in 6 deutschen Großstädten – Ergebnisse einer repräsentativen Telefonbefragung 2001 und 2004. Nervenarzt 2007;78:787-795.

Baumann A, Zaeske H, Gaebel W. [The image of people with mental illness in movies: effects on beliefs, attitudes and social distance, considering as example the movie "The white noise"]. Psychiatr Prax. 2003 Oct;30(7):372-8.

Gaebel W, Baumann AE. Interventions to reduce the stigma associated with severe mental illness: experiences from the open the doors program in Germany. Can J Psychiatry. 2003 Nov;48(10):657-62.

Gaebel W, Baumann A, Zäske H. Intervening in a multi-level network: Progress of the German Open the doors-projects. World Psychiatry 2005; 4, S1: 16-20.

Gaebel W, Zäske H, Baumann AE, Klosterkötter J, Maier W, Decker P, Möller HJ: Evaluation of the German WPA "Program against stigma and discrimination because of schizophrenia – Open the doors": results from representative telephone surveys before and after three years of antistigma interventions. Schizophrenia Resarch 2008;98:184-193

World Psychiatric Association. Fighting Stigma and Discrimination because of Schizophrenia. World Psychiatric Association, New York 1998

World Psychiatric Association. Fighting stigma and discrimination because of schizophrenia. Training Manual Version II. World Psychiatric Association, New York 2003

BASTA (Bavarian Anti Stigma Action)

BASTA has been founded in the framework of the initial German Open the Doors activities. It is located in Munich but acts on supra-regional level. As in the other local anti-stigma projects, service users are involved within the BASTA project. It pursues the following aims:

Education of the public about mental illness via local and regional events and co-operation with the media;

Addressing specific target groups (pupils, teacher, police officers)

Protesting against discrimination and stigmatisation by means of an organised stigma-alarm network (SANE);

Initiating contact with people with mental illness.

Main activities of BASTA are a specialised seminar for police officers providing information about mental illness (Kissling et al. 2006), specifically about its treatment and dangerousness that has been evaluated (see below), a school project with a learning toolkit that has been applied in 17 cities with more than 3100 pupils reached, and SANE, the stigma alarm network that works with a methodology adopted from amnesty international.

The evaluation of the police project has been published in a peer-reviewed paper (Wundsam et al. 2007). Contact with police officers due to schizophrenia and resort to violence in such interactions is a common occurrence and represents a source for stigmatisation of mentally ill people. Aim of the project was to establish a program for police officers to reduce that stigma. The seminar was developed by BASTA in cooperation with sociology teachers of the Bavarian police academy. The evaluation included 12 classes of police students (N=229) and focused on the police officers' social distance and negative stereotypes towards people with mental illness. Providing personal contact between officers and the referees (patients, relatives and mental health professionals) was a main element of the project. Results of a debriefing after the pilot project were overall positive. A significant improvement within the social distance scale and amelioration in the stereotype categories violence and treatability were found. The need for special training of the police regarding mental illnesses was acknowledged by all participants. Personal contact of police officers with patients and relatives appeared to be important for the efficacy of the intervention.

Weblink: www.openthedoors.de/de/index.php

Kissling W, Wundsam K. [The police - there to serve and protect]. Psychiatr Prax. 2006 Jul;33(5):205-6.

Wundsam K, Pitschel-Walz G, Leucht S, Kissling W. Psychiatric patients and relatives instruct German police officers - an anti-stigma project of "BASTA - the alliance for mentally ill people". Psychiatr Prax. 2007 May;34(4):181-7.

### "Irre menschlich Hamburg e. V."

Irre menschlich has been founded in the framework of the initial German Open the Doors activities. It evolved from the psychosis seminars in Hamburg which were organised as a "trialogic" communication platform for users, relatives, mental health professionals and laypeople on equal terms. It defines itself as "Anti-Stigma Campaign from Below" (Bock et al. 2003), emphasizing psycho-social aspects of therapy and rehabilitation in (alleged) contrast to biogenetic and medical approaches in "official" anti-stigma-campaigns as well as the trialogic approach as basis for credibility. Initially the activity focus was laid on school projects. Meanwhile, service user offer specialised school programs about ten topics including depression and mania.

In addition to the school projects, Irre menschlich offers workshops aimed at various target groups as companies, police officers and journalists and supports film and theatre projects which draw a suitable human picture of mental illness.

Weblink: www.irremenschlich.de

Bock T, Naber D. ["Anti-stigma campaign from below" at schools. Experience of the initiative "Irre menschlich Hamburg e. V."]. Psychiat Prax 2003;30:402-408.

## "Irrsinnig Menschlich e. V."

Irrsinnig Menschlich e.V. has been founded 2000. Foundation members were members of the German parliament, of the German Aktion psychisch Kranke e.V. [Action mentally ill], and of the Saxonian self-help association of relatives of people with mental illness. The association is foundation member of Open the doors Germany. General aim of Irrsinnig menschlich is to

inform about mental health and to reduce fears and prejudices against people with mental illness. To reach this aim, a variety of projects have been initiated and been conducted: School project "Crazy? So What!",

Award "Mut" [Courage] for politicians engaged for people with mental illness,

Film/media project "Gegen die Bilder im Kopf" [Against the images in the head],

Film festival "Ausnahme Zustand" [State of emergency], and

Services for journalists

The school project "Crazy? So What!" has been evaluated in a control-group design (Schulze et al. 2003) including N=90 pupils in the intervention group and N=60 in the control group. Intervention was a 5-day project week to promote young people's mental health and to reduce stigma towards people with schizophrenia. Key element was an encounter with a person with schizophrenia. Negative stereotypes about and social distance towards people with schizophrenia were assessed pre, post and one month after the project week. Both stereotypes and social distance improved in the intervention group but not in the control group. The effects remained stable after one month.

The film festival "Ausnahme Zustand" has also been evaluated in a control-group design (Winkler et al. 2008). Five films with together N=405 viewers formed the intervention group. The control group (N=104) was drawn from spectators of a film not addressing the topic "depression". Social distance towards people with mental illness was assessed pre and post watching the film. The results were mixed: Only in the case of one film ("Seelenschatten" [Soul shadows]), social distance decreased. In contrast to this, social distance increased in the audience of the film "Tarnation". The audiences of the other films showed no social distance changes.

The "Irrsinnig menschlich" project website offers several resources for anti-stigma interventions, e.g., an exhibition "Gut drauf?" [up to scratch], a crisis guide for young people, pocket guides and posters for mental crises (about 8 different topics), and an accompanying book for the school project "Crazy? So What!"; as well as films and spots.

Weblink: www.irrsinnig-menschlich.de

Winkler I, Richter-Werling M, Angermeyer MC. Strategies against the stigmatisation of mentally ill subjects and their practical realisation in the example of Irrsinnig Menschlich e. V. Gesundheitswesen 2006;68:708-713.

Schulze B, Richter-Werling M, Matschinger H, Angermeyer MC. Crazy? So what! Effects of a school project on student's attitudes towards people with schizophrenia. Acta Psychiatrica Scand 2003;107(2):142-150

Winkler I, Zink A, Schomerus G, Richter-Werling M; et al. The film festival "AUSNAHME ZUSTAND" ("State of Emergency") – A strategy against stigmatization of the mentally ill? Psychiat Prax 2008;35:33-39.

# German Alliance against Depression

The German Alliance against Depression is an association for people with depression and their relatives, experts and persons working in mental health care services with the aim to educate the public about depression and to improve mental health care services for depression. Interventions take place on four different levels: a) co-operation with general practitioners (advanced training), b) public relations and information of the public (poster, leaflets, and events), co-operation with community facilitators (e.g., priests, teachers, police, media), and d) help offers for patients and relatives (self-help groups, high risk groups). Main messages of the Alliance are:

Depression can affect everybody

#### Depression takes many forms

Depression is treatable

Local alliances against depression have been founded in more than 50 regions and cities in Germany. The German alliance (located in Leipzig) provides materials and counsels local alliances in their activities. Several videos and information brochures are available on the alliance's website. Meanwhile, the Alliance against depression is also organized on a European level with 18 international partners in 16 different European countries (Hegerl et al. 2008).

The initial campaign launched in 2000 has been evaluated regarding its effects on suicidal behavior in the population (Hegerl et al. 2006). Suicidal acts (comprising suicides and suicide attempts) decreased by 20% in Nuremberg where the campaign was located, whereas no decrease was detected in the control town Würzburg. In a further series of population surveys conducted in Nuremberg and Würzburg in the years 2000, 2001 and 2002, negative attitudes towards depression (e.g., "you have to pull yourself together to get rid of [a depression]") decreased in Nuremberg in the subgroup of people being aware of the Alliance against depression, but not in the control town Würzburg (Dietrich et al. 2010).

Weblink: www.buendnis-depression.de

Hegerl U, Althaus D, Schmidtke A, Niklewski G. The alliance against depression: 2-year evaluation of a community-based intervention to reduce suicidality. Psychol Med. 2006 Sep;36(9):1225-33.

Hegerl U, Althaus D, Stefanek J. Public attitudes towards treatment of depression: effects of an information campaign. Pharmacopsychiatry. 2003 Nov;36(6):288-91.

Hegerl U, Wittmann M, Arensman E, Van Audenhove C, Bouleau JH, Van Der Feltz-Cornelis C, Gusmao R, Kopp M, Löhr C, Maxwell M, Meise U, Mirjanic M, Oskarsson H, Sola VP, Pull C, Pycha R, Ricka R, Tuulari J, Värnik A, Pfeiffer-Gerschel T. The 'European Alliance Against Depression (EAAD)': a multifaceted, community-based action programme against depression and suicidality. World J Biol Psychiatry. 2008;9(1):51-8.

Dietrich S, Mergl R, Freudenberg P, Althaus D, Hegerl U. Impact of a campaign on the public's attitudes towards depression. Health Educ Res. 2010 Feb;25(1):135-50.

## MENTAL ILLNESS STIGMA AND WAYS OF DIMINISHING IT IN GREECE

By Marina Economou, Lily Peppou, Eleni Louki and Klio Geroulanou University Mental Health Institute, Athens

### **INTRODUCTION**

The University Mental Health Research Institute (UMHRI-EPIPSI) constitutes the Greek site of the Anti-Stigma Programme: European Network (ASPEN), an international collaboration for reducing the stigma and discrimination surrounding patients with mental health problems. In this context, a literature review was conducted in order to address the following research aims:

To explore known patterns of stigma and discrimination associated with mental illness in general and depression in particular in the country. Public surveys, controlled studies or evidence stemming from research on specific target groups, such as young people, medical students and mental health professionals among others, will be entailed under this aim.

To summarize the evidence base concerning best practices for effective anti-stigma interventions. Details on the methodology, target group, scale of the study and strength of the evidence will be encompassed.

### METHODOLOGY

To review the literature, the EMBASE, PsychINFO, Web of Knowledge and Medline databases were searched using various combinations of the search terms provided by the leading site of the 4th package of the project:

Greece OR Greek OR Athens AND stigma OR attitud\* OR prejudic\* OR stereotyp\* OR discrmina\* AND mental OR depressi\* OR psychiatr\* OR psychologic OR affective disorder OR mood disorder OR Affective symptoms AND intervention OR education OR information OR television OR media OR communicati\* OR film

The electronic search yielded one paper only.

Furthermore, hand search of the two primary Greek journals: Psychiatriki and Psychiatrika Tetradia was conducted, while additional information was gleaned through cross-referencing existing research reports. Experts on the field were also contacted in order to find out unpublished research work.

### FINDINGS

### 1) Patterns of stigma and discrimination associated with mental illness – General Population

Attitudes towards mental illness in the Athens area – Findings from 1987 (Madianos et al 1987)

Method: A probability and representative sample of 1574 residents of two boroughs in greater Athens area was interviewed in order to investigate their attitudes towards mental illness before the establishment of community mental health services in the area. The instrument utilized was the Opinion about Mental Illness Scale (Cohen & Struening, 1962). Results: Age, education, place of residence and occupation showed a significant impact on the social discrimination and restriction subscales of OMI with young people, participants raised in urban centre and those who have attained a higher educational level being less likely to perceive people with mental illness as "different from normal people", "behaving like little children" and "not allowed to get married". No socio-demographic variable was found to be associated with the social care and integration subscales, indicating a common acceptance of a need for social care for mental patients.

Attitudes towards mental illness in Athens area - Findings from 1994 (Madianos et al, 1999)

Method: A two-stage systematic community sample of 400 adult residents (and household members) from two boroughs of greater Athens were selected for participation in the present study. Data were collected in the form of a personal interview, which incorporated the Opinion about Mental Illness scale (Cohen & Struening, 1962). Results between the present sample and that of 1987 were compared.

Results: The 1994 study respondents expressed less authoritarian views on factors A and B in comparison with the respondents of 1987. Furthermore, they were found to hold a more positive attitude towards community integration of the mentally ill and the provision of social care for them. Female gender, urban place of residence, high educational status and occupation were all associated with more positive attitudes towards patients with mental illness.

Eurobarometer Mental Well Being (European Commission 2006)

Method: Special Eurobarometer reports are based on thorough thematic studies carried out in the context of the European Union. The special edition of interest covered well-being, entailing a section on respondents' perceptions of people who face psychological or emotional problems. In Greece, 999 in-depth interviews were conducted for the particular survey.

Results: With regard to the view that people with psychological or emotional health problems are unpredictable, Greek respondents rank first among countries in espousing the particular belief (77% agree with the item). Furthermore, 42% of them believe that people with emotional and psychological health problems are dangerous, 24% of them that they cannot recover and 21% that they should be blamed for their illness.

Public Attitudes to Schizophrenia (Economou et al 2005)

Method: A national survey was conducted in 13 geographical regions of Greece covering urban, semi-urban and rural areas. The sampling strategy of the survey was a three-stage stratified sampling method (building block, household, individual) yielding a sample representative of the general population. A total of 1199 people were interviewed face-to-face via utilizing the Alberta Pilot Site Questionnaire Toolkit (Thompson et al. 2002).

Results: The Greek sample was found to display greater levels of desired social distance from patients with schizophrenia in comparison to their counterparts in Canada and Germany, where a similar survey was conducted. Greater social distance was recorded for social interactions requiring high levels of intimacy, for respondents of lower educational or socio-economic status, who live in semi-urban or rural areas and are of older age. With regard to the establishment and operation of small group homes in the community, 51.2% were in favour and 19.9% were against it. Among the participants who were negative towards such a prospect, 56.6% reported that they would actively resist such an initiative. In addition, when people with schizophrenia

were compared to other vulnerable to stigmatization groups (e.g. people with HIV), respondents were found to be more disturbed about working with or moving next door to a person with schizophrenia.

Knowledge about Schizophrenia and Public Attitudes towards the people who suffer from it-2009 (Economou et al 2009)

Method: A household survey conducted by a professional survey institute specialized in social surveys. The survey covered urban, semi-urban and rural areas in 13 randomly selected areas in Greece. Face to face interviews were conducted via utilizing the Alberta Pilot Site Questionnaire Toolkit (Thompson et al. 2002). The sample was representative of the general population in the country.

Results: When participants were enquired about their source of information about schizophrenia, 65.9% of participants spontaneously identified television as their primary source. With regard to the causes of schizophrenia, the most common attribution among respondents was psychosocial-environmental factors (34%). Concerning social distance items, most respondents stated that they would not marry a person with schizophrenia (92%), 50.5% that they would be disturbed to work with him/her and 32.9% that they would feel afraid to a start a conversation with him/her. It is noteworthy that 81.3% considered patients with schizophrenia to suffer from split personality, 74.6% considered them to be dangerous and 68% a public nuisance. Only a minority of respondents perceived people with schizophrenia as capable of working at regular jobs (16.8%).

Public opinions about mental illness in a Greek area (Mouzas et al 2008)

Method: A random sample of 2010 households was selected through a systematic cluster sampling method. From each household an adult (age range 18-65) was chosen randomly for the interview. The final sample of the study entailed 1975 participants, who answered the Opinions about Mental Illness scale.

Results: Findings showed that the inhabitants of rural areas displayed higher degrees of social discrimination and exclusion (factors A and B), while they were found to endorse to a less extent the view that intra-familial relationships play a prominent role in causing mental illness (factor D). In addition, they were found to favour to a lesser extent the social integration of people with mental illness. No differences emerged between inhabitants of rural and urban areas in terms of their opinions about social care. Apart from place of residence, educational level and age were the other two main socio-demographic variables on which the Opinions about Mental Illness score depended.

Anti-Stigma Athens Programme (Submitted for publication at a local journal. In addition, it constituted an oral presentation at the 2nd Psychiatric Conference on Primary Health Care).

Method: A telephone survey of 600 randomly selected residents of Athens metropolitan area was carried out. Public attitudes and social distance towards multiple disenfranchised groups of people (psychiatric patients, immigrants, homeless, drug addicts, people with HIV, physically disabled and ex-prisoners) were recorded and analysed as well as their attitudes towards the implementation of anti-stigma interventions by the municipality.

Results: About eight out of ten participants considered at least one of the groups to be a public danger and incapable of working in regular jobs. Specifically, 57% of participants agree that

substance users are a public danger (42% believed the same for the mentally ill) and 62% of participants agree that mentally ill patients cannot work in regular jobs (60% believed the same for substance users). Social Distance results indicated that overall the most stigmatized groups were substance users and mentally ill patients, whereas the least stigmatized group were physically disabled persons. The majority of participants were in favour of the creation of services for the studied groups in their community (61-89%) and 94% were in favour of their municipality conducting anti-stigma campaigns for these groups. Finally, a majority (73.7%) of participants indicated that they would be likely to participate in such campaigns.

Public attitudes towards depression and psychiatric medication Poster presented at the 10th International Forum on Mood and Anxiety disorders, November 2010).

Method: Telephone interviews were conducted on a random and representative sample of 632 people living in a representative borough of Athens. The interview entailed open-ended questions about the core symptomatology of depression, a standardized questionnaire on public attitudes towards depression and psychiatric medication as well as close-ended questions about help seeking intentions.

Results: Most of the respondents were capable of spontaneously citing the main symptoms of depression. Nonetheless, the majority of them believed that people with depression are weak (61.7%), unpredictable (53.9%) and could snap out of the disorder if they wanted to (82.2%). Contrary to expectations, they regarded depression as a real medical illness (66.3%). Concerning their attitudes towards medication, the majority endorsed the belief that they are addictive (67.4%), less effective than natural herbs and homeopathy (42.2%) and capable of altering one's personality (56,9%). Nonetheless, most of them reported that they would contact a health professional in case they manifested persistent symptoms of depression (71%). Various factors were found to influence these attitudes, which in turn affected help seeking intentions.

Depression Helpline Poster (presented at the 3rd European Congress of the International Neuropsychiatric Association, WPA, November 2010).

Method: Since the commencement of its operation, the Depression Helpline has received 6.772 calls (May 2008-December 2010). A data collection form accompanies every call and covers areas such as the basic socio-demographic characteristics of the person who suffers from psychological problems, his/her symptomatology and its duration, his/her previous contact with mental health professionals and mode of treatment received and whether he/she is aware of the public mental health services in his/her area. In addition, the symptomatology he/she manifests corresponds to a particular checklist of symptoms, whose overall score indicate whether the person is likely to be presenting a clinical important disturbance (the checklist and the cut-off points can be found in Goldberg et al. 1988, BMJ 297, 897-899.)

Results: When the characteristics of all calls were analysed the following results emerged. In 67.97% of the data, the person who called did it for personal reasons, whereas 26.66% of the calls were made by family members who were concerned about their relatives. The source of information about the help-line was television in 49.84% of the cases (in particular for half of them was the TV spot pertaining to the fighting depression campaign) and in 22.02% was the Internet. The gender of the person for whom the call was made (either by himself/herself or the relative, hereafter to be referred to as "patient") was female in 66.55% of the calls and male in 33.45%. The mean age of the patients was 41.70 years old (sd = 14.93) and the majority of them were either single (39.6%) or married (38.5%). Most of them were living in the capital (Athens:

60.52% of calls) and had high educational status (42.41% had completed a university degree). Nonetheless, the majority of patients were unemployed (59.17%), with the prevailing reasons for unemployment being retirement (27.66%) and mental health problems (17.97%). In terms of symptoms, depressed mood was most frequently reported (48.17%), followed by low energy and fatigue (24.18%), loss of interest for daily activities, which used to be pleasant (17.46%), despair (17.46%) and relentless worrying (16.99%). The mean duration of the reported symptomatology was found to be 36.72 months (sd= 81,2). Among the patients, 58.07% had already been diagnosed with a psychiatric disorder. Among those who had received a diagnosis, 58.35% had been diagnosed with depression, 15.99% with bipolar disorder and 9.42% with schizophrenia. The majority of the callers had visited a mental health professional (45.33%) and especially a psychiatrist (81.8%). Furthermore, 50.12% of them were receiving some mode of treatment with pharmacotherapy being the preponderant one (93.46%). When the reasons for calling the help-line were explored, the majority of callers just wanted to speak to someone about their problems (56.14%), to be advised on how to handle their problems (33.78%), to be informed about mental health services (28.03%) and to be informed about their diagnosis and symptomatology (27.48%). It is noteworthy that 45.28% of the callers did not know that there were public mental health services in their area. In 54.82% of the calls, the person who called was given information about his/her local public mental health services and was advised to pay a visit there. Finally, the results from the depression scale of Goldberg et al. revealed that 34.38% of patients displayed a 50% chance of suffering from a clinically important disturbance.

# 2) Patterns of stigma and discrimination associated with mental illness – Specific Population Groups

Health service staff's attitudes towards patients with mental illness (Arvaniti et al 2009)

Method: The present study followed a postal survey design. In line with this, envelopes were sent to 480 employees in 11 randomly selected sectors of the General Hospital of Alexandroupolis and to 300 medical students of the Medical School, Democritus University of Thrace. The Opinions about Mental Illness scale, the Level of Contact Report (Corrigan et al. 2001) and the authoritarian Scale (Adorno, 1950) constituted the study instrument.

Results: An important part of the sample held negative attitudes towards mental illness and especially with regard to social discrimination and restriction of the patients. Women, older and less educated respondents, nursing staff and participants who scored highly in the authoritarian trait endorsed the most prejudicial attitudes towards mental illness. On the other hand, familiarity with mental illness was associated with positive attitudes to mental illness.

Psychology students' attitudes towards depression and its treatment (poster presented at the national conference on Clinical Psychology, November 2010).

Method: A convenience sample of 143 undergraduate psychology students completed a self-reported questionnaire, after reading a vignette describing a patient going through a major depressive episode. Participants were asked to indicate whether the person described in the vignette suffered from a mental disorder. Furthermore, they were asked to complete the Attitudes to Depression scale (Griffiths et al.), while omitting from its item the term "depression" in order to elicit participants' attitudes to the behaviours described in the vignette. In addition, participants were instructed to indicate to what degree they think that various

available treatments for depression (again without stating the diagnosis) would be helpful for the person described in the vignette (e.g. CBT, antidepressants, antibiotics, yoga, etc). Results: The vast majority of students identified correctly that the person in the vignette was going through a depressive episode; however 80% of them underestimated its severity (considered it to be a mild episode). Regarding their attitudes towards the person described in the vignette; 55.3% held the belief that she could snap out of it by herself, if she wanted to, 44.1% believed that she has weak personality and 65% claimed that the woman in the vignette is not suffering from a real medical illness. Only 6.3% deemed the person in the vignette dangerous and 16.1% considered her to be unpredictable. As far as treatment modalities are concerned, chatting with a close friend was regarded as the most helpful treatment for overcoming her psychological problems, followed by counselling, CBT, psychoanalysis, changes in lifestyle (exercise or eating properly), art therapy etc. Taking antidepressants was not considered more helpful than taking vitamins.

Health service staff's attitudes towards suicide (Velergaki et al 2008)

Method: A random sample of health service staff employed at the General Hospital of Rethimno and at 4 health centres of the area took part in the present study (N= 104). Participants had to complete the Attitudes towards Suicide scale (Botega et al. 2005).

Results: Nursing staff was found to be more sympathetic towards people who had committed suicide in comparison to doctors. At the same time, they were found to object to a greater extent the person's right to commit suicide. Women and religious individuals were also found to be more sympathetic towards patients. Family history of suicide, age of the respondent and years of professional experience were not found to exert a statistically significant effect on attitudes to suicide. It is noteworthy that 26% disagreed with the view that people who commit suicide suffer from a mental illness. Nonetheless, only 3.6% would not refer such a patient to a psychiatrist.

Patients' subjective experiences of stigma and discrimination (INDIGO study, the Greek data was presented in the 2nd Psychiatric Conference of Primary Health Care)

Method: The International Study on Stigma and Discrimination was a large international study under the overall co-ordination of the Institute of Psychiatry. The Greek site interviewed 25 individuals with schizophrenia on their stigma and discrimination experiences. The sample was recruited from rehabilitation programmes in Athens area and comprised mainly patients with chronic schizophrenia. The study used the Discrimination and Stigma Scale, a structured interview schedule, to assess stigma and discrimination experiences.

Results: Patients reported being treated unfairly primarily when they expressed a desire to start a family (71% of patients reported unfair treatment), when they decided to get married or take a divorce (68%), during their studies (57%) and when they tried to have a relationship (50%) or start a friendship (49%). On the other hand, they have not experienced discrimination from mental health professionals, neighbours, nor police officers. In addition, when participants were asked being discouraged to pursue various activities lest they experience anticipation, 50% of them stated that the anticipation of discrimination has prevented them from applying for a job and 39% of them have having a close romantic relationship.

# 3) Interventions targeting stigma and discrimination

Various interventions have been implemented in the country with regard to raising awareness about mental health issues and fighting the stigma and discrimination attached to them (e.g. targeting priests and spiritual leaders, local communities, journalists, pharmacists etc.). Nonetheless, the vast majority of them were not systematically evaluated.

Fighting stigma and discrimination in high schools students (publication submitted to the International Journal of Social Psychiatry)

This is a large programme, designed and implemented by the University Mental Health Research Institute. It addresses the stigma surrounding mental illness in general and schizophrenia in particular. Twenty schools have been targeted and more than 572 students have attended the intervention. The control group (N = 283) usually attended a talk about nutrition and healthy living.

Intervention: The approach adopted has been primarily based on the education strategy. Students were provided information about mental illness and schizophrenia on the first part of the intervention, whereas during the second they were informed about the stigma surrounding mental illness. Service users were not entailed in the intervention due to reactions from the local communities; however, some of their narratives were read to students. The intervention on the use of sensitive, accurate and appropriate language when one talks about people with mental illness.

Instrument: The Alberta Pilot Site Questionnaire Toolkit for high school students was used and was administered at three time points: at baseline, upon completion of the intervention and at 12-month follow-up.

Results: Data was based on a sample of 580 students. Baseline measurements indicated that students espoused certain stereotypical beliefs about patients with schizophrenia and were reluctant to interact with them on some occasions. Upon completion of the intervention, positive changes were recorded in students' beliefs, attitudes and desired social distance; however, only the changes in beliefs and attitudes were maintained after one year.

Fighting stigma and discrimination in elementary schools students (This pilot study was presented at the American Psychological Association Congress 2011 and the manuscript will be submitted for publication).

A similar approach to the one adopted for high schools students has been followed. Nonetheless, the intervention does not address schizophrenia, as some previous fieldwork showed that the diagnosis does not connote something to the elementary school students.

Intervention: Similar to the one delivered to high schools students after being adjusted to the population it targets. A greater emphasis was given to artistic activities facilitating the expression of emotions rather than on open discussions. For this reason, a mixed methodology has been employed for its evaluation.

Instrument: Alberta Pilot site Questionnaire Toolkit for students was used. Children's drawings were also analysed qualitatively in order to explore their baseline beliefs and attitudes about mental illness

Results: In terms of the quantitative results of the present study, improvements were recorded with regard to social distance measure and specific beliefs and attitudes to mental illness. For example, the percentage of children who deemed patients with mental illness dangerous fell from 61% to 10% after the end of the intervention. Similarly, their knowledge about mental

illness was advanced. Before the intervention, 61% of children believed that patients with mental illness have split personality and 52% considered them to be of lower intelligence. After the intervention the percentages were reduced to 19% and 17% respectively. As far as the qualitative data are concerned, analysis of the artwork showed that girls tend to view people with mental illness in more empathetic terms and boys tended to ridicule them.

Fighting stigma and discrimination in medical students-the role of psychiatric attachment (manuscript submitted for publication to Psychiatry and Clinical Neurosciences).

A couple of years ago, the undergraduate psychiatric attachment for medical students set an aim to address stigma and discrimination surrounding schizophrenia. A research study was conducted at the time to evaluate if it succeeds in achieving this aim.

Sample: A cohort of 158 sixth-year students participated in the present study. Students completed the same self-reported questionnaire before and upon the completion of their psychiatric attachment.

Undergraduate Psychiatric Training: The psychiatric attachment has a 4-week duration and encompasses both theoretical and practical aspects. Lectures on psychiatric disorders and their treatment, adopting primarily a biological model for explaining them, are complemented by clinical work at the inpatient and outpatient settings of the main psychiatric hospital in Athens. Students assume partial responsibility of clinical cases under the overall supervision of psychiatric residents and the psychiatrists of the hospital.

Instrument: Alberta Pilot site Questionnaire Toolkit, validated for medical students (Thompson et al. 2002). The Greek version of the instrument was field tested prior to being incorporated in the study.

Results: The exploration of medical students' baseline beliefs and attitudes revealed that students did not endorse stereotypes commonly attached to people with schizophrenia, such as being dangerous, lazy or of lower intelligence; but they held the view that they are unpredictable and suffer from split personality. Furthermore, the baseline level of desired social distance was found to increase, as the intimacy of the interaction increased and the only variable associated with it was personal experience with serious mental illness. Moreover, the attachment was found to have either no influence at all or in a negative direction. Upon its completion more students were found to believe that people with schizophrenia cannot recover, have no insight into their condition, cannot make reasonable decisions, cannot work in regular jobs and are dangerous to the public. No difference was recorded in terms of social distance scores.

Finally, concerning the national campaign against the stigma surrounding depression, no formal evaluation has taken place. The only data available from the Ministry on this regard is the number of leaflets distributed across Greece (more than 3,000) and the number of times the TV spot was broadcast (284 times within a 6-month period).

### CONCLUSIONS

Research on the stigma surrounding mental illness in Greece has focused to a great extent on the investigation of beliefs and attitudes towards patients with schizophrenia, with attitudes towards patients with depression being still on its infancy. Furthermore, the vast majority of anti-stigma interventions are not systematically evaluated and as a result of this, it is difficult to draw safe conclusions about evidence-based anti-stigma practices in the country.

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# LITERATURE REVIEW; PATTERNS OF MENTAL HEALTH STIGMA AND ADDRESSING STIGMA IN HUNGARY

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### INTRODUCTION

As part of the ASPEN (Anti-Stigma Programme - European Network) project's Work Package 4 ('Best practice anti-stigma'), Aspen sites were to conduct a literature review on stigma in their country. This would include a thorough analysis of all the peer review publications and reports about mental health stigma in their country.

This country report is intended to cover two areas:

1) Known patterns of stigma and discrimination associated with mental health, and depression in particular. These can be derived from e.g. public surveys, controlled studies, patterns of stigma and discrimination in key settings, such as schools and workplaces.

2) The evidence base and pointers for promising practice for effective interventions to address stigma and discrimination in relation to mental health problems. These interventions will be described in terms of the approaches used, the target group, the scale of the study, and the strength of the evidence.

### **METHODS**

We used the words:'Hungary, Depression' on PubMed AND 'stigma, stigmatization' OR 'mass media, education' without results. We also used the Hungarian Medical Bibliography on Eski.hu using the password: 'depresszió' (depression) AND 'stigma' OR 'attitûd' (attitude),OR:' megkülönböztetés' (discrimination), OR:' média' (media),OR: 'sajtó' (press), OR: 'oktatás' (training), OR: 'képzés' (education) without result. Using Proquest, 'Depression AND Hungary AND Health services'- no results, 'Depression AND Hungary AND Stigma OR Attitud OR Prejudice OR Discrimination – no results, 'Depression AND Hungary AND Stigma OR Attitud OR Prejudice OR Discrimination – no results, 'Depression AND Hungary AND Intervention OR Health education OR Mass media – no results, 'Depression AND Hungary AND radio OR television OR printed media OR telecommunication OR mass media – 5 results, but not related to our topic. In a next step we repeated the search but did not narrow down the search to pair-reviewed articles. We did not find more results.

We checked thesis papers of students at Semmelweis University of Medicine and at ELTE (Lóránt Eötvös University of Arts and Sciences) with 4 results.

We used the database and knowledge base of our Antistigma Programme that joined the European Alliance Against Depression (EAAD Hungary) and our publication that collected the antistigma activities of NGO's in Hungary (in 2006) published in the EAAD handbook. We read

the whole book where all the significant centres involved in the prevention of depression were cited/mentioned.

## RESULTS

European Alliance Against Depression (EAAD)

Involved Hungary under the leadership of Maria Kopp (MD, PhD) and the Dpt. of Behavioral Medicine of the Budapest University of Medicine, from 2005.

Background: According to the results of a representative research of this centre in the general population, called Hungarostudy (1,3), the frequency of mild to moderate depression increased between 2002 - 2005, from 11% to 15%, among males and from 15% to 19%, among females. The suicide rate in Hungary is one of the highest in the world. The data related to depression show close association with low scores in general health indicators in the general population, especially with the highly increased death risk of men in their active age. The results of Hungarostudy show that several social factors, including: hostility, rivalry, uncertainty of work, unfavourable work circumstances (frame of mind), family conflicts, the lack of free time and work at week-ends are related to the risk of poor (mental) health. Protecting factors were: trust, strong social relationships, belonging to church, and belief in the meaning of life (1).

Goal of the project: EAAD in Hungary set up goals to increase screening and involvement of people with depression into treatment in Hungary. Decreasing stigma was part of these project goals (2).

Method: This programme gathered most of the good practices in Hungary against depression. A priority of this programme was the education of the community and various professionals, as well as the involvement of self-help organizations and initiatives. A book was published with the chapters on the local good practices, a home page with educational materials started and a short film was shot to inform the public about the disorder and the treatment possibilities. A lot of media-activities were done. Project leaders had several meetings and, in the Szolnok region, the development of a local educational and treatment programme took place.

Method of reviewing the EAAD project: As the project is not only about stigma, discrimination and attitudes, we selected the programmes that were related to stigma, discrimination and attitudes regarding depression and suicide.

Results were evaluated in the Szolnok region, where suicide decreased significantly (with 47%) during the project period (3). (<u>http://www.depressziostop.hu/ospi/ospi bemtat.pdf</u>) These results were conducive to the continuation of the programme (OSPI) from 2010.

1. <u>Kopp M.</u>: Magyar lelkiállapot 2008. Esélyerősítés és életminőség a mai magyar társadalomban: <u>Semmelweis Kiadó</u>, 2009.(Hungarostudy)

2.Csépe Andrea (ed.): Összefogás a depresszió ellen Kézikönyv a segítő foglalkozásúak számára.(Alliance against depression. A handbook for helpers.) Semmelweis Kiadó és Multimédia Stúdió, 2007 (EAAD handbook)

3.Kopp M.: The Hungarian EAAD Programme in Szolnok Region. Presentation on the EU Conference 'Prevention of Depression and suicide –Making it Happen', Dec. 2010. Budapest: //ec.europa.eu/health/mental\_health/docs/ev\_20091210\_rep\_en.pdf

## Research on attitudes and stigma

2.1.Method: Susánszky É.; Hajnal Á. and Szirtes M., participants of the EAAD project examined the attitudes of helper professionals and the general population regarding depression and suicide. Questionnaire was used in Szolnok and the surrounding region – a focus point of EAAD, due to the extremely high level of suicide.53 people were chosen from local telephone books and 76 people with helper profession took part in the survey.

Results show that the general population group often judges depression to be a personal fault or character problem, comparing to the helper professionals. Many of those who had experienced suicide in their surrounding found it 'unexpected'. Most of the respondents thought that the most important help is the support by others and self-help. Medical therapies were the fourth choice. This research has low scientific evidence because of a nonrepresentative sample with small number of participants (1).

2.2.Method: Zonda et al. (2000) studied the acceptance of suicide in the general population of Budapest with the involvement of a representative sample of 750 people.

Results: 15.5 % of respondents said that suicide is an accepted way in "certain cases" especially in the case of severe physical disorder. Acceptance was much higher with those who suffered from major depression or disthymia (50-45.5%) (2).

Conclusion: These studies show with a moderate evidence that the Hungarian population is quite inattentive and intolerant with those with depression, putting responsibility on the suffering person, while they are quite tolerant towards suicide. The knowledge/information-level regarding depression is low.

1.Susánszky É., Hajnal Á., Szirtes M.: 1.2. Depresszióval és öngyilkossággal kapcsolatos lakossági attitűdök vizsgálata. (Research on the attitudes of general population related to depression and suicide.)In:Csépe A. (ed): Összefogás a depresszió ellen Kézikönyv a segítő foglalkozásúak számára.Semmelweis Kiadó és Multimédia Stúdió, 2007 (EAAD handbook)

2.Zonda T., Bartos É., Nagy G. (2000): Az affektív zavarok felmérése egy fővárosi kerület népessége körében. (Affective disorders at one district of Budapest.) Orvosi Hetilap, 141. évf, 26.szám

2.3. Three medical students and one studying social work wrote their thesis (with the mentorship of dr. Harangozó) about stigmatization of mental disorders in the media. Two of these included affective disorders as well. The study of Halász, J.and Gallai, V. only included schizophrenia.

# 2.3.1.

Method: Frey É. (2004) used the media-archives of the Hungarian National Radio. 83 articles were gathered between 2001-2003 that dealt with mental disorders. The majority of these were related to affective disorders and suicide (36). The author used content analysis.

Results: Mostly focused on schizophrenia, a few articles reported criminal events committed by 'mads'. Some represented these in a fair manner. All other articles about schizophrenia were correct. Stigma related to affective disorders and suicide was even lower in number. Most of the

articles showed positive aspects of treatment facilities, there were a lot of interviews with professionals. Tabloid media was under-represented in the study so it is of moderate evidence.

# 2.3.2.

Method: Kovács K. (2007) observed the Hungarian media reporting on the internet for a week in 2007 using passwords: mental patient, mental disorder, schizophrenia, depression, panic disorder, anxiety, anxiety disorder. 365 articles were content-analysed.

Results: Stigma related to mental disorders was low. Even the majority of reports about criminal events associated with mental disorders showed an objective, informative aspect. In most of these, journalists mentioned that mental disorder could be a way of escaping prison for many criminals. Evidence: high

Conclusion: The two studies showed low level of stigmatization in the media. A great change occurred when the Hungarian Psychiatric Association started a stigmatizing media campaign in 2008 after the closure of the National Institute of Psychiatry and Neurology, and from 2009, when the first attack, by a university student who had previously been examined by a psychiatrist, with the death of one student happened. The media analysis should be repeated and compared to the previous studies.

Frey É.: Az elmebetegségek tükröződése a médiában. Szakdolgozat, (Mental disorders in the media. Thesis) Semmelweis Egyetem, Pszichiátriai és Pszichoterápiás Klinika, 2004.

Kovács K.: Az elmebetegségek tükröződése a médiában. Szakdolgozat, (Mental disorders in the media. Thesis) Semmelweis Egyetem, Pszichiátriai és Pszichoterápiás Klinika, 2007.

Education and anti-stigma activities available on NGO home pages

### 3.1.depressziostop.hu

Goals and methods, target group: This is the home page of EAAD providing information about depression for users and the public and also informing the public about the whole programme. A film was produced to sensitise and inform the public about the effective treatment possibilities (also available on the home page). Information for professionals is available aswell. Data on results are not available.

### 3.2.lelekbenotthon.hu

Goals and methods, target group: this provides information about depression and suicide prevention for the public and for patients as well, also contains information about books and other publications. Data on results are not available.

### 3.3.bura.hu

Goals and methods, target group: it provides education and created an interactive surface for users and their relatives where people could consult psychiatrists as well. (The initiator of bura.hu, Eszter Babarczi, a well-known journalist and writer speaks about her depression and borderline personality disorder in a very proper way, also describing the effective treatment.) Data on results are not available.

3.4.bipolaris.hu

Goals and methods, target group: it is the home page of the advocacy group, called: 'Dark days, bright nights' serving bipolar patients. This provides information and self reports for people with mental disorders. Data on results are not available.

### 3.5.mentaradio.hu

Goals and methods, target group: Active between 2000-2005. Psychiatrists at the Szeged Medical University produced programmes for radios about various mental disorders including depression targeting the public. Data on results are not available.

### 3.6.ebredesek.hu

Goals and methods, target group: Awakenings Foundation displayed on its home page (ebredesek.hu) a training material written by Prof. I. Falloon et al. to be used (also) on a self-help basis in families and advocacy, self-help groups.

Results: There were appr. 3000 visitors of the home page in 2009.

## 3.7.nyitnikek.hu

Goals and methods, target group: Awakenings started an anti-stigma programme from 2000 with a new home page: nyitnikek.hu, targeting the public, users, families and also NGO's, volunteers who joined the programme. The focus of this programme is on schizophrenia. With the leadership of Awakenings, a national NGO network was initiated with more than 15 NGO-s and several volunteers called NYITNIKEK Hungarian Initiative against Stigma. It started to work in 2010. Now the Initiative has several activities, all of them are showed in the home page, including:

information on new results by the follow-up of the scientific literature

information on treatment facilities

press observer service: gathering correct and incorrect media representations and media representations of our activities

publishing press releases for the media.

an interactive forum is also available on this home page.

Results: Visitor number increased to 30 per day from May, 2010. Two press releases, more than 20 media-reactions to these.

# 3.8.lefnet.hu

Goals and methods, target groups: Awakenings has a third home page as well. We set up an NGO-based network with representatives of 'reform-psychiatry', good practices and various stakeholders. There are app. 300 members who joined to Mental Health Forum (list is available on the home page). This movement is involved in the reform process of mental health in Hungary, committed to the values of recovery, democracy, ethno-psychiatry, also supporting the psychosocial approach and activities against corruption. On the home page FORUM and the joining e-mail list, we started communication between users, families and various professional groups. Hot topics in psychiatry, including the effectiveness of SSRI's and other drugs, alternative therapies, relationships with the 'Big pharma', patients' experiences, etc. are discussed, with the involvement of the latest international literature, i.e. NICE guidelines. The most exciting topics and a lot of information are available on this home page which targets all the stakeholders involved in a democratic and community-based change of mental health system in Hungary.

Results: Appr. 60 visitors per day, more than 20 topics discussed on the FORUM (from 2008), full documentation of 4 meetings with (1) 123, (2) 22, (3) 41, (4)52 participants, the last one is open for the public.

# 3.9. pef.hu

Goals and methods, target group: This is the home page of the Mental Health Interest Forum, a nationwide advocacy organization of mental patients led by users themselves. Stigma is not the main focus of this NGO but many of their activities represent fight against discrimination of people with mental disorders. It contains a Forum, a media-observer section, as well as information about their activities, information on human rights issues, etc..

Results: The leader of PÉF informed us, that they deal with about 100 cases of users' complaints related to discrimination.

## Famous people about (their) depression

4.1. Eszter Babarczy, who established bura.hu, speaks about her depression and borderline personality disorder publicly.

Resource:

http://videotar.mtv.hu/Videok/2009/10/08/10/Zarora 2009 oktober 7 Vendeg Babarczy Es zter.aspx

4.2. Györgyi Albert, a journalist, published a book about her depression some years ago. She described her problem and the treatment in details. She also took part in the Anti-stigma Programme of Awakenings, when she took part in our programme at Sziget Festival in two consecutive years. (Once she made an interview with a user who lives with schizophrenia, where she compared his symptoms to hers. She also conducted a conversation with a poet about the mental problems of Sylvia Plath.) Later Györgyi's 'anti-stigma role'decreased because she got too much attention from the tabloid media, her alcohol dependency became far too public. A sudden death by heart attack put an untimely end to her life.

Albert Gy:: Miért pont én? A depresszió szorításában. (But why me? In the clutches of depression.) Park Kft Könyvkiadó, 2005.

4.3. Henrik Havas, one of the most popular TV-stars once claimed that he had bipolar disorder. He described the symptoms in a proper way. The media picked up this story. He is mentioned on several lists of famous people with bipolar illness incl. Wikipedia.

Resource: <u>http://www.hirado.hu/Hirek/2009/12/11/06/Sulyos\_beteg\_Havas\_Henrik\_aspx</u>

4..4. Miklós Vámos, a renowned contemporary writer published a popular book about her mother with bipolar disorder with great empathy.

Vámos M.: Anya csak egy van. (There is only one mother) Ab ovo Könyvkiadó, 2006.

4.5. Földényi F. László published a book about melancholy, which includes an essay about Goya's depression at his old age. The author also dealt with the suicide of Kleist. He analysed the cultural history and philosophical aspects of melancholy of the person after the Age of Enlightment. Target group: intellectuals. Published also in German, Spanish and Slovak languages.

Földényi F. L.: Melankólia. (Melancholy) Magvető Kiadó, 1992.

# 5. Other NGO activities – events, training, media-campaigns

### 5.1. Awakenings Foundation

Goals, methods, target group: Awakenings Foundation has been actively present at the 'Sziget Festival' (a youth music and other performing art festival with about 300,000 visitors yearly) for the past ten years with an educational, screening and anti-stigma programme that focuses on psychosis, depression and alcohol dependency. We organise various attractive programmes, films, conversations, simulation (of psychosis) on film, quizzes, and activities like painting the wall of madness, etc. We have hundreds of visitors every year. From 2010 partner NGO-s from NYITNIKÉK network will also take part in our Sziget Programme. The focus of the other Antistigma programmes of Awakenings was on psychosis. This programme was part of the good practices that joined EAAD in Hungary.

Approach: contact strategy, and campaign, education. Attractive communication strategies and attractive ways of education to the young people taking part on the Festival using witty effects, i.e. the radio of the Festival read out the following invitation to our daily program: 'Do you know what is mental illness? Nor do we, but we are pleased to explain to you in the Brain Circus'...or: 'Have you seen a psychiatrist in strait jacket? – today you can meet one ... you can also learn, why advocacy work is important to protect human rights'.

### Scale of the study:

Number of programmes delivered: 10

Number of people reached: appr. 5000

Results: level of stigma is assessed by filling a questionnaire on a voluntary basis by visitors of our program. Analysis was done of 320 questionnaires in two different years. These show a low level of stigma and also low level of information of mental disorders, especially about schizophrenia. Evidence is moderate for the special population of the Youth Festival (not for the general population).

Resource: Kristóf J., Harangozó J., Fehér L., Molnár K: Anti-stigma program a fiatalok részére. (Antistigma programme for the young population.) In: Csépe A. (ed.): Összefogás a depresszió ellen Kézikönyv a segítő foglalkozásúak számára.(Alliance against depression. A handbook for helpers.) Semmelweis Kiadó és Multimédia Stúdió, 2007 (EAAD handbook), 118-134

# 5.2. NYITNIKÉK: Hungarian Initiative against Stigma

Goals, methods, target group: This NGO network for fighting against stigma related to mental disorders is the continuation of the Awakenings programme. It targets the public, professionals and users, families, NGO's and it joined the WPA Programme 'Open the Doors'. In 2010 we published a press release reacting to criminal events and their presentation in the media also teaching the proper communication of these. This was disseminated in the media, also interviews were on the radio and TV. Another press release reacted to the suicide of a famous person that got a huge media interest. In this press release we provided information about the WHO guidelines (available on lelekbenotthon.hu in Hungarian). This press release got high media attention including radio and TV as well. These media activities are also shown on nyitnikek.hu.

Approach: networking for NGO-s and volunteers, education, use of media: press releases Scale of the study:

Number of programmes delivered: 2 press releases, one home page development Number of people reached: 10,000 through the media

Results: 20 media representations. More than 15 NGO's joined the program. Homepage visitors. Scientific evidence is low.

# 5.3. Moravcsik Foundation

Goal, method and target group: Started its anti-stigma activity with a legal counselling service (only partly dealing with discrimination problems) for users in Budapest. From 2010 they organized a big exhibition at one of the most popular cultural centre (MUPA), and then opened a gallery that shows the paintings of patients with mental health problems called 'Art Brut' Gallery targeting the general population.

Approach: contact through art, showing talent and the suffer of mental patients Scale of the study:

Number of programmes delivered: 2 exhibitions

Number of people reached: 600 on the exhibition, appr. 300 in the gallery

Results: a guest book was used at the exhibition, with 120 remarks. 90% were positive, while 5% were stigmatizing. An art review with extremely positive feedback was published in one of the leading periodicals. Scientific evidence is low

## 5.4. Egyensúlyunkért Foundation

Goal, method and target group: They provide training for GP's and other professionals about depression from 2006 at Székesfehérvár, partner of EAAD.

Approach: Education directly to professionals and the public by the involvement of the local media.

Scale of the study:

Number of programmes delivered: 4

Number of people reached in training: 150, through the local media: approximately 2000 Results: not available. According to experiences they built up a good network that supports the rehabilitation of users. Low evidence.

### 5.5.Menta Foundation

Goal, method and target group: Menta Foundation in Nagykálló, the Northern-Eastern part of Hungary involved the local media in a highly professional level. They organise events and local campaigns to inform the public and decrease stigma. They work together closely with the local hospital that is recently building up its 'user-friendly' services.

Approach: Education through the media, contact strategy: meeting with professionals and patients at events and involvement of the local population, focusing on the local intelligence through attractive programs. Involving well-to-do people in charity activities.

Scale of the study:

Number of programmes delivered: appr. 4 events/year

Number of people reached: appr. 3000 (through media), appr. 300 in charity-network

Results: More than 30 media representations in the local media in 2009. Experience: A great support of the local population and decision makers for the services. Low scientific evidence.

# CONCLUSION

There are very few, unrepresentative studies on attitudes towards depression. Research on the effectiveness of anti-stigma activities is practically missing. Because of these limitations we widened the focus of our review and involved all the known publications and programs. Most of the research and activities were focused on schizophrenia in Hungary and initiated by Awakenings Foundation in the last 10 years. A development is waited for as a result of the ASPEN activities, which will be assisted by the establishment of a national network of NGO's and

volunteers called NYITNIKEK Hungarian Initiative against Stigma that started to work from 2010 with the leadership of Awakenings Foundation.

Mental health in Hungary has strong clinical traditions and a rich history of community-based attitudes and social psychiatry as well. On the other hand in the last 15 years biological psychiatry had its honeymoon period with 'the industry' and dominated the whole profession suppressing psychosocial practices and professionals using this approach. The Hungarian Psychiatric Association (HPA) did not join to the WPA Anti-stigma Programme. On the other hand, before 2008, media activities were mostly supported and organized by pharmaceutical companies that provided mostly proper information with effective educational strategies, with the involvement of a lot of good psychiatrists. The theses of medical students showed in our review described the effects of these activities. From 2008 unfortunately two stigmatizing campaigns were initiated by professionals: one in 2008, after the closure of the National Institute for Psychiatry and Neurology by HPA, when leading professionals informed the public about 'mads' who potentially can kill people if beds are decreased in hospitals. The other was initiated by Bluepoint Foundation (Kékpont Alapítvány), one of the leading NGO's serving drugaddicts, which started a media-campaign called 'Narkógettó' (Ghetto of drug-users) in 2010, stigmatizing the heroin-users and also a certain part of the city where many of them live. They generated hundreds of media-reactions. Today media-reports are still dominated by the first campaign's message that became even stronger after some tragic criminal events in 2009. These destructive events energised and helped those professionals who were committed against stigma, also NGO's and other stakeholders to join their efforts against stigma. These were mostly focused on activities to save patients with psychosis from stigma until now. NYITNIKEK is the result of this process. The visit and training for NYITNIKEK members by Norman Sartorius in September 2010, Awakenings' partnership in ASPEN Programme and NYITNIKEK's membership in WPA 'Open the Doors' hopefully will strengthen the activities and also the quality and evaluation of these activities in Hungary.

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#### **ANALYSIS OF ANTI-STIGMA PROGRAMMES IN ITALY**

By Silvia Zoppei (University of Verona) and Mariangela Lanfredi (IRCCS Fatebenefratelli of Brescia)

#### INTRODUCTION

Studies on depression in Italy estimate that 5 million people are affected by depression. According to the Italian findings of The European Study of the Epidemiology of Mental Disorders (ESEMeD/MHEDEA, 2000) Project, about one person in 10 in this national sample met criteria for major depression at some time in his or her life, 3% in the prior year and 1.4% in the prior month. Depressive disorders were twice as common among those who were separated, divorced or widowed, and the unemployed, and four times more common among those with a low level of education (De Girolamo et al, 2006).

Moreover there is another circumstance that raises alarm: the increase of cases amongst young people. In Italy, this problem concerns about 8-10% of adolescents, data that coincides with the number of suicide cases in this age group. Suicide represents the third highest cause of death between young people between 14-24 years old. Often this act is induced by major depression.

The Italian preadolescent mental health project (PrISMA-Progetto Italiano Salute Mentale Adolescenti) is the first Italian study designed to estimate the prevalence of mental disorders in 3418 preadolescents (10-14 years old) living in urban areas (Frigerio et al, 2006). The findings of this study revealed that 8.2% were affected by mental illness. Anxiety and depression disorders are the most common individual disorders (6.5%). Additionally the distribution of cases of depression recorded a disparity between males and females, according to the data of OMS: 15% against 8% of the men.

Several studies highlighted this factor.

Binkin et al (2007) analyzed data from PASSI, the Italian behavioural risk factor surveillance system, based on telephone interviews of residents. The study showed that 9.4% of adults between the age of 18 and 69 years met the case definition of depressive symptoms, measured with a modified version of PHQ2 (Patient Health questionnaire-2). The most important risk factors included female sex, low educational attainment, having serious economic problems and having chronic diseases. The study showed that almost half had not talked with anyone about their problems, with the most risk factors being male sex, having moderate financial problems, and having a regular job. According to the authors, having depressive symptoms is a common condition among working-age adults in Italy, although only the minority are recognized and appropriately advised and treated. They suggested that formal recommendations for the screening of mental disorders in non-psychiatric settings may be useful.

Battaglia et al (2004) conducted a survey on the 6-month prevalence of depression in the Italian community using the modified-Mini-International Neuropsychiatric Interview (MINI) administered with a computer-prompted interview to a sample of 5566 individuals. Prevalence

of major depression accounted for 10.8% of the cases, it was more prevalent in women (1.4-fold). The majority of subjects of all MINI depression categories, including depression did not consult any healthcare professional for their symptoms. Among the major depression subjects undergoing medical treatment, 34.2% were not prescribed any therapy or intervention, while 36.8% reportedly started a drug therapy.

This report aims to evaluate different projects addressing stigma in mental health and especially in depression. In particular the intention is to analyze the literature, the public surveys, the controlled studies, the programmes and interventions relating to stigma and discrimination associated with depression.

# METHODOLOGY

We performed Web, MedLine and PsycINFO searches from 1995 to 2010. The following search terms were used: "depression", "dysthymia", "adjustment disorder", "mood disorder", "affective disorder" and "affective symptoms" for depression; "stigma", "attitudes", "prejudice", "stereotype", "discrimination" for stigma; and "intervention", "health education", "mass media", "communication", "multimedia", "mass communication", "audiovisual equipment", "patient information", "visual information", "radio", "television", "leaflet", "posters", "pamphlet", "print media", "skit", "folk media", "broadcast", "film", "telecommunication" for anti-stigma interventions.

We reviewed the anti-stigma programmes that were described with results or evaluation, and we selected those concerning the theme of depression or general mental health. Specific programmes on schizophrenia we excluded.

# FINDINGS

Not many articles and initiatives, with above-mentioned criteria, were found.

In general, results showed that in Italy the topic of depression isn't well explored, we found a lot of anti stigma studies about mental health and psychoses.

Often programmes are presented with a clear description of the initiative (focus of project, main aims, approaches used), but without other key information such as results and evaluations. The last information are relevant for properly analyze the efficacy of projects, its implications and the effects on short and long time.

These matters would be important not only locally, to see if the project was really effective for the people to whom it is directed, but also at national level, because it could be replicated in other contexts and other regions. We describe the results considering the following areas: Prevention and Rehabilitative programmes, Evaluation of stigma, Informative campaigns, communications and media.

# Prevention and rehabilitation programmes

EADD (European Alliance Against Depression) Prevention Project (Giupponi, 2008)

The Trentino Alto Adige region joined the project of the European Alliance against depression in 2004. The campaign is an action programme with the object of finding, contacting, dealing with and assisting people affected by depression and of preventing the risk of suicide. The project

had the purpose of changing the opinions of community toward depression with reduction of related stigma.

The campaign in Alto Adige, as in the other 16 European nations involved, has arranged a set of initiatives on four levels: formative level, addressed to primary care, psychologists and chemists; informative level, addressed to community facilitators (nurses, teachers, assistant in old people's home, etc); level addressed to support of initiatives of self mutual help and of phone counselling; level addressed to public opinion and to media. In its development the project has entailed the collaboration of outsiders too. A work in the net has been promoted; groups, associations and institutions have been invited to take part in it.

The Trentino Alto Adige Region has joined the project in order to make the population more aware and to attempt to reduce a suicide rate that has remained constantly high. The programme is aimed at primary health care workers, community facilitators, people suffering from depressive disorders, general population. Some parameters have been evaluated: the number of suicides, of attempts of suicides, the use of drugs, number of patient referrals, a change in public opinion, a variation in the consideration of the media for suicide and the depressive pathology. The earlier monitoring results indicate deeper knowledge of depression and better treatment in the Alto Adige population compared with other areas that have been investigated.

There were 1000 questionnaires administered and 458 interviews undertaken, this study shows that people living in Alto Adige regards depression as a real illness more frequently (and not as a lazy attitude for example) when compared with people of other countries joining the study. In their opinion, psychotherapy and pharmacotherapy were considered more useful compared with other studies. Results showed however a high level of stigmatization of pharmacological treatment at national and international level, with considerable compliance problems that aggravate the therapeutic deficit.

Two books were published for priests ("Pastoral of Crisis": church service texts about depression) and teachers ("Ups and downs: Crisis as a school matter": 4 school lessons about depression). Further, a modern art exhibition with the title "The Exhausted Self" was organized that received very controversial feedback from the general public and the media.

There were 11 informative seminars organised for general practitioners, pharmacists, psychologists and 20 training of community multipliers.

They build up new regional self-help groups (12 groups in German, 3 in Italian language) and promoted a co-operation with telephone outpatients services. An outpatients service was opened. There were testimonies of famous people, 3 congresses, 2 meeting with local press agencies, 7 meetings with clergy, information points in hospitals, a website was developed, dissemination of brochures and leaflets. They operated for promoting a network involving police, employment agencies, schools, social services, municipalities, trade unions. In collaboration with Innsbruck University they analyzed the changes in opinions of a sample of German citizens on depression and suicide (170 volunteers, 30 physiotherapists, 160 hairdressers, 100 bartenders).

The shared objectives (reduction of suicide's rate, changing of public opinion with reduction of social stigma, outreach to groups at risk, improving of therapeutic approaches, acceptance of pharmacological and psychological treatment, family members involvement, better compliance

to the therapy) seem achieved. From 2008, the project has been extended to other regions of Italy, a further research will be made to experiment its effectiveness in different conditions. Three responsibility regions were established (northern, central and southern Italy – Trentino, Lazio, Abruzzo) with one main coordinator, Prof. Roberto Tatarelli of Rome University and three sub-coordinators for the three regions. EAAD is going to be implemented in three regions in a restricted way due to lack of funding.

In our research we found some prevention programmes specifically dedicated to the suicide issue.

In Veneto region there is a programme to prevent suicide with the cooperation of stakeholders (<u>www.azisanrovigo.it/media/csm/documenti/progetto\_suicidio\_</u>senza.pdf). It is a local programme still in progress (2009-2011) located in Veneto Region and promoted by LHU 18 of Rovigo city. They have set up a Project Committee, consisting of representatives of institutions and a Scientific Committee formed by experts from LHU. They identified three areas of interest: adolescent, elderly, people who have attempted suicide. It has developed a web-site – www.perdersidanimomai.it – and planned a dissemination of information to raise awareness. The partners were composed of different agencies including health, police, volunteers, general practitioners, chemists, Diocese, Provincial school office. The prevention project includes a multi-level intervention with two distinct projects:

1. Delta Project: evaluation, coordination and integration of a set of programmes for mental health prevention, with special attention to suicide. It is included also an intervention for suicide prevention in jails.

2. Do not lose heart Project: the stakeholders' group has the role of disseminating the project, promoting selected interventions, producing scientific articles or participating in conferences about suicide. It has promoted the website: <u>www.perdersidanimomai.it</u>. The project is divided into five type of actions:

formation in schools for adolescences, parents and teachers

dissemination of prevention practice to stakeholders: nurses, general practioners, volunteers, religious institutions, Police agencies, chemists, social workers, users.

support to survivors of individuals who completed suicide

dissemination of web-site

epidemiological research

Indicators of results are: Evaluations with questionnaires of the presence of suicidal ideation in target groups, i.e. in cooperation with general practitioners. Knowledge of services with specific questionnaires. Opinion on suicide and depression: useful for evaluating stigma and consequently the help-seeking barriers.

Another programme in this area is dedicated to the elderly and promotes support initiatives, it is "Suicide among the elderly: the long-term impact of a telephone support and assessment" (De Leo D et al, 2002).

It is a programme for persons at risk (either somatic or psychological) implemented in the Veneto region of northern Italy (<u>De Leo et al, 1995</u>). The government-sponsored and privately provided service was originally established in 1988 as the TeleHelp-TeleCheck service, a broad public health intervention providing twice-weekly telephone support and emergency response for up to 20,000 persons. A 4-year evaluation reported lower than expected suicide rates among TeleHelp-TeleCheck users than among comparable general community members.

General practitioners or social workers from local health services typically initiated the referrals to the TeleHelp-TeleCheck service. Following referral, clients were placed on a waiting list and subsequently contacted following regional government authorisation. Service users received an alarm device to remotely trigger a pre-established response network (TeleHelp). Users also received welfare monitoring and emotional support from trained and paid staff, via short and informal twice-weekly telephone interviews; users were also able to initiate calls at any time, 24 hours a day and 7 days a week (TeleCheck). Participants were 18,641 individuals, 65 years of age or older, and connected to TeleHelp-TeleCheck between 1988 and 1998. Observed and expected suicide rates among older TeleHelp-TeleCheck users were compared. The mean age of the users at time of connection to TeleHelp-TeleCheck was 79.97 years (s.d. 6.8 years). The majority of participants were widowed (68%), females (84%) and living alone (73%) in partially self-sufficient (63%) circumstances. During the overall evaluation period, 13% of TeleHelp-TeleCheck users on average stopped using the service. Almost two-thirds of these losses were caused by death (45%) or the admission of the user to an institution (21%), with the remainder due to events such as a move to another region or into a relative's home. The number of observed suicides (n=6) of TeleHelp-TeleCheck users over the 11 years of the evaluation was significantly lower than the number expected (n=20.86; X2=10.58, d.f.=1, P<0.001); only 28.8% of the expected mortality from suicide was observed to occur. Examination of data also shows that there were significantly fewer suicides of older female TeleHelp-TeleCheck users (n=2) over the 11-year evaluation period than would be expected (n=11.98). This evaluation confirms a previous report on the apparent effectiveness of the TeleHelp-TeleCheck service in preventing suicide, especially by older females, in the Veneto region. The present sample is characterised by higher than usual rates of psychiatric disorders and a higher proportion of females. Twenty-two per cent of the user sample had clinical depression, compared with 1.98% of the general control population (De Leo et al, 1997). The present evaluation of the TeleHelp-TeleCheck service is unique in being a rare example of a long-term longitudinal naturalistic observation of an intervention to prevent suicide in older people. Overall, this body of research indicates the need for alternative and innovative interventions for preventing suicide in males.

Several studies were developed to promote mental health in the schools, including the School intervention for promoting psychological well-being in adolescence (Ruini et al. 2009)

It is a program for promoting psychological well-being, it has been compared with an attentionplacebo intervention in a high school setting. Nine classes (227 students, 139 F, 88 M; mean age = 14.4 year; SD = 0.673) were assigned at random to: a) well-being intervention (5 classes); b) attention-placebo (4 classes). Assessment was performed at pre and post-intervention, and after six months using: 1) Symptom Questionnaire (SQ); 2) Psychological Well-Being Scales (PWB); 3) Revised Children's Manifest Anxiety Scale (RCMAS). Both school-based interventions consisted of six, two hour sessions in class. WBT and placebo school interventions were carried out by two clinical psychologists, involved in both interventions. The first session was common in both interventions and was based on recognition of different emotions and improvement of teamwork in classes. The second session of the WBT protocol was focused on the relationship between thoughts and emotions, according to the cognitive model of A. Beck and Muris et al. The last three sessions were a novelty introduced by this school program because they were based on Ryff's model of well-being, encompassing six dimensions: autonomy, environmental mastery, positive interpersonal relationships, personal growth, purpose in life and selfacceptance, which were never applied in adolescence in the past. The fifth session was focused on autonomy and purpose in life. The last session was based on happiness and emotional wellbeing. The results reveal a significant effect of WB school intervention in improving Personal Growth (PWB), and in decreasing distress. This is in line with a preliminary investigation on WBT school program performed in junior high school (<u>Ruini et al., 2006</u>). The beneficial effect in decreasing anxiety was maintained in the six-month follow-up.

Another school intervention supported by the Mental Health Department of National Centre for Epidemiology, Surveillance and Health Promotion was "Development of an intervention in schools, with particular attention to primary prevention of depression" (www.ccmnetwork.it/documenti Ccm/prg area5/Prg 5 Salute mentale Cnesps.pdf).

It is a intervention program (principal investigator Dr Antonella Gigantesco) which took place in 13 classes of a total of 11 schools located in several Italian cities. They realised an intervention based on a manual aimed at developing well being and life skills of students in the first and second year of secondary school. It encompassed training conducted by peer students or psychologists. The manual has been evaluated by students. The teachers and some students were formed as facilitators. The study aimed to evaluate a program of primary prevention of mental health by using peer education with the aid of a manual composed in sections (from 17 to 24, 60-90 minutes per units) dedicated to improving social skills, cooperation, problem solving ability, empathy and control of impulsive acts.

The results actually are not published. The manual for students is composed by sessions and has attachments including some self-administered questionnaires as schedules. They are: Questionario emotivo-comportamentale (Di Pietro, 1992); Psychap Inventory (Goldwurm 2004); Scale di autoefficacia percepita APEN/G e APEP/G V (Caprara 2004); SDQ Strenghts and Difficulties Questionnaire in form 1, 2, 3 (Goodman, 2001); Warwick-Edinburgh Mental Wellbeing Scale (Tennant, 2006); NMR - Negative Mood Regulation (Catanzaro 1990).

The manual is based on components of the social and emotional education, Life Skills of the World Health Organization and even "emotional intelligence", but with greater emphasis on setting personal goals and gaining self-discipline. The book takes into account the approaches of Mario Di Pietro for younger students, Giovanni Fava, author of "wellness therapy" for vulnerable adolescents with depression and the manual "Comprehensive Management of mental disorders" of Ian Falloon.

The Ministry of health promoted a campaign against stigma in 2004, "National Programme of communication and information against stigma and prejudice in mental health" (www.campagnastigma.it/campagnastigma/index.htm)

From this national programme emerged several initiatives and studies. To achieve success in the programme, The Ministry of Health considered it important involve the Ministry of Instruction to improve the interest of the school about this theme and to use the students' contributions to produce communicative messages. The project is divided in two sub projects (Grossi et al., 2006; Buizza and Pioli, 2006), one is located in Brescia and one in Rovigo. They involved teachers and students 16-18 years old. The project lasted for 18 months. There were two phases:

1) evaluation of two interventions in which are used different resources:

- model 1 (Rovigo): meeting with students and an actor/writer/journalist, a meeting with two operators of local mental health services, a group of students for peer education

- model 2 (Brescia): informative materials and meetings about mental health for students and teachers.

2) Reinforcement intervention at 6 months post-intervention (it is given to 50% of the sample with other informative materials or with an elaboration of the themes during the school year). There was a stage for students in a mental health service and they used a peer education strategy. The assessment was obtained with questionnaire ad hoc, adaptation from Myths and Facts about Schizophrenia school evaluation (WPA 1996) and from Questionnaire on attitude towards mental illness (Kemali 1989) at beginning of the project and at 6 months follow-up; the aim of the evaluation was to assess the knowledge of students about mental health to have a correct information to promote specific actions for prevention against discrimination and prejudice in specific social groups.

105 students were recruited from Brescia and 135 from Rovigo. The results of Brescia and Rovigo respectively showed that 70% and 76% of students believed that mental diseases are due to emotional sensitivity, 65% to stressors or trauma, 31%-34% to environmental factors.

The analysis of the questionnaires highlighted negative information amongst students, not only about the treatment of mental disease but about mental disease in general and its causes. A lot of students believed that patients are dangerous (25% and 41%). Almost all the sample states that patients should not be isolated, even if this statement isn't followed by an appropriate behaviour. 15% reported fear to talk with somebody suffering from a mental disturbance; 15% have difficulties accepting them in class. Qualitative analysis of questionnaires after the educational programme revealed a reduced rate of prejudice from students and improvement of knowledge about mental diseases in both interventions.

Another programme that involved schools was "All equal, all different".

It was an information campaign aiming to change the popular conception about mental illness. It is a campaign against stigma based on creativity and integration between patients and population. The project offers opportunities for meeting, for discussion and exchange. Specifically some meetings for students (about 100 students) of the Academy of Art of Foggia were organized, aimed at telling the story of "madness" through videos, testimonials, role-play and other interactive teaching methods, with the participation of people with mental disorders. At the end of the meetings the students produced artistic representations (paintings, photography, television or radio spots, exhibitions, musical shows, leaflets...) about the theme of the fight against stigma related to mental health. They produced 70 art works, exhibited during a local exhibition called "Corte dei Miracoli" (Court of Miracles). This project ended with an international congress called "All equal, all different: get to know me as a person and not for my mental illness".

Some projects are aimed to improve rehabilitation strategies, by using sports or support telephone lines.

"Mad for Sailing" is an example of psycho-social rehabilitation through sports.

The authors utilized the sailboat experience as mediator of therapeutic relationship. They used two dimensions as indicators of a possible change: prevention of relapses; degree of social ability and disability containment. For the first domain (prevention of relapses) the indicator is represented by the number of hospitalizations before and after the activity (from 15 inpatients rate before intervention to 5 inpatients rate after the activity). For the second domain (degree of social skill and disability containment) they estimated the frequencies of number of patients

that carry out a working activity before and after the sport experience (5 patients previously employed have maintained their job, 17 unemployed patients did not find work at post-intervention, while 10 unemployed patients have found a job at post-intervention).

The sailboat and the sea were chosen because they represented the "adventure" that is the key element to develop the growth process and significant changes. The boat could sail only if the individual potentiality, the auto responsibility, the independence and the cooperation as modality of interdependence were developed. This project was structured by a theoreticalpractical course with some voyages. The course was finalised also to participate in some national boat races. It was conducted by different professional figures: Mental Health Center operators (psychiatrists, psychologists, nurses) navigation professionals (as course conductors) and volunteers. The possibility to relate with people outside the psychiatric context is important in terms of education / imitation and transmission of competence, for the opportunity to try new relationships, not stiff in the inevitable stereotypes of the relationship operator / patient. Naturally the operators, instead, allowed the mediations among different people and supported the patients in difficult moments. This project started in 1999 and lasted 3 years and 39 patients participated (age-range 24-44 years old). During the first year there were 7 patients, in the second year 14 and in the third 23. In this period 9 left the project (5 for a change of their situation with new friends or job, 1 for the beginning of a work grant and 3 because they concluded a positive experience but they weren't interested in continuing). The continuous attendance at the rehabilitation project seems to play a strong role encouraging decrease of relapses and self-efficacy reinforcement. This work gave the possibility to the patient to emerge from the unique role of the mentally ill. The "protected place" of the sport rehabilitation was called in this way because it was considered a place in which every participant could prove himself without consequences if they made a mistake.

The Association "Progetto Itaca" created a telephone line for people suffering from depression, anxiety, panic attacks, eating disorders and for their families.

This project aims to give correct information for people who phone, promotes the relationship between services and users, identifies problems and needs, planning initiatives of support and assistance through other initiatives of the Association as Self Help Groups. The project foresees also a consultation via email (<u>linea.ascolto@progettoitaca.org</u>) for people who don't wish to call because of stigma and discrimination. Another aim of the telephone line is to try to reduce caregivers' isolation. Unfortunately data about the impact of the project is not available at present.

Another local initiative is the "Service for Monitoring and early Intervention against psychoLogical and mEntal suffering in young people (SMILE)".

This project aims to establish a comprehensive early intervention service for young people with mental health problems and to evaluate its effectiveness in delivering user-friendly integrated interventions. It is translated into an earlier recognition of signs and symptoms, systematic evaluation of psychological distress and promotion of attitudes that encourage young people to seek care. Specifically, the aims of the project concern the development of innovative approaches for destigmatising mental illness, the attempt to link a psychiatric care service with primary care practitioners, and the idea of having severe mood and anxiety disorders as targets for early intervention and as a strategy for detecting more prodromal cases of schizophrenia.

Different professions work at this project: senior psychiatrist, resident psychiatrists, child neuropsychiatrists, neuropsychologists, psychiatric rehabilitation technicians, half-time paediatricians and half-time education technicians. SMILE proposes first time visits and therapeutic sessions. Forms for second and third visits are labeled as 'SMILE visit' rather than 'Psychiatric/psychological visit' in order to reduce stigma.

The professionals assess clinical symptoms using the following instruments: the "Integrated System for Assessment in Psychiatry", the "Youth Psychosis at Risk Questionnaire", the "Symptom Onset in Schizophrenia" and the "Brief Psychiatric Rating Scale". Moreover, patients are rated on an original assessment tool termed "Symptom Onset SMILE" (SoSMILE). The premorbid functioning and psycho-behavioural patterns are rated with the use of the "Premorbid Adjustment Scale" and the "Child Behaviour Checklist" respectively. Unmet need is assessed using the "Camberwell Assessment of Need" and quality of life with the "Quality of Life Enjoyment" and "Satisfaction Questionnaire" (Q-LESQ). In order to evaluate the psychological profile of the relatives, they are asked to fill the Family Attitudes Questionnaire, Jalowiec Coping Scale and the Q-LES-Q. The Brief Neuropsychological Examination is used to assess cognitive performances.In this project, cognitive-behavioural therapy (CBT), integrated psychosocial therapy (IPT) and psychopharmacotherapy are used. Besides them, other techniques are currently used: problem-solving training, cognitive-emotional training, social skills training, psycho-educational training, early warning signs training, peer education group and self-help group.

The authors decided to use, as a criteria of evaluation, the difference between the number of young people (16-30 years old) who were referred to specialty and general mental health care ambulatory services in the year before SMILE establishment (from November 2004 to November 2005), to the rate registered on its first year of SMILE operation (from November 2005 to November 2006). The result shows that the number of referrals grew by 64% compared with the previous year. The most frequent symptoms upon admission were anxiety, irritability, depressed mood, sleep disturbances, social withdrawal, suspiciousness and deterioration in role functioning. The results highlighted also the positive effect of a multidisciplinary approach, for an effective interventional strategy aimed to optimal symptom management and treatment.

# **Radio projects**

In the last few years some Mental Health Services, with the collaboration of Associations, radios or Universities, utilsed the radio as tool of diffusion of information. Different web radio stations, conducted by services users and speakers, in fact were created with the main aim to support the rehabilitation of people with mental illness, reconnecting them with life.

These projects aim to give service users an occasion to explain, to tell freely their story, their emotions, their thoughts, to discuss issues of mental illness and to interact with listeners. With these intentions different projects were born, including: "Fuori Onda Radio" "Radio Tab" (www.radiotab.it), "Radio Charlie" (www.radiofuorionda.net/), (www.unitedradio.it/node/6452) with a particular focus on adolescents, "Psicoradio" (www.psicoradio.it/) and "Radio 180, the voice of those who hears the voices" (www.rete180.it/).

# **Evaluation of stigma**

During 2004 the Ministry of Health and Education promoted a communication programme about mental health. It gave specific attention to stigma related to schizophrenia and severe mental diseases. In this context they promoted two different surveys. The first measured knowledge and attitudes toward mental health problems in a sample of 1900 high school students by using a questionnaire. The second one collated questionnaires filled out from headmasters, they analysed the issue from their opinions and from the teachers views, and the level of presence of the theme in teaching programmes and school plans. They organised a national seminary "Mental health and social stigma" for teaching staff, experts and staff involved in prevention of mental health. The website encompass the main results of surveys, about mental health problems and general information symptoms and links (www.campagnastigma.it/campagnastigma/index.htm). Castiello (2007) carried out a comparative study on a sample of 445 secondary school students about their beliefs on psychosocial consequences of schizophrenia and depression. The two groups were asked to read a case-vignette describing a case of schizophrenia or depression and to fill out the Questionnaire on the opinions about mental illness - general population's version. The results revealed that 35% of students in the "schizophrenia" group compared with 85% in the "depression" group attributed a correct diagnosis to the case-vignette. 19% vs 39% believed that people can recover from these mental health problems. 94% vs 90% believed that mentally ill patients were unpredictable and socially dangerous. 60% vs 45% believed that they should not have children, and that there could be problems in their son's development. Students who reported TV stories on people with mental illness were more frequently convinced about their unpredictability and social dangerousness. The authors outlined the need to plan educational campaigns for students and to alert media professionals about the impact that the way they present crimes committed by people experiencing mental illness, has on community attitudes.

Morselli PL (2002) reported a survey on social adjustment. It recruited subjects chosen randomly from among the members of the Fondazione Idea (Institute for the research and the prevention of depression and anxiety - no profit advocacy organization) using the Italian version of Social adaptation self-administration scale (SASS). They collated 2320 questionnaires (1304 filled by patients, 1016 by relatives/friends). A total of 94% of the patients stated they suffer or to have suffered from mood disorders, with 4% reporting major depression, 22% reporting bipolar disorders, 6% dysthymia. The majority of the patients groups considered themselves to be "stabilised". 20% of the respondents considered themselves to be stigmatised and rejected by others. This findings confirmed the presence of persisting lingering effects on social adjustment in depressed patients, even for a considerable time after their last acute clinical episode and indicated the difficulties with integration.

At local level we found two specific surveys with the topic of depression. The Association for Research on Depression of Torino city (Piemonte Region) conduced different studies about depression. In these studies the theme of prejudice emerged:

The first study concerns the relationship between the depressed patient and the chemist ("Il paziente depresso ed il farmacista"): The association administered a multi-choice questionnaire on opinions about depressed and anxious patients to a sample of 399 chemists. The investigated areas concerned: the fear of the patient at the moment of purchasing drugs, the reassurance that often they ask from chemist and their knowledge of mental illnesses. This study aims to improve patients' awareness about their needs and to overcome the prejudices still present. The results showed that misinformation, based mainly on prejudice, constitutes a barrier

between people with mental illness and those who take care of them. The misinformation concerns the nature of the illness, the role of the specialist and the drugs. Moreover this element involves often also the caregivers and this causes a vicious circle that brings an increase of suffering.

The same Association conduced another study about depressed patients and general practitioners ("Il paziente depresso e il medico di famiglia"): This research started in June 2006 and ended in June 2007, and consisted of the administration of a multiple choice questionnaire, created by the Association, to general practitioners of Torino. They are often the first professionals contacted by depressed people. The questionnaire comprised 20 items. 532 questionnaires were analysed. The main aim was to underline the most frequent attitudes towards their illness, drugs and their assumptions. The results, in line with those of previous research, confirm a misinformation based mainly on prejudice, that determines a great interference on therapy compliance. The prejudices concern the nature of the illness; often depression isn't recognised as such. Commonly people think that it has to be overcome with willpower. For this reason, frequently depression is not considered like an illness, with the consequence that the medical competence isn't recognised. Other prejudices concern the specialist (psychiatrist) and drugs.

## Information campaigns

In recent years, informative campaigns, in Italy, are promoted by the European Depression Association (EDA). Every year it promotes the "European Depression Day". It is an informative day about depression and other mood disorders. This day is addressed to the general population and different meetings and congresses are developed in different Italian regions. The European Depression Association aims to improve the quality of life of people suffering from depression. They stimulate the social inclusion, the fight against stigma and discrimination associated with depression. For these reasons the Association promotes different events and activities (as European Depression Day and Self Help Groups) to make people aware and support their needs.

In 2009, 35 events (conferences, meetings...) were developed in all Italian regions.

In 2006, in Ferrara, a project called "Don't call it the dark illness anymore: Knowing more to prevent it, to avoid it, not to have more fear to overcome it" was born. It is an information campaign about female depression. This programme aims to give precise information, overcome the shame of seeking help and give useful resources to face depression. They produced a brochure on depression, with practical advice about how to face it and disseminated these at local level and by web.

A similar project is called "Depressive Diseases" an informative and online campaign promoted by ARETE Association. This is characterised by a brochure (available on web) with information about depression: what depression is, how it can occur, the different mood disorders, main causes of depression, depression treatments, how other people can help a depressed person and where to find help.

### Communications and media

In a lot of studies the importance of the role of mass media emerges (Warner 2005; Warner 2008) which shapes public knowledge.

One study "Malattia mentale e mass-media: un' indagine su un quotidiano locale" (Mental illness and mass media: a survey based on a local journal) was by Magli et al (2004)

This tried to characterise the type of information concerning mental illness diffused from the local daily paper "Giornale di Brescia" in the year 2001. From all articles published by "Giornale di Brescia", 344 articles were considered. They reported the following key words: "madness", "psychosis", "depression", "psychiatry", "mental illness", "psychiatric care".

The qualitative analysis showed substantially a negative image of mental illness. It was often linked to crime news and the words "crazy", "mad" and "madness". It is also important to notice the presence of some sensitivity towards this problem, provided by scientific papers. They showed, in fact, a particular interest and attention to the theme (publications of recent studies, attention in the using of scientific notions). In conclusion the results of the analysis showed as mental illness was negatively connoted and the prejudice against the mentally ill, seemed to remain still, for the study's period, a consistent trend.

Carpiniello et al. (2007) in Immagine sociale del disturbo mentale e ruolo della stampa (Social image of mental disorders and role of the press)

This project involved a survey about the language used by regional and national newspapers. The authors proposed a comparison among two national newspaper (II "Corriere della Sera" and "La Repubblica") and two local newspapers ("L'Unione Sarda" and "La Nuova Sardegna"). All articles published over a six month period (1/10/2002-31/3/2003) relating to homicides, suicides or attempted suicides, and acts of violence were evaluated.

Each article was examined according to the following parameters: whether or not the deed had been attributed to a mentally ill person (actions were deemed to have been attributed to the mentally ill only when clearly stated or strongly alluded to by the author of the article); paging of the article (front or inner pages); type size of the title; presence of accompanying photos; word count - both of titles and texts. The use of stigmatising language to describe the facts was also assessed. 2279 articles were examined by the authors (54% regarded homicides, 8.2% suicides and attempted suicides, 2.1% homicides/suicides; the remaining 35.8% regarded other acts of violence).

The results of quantitative analysis showed that about 40% of all deeds reported were attributed to a mentally ill person; it is however worth mentioning that in several cases this attribution was not based upon reliable data concerning the alleged mental insanity of the perpetrator of the act of violence. This finding supported the conviction that media reports are often based upon personal judgments and stereotypes of the journalists rather than on evidence based knowledge. The authors found that the number of words used in the headings and the placement of the articles were similar, irrespective of whether or not the facts had been attributed to a mentally ill person, although a significantly higher number of words (approx. 20%) were used in the text whenever the deed reported was attributed to a person suffering from mental illness. It was moreover more likely that photos accompanied these articles. At the same time, the result tended to be contrasting. A factor to note, in fact, was represented by the limited use of a stereotypic language in describing persons and deeds (i.e. terms such as mad/madness, insane/insanity, crazy/craziness, maniac/maniacality, monster/monstrosity etc...), thereby supporting the overall impression that the approach to mental illness issues was actually less stigmatising than expected. Finally, media reports mirror the enduring stereotype

of "diversity" of the mentally ill, although the role and the extent of the latter stereotype in contributing to the stigma towards mentally ill people is far from being defined.

Community and health professionals' attitude toward Depression: a pilot study in nine EAAD countries (Scheerder g et al., 2010).

Italy participated to a European project promoted by European Alliance Against Depression (EAAD), a non-profit organization, that intents promote public health and education, proposing community-based intervention programmes, with a particular interest on depression. In this case EAAD proposed a survey involving 9 different countries (Belgium, Estonia, France, Germany, Hungary, Ireland, Italy, Scotland, Slovenia) to investigate attitudes of Community Facilitators (pharmacists, policemen, teachers and clergy) toward depression. They cover an important role in the community and often they represent a resource for people experiencing depression and other mental health problems. In this study the main aim was to investigate Community Facilitators' attitudes toward depression and compare them with those of (mental) health professionals and nurses.

Data were collected in nine EAAD partner countries from 2003 to 2007. The results showed as, in comparison to mental health professionals and doctors, Community Facilitators and nurses had less favorable attitudes toward patients with depression and toward antidepressants, and more limited knowledge of depression symptoms. They may have a different understanding of depression, not recognising it as a mental illness but rather as a 'crisis' or a fluctuation of mood under the individual's control, something that has also been observed in the general population. Another important difference regarded the attitude towards antidepressants: the Community Facilitators and nurses seemed to have a more negative attitude than the mental health professionals. In fact, only about half of them believed in the efficacy of antidepressants and saw them as an advisable treatment option. An encouraging finding is that most Community Facilitators and nurses supported contacting a professional for depression, such as a general practitioners or psychotherapists. Gender and age differences seemed to be present: an older age, in fact, seemed to be related to a more negative attitude toward patients with depression and a more limited knowledge of pathology, while male gender seemed to have a better knowledge of depression and agreed more with contacting a professional.

## CONCLUSIONS

In Italy few studies have been conducted about stigma, especially about stigma related to depression. The fight against stigma represents a complex theme that needs to be investigated on different levels. Amongst the studies presented in this review, few involve surveys and projects with an efficacy evaluation. It would be important to use evidence-based approaches, coming from rigorous studies and research, as foundation of new programmes.

An important aspect concerns the general population. If, on the one hand, it is important educate people, on the other hand it must be essential to train those who are most in contact with people who have mental illnesses (pharmacists, clergy, police etc.).

The National Health Plan 2006-2008 suggested the need to improve anti-stigma programmes on mental illnesses, but until now our report points out the lack of national guidelines about best practices to accomplish this purpose. In December 2009 the Ministry of Equal Opportunity promoted a congress "Depression and anxiety disorders: ask for help, don't be afraid", which outlined the depression features, the stigma and costs related to depression and anxiety. There

were testimonies of famous people who have overcome depression successfully and the role of volunteers and mutual-self-help groups was reported. The main purpose of the initiative was to overcome shame and facilitate help-seeking for people who experience depression.

Communication represents an important tool of diffusion of information about depression, drugs, care. Utilising the different mass media properly can offer opportunities to disseminate accurate information and creates new possibilities for cooperation and exchange.

In the specific issue of depression we find few local or regional programmes. However, one promising element is the use of a multi-level approach as suggested by Hogan (2002) and Link (2001), involving a network of several health professionals, facilitators, caregivers and groups target of the community. The EAAD project in Veneto region has been a pilot intervention with these features, further studies about its impact in more extensive areas are needed. Another project in Rovigo city is in progress and involves adolescence, elderly and involves several stakeholders' cooperation.

The schools surveys revealed the need to disseminate information about the topic to young people. Some interventions encompassed psycho-educative approaches and social skills training in the schools, those programmes seem to reduce the rate of prejudice from students and to improve the knowledge about mental illnesses. Another important aim is to make it easier for young people to approach early intervention services, SMILE project is an example of a multidisciplinary approach that is fitting to the adolescent culture.

In terms of gaps, we did not find any specific intervention in work places about Italian employers attitudes towards depression or mental illness. Regarding elderly people we find only the evaluation of one support intervention by using a phone-center, that seems to have had an appreciable impact in suicide prevention. De Leo (1995) suggests developing programmes for elderly people with depression can make feel them a sense of "connectedness".

A lot of studies (Watson, 2007) highlight the importance of involving people with mental illness in the projects (as organizers, witnesses etc.). Different projects (web radios, programmes with schools...) used this element as an important characteristic and resource of the programme. The contact with a person with mental illness can represent a way of knowing new information, and can contribute to reduce stigma associated with mental illness.

In conclusion we consider the importance of a multi-level and multifaceted approach for promoting changing of beliefs in several target groups, using different strategies to reach the different components of the process of discrimination. Programmes to reduce stigma with regard to depression need more evaluations about effectiveness and to be implemented and disseminated. Limited resources limit the implementation of these projects in extended area, however it is important that studies of efficacy of the interventions are carried out in order to promote best practice in overcoming stigma and to deploy resources for meeting the real needs of the people who experience mental illnesses.

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### A LITERATURE REVIEW ON MENTAL ILLNESS STIGMA RESEARCH IN THE NETHERLANDS

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### **INTRODUCTION**

This report is part of Work Package 4 ('Best practice anti-stigma') of the ASPEN (Anti-Stigma Programme - European Network) project. We conducted a literature review on stigma related to mental illness, specifically to depression. The review includes an overview of all peer review publications and reports on this subject in the Netherlands. It covers the known patterns of stigma and discrimination associated with mental health, and depression in particular. We also searched for articles on evidence based interventions but they were absent. Therefore we have added a separate summary of interventions to the report. This attached summary is not part of the (scientific) literature search.

### METHOD

To review the Dutch work on stigma related to depression, a literature study was done. References were collected through a search in Medline, PsycINFO, CINAHL and Psychology and Behavioral Sciences Collection. Different keywords and different combinations have been used to ensure that all relevant articles were found.

For the first part of the review I performed the following search:

Netherlands OR Dutch

AND (stigma\* OR attitudes OR prejudice OR stereotyp\* OR discrimina\*) AND (mental\* OR psychiatric\* OR depress\* OR Dysthymi\* OR Adjustment Disorder OR Mood Disorder OR Affective Disorder OR Affective Symptoms)

Only 'peer reviewed' articles were searched. This resulted in 1289 articles.

To look for studies describing anti-stigma interventions in the Netherlands, we used the following combination of search terms:

Netherlands OR Dutch

AND (stigma\* OR attitudes OR prejudice OR stereotyp\* OR discrimina\*)

AND (mental\* OR psychiatric\* OR depress\* OR Dysthymi\* OR Adjustment Disorder OR Mood Disorder OR Affective Disorder OR Affective Symptoms)

AND (Interven\* OR health education OR mass media OR communication OR multi media OR multimedia OR mass communication OR audiovisual equipment OR patient information OR visual information OR radio OR television OR leaflet\* OR posters\* OR pamphlet\* OR print media OR printed media OR skit\* OR folk media OR broadcast\* OR film\* OR telecommunication\*).

This search resulted in 186 articles.

The next step was to assess whether an article was really about stigma and mental illness, by looking at the title. All articles about non-relevant subjects were excluded. Relevant titles were written down systematically. Of all the results of the two searches, only 44 articles appeared to be relevant.

The next strategy was to search in Dutch journals/magazines that are not included in the databases. Furthermore we searched the database of the Trimbos Institute (Netherlands Institute of Mental Health and Addiction). We also performed a more intuitive search on Dutch websites of mental health institutes or experts. Relevant articles that we missed in the initial search were included. After that we looked at the reference lists of the articles that were found in the initial search and included relevant ones. This broader (snowball) search resulted in 7 additional articles.

So, in total 51 articles were found that have something to do with stigma in the Netherlands.

All abstracts were examined to find out the exact subject of the article and to assess whether it still belonged in the selection of relevant articles. All general articles (experimental/theoretical) on stigma or stereotyping but not related to mental illness were excluded. All Dutch reviews of English literature were excluded. Articles in which stigma is not one of the research subjects but just a minor and not well researched subtopic were excluded. 3 Dutch articles that contained descriptions instead of research results were excluded from this part but used in the separate summary of interventions in the end of the report.

Full texts were obtained from the 23 articles that were remaining. These articles are about experiences with stigma and discrimination, about the attitudes of the general population and some about the effects of stigma. No relevant articles were found on anti-stigma interventions.

After collecting all relevant articles, data was extracted and summarized. This led to a description of the studies, classified by subject, including aim, methods and main results. A summary of main patterns and results is given and interpretations are formulated.

# **FINDINGS**

23 articles on 18 different studies were found dealing with patterns of stigmatization and discrimination in the Netherlands. Only one study specifically focused on depression, so the description given will include all research on stigma and mental illness in general. The number of participants in the studies differed greatly and ranged from 17 to 2372, on account of different research methods. The research methods used were self-report questionnaires (11 studies), fully structured interviews (3 studies), qualitative in-depth interview (1 study), semi-structured interview (1 study), vignette method (1 study) or content analysis (1 study). Most studies can be classified in one of the two following categories: 1) patient / family studies, in which experiences of patients and family members with stigma are examined, and 2) general/sub population studies, in which stigmatizing attitudes in society are examined. The remaining study is a content analysis of television images. For every study, aim, method and results are described.

# Patient and family studies: experiences with stigma and discrimination

1. EseMed / World Mental Health Survey

Alonso et al (2008) and Alonso et al (2009)

Aim: To assess the prevalence of perceived stigma among persons with mental disorders and chronic physical conditions in an international study.

Method: The European Study of Epidemiology of Mental Disorders (ESEMeD) is a representative population survey conducted in 6 European countries, including the Netherlands. The survey in the Netherlands included n=2372 respondents (non-institutionalized, with various mental health problems). While this study primarily investigated epidemiology of mental disorders, 2 questions about perceived stigma were also assessed in people with a mental disorder experiencing significant disability. These questions referred to experienced embarrassment and discrimination. The data from the ESEMeD study are also part of the World Mental Health Surveys.

Results: Among the 815 participants with a 12-month mental disorder and significant disability, 14.8% had perceived stigma. This rate is slightly higher than the mean of other countries in the study. Stigma in the Dutch sample was significantly associated with low education, being married/living with someone and being unemployed. Perceived stigma was associated with decreased quality of life (SF-12 PCS score -4.65; p<0.05), higher work and role limitation and higher social limitation.

2. International Study on Discrimination and Stigma Outcomes (INDIGO) Plooy and Weeghel (2009) and Thornicroft et al (2009)

Aim: To do a systematic international assessment of anticipated and experienced discrimination based on the reports of people with schizophrenia.

Method: A structured interview was held with patients, using the Discrimination and Stigma Scale (DISC), which assessed experiences of being treated (dis)advantageously for several life domains. In the Netherlands, 50 patients were interviewed in both residential and outpatient settings.

Results: In comparison to the other countries in the study, patients in the Netherlands had an average level of stigma and discrimination experiences. For the majority of subjects, respondents stated that they experience "no difference in treatment". This applies to use of public transport, paying for medical care, somatic care, dental care, voting, payment requests, open bank accounts and insurance policies. In terms of perceived discrimination these are the most neutral subjects. Positive discrimination is relatively rare: in most subjects, less than 10% of respondents perceived benefit. Exceptions are: the impact of the diagnosis (50%), housing (46%), police (28%) and dental care (22%). In these areas the number of respondents who experienced the benefits exceeds the disadvantages encountered. Negative experiences are mostly observed in relationships with family (54%) and in personal privacy (48%). Furthermore negative experiences are apparent in the areas of security (46%), getting and keeping friends (44%), influence on the diagnosis of schizophrenia (40%) and relationships with neighbours (36%). The majority of the respondents feel to a greater or lesser degree limited in applying for jobs or starting a training (68%), in entering a close personal relationship (56%) or in something else they consider important (72%), because of their psychiatric diagnosis. Respondents often mentioned also the hampering influence of the psychological problem itself. Furthermore, 66% of respondents felt somewhat or highly forced to keep the psychiatric diagnosis a secret.

3. Dissertation study on perceived and expected stigma (by patients and family members)

Study A, Van 't Veer et al (a):

Aim: To examine mental health consumers perception of the amount of stigmatization they perceive, their emotional response to stigma and how they attribute the causes thereof and how the latter were related.

Methods: A Dutch sample of mental health consumers (n=205) from the programme for longterm psychiatric care and rehabilitation were examined with Link's Devaluation-Discrimination Beliefs Scale by means of a structured interview. This measures the believed probability of rejection of mental patients by 'most people'. A series of follow-up items focused on patients' emotional reactions and causal attribution.

Results: Most patients expressed high expectations of stigma. Generally, the group that expresses these strong beliefs also expresses a negative emotional impact and predominantly attributes stigmatization 'externally' (i.e. caused by ignorance and prejudice of others). Internal attribution (i.e. stigma caused by one's own traits and behaviour) is associated with decreased emotional response to stigma. Patients regard psychiatric stigma as an evident problem.

Study B, Van't Veer et al (b):

Aim: To examine to what extent patients believe that mentally ill persons encounter stigmatization and to compare their beliefs with those of non-ill relatives of patients.

Methods: Patients from the programme for long-term psychiatric care and rehabilitation (n=205) and non-ill relatives of patients (n=72) are examined with Link's Devaluation-Discrimination Beliefs Scale by means of a structured interview. This measures the believed probability of rejection of mental patients by 'most people'

Results: On the most items of the scale a majority of the patients expressed high expectations of stigma. Non-ill relatives showed a similar scoring pattern. In general, non-ill relatives had higher stigma scores than the patients. It is concluded that both patients and non-ill relatives see psychiatric stigma as an evident problem. Outcomes suggest that patients' views about stigmatization are neither unreliable nor exaggerated.

Study C, Van't Veer et al (c):

Aim: To examine whether mental illness leads to family stigma.

Methods: Among 72 family members of psychiatric patients levels of family stigma were examined, with measures referring to 'perceived avoidance', or to 'efforts of concealment' by means of a structured interview. More general feelings of burden were monitored by measuring the extent to which the illness of a relative is believed to play a central part in the family respondent's life, generate worry or generate feelings of responsibility.

Results: Results revealed that family members were rather burdened with the relative's illness and recognized stigma's impeding effects for patients. However, most family members perceived no apparent avoidance from their social environment, nor did they attempt to conceal their relative's illness. Family stigma was not associated with socio-demographic variables, relative's type of illness, or family members' ideas about stigmatization of patients.

4. Studies on perceived and expected stigma, and the effect of residence

Study A, Kaiser (1993):

Aim: To examine whether decentralization decreases stigma expectations.

Methods: The sample consisted of 208 patients with various diagnoses, of whom 184 were patients at the socio-therapeutic centre at the site of a psychiatric hospital, and 24 patients in locations 15 kilometres away from the hospital. Two structured questionnaires were used. The first list was given to nurses and asked about the degree of social integration of patients. A second questionnaire was for patients and their motivation to rehabilitate. In the second questionnaire patients were asked for expected devaluing attitudes of family and of other people in the bus, shop on the street. train, or Results: A slight majority of patients (61%) expect that both the family and others do not regard them to be inferior. The remaining 39% expect that at least one of these groups regard them to be inferior. The expectation of patients regarding the family is predominantly positive: 76% expect their family to help them. Although 39% of the patients expected some form of rejection because they are hospitalised, the total number of people that both expected rejection by people outside the hospital and expected themselves to have problems with coping with that, is only 15% (n=31). The fear of rejection is hardly a significant issue for patients. The location of housing (decentralized or centralized in the area of the APZ) has no effect on the expectation of rejection by family or people from the area.

Study B, Depla et al (2005)

Aim: To investigate whether stigmatization of older adults with mental disorder is associated with the type of residential institution they live in or the type of disorder they suffer and to assess the role of stigma experiences in their quality of life.

Methods: A cross-sectional study was carried out on 131 older adults with severe mental illness, recruited in 18 elder care homes operating supported living programmes and in eight psychiatric hospitals throughout the Netherlands. Stigmatisation was assessed with an 11-item questionnaire (which is an adjusted version of the Consumer Experiences of Stigma Questionnaire, CESQ) on stigma experiences associated with mental illness. Quality of life was assessed with the Manchester Short Assessment of Quality of Life (MANSA). To better ascertain the role of stigma, the relationship of social participation to quality of life was also assessed in comparison.

Results: 57% of the respondents had experienced stigmatisation. No association emerged between residential type or disorder type and the extent of stigma experiences. Stigmatisation did show a negative association with quality of life, a connection stronger than that between social participation and quality of life.

5. Studies on the impact of stigma on the self

Study A, Vinken et al (2005)

Aim: To investigate the impact of perceived stigmatization on self-esteem of psychiatric clients and to examine if social comparison moderates this relationship.

Methods: Consumer Experiences of Stigma Questionnaire (CESQ), Rosenberg self-esteem scale, measures of upward and downward social comparison, and general background questions were completed by 139 psychiatric clients with various (severe) diagnoses.

Results: A trend toward a main effect of perceived stigmatization on self-esteem was found. Downward social comparison had a direct positive impact on self-esteem, whereas upward social comparison had a negative impact. Downward social comparison did moderate the relationship between perceived stigmatization on self-esteem, whereas upward social comparison did not.

Study B, Staring et al (2009)

Aim: To investigate whether the negative associations of good insight with mood, self-esteem and quality of life are moderated by perceived stigma.

Method: Respondents were 114 outpatients with schizophrenia spectrum disorders. The following measures were performed by means of a self-report questionnaire: insight (self-report-8-item Insight Scale), stigma (Link's 12-item Perceived Devaluation and Discrimination Scale), quality of life (self-report Euro-QOL Scale), self-esteem (20-item Self-Esteem Rating Scale-Short Form), and depressed mood (depressed mood item of the Positive and Negative Syndrome Scale). Analyses of Variance (ANOVA) and Structural Equation Modelling (SEM) were used to test moderation.

Results: Good insight was associated with high service engagement and high compliance. Also, good insight was associated with depressed mood, low quality of life, and negative self-esteem. This association was strong when stigma was high and weak when stigma was low. SEM showed that the constrained model performed significantly worse than the unconstrained model, in which detrimental associations of insight were free to vary across stigma groups (chi (2)=19.082; df=3; p<.001).

6. Study on the impact of stigma on accepting diagnosis Wittkampf et al (2008)

Aim: To better understand the views of patients who screened positive in a screening programme for depression.

Methods: A qualitative study with semi-structured in-depth interviews with 17 patients of general practices in the Netherlands. Nine adult female patients, all experiencing major depressive disorder, were identified through a screening programme for depression performed within 11 Dutch general practices. The aim of the interview was to provide an in-depth viewpoint based upon personal experience, centred around the topic of the recent diagnosis of depressive disorder. The transcripts were independently analysed by two researchers using MAXqda2.

Results: Fifteen of the patients recognized the depressive symptoms but nine of them did not accept the diagnosis. The first explanation for resistance to the diagnosis of depression is fear of stigmatization and scepticism about the usefulness of labelling. Secondly, patients experienced their depressive symptoms as a normal and transitory reaction to adversity. Thirdly, patients had doubts about the necessity and effectiveness of treatment.

7. Study on stigma and disclosure. Bos et al (2009)

Aim: To examine the consequences of coming out of the closet.

Methods: The present study investigated disclosure patterns amongst 500 mental health consumers of a Dutch mental health institute with outpatient services and examined the relationships between disclosure, perceived stigmatization (measured with Consumer

Experience of Stigma Questionnaire), perceived social support (measured with Social Support List –Interactions), and self-esteem (measured with Rosenberg's Self-Esteem Scale). Results: Selective disclosure optimizes social support and limits stigmatization. Perceived stigmatization has a detrimental impact on self-esteem, especially for those who are relatively open about their mental disorder.

# General/sub population studies: Stigmatising attitudes in society

1. Studies on attitudes of the public towards psychiatric patients Study A, Van't Veer et al (2006)

Aim: To examine a sample of the Dutch public's willingness to interact with patients with mental illness.

Methods: A questionnaire survey was employed amongst two sub-samples of the Dutch public (n = 812, response 33%). A number of determinants were examined concerning their influence on levels of social distance: demographical characteristics of the public, their beliefs about stereotypes of mental patients, their beliefs about causes of mental problems, their familiarity with mental illness.

Results: Attributing psychiatric problems to structural causes (i.e. causes beyond patients' control and responsibility, such as genetic transmission) is associated with less social distance. Conversely, attribution to individual factors (e.g. drug abuse) related to more distant attitudes. Stereotypical beliefs about mental patients (e.g. untrustworthiness, aggressiveness, causing disturbances) relate to more social distance from mental patients.

## Study B, Weerden-Dijkstra (1972)

Aim: To examine the attitudes of the general public towards psychiatric patients. Methods: Analysis of questionnaires and rating scales completed by 418 'normal' adults. In the investigation 'appreciation' was measured by the method of the semantic differential, the 'readiness to establish contact' with a factor-analytical scale, also 'prognosis' and 'danger', with the aid of a score, capable of giving factual information on mental illness.

Results: Results indicate that attitudes towards the mentally ill were very ambiguous, and were connected with the perception of what constitutes mental illness. The belief that a mentally ill person will recover completely and confidence that they constitute no threat to other people were the main factors exerting a positive influence on readiness to establish contact with a discharged mental patient. There was no direct relationship, however, between favourable attitude and real contact with people with mental illness.

# Study C, Kwekkeboom (2000)

Aim: To examine the prevailing norms and values in society about people with long-term psychiatric problems.

Methods: Telephone interviews with 500 Dutch people were conducted. A comparison was made with data from surveys of ten- and twenty years before (1979; 1987).

Results: In 1999 83% agree with the policy measures to integrate people with psychiatric problems in society. However, 60% were unsure whether reintegration is actually possible for people that have been treated in outpatient Mental Health Care. Only 30% think it is possible for people that have been admitted in a psychiatric hospital to reintegrate. 80% would accept a

psychiatric patient to be their neighbour or colleague. This percentage is comparable to the data of ten and twenty years before. Between 1979 and 1989 the percentage of people that are willing to include someone in their personal life increased, but between 1989 and 1999 this percentage decreased. This is particularly true for 'accepting a psychiatric patient to be the teacher of your child' (1979: 51%, 1989:66%, 1999: 56%) and 'accepting a psychiatric patient to be a nanny' (1979: 33%, 1989: 46%, 1999: 31%).

2. Studies on attitudes in neighbourhoods with, and without, psychiatric facilities.

## Study A, Boon et al (2004)

Aim: To examine the cognitions and emotions that are associated with psychiatric patients and how and to what extent these cognitions and emotions contribute to social rejection. Methods: A representative sample was taken among residents of two neighbourhoods. 267 completed surveys were returned (30%), 240 were suitable for use in the research. The questionnaire included questions about social rejection, emotions towards psychiatric patients, cognitions regarding psychiatric patients and familiarity with psychiatric patients. Results: Nearly 43% of the respondents (n = 105) think psychiatric patients are unpredictable and 50% (N = 119) of the respondents had the idea that psychiatric patients can be aggressive. However, only 3% (n = 8) regards psychiatric patients as being dangerous. 14% (n = 34) agree with the idea that psychiatric patients cause inconvenience. Approximately one third (N = 80)said psychiatric patients are friendly. 34% (n = 82) of the respondents believed that psychiatric patients struggle. 56% (N = 135) believed that patients themselves can be held responsible for their illness. About half of respondents say they feel annoyed when they see or speak to psychiatric patients (51%, n = 113). Slightly less than half (45%, n = 100) were afraid of psychiatric patients, while 55% (n = 122) feel insecure among patients. Sympathy for psychiatric patients is apparent in 41% (n = 93). About half (52%, n = 118) feel involved. 51% (n = 116) feels sorry for psychiatric patients. 59% (n = 127) say they feel touched and 41% (n = 88) feel admiration when they see or speak to a psychiatric patient. About half of respondents (52%, n = 124) accept psychiatric patients as a neighbour. But 58% (n = 138) wouldn't accept a psychiatric patient as a teacher and 65% (n = 155) as a nanny for their children. A psychiatric patient as colleague is accepted by 53% (n = 125) of the respondents. Nearly half of respondents (48%, n = 112) are positively disposed towards the idea that psychiatric patients live in the district. But in the district in which no psychiatric facilities were present, people have more feelings of fear and insecurity. People living in a district with facilities think more positively about psychiatric patients.

# Study B, Van't Veer et al (2005)

Aim: To measure the degree to which the lay public stigmatises psychiatric patients and to examine the extent to which public stigmatisation is associated with the de-concentration of mental health services.

Methods: A sample was taken from the Dutch general population (n = 445; response 30%) and from people living near mental health facilities (n = 367; response 34%). Stigmatisation in terms of the desire for social distance (measured with Whatley's social distance scale) and the attribution of several stereotypical characteristics were measured by means of a self-report questionnaire.

Results: The public kept its distance and remained basically reserved. The psychiatric patient is mainly stereotyped as being aggressive. In attributing stereotypical characteristics the public differentiates clearly between specific illnesses (schizophrenia, depression, drug addiction, and dementia). No differences were found in the degree of stigmatisation attributed to the 'mentally-ill' by the general public and by the sample of people living close to mental health facilities. Results indicate that people with personal experience of psychiatry are less inclined to stigmatise.

## Study C, Heesbeen et al (2006)

Aim: To investigate the cognitive and emotional factors that influence stigmatising reactions from local residents regarding psychiatric patients in their home environment and to investigate how proximity of psychiatric facilities influences the extent to which residents reject or accept people with psychiatric diagnoses.

Method: In two neighborhoods (a district with- and without - psychiatric facilities) a written survey was plotted. On the basis of zip codes, a sample of 300 addresses were drawn. In total 201 questionnaires returned (108 from the area without facilities, 93 from the area with facilities). The questionnaire was based on the conceptual model of Dijker & Koomen (1996), which includes emotions and cognitions that are evoked when getting into contact with deviance. In this study this model is applied to the situation of psychiatric problems. The factors 'familiarity' and 'presence of mental health facilities' are included.

Results: 57% of the total sample associated the label 'mental disorder' with severe mental disorders like psychosis and bipolar disorder, and 20% associated it with anxiety, depression or phobias, and 20% associated it with both. Only 2% didn't know what 'mental disorder' means. The most common cognitions respondents have about psychiatric patients are: they are suffering (75%), they have a psychological burden (67%), or they are unpredictable (45%). Less common cognitions are: patients are responsible for their situation (11%), they are dangerous (14%), they create nuisance (21%). The most common emotion for psychiatric patients is pity. 55% agreed that it is a good thing that psychiatric patients live among 'normal' people. 28% disagreed. In the neighborhood in which psychiatric facilities were present, respondents had significantly more negative cognitions (including higher levels of believed dangerousness). District seems to be a better predictor for negative cognitions than any other socio-demographic variable.

3. Study on attitudes of nursing students. Hoekstra et al (2007) and Hoekstra et al (2010)

Aim: To examine how first-year nursing students' perceptions of psychiatric patients and mental health care influence their choice of specialization in mental health care and future working in this sector.

Methods: A descriptive qualitative study design with semi-structured interviews was performed. Respondents were selected through purposive sampling among all first-year bachelor students attending a Dutch school of nursing.

Results: First-year nursing students have stereotypes, mostly negative perceptions of psychiatric patients (aggressive and incalculable) and mental health care. These perceptions strongly influence their future professional choices. The respondents provided various reasons for their decision not to major in mental health care, one of these being that the school did too little to

counsel and inform them about mental health issues and a career in mental health care. As a result, their unrealistic perceptions prevailed.

4. Study of barriers to rehabilitation of depressed workers. Graaff-Wijnberg et al (2006)

Aim: To investigate the effect of personal responsibility for the onset of depressive complaints, seriousness of depressive complaints, and openness about depressive complaints on cognitive and emotional reactions towards employees with depression.

Methods: In this study the vignette method was used. Health service workers (N = 320) were administered a scenario about a colleague who returned to work after absence due to depressive complaints. Personal responsibility (high vs. low), seriousness of complaints (high vs. low), and openness (open vs. closed) were manipulated. After reading the scenario, participants were requested to evaluate personal qualities of this colleague (the target person) and to rate their emotional reactions towards that person.

Results: Participants rated the target person more positively in the high versus the low personal responsibility condition. Participants reported more fear when the target person had serious versus less serious complaints and also attributed more negative personal attributes towards the person in the serious condition compared to the less serious complaints condition. Finally, if the target person was open about his depressive complaints, participants reported stronger feelings of fear, pity and anger, and attributed more positive qualities to him, compared to being less open about his condition.

5. Media; study on the representations of psychiatric patients in television images. Boumans and Oderwald (2009)

Aim: To investigate the development of the (moral) representation of psychiatric patients in non-fictional Dutch television.

Method: Audiovisual material from the Dutch Institute of Image and Sound (which collects audiovisual material from the public broadcasters) was studied. A sample of 30 documentaries were watched and analysed and an analysis was made of the descriptions of 312 topicality programs. The method of inter-subjectivity was applied.

Results: In the 1960s the situation of psychiatric patients is re-enacted and staged in television programs. Patients are portrayed as being piteous and helpless. In the 1970s real patients are filmed, but the representation devoted to victimhood and the revolt against the repressive psychiatry still gives little to no nuance. Only in the 1990s does this really change. Documentaries leave the one-dimensional representations behind and begin to show a much more nuanced image of patients and psychiatric care. However, the topicality programs remain broadcasting one-dimensional representations. In these programs there are only a few images of patients represented: patients are portrayed as being piteous, or repressed, or dangerous. Those are old stereotype images, but apparently still clearly present in the Dutch culture.

### **DISCUSSION / CONCLUSIONS**

The purpose of this review was to describe patterns of stigma and discrimination associated with mental health (depression in particular) and evidence based interventions in the Netherlands. In order to do so all literature on Dutch studies investigating stigma and discrimination and mental health, were collected. Because the search didn't lead to articles on

interventions, we were forced to limit the review to articles on patterns of stigma. 21 articles on 15 studies were included. It is very hard to draw systematic conclusions on common findings because of the diversity of the studies. Nevertheless it is useful to describe overall findings and implications here.

## Patient and family studies: experiences with stigma and discrimination

It is clear that stigmatization related to mental illness is an evident and common problem in the Netherlands. Included studies indicate that patients both perceive and expect stigma. However, based on these studies no statements can be made on the exact extent of this problem. The rates of perceived and expected stigma differ greatly and cannot be compared because of the variation in study design and target group. International comparison studies indicate that the level of stigma in the Netherlands is slightly above average.

The included studies show that stigma is associated with: decreased quality of life (in two studies), higher work and role limitations, higher social limitation, decreased self-esteem, and resistance to accepting the diagnosis. Furthermore, stigma increases the effect of good insight on depressed mood, low quality of life, and negative self-esteem. The negative emotional impact of stigma is higher when patients have higher expectations of stigma. Stigma seems to be unrelated to residential type (including the extent of decentralisation). Selective disclosure seems to optimise social support and limits stigmatisation.

It is not only patients that regard stigma as an evident problem, family members appear to be burdened by the relative's illness and they recognise stigma's impeding effects for patients. Yet most family members perceive no apparent avoidance from the social environment, nor do they attempt to conceal their relative's illness. Perhaps this indicates that wanting to give unconditional support is stronger than the driving force of stigmas, but it definitely stresses the complex position of family members dealing with both the mental illness of the relative and the negative attitudes in society. Future studies on stigma should therefore include views and experiences of family members.

# General population studies: Stigmatising attitudes in society

The included studies indicate that there are still persistent stereotypical perceptions of psychiatric patients in the general public and that these perceptions can influence the degree of contact with people with mental illnesses. Most common stereotypes are 'unpredictable' and 'aggressive'. Another stereotype belief is that patients themselves can be held responsible for their illness. Two studies show that attributing psychiatric problems to structural causes (i.e. causes beyond patients' control and responsibility) is associated with less social distance and attribution to individual factors related to more distance. However, the literature is not consistent on this point. One study indicates that patients with high personal responsibility are rated more positively by participants.

Stereotype perceptions have profound consequences. One study shows that respondents will generally accept a psychiatric patient as a neighbour or colleague but not as a teacher or nanny for their children. Furthermore these beliefs are so strong that they can influence the future professional choices of nursing students.

In attributing stereotypical characteristics the public differentiates clearly between specific illnesses (schizophrenia, depression, drug addiction, and dementia) and also determines the 'seriousness' of the illness. In a study on employees' perceptions of a depressed colleague, participants reported more fear when the target person had serious versus less serious complaints and also attributed more negative personal attributes towards the person in the serious condition compared to the less serious complaints condition. The mechanisms underlying this 'fear-becoming-negative perceptions' need to be further investigated.

Finally, these studies show interesting results that raise questions about the contact-theory, which states that people are less inclined to stigmatise when they get into contact with patients. In one study no differences were found in the degree of stigma attributed to people with mental illness by the general public and by the sample of people living close to mental health facilities. In one study people living in a district without psychiatric facilities have more feelings of fear and insecurity regarding patients. The same study indicates that people living in a district with facilities think more positively about psychiatric patients. Another study proves the opposite: people living in a neighborhood in which psychiatric facilities are present have significant more negative cognitions about patients (including higher levels of believed dangerousness). Results are no consistent support for the contact theory, which is a basis for many interventions, but it also doesn't falsify it. More research on this subject is needed, that includes frequently and nature of contact between people with a mental illness and the general population.

## Stigma and the media

In the Netherlands there is remarkably little knowledge on the subject of stigma and media. Internationally there have been many efforts to investigate the way psychiatric patients are portrayed in the media. From international studies we know that for example television images play an important role in the development and perpetuation of one-dimensional representations (Domino, 1983; Fiske, 1987; Fisshof, 1996; Rose, 1998; Francis, Pirkis, Dunt e.a., 2001; Cutcliffe & Hannigan, 2001; Sief, 2003). But there are still many questions unsolved. For example, are media representation a reflection of public attitudes or are media representations influencing the public attitudes, or both? More research on this is needed.

#### Discussion

Considering the fact that stigma causes patients as much damage as the mental illness itself (Corrigan & Penn, 1999) it is remarkable that there is so little knowledge available in the Netherlands. The amount of research undertaken is not commensurate with the burden it poses for patients. Nevertheless, there have been several important efforts to examine the stigmatising perceptions of the general population and the experiences of patients. These studies prove that there are (still) many stereotypical beliefs about mental illness in Dutch society and they also confirm the negative impact these beliefs have on patients. These findings are largely in line with findings from studies in other western countries. It is interesting but also quite shocking that the problem of stigma seems part of the Western culture.

It is for example quite remarkable that the stereotypical images found in Dutch research are also found in other countries. The international literature is very consistent on that point: patients are perceived as 'unpredictable' and 'dangerous' (Edney, 2004; Penn et al, 1994; Angermeyer en Matschinger, 2005; Angermeyer et al, 2003) and they are being held responsible for their illness

(Corrigan et al, 2000; Weiner et al, 1988). It is widely supported that these negative images can lead to social distance to psychiatric patients (Angermeyer et al, 2003; Angermeyer &Matschinger, 2005). Furthermore, the Dutch results on the impact of stigma are also supported by international literature: stigma can decrease quality of life, decrease social inclusion and self-esteem, and increase limitations to work (Corrigan & Watson, 2002).

The included Dutch study on barriers for rehabilitation of depressed employees deserves to be highlighted here because this was in fact the only study focusing on stigma and depression in particular. This study reveals an important problem: not only that people with severe chronic mental illnesses are subject to stigmatisation but also the mostly transient mental illnesses that everyone can go through at some point in his life. Apparently depression still encounters s a lot of misunderstanding and fear in the workplace. For employees with depression this has of course major consequences. This problem stresses the importance of developing anti-stigma interventions in the workplace. The Fund Mental Health is now working on such an intervention, which is planned for implementation in 2011.

#### SUPPLEMENT: A SUMMARY OF DUTCH INTERVENTIONS

The searches in the databases and the snowball method did not reveal any well-researched intervention. Dutch researchers do discuss all kinds of initiatives in the fight against stigma in general (review) articles but there's a lack of evidence for these programmes. So the programmes don't have the support and status yet they deserve. Nevertheless, a description of the most important (and written about) Dutch initiatives is in place. All the initiatives are aimed at increasing the understanding in society for people with mental health problems or improve the societal position of mental health patients.

## 1. Pandora Foundation Goei et al (2006)

Since it's founding in 1964, the Pandora Foundation is deployed to improve the (legal) position and the perception of people with mental and / or psychiatric problems. Great steps were achieved. Pandora Foundation was the first organization in the Netherlands that began providing advice to institutions, schools and businesses by (former) psychiatric patients themselves (1971). Many people were stimulated to think critically by the Pandora campaign "Ever met a normal person? ... and liked it? ". A series of films and documentaries from the perspective of clients were made including the Golden Calf award-winning documentaries "Kind van de Zon" (Child of the Sun) and "Levenslied" (Life song). There has been attention to the social and employment situation of people who have (had) psychiatric problems. Pandora Foundation also was at the base of the formation of several organizations, including the family organisation "Labyrint Foundation" and "Platform Insurance and Work". The fact that in the Netherlands nowadays client perspectives are being taken seriously and that experiential expertise is widely recognized and appreciated, is mainly due to Pandora. Unfortunately, early this year foundation Pandora is dissolved due to the termination of grants. The activities carried out by volunteers are continued within the Dutch Client Association. See www.stichtingpandora.nl/jcms/

2. 'Kwartiermaken' (Making room for people with mental disabilities) Weeghel and Zeelen (1990), Kal (2001) and Goei et al (2006) Historically, "Kwartiermaken" is an established concept in the Dutch rehabilitation practice. 'Kwartiermaken' is about activities that provide space for people with limitations in their mental health so that they can participate in the 'ordinary' life (Van Weeghel & Zeelen, 1990). Kal (2001) developed this concept further based on practical experiences in Amsterdam and Zoetermeer. Kwartiermaker's projects nuance the images/representations about people with mental constraints, increase awareness about exclusion in institutions and organize more hospitality in society (Scholtens & Tomassen, 2001). In Zoetermeer a 'hospitality officer" funded by the municipality, is appointed in a charity organization. This helps participants to find out what they want and mediates the desired activity. Some cities have a 'Kwartiermakers' festival, in which people try to break through the negative image of people with mental limitations, through art and cultural expressions and promote positive involvement. Clients have a central role in this and experience much recognition for their contributions.

# **3.** Neighbourhood projects

# Project A "My neighbour crazy", Eisenga and Dijkslag (2000), Slebos-Eisenga (2003) and Goei et al (2006)

In the city of Groningen, since 1993 there is the project "My neighbour crazy" that wants to increase the support for the socialization of mental health services. To improve the representation about psychiatry, the exhibition "Verstand van misverstand" (Expert in misunderstanding) was organized, with pictures of people with mental health problems. Further it appeared that many people with mental health problems do not know how to deal with being a neighbour. They don't know what others expect of neighbours and lacking the skills for a good neighbour contact. Therefore, the project "Neighbourhood Contacts in the street" was launched, on which the Public Health Service of Groningen, mental healthcare Groningen, the community development and housing associations participated. The mental health care together with 'experience-experts' provide the course "The art of living" for clients who live independently. In addition, volunteers are deployed to welcome and guide new residents with mental health problems in the neighbourhood.

# Project B "Our Neighbours', Verschure (2004) and Goei et al (2006)

The project "Our Neighbours' is a collaboration of different organizations in the 'Vogelbuurt' neighbourhood in Dordrecht (Verschure et al, 2004). The project arose in response to complaints of nuisance from residents with drug addictions or psychiatric problems. Mental Health Institution, 'De Grote Rivieren', the housing corporation and police joined forces to decrease trouble and to increase mutual confidence among residents with mental health challenges and other residents. For example, a neighbourhood store opened where one can turn for information and where various institutions have daily office hours. Furthermore, a workplace was designed from which all activities for the area are set up (including doing home tasks at peoples houses and refurbishing bicycles). There is a garden available for vegetables and a friend set up service is founded. The evaluation shows that there is support in the neighbourhood for residents with psychiatric problems and the project 'Our Neighbours'. The clients are satisfied with their home and neighbourhood. They feel accepted and find it pleasant to live in a neighbourhood of blended composition.

### Project C "The Red Carpet", Swildens et al (2003) and Goei et al (2006)

In Utrecht, there is a project called "The Red Carpet" in a community centre in the district Overvecht. It offers people with mental vulnerabilities the opportunity to meet peers and do activities in a 'normal' environment. They are also encouraged to make use of the regular community centre. The project, in which mental health institutions, district and municipal welfare participate, is putting a priority in the social support system for people with mental constraints and the promotion of social contacts within mainstream facilities.

## 4. "Multiloog"

# Kal (2001), Mölders (2001) and Goei (2006)

Inspired by the Psychosis-Seminars in Germany, Mölders (2001) developed The Multiloog in the Netherlands. It tries to speak in a non-medicalising way about psychiatric experiences with different stakeholders: clients, family and friends, caregivers and others that deal with people with psychiatric experience in work or private life. Especially during a psychosis the 'incorrect' realities cause a communication break. Multiloog aims at the exchange between all stakeholders to increase understanding in the meaning of psychological suffering and in the things people with psychosis need. After the start in Amsterdam Multiloog meetings are now also organized in many other cities. According to Kal (2001) Multiloog needs to fulfil a broader function: not only to get to know the perspective of people with mental health problems and make room for own experiences with these people, but also to bring other relevant life experience into the process. For example, a Multiloog can contribute even more to recovery of reciprocity between people with and without psychiatric background.

# 5. National Mental Health Fund Goei et al (2006)

The Mental Health Fund is committed to support people with mental illness and their environment and to improve the mental health of people in the Netherlands. 'Schizophrenia, less crazy than you think' was the theme of the seventh National Day for the Mental Health in 2003. The Mental Health Fund organized this conference in cooperation with Pandora Foundation, the Trimbos Institute, and different client/family organisations. In about sixty places in the Netherlands public events were organized on October 10, 2003. The objective was to promote understanding of people with schizophrenia. The events included: theatre, interviews, experiential-experts and the presentation of results of the research project that specifically was performed for the National Fund by research institute TNS-NIPO. This research shows that fifty percent of friends, colleagues, classmates and friends lost contact with the person with schizophrenia they know. Forty percent of them attributed the termination of the contact to the disease. Openness, understanding and flexibility prove to be necessary to keep in touch with someone with schizophrenia. Successes of this campaign were the large amount of local activities and attention for schizophrenia in the media. Less successful was the smaller number of public comments than other years, both in the action-telephone number and the Campaign website. One explanation is that the campaign was directed at understanding and awareness and not to information. To what extent the campaign has helped the area get along better with someone with schizophrenia - as was the objective - it is difficult to obtain.

In 2010 the Fund starts a new education and prevention programme: 'Samen Sterk tegen Stigma' (Together we are strong against stigma). The ambition of this program is a diverse society in which people with a mental problems share an equal place. The starting point is the fact that although 1 in 5 people will be dealing with psychological problems, there are still prejudices and misconceptions about people with mental health problems. 'Samen Sterk tegen Stigma' combines, connects and reinforces anti-stigma initiatives. In 2010 it is examined whether it is feasible the implement an anti-stigma campaign similar to the English example (Time to change: let's end mental health discrimination). This is a national campaign in conjunction with local projects in the field of sport, work, culture and education. In 2010 two projects are planned: 'Stigma within the walls and work' and 'Sports (mental and physical) health and contact'. The first project aims at changing the stereotype views of Mental Health Care Institutions in order to eventually change the attitudes of employers and increase the possibility for clients to get employed. The second project aims at stimulating to encourage physical activity for its health and social benefits. Details at www.psy.nl/meernieuws/nieuwsbericht/article/ambitieuze-campagne-moet-stigmatisering-tegen-gaan/ and www.psychischegezondheid.nl/antistigma

# 6. Towards Recovery, Empowerment and Experiential Expertise (TREE, or HEE in Dutch) Boevink (2009)

The Trimbos Institute is active in combating stigma towards people with psychiatric illnesses through the TREE-programme. The programme provides effective methods and strategies developed by people with mental health vulnerabilities in order to help themselves. The TREEprogramme aims at enabling people with psychiatric disabilities to manage their own lives and to counter their marginalization in society. To this end, the programme enables its participants to exchange experiences and offer mutual support. It also encourages them to develop knowledge and to use such knowledge by making it available to others. Last but not least, the programme promotes user-led change within mental health care organisations in the direction of recovery-based services. The programme consists of: self-help groups and working groups, one day training courses and group discussions for fellow users of psychiatry, training programmes for professionals, consultancy and coaching in organisations that wish to implement the programme. In the Netherlands the TREE-programme, or parts of it, is becoming more and more popular among people with psychiatric illnesses themselves as well as amongst care providers. Several mental health care organisations have started to facilitate their users to implement the programme. A nationwide operating team of experiential experts is now hired frequently to provide kick off meetings, support fellow users in their recovery and in making recovery narratives, coach persons with psychiatric illnesses to become experiential experts, train fellow users and professionals, give lectures, design new programme parts and guide the implementation of the programme. People that participate in the TREE programme develop colourful identities, find courage to start moving again, discover their talents, find hope in stories of others, develop pride and they develop into gifted and powerful story-makers and presenters. All these features of the TREE program have the potential to contribute to improving the position of people with a psychiatric diagnosis and to the reduction of stigmatising public images.

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#### **REVIEW OF STIGMA RELATED TO MENTAL ILLNESSES IN ROMANIA**

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#### **INTRODUCTION**

As part of the ASPEN (Anti-Stigma Programme - European Network) project's Work Package 4 ('Best practice anti-stigma'), the Romanian site conducted a national literature review on stigma. This included a thorough analysis of all the peer review publications and reports about mental health stigma in Romania. This country report is intended to cover two areas:

1. Known patterns of stigma and discrimination associated with depression (e.g. public surveys, controlled studies, patterns of stigma and discrimination in key settings, such as schools and workplaces).

2. A summary of the evidence base and pointers for promising practice for effective interventions to tackle stigma and discrimination in relation to mental health problems.

A stigmatised person is a person whose social identity, for example affiliation to one specific class, can lead others to the conclusion that their very humanity is questionable. The person is devaluated or marked down (stigmata) by the way the others perceive them. Stigma is a very strong social phenomenon that is tied into the way in which we make judgements upon other people's different social identities. Stigma implies 2 components: 1) Acknowledging differences due to some particular feature and 2) Devaluing the person with this feature. Discrimination, stigma and social exclusion can make it impossible for the person with a mental health problem to participate fully in the life of the society. Therefore it is important to measure stigma and discrimination, and approaches to reduce it, in order to improve the quality of life of these persons affected. Romania currently has a number of social challenges that make it even more difficult to understand and tackle stigma associated with mental illnesses. Despite many efforts, with some successes and failures, Romanian society is still not well equipped for the functioning of a strong democratic system. The politicians, mass media and civil society (and many others that are involved in modelling and shaping public opinion) have an essential role in construction of a democratic culture in Romania. A further feature of Romanian society is an appetite for intolerance, which is well documented in the cultural patterns of the last decades and worsened by a recent history of poverty, inequality and corruption, which weakens human rights.

#### **METHOD AND FINDINGS**

A web search of the Romanian peer reviewed literature yielded no results at all for stigma and mental health. There were no public survey, nor studies regarding patterns of stigma about depression. However, in the last 2 years the number and quality of anti-stigma programmes have been intensifying in different fields, including in mental health. The majority of the initiatives have been planned and implemented locally and with little funding. Regarding mental health, the majority were campaigns for general mental illness and in particular with a specific focus of getting the public to recognise the rights of people with severe mental health problems.

Unfortunately there is no campaign that focuses upon depression. We did find details of some practical campaigns that have been developed. There were three different types of campaigns:

### 1. Online campaigns

There were several online campaigns. For example "Trust Their Mind" was a campaign that addresses different target groups including young people over 18 years, journalists, businessmen, teachers. They use radio spots, advertising and leaflets all with reference to the online campaign to decrease mental health stigma and work groups. There was no evaluation of the campaign so we are unable to assess its' effectiveness.

## 2. Campaigns using cultural activities

This campaign aims to decrease stigma by improving knowledge and attitudes of the general population towards mental illness, by raising awareness of the abilities of people affected by mental illness. The campaign organised exhibitions of photography, theatre plays with persons with mental health problems, and screenings of movies with persons with mental health problems as the theme. Again there were no evaluations of the campaign.

## 3. General information campaigns

This type of campaign is about giving information to the general public through information materials. For example placing some tents or stalls with leaflets and other information materials or screening in very public places (central place of the town, near city hall). This is a kind of anti stigma action with great visibility and large reach within the community and can reach a high number of people when the target is the general population. For the moment the majority of the projects to tackle stigma in Romania were this kind of campaign. And the many of the projects combine the 3 types of campaign approaches.

#### 4. Research with the public

There was research conducted in September 2003 by the Institute of Public Politics regarding discrimination towards minority groups including mental health. The research examined the attitudes and opinions of the Romanian people regarding "others" (national minorities, ethnical minorities, religious and others). There was a cohort of 1500 people aged over 18 years. A second study was completed assessing community attitudes towards mental health problems. A cohort of 1275 people aged over 18 years were presented with examples of people with different mental health issues and asked to choose which of them they would like as a neighbour, friend etc. These studies are not published and their methods and reliability debatable, however they give a general sense that intolerance towards people with mental health problems is high.

#### **CONCLUSIONS**

There were few published studies evaluating the impact of anti-stigma programmes for depression and mental illness in Romania, or the problem of stigma of depression in the public or key institutions. This links to the fact that there is not a culture of evaluation amongst ONG's, where the main source of information tends to be web-based descriptions of project activities published when the project finishes. A central point of contact that can synthesise all the initiatives on stigma in mental health and co-ordinate the projects would be valuable.

# ADDRESSING MENTAL ILLNESS STIGMA AND DISCRIMINATION: REVIEW OF LITERATURE AND ANTI-STIGMA PROGRAMMES IN SLOVAKIA

By Dita Leczova and Janka Hurova Association for Mental Health INTEGRA, o. z.

#### **INTRODUCTION**

As part of the ASPEN (Anti-Stigma Programme - European Network) projects' Work Package 4 (Best practice anti-stigma), Aspen sites were to conduct a literature review on stigma in their country. This would include a thorough analysis of all the peer review publications and reports about mental health stigma in their country. In Slovakia, this task was completed by the Association for Mental Health INTEGRA, o. z. Our aim was to identify and summarize available stigma-related literature from Slovakia, as well as to provide information about interventions and programs that address stigma and discrimination in relation to mental health problems. This study does not intend to discuss stigma-related issues in depth or to draw comprehensive conclusions from the identified literature.

#### **METHODS**

The study was conducted by applying several sequential and systematic steps that constitute the following framework:

#### Setting main categories of interest

In order to provide a comprehensive and structured review on stigma-related literature and anti-stigma programmes in Slovakia, we decided to define three main categories divided into subcategories. This had made our later search for literature and programme information easier and better-arranged. The categories were derived on theoretical basis and served as guidelines for literature search. They reflect a presumable schema of available literature at this stage of the research.

Books	books devoted to mental illness stigma and/or discrimination
	books or chapters in books aimed at destigmatization
	academic dissertations (at bachelor, master's or doctor level)
Articles	peer reviews published in Slovak journals and/or in Slovak language
Anti-stigma programmes	national and regional programmes with anti-stigma potential
	international programmes with anti-stigma potential with participation of Slovak organizations

**Setting methods** – the main sources and ways of identifying items related to the categories. The next step consisted of planning the ways of identifying items related to the defined categories. The Internet was the main data source and the planned ways of data search can be summarized as follows:

Books	<ul> <li>a) web page of F-publishing (Vydavateľstvo F, <u>www.vydavatelstvo-f.sk</u>) that focuses on scientific literature and texts from psychology and psychiatry</li> <li>c) registers of academic dissertations in psychology (We seared the registers of 2 most important universities with psychology department in Slovakia.)</li> </ul>
Articles	d) the PubMed scientific database
	e) web pages of the most important Slovak scientific journals in psychology and psychiatry (Studia psychologica - <u>www.psychologia.sav.sk</u> , Československá psychologie – <u>www.cspsych.psu.cas.cz</u> , Psychiatria pre prax - <u>www.solen.sk/index.php?page=magazine_info&amp;magazine_id=2</u> , Psychiatria - Psychoterapia – Psychosomatika - <u>www.psychiatria- casopis.sk/psychiatria/</u> )
Anti-stigma programmes	f) Web pages of Slovak NGOs working in the field of mental health (League for Mental Health –www.dusevnezdravie.sk; Association of relatives and friends of people suffering from mental illness - <u>www.opora-vz.com/uvod</u> ; KOMPAS - Community care and assistance – <u>www.kompasno.sk</u> ; ODOD – Open doors, open hearts– <u>www.odos-sk.com</u> )

Apart from the listed internet resources, we have searched the web for any additional literature with Google. We also contacted 5 professionals working in the field of psychology or psychiatry to check for other possible unpublished studies or reports on anti-stigma programmes. Through their recommendations we gained some other tips for search.

# Performing the research

We finally performed the research based on the defined categories and ways of searching. We used the range of search terms suggested by the WP4 colleagues. To look for literature (books and studies) describing patterns of stigma and discrimination with regard to mental health in Slovakia, we used the following combination of search terms where possible:

(Slovak)

AND (stigma\* OR destigmatiza\* OR prejudice\* OR stereotype\* OR discrimina\*)

AND (mental OR psychic OR psychiatr\* OR depressi\* OR schizophreni\* OR patient OR relatives)

To look for reports on anti-stigma programmes in Slovakia, we used the following combination of search terms:

(Slovak)

AND (stigma\* OR destigmatiza\* OR prejudice\* OR stereotype\* OR discrimina\*) AND (mental OR psychic OR psychiatr\* OR depressi\* OR schizophreni\*) AND (intervention OR programme OR psychoeducation OR patient advocacy )

This resulted in numerous findings. However, after all titles and abstracts were checked for relevance, many of them were excluded from the review.

#### RESULTS

The primary search resulted in 342 findings in total. After checking these for relevance to the study, we gained 7 book titles, 29 academic dissertations, 2 peer reviewed articles and 4 antistigma programmes realized in Slovakia. The 42 items included into the review are listed below.

#### a) Books devoted to mental illness stigma and/or discrimination

We have not found any books dedicated directly to mental illness stigma and/or discrimination in Slovak language.

#### b) Books or chapters in books aimed at destigmatization

Elgie, R., Amerongen, A. P. V., Byrne, P., D'Arienzo, S., Hickey, C., Lambert, M., McCrae, J., Sappia, S. (Eds.) (2006). Objavte cestu ako ísť ďalej : Podpora a rady pre každého, koho postihla schizofrénia. (Discover the way to move on. Support and advice for everyone suffering from schizophrenia) Trencín: Vydavatelstvo F.

Abstract: The aim of this manual is to provide support to everyone suffering from schizophrenia or other psychosis. It provides not just numerous useful information enriched with many illustrative case-studies, but also gives hope to those with this diagnose that as far as they respect the recommended therapy they can live a meaningful and dignified life. A discrete part of the manual describes different ways to deal with mental health stigma and discrimination.

#### Hahlweg, K., Dose, M. (2000). Schizofrénia. (Schizophrenia.) Trenčín: Vydavateľstvo F.

Abstract: This book provides actual information about diagnostics and treatment of patients with schizophrenia. It is a therapeutic manual that gives new suggestions for practice. Description of methods of reducing distress from "expressed emotions" by communication training and learning how to deal with interpersonal problems is especially valuable and helpful.

#### Hautzinger, M. (2000): Depresia. (Depression.) Trencín: Vydavatelstvo F.

Abstract: This book informs about the current state of knowledge in the field of diagnostics, aetiology and psychotherapeutical treatment of depressive disorder. It provides recommendations for psychotherapeutic and psychopharmacological treatment of depression, points out adequate and inadequate therapeutic methods, as well as discusses ways of dealing with crisis. The publication is enriched with information regarding structuring of therapeutic sessions and describes discrete components of therapy.

Hell, D., Schüpbach, D. (2000). Schizofrénia: Základy pre porozumenie a orientáciu. (Schizophrenia: the basics for understanding and orientation.) Trenčín: Vydavateľstvo F.

Abstract: The diagnosis of schizophrenia means struggles for patients and their relatives for many years. They face stigma that is still connected with this illness in the society. For this reason, it is very important to gain sufficient information about this diagnosis. Information about onset, course and treatment of schizophrenia can improve confidence needed in dialog with psychiatrists and psychologists, as well as in communication with friends and neighbours who are often withdrawn because of the illness.

Kühner, C., Weber, J. (2004): Predchádzanie depresiám (Depression prevention). Trenčín: Vydavateľstvo F.

Abstract: This manual is describes the methods of psycho-educationally-orientated cognitivebehavioral group intervention. It is based on the well-established standardized American manual of R. F. Munoz: Depression Prevention Course. The program is compatible with parallel psychotherapeutical treatment and pharmacotherapy or medical thymoprophylaxis.

Nawka, P., Černák, P., Hašto, J. (Eds.) (1998): Reintegrácia psychosociálne postihnutých do spoločnosti: Súčasný stav a perspektívy. (Reintegration of psychosocially disabled people into society: actual state and perspectives.) Trenčín: Vydavateľstvo F.

Abstract: Mental health care in Slovakia is inadequate and needs to be reformed. To achieve optimal changes, permanent discussion has to be developed between 4 partners: service users, professionals, relatives and public ("tetralog"). In 1997 the second "tetralog" conference took place in Slovakia. In this publication you find all of the four voices.

Schaub A., Bernhard, B., Gauck, L. (2005). Kognitívne-psychoedukačná liečba bipolárnych porúch: Terapeutická príručka. (Cognitive-psychoeducational therapy of bipolar disorders: Therapeutic manual.) Trenčín: Vydavateľstvo F.

Abstract: The aim of this book is to boost the use of cognitive psychoeducational interventions in patients with bipolar disorders. The book provides review on aetiology, epidemiology and diagnostics of bipolar disorders and informs about current findings from therapeutic research.

#### c) Academic dissertations (at bachelors', master's or doctors' level)

Lacková, O. (2007). Vplyv psychosociálnych nástrojov na kvalitu života schizofrénnych pacientov. Rigorózna práca. (The impact of psychosocial tools on quality of life of patients with schizophrenia. Academic dissertations doctor level.) Bratislava: Vysoká škola zdravotníctva a sociálnej práce sv. Alžbety, n.o. v Bratislave.

Abstract: The dissertation focuses on the onset, therapy and reintegration to the original social environment of people with schizophrenia, and on the impact of psychological and social tools on quality of life of these people. The primary aim of the research was to explore the relationship between the usage of psychological and social tools and quality of life, in relation to attendance of a day-care psychiatric and psychotherapeutic centre. We have also examined the impact of schizophrenia disorder to social status of these people.

Ráczová, R. (2009). Zvnútornená stigma a sociálna opora u ľudí so schizofréniou. Diplomová práca. (Internalized stigma and social support in people with schizophrenia. Academic dissertation at masters' level) Trnava: Trnavská univerzita v Trnave.

Abstract: Many people with schizophrenia suffer due to their illness not just from public stigma, but also from internalized self-stigma. Stigma can slow down or inhibit the process of recovery from mental illness. It is therefore very important to recognise the factors that have impact on stigma, either in positive or negative way. Our study focuses on internalized stigma of people with schizophrenia and their perceived social support. Social support is seen as a potential factor, which can positively affect internalized stigma. The sample of the study consists of 35 clients with schizophrenia, attending different community-based and health care facilities that provide support, therapy and skills training to their clients. We also explore some other aspects of the key variables. MSPSS (Multidimensional Scale of Perceived Social Support) and ISMI (Internalized stigma of Mental Illness Inventory) scales were used in the study. Our findings did not confirm the anticipated relations between the key variables; however, we explored significant gender differences in perceived social support and stigma resistance. The importance of family in social network of people with schizophrenia was also confirmed.

### Some other dissertations were identified without published abstracts:

Albertyová, V. (2002). Psychoedukačné programy a ich využitie: Nové trendy v liečbe psychiatrických pacientov. Rigorózna práca. (Psychoeducational programmes and their utility: new ways in treatment of psychiatric patients. Academic dissertation at doctors' level.) Bratislava: Comenius University in Bratislava.

Bagová, J. (2002). Diskriminácia v podmienkach liečenia a ošetrovania. Diplomová práca. (Discrimination in conditions of therapy and nursing. Academic dissertation at masters' level.) Martin: Comenius University in Bratislava.

Bartalová, Ľ. (2005). Integrácia pacientov trpiacich schizofréniou do spoločnosti. Diplomová práca. (Integration of patients with schizophrenia to the society. Academic dissertation at masters' level.) Martin: Comenius University in Bratislava.

Belanová, B. (2003). Rodina deperesívneho pacienta. Diplomová práca. (Family of a depressive patient. Academic dissertation at masters' level.) Bratislava: Comenius University in Bratislava.

Buricová, N. (2009). Spolužitie s depresívnym jedincom z pohľadu teórie a praxe. Diplomová práca. (Co-existence with a depressive person: theoretical and practical view. Academic dissertation at masters' level.) Trnava: Trnavská univerzita v Trnave.

Černá, P. (2005). Niektoré interpersonálne problémy depresívnych pacientov. Diplomová práca. (Som of the interpersonal problems of patients with depression. Academic dissertation at masters' level.) Trnava: Trnavská univerzita v Trnave.

Dobšovičová, E. (2008). Schizofrénia ako vážny sociálny problém súčasnosti. Diplomová práca. (Schizophrenia as a serious problem today. Academic dissertation at masters' level.) Trnava: Trnavská univerzita v Trnave.

Góbis, O. (1999). Psychoedukačný modul v liečbe psychotických ochorení. Rigorózna práca. (Psychoeducational module in treatment of psychotic diseases. Academic dissertation at doctors' level.) Bratislava: Comenius University in Bratislava.

Godinová, S. (2009). Úroveň vybraných kognitívnych funkcií u hospitalizovaných pacientov s unipolárnou depresiou. Diplomová práca. (Level of cognitive functioning in in-patients with unipolar depression. Academic dissertation at masters' level.) Trnava: Trnavská univerzita v Trnave.

Heretik, A. (1997). Skúmanie efektu psychoedukačného programu PRELAPS. Diplomová práca. (Examining the effect of psycho-educational program PRELAPSE. Academic dissertation at masters' level.) Bratislava: Comenius University in Bratislava.

Heretik, A. (2001). Porovnanie efektu psychoedukačných programov v liečbe schizofrénie. Dizertačná práca. (Comparing the effectivity of psychoeducational programmes in schizophrenia treatment. Academic dissertation at doctors' level.) Bratislava: Comenius University in Bratislava.

Hiľovská, Z. (2006). Osobnostné faktory, naučená bezmocnosť a potreba kontroly ako možné prediktory depresivity v depresívnej a zdravej populácii. Diplomová práca. (Personality factors, learned helplessness and need of control as possible predictors of depressivity in depressive and health population. Academic dissertation at masters' level.) Trnava: Trnavská univerzita v Trnave.

Hrmová, D., Jediná, M. (1998). Prelapse - možnosti a obmedzenia psychoedukácie v kontexte starostlivosti o schizofrénneho pacienta. Diplomová práca. (Prelapse – possibilities and bariers of psychoeducation in kontext of care of patient with schizophrenia. Academic dissertation at masters'

level.) Bratislava: Comenius University in Bratislava.

Javorková, A. (2006). Stigmatizácia a diskriminácia ľudí s problémami v oblasti duševného zdravia. Diplomová práca. (Stigmatization and discrimination of people with mental health problems. Academic dissertation at masters' level.) Bratislava: Comenius University in Bratislava.

Kollárová, S. (2005). Vzťah životných udalostí a depresie u dospelej populácie. Diplomová práca. (Relationship between life events and depresion in adult population. Academic dissertation at masters' level) Trnava: Trnavská univerzita v Trnave.

Kočibalová, A. (2005). Zvládanie záťaže u príbuzných ľudí s psychotickým ochorením, najčastejšie z okruhu schizofrénie. Diplomová práca. (Coping with stres in relatives of people with psychotic disease, most frequently from schizophrenia spectrum. Academic dissertation at masters' level.) Trnava: Trnavská univerzita v Trnave.

Kostecká, M. (2006). Stigmatizácia duševne chorého. Bakalárska práca. (Stigmatization of mentally ill people. Academic dissertation at bachelor' level.) Martin: Comenius University in Bratislava.

Kuchtová, M. (2008). Miera depresie v partnerskom vzťahu a vzájomných očakávaniach partnerov. Diplomová práca. (Depression degree in partnership and mutual expectances of partners. Academic dissertation at masters' level.) Trnava: Trnavská univerzita v Trnave.

Májska, I. (2009). Stigmatizácia ako jeden z nepriaznivých sprievodných javov psychiatrických klientov na Slovensku. Rigorózna práca. (Stigmatization as one of the disfavourable phenomena in psychiatric clients in Slovakia. Academic dissertation at doctors level) Trnava: Trnavská univerzita v Trnave.

Müller, K. (2006). Spiritualita ako mediátor depresie a suicidality u študentov vysokých škôl. Diplomová práca. (Spirituality as mediator of depression and suicidality in undergraduate students. Academic dissertation at masters' level.) Trnava: Trnavská univerzita v Trnave.

Ondrejka, I. (2000). Kvalita života: sociálne činitele a liečba-vzájomné vzťahy u depresívnych stavov. Dizertačná práca. (Quality of life: social factors and treatment – mutual relationships in depressive patients. Academic dissertation at doctors' level.) Martin: Comenius University in Bratislava.

Poluchová, J. (2008). Stigma duševných porúch z pohľadu ľudí s diagnózou schizofrénie. Diplomová práca. (Stigma of mental illnesses: the view of people with schizophrenia. Academic dissertation at masters' level.) Comenius University in Bratislava.

Priesolová, S. (2008). Depresia a suicidalita. Bakalárska práca. (Depression and suicidality. Academic dissertations at bachelor level.) Trnava: Trnavská univerzita v Trnave.

Retlichová, I. (2000). Podpora kvality života u pacientov so schizofréniou. Diplomová práca. (Improving quality of life of people with schizophrenia. Academic dissertation at masters' level.) Martin: Comenius University in Bratislava.

Schindzielorzová, M. (2005). Sebahodnotenie u osôb so schizofrénnym ochorením. Diplomová práca. (Selfesteem in people with schizophrenia. Academic dissertation at masters' level.) Trnava: Trnavská univerzita v Trnave.

Semiglazová, I. (2008). Podporný liečebno-pedagogický program u psychiatrických pacientov. Diplomová práca. (Supportive therapeutic-pedagogic program form psychiatric patients. Academic dissertation at masters' level.) Bratislava: Comenius University in Bratislava.

Zríni, S. (2007). Depresia ako psychologický problém súčasnosti. Diplomová práca. (Depression as actual psychological problem. Academic dissertation at masters' level.) Trnava: Trnavská univerzita v Trnave.

# d) Peer reviews published in Slovak journals and/or in Slovak language

Heretik, A., Mullerová, Z. (2005). Depresia očami občanov Slovenskej republiky: Sociálne reprezentácie pojmu depresia u prispievateľov v on-line diskusii k článku o výsledkoch EPID štúdie v denníku SME. Depression by citizens of Slovak Republic: Social prezentation of depression by on-line participants discussing an article on the EPID study results in daily SME.) Psychiatria, 12, 1, 15 – 27.

This article presents some parts of analyzed internet discussion related to the article from daily SME, 29.4.2003, entitled "Psychiatrists: depression dominates", which was the first published report of the EPID study – first epidemiologic study of depression in Slovakia. On/line, non/conducted discussion, related to the article, was held from 29.4. - 4.5.2003. The paper provided the review of presentation of depression and related events, designated by discussion participants. The language was preserved or the statements were carefully shortened in order not to affect the context. Participants' statements were sorted according to discussed topics. Subsequently the authors developed a system of classification. Authors tried to interpret some findings, in their opinion remarkable. Authors were aware other alternative interpretations exist as well, providing a different view to depression. At the end of the article authors suggest some ideas/topics/study questions, developed from analyzed material.

Poluchová, J., Heretik, A. (2009). Stigma duševných porúch z pohľadu ľudí s diagnózou schizofrénia: výsledky výskumu. (Stigma of mental disorders from the perspective of people with schizophrenia: research results.) Psychiatria-Psychoterapia-Psychosomatika, 16, 1, 2-11.

Methods: Qualitative method semi-structured interview was used to collect data. Interviews took place in mental health centres and participants' homes. The sample consisted of 10 clinically stable outpatients who have been diagnosed with schizophrenia or schizoaffective disorder. Snowball sampling strategy was utilised.

Results: Four dimensions of stigma were extracted from the participants' data: interpersonal interaction, structural discrimination, access to social roles and public images of mental illness. All participants indicated having various stigma experiences and by 9 of them were described as very painful. Concealment of illness and avoidance of potentially dangerous social contacts are common reactions to those experiences.

Conclusion: Participants describe a great variety of stigma and discrimination experiences in all areas of life, including health care. Publicizing these stigma and discrimination experiences could help to reduce negative stereotypes in society and result in healthier reactions from patients, favouring a better course of the illness.

#### e) National and regional programmes with anti-stigma potential

#### Mental Health at High Schools

The Slovak League for Mental Health developed a project aimed at high-school students and tries to break mental health stigma and discrimination through series of open discussions with psychiatrists and psychologists. The interactive meetings are held on several different topics, including mental health, depression, stigma or suicidality. Within the project, high-school teachers and school psychologists are also trained to further disseminate the information about the main topics.

#### Campaigns for mental health

Campaigns for mental health have a well-established tradition in Slovakia as they take place in

different towns (e.g. in Trnava organised by KOMPAS, n.o.). The Slovak League for Mental Health also organises a countrywide campaign each year, in 2010 the 7th took place. These events aim to initiate discussion regarding mental health, stigma and discrimination, to provide adequate factual information to range of groups in society (e. g. patient, relatives, students, public) and commonly consist of series of discussions with professionals on different topics, presentation of art-works of mentally ill patients, presenting organizations working in the field of mental health in media, etc.

# f) International programmes with anti-stigma potential with participation of Slovak organizations

#### **Projekt Prospect**

PROSPECT is the EUFAMI training pilot project under the EU Leonardo programme. PROSPECT has developed and piloted training that will open up and support new perspectives for social integration and employment of people with experience of mental illness and their families and friends.

ODOS - Open doors, open hearts actively participated in this educational program and 2 members of the association were trained. These delegates subsequently organised and trained members of other regional patients' associations in Slovakia, particularly in strengthening their associations, leading and maintaining organizations and communication.

## Projekt Indigo (International Study of Discrimination and Stigma Outcomes)

ODOS - Open doors, open hearts took part in an international epidemiologic study regarding the impact of stigma and discrimination on day-to-day life of people with schizophrenia and on their possibilities to social participation in society. In Slovakia, participants of the study expressed that the most negative impact of their chronic mental illness is on getting and maintaining a job.

#### CONCLUSION

Based on the realised review on stigma-related literature, it is apparent that this area lacks adequate attention from competent experts and institutions in Slovakia. The growing number of academic dissertations, however, shows increasing interest of young professionals in this field. In spite of this, we believe that more intensive and systematic work has to be done by all stakeholders.

# <u>REVIEW OF THE LITERATURE AND MEDIA REPORTS OF PATTERNS OF MENTAL ILLNESS STIGMA</u> <u>AND ADDRESSING STIGMA IN SLOVENIA</u>

By Vesna Švab and Maja Valič University Psychiatric Hospital, Ljubijana

#### INTRODUCTION

As part of the ASPEN (Anti-Stigma Programme - European Network) project's Work Package 4 ('Best practice anti-stigma'), Aspen sites were to conduct a literature review on stigma in their country. In Slovenia we included besides the peer review publications and reports also all media reports on stigma in last five years to illustrate the impact of various professional and public initiatives to reduce stigma and discrimination of depression.

The Slovenian report includes several areas of mental health stigma defined through peer reviewed literature and other professionals' publications.

NGO programs against stigma Organization of mental health care Suicide in Slovenia, EAAD study INDIGO study Reports about education against stigma Publications of mental health professionals in Slovenia

In Slovenia there was little research done on stigma. The national report of the INDIGO study included only 25 people with schizophrenia. Participation in the European Alliance Against Depression (EADD) will be reported separately. Most of the reported literature is important for mental health prevention and promotion and isn't directly connected to stigma and depression.

This introduction deserves to include also a historic point of view as stigma and mental illness in Slovenia can only be understood in it's social and cultural context. The first public anti-stigma statement in Slovenia dates to 1881 when the first psychiatric hospital was opened with the speech of Doctor Karl Bleiweiss saying that people with mental illness are equal to all other people and that all society should accelerate their social involvement (1). This statement in many ways determined the attitudes of Slovene psychiatric professions as well as many other initiatives evolving in the next centuries with the goal of improving accommodation, employment and participation of people with mental disorders. Slovenia has a rich history of anti stigma work, in last years undertaken mostly by nongovernment organizations, who find it harder to get access to financing research work. Their endeavours may be measured only through perceived public interest and personal responses of patients and carers.

The largest amount of data gathered in this report was derived from the database established by the largest Slovenian NGO working with people with anxiety and depression in Slovenia called DAM (GIVE). They provided us with an almost complete overview of media reports on anxiety and depression and the anti-stigma movement.

#### METHOD

Peer reviewed articles were searched for in the Pubmed, Science Direct, Google Scholar and Virtual Library of Slovenia (Cobiss). We used the following combination of search terms: Slovenia AND (stigma\* OR attitud\* OR prejudice\* OR stereotype\* OR discrimina\*) AND (mental OR Depress\* OR Dysthymi\* OR Adjustment Disorder\* OR Mood Disorder\* OR Affective Disorder\* \*OR Affective Symptom\*) AND (Intervention OR Education OR Informatio OR Project). All search terms were used also in the Slovenian language.

The search resulted in 37 peer reviewed articles. All retrieved articles are included in the report. The media and web reports search was performed through Najdi.si and Google search using the same combination of terms. The DAM web-page described above was searched separately. The search resulted in 131 media reports. All reports were checked for relevance and 33 selected after taking account of relevance and duplication.

# **FINDINGS**

# NGO programs against stigma

The first anti-stigma report was published in 2000 predicting development of anti-stigma movement in Slovenia with the guidance of NGOs, as one of them (ŠENT) in 1996 organized serial of public events to challenge stereotypes about mental illness. ŠENT started a public debate on the social position of people with mental disorders and their carers (2). One of the first round tables in the centre of Ljubljana about stigma and discrimination of mental illness was the launch of an anti-discrimination program in Slovenia, but with no resources at that time (3).

In 2002 one of the newspapers published an article on the depression of an NGO activist, psychologist and patient Doctor Tanja Lamovec. The article covered her depression and her personal strengths in coping with the illness. Therapeutic methods were presented (4). Other personal testimonies were published consequently (5,6).

In 2004 the Association DAM was established which quickly provided holistic web support (<u>www.nebojse.si</u>) with accessible information about depression and anxiety, self help, service and practitioner contacts, literature, manuals, consultations and advice about medicines, psychotherapy, coping and self-help. A web forum, chat-room and blog forum, were available from then on (7,8).

In 2006 several debates and round tables organized by NGOs continued (9). DAM translated 'Mental Illness and stigma: Coping with the ridicule', and article explaining stigma, prejudice, discrimination and stereotypes (10). In 2007 a book on depression DEPRA was published by the journalist with personal experience of depression Renata Ažman (11), which was followed by several public debates on depression and stigma. The call for destigmatisation of depression started to be called the Movement Against Depression in several web reports (12). In the 2008 the users' (consumers') organization called Mostovi (Bridges) started to function and opened web page on destigmatisation of mental disorders, calling for better professional mental health networks and psychiatric beds in general hospitals. Professionals, however, were their main speakers (13). NGO ŠENT organized an international EuroPsy Rehabilitation festival called 'Merry

Go Round With Culture' with a strong empowerment mission for consumers of mental health services. The strongest emphasis was on fighting discrimination regarding employment (14). Psychology students prepared a mental health promotion project 'How are you?'

In the same year the president of DAM presented her own experience with depression and active involvement in self-help, education and empowerment of people with similar problems. DAM introduced its work as fighting against the stigma of depression and anxiety (15) and published in 2008 and 2009 several publications on coping with depression and anxiety, about self help and treatment in a user-friendly way. Depression for Dummies and Bipolar Disorder for Dummies were published (16, 17).

In 2009 NGO ŠENT published the book of psychiatrist Vesna Švab, 'Mental Illness and Stigma' (18), paying attention to various aspects of stigma and discrimination of people with different mental disorders and the results of the INDIGO study described below. This work was promoted in several web reports and journals (19). One of the articles was connected to the infanticide of two children, which was presumed to have been by their 'mentally ill' mother (20). It led to improved reporting on this event.

In 2009 a big concert in the memory of Doctor Andrej Marušič, who launched the major movement of the anti-stigma depression campaign, was performed at the Slovenian coast. Depression was described as a curable disease in the frontlines of media reports (21, 22).

A comic drama on Slovene suicides was performed with the NGO OZARA, using comedy as a tool against stereotypes about suicide in Slovenia (23). Press conferences, round tables about destigmatising mental disorders and public events highlighting stereotypes on mental disorders continued (24, 25). A videospot / advert on stigma of depression was made by NGO OZARA (26). In 2010 an informative and personal report on depression from the perspective of Maja Valič, DAM president, was published(27).

# Organization of mental health care

The problem of stigma was addressed in the research on how to organise mental health services in Slovenia, which included evidence based proposals for community treatment (28,29,30). In addition, The European Pact for mental health and wellbeing was published in 2008 under the Slovene presidency of the EU. The Green Paper on Mental Health was published in web pages of The Institute for Public Health (IPH) (31). Depression, anxiety and suicide were identified as major public health problems in Slovenia at the round table organized in order to inform about the process of accepting a new National Mental Health Plan in Slovenia in 2009 (32, 33). Fighting against stigma is defined as one of the priorities in this still developing document. In the IPH publication Mental Health in Slovenia, depression and anxiety were identified as most common mental health problems and the frequency of these disorders was identified and publicly presented (34). Major goals of the Slovenian mental health policy were identified (35).

#### Suicide in Slovenia

In 2003 the Suicide Attitudes Questionnaire (SUIATT) was sent to a representative sample of adult Slovenian citizens and 21.6% of them reported suicidal ideation (SI). More respondents with SI than respondents without SI reported: 1) the suicidal act as deliberated, 2) less

importance attached to the mental illness in suicidal behaviour, 3) that a person has the right to commit suicide, and 4) the suicidal act as an act of cowardice. Results did not allow a general statement whether attitudes towards suicide are permissive or restrictive in Slovenia. However, in the subgroup of respondents with SI they found a tendency towards permissiveness regarding suicide (36).

In 2005 Slovene author Doctor Andrej Marušič participated in analysis of risk factors for suicide and evidence-based prevention strategies. The study concluded that physician education in depression recognition and treatment, and restricting access to lethal methods can reduce suicide rates. Other interventions need more evidence of efficacy. Ascertaining which components of suicide prevention programs are effective in reducing rates of suicide and suicide attempt is essential in order to optimize use of limited resources (37). This study influenced the prevention of suicide including destigmatisation in Slovenia in further years and made way for the majority of public actions later. Stigma of suicide was discussed in two other articles of Slovenian authors about reducing suicide in Slovenia, and about mental health prevention (38, 39).

The first report on suicide reduction in Slovenia was also published in the media (40). Also, there are two articles in peer review at the moment, one about Slovene suicide prevention, i.e. Slovene Gotland study by authors from IPH and an article trying to explain reasons for suicide reduction in Slovenia in the last five years by V. Švab and L. Beškovnik.

## EADD The European Alliance Against Depression

The IPH was involved in anti-stigma research in 2004 by entering the project EAAD (European Alliance Against Depression:(2004-2008), with the leadership of dr. Andrej Marušič. The EAAD was active in 17 countries creating community-based networks that used an evidence-based approach to improving care for depressed persons and preventing suicides. A shared multilevel approach was used that included interventions on four levels: education of primary care physicians, a professional public relations campaign, training of community facilitators, and interventions with affected persons and high-risk groups. In 2009 EAAD reports were published (41,42, 43). It was stressed that EAAD had broader destigmatising effects. Although the public campaigns focused on depression, their effects were likely to generalize to other areas of mental health. For the general population, the campaign was successful in creating campaign awareness for Alliance Against Depression (Germany). For persons who reported experience with depression analyses showed positive desirable effects, more positive attitudes towards medication treatment and antidepressants developed and also 'lack of self-discipline' declined as a causal explanation as did the notion that people should 'pull yourself together'.

The report on education of primary care physicians (Slovene Gotland Study) was published on IPH web page (44), and also in several newspapers. The project took place in two Slovenian regions with cooperation of mental health NGOs. The goals of the project were to cooperate with family physicians, public destigmatisation of depression, education of professionals (for example social workers, pharmacists, priests and policemen) and to work on key parts of the population including self-help for people with depression. The publication with information about depression for patients was published in 2005 and attached to IPH web page (45). The media campaign 'I Survived Depression' was launched in 2005. Local government and non-government organizations supported EAAD by preparing public discussions and education

seminars (46, 47). The campaign lasted for one month and used leaflets, TV and cinema spots and posters in public libraries, general practices, hospitals and centres for social work (48). In Slovenia there is no evaluation of this campaign yet, but suicide reduction tried to be explained with closer look to GP antidepressant prescribing (49) and to prevention activities of NGOs (Beškovnik, Švab , 2010 in review).



# International Study on Discrimination and Stigma Outcomes (INDIGO)

Slovenia took part in the INDIGO international study (50), led by Professor Thornicroft, on perceived stigma and discrimination of people with schizophrenia. A structured interview was completed with patients, using the Discrimination and Stigma Scale (DISC), which assessed experiences of being treated (dis)advantageously in several live domains. In Slovenia, 25 patients diagnosed schizophrenia in outpatient settings were interviewed. The average levels of stigma and discrimination in Slovenia were comparable to other European countries. There are above average, even if not statistically significant, levels of discrimination in employment, getting and keeping friendships, establishing family, housing, getting and keeping driving license and gaining social allowances. Overall, the diagnosis was a higher obstacle for schizophrenia patients in Slovenia than in other countries. But they nevertheless feel less discriminated in education, regarding personal safety, marriage, divorce and parenting (51).

#### Reports about education against stigma

In 2002 stigma and discrimination were addressed in an article about supervision in mental health (52). In 2004 an International Conference on Education in Mental Health was organized in Nova Gorica, involving discussion and research reports on stigma among other educational issues (53). In 2007 an evaluation of Slovenian university students' attitudes towards patients with mental health problems was published, showing big differences among faculties and lack of educational impact on students' attitudes towards psychiatric patients (54). The problem of self-stigma was reported through the research on prejudice regarding mental illness comparing university students and psychiatric patients, which revealed that patients stigmatise people with mental illness even more than the students (55). The first article about educating and communicating with media to reduce stigma was published (56).

Medical nurses researched nurses' attitudes towards depression and to test for the impact of education on these attitudes. They developed a questionnaire on attitudes towards depression by using principal component analysis. Nurses had positive attitudes towards people with depressive disorder and towards curing and healing from depression itself, but a somewhat neutral opinion on possible complications caused by depression. They concluded that overall, nurses' attendance at education workshops contributed to improvement in their attitudes. This in turn probably led to a decrease in the stigmatisation of depression (57).

## Mental health professionals

Mental health professionals have been involved in a range of articles and initiatives to develop the public and professional dialogue about stigma and mental illnesses over the last decade.

In 2002 the stigma of addiction disorders was addressed in the research of Bilban (58). In 2003 the biggest Slovenian journal published an interview with two psychiatrists aiming at reducing the stigma of severe mental disorders and informing readers about several groups of diagnosis linked to age and gender (59).

Four journal interviews with Andrej Marušič, who was leading the EAAD project about depression, treatment and overcoming prejudice were published in newspapers in 2005 (60). In these, European guidelines for stigma prevention were proposed. In this work the Slovenian author Andrej Marušič took part (61).

A handbook for teachers, students and researchers was published stressing the need for antistigma work in mental health environments (62).

Depression in the elderly population was addressed with the interview with the leading Slovene psychiatrist (63). Suicide in old age in Slovenia has been detected as a major mental health problem in Slovenia.

Nurses published another article about attitudes in the nursing process with depressed patients (64). They also researched attitudes and approaches to involuntary admitted patients and found that nurses emphasise the importance of ethics and personal values. The results indicate the importance of nurses' formal education, especially when caring for patients with mental illness (65).

Three brochures were published by a pharmaceutical company about depression, the connection of depression with somatic illness (coronary heart disease and cancer), with all three being available without charge in medical institutions (66).

Depression was connected with economic crisis, personal stress and unemployment, increased use of psychiatric services and suicide in several newspapers interviewing psychiatrists (67).

Slovenian general practitioners addressed the problem of discrimination of different marginalized groups as part of an international qualitative study with 233 general practitioners (GPs) in 11 countries and concluded that GPs should have adopted a more developed concept of patient involvement in their work (68). They researched also reasons for under-use of screening and brief intervention early response (SBI) by healthcare professionals to their patients' alcohol-

related problems. This qualitative research study, which used focus group discussions with GPs to identify incentives that may increase the use of SBI in Slovene general practice, showed that besides other motivation, adequate knowledge, skills, and record-keeping, and more extensive community action on the part of society as a whole e.g. government intervention is needed to improve their working conditions (69).

In 2008 a report on factors influencing early recognition of anxiety and depression in primary care was published (70). The results of two independent observational studies that were performed at the same time on a representative sample of family medicine practice attendees in Slovenia were compared. 10,710 patients participated in this Slovenian cross-sectional survey (SCS) and 1118 patients in a first round of a cohort study (PREDICT-D study). Logistic regression was used to examine the effects of age, gender and educational level on detection of depression and anxiety. A surprisingly low prevalence of major depression was found in PREDICT, especially considering the high rate of suicide and alcohol consumption previously reported in Slovenia (71). The problem of possible under-diagnosis was not discussed in these articles.

The attitudes of GPs towards the patients' right to self-determination was researched and found to be less important than other values, e.g. the obligation to promote medical benefit, to protect from harm, to distribute public resources fairly and to enhance the patient-physician relationship (72).

Two other articles were published about stigma connected with side effects of medication (73) and about stigma attached to children of people with severe mental disorders (74).

#### CONCLUSIONS

The overview of Slovene research and public media reports on stigma and discrimination presents a serious lack of research of known patterns of stigma and discrimination associated with depression (e.g. public surveys, controlled studies, patterns of stigma and discrimination in key settings, such as schools and workplaces), but relatively strong pointers for promising practice for effective interventions to reduce stigma and discrimination in relation to mental health problems and strong involvement of NGOs and the National Institute for Public Health. Professionals, NGOs, individuals with personal experience of stigma and researchers are strongly interested in stigma, particularly regarding suicide, which is a major public health problem in Slovenia. The overview also shows an important media contribution to reducing stigma in this country and several examples of good practice. In spite of lack of funds for programmes and research (except from short EAAD funding), high sensitivity for stigma issues is perceived, which might be culturally influenced. A systematic and growing amount of data on prevention activities is observed, influenced by international guidelines. We also perceived a very coordinated set of actions amongst the government institution (IPH) and NGOs with participation of empowered individuals, even though supported with little or no resources. The relatively small population number that demands openness to other experience and praxis abroad and high commitment allows Slovenia to build a strong anti-stigma campaigns. The National Plan for Mental Health in procedure right now should facilitate improvements to research, the evidence base and upgrade of this action.

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#### **ANALYSIS OF THE LITERATURE ON ADDRESSING STIGMA IN SPAIN**

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#### **INTRODUCTION**

Mental health policy-making power in Spain lies at regional level, with health authorities and regional health governments playing a central key role. The Ministry of Health and Consumer Affairs maintains responsibility for several health policy issues, including coordination and education. Ten of the seventeen regional health ministries have planning offices. "Health Plans" developed by the Ministry of Health and Consumer Affairs and the autonomous communities are the principal instruments for achieving health goals. The 17 autonomous communities hold health planning powers as well as the capacity to organize their own health services in their regions. The Inter-territorial Council of the NHS, composed of representatives of the autonomous communities and the State, promotes the cohesion of the system.

Mental Health policy is born out of the previous public health legislation. The components of the policy are advocacy, promotion, prevention, treatment and rehabilitation. A national mental health programme is absent, however, there are mental health plans formulated by each Autonomous Community. These plans are very similar in their theoretical formulation but they differ in their application. There are also significant differences with regard to funding of resources for psychiatric care among them.

Health plans are the principal instrument used by the health authorities to guide and direct their resources towards previously defined objectives of health. They embrace the main objectives of the corresponding health authorities and establish the actions and resources required for their development. Health plans are the essential strategic tool at regional level for the planning and coordination required when establishing the framework for all the actions to be carried out in the health areas of the autonomous communities.

Health plans drawn up by the autonomous communities take their references from the initiatives established at national and supranational level such as the community action programme for health 2003-2008. Their elaboration is based essentially on demographic analysis and the analysis of morbidity and mortality, epidemiological indicators and expenditure on health and social services. They have incorporated strategies for including cross-sector participation and gender perspectives. Instruments have been established to monitor them, and there are even institutions specifically created for this end (such as the Health Plan Office of the Balearic Islands).

Each autonomous community has developed its respective health plan, which may vary in duration (from two to four years on average), and in its content, which responds both to the circumstances and the priorities of the public health policy of the community concerned. (Ministry of Health and Consumer Affairs 2008, www.msc.es)

Recently, the Royal Decree law 1030/2006 of 15 September defined the NHS's portfolio of regular services. The portfolio guarantees citizens' rights to the same services regardless of the Autonomous Community and the providers identity. Guaranteeing equality of access, irrespectively of an individual's place of residence, is particularly relevant in the Spanish context, given the irregular population distribution amongst the various AC. The main political initiatives aimed at curtailing inequalities in terms of access to health services have focused on this objective. The royal Decree takes in the entire range of services provided by the health system without introducing any new elements. With regards to the ordinary clinical services, this Decree establishes the appropriate method of coordinating and organising the provision of healthcare, thereby contributing to the improvement of access to health care in remoter areas.

This measure will contribute to ensuring each citizen's access to effective and egalitarian conditions, defining quality health care, improving cohesion and helping structure the Spanish NHS. Some of the criteria used to elaborate the portfolio are the following: care for less protected groups and high-risk groups and care for those with greater social needs.

An extensive analysis of all the peer review and report literature available has been conducted in order to elaborate the present report on the evidence base and pointers for promising practice for effective interventions to avoid stigma and discrimination in mental health issues. In the elaboration, a search for patterns of stigma and discrimination associated to depression has been carried out.

## **METHODOLOGY**

Databases and internet searches have been used in order to identify programs and public surveys related to the reduction of stigma in mental illness problems.

The terms used for the search were the following: Depression OR Dysthymia OR Adjustment Disorder OR Mood Disorder OR Affective Disorder OR Affective Symptoms AND Spain/AND Spanish. Stigma OR Attitudes OR Prejudice OR Stereotype OR Discrimination AND Spain/AND Spanish. Mental Disorders/Education OR Mental Disorder/Legislation and jurisprudence OR Mental Disorders/Prevention and control OR Mental Disorder/Rehabilitation AND Spain.

The Databases used for this research are the following:

PUBMED: Pubmed is a service of the US National Library of Medicine that includes over 19 million citations from MEDLINE, biomedicine, other life science journals and online books. Scientists all over the world consult this database for their daily research.

PSYCHINFO: PsycINFO is an abstract database that provides systematic coverage of the psychological literature from the 1800s to the present. It is used by psychologists and professionals working in a field related to mental health.

EMBASE: Embase is a comprehensive database which holds over 20 million indexed records from more than 7,000 active, peer-reviewed journals. It is used by professionals working in biomedical, clinical or regulatory fields.

COCHRANE PLUS Library: the Cochrane Library includes a collection of systematic checking based on controlled clinical trials and effectiveness and evidence checking based on other sources.

WEB OF KNOWLEDGE: the Web of Knowledge is a web technology-based platform including references from the main scientific publications related to any kind of discipline of knowledge.

Other WebPages used for the research were: The Ministry of Health webpage The Spanish Federation of Associations of Families and People with Mental Illness webpage

### **FINDINGS**

There appears to be a lack of information related to stigma and mental illness in Spain, and more concretely related to stigma and depression. It has been difficult to find initiatives in this field and the most part of the information is on mental illness and not specific for depression.

Programs or initiatives found through the methods specified:

Competition of short movies on "Cinema against stigma and depression"

Organised by Lundbeck enterprise in 2008-2009 where the short movies "Tres tigres" by Artur Rodríguez, "En zapatillas" by Daniel Alfonso and "Nuestras estrategias" by Dudac y Sergi Cervera were the winner. The prize was 15.000 Euros for each one. The members of the jury were: José María Sánchez-Monge, the chairman of FEAFES (Spanish Federation of Associations of Families and People with Mental Illness); Tricicle (Spanish comedians related to public environment) and the psychiatrist Juan José López-Ibor, expert in mental health issues. The short movies showed an original reading of the role of stigma, treatment and recovering in the life of a person with depression. (FEAFES, 2010)

Collaboration agreement between the Ministry of Health and FEAFES

Developed in order to establish awareness actions and fight against social stigma in people with mental illness and their families. It will include multidisciplinary teams with different professionals in mental health, in order to guarantee a global and assertive care. The objective is that the very person with mental illness has the guarantee of an integrative treatment including all the therapies required for her/him. The Mental Health Centre would be the basic care structure. The collaboration agreement will also include the support to the "training of trainers" in mental health, through the Families' School and the Patient's School (Spanish Ministry of Health, 2010).

Observatory of Mental Health

October 9th 2008 The Ministry of Health creates the Observatory of Mental Health together with the Spanish Psychiatry Foundation. The objective is to cover the information needs for these disorders into the National Health System (Spanish Ministry of Health, 2010). The functions of the Observatory are: 1) Dissemination studies, researches and actions (information campaigns) on risk factors and mental health in the population, 2) Reports on the sociological and health data and indicators, according to the contents of the Mental Health Strategy and the Mental Health Information System, 3) Reports, studies or analysis on the needs in mental health and 4) The main aim is to favour the cohesion, equity and care quality, to correct the inequalities on mental health in the Mental Health Strategy Framework.

Emilia Project (2005-2010)

The objective is to improve social inclusion and to make it easier to gain employment for mental health services users. This will be achieved through Lifelong Learning (LLL) and the promotion of the users' empowerment. It intends to create work places inside the mental health services in order to give trained users the opportunity of work as trainers and educators for other less-experienced users. The methodology is the creation of users, families and professionals groups with content based on the Lifelong Learning methodology. (Paz Flores et al, 2008)

Severe Mental Disorder Care Program (PA-TMG)

On January 2005 the Department of Social Well-Being from the Navarra's Government published the "Care Program for People with Severe Mental Disorder" (PA-TMG). (Brugos et al, 2007)

Others

Epidemiology of major depressive episode in a southern European country: Results from the ESEMeD-Spain project" (Gabilondo 2010).

Mental Health, Style Guide for Mass Media (elaborated by FEAFES). Source: Internet Explorer, Google Research.

Evaluations of the programs previously sent to the ASPEN group:

"One out of four" (Uno de cuatro)

There has been an evaluation of this program through a report in peer reviewed journal papers. Aim: The aim of the evaluation is to understand the changes of the perception of the mental illness in the general population and other specific groups. However this evaluation is difficult to achieve. We also intend to measure the satisfaction of the users attending the activities of the project.

Method: The method of the evaluation was the number of people attending the activities, the audience of the TV and radio campaign, the satisfaction questionnaires and other qualitative evaluations.

Results: The results of the evaluation were there are known difficulties to measure the interventions impact, especially those related to communication campaign. Measurement of effectiveness in mass media advertisement requires complex and limited reliability studies. It is risky to offer ciphers about reached public and impact.

"Chamberlin project"

There has been an evaluation of this program through a report in peer reviewed journal papers. Aims: The aims of the evaluation were to assess the integration, rehabilitation and attitude changes related to people with mental illness.

Method: The methods of evaluation were: Presence in mass media, number of visits to the web page, number of links references to the project's web page, petitions of the comic/DVD, number of beneficiaries of the materials' project, reached population, collaborators, number of conferences/training courses etc, cooperation with other countries, material utility, impact of the project in different sectors of population, impact in national and international territories,

number of entities applying for collaboration, training courses for workers, and number of contracts.

Results: A continuous evaluation will be done throughout the project using the following indicators: 1) The improvement of the mental illness social image, 2) Impact on social/education/health approaches, 3) Improvement of effectiveness in labour integration, and 4) Labour integration of people with mental illness.

"Radio Nikosia"

There has not been any evaluation of the program. The only way of evaluating the radio program is the number of listeners (more than 110,000) and comments of people, blogs and forum opinions.

"Schizophrenia Open The Doors"

There has been an evaluation of this program through reports and peer reviewed journal papers.

Aim: The aims of the evaluation were to demonstrate the effectiveness of the program.

Methods of evaluation: Before the start of a number of antistigma interventions in 2001, a professional survey institute was commissioned to conduct a representative telephone survey in 6 German cities (N=7225). The cities were chosen with respect to the implementation of antistigma programmes (Düsseldorf, Munich), awareness programmes (Bonn, Cologne; with the aim to enhance early recognition of schizophrenia), and none of the programmes (Berlin, Essen). A panel design follow up survey (N=4622) was conducted in 2004. Stereotypes, beliefs and attitudes about schizophrenia and social distance i.e. the distance between different groups of society towards people with schizophrenia, and the knowledge of antistigma projects were assessed.

Results of the evaluation: Several measures to tackle the stigma in certain target populations have been proven successful. The studies carried out after the project provided limited evidence for the efficacy of anti-stigma interventions on the population level in Germany.

Studies

After analysing the existing literature addressing stigma in our country, the following studies were found relevant for the purpose.

"Metacognitive profile of paranoia and depression: are there moderation effects of metacognition into psychological wellbeing" (Valiente et al 2010)

Methods: Participants were 40 in-patients experiencing persecutory beliefs (meeting DMS IV-TR criteria for Schizophrenia or other Psychotic Disorders), 35 depressed patients who met DSM-IV-TR criteria for a current depressive disorder (mainly outpatients) who had never experienced persecutory delusions and 44 non-psychiatric controls. Each participant completed the Scales of Psychological Well-Being (SPWB) (Ryff & Keyes, 2002), the Meta-cognitive Questionnaire (MCQ-30; Wells & Cartwright- Hatton, 2004), the Beck Depression Inventory (BDI-II; Beck, Steer & Brown, 1996) and the Persecution and Deservedness Scale (PaDS; Melo, Corcoran, Shryane and Bentall, 2008). One-way between-groups analyses of variance were used to investigate the group effect and meta-cognitive level effect for all psychological wellbeing dimensions. Stepwise

multiple regressions were used to assess the moderating effect of meta-cognitive beliefs in paranoia to explain subjective wellbeing. In all analyses current depressive mood was controlled for.

Results: According to the analyses of variance, high positive beliefs about worry are related in paranoid patients to higher self acceptance, relationships with others and self-knowledge scores whereas is related to lower scores in depressed patients. Moderation analyses show that self-consciousness moderates the relationship between paranoia and all psychological well-being dimensions. All moderation analyses show a greater level of psychological well-being when participants presented high scores in both meta-cognition and paranoia.

"Perceived stigma among individuals with common mental disorders" (Alonso et al 2000)

Aims: To identify the correlates and the impact of stigma among individuals with common mental disorders.

Methods: Cross-sectional, household interview survey of 8796 representing the noninstitutionalized adults of Belgium, France, Germany, Italy, the Netherlands and Spain. Two perceived stigma questions (embarrassment and discrimination) were asked to respondents with significant disability. Health-related quality of life measured by the SF-12, work and activity limitation and social limitation were also assessed.

Results: Among the 815 participants with a 12-month mental disorder and significant disability, 14.8% had perceived stigma. Stigma was significantly associated with low education, being married/living with someone and being unemployed. Perceived stigma was associated with decreased quality of life (SF-12 PCS score –4.65; pb0.05), higher work and role limitation and higher social limitation.

Conclusion: Individuals with mental disorders are more likely to report stigma if they have lower education levels, married or unemployed.

"Stigma and discrimination towards people with schizophrenia--a survey of studies and psychological mechanisms" (Jackowska 2009)

The stereotypes and sigma associated with mental disorders are frequently the main obstacles preventing early and successful treatment. Particularly in the case of schizophrenia, the burden of stigma often leads to chronic social impairment. In the paper, the prevalence of different public beliefs about mental disorders and varied components of the stereotypes of schizophrenia among respondents living in several European countries (Poland, Switzerland, Germany, Croatia and Spain) are presented. The data have indicated that patients with schizophrenia and their families have experienced social distancing, exclusion and rejection not only from the general public but also from mental health professionals. In general, respondents are fearful of people diagnosed with schizophrenia and desire emotional distance from them. The public attitudes tend to characterize people suffering from schizophrenia as dangerous, unpredictable, unreliable and so on. The article describes chosen psychological mechanisms that are associated with the presented results and explain the stigma attitudes of respondents.

Descriptive study of stigma associated with severe and persistent mental illness among the general population of Madrid, Spain (Crespo et al 2008).

The aim was to analyse the stigma associated with severe and persistent mental illness in the general population of the community of Madrid, Spain, as a first step to promote strategies to

fight against it. 439 participants showed adequate general knowledge about mental illness, but a high degree of confusion with learning disabilities. Stigmatising attitudes focused mainly on the disposition to help and on pity. Moreover, there were some perception of contamination and pity toward other family members. Psychosis seems to attract more stigmatising attitudes than cancer and depression, but less than cocaine addiction and AIDS.

Means of communication, stigmatisation and discrimination in mental health: Elements for a reasoned strategy (López 2007).

This article provides an overview of current knowledge on the role of communication in reproducing negative social attitudes towards persons with severe mental illnesses, and indicates the possibilities and the limitations of any attempt to alter these messages. A technological approach is used (based on scientific knowledge and the best available empirical evidence) to consider the role of the media (in reproducing and reinforcing existing attitudes), the uses and limits of politically correct language, and the culture of professionals, in order to develop a complex, comprehensive, long-term study. This article also gives some examples of such work carried out in Andalusia

Attitudes toward psychiatric drug treatment: the experience of being treated (De las Cuevas and Sanz 2007)

Background: Effectiveness and tolerability of psychiatric medications are not only determined by the drug's pharmacological profile but through the interaction of different factors, including patients' attitudes toward their prescribed medications. Increased knowledge about those attitudes may help prescribers to improve patient concordance and thereby the effectiveness of the pharmacological therapy.

Objective: The goal of this study was to assess stable psychiatric outpatients' attitudes toward psychiatric drug treatment and to what extent patients and public opinions on this subject diverge as a consequence of being on this type of medication.

Methods: Two anonymous self-reported questionnaires [Drug Attitude Inventory (DAI)-10 and an abridge version of Beliefs about Medicines Questionnaire (BMQ)] were administered to 270 stable psychiatric outpatients under treatment and 292 citizens naïve to psychotropic medication.

Results: Psychiatric patients showed a more positive attitude toward medication (DAI score 3.6 vs. -0.7; range -10 to +10; negative to positive). Up to 77% of patients showed positive scores compared with only 36% in the general population. Multiple regression analysis showed that none of the variables in the analysis have a predictive value with regard to the attitude toward psychiatric drugs used.

Conclusion The continuous use of psychotropic medication shapes the opinion of the users toward a more beneficial perception of medications, but opinion amongst the general population, where stigmatizing attitudes are born, is more negative toward them. For psychiatrists and their patients, trying to achieve a better understanding of each other's expectations and reaching concordance is mandatory.

Stigma and discrimination towards people with schizophrenia and their family members (González-Torres et al 2007)

Background: There is a scarcity of data regarding the actual stigma and discrimination experienced by patients with schizophrenia and their relatives. Those experiences can vary significantly depending on the specific social group involved. We have explored such phenomena in our culture with a qualitative technique.

Methods: We developed a qualitative study with focus groups of clinically stable outpatients with schizophrenia (N = 18) and relatives (N = 26). Three groups were performed in each sample. Results: Six categories of stigma and discrimination experiences were extracted from the patients' data: Mental illness versus lack of will, Prejudice related to dangerousness, Over-protection-infantilisation, Daily social discrimination, Discrimination in health care, Descendants, Avoidance-social isolation. Data from relatives were divided into three sets: discrimination towards the patients witnessed by relatives, discrimination suffered by the relatives themselves and discrimination exerted by the relatives on the patients.

The point of view of relatives of patients with bipolar disorder (Sierra San Miguel et al 2006)

As a result of the progressive deinstitutionalisation of psychiatric patients, there has been a growing interest in the role of carers over the past few years. In order to find out about the impact of the illness on carers, 88 relatives of patients diagnosed with bipolar disorder (DSM-IV) were asked to complete a self-administered questionnaire. This contained 65 items, covering, among others, various clinical and demographic aspects, the burden felt by relatives, their knowledge of the illness and attitudes towards it. It was found that a high percentage of relatives needed psychiatric help. They experienced disruption to their work, economic and social lives, as well as suffering a social stigma. While making a major contribution to the implementation of treatment, they complained of lack of information about the nature of the disorder and limited resources. Spouses, who were also questioned, described the high impact on their marital and sexual relationships and co-parenting. It is therefore necessary to identify the factors that contribute to stress on the family. Psycho-educational groups for relatives can help to do so, improving their coping skills and knowledge of the illness, and reducing their distress and subjective burden.

Work integration of people with severe mental disorder: A pending question (<u>Rodríguez-Pulido</u> et al 2004)

For most people, work is psychologically beneficial. Scientific discoveries in brain regeneration and stimulation, the new integrative concepts on incapacity and the social tendencies towards full employment offer in this 21st Century new opportunities for all of us, including people with severe mental disorders. This paper argues that the elimination of cultural barriers related to stigma and discrimination would be essential for this reality to be implemented. With appropriate support they argue that between 30 % and 40% of people with severe mental illnesses are able to keep a job. More research has to be undertaken on ways and techniques for helping patients to obtain and maintain a job. Whereas new legal developments promote their integration in the work force, the lack of adequate psychiatric support systems would make this aim ineffectual. We have to apply techniques with demonstrated scientific efficacy. Most experts from several countries coincide on the validity of normalized contexts as the appropriate terrain for social integration in its most ample sense.

Knowledge and perception about depression in the Spanish population (Comas & Álvarez 2004)

The aim of this study is to investigate the Spanish people's perception of depression. Identification of misconceptions about depression will be the first step to correct them and to contribute to the patients' well being.

Material and methods: More than 1,000 structured surveys were conducted all around Spain with segmented representation for each regional community.

Results. Two out of three interviewed people considered depression to be a disease, in a somewhat higher degree those who had experienced depression (67%). Forty two percent of people thought depression affects more than 25% of the population. Spanish people think that the incidence of depression will increase in the future. Their opinion of the importance of depression is high, considering it among the three most prevalent diseases, even exceeding that of coronary diseases. Most people interviewed would not accept a pharmacological treatment of at least one year of duration. The most mentioned adverse effect of antidepressants is dependency, and it is the reason why interviewed people are reluctant to maintain long term treatment. Only 50 % of people treated for depression thought they had had enough family and social support. Eighteen percent of depressed people hide their diagnosis, basically for fear of stigma at work.

<u>Multi-centered study on the stigma, needs, and care of persons with long-evolving mental</u> <u>disorder</u> (Runte-Geidel et al 2004)

The main purpose of the MARISTAN Network multi-centred project was to study the stigma, needs, and non-formal care of persons with long-evolving psychotic illnesses.

Method: In its initial phase the study used a focus group technique, the idea being to obtain a global picture of stigma, needs and non-formal care from three different but complementary points of view: that of the patients themselves, that of relatives taking care of them, and that of professionals providing formal care.

Discussion: Results are still being analysed, but the importance of the study is evident at two main levels: that regarding the trans-cultural burden and that having to do with systematizing different phases of a qualitative research.

#### Fight against schizophrenia stigma (López-Ibor 2001)

Stigma, discrimination and prejudice against mental illnesses, those who have them and their families are common. Reducing stigma towards schizophrenia is essential for a better outcome of the disease. Stigma interferes with the detection of the illness, with adherence to treatment, with rehabilitation and with social reintegration. Stigma is prevalent within the family, health care systems and society at large. The WPA has developed a programme to fight the stigma of schizophrenia consisting on several modules: 1) Instructions on how to implement a campaign. 2) A monograph in schizophrenia. 3) A summary of the experiences in the sites where the program has been tested. 4) Further modules include information on similar campaigns and material such as leaflets, books and videos and concrete examples of discrimination.

A pilot study of the WPA Program was carried out in Madrid in 1999. A survey was undertaken to identify target populations and specific messages, showing little knowledge about the disease and a small amount of stigma. It was decided not to carry out an awareness campaign in the population, which has the risk of increasing stigma in parallel to increasing awareness but to explore the amount of stigma in the environment closer to the patient such as patients themselves, relatives, neighbours and health services staff. The stigma degree was much more significant. Activities related to this group of people were undertaken specially by training psychiatrists to identify stigma and discrimination and to fight it.

The outcome showed a great satisfaction among patients, relatives and physicians. A pilot media campaign was also undertaken. In previous years there was little information about schizophrenia in the mass media, only news on incidental problems of patients with schizophrenia. After the campaign news on the disease itself appeared in the mass media. The Madrid experience shows that the WPA Program strategies, based on doing population research and adapting the campaign to local needs, are most appropriate and that an anti- stigma campaign can be carried out with success. The same experience has been repeated in the year 2000 and part of 2001 in the whole of Spain. Health authorities of the Autonomous Community of Madrid, the City Council, the Department of Health and Consumption and the Department of Social Affairs and the INSALUD (National Institute of Health) were very helpful with the campaign. The program is supported by an unrestricted grant by Eli Lilly and various institutions and foundations have also collaborated.

# <u>Attitudes towards the mental disease among the general population of La Rioja</u> (Ortega Esteban et al 1994)

The objective of the study was to obtain information about the popular conceptions of mental illness. The Cohen and Struening Questionnaire of attitudes towards mental illness was administered to a representative sample of the population of La Rioja (Spain) aged between 15 and 65 years. The results obtained show a positive attitude towards mental illness but with significant differences regarding socio-demographic variables. The stigma factor of mental illness is present, and the positive attitude towards mental illness appears associated with a humanitarian approach towards people with mental illness.

# **CONCLUSIONS**

Nowadays, the Spanish population has a good knowledge of depression. However, there are still some prejudices that make it more difficult in terms of both the treatment and the recovery of depressed people and their social readjustment. These beliefs make up small stigmas that hinder treatment adherence, which is the most important factor to improve the outcome of depression. As it has been exposed in the present report, programmes created to tackle generalised stigma in mental health do exist, however no specific programmes to tackle stigma and discrimination in depression seem to exist. Patients and relatives describe a great variety of stigma and discrimination experiences in all areas of life, including health care. Isolation and avoidance are common reactions to those experiences. Publicising these stigma and discrimination experiences could help to reduce stigmatising attitudes in society and result in healthier reactions from patients, favouring a better course of the illness. Regarding medication, the continuous use of psychotropic medication shapes the opinion of the users toward a more beneficial perception of medications, but the opinion on the general population, where stigmatising attitudes are born, is more negative toward them. For psychiatrists and their patients, trying to achieve a better understanding of each other's expectations and reaching concordance is mandatory.

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# **REVIEW OF STIGMA AND DISCRIMINATION ASSOCIATED WITH DEPRESSION IN TURKEY**

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# **INTRODUCTION**

In terms of the literature on depression, stigma and discrimination, the number of research studies or surveys conducted on this subject are very limited in Turkey. The small number of studies investigating the attitude of the public towards people with mental illnesses show that the level of knowledge is very restricted and in general, the public has a stigmatising and discriminating attitude against people with mental illnesses.

Also, as opposed to the vast number of organizations and associations fighting against stigma and discrimination against schizophrenia patients, like the Schizophrenia Friends Association, there is no such organization related to people with depression.

We had indicated that there is no controlled study based on stigma and discrimination against people with depression, therefore we made a further literature review and managed to find a recent study investigating the attitude and knowledge of outpatients admitted to a psychiatry clinic in Turkey, about people with depression (Taskin, Yuksel, Deveci & Ozmen, 2009). Also in 2003 (Ozmen et al.), a vignette was published about the knowledge and attitudes of the public about depression. Ozmen has conducted another survey with students of a health school about their knowledge and attitudes against depression (Ozmen, Ozmen, Taskin, Demet, 2003).

The limited amount of research conducted on this subject indicate that the public can recognize mental illnesses sufficiently, but that they have a negative attitude towards people with mental illnesses and they are afraid of having a social relationship with those people. An important reason of this avoidance is that people with mental disorders are perceived as dangerous or violent by the public.

# METHOD

The research study of Ozmen et al. (2003) was based on the data which was gathered as part of the Investigating the Attitude of the Public about Mental Disorders Project (RUTUP) carried out by the Psychiatric Research and Education Centre Association (PAREM). A questionnaire consisting of 5 different sections and 142 questions was developed by the researchers for this project. One section consists of questions on attitudes and knowledge about depression. The research was carried out with 707 people over the age of 15, who were living in Istanbul, in year 2000. Face to face interviews with the sample were conducted in order to fill out the questionnaires.

The research study that was conducted with 200 outpatients applying to Psychiatry Polyclinic of Celal Bayar University Education and Application Hospital generated similar results (Taskin, Yuksel, Deveci & Ozmen, 2009). Again the depression sub-scale of the questionnaire developed

as part of the Investigating the Attitude of the Public about Mental Disorders Project (RUTUP) was utilized for data collection.

The same questionnaire that was developed within RUTUP was employed for the survey which was conducted with graduate students of the Health School of Manisa Celal Bayar University (Ozmen, Ozmen, Taskin, Demet, 2003). 268 participants, consisting of nursery, and health service department students were enrolled in the study.

# **FINDINGS**

The results of the study carried out by Ozmen (2003) reveal that 63.8% (n=451) of the sample think that depression is an illness and 14.3% think that it is a mental disorder. At the same time, a great majority of the sample (91.4%, n=646) think that depression is not a disorder, and that it is solely a condition which everyone experience from time to time. Also, with respect to the attitude of participants about a patient with depression living in the community; 22.8% (n=161) of the sample has claimed that patients with depression should not be walking around in the community freely, 40.2% (n=284) said they would not work with a person with depression, 64.6% (n=457) said that they would not marry a person with depression, 27.6% (n=306) said that people with depression would be violent.

Majority of the participants (%86, n=172) involved in the study about attitudes and knowledge of psychiatry outpatients with depression (Taskin, Yuksel, Deveci & Ozmen, 2009), think that depression is a mental disorder, 3.5% (n=7) think that people with depression are mentally disordered and 83.5% (n=166) think that depression is caused by social problems. Regarding the attitudes of outpatients against people with depression living in the community, 52.5% of the sample (n=105) said that people with depression would not be able to make right decisions about their own life, 50.1% (n=101) said they would not marry a person with depression and 28% (n=56) said that people with depression would be violent.

In the research study with graduate students from a Health School (Ozmen, Ozmen, Taskin, Demet, 2003), 78.1% (n=207) of the participants indicated that depression is a mental disorder, 74.3% (n=199) claimed that this situation results from the social problems a person experiences, 81% (n=217) said it is a condition of excessive worry and 87.3% (n=233) think that everyone can experience this condition from time to time. With respect to their attitudes about people with depression living in the community, 8.2% (n=22) said that people with depression should not be walking around freely within the community, 15.7% said people with such problems are violent, 22.4% (n=60) said they would not want to work with such a person and 65.6% (n=172) said they would not marry such a person.

# **CONCLUSIONS**

The survey which was carried out in Istanbul in 2000 (Ozmen, 2003) shows that a significant number of people think that depression is not an illness. It has been claimed that this could be due to the fact that depression as a clinic situation and depression as a term used for all kinds of hardship and demoralization are used intertwiningly. It was also observed that the public conceptualize depression as a state of mental weakness and excessive worry. Another outcome of the survey is that a great number of participants think that depression is caused by a condition of mental weakness and social problems. Only a small percentage think that it is a

genetically determined condition. Overall, the results of the survey indicate that the public living in Istanbul have a stigmatizing and discriminating attitude against people with depression. Half of the participants have claimed that they would not work with a person with depression, that patients with depression are violent and one fourth of the participants think that people with depression should not be walking around freely in public. The fact that they perceive people with depression as violent and disturbing individuals, exempt from ordinary relations and freedom to live in the community provides evidence for this assertion. However, it was also claimed that the survey results of the sample from Istanbul could not be generalized to the whole public.

The outcome of the study conducted with psychiatry outpatients shows that depression is mostly defined as a 'disorder' and a 'mental disorder'. Those ratios are higher than the results of the survey which was conducted with the general public in Istanbul. Those results indicate that being acquainted with psychiatry is a positive factor in terms of recognizing depression. Also the participants who define people with depression as 'mentally disordered' are considerably lower too. The reason for this is the stigmatizing quality of the term. The outpatient sample has more knowledge and experience about treatment, causes and implications about psychiatric conditions; therefore their attitudes are not as stigmatizing or discriminating against people with mental disorders as the general public. They have more positive attitudes against people with depression living in the public as well. Another explanation for their positive attitude could be the fact that they might be subject to discrimination and stigma of the public themselves. Still, it was observed that the participants are hesitating about marrying with someone with depression It was also observed that having a diagnosis of depression for the participant himself/herself did not make any difference in terms of the measured attitudes, whereas experiencing a depressive episode during the time of the interview caused the participants to display more negative attitudes against people with depression. The most probable reason for this difference is explained with the negative perception of people experiencing a depressive episode about their own self and the world (Taskin, Yuksel, Deveci & Ozmen, 2009).

The results of the survey conducted with graduate students of a Health School (Ozmen, Ozmen, Taskin, Demet, 2003), show that participants can differentiate between concepts of mental illness and mentally disordered and neurological disorder. They conceptualize depression mostly as a mental illness. As with other samples, depression is mostly thought as a condition resulting from social problems and a weakness of personality, which everyone can experience from time to time. When we compare the attitudes of graduate health school students against people with depression to the attitudes of other samples, it is evident that they have a much more positive attitude for people with depression living in the community. However, the ratio of the sample indicating that they would not marry a person with depression is almost the same with the results of the survey conducted with people living in the city. The most important socio-demographic factor influencing the attitude was found to be the gender. It was observed that men have a more positive attitude against people with depression living in the community.

Overall, more research on the subject of stigma and discrimination against people with depression as well as other mental illnesses are required in Turkey. The studies described in this report display current understanding and attitudes of different groups of samples. However, currently there is no association working in this field about people with depression and no suggested interventions for fighting against the stigma and discrimination of depression as a mental illness.

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