

MENTAL HEALTH AND INTEGRATION

PROVISION FOR SUPPORTING PEOPLE WITH MENTAL ILLNESS:
A COMPARISON OF 30 EUROPEAN COUNTRIES



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About this research

Few diseases are more poorly understood and more subject to prejudice than mental illness, and few impose the same magnitude of burdens on both the afflicted and society at large. And while a consensus has formed among caregivers, policymakers and patient advocates on the benefits of integrating the affected individuals into society and employment rather than sequestering them in institutions, few countries have come close to realising this ideal.

With this as background, The Economist Intelligence Unit (EIU) undertook a study aimed at assessing the degree of commitment in 30 European countries—the EU28 plus Switzerland and Norway—to integrating those with mental illness into their communities. The research was commissioned and funded by Janssen Pharmaceutica NV, part of the Janssen Pharmaceutical Companies of Johnson & Johnson, and was carried out during the first eight months of 2014.

This report focuses on the results of this benchmarking study, called the Mental Health Integration Index. The index compares the level of effort in each of the countries on indicators associated with integrating individuals suffering from mental illness into society. The set of 18 indicators were grouped into four categories:

- Environment for those with mental illness in leading a full life
- Access for people with mental illness to medical help and services
- Opportunities, specifically job-related, available to those with mental illness, and
- Governance of the system, including human rights issues and efforts to combat stigma

A full description of the methodology for building the index appears in the Appendix to this report.

In addition to the benchmarking study, the Economist Intelligence Unit carried out extensive desk research and conducted a programme of in-depth interviews with experts in the topic. We would like to thank the following experts for their participation in the interview programme:

- Mary Baker, past president, European Brain Council
- Gregor Breucker, division manager, Department of Health Promotion, BKK Federal Association
- Professor José Miguel Caldas de Almeida, professor of psychiatry and dean, Faculty of Medical Sciences, New University of Lisbon and co-ordinator of the European Union Joint Action for Mental Health and Wellbeing
- Johanna Cresswell-Smith, project co-ordinator, National Institute for Health and Welfare, Finland
- Angelo Fioritti, director, Mental Health and Substance Abuse Department, Bologna Health Trust, Italy
- Dr Josep Maria Haro, psychiatrist and project co-ordinator, ROAMER (Roadmap for mental health research in Europe)
- Dr Thomas Insel, director, US National Institute of Mental Health and chair, World Economic Forum's Global Agenda Council on Mental Health
- Kevin Jones, secretary-general, European Federation of Associations of Families of People with Mental Illness (EUFAMI)
- Martin Knapp, professor of social policy, London School of Economics and director, Personal Social Services Research Unit, National Institute for Health Research, UK

- Pedro Montellano, president, Global Alliance of Mental Illness Advocacy Networks (GAMIAN) Europe
- Dr Massimo Moscarelli, director, International Centre of Mental Health Policy and Economics
- Christopher Prinz, lead, Mental Health and Work project, OECD
- Stephanie Saenger, president, Council of Occupational Therapists for the European Countries
- Kristian Wahlbeck, research professor, National Institute for Health and Welfare, Finland and development director of the Finnish Association for Mental Health.
- Hans-Ulrich Wittchen, chairman and director, Institute of Clinical Psychology and Psychotherapy, Technische Universität Dresden
- Alina Zlati, director, Open Minds: Centre for Mental Health Research, Cluj-Napoca, Romania

We would also like to thank the following experts for their insights contributed during a separate series of in-depth interviews focused on individual countries. While most of their comments appear in a separate series of in-depth profiles of individual countries, some of their insights are found in this report as well:

Belgium

- Piet Bracke, president, European Society for Health and Medical Sociology
- Tom Declercq, professor, University of Ghent

France

- Yann Hodé, psychiatrist, Centre hospitalier de Rouffach; head, Profamille
- Pierre Thomas, professor of psychology, University of Lille

Germany

- Thomas Becker, professor and department head, Department of Psychiatry II, University of Ulm and BKH Günzburg
- Nicolas Rüsch, professor of public mental health, Department of Psychiatry II, University of Ulm and BKH Günzburg

Greece

- Christos Lionis, professor and director of the Clinic of Social and Family Medicine, University of Crete
- Stelios Stylianidis, professor of social psychiatry at Panteion University of Athens and scientific director, Epapsy

Hungary

- Dr Istvan Bitter, director, Department of Psychiatry and Psychotherapy, Semmelweis University, Budapest
- Tamás Kurimay, president, Hungarian Psychiatric Association

Italy

- Roberto Mezzina, director, Mental Health Centre, Trieste
- Lorenzo Toresini, recently retired head of South Tyrol Mental Health Service and president, Italo-German Society for Mental Health

Ireland

- Dr Shari McDaid, director, Mental Health Reform
- John Saunders, chief executive, Shine and chair, Irish Mental Health Commission

Netherlands

- Rene Keet, psychiatrist and director, Mental Health Centre, GGZ North Holland
- Frank van Hoof, senior scientist, Trimbos Institute

Poland

- Wanda Langiewicz, researcher, Institute of Psychiatry and Neurology, Warsaw
- Dr Jacek Moskalewicz, head, Department of Organisation of Health Service, Institute of Psychiatry and Neurology, Warsaw
- Dr Slawomir Murawiec, medical doctor, Institute of Psychiatry and Neurology, Warsaw

Spain

- Manuel Gómez-Beneyto, professor, University of Valencia and scientific co-ordinator of National Mental Health Strategy
- Pablo García-Cubillana, Andalusian Health Service
- Evelin Huizing, Andalusian Health Service

United Kingdom

- Paul Farmer, CEO, Mind
- Dr Helen Gilbert, fellow in health policy, King's Fund

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Executive summary

Mental illness exacts a substantial human and economic toll on Europe. World Health Organisation (WHO) estimates for 2012 show that in the 30 countries covered by this study, 12% of all disability-adjusted life years (DALYs)—a measure of the overall disease burden—were the direct result of mental illness. These conditions almost certainly also contributed to the large number of DALYs attributed to other chronic diseases. On the economic front, the best estimates are that mental illness cuts GDP in Europe annually by 3-4%.

Although the prevalence of many serious mental illnesses has remained stable over the long term, it is only recently that epidemiologists have begun to appreciate the scale of the challenge they represent. The ongoing ignorance about these conditions and the substantial stigma attached to them in much of society—including among policymakers and even medical professionals—continue to impede effective responses. The so-called “treatment gap” in mental health therefore remains huge: according to a recent, major review, only about one-quarter of those affected in Europe get any treatment at all, and just 10% receive care that could be described as “notionally adequate”.¹

Complicating Europe’s ability to respond to mental illness has been a sea-change in recent

decades in perceptions about what proper treatment and support should consist of. The consensus has moved away from hospital-based care—too often involving the literal locking away of a perceived problem—to finding ways for people living with mental illness to be treated, and to lead active lives, within the wider community. Even the definition of the goal of care has moved from a biomedical model of doctor-directed treatment aimed at alleviating symptoms to a psycho-social one focused on enabling affected individuals to recover their ability to live the lives they choose.

Overall, progress toward creating structures that can provide the mental health services Europe needs has been highly uneven. José Miguel Caldas de Almeida, professor of psychiatry at the New University of Lisbon and co-ordinator of the EU Joint Action for Mental Health and Wellbeing, explains: “Some countries ... have been very successful, others less so, and there are still many places where the transition is only partial.”

To better understand the current state of these efforts, The Economist Intelligence Unit, sponsored by Janssen, has created the Mental Health Integration Index, which looks not just at medical provision but also at factors related to human rights, stigma, the ability to live a fulfilling family life and employment, among

¹ Hans Wittchen et al, “The size and burden of mental disorders and other disorders of the brain in Europe 2010”, *European Neuropsychopharmacology*, 2011.

others. This study presents the findings of that index, while also drawing on in-depth interviews with experts in the field and substantial desk research. The report's key findings include the following:

- **The country leading the index is a surprise, but the weakest countries are less so.** Germany, the country with the highest overall score in the index, is unexpected in the leading position. Rarely listed by experts as on the cutting edge in this area, Germany's strong general healthcare system and generous social welfare provision have many attributes that are helpful to the effective integration of those with mental illness into society. More consistent with the conventional wisdom, the countries which follow close behind—the United Kingdom and several Scandinavian states—are frequently named as having examples of good practice in this area. Similarly, that the weakest countries in the index are largely from Europe's south-east is not a surprise. This is not merely a result of the need to overcome the legacy of communist-era psychiatric care: Estonia is 8th in the index and Greece, also in the south-east but never in the Eastern Bloc, finishes 28th. Instead, the south-eastern region has a long history of neglecting mental illness.

- **The leaders are not the only sources of best practice.** Experts from Germany and the UK readily admit ongoing, substantial problems with their care and integration efforts. On the other hand, because mental healthcare is frequently organised by region rather than at the national level, important islands of excellence exist in countries that are in the middle of the index rankings, such as Trieste in Italy, Lille in France and Andalusia in Spain.

- **Consistency pays off.** Of the top five countries in the index, Germany, Norway and the UK have consistently been looking at ways to improve mental healthcare and integration since the 1970s and 1980s. For Denmark and Sweden, this started in the 1990s. Moreover, generally those with the highest overall scores tend to do well

across all four index categories, while those in the middle tend to be less consistent.

- **Real investment sets apart those seriously addressing the issue and those creating "Potemkin policies" which are more façade than substance.** Overall country scores in the index correlate strongly with the proportion of GDP spent on mental health (figures are not available for spending on all areas of integration). To some extent, this connection arises because certain index indicators—such as the number of clinicians—are directly related to such spending. The correlation also exists, however, for index categories where such a direct link does not exist. This suggests that the investment figure is a proxy for seriousness in establishing good policy and practice. Such sincerity of intent is not always present: the area of mental health has many examples of policies—including entire national mental health programmes—that are largely aspirational.

- **Europe as a whole is only in the early stages of the journey from institution-based to community-centred care.**

- **Even deinstitutionalisation is still very much a work in progress:** Index data show that in a slight majority of the countries covered (16 out of 30) more individuals continue to receive care in long-stay hospitals or institutions than in the community, although of these, 13 countries have policies aimed at shifting more to community-based care. Slowing the change are the general complexities of large-scale innovation present in any medical field as well as the institutional interests of existing structures, such as psychiatric hospitals.

- **Data in the index's "Access to health services" category indicate that availability of therapy and medication is inadequate and that medical services for those with mental illness are poorly integrated:** The type of clinicians available vary notably within countries. Germany, for example, which comes first for Access, scores full points for its

number of specialist social workers per capita, but only 25.4 out of 100 for its number of psychologists. The type of services available by country can also be unpredictable: Latvia, for example, comes 25th in the Access category but is one of only four index states to provide a full range of mental health support in prisons. Such varying levels of strength impede the provision of holistic care.

● ***Effective care for those with mental illness includes integrated medical, social and employment services, but government-wide policy in these areas is the exception:***

Unemployment, social exclusion and poor housing are statistically both risk factors for and consequences of mental illness. The lines between medical care, social care and employment support are therefore blurry in this field. The index, however, shows that just eight out of 30 countries have even collaborative programmes between the department responsible for mental health and all of those tasked with education, employment, housing, welfare, child protection, older people and criminal justice. Worse still, such programmes do not necessarily produce fully cross-cutting policies.

● ***Such integration as exists is typically accomplished through locally focused mental health teams that can help the patient negotiate a range of government services:*** Index data indicate that some form of community-based assertive outreach is available in just 21 of 30 countries. Nevertheless, these programmes are often embryonic, and there are few examples in existence.

● ***Employment is the field of greatest concern for people living with mental illness and their families, but is also the index area with the most inconsistent policies across Europe:*** Inability to obtain gainful employment is, according to interviewees, the biggest frustration for those with mental illness. At the same time, policies related to work and mental illness differ markedly; the relevant

category of the index—the Opportunities category—sees the highest variation of any in the index. Moreover, only a handful of countries, notably Finland and France, get very high scores in the Opportunities category. Strength in this area may result as much from extensions to mental health of generous general social welfare provision as an integrated approach to mental health services. Also noteworthy here is that much direct assistance involves the provision of sheltered employment, which has a poor record of helping people with mental illness return to the mainstream world of work.

● ***Carers and families are an insufficiently supported resource:*** Only 14 of 30 countries have all of the following: funded schemes to support carers; guaranteed legal rights for family carers; and a support organisation. Meanwhile, 11 countries have either just one or none of these relatively basic forms of assistance. Families, however, play a substantial role in caring for many aspects of the lives of those with mental illness living in the community.

● ***Lack of data makes greater understanding of this field difficult.*** Lack of availability of pertinent data has greatly restricted what the index can cover. This is no surprise to experts interviewed for this study, who use words like “astonishing” and “daunting” to describe the data gaps surrounding mental health and integration. Even basic definitions are often contested, or at least not standardised, across national and professional boundaries. Better data, however, are essential to knowing how to make real progress. In particular, comparable information on outcomes, both clinical and patient-reported, still does not exist but is crucial for knowing what strategies and treatments work best. As Professor Hans-Ulrich Wittchen, chairman and director of the Institute of Clinical Psychology and Psychotherapy at the Technical University of Dresden puts it: “You can’t just triple the number of psychiatrists and hope things will improve.”

Five areas requiring greater attention

The index and accompanying analysis show five areas on which many European countries need to focus to provide better integration of people living with mental illness into society:

- Obtaining better data in all areas of medical and service provision and outcomes
- Backing up mental health policies with appropriate funding
- Finishing the now decades-old task of deinstitutionalisation
- Focusing on the hard task of providing integrated, community-based services
- Including integrated employment services provision

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Introduction: Europe's mental illness burden

About 38% of residents of the EU, or around 165m people in the region, are affected by a mental illness at some point in any given year

² Figures derived from WHO national figures for individual index countries for 2012, available at http://www.who.int/entity/healthinfo/global_burden_disease/GHE_DALY_2012_country.xls?ua=1. The WHO estimates do not include dementia as a mental illness, although it is listed as one under ICD-10.

³ Wittchen et al, "The size and burden of mental disorders." This study includes dementia among mental illnesses.

⁴ Sick on the Job? Myths and Realities about Mental Health at Work, OECD, 2012.

⁵ Chris Naylor et al, "Long-term conditions and mental health: The cost of co-morbidities", Kings Fund and Centre for Mental Health, 2012.

A substantial challenge

Mental illnesses are among Europe's most burdensome yet least addressed groups of ailments. Their impact is felt widely in the region, and yet the exact measure of the human toll is hard to determine. The measure depends on the precise boundaries of sometimes contested definitions of specific mental illnesses and their effects, as well as on the disputed dividing line between neurological and mental conditions.

Nevertheless, a variety of data indicate that the impact is substantial. The most restrictive measures consider only the *direct* results of the conditions defined as mental and behavioural disorders in the International Classification of Disease (ICD)-10 system of the World Health Organisation (WHO). These conditions include, among others, depression and schizophrenia as well as disorders related to anxiety, alcohol or drug use. According to the WHO's 2012 estimates, in the 30 European countries covered in this study such conditions account for 12% of the total burden from all diseases as measured in disability-adjusted life years (DALYs), a measure that takes into account both early mortality and years lived with disability. By comparison, this is over half the impact of cancer or heart disease and more than four times that of diabetes.²

A recent major study of brain diseases by the European College of Neuropharmacologists (ECNP) and the European Brain Council (EBC) paints an even starker picture. It found that 38% of residents of the EU, or around 165m people in the region, are affected by a mental illness at some point in any given year and that depression

is the single condition with the greatest burden of any disease on the continent.³

The full impact of mental illness, though, is likely to be much higher. Suicides, although sufficiently linked with mental illness to be used as a common proxy for the overall mental health of a population, are treated separately by the WHO in its estimate. So are deaths and disabilities resulting from other major chronic diseases, even though mental illness frequently co-exists with them: the Swedish Survey on Living Conditions in 2005 found that over half of those with a mental illness had at least one other major condition. Data for Europe as a whole suggest that this figure reaches 80% among those with mental illness aged over 50.⁴

Depression, for example, is common among those suffering from neurological conditions. Going beyond diseases of the brain, individuals with diabetes, heart disease and chronic obstructive pulmonary disease are around two to three times more likely than the general population to have a mental illness—typically depression or an anxiety disorder.⁵ The difficulties this raises in managing their physical ailments, and the resultant negative health outcomes, are also marked. Studies in the United States and Scandinavia indicate that overall life expectancy for those with a serious mental illness is between 15 and 25 years lower than for the general population, even though the mental conditions themselves are rarely deemed to be the cause of death. The American research, in particular, indicated that this early mortality was often attributable to complications from chronic physical conditions.

A recent academic study found that in 2010 mental illness led to direct and indirect costs of €461bn (about US\$600bn) in Europe, roughly 3.4% of GDP.

Mental illness is often an illness of young people: 75% have their onset before the age of 25.

⁶ Barbara Mauer, "Morbidity and Mortality in People with Serious Mental Illness", National Association of State Mental Health Program Directors Medical Directors Council, Technical Paper 13, 2006; Kristian Wahlbeck et al, "Outcomes of Nordic mental health systems: life expectancy of patients with mental disorders," *British Journal of Psychology*, 2011.

⁷ Anders Gustavsson et al, "Cost of disorders of the brain in Europe 2010", *European Neuropsychopharmacology*, 2011.

⁸ *Sick on the Job? Myths and Realities about Mental Health at Work*, OECD, 2012.

⁹ Naylor et al, "Long term conditions and mental health", King's Fund and Centre for Mental Health, 2012.

As a result, they would not be included in calculations of the impact of mental illness.⁶ This arises from a combination of often sub-standard physical medical care for those with mental illness and a statistically higher willingness of these individuals to engage in risk-laden behaviour such as smoking.

Mental illness also takes a large economic toll. Again, figures are inexact, but a recent academic study found that in 2010 mental illness led to direct and indirect costs of €461bn (about US\$600bn) in Europe, or roughly 3.4% of GDP.⁷ This is consistent with other research over the last decade that puts the figure between 3% and 4% of GDP. The indirect costs, in particular, have been rising rapidly. The OECD reports that mental disorders are responsible for a rising proportion of work disability claims in virtually all member states. On average, the figure is around one-third of all such claims, and in some countries it reaches nearly one-half.⁸ Hidden costs from unrecognised effects also drive up the economic burden. A 2012 study by the Kings Fund and Centre for Mental Health estimated that the UK's National Health Service (NHS) spent £10bn (US\$16bn) per year dealing with the negative effects of mental illness on other long-term chronic conditions.⁹

Most research indicates that the extent of mental illness in Europe has remained relatively constant in recent decades. What is different, however, is a greater recognition of the extent of the problem, which helps explain the rising number of disability claims. As Angelo Fioritti, director of the Mental Health and Substance Abuse Department of the Bologna Health Trust in Italy notes: "Thirty years ago the predominant perception was that mental illness was limited to a few thousand people secluded in a hospital. Now we know that anxiety, depression and other problems are common and something that can involve any person." Professor Caldas de Almeida agrees: "Until even ten years ago there was a large ignorance about the real importance and magnitude of mental health problems,"

something which epidemiological data have helped to dispel.

An important reason for this shift has been a change in how we understand the burden of disease. Before the introduction of the DALY, this was seen largely in terms of mortality, but the difficulty of mental illness is not so much death as often many years of disability. Using DALYs, says Dr Thomas Insel, director of the US National Institute of Mental Health and chair of the World Economic Forum's Global Agenda Council on Mental Health, "helps us to realise that in a world of chronic diseases, mental illness will represent more disability than previously appreciated." In particular, he adds: "One of the ways that mental illness differs from all other illnesses is that we are talking about illness of young people: 75% have their onset before the age of 25."

A weak response

This revelation in epidemiological data of the extent of the mental illness burden, while necessary for progress to occur, has also made clear significant problems with provision for those affected by mental illness. Professor Wittchen explains that it has become apparent that "mental disorders are *the* challenge of the 21st century, not because mental health is deteriorating, but because we are unable to cope by providing effective prevention and treatment of them."

The most obvious indication of this inability is the huge treatment gap between those who have a mental illness and those who receive appropriate care. The ECNP/EBC study found little change from earlier research indicating that only about one-quarter of those with a mental illness in Europe received any treatment, and about 10% had care which could be called "notionally adequate". Given the disease burden, this represents "an appalling ethical challenge that doesn't generate the response it should", according to Mary Baker, past president of the European Brain Council.

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The treatments available are not always adequate. Dr Insel notes that “we don’t have the kind of consistently and comprehensively effective treatments we need. Not everyone will fully recover.” Nevertheless, he adds, even these restricted tools can make an important difference. “Many [people living with mental illness] can function independently to some extent, and some can recover completely for extended periods.” Professor Wittchen adds that much of the progress in this field has occurred in the last two decades and expects that, as new treatments and strategies become established, the effects on incidence and prevalence should become apparent.

The barriers to the people who need it receiving the care available are many and varied, but ongoing ignorance remains an issue. Although people in general are more aware of certain conditions, notably depression, than they were in the past, says Pedro Montellano, president of GAMIAN-Europe, a pan-European alliance of mental health patient groups, he does not “think that they are aware of the real burden” on society, especially the direct and indirect impact on GDP. Similarly, for employers, Christopher Prinz, lead of the OECD’s Mental Health and Work project, says that it is “not a given” that even sympathetic employers will understand the business case for steps to enhance the integration of those with mental illness into the workplace. There has been some improvement, but from a very low base. As late as 2006 a British survey of major employers found that 31% of executives—drawn from human resources and general management—believed that none of their employees would develop any mental illness throughout their careers. This has now declined to 4%, but other misperceptions remain.¹⁰ Mr Montellano says: “If you tell employers that a person with bipolar disease can work as well as other employees, they would be quite surprised. It is something new for them.”

Lack of understanding among policymakers

Despite some improvement noted by interviewees, a lack of understanding also still affects policymakers in a number of European countries. Alina Zlati, director of the Open Minds: Centre for Mental Health Research in Cluj-Napoca, Romania, believes that in eastern Europe “we have not yet reached the point where policymakers are well equipped to take decisions [on mental health]. They are made more based on politics than on evidence.” Similarly, Stelios Stylianidis, professor of social psychiatry at Panteion University in Athens and scientific director of Epapsy, a Greek mental health non-governmental organisation (NGO), notes that “over 20 years I have met 42 ministers and vice-ministers of health with suggestions and proposals for the future. I’m not eager to meet another one. I’m worn out with all the efforts to convince political decision-makers and make them understand what we are talking about.” Others see greater progress, especially in western Europe, but are not sure whether better information will bring about change. As Martin Knapp, professor of social policy at the London School of Economics (LSE), puts it: “If the message hasn’t got through [to officials], I don’t know what they do with their lives to avoid it. If they act is another matter, because they operate under many constraints.” This caution is understandable. Mental healthcare receives so little attention that it is frequently referred to as a “Cinderella service”.

More important than simple ignorance in explaining the poor response to mental illness in Europe, say a large number of those interviewed, is stigma. Mr Montellano agrees: “People are not very familiar with mental illness and how it is treated. They feel frightened and don’t want to be involved.” A 2010 Eurobarometer poll found that in the EU 22% of people admitted they would feel uncomfortable talking to somebody

¹⁰ Claire Henderson et al, “Mental health problems in the workplace: changes in employers’ knowledge, attitudes and practices in England 2006–2010”, The British Journal of Psychiatry, 2013.

Shifting models of care requires any number of inter-related changes, from extensive training to new budgetary arrangements to developing new, co-operative working relationships.

with a significant mental health problem, and another 11% said that they did not know how they would feel in such a situation. Nor is the issue confined to the public. Stigma among clinicians—both general and psychiatrists—as well as medical students is often a problem.¹¹ Similarly, Stephanie Saenger, president of the Council of Occupational Therapists for the European Countries (COTEC), explains that “mental health is still seen as something for other people, something different and spooky. If I work with [occupational therapy] students and they think about mental health, most of them get uncomfortable or even frightened.”

The impact of this stigma is not restricted to lack of attention to mental health by healthcare systems and policymakers. A recent meta-analysis of studies involving over 90,000 people found that it is, perhaps predictably, a leading barrier to seeking out treatment.¹² A number of large-scale national efforts have attempted to address stigma against those with mental health problems. Simply educating people, however, does not seem to be enough. As the experience of the Time to Change campaign in England shows, progress is possible with more nuanced campaigns, but not easy [see box].

Beyond ignorance and stigma, efforts to provide better care for those with mental illness also face important practical impediments. Over the last few decades views on how and where patients should be treated have changed dramatically. Rather than, literally, locking the problem away in remote hospitals, the consensus is now that patients are best treated through the collaborative provision of integrated medical and social services in community settings, with only those who are most unstable going to sheltered housing or wards in general hospitals. This change in thinking has coincided with an equally dramatic and related shift in defining the appropriate goal of care. Rather than a focus on the alleviation of medically defined symptoms, the emphasis is increasingly on “recovery”, or attempting to help individuals affected by mental illness achieve a reasonable quality of life

and level of independent functioning largely as defined by them. Both these trends require a shift away from an institutional focus to integrated care that combines medical elements with support in areas such as housing, employment and social relationships.

Barriers to integration

Getting from A to B on this journey is no small task. Healthcare is an area where innovation is notoriously difficult. Although shifting the approach to community-based and recovery-oriented care is broadly accepted in principle, the change is not complete everywhere. Kevin Jones, secretary-general of the European Federation of Associations of Families of People with Mental Illness (EUFAMI), notes that for many health professionals “part of their training still includes a negative approach to mental illness. The focus is about getting the patient stable, rather than on the recovery of the patient.” This slowness to change has important practical implications. For example, Christos Lionis, professor and director of the Clinic of Social and Family Medicine at the University of Crete, notes that the poor integration of mental health into the Greek curriculum for general practitioners (GPs) leaves them ill equipped to manage mental illness in an integrated model: “The knowledge and skills, even the concepts, are lacking to apply psychological modalities in coping.”

Moreover, even in the best of circumstances, bringing into being new models of care is difficult. Shifting requires any number of inter-related changes, from extensive training to new budgetary arrangements to developing new, co-operative working relationships between a range of professionals and carving out a new role for patients. The result has been slow, highly uneven progress. Professor Caldas de Almeida explains: “Some countries in Europe have been very successful, others less so, and there are still many places where the transition is only partial.”

At the same time, this transition is taking place against a background of hostility among

¹¹ Graham Thornicroft et al, “Discrimination against people with mental illness: what can psychiatrists do?”, *Advances in Psychiatric Treatment*, 2010.

¹² S Clement et al, “What is the impact of mental health-related stigma on help-seeking? A systematic review of quantitative and qualitative studies”, *Psychological Medicine*, 2014.

This transition is taking place against a background of hostility among stakeholders that is much more pronounced than in almost any other branch of medicine

stakeholders that is much more pronounced than in almost any other branch of medicine. This goes well beyond disputes between professionals from different types of medicine over the appropriate definition and treatment of disease. The movement for deinstitutionalisation, for example, grew as much out of human rights activism as purely clinical considerations. Moreover, many patient groups use the terms “users of psychiatric services”—or service users—and “survivors of psychiatry” almost interchangeably.

Ms Baker notes that coming from being a patient representative for those with Parkinson’s Disease—where patient-clinician relations are very positive—to mental health she was surprised to find “a totally different world” in which some leaders in the patient community typically “had little regard for their doctors” because of the legacy of past treatment. “Some of them had

had electric shock, some had been restrained. It wasn’t a wonderful patient-doctor relationship, where you discuss and agree. It was a battle.” In such circumstances, encouraging better social integration of those with serious mental illness requires more than the usual degree of sensitivity.

To help with this task, this study draws on a unique new tool—the Mental Health Integration Index. The intention is to provide a better understanding of variations in the area of active integration of those with serious mental illness into community life and mainstream medical care across Europe and, in so doing, to shed light on how well different countries do in this area. It also hopes to point towards best practice in order to help countries trying to address the substantial and underestimated burden of mental illness in Europe.

Time to Change: Slow progress is better than none

Campaigns, large and small, to address stigma against those with mental illness have taken place for decades. Most disappear, having had little effect. Although public health education can be valuable, data have for some time suggested that contact between those with mental illness and members of the general population is much more likely to change attitudes and behaviour.¹³ The problem is using this insight in a large-scale campaign that could affect a substantial proportion of the population.

Time to Change, an English anti-stigma campaign launched in 2007 by two mental health charities—Mind and Rethink Mental Illness—has attempted to do just that. Several attributes set Time to Change apart. One is resources. It has been the largest such effort ever in the country, with roughly £5m (US\$8m) per year in core funding from grant-giving charities and the UK Department of Health as well as receiving additional programme-specific grants. The next is scope. The campaign has launched a wide range of different programmes, including 35 in the first four years alone. Some were general, ranging from road shows combining local advertising, events and making individuals with experience of mental illness available for discussions in town centres; through mass-participation sports and cultural events, where those with mental illness and members of the general population mingled in a shared activity; to social media campaigns and even a one-minute online film, “Schizo: the movie”.

Other efforts were targeted at specific audiences, such as employers and medical students. The hope was to have an impact on those directly involved in programmes as well as, through them, the population as a whole. Finally, Time to Change’s first phase—from 2007 to 2011—also had an extensive, independent

evaluation process to gauge its overall effectiveness and the success of individual programmes. These evaluations relied on surveys using statistically validated measures of knowledge about mental health, attitudes concerning those with mental illness, and reported as well as intended behaviour towards such individuals.

The results of the first phase were mixed. Various efforts certainly had a wide reach: according to Time to Change, “Schizo” was downloaded 446,000 times in the summer of 2009, and nearly 600,000 people took part in sports and cultural mass events between 2007 and 2011. On the other hand, although evaluation studies showed that specific programmes had some measurable impact on those involved, this was often small. A follow-up study of road-show and mass-participation sports events, for example, showed that they did facilitate contact between those with and without a mental illness, and that this in turn led to better scores on intended actions, but had little effect on knowledge or attitudes. Similarly, a study of the social media campaign found little change in the target population as a whole, but among the minority who remembered specific campaigns there was a modest improvement in knowledge, attitudes and intended behaviour. Some efforts were not at all fruitful: the programme targeting medical students had no long-term effect on those involved.¹⁴

The likely impact on stigma in England as a whole was also only partial. Academic analysis showed no statistically significant change in levels of knowledge, attitudes and actual behaviour, although answers about intended behaviour were more positive. Also, media articles that were stigmatising continued to be greater in number than those that were anti-stigmatising between 2008 and 2011. The proportion of the former stayed constant, but

¹³ Patrick Corrigan et al, “Challenging the Public Stigma of Mental Illness: A Meta-Analysis of Outcome Studies”, *Psychiatric Services*, 2012.

¹⁴ Sara Evans-Lacko et al, “Mass social contact interventions and their effect on mental health related stigma and intended discrimination”, *BMC Public Health*, 2012; Sara Evans-Lacko, “Influence of Time to Change’s social marketing interventions on stigma in England 2009–2011”, *The British Journal of Psychiatry*, 2013; Bettina Friedrich et al, “Anti-stigma training for medical students: the Education Not Discrimination project”, *The British Journal of Psychiatry*, 2013.

the latter at least rose through a drop in the number of neutral articles. More reassuringly, those with mental illness themselves reported some improvement in levels of discrimination: those experiencing no discrimination at all rose from 9% to 12% between 2008 and 2011, and a combined index of discrimination created by researchers dropped by 11.5% in those years.¹⁵

It is impossible to say how much even this shift was the result of Time to Change and related efforts, but it is worth noting that UK data prior to 2007 show that the situation had been getting worse. Presumably the campaign had an impact, but the extent to which it can be termed a success is less clear. Time to Change fell far short of some of its original goals, including a 5% positive shift in public attitudes toward people with mental illness. Moreover, even with

the reduction in discrimination, half of service users report recent experiences of having been shunned.¹⁶ On the other hand, Norman Sartorius, former director of the World Health Organisation's Division on Mental Health, said in 2012 that stigma was actually rising worldwide.¹⁷ In this context, even a modest improvement is an important gain.

Looking ahead, Time to Change is seeking to expand its impact, continuing its main programmes but also launching pilot projects for black and minority ethnic communities—which are traditionally underserved in this area—and for children, a particularly important group given the early onset of most mental illness. What this second phase of activity teaches about how to address stigma will therefore be at least as important as the lessons of the first. ■

¹⁵ E Corker et al, "Experiences of discrimination among people using mental health services in England 2008–2011", *The British Journal of Psychiatry*, 2013.

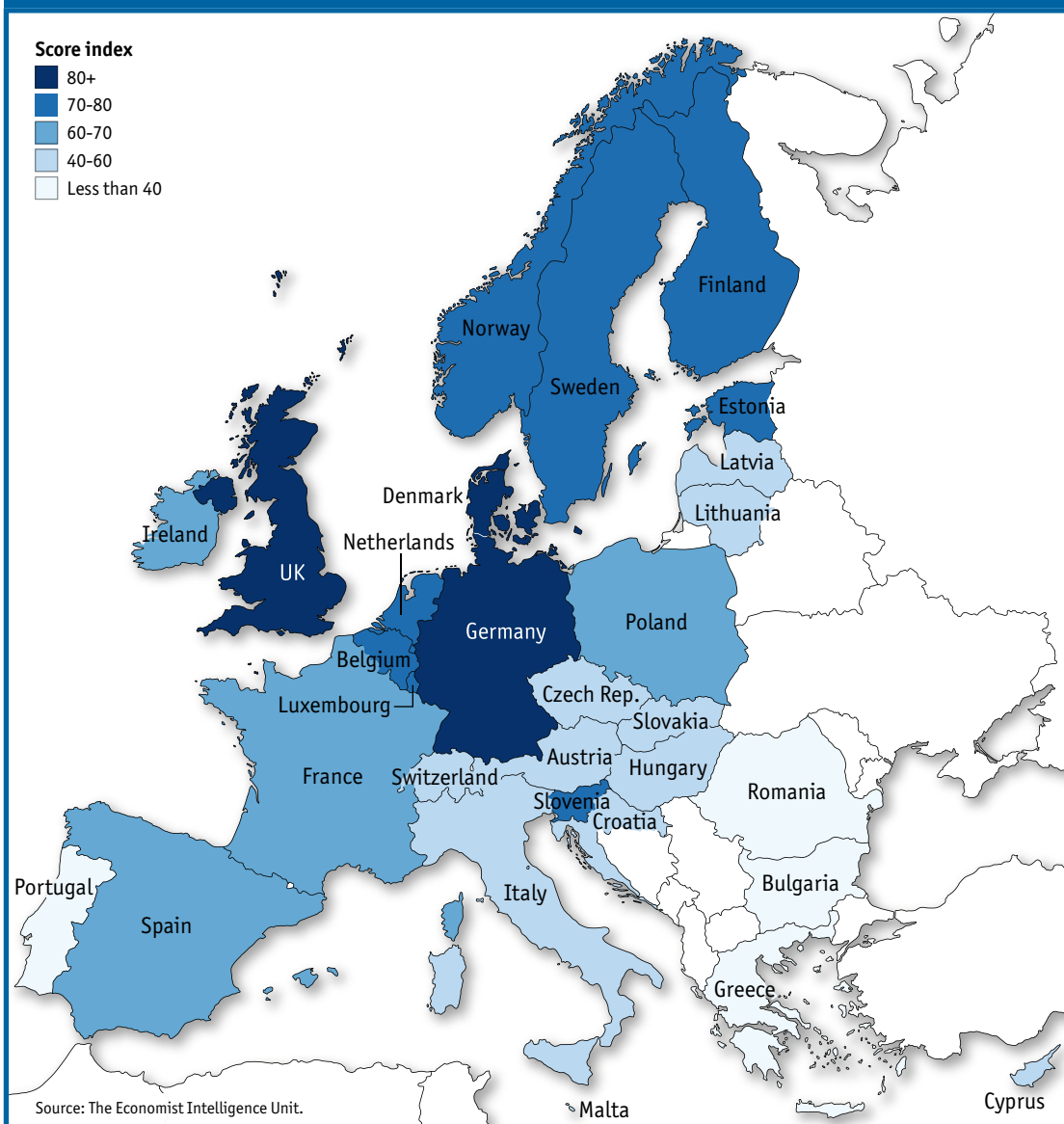
¹⁶ Sara Evans-Lacko, "Public knowledge, attitudes and behaviour regarding people with mental illness in England, 2009–2012", *The British Journal of Psychiatry*, 2013.

¹⁷ *Together Against Stigma: Changing How We See Mental Illness. A Report on the 5th International Stigma Conference*, 2012.

2

Lessons from the index results

Overall score



The Mental Health Integration Index rankings begin with a small surprise. The overall leader, Germany, is rarely listed by experts among the top European countries in the integration of those with serious mental health issues. On

the other hand, with a reputation for a strong general healthcare system and generous welfare provision, Germany has the building blocks to do well. More consistent with the conventional wisdom are the countries which follow close

Even in the highest-ranking country, Germany, half of those with a serious mental illness still receive no targeted medical treatment.

OVERALL SCORE		
RANK	COUNTRY	SCORE
1	Germany	85.6
2	United Kingdom	84.1
3	Denmark	82.0
4	Norway	79.5
5	Luxembourg	76.6
6	Sweden	74.1
7	Netherlands	72.8
8	Estonia	71.4
9	Slovenia	71.1
10	Belgium	70.7
11	Finland	70.0
12	Spain	68.8
13	France	68.4
14	Ireland	68.0
15	Poland	64.1
16	Italy	59.9
17	Malta	59.7
18	Czech Republic	59.4
19	Austria	57.9
20	Lithuania	53.5
21	Latvia	51.9
22	Slovakia	46.8
23	Cyprus	46.6
24	Switzerland	45.7
25	Hungary	43.9
26	Croatia	40.1
27	Portugal	38.1
28	Greece	38.0
29	Romania	34.7
30	Bulgaria	25.0

behind: the United Kingdom, Denmark, Norway and Sweden are frequently named as examples of good practice.

If the countries with the best results tend to be in the north and west of Europe, the weakest are largely in the south-east [see map]. Again, this is no surprise. Ms Zlati from the Romanian think-tank Open Minds, points to the low levels of investment and state activity surrounding those with mental illness and says it is “obvious that [their] social inclusion is not a priority”.

More interesting than abstract scores, however, are what sets those countries that did well apart

from those which lagged behind and what these similarities say (and do not say) about improving the lot of service users across the continent.

Even the leaders have a long way to go and the ‘non-leaders’ much to teach

The first lesson from the index is that even those near the top still are far from perfect in delivering care and integrating those with mental health problems. In Germany, over half of those with a serious mental illness still receive no targeted medical treatment.¹⁸ Professor Thomas Becker, head of the Department of Psychiatry II at the University of Ulm and BKH Günzburg, adds that the provision of various types of care for service users—the general term used by caregivers and patient groups for those with mental illness—remains highly fragmented. Similarly, Dr Helen Gilbert, fellow in health policy at a leading UK medical think-tank, the King’s Fund, notes that for England, although there is some integration of mental health and social-care provision, there is much less integration between mental healthcare providers and those providing predominantly acute and primary healthcare to the general population.

That said, because efforts to provide and co-ordinate services are frequently organised at the regional level, important islands of excellence exist in countries that appear at first glance to have middling results in the index. Since Franco Basaglia—an Italian psychiatrist and neurologist and one of Europe’s pioneers in crusading for a human rights-based treatment of those with mental illness—came to prominence in the 1960s, for example, Italians have been leaders in European mental healthcare reform. Trieste, where the last psychiatric hospital closed in 2000 and patients are now served entirely through integrated community-based care, is commonly held up as a model of best practice. Similarly in Spain, a number of autonomous regions, notably Andalusia and Catalonia, have also achieved much in this field, as has Lille in France. As the OECD’s Mr Prinz puts it: “You can find interesting practice and pieces of the solution in every country.”

¹⁸ Simon Mack et al, “Self-reported utilisation of mental health services in the adult German population—evidence for unmet needs? Results of the DEGS1-Mental Health Module (DEGS1-MH)”, *International Journal of Methods in Psychiatric Research*, 2014.

This is a field where policies are too often aspirational rather than intended for timely implementation.

Consistency pays off

The next lesson from the index is that long-term consistency yields results. Overall, those that finish highest tend to do well in all categories, while those that finish near the bottom also tend to do so in most areas. Those in the middle, however, have varying results in different categories. The consistent performance at the top of the scale may result from having worked on mental health issues for an extended period. In Germany, the UK and Norway the shift towards community care for those with mental illness began as early as the 1970s and 1980s, while in Denmark and Sweden this occurred in the 1990s. Professor Becker says of Germany that, even though important weaknesses remain in integration, “there has been long-term moderate to high commitment to improving the care of people with mental illness.” Similarly, Paul Farmer, CEO of the British mental health NGO Mind, believes that one of the strengths of the UK in this field is “a fairly long-term, progressive commitment at a policy level around mental health and changing the position of people with mental health problems in society,” leading to gradual improvement.

In some countries history is still shaping today's outcomes, but a change of direction is possible. A recent article published by BMC Health Services Research argued that the legacy of poor practice from communist-era mental healthcare lingers on in eastern Europe as, despite “20 years of health reforms and reforms of health reforms” the transition to a modern, community-centred system of care remains incomplete.¹⁹ An ongoing hospital focus in this area certainly remains in several of these states, which, notes Dr Fioritti of the Bologna Health Trust in Italy, “have acknowledged only in part the transition from institutional to community-based treatment”. Nonetheless, other countries in the region have moved ahead quickly. According to Eurostat, between 1991 and 2001 Estonia cut the number of psychiatric hospital beds per capita by 63%. This, as well as other reforms, has helped Estonia to rank eighth overall in the index.

¹⁹ Martin Dlouhy “Mental health policy in Eastern Europe: a comparative analysis of seven mental health systems”, *BMC Health Services Research*, 2014.

Real investment is essential in a field rife with “Potemkin policies”

Addressing the burden of mental illness requires incurring up-front costs. Although data covering all aspects of integration were impossible to find, country scores in the index correlate strongly with the proportion of GDP spent on mental health.

For some indicators, the link is straightforward. The index's Access category is based largely on the size of the healthcare workforce and the extent of healthcare services available to service users. These are tied closely to governments' budgets and so, not surprisingly, this category sees the greatest correlation between its scores and mental health spending as a proportion of GDP. Less clear, though, is why the overall score, as well as the scores for the Environment and Occupational categories, are also significantly linked to mental health spending per GDP, especially as the latter two focus largely on the existence or absence of policy. Some policy initiatives included in the index—such as legal protections against those with mental illness being deprived of custody of their own children, or requiring employers to make reasonable accommodation for those with a mental illness—involve no direct cost to the state. Others, such as funding workplace schemes, come out of other budgets. The most likely reason for this correlation is that the amount which countries are willing to spend on mental health is a proxy for how seriously governments take the issues surrounding integration and the extent to which their policies are true political priorities—as opposed to “Potemkin policies”, which are more façade than reality.

It is a necessary caveat for an index with such a strong policy element to acknowledge that such seriousness can be missing despite official pronouncements. This is a field where policies are too often aspirational rather than intended for timely implementation. At an extreme are the Polish National Mental Health Programme of 2010 and Hungary's 2009 National Programme of Mental Health. Both would have represented

Is GDP or spending at work?

At first glance, there appears to be a link between national wealth and index scores: except for a few outliers, notably Switzerland and Austria, richer countries do better. GDP per capita correlates closely with a higher overall score and reasonably well with results in each of the categories. More to the point for this index, high GDP per capita is also closely correlated with high mental health spending as a proportion of GDP. It is therefore impossible statistically to separate the two factors—wealth generally and a commitment to spend on mental health—in the same model. However, because the statistical degree to which mental health spending as a share of GDP seems to explain the overall scores is slightly higher than that of GDP per capita, and because the likely causal link is

easier to understand, this analysis has focused on the importance of adequate spending.

Does this mean national income is irrelevant to active integration? Perhaps not. The correlation between GDP and the proportion of GDP spent on mental health is itself suggestive, indicating that Europeans might consider mental healthcare, as well as the integration of those with mental illness, as a type of luxury good to be paid for when finding money for necessities is no longer pressing. This is consistent with findings discussed below that in an economic downturn those with mental illness tend to suffer more than the general population. If this is the case, it is worrying, given the burden of mental illness on Europe. Mental health is no luxury.

shifts towards better community-centred care, but both lacked anything like adequate budgets. These, however, are only among the more egregious examples. Mr Jones of the EUFAMI explains that “we look across Europe and see lots of plans at the strategic national levels, but people become frustrated at the lack of implementation.”

Specific organisational lessons are difficult to find

The index results do not show any strong link to how healthcare is organised. Intuitively, one might imagine that systems with a strong gatekeeper or care co-ordinator would do better because they should, all things being equal, see more integration of medical provision. In practice, the countries which scored highly on the co-ordination role of primary care in a recent trans-European study were among both the leading finishers and those doing worst in our index.²⁰ For example, the UK (where GPs play a strong gatekeeping role) and Germany (where they do not) have very similar results on mental health integration. More generally, Professor

Wittchen notes: “All countries fail to various degrees to provide care and effective treatment to the majority of people suffering simply because of insufficient resources. Additionally, every country in Europe is different in the way it organises mental healthcare. This makes it hard to interpret in which areas of mental healthcare the deficiencies are most pronounced and to identify the reasons as well as to find general solutions. Undoubtedly, though, some countries, such as the Netherlands or those in Scandinavia, seem to fare much better than other EU countries, where only 2-3% of patients receive adequate care. We have currently no strategy to solve such problems.” If this is the case for medicine, the index, which seeks to measure integration across a range of services, has to deal with even greater complexity, making national lessons still harder to find. Nevertheless, as discussed in the following section, index data do help to illuminate the state of Europe’s transition from institutional to community care for people living with mental illness.

²⁰ Dionne Kringos et al, “The strength of primary care in Europe: an international comparative study”, *British Journal of General Practice*, 2013.

3

From hospitals to recovery: A slow journey

Now largely the consensus, the idea of transforming mental healthcare from an institution-based, medically focused, clinician-directed system to integrated medical care and social support provided in the community is far from new. Critiques of existing arrangements that were once considered radical began to bear fruit in the late 1970s and early 1980s in countries as far apart, geographically and at the time politically, as Italy and the UK. Governmental attention afforded to mental health in Europe has increased ever since. In 2005 the European Commission estimated that roughly three-quarters of legislation relating to mental health provision on the continent was enacted after 1990.

Given the time that these ideas have held sway, one of the index's most surprising findings is how little has been done. Considering Europe as a whole, even the relocation of care away from psychiatric institutions remains very much a work in progress. Moreover, as Ms Saenger of COTEC points out: "Closing hospitals has consequences." It requires the creation of alternative structures to provide care and accessible services to care for those with a mental illness, and to enable them to function successfully in society. Our figures also show, however, that if anything, progress in this area has been even slower than deinstitutionalisation, leaving service users to fall between the cracks in some areas.

Deinstitutionalisation: A road only partly travelled

Innovation in any field of healthcare is notoriously hard, and mental healthcare is no exception. Index data show, though, that

many countries are still struggling with the first hurdle: getting people out of institutions or similar establishments. In a slight majority of the countries covered (16 out of 30) more individuals continue to receive care in long-stay hospitals or institutions than in the community, although of these, 13 have policies aimed at shifting more to the latter.

The reasons for this slow progress are diverse. First, although far less intense than before, as noted earlier, pockets of cultural resistance remain. GAMIAN's Mr Montellano adds that psychiatrists often find it difficult to deal with the loss of organisational power that accompanies a shift towards a more collaborative, less hospital-based system.

Such cultural resistance is the norm at first, according to Professor Caldas de Almeida, but in his experience it invariably declines over time. A more persistent issue is structural legacy. To begin with, the large number of people still in hospitals, notes Dr Fioritti, presents "a tremendous barrier to integration", as it is difficult to move people who have spent many years in such institutions back into the community.

More difficult still is overcoming entrenched institutional interests. Romanian psychiatric and general hospitals, for example, still receive most of their funding from that country's mental health reform, even though the reform was ostensibly aimed at creating a more modern mental health system with a larger number of community mental health centres. Similarly, in Poland, "vested interests in the existing

Deinstitutionalisation is not a magic bullet that solves all problems. It has to happen in tandem with the creation of services in the community

treatment system”, such as professionals and communities with large hospitals, have in effect led to substantial delays in the introduction of community-based reforms, according to Dr Jacek Moskalewicz, head of the Department of Organisation of Health Service at Warsaw’s Institute of Psychiatry and Neurology.

Across the continent in Belgium, Piet Bracke, president of the European Society for Health and Medical Sociology (ESHMS), notes that the budget for recent efforts to build integrated networks of psychiatric and other care providers is also in the hands of hospitals: “The old powerhouses still controlling financing in the regions temper the energy with which deinstitutionalisation is implemented.” The opposition need not even be at the ideological level. John Saunders, chief executive of Shine, a national Irish mental health NGO and chair of the Irish Mental Health Commission, adds that one important factor slowing his country’s recent deinstitutionalisation effort was that, although organisations representing mental health professionals supported the change in general, “when it came to action on the ground, there was much local and national resistance to the closure of local units and the reduction of bed numbers.” Local communities also protested at the loss of larger institutions that played an important role in their economies.

Even when everyone is on side, Professor Caldas de Almeida notes: “It is not easy to make the transition away from mental hospitals. It is a complex process. You have to reallocate resources, and it implies a lot of preparation, training or retraining.” Indeed, in many cases team personnel must change completely to include a wider range of specialists who may see their own existing roles revolutionised. A case in point is occupational therapy: Ms Saenger recalls that “when people with mental illness were purely in institutions, therapists tended to do handicraft things to keep them busy. Now what we teach is far more about living skills and work.”

Finally, as Professor Bracke puts it: “Deinstitutionalisation is not a magic bullet that solves all problems.” It has to happen in tandem with the creation of services in the community. The mere closure of hospitals without adequate provision for patients purely with the aim of saving money in times of austerity—a frequent, sometimes justified, accusation in political debates around deinstitutionalisation—can be disastrous for many patients. As the index data indicate, however, creating adequate community structures for those with mental illness remains a pervasive challenge in Europe.

Integration: A palliative approach

The index’s Access category measures the state of the overall provision of different aspects of medical care related to mental illness. The ranks of the leading countries are similar to those for the index as a whole: three of the top four in both cases are Germany, Norway and Denmark, while Slovenia and the United Kingdom approximately swap places from the overall results.

A closer look at the data, however, reveals that the leaders—and indeed all the countries—do not exhibit high levels of integrated care, but a higher intensity of hits in what often looks like scatter-gun provision. For example, the type of clinicians and service providers available varies notably by country. Germany scores full points for its number of specialist social workers per capita, but only gets 25.4 out of 100 for its number of psychologists. Similarly, Denmark gets 73.4 out of 100 for its number of psychiatrists, but roughly half that (36.9) for the psychiatric nurses available to the population. Moreover, the type of services available by country also seems to be somewhat unpredictable: Latvia, for example, comes 25th in the Access category but is one of only four index states to provide a full range of mental health support in prisons. Such varying levels of provision strongly suggest a lack of integrated care.

The lines between the medical, social welfare and occupational needs of those affected are highly blurred.

Going beyond formal medicine, the situation grows worse. With problems such as unemployment, inadequate housing and a sense of social exclusion—all significant risk factors for and frequent outcomes of many types of severe mental illness—the lines between the medical, social welfare and occupational needs of those affected are highly blurred. A recent European study, for example, found social exclusion and poor mental health to be highly correlated.²¹ As Mr Montellano puts it: “Mental illness is not just a clinical problem. Lots of components should be addressed: cultural, societal, biological and psychological.”

Meanwhile, governments still typically offer fragmented, siloed services. The OECD’s Mr Prinz notes that across much of Europe “the health system aims to cure people and doesn’t think about integrated services, while other systems [such as employment and housing assistance] say, ‘let the health system cure people first, then we can help’.” Fragmentation is a general feature of government services that everyone has to deal with, but for those with a mental illness the issues can be almost insurmountable. Finding ways to integrate diverse types of provision for these service users is, then, in the words of Johanna Cresswell-Smith, project co-ordinator at Finland’s National Institute for Health and Welfare, “the million dollar question”.

The solution involves finding a balance. Simply transferring facilities from hospitals to the community is insufficient. Pablo García-Cubillana of the Andalusian Health Service recalls that doing so in his region only meant that “those with mental illness got excluded from social support”, rather than being able to use generic social services open to the general population. In order to cover this gap, a specific public foundation for social support of people with severe mental illness had to be developed. Targeted help for those with mental illness, however, can bring its own pitfalls. For example, Shari McDaid, director of the Irish NGO Mental Health Reform, notes that such an approach in her country led people

living with mental illness to “develop a kind of shadow life, living in a parallel universe of mental health accommodation, going to sheltered workshops and specialist training centres, at best doing supported employment, going to mental-health day centres, all in the context of health service provision, but not engaging in the community.” Dr Fioritti agrees: “You can spend in the community in a way that does not integrate but creates a parallel system.”

One element of more effective integration should be a coherent policy framework. Kristian Wahlbeck, research professor at the Finnish National Institute for Health and Welfare and development director of the Finnish Association for Mental Health, explains that “putting mental health in all policies—labour policy, social policy and so forth—is the only way to address the determinants of mental health. A whole-of-government approach is needed.” In Europe, such arrangements remain the exception rather than the rule. In the index, only eight out of 30 countries have gone so far as to have collaborative programmes between the department responsible for mental illness and all of those tasked with education, employment, housing, welfare, child protection, older people and criminal justice. Such programmes do not necessarily mean fully cross-cutting policies. The WHO Europe’s Health 2020 strategy called on the region’s countries to adopt whole-of-government approaches on health as a whole because they are so uncommon.

Even a commitment to a more integrated approach, though, can reveal structural barriers to integration. The UK, for example, is one of the countries which scores full marks for cross-cutting policy in the index but, as Mr Farmer of Mind notes, one impediment to integrated service provision there is that mental health trusts and social services are run at the local level—and frequently co-operate well—but “the [national] Department of Work and Pensions doesn’t have a local strategy”.

²¹ Stefanie Dreger et al, “Material, psychosocial and sociodemographic determinants are associated with positive mental health in Europe: a cross-sectional study”, *BMJ Open*, 2014.

Ironically money should not be a problem because integrated care costs much less than keeping hospitals open.

Similarly, budget flows frequently impede integration. Dr Insel notes that “collaborative medical care and using a team-based approach works very well for mental illness, whether you are talking about depression or schizophrenia; the problem is getting it paid” when funding is based on payment for individual services. Adding in social services only complicates matters further. Frank van Hoof, senior scientist at the Netherlands’ Trimbos Institute, a research body focused on mental health, addiction and mental resilience, explains that “in many countries, reimbursement of healthcare is based on individual entitlements, while social care is funded as a general population-based service. You need clear reimbursement systems that reward co-operation.” The King’s Fund’s Dr Gilbert agrees: “Integration is difficult when there are different budgets. You have to think about outcomes and where the money is.”

To improve co-ordination, in many European countries mental health services are often locally or regionally based. This does not always remove structural difficulties—in Greece for example, the regional medical authorities and the other elements of local government are run by separately elected regional councils—but it tends to allow relevant parties to create more effective solutions on the ground. Thus, as noted earlier, cities and regions such as Trieste, Lille and Andalusia are often cited as examples of best practice in mental health integration. In the case of France, this local approach is “a great strength but also a weakness,” according to Pierre Thomas, professor of psychology at the University of Lille. Even on the purely medical level, some sectors are well equipped, but others are not. “It depends on their governance,” he adds.

At its best, this integration takes the shape of multi-disciplinary care teams, the experts on which are not only able to provide specialised care for individuals, but are also able to negotiate the different medical and social care systems on behalf of service users. One common version of this kind of arrangement is the Assertive

Community Treatment (ACT) team, which interacts with clients in the community or even in their homes. These teams typically include not just psychiatrists and psychologists, but also social and employment counsellors.

Such arrangements, however, are far from universal in Europe. Index data indicate that some form of community-based assertive outreach is available in just 21 of 30 countries. They are also often embryonic, vary widely in quality and extent over the 21 countries and are normally reserved for those most at risk or difficult to reach. The Dutch experience, though, shows that when done well they can be successful in expanding their purview to everyone being treated for mental illness through Flexible ACT (See Box: “Doing more than ACT”).

Moreover, the existence of some ACT teams is having little effect on the overall picture. Professor Wittchen explains that “there are models that have overcome fragmentation on the regional or local level, but in general things are still the same. There is a lack of integration between inpatient and outpatient care as well as with rehabilitation measures. Patients frequently fall in between these sectors.” Ms Baker, past president of the European Brain Council, goes further, calling the lack of integrated services “desperate. I haven’t seen much change over the years.”

In general, creating effective integrated care is a question of resources. Professor Wittchen says that “there is a lot of willingness and a lot of theoretical models. Mental healthcare requires multi-disciplinary teams involving not only scarce psychiatrists but in particular psychologists. However, collaboration is time-consuming and costly. Most regions can’t afford it.” The LSE’s Professor Knapp adds that recognition of the need for integration exists, but such change as exists is “on the margins”. Worse still, it is vulnerable to economic difficulties. “You want to have employment specialists in community mental health teams, but those are jobs that

go when the budget gets tight,” he explains. Ironically, argues Dr Roberto Mezzina, director of Trieste’s Mental Health Centre, money should not be a problem because integrated care costs much less than keeping hospitals open. “Resources

are a huge problem,” he continues, because “the closure of big institutions has not been conceived as a process of conversion [from spending on hospitals to spending on community-based care] anywhere.”

Doing more than ACT: The Dutch FACT model

Assertive Community Treatment, or ACT, is one of the most widespread approaches to providing integrated care for service users. Originally developed in the 1970s in the United States, it has since spread through much of the world, including, with local variations, to 21 of the countries in the index. With ACT a small, interdisciplinary team provides individualised, time-unlimited service to users at the greatest risk of relapse. These efforts involve integrated support across a range of areas—including, among others, healthcare, housing, employment and interpersonal relationships—and interaction takes place where the service user wants it, often at home but also elsewhere in the community. The treatment team manages the patient’s case collectively and team members may see users once or even several times per day, depending on the individual situation. Such manpower-intensive care is expensive, but over the years repeated studies have shown that its reduction on the need for hospitalisation makes it cost-effective. ACT also is typically well received by service users and maintains better contact with individuals who tend to interact poorly with health services.²²

The Dutch began grappling seriously with deinstitutionalisation in the mid-1990s, but when considering existing ACT models, mental healthcare providers there found two problems. The first was practical: in some rural areas too few patients existed to justify an ACT team, and multi-regional teams tend to be less effective. Second, ACT is reserved for the most unstable minority of cases. This instability, though, is not a permanent condition. Some individuals improve and others worsen, but the

handover between ACT care and traditional case management was problematic.

In 2003 local care providers in the province of North Holland began experimenting with a new model which has come to be known as Flexible Assertive Community Treatment (FACT). According to Rene Keet, director of the Mental Health Centre GGZ North Holland, it has spread and evolved to become “a very strong bottom-up movement of integrated care. It was not a part of government health policy, but was typically Dutch in that something bottom-up has become well organised with extensive certification.” Now having a detailed model, described in an extensive manual,²³ there are 150 certified FACT teams in the country, a number expected to grow to potentially 400 or 500 in the near future.

The model uses multi-disciplinary teams of around a dozen people, including psychiatrists, psychologists, nurses, substance-abuse specialists, individual employment placement service workers and peer counsellors. They provide collective, ACT-style care for the 20% or so of those with mental illness who are most unstable. The other roughly 80% of people with a mental illness within a FACT team’s region instead receive case management co-ordinated by an individual from the same multi-disciplinary team. This draws on the expertise of all team members to provide multi-disciplinary care that focuses on recovery and rehabilitation. Those in the larger group see their case manager two to four times per month as well as having regular appointments with psychiatrists and psychologists at the FACT offices. Included in

²² See, for example, literature review in A Rosen et al, “Assertive community treatment – Issues from scientific and clinical literature with implications for practice”, *Journal of Rehabilitation Research & Development*, 2007.

²³ J Remmers van Veldhuizen and Michiel Bähler, *Manual Flexible Act: Vision, model, practice and organisation*, Groningen, 2013.

²⁴ M Bak et al, "An observational, 'real life' trial of the introduction of assertive community treatment in a geographically defined area using clinical rather than service use outcome criteria", *Social Psychiatry and Psychiatric Epidemiology*, 2007; Mike Firn et al, "A dismantling study of assertive outreach services: comparing activity and outcomes following replacement with the FACT model", *Social Psychiatry and Psychiatric Epidemiology*, 2012.

these patients' treatment plan is a so-called "crisis plan" with early warning signs. If the case manager believes that the level of care needs to be increased, the patient's name can be put on a shared, electronic whiteboard. Once this occurs, the patient is immediately given more intensive, ACT-style treatment. Conversely, once the team as a whole is convinced that the patient is out of crisis, his or her name is removed from the board and regular care resumes, and the focus shifts to increasing resilience and fostering recovery.

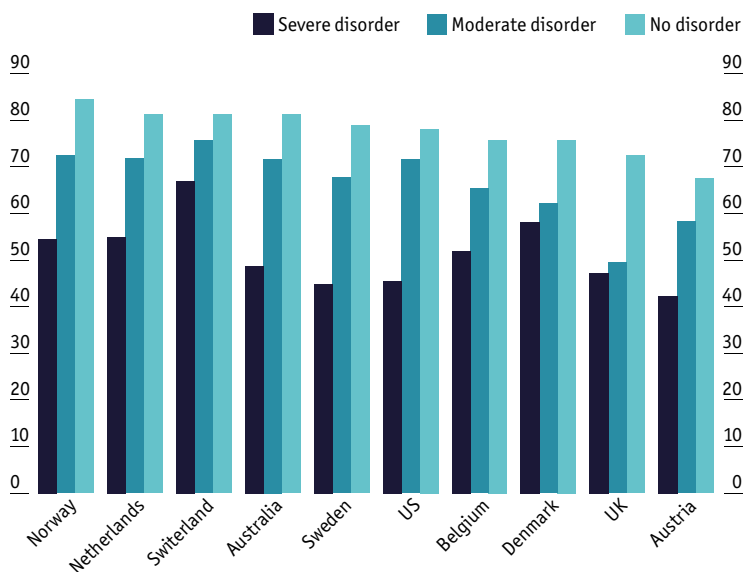
For Dr Keet, this flexibility of care is FACT's greatest strength. "As a psychiatrist, I work with a team and I have an alternative to an admission. When in a crisis, in the past the only response was to admit the patient to hospital. Now I can admit him or her to the digital board and have a daily or more frequent response. When it is no longer necessary, I can simply stop doing it. ACT teams have to keep looking at such patients."

The outcomes data show the effectiveness of FACT, with an initial assessment in the south of the Netherlands finding that patients going into remission increased from 19% before its introduction to 31% afterwards. Nor is its utility culture-specific. A recent British study comparing a switch from a diverse system with ACT and other community-based teams to a single one modelled on FACT also found that the number of admissions required dropped and total patient time in hospital declined by half, even though the average time service providers spent with users was also reduced—shifts which it credited to the ability of the FACT model to allocate human resources more efficiently. This does not mean the Dutch system can simply be copied by others. Dr Keet notes that every country has different local conditions, but adds that everywhere "the need for integration is vital". FACT provides a model of such integration well worth adaptation by others.

Chart 2

People with a mental disorder face a considerable employment disadvantage

(employment/population ratio*)



* Employed people as a proportion of the working-age population, by severity of mental disorder, ten OECD countries, latest available year.
Source: OECD Sick on the Job?

Employment: Finding real jobs

Policies related to work and mental illness are highly inconsistent across Europe, with the relevant category—Opportunities—seeing the highest variation of any in the index. Moreover, only a handful of countries get very high scores, with Finland and France having 100% of the policies covered in the index and Denmark and Estonia getting a rating of 83.3 out of 100. Also noteworthy is that in this category, the leaders differ from the countries which do best overall and which are at the top of the other categories. Finland and France, for example, which lead in the employment category, are only slightly above average in the index as a whole, coming in 11th and 13th, respectively. This may indicate, in part, that employment policies consistent with the European social model—including a high emphasis on workplace health and safety—also hold potential benefits for active integration. On the other hand, the relative weakness in the Opportunities category in countries which

The most important item in integration is integration in work.

Work provides much more than a salary: it provides confidence, responsibility, a sense of belonging—things that are important for anybody.

are leading in other areas suggests that the workplace may be receiving less attention than other aspects of integration.

This is regrettable. “The most important item in integration is integration in work,” says Dr Lorenzo Toresini, recently retired as head of the Mental Health Service in Italy’s South Tyrol. Mr Montellano of GAMIAN-Europe reports that the single biggest frustration for those with mental illness involves the workplace. He explains that when someone is diagnosed, gets on the right medication and goes through therapy, “the patient wants to have a normal life, a job to earn some money, live on his or her own, then maybe settle down and have children. When they want jobs, though, there are none for them. People relapse because their only activities are some things to kill time. Work provides much more than a salary: it provides confidence, responsibility, a sense of belonging—things that are important for anybody.”

Although comprehensive data are again hard to come by, those that exist indicate that the employment barriers for people with mental illness, especially severe mental illness, are substantial. The UK is one of the few to collect data consistently. Figures from its spring 2014 Labour Force Survey show that the labour market participation rate of all people with mental illness is 36%, compared with 59% for all people with a long-term conditions—including a mental disorder—and 73% for the population as a whole. Other data from across Europe over the previous decade tell a similar story, albeit with varying numbers. These studies also typically show, not surprisingly, that those with a more severe illness are the least likely to be employed [see chart].²⁵

It is not simply a matter of correlation: a 2010 German study found that weakened mental health contributed directly to higher unemployment levels.²⁶ Moreover, those with mental illness suffer worst when the economy goes poorly. An analysis of Eurobarometer data found that the gap in the unemployment rate

in the European Union for those with any sort of mental illness and other individuals rose markedly between 2006 and 2010 as the 2008 recession hit. Stigma almost certainly played a role, as the effect was more pronounced in countries where people believed that those with a mental illness were dangerous.²⁷ Those with a mental illness are all too aware of the dangers. Gregor Breucker, division manager of the Department of Health Promotion at the BKK Federal Association, a German occupational health insurers’ trade body, notes that even in Germany, which has strong legal protections for the jobs of those who develop a mental illness, “the vast majority of employees see it as a high risk to go public to an employer with a mental health problem. He or she might be the next ‘victim’ of a reorganisation.”

Amid these difficulties, our index indicates that helpful specific policies are often lacking. Something as basic as rules created jointly by health and employment officials on workplace stress—which benefit all employees—exist in only ten countries. In most others, such regulations have been created, but without consultation between different departments. Mr Prinz adds that health-and-safety inspection services which include workplace stress are uncommon, although Denmark and Belgium are an exception. In much of Europe, he adds, health-and-safety policies “miss the point because the majority of [work-induced] problems are psychological, but the majority dealt with in the policies are physical issues.”

Extensive structures to protect the jobs of those who fall ill and to support them on their return to work are also few on the ground. Only five countries have all three components of: a legal duty for employers to make “reasonable adjustments” to someone’s work in order to support them when they come back; benefits to pay for practical support in this process; and official medical statements of fitness for work. Even the existence of such policies does not mean they are always effective. Mr Breucker

²⁵ David McDaid et al, “Employment and mental health: Assessing the economic impact and the case for intervention,” *MHEEN II Policy Briefing*, 2008.

²⁶ Paul Frijters et al, “Mental Health and Labour Market Participation: Evidence from IV Panel Data Models”, Institute for the Study of Labour Working Paper 4883, 2010.

²⁷ Sara Evans-Lacko et al, “The mental health consequences of the recession: economic hardship and employment of people with mental health problems in 27 European countries”, *PLOS One*, 2013.

In Germany, “the vast majority of employees see it as a high risk to go public to an employer with a mental health problem. He or she might be the next ‘victim’ of a reorganisation”.

notes that, although Germany requires the creation of a back-to-work management scheme for individuals away for extended periods, the reluctance of employees to tell their employers of their condition greatly reduces the likelihood that this will be relevant. Similarly, the structure of disability benefits means they can do more harm than good. In a number of countries those receiving such money are placed outside of the labour market and cannot do any work. Attempting to return to even part-time employment therefore involves the risk of losing government support that may take some time to recover if the job does not work out.

Comprehensive assistance in helping service users find work is also relatively rare: only ten countries get full marks for this indicator, showing that they have funded placement schemes, vocational support and individual job coaches. Here again, though, well-meaning policies do not necessarily lead to ideal results. Often work placement is in sheltered jobs reserved for the disabled. For example, Italy’s extensive network of co-operative social enterprises provides just such employment. On one level, these organisations are highly successful in providing sustainable jobs, especially compared with other countries, such as Greece, where efforts to set up such organisations largely foundered after 2010 owing to a lack of economic sustainability. Dr Fioritti says, though, that the social enterprises “constitute a niche in the work market, not part of an integrated environment. The chances that a person in a social enterprise can get a job in the free labour market are only about 5%.”

The increasing consensus on the best way to encourage greater employment of those with a mental illness in the general job market again involves integration through programmes known as Supported Employment or Individual Placement and Support (IPS). In such schemes, those providing employment services are a full part of the team providing care. They help the patient find jobs in the competitive market—

based on the service user’s own preferences—and then provide ongoing support to them. Unlike the previous vocational model, which involved training and then a job search (“train and place”), IPS follows a “place and train” approach. A substantial amount of research indicates that IPS is more effective than previous models. A major European study, for example, found that those who had an IPS-based service were nearly twice as likely as those without to get at least one day’s work (55% to 28%) and were far less likely to be readmitted to hospital (13% to 45%). Later Dutch research found that IPS also correlated with a greater likelihood of longer-term employment.

Lack of a holistic approach, on the other hand, can undermine even such a positive approach. A pilot project in Sweden failed because participants feared that taking work which they might not be able to maintain would lead to loss of social benefits. In general, IPS appears to be cost-effective, or at least no more expensive than alternatives. The Dutch investigation found only a slight net societal cost to IPS, and a recent RAND study for the UK Department of Work and Pensions found substantial savings: for every £1 spent, society’s other direct costs declined by £1.59. Most of the latter figure (£1.41) represents gains for the government, from reduced disability and unemployment benefits as well as healthcare spending, along with increased income tax. The remainder was mainly reduced statutory sick pay by employers. At the moment, however, IPS is rare, with only scattered examples even in countries such as the Netherlands and the UK.²⁸

IPS is not a complete solution: no employment strategy with only a 55% success rate could be. Nevertheless, it shows that substantial improvement is possible in reintegrating those with mental health issues into the world of employment.

Moreover, care providers, counsellors and service users are not the only actors in the area of employment. For active integration of

²⁸ Tom Burns et al, “The effectiveness of supported employment for people with severe mental illness: a randomised controlled trial”, *Lancet*, 2007; H Michon et al, “Effectiveness of the Individual Placement and Support (IPS) model of vocational rehabilitation for people with severe mental illnesses in the Netherlands,” *Psychiatrische Praxis*, 2011; Christian van Stolk et al, “Psychological Wellbeing and Work: Improving Service Provision and Outcomes”, Report for UK Department of Work and Pensions, 2014; H Hasson et al, “Barriers in implementation of evidence-based practice: Supported employment in Swedish context”, *Journal of Health Organisation and Management*, 2011.

The best way to encourage greater employment involves integration through programmes known as Supported Employment or Individual Placement and Support.

those with mental illness into society to occur, employers will have to be a major part of the solution. Working conditions, health-and-safety policies, sick leave and reintegration policies and processes are just some of the areas where companies have an important effect on the prevention, recognition and proper care of mental illness among their employees. That said, the effect of mental illness on workers, in terms of lower productivity, time away from

work and early retirement, represents a growing cost. Mr Prinz notes that “the business case for employers is very clear and strong, but not fully understood.”²⁹ As Germany’s experience shows, education may be a more effective way to address this deficiency than just regulation.

Raising mental health’s profile in the workplace

Gregor Breucker, division manager at the Department of Health Promotion at the BKK Federal Association, a German occupational health insurers’ trade body, notes that however slow other businesses may be to understand, for insurers the costs of poor mental health have become all too clear. His organisation’s data show that, despite the actual prevalence of mental illness remaining stable, it has become an increasingly prominent cause of time away from work as the impact of other conditions has lessened. “Disease prevention used to be a niche area, mainly regarded as a nice-to-do, marketing-like activity,” he says, but today for health insurers—and even pension insurers concerned about early retirement—it has become a priority. As a result, these organisations, both private and social insurers, now regularly provide consultancy services on disease prevention, including mental illness, as a competitive differentiator.

Most employers, however, have been slow to understand the challenge of mental illness. Mr Breucker notes that although in general the atmosphere, especially among human resources and occupational health professionals, has improved markedly over the last decade, “you still have cases where management teams are very cautious about how they approach such a still taboo subject,” and do not wish their businesses to be associated with public discussions.

Regulation, he notes, can only improve matters to a degree. Although in Germany employers are required to carry out health risk assessments that include mental demands at work, a majority of small and medium-sized enterprises do not. He adds that most employers are also unaware of legal requirements to offer any employee on sick leave for more than six months a return-to-work management plan. Even when companies do provide such a plan, he adds, “employers and normal working teams are only very rarely trained to handle mental health-related cases, and so may lack the knowledge to do a good job”.

To improve the understanding of the requirements and benefits of workplaces that offer a friendlier atmosphere to employees with mental health problems, the BKK Federal Association has taken the lead in a multi-stakeholder campaign—involving insurers, companies the government and unions—called psyGA (an acronym of the German for Mental Health in the World of Work). It provides briefing documents for corporate and public service leaders and managers dealing with mental health issues, templates for self-assessment tools and procedural guidelines and e-learning tools. It also conducts seminars for groups of large companies and raises awareness through giving prizes for excellent practice.

This year psyGA commissioned an independent assessment of its efforts between 2011 and

²⁹ For examples of cost-effective mental health programmes at work, see Matrix, “Economic analysis of workplace mental health promotion and mental disorder prevention programmes and of their potential contribution to EU health, social and economic policy objectives,” Final Report, May 2013.

Individual Placement and Support shows that substantial improvement is possible in reintegrating those with mental health issues into the world of employment.

2013. It concluded overall that the programme has had “a very great success” in its goal of spreading information on mental health at work. For example, not including downloads from the website, it distributed 332,000 copies of its materials during those years; 82% of surveyed users found that these documents helped them in their daily work, and 14 companies adopted psyGA’s model procedural guidelines as their own.³⁰ According to Mr Breucker, “this may not change practice right away, but management teams and employee representatives are more aware of the factors

which they can steer and influence.” Also important, in the German context, has been finding a way to raise understanding of the issue and best practice that has obtained wide support. “psyGA now has approval from both the Federal Employers Association and the umbrella organisation of the trade unions. This happens very rarely in such a sensitive area.”

Families: Considering the needs of carers

Effective integration of those with mental illness into society is not confined to helping the individual service users themselves. A major element of this is the informal care which those in the family provide. As Professor Knapp notes: “Often mental health issues spill over to family members.” Exact data on informal family caring for most conditions are rare, although the OECD states that family members acting as “informal carers are the backbone of long-term care systems in all OECD countries”. For mental health, this is growing with deinstitutionalisation, and the “additional burden placed on families is still not recognised,” according to EUFAMI’s Mr Jones. This is especially the case where effective community services have not been created to help fill the gap. Family members typically give assistance willingly, but when it comes to mental health, the negative effects on them are also great. An extensive body of research shows that taking care of a mentally ill relative imposes greater psychological burdens on individuals than those resulting from tending to someone with a long-term purely physical ailment.

all of it—funded schemes to support carers, guaranteed legal rights for family carers and a support organisation, typically an NGO—while 11 have either just one or none of these relatively basic forms of assistance. In general, notes Mr Jones, in terms of “support for families with coping skills and intervention programmes, across Europe there is very little available in terms of family programmes at the national/regional level.” His own organisation, EUFAMI, a coalition of national family support groups, has developed PROSPECT. Rolled out in 14 countries, this provides training for family carers in meeting their own needs as well as for professionals in understanding the requirements of people living with mental illness and their families.

The issues for family carers, however, go beyond assistance in knowing how to cope. Other aspects of their lives are affected. Mr Jones explains that lack of workplace flexibility for carers is a major difficulty for them providing the kind of assistance needed for the active integration of relatives in poor mental health. In fact, the provision of back-to-work schemes for families and carers of those with mental health disorders was one of several indicators left out of the index because the relevant data were simply unavailable. Professor Knapp adds that stigma often easily transfers from the family member suffering from a mental health issue to the family as a whole. More effective integration therefore

³⁰ Christina Meyn, *psyGA-transfer: Abschlussbericht der Evaluation*, 2013.

Our index data indicate, however, that such carers are an insufficiently supported resource: only 14 of the 30 countries surveyed have

A shift towards a better system of integrated care will not come from psychiatry but from patients and the families of patients.

needs to consider not just people living with mental illness but those surrounding them as well.

The benefits could be substantial. Yann Hodé, a psychiatrist in Rouffach, France and head of Profamille, a network dedicated to the education of the families of those with mental illness,

believes that the potential value of families goes well beyond providing unpaid help. He says that a shift towards a better system of integrated care “will not come from psychiatry but from patients and the families of patients. With AIDS, these associations changed things. We need to give power to patients and families to change things [in mental health].” ■

4

The data chasm

Europe needs better data on how care is organised in general and what treatments are best provided by whom and when. All these data are lacking.

Any index such as this must seek to build on accurate, comparable data from all the countries covered. Efforts to do so for this study have put into sharp relief one of the most worrying findings of the index project: the poor quality of information available across the area of mental health in general, and on the active integration of those with serious mental illness into society in particular.

The problem affected the index from the start. It intentionally has a large proportion of indicators based on the state of government policy in relevant areas simply because other types of data were known to be unavailable. For example, the OECD reports that only a handful of its member states are able to report on such simple medical process data as timely follow-up or continuity of care after mental health-related hospitalisation.³¹ Even within our restricted ambitions, finding information proved a struggle: late in the process, the index had to drop efforts to include such basic data as the number of occupational therapists and of mental health outpatient facilities per capita because it proved impossible to obtain figures for all index countries.

Nor is this experience unusual. Mr Prinz recalls that when the OECD launched the Mental Health and Work project, those involved were shocked by the lack of information in this field. "The data gaps are astonishing, knowing how large the costs of this problem are," he adds. Looking at mental health more broadly yields a similar picture. Professor Wittchen calls "the range of data deficits and methodological problems a

daunting issue. Many countries have no data, and existing data are not homogenous, so you have to use heuristic approaches." The implications of such poor information are far more substantial than frustrated research agendas. Data are central to addressing the substantial burden of mental illness. As Professor Wittchen puts it: "You can't just triple the number of psychiatrists and hope things will improve."

There has been progress over recent years, notes Professor Caldas de Almeida, especially since 2001, when the WHO's World Health Report examined deficiencies in the understanding of mental illness. Nevertheless, even information on the extent of poor mental health is spotty. An analysis of available information for the WHO's Global Burden of Disease project found that for major mental illnesses, such as anxiety disorders and major depression, prevalence surveys had looked at sub-groups making up only 82% and 74% of the population of western Europe respectively. Heading east, the numbers dropped precipitously to around 25% at best.³² The effect in south-eastern Europe, notes Ms Zlati from Romania's Open Minds, is that "we don't even know what the prevalence of different diagnoses is." For less common mental illnesses, the situation is even worse: in western Europe, prevalence surveys of bipolar disorder and schizophrenia cover under 20% of the population, in central and eastern Europe a mere tenth of that, or under 2%.

Moving away from diagnosis to more complex information, the fog gets far thicker. On the medical side of care, says Professor Wittchen "we

³¹ Making Mental Health Count, OECD, 2014.

³² Amanda Baxter et al, "Global Epidemiology of Mental Disorders: What Are We Missing?", PLOS One, June 2013.

Integrated medical, social, employment and psychological provision is key to recovery, but the only data we have are from within the health system.

If we are thinking about integrated responses, we need integrated data.

don't know how and in what way health systems need to be harmonised or improved. Europe needs better data on how care is organised in general and what treatments are best provided by whom and when. All these data are lacking." Similarly, various studies indicate that integrated medical, social, employment and psychological provision is key to recovery, but "the only data we have are from within the health system," says Mr Prinz. "Public employment services are confronted with mental health issues on a large scale, but they do not measure or tackle them. They are unaware of them." Professor Knapp agrees: "In the NHS, we have some good data, but we can't link them up well with data in other systems, such as welfare, benefits or justice. If we are thinking about integrated responses, we need integrated data."

Finally, and most important, detailed data on how patients react to and perceive the success of care are lacking. Just eight index countries have committed to adopting the use of Patient Reported Outcomes Measures (PROMs) to monitor health service delivery or modify policy at some point, and none has fully implemented this yet. Dr Massimo Moscarelli, director of Italy's International Centre of Mental Health Policy and Economics, believes that PROMs are crucial, because they can look at a range of impacts that are personally meaningful to the patient. "Someone with schizophrenia," he notes, "may be personally disturbed by experiences or symptoms of the disorder. However, only very recently are measures beginning to focus on these experiences and to evaluate the effectiveness of treatment in reducing this disturbance—an outcome that qualifies as and indicates treatment success from the patient perspective. Also, the persistence of these personally disturbing experiences and symptoms of the disorder, if not successfully relieved by

dedicated treatment, may become a severe hindrance to social relationships or working activities, and in general to social participation." At the centre of a recovery-based model should be consideration of the extent to which those affected by mental illness feel they have successfully recovered a range of abilities.

Practical obstacles to the collection and collation of all these types of data are legion: even diagnoses of certain mental conditions are not always rigorously standardised across international borders. Nevertheless, it has been possible to develop metrics in other complex areas of medicine, and efforts in mental health are starting to bear fruit. The Mental Health Recovery Star, for example, is a joint PROM and intervention tool to help with recovery that has been adopted in several parts of the UK. More important than practical barriers, though, says Dr Moscarelli, are attitudinal ones: "The real issue is the value which society decides to assign to systematic, continuously updated information on the outcomes of all the persons affected by severe mental disorders, both in terms of health and of social participation."

Given the socioeconomic burden of these illnesses, he says, it is simply not efficient that major decisions—including those related to clinical treatment; health and social services organisation and financing; health policy formulation; and patients and advocacy groups—are made without appropriate information about the outcomes for the affected persons. "To evaluate regularly if patients are improving or worsening over time is basic information, and patient-reported outcomes are a crucial component of this," says Dr Moscarelli. "In future, this information cannot be avoided." The sooner it is collected, the better Europe will be able to address the challenge of mental illness.

It is simply not efficient that major decisions are made without appropriate information about the outcomes for the affected persons.

A roadmap to better understanding of mental health

One current effort to light a candle rather than curse the data darkness is the Roadmap for Mental Health Research in Europe (ROAMER) programme. It is also an attempt to overcome the divisions so characteristic of the mental health field.

Dr Josep Maria Haro, project co-ordinator, notes that mental health research and data gathering tend to have a lower funding than similar efforts in other medical fields and to receive little funding overall. One barrier to impact and investment, he says, is the large number of views and perspectives on what needs to be done. ROAMER, a three-year research consortium funded by the European Union, rather than adding yet another voice to the din is seeking to create a consensus pan-European roadmap for the promotion and integration of mental health and wellbeing research. "ROAMER is not a research project," Dr Haro explains, "but an exercise in putting mental health research in the place it should be."

The project is nothing if not broad. Dr Haro believes that it is the first such review that encompasses mental health as a whole. It has six research foci: research infrastructure, biomedicine, psychological research and treatments, social and economic integration, public health, and wellbeing. For each a large team seeks to determine what data exist and to reach a consensus on where the biggest gaps are.

Breadth is also a characteristic of participant backgrounds. The teams include not just research scientists but all relevant stakeholders, such as clinicians, policymakers, mental health service users, family members and carers. Such diversity is not simple to pull off in mental health. Dr Haro notes that "the first thing

ROAMER achieved was to put all stakeholders at the same table, and the big surprise is that we can all work together. At the beginning of the meetings, for example, even the concept of a mental disorder was different for public health and clinical researchers. Our main achievement so far is we can agree."

As part of the project, ROAMER participants have already submitted or published over a dozen papers in peer-reviewed journals.³³ For the most part, these have found substantial gaps in even basic knowledge. As Dr Haro puts it: "The vast majority of the time we do not know what causes mental disorders; our treatments are empirical and not based on pathological understanding, and there is very little research on how to make treatments accessible."³⁴ On the positive side, he notes, research in individual countries has focused on different areas of mental health, making it possible to take advantage of complementary work. Another interesting finding in the context of the Mental Health Integration Index is that the extent of research varies greatly between countries. "The leaders in publications," says Dr Haro, "are the UK, the Nordic countries and, to some extent, Germany."

Looking ahead, the project is set to wrap up in early 2015, with a multi-stakeholder consensus event to launch an agreed roadmap. Dr Haro notes, however, that this cannot be the end of efforts to improve understanding about mental illness and its treatment. "Progress will only happen if there is a continuous push for it. The next step will be maintaining a continuous dialogue between all stakeholders—basic research scientists, clinicians, funders, patient associations, primary-care doctors, psychologists—in order to push policymakers."

³³ For a current list, see http://www.roamer-mh.org/index.php?page=5_9

³⁴ For an overview of findings in all the focus areas, see Haro et al, "ROAMER: roadmap for mental health research in Europe," *International Journal of Methods in Psychiatric Research*, 2014.



Conclusion

Despite quite a few differences across countries, we find the same issues again and again, including silo thinking as well as a lack of integrated support.

Coming to grips with mental illness

Europe has long faced a substantial burden from mental illness, but now the epidemiological data—incomplete as they are—make the issue impossible to ignore. Thirty-eight percent of Europeans suffer from such a condition every year. Nevertheless, the Mental Health Integration Index shows that, to use Mr Prinz's words, "despite quite a few differences across countries, we find the same issues again and again, including silo thinking and acting as well as a lack of integrated support."

Solutions are not lacking, but they have not been put in place. As Nicolas Rüsch, professor of public mental health at the Department of Psychiatry II, University of Ulm and BKH Günzburg puts it, often "we know what would work, but it is not implemented."

This study indicates a variety of areas where action is needed in order for progress against these diseases to occur. These include the following.

- *Obtaining better data:* Epidemiological, medical and social care process and outcomes figures are all sparse or non-existent, impeding the formation of an overarching policy and

the understanding of best practice at the local and individual level. Even definitions of basic concepts such as "chronic mental illness", or of professions such as "occupational therapist" require standardisation. More important than understanding processes, other fields of medicine have benefited greatly from the development of outcomes measures, including those reported by patients themselves. Without these, it will be impossible to understand whether other efforts are making a positive difference or not.

- *Providing funding appropriate to the task:* Mental healthcare provision is itself a Cinderella service. Political will to invest is often lacking with, in extreme cases, even national policies being aspirational rather than adequately funded. Even where this will exists, integrated care provision can often be impeded by the existence of budgetary silos mirroring institutional ones. On the other hand, the potential savings from appropriate investment are substantial, with mental illness costing Europe €461bn in 2010.

- *Finishing the task of deinstitutionalisation:* Deinstitutionalisation has been a widely accepted policy for decades. In most index countries, however, the majority of those with mental illness remain in long-stay institutions. These facilities may be necessary to provide care,

temporarily, to the most extreme cases, but should not be the core element of mental health provision. Six of the seven highest finishers in the index treat most patients in the community, giving a range of successful models for change.

● *Focusing on the hard task of providing integrated, community-based services:* Although 21 of the 30 countries have some version of ACT (Assertive Community Treatment) teams, only just over half provide domiciliary care or home visits. Moreover, experts interviewed for this report suggest that, while there are individual models and programmes that provide an excellent service, these are not always widespread. Scaling them up, as FACT (Flexible Assertive Community Treatment) is showing in the Netherlands, is not only possible but can yield better outcomes. Failing to provide effective, community-based care, however, turns deinstitutionalisation from a promising start of a new approach into a disaster for people living with mental illness.

● *Including integrated employment services in community-based care provision:* Employment is often a key component of recovery, but those with mental illness are much less likely to be in work. Moreover, efforts to improve the situation

can side-track these individuals into employment ghettos outside the mainstream. Although by no means perfect, integrated placement services show great promise in helping those with mental illness to reconnect to the world of work.

Change in all of these areas, however, requires political leadership so that mental health receives the attention it needs. Dr Toresini explains the current dilemma in many countries: “As long as the mentally ill person is regarded as a dangerous person, there is a tendency for the government to give out money for asylums. On the other hand, when a government, as well as public opinion, recognise that the problem of dangerousness is no longer there, the readiness of governments to give money decreases drastically.” True integration will require a different point of view: the understanding that individuals living with mental illness, rather than being outsiders worthy of exclusion, are as much a part of the community as anyone else. Perhaps the most important finding from this index is therefore that its top-ranked countries share a long-term, widely supported commitment to change. Once that is in place, progress may be slow, but it will occur.

Appendix I

Overview of index

OVERALL SCORE			ENVIRONMENT Providing a stable home and family		ACCESS Access to health services		OPPORTUNITIES Improving work and education opportunities		GOVERNANCE Reducing stigma and increasing awareness	
RANK	COUNTRY	SCORE	RANK	COUNTRY	RANK	COUNTRY	RANK	COUNTRY	RANK	COUNTRY
1	Germany	85.6	=1	Germany	1	Germany	1	France	1	United Kingdom
2	United Kingdom	84.1	=1	United Kingdom	2	Slovenia	2	Finland	2	Finland
3	Denmark	82	=3	Denmark	3	Norway	=3	Denmark	3	Denmark
4	Norway	79.5	=3	Netherlands	4	Denmark	=3	Estonia	=4	Germany
5	Luxembourg	76.6	=3	Norway	5	Spain	=5	Germany	=4	Luxembourg
6	Sweden	74.1	=3	Sweden	6	Luxembourg	=5	Netherlands	6	Sweden
7	Netherlands	72.8	=7	Latvia	7	Netherlands	=5	Norway	7	Belgium
8	Estonia	71.4	=7	Luxembourg	8	United Kingdom	=5	Spain	8	Norway
9	Slovenia	71.1	=9	Ireland	9	France	=9	Luxembourg	9	Estonia
10	Belgium	70.7	=9	Spain	10	Austria	=9	Poland	10	Poland
11	Finland	70	=11	Belgium	11	Malta	=9	United Kingdom	11	Ireland
12	Spain	68.8	=11	Slovenia	12	Lithuania	12	Austria	12	Cyprus
13	France	68.4	=13	Finland	13	Sweden	=13	Belgium	13	France
14	Ireland	68	=13	Poland	14	Estonia	=13	Italy	14	Slovenia
15	Poland	64.1	15	Italy	15	Belgium	=13	Malta	15	Netherlands
16	Italy	59.9	16	Estonia	16	Ireland	13	Sweden	16	Romania
17	Malta	59.7	17	Czech Republic	17	Czech Republic	=17	Cyprus	17	Lithuania
18	Czech Republic	59.4	18	Slovakia	18	Italy	=17	Ireland	18	Czech Republic
19	Austria	57.9	19	Malta	19	Slovakia	=17	Slovenia	=19	Hungary
20	Lithuania	53.5	20	France	20	Switzerland	20	Czech Republic	=19	Slovakia
21	Latvia	51.9	20	Portugal	21	Poland	=21	Hungary	21	Switzerland
22	Slovakia	46.8	22	Austria	22	Cyprus	=21	Latvia	22	Portugal
23	Cyprus	46.6	23	Hungary	23	Croatia	=21	Switzerland	23	Croatia
24	Switzerland	45.7	24	Lithuania	24	Finland	=24	Croatia	24	Malta
25	Hungary	43.9	24	Romania	25	Latvia	=24	Greece	25	Greece
26	Croatia	40.1	26	Greece	26	Hungary	=24	Lithuania	26	Spain
27	Portugal	38.1	27	Switzerland	27	Greece	27	Portugal	27	Latvia
28	Greece	38	28	Bulgaria	28	Portugal	=28	Bulgaria	28	Italy
29	Romania	34.7	29	Croatia	29	Bulgaria	28	Romania	29	Austria
30	Bulgaria	25	30	Cyprus	30	Romania	30	Slovakia	30	Bulgaria

Appendix II

Index methodology

The EIU's Mental Health Integration Index measures the degree of support within European governments for integrating people with mental illness into society. It compares levels of such support in 30 European countries—the EU28 plus Norway and Switzerland. The aim of this comparison is to contribute to the debate on integration by showing where the strengths and weaknesses lie in individual countries, and therefore where policy improvements may be needed.

Indicators

The comparison of countries in the index is achieved by compiling a score for each country based on a set of indicators applied uniformly across all 30 countries. The index has a total of 18 unique indicators which focus on the degree of governments' commitment to integrating people with mental illness, and seven additional background indicators on each country. Some of the 18 unique indicators are composites consisting of several sub-indicators.

The 18 indicators dealing with mental health integration fall into four categories, as follows:

- **Environment:** This category considers the presence or absence of policies and conditions

enabling people with mental illness to enjoy a stable home and family life. This includes indicators such as availability of secure housing and of financial support.

- **Access:** This category considers the presence or absence of policies and conditions enabling access by people with mental illness to healthcare and social services. This includes indicators such as outreach programmes to ensure awareness of such services.

- **Opportunities:** This category considers the presence or absence of policy measures that help people with mental illness to find work, stay in work, and work free of discrimination.

- **Governance:** This category considers the presence or absence of policy measures to combat stigma against people with mental illness. It includes such indicators as awareness campaigns and policies encouraging people with mental illness to influence decisions.

Each country's score can be viewed at the aggregate level—ie, as the sum of its scores on all the indicators—as well as at the category level, ie, as the sum of its scores on the indicators within a given category. In this way, countries can be compared both overall and at the category level.

Because each category has a different number of indicators in it, and because each of the 18 indicators has the same weight in the index (namely 5.55%, or one-eighteenth of 100%), the various categories have different weights within a country's overall score. In particular, the individual categories have the following approximate weights within the index:

- Environment (5 indicators) 28%
- Access (5 indicators) 28%
- Opportunities (3 indicators) 17%
- Governance (5 indicators) 28%

The background indicators, as the name implies, were not included in the calculation of each country's score. Instead, these indicators were used as background when analysing the results. The exclusion of the background indicators from the overall score was intended, among other things, to remove the effect that wealth alone would have on a country's performance, and focus instead only on each country's commitment—irrespective of wealth—to integrating people with mental illness into society and work.

Here is a description of the indicators in the index:

Environment (5 indicators)

- **Benefits and financial control:** Presence or absence of social welfare benefits, and control over personal finances, by those with mental illness
- **Deinstitutionalisation:** Presence or absence of a deinstitutionalisation policy, and degree of financial support for community-based, deinstitutionalised care
- **Home care:** Score reflects whether the number of people with mental illness who receive long-term support in the community is greater or smaller than the number in long-stay

hospitals or institutions

- **Parental rights and custody:** Score reflects whether countries have policies which protect the child-custody rights of parents with mental illness insofar as possible
- **Family and carer support:** Presence or absence of funded schemes to assist carers, guarantees of legal rights of carers, and/or the presence or absence of family support organisations

Access (5 indicators)

- **Assertive outreach:** Presence or absence of community-based outreach services and other specialist community mental health services
- **Mental health workforce:** A composite score reflecting the number of psychiatrists, psychologists, mental health nurses and social workers per 100,000 population
- **Advocacy within the healthcare system:** Score reflects whether the country provides

funding for advocacy schemes for mental health service users

- **Access to therapy and medication:** A composite score reflecting the degree of access of people with mental illness to various therapies, mood stabilisers and/or antipsychotic medication
- **Support in prison:** Score reflects the prevalence of mental health support measures for incarcerated people who have a mental illness, and for such individuals post-release

Opportunities (3 indicators)

- **Back-to-work schemes:** Presence or absence of back-to-work schemes for people with mental illness; legal duty for employers to make reasonable adjustments to accommodate such employees; funding for practical support when returning to work; availability of “fitness for work” statements from physicians, for example
- **Work-placement schemes:** Presence or absence of mechanisms to help people with

mental illness find work; funded schemes to provide individual work placements; training and vocational support programmes; and funding for individual “job coaches”.

- **Work-related stress:** Score reflects whether countries have occupational health policies and safety regulations that include preventing work-related stress

Governance (5 indicators)

- **Involuntary treatment:** Score reflects the number of criteria which must be fulfilled in order to confine or treat a person with mental illness against his/her will
- **Human rights protection:** Score reflects whether a country has signed/ ratified human rights treaties, and whether it has review bodies to assess human rights protection of users of mental health services
- **Cross-cutting policies:** Score reflects the presence or absence of formal collaboration

among government agencies (education, employment, housing) to address the needs of people with mental illness

- **Changing attitudes:** Score reflects the prevalence of mental health promotion programmes in the workplace and in schools
- **Assessment from patient perspective:** Score considers the degree to which patients’ opinions and feedback are taken into consideration in measuring the quality of mental healthcare

Background (7 indicators)

- **Discrimination:** A qualitative measure of discrimination against people with mental illness
- **Suicide rate:** Number of suicides per 100,000 population per year
- **Health expenditure:** as a percentage of GDP

- **Mental health expenditure:** as a percentage of total health budget

- Population size
- GDP
- GDP per capita

Scoring system

The index is based on a point system, with the points received for each indicator added up to provide an overall score for each country. The maximum score a country could receive for all 18 indicators together is 100. For the qualitative indicators, countries received points based on the quality of their result for each indicator. For the sole quantitative indicator (the measure of the mental health workforce per population), points were assigned based on a scale in which the best-performing country received ten points and the worst-performing country zero points.

In some cases involving quantitative data, outliers were ignored to avoid skewing the rest of the index. For example, the “best” rating for the number of mental health nurses per 100,000 people was assigned to the Netherlands, which has 132 nurses per 100,000 people, even though Bulgaria reported having 431 nurses per 100,000 people. The rest of the countries were scored with reference to the Dutch maximum of 132 and not the Bulgarian maximum of 431. The reason is that the Bulgarian figure was considered a significant outlier, most likely the result of a problem with data collection or a difference in definitions.

³⁵ Here is the difference in the scoring schema: In the **first** type of qualitative indicator, countries are scored based on the **degree** to which a particular policy or scheme is present. For example, in the “changing attitudes” indicator (within the Governance category), countries received a high score when they have integrated mental health awareness into school curricula through formal partnership between the education and health sectors; a middling score if awareness is integrated into the curriculum but not through a formal partnership; and a low score if mental health awareness is not integrated into school curricula at all. In the **second** type of qualitative indicator, countries are scored based on **how many criteria** they fulfil from a “checklist” of relevant activities. For example, in the “support in prison” indicator (within the Access category), countries received the maximum three points if they offer all of the following: suicide prevention programmes in prison; mental state assessment procedures prior to release; and referral mechanisms of mentally disordered prisoners to mental healthcare services upon release. They receive middling scores if they offer only part of that checklist, and a low score if they offer none of those services.

³⁶ The eight countries from which we did not receive timely replies are: Croatia, Denmark, Greece, Norway, Portugal, Switzerland, Sweden and Spain.

Qualitative vs. quantitative indicators

Virtually all of the indicators in the index are qualitative—that is, the data were developed based on scoring performed by EIU analysts to reflect the performance of each country on each indicator. Their assessments, in turn, were based on extensive research on conditions and policies in each country. Detailed scoring guidelines ensured that different analysts applied the criteria uniformly, thereby generating scores that can be compared across countries. Due to slight differences in the scoring schema for different types of qualitative indicators, the qualitative indicators appear in the index under two separate tabs; but this separation does not affect the outcome of the benchmarking exercise.³⁵

To add a second level of expertise to that of the analysts making these assessments, the scoring of the indicators was checked with mental health experts familiar with—and in most cases, based in—each country under review. The network of country experts ranged from officials of national and international mental health organisations to caregivers, public health officials and policymakers. Such contacts were identified in nearly all countries covered in the index; the exceptions were Romania and the Netherlands. Of the 28 countries contacted, feedback was received from experts in 20 countries.³⁶ Country scores were also reviewed by officials of Mental Health Europe, a Brussels-based advocacy organisation focusing on mental health policies.

The sole exception to the preponderance of qualitative indicators is “Mental health workforce”, the second indicator in the Access category. This one is a quantitative indicator with assessments based on existing national and international data. In particular, this indicator considers the number of psychiatrists, psychologists, social workers and mental health nurses per 100,000 people in each country. The highest scores go to the countries that have the greatest presence of mental healthcare-givers per 100,000 population.

Advisory panel

The list of indicators and the scoring system for each indicator were developed in consultation with a panel of experts on mental health in Europe. The panellists were:

- Professor Peter Huxley, professor of mental health research, Bangor University, Wales
- Kevin Jones, secretary-general of the European Federation of Associations of Families of People with Mental Illness (EUFAMI)
- Pedro Montellano, president, Global Alliance of Mental Illness Advocacy Networks (GAMIAN) Europe
- Dr Slawomir Murawiec, co-organiser of the most recent European Mental Health Systems Network conference for the European Health Management Association (EHMA)
- Stephanie Saenger, president, Council of Occupational Therapists for the European Countries (COTEC)

Information sources

To assess the presence or absence of relevant programmes and policies, the EIU collected country data and other information during the first half of 2014. Wherever possible, the information was taken from official sources such as national and regional health ministries, the WHO and the OECD. Further information was sought from academics, academic journals and government officials with a mental health policy remit. Most data are for the year 2014. When these were not available, data from earlier years were used.

Terminology

The index measures activities or programmes which are called different things in different countries. For example, the term “assertive outreach” in the index and in this report is used in the UK to refer to reaching “difficult to engage” people with mental illness. The same activity is known as “assertive community treatment” in the Netherlands. In the interest of clarity, this

research uses the same term throughout to refer to a particular activity—in this example, using the UK term assertive outreach—rather than using the varying national terms.

For purposes of the index, the EIU used the following definitions:

- **Assertive outreach:** Reaching people with mental illness who are usually difficult to engage
- **Active integration:** Ensuring a community-based approach to care, and aiming for meaningful participation in society by those with mental illness
- **Deinstitutionalisation:** The process of transferring the care of those with mental illness from long-term institutions to integrated community-based mental health services
- **People with mental illness:** Individuals who have or have had a mental disorder as defined by the WHO's International Classification of Diseases ICD-10 classification. This includes depression, anxiety and schizophrenia. It excludes mild depressive symptoms which do not meet the criteria for depressive episodes.

Data availability

This research casts a spotlight on the limitations—both in terms of availability and

comparability—of European data on mental health integration. The focus on policies and inputs into integration of those suffering from mental illness—rather than on the outcomes of policies and the success of integration efforts—is largely due to the absence of data on the latter. Qualitative data were developed in large part because of the absence of quantitative data comparable across the 30 countries under review.

The dearth of data is rooted in under-resourcing of data collection and is exacerbated by inconsistent definitions of key terms and concepts. Moreover, international organisations such as the WHO lack sufficient resources to fully validate the information they receive from individual states. Beyond the dearth of high-quality data, the EIU's scoring of qualitative indicators was complicated by the lack of standard definitions of key services and policies across the countries under study. In addition, data at national level often omit initiatives at regional or local level, in some cases because the regional/local activities are themselves poorly documented. These information gaps are a major hindrance to developing policies aimed at improving the integration of those with mental illness into society.

While every effort has been taken to verify the accuracy of this information, neither The Economist Intelligence Unit Ltd. nor the sponsor of this report can accept any responsibility or liability for reliance by any person on this white paper or any of the information, opinions or conclusions set out in this white paper.

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