Psychiatric rehabilitation in Europe

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To describe the core elements of modern psychiatric rehabilitation. Based on selected examples we describe the discussion about values in mental health care with focus on Europe. We present outcome data from studies, which have tried to implement care structures based on this value discussion. In the second half of the 20th century, mental health care in all European and other high-income countries changed conceptually and structurally. Deinstitutionalisation reduced the number of psychiatric beds and transferred priority to outpatient care and community-based services, but community mental health programs developed differently across and within these countries. High-income countries in Europe continued to invest in costly traditional services that were neither evidence-based nor person-centered by emphasising inpatient services, sheltered group homes and sheltered workshops. We argue that evidence-based, person-centred, recovery-oriented psychiatric rehabilitation offers a parsimonious solution to developing a consensus plan for community-based care in Europe. The challenges to scaling up effective psychiatric rehabilitation services in high-income countries are not primarily a lack of resources, but rather a lack of political will and inefficient use and dysfunctional allocation of resources.

Introduction

In the second half of the 20th century, mental health care in all European and other high-income countries changed conceptually and structurally. Deinstitutionalisation reduced the number of psychiatric beds and transferred priority to outpatient care and community-based services, but community mental health programs developed differently across and within these countries (Feachem, 2000).

High-income countries in Europe and elsewhere continued to invest in costly traditional services that were neither evidence-based nor person-centred by emphasising inpatient services, sheltered group homes, day treatment centres and sheltered workshops (Salize *et al.* 2009). Only a minority of patients received appropriate outpatient treatment and evidence-based psychiatric rehabilitation interventions (Kessler *et al.* 2005). In addition, public policies often discouraged employment (Burns *et al.* 2007) and segregated people with mental illness from the mainstream (de Girolamo *et al.* 2007).

One fundamental difficulty in developing community-based care has been that patients and professionals often disagree over the nature of mental disorders and the goals of treatment. Disputes range between models of biological dysfunction on one end and psychosocial distress on the other. Physicians often emphasise multiple medications to relieve symptoms of a biological disorder, while patients emphasise the need for supports to reduce psychological distress and improve functional adjustment. Similarly, professionals highly value stability (symptom control) as a primary goal, whereas people with mental illness prioritise satisfying, meaningful lives (Deegan, 2005). In part because of these differences, most people with mental disorders avoid the mental health system and find it stigmatising (Thornicroft, 2006).

We argue that evidence-based, person-centred, recovery-oriented psychiatric rehabilitation offers a parsimonious solution to developing a consensus plan for community-based care in Europe. Of course the problems facing high-income countries differ from those of middle- and low-income countries: the challenges to scaling up effective psychiatric rehabilitation services in high-income countries are not primarily a lack of resources, but rather a lack of political will and inefficient use and dysfunctional allocation of resources.

Psychiatric rehabilitation

By the early 21st century, the philosophy of recovery and the practice of psychiatric rehabilitation have

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matured. Recovery represents a hopeful philosophy articulated, endorsed and activated by people with lived experience of mental illness (Deegan, 1988). It asserts that people with mental illness can lead satisfying and meaningful lives with or in spite of the restrictions imposed by the illness. Recovery philosophy does not presuppose cure but rather advocates for meaningful participation and inclusion in societal life (Davidson *et al.* 2006; Slade, 2009). In addition to optimism, it emphasises empowerment, self-determination, quality of life and overcoming stigma.

Psychiatric rehabilitation actualises the philosophy of recovery by helping people to work toward and achieve personal and functional goals (Rössler, 2006; Corrigan *et al.* 2008; Dixon *et al.* 2010; Corrigan, 2016). For people with serious mental illness in Europe, as for most people everywhere, personal goals typically involve decent housing, safe neighbourhoods, decent income, education, competitive employment, social opportunity and full participation as citizens in their communities. Rehabilitation specialists or teams help people to develop the skills, supports and environments to pursue these goals.

Principles of psychiatric rehabilitation

Basic principles of psychiatric rehabilitation include respect for autonomy, therapeutic relationships, shared decision-making, enhancing skills, increasing opportunities, providing supports and improving the environment to minimise discrimination and stigma (Corrigan, 2016). Many examples of specific, evidence-based models of psychiatric rehabilitation exist, for example, supported housing and assertive community treatment. Bond reviews these in a companion essay in this volume. In this essay we explain the principles of psychiatric rehabilitation and illustrate how they are implemented with examples from Individual Placement and Support (IPS), the evidence-based model of supported employment (Drake *et al.* 2012). IPS serves as an exemplar because it incorporates all of the principles of psychiatric rehabilitation and 24 randomised controlled trials have proven its effectiveness. Approximately two-thirds of IPS participants have obtained competitive employment in European countries and other high-income countries in Asia and North America.

Respect for autonomy

In modern, liberal democracies, ethical and legal standards include the right to make decisions regarding one's person. This right is only abrogated in extreme circumstances, such as immediate dangerousness. Thus

people with serious mental illness have a right to choose preferred interventions (they often choose independent living and employment services) and to refuse others (they often reject living in group homes and using medications that cause distressing side effects). Autonomy also implies that coercion, in all of its forms, should be avoided to the greatest extent possible.

As an example, in IPS the client takes the lead in all decisions regarding employment: when to pursue employment, what kind of job to pursue, how many hours to work, how to approach employers, what to disclose about health issues, what kinds and amounts of support for the job and when to leave a job. The IPS specialist may offer advice based on experience (e.g., starting to work full-time can be stressful for most people), but generally acts as the client's agent in selecting, finding and maintaining a job (Swanson & Becker, 2013).

Engagement and relationship

Effective psychiatric rehabilitation requires close cooperation between clients and professionals. Engaging people with the most serious disorders in a trusting relationship (McCabe *et al.* 2012; Dixon *et al.* 2016) is essential. Coercion can undermine success: a perceived loss of autonomy may create a more negative dynamic between client and clinician (Theodoridou *et al.* 2012), while a good relationship improves quality of life and functional outcomes (Catty *et al.* 2010, 2011). In psychiatric rehabilitation, the working relationship often encompasses an entire team or several members of a team and the client's family or other social network members.

As an illustration, IPS uses outreach, motivational interviewing, valuing the client's goals and following the client's lead to develop a trusting relationship. The relationship encompasses a team: an IPS specialist, as care manager, a prescriber, the client and the client's family. When clients fail to engage or drop out of IPS (Milfort *et al.* 2015), the effect is to reduce chances of employment, confirming the importance of relationship.

Shared decision-making

The evidence sometimes indicates that one specific treatment (or algorithm) is best for everyone with a specific condition due to a preponderance of research showing consistent positive outcomes and minimal harms. But few health care decisions in general and almost none in mental health meet this standard. Instead, most decisions are preference-sensitive (Wennberg, 2010), which means that several interventions have positive evidence and people could reasonably make different choices. When several treatments may be effective – each with a balance of positive and negative outcomes – clients'

preferences should determine actions (Drake *et al.* 2010). Shared decision-making requires collaboration: the clinician provides expert information on available treatments, the client provides expert information on personal preferences and goals, and they work together to develop a plan (Elwyn *et al.* 2012). In Europe patients' desire for participation in decision-making varies considerably between countries. More research is needed on identifying specific cultural and social factors in various countries to further explain observed differences across Europe (Bär Deucher *et al.* 2016).

Although IPS is the only evidence-based approach to employment for people with psychiatric disabilities (Bond *et al.* 1999), many decisions within IPS are subject to shared decision-making. As described above, the client takes the lead on all decisions regarding job choice, attaining a job and staying employed; and the IPS specialist and psychiatric rehabilitation team provide expertise regarding the job environment (Swanson & Becker, 2013). Together, they develop a plan for each step. For example, if the client wants to work with animals, they identify possible jobs at pet stores, veterinary clinics and farms. If the client wants to interview for a sales job but has a criminal justice system record, the employment specialist helps him/her to prepare an explanation that employers will accept. If the client wants to disclose mental illness to co-workers, the employment specialist can help him/her practice an interview. If the client wants job supports away from the job site, the employment specialist can meet him/her up at the end of the workday for the first week to review the experience.

Enhancing skills

The traditional approach to psychiatric rehabilitation entailed a 'train-and-place' model, usually teaching specific skills, for example cooking, working, or social skills, in a group format within the hospital, a clinic, or a day program (Anthony *et al.* 2002; Bellack, 2004). Over time, however, the difficulty of transferring skills learned in clinical settings to real-world environments has become evident. For example, clients may learn clerical skills in a day program and then get a job on a farm. Or clients may learn how to cook using equipment different from their own. Assertive community treatment teams began to emphasise helping people to learn relevant skills in the community in the 1980s (Stein & Test, 1980). Subsequently, teaching and learning skills in ecologically valid environments have become mainstream. New approaches use 'place-and-train' models, in which people learn skills in their own environments. For example, people learn to cook in their own apartment using their own stove, learn the skills for a job

on the job and learn to ride the bus route by practicing with some guidance initially.

IPS avoids lengthy testing or training before searching for a job by using a rapid job search method. Clients often choose jobs that align with their existing skills but learn new work skills (if needed) in the context of a real job (Swanson & Becker, 2013). The employment specialist may be on site the first day of work as a job coach and may help with learning social, transportation, or other skills related to the specific job. But as described below, IPS emphasises natural supports from a supervisor at work.

Supports

In the traditional approach to psychiatric rehabilitation, mental health professionals acted as the clients' support system as well as treatment providers. Sometimes professionals recruited family members and used education to improve the family's coping skills and reduce harmful interactions, termed 'expressed emotion.' As psychiatric rehabilitation has evolved, however, approaches have emphasised community-based supports in real-world settings: friends, family members, landlords, bosses, teachers, co-workers and others who can provide more natural supports.

In addition, the involvement of users, or peers, in treatment and supports outside of treatment has become widely accepted. Various forms of user involvement include: peer-run services, mutual support and peer support (Davidson *et al.* 2006). Peer supports in various psychiatric services have produced encouraging results (Rummel-Kluge *et al.* 2008).

In IPS, employment specialists help the client to obtain and succeed in an appropriate job, but prefer that supervisors and co-workers provide natural supports on the job – the same supports that other employees use to learn their jobs and solve workplace problems. Peers also sometimes help the IPS team with engagement, modelling, practical assistance and transportation.

Increasing opportunities

To succeed in community settings of their choice, people require opportunities to obtain housing, employment, social participation, citizenship and other roles. The main barriers to opportunity have been financial factors, attitudes, health issues and unemployment (Hästbacka *et al.* 2016). Psychiatric rehabilitation therefore uses key facilitators of opportunity such as legislation and disability policies, support from advocates and champions, anti-stigma campaigns and employment campaigns for people with disabilities (Hästbacka *et al.* 2016).

Specific legislative initiatives, such as the Americans with Disabilities Act (1990) and the World Health Organization' Right to Health (2002), promote equal opportunities and accommodations in many countries. Most high-income countries in Europe and elsewhere have right-to-work laws to protect people with disabilities (Nardodkar *et al.* 2016). Nevertheless, overcoming prejudice in everyday life remains problematic.

IPS specialists and psychiatric rehabilitation teams meet with employer organisations, such as community business groups, to explain the practice and advantages of supported employment (Swanson *et al.* 2013). Many employers want to hire a more diverse workforce and may even have government directives to hire people with disabilities but do not know how to find employees with psychiatric disabilities. Public education and individual contacts with employers are therefore critical.

Mental healthcare reform and psychiatric rehabilitation

High-value mental health care should centre on service recipients and what matters most to them (Mulley *et al.* 2016). Respect for clients' preferences and goals must be routinely integrated into daily procedures and measures to move systems toward outcomes that are valued by clients and their families rather than by professional organisations, institutions and profit-making industries. Several European countries have implemented some model programs of psychiatric rehabilitation, but no country in Europe or elsewhere has fully implemented the above rehabilitation principles in its national mental health policies. Instead, historical, cultural and social developments have created large differences between countries (McMichael & Beaglehole, 2000). Economic, social and professional factors have outweighed values and science.

Current mental health systems are typically not client-centred, not evidence-based and not recovery-oriented. Rather, health, social and legal systems emphasise segregation for people with serious mental illnesses: hospitals, group homes, day centers, sheltered work, nursing homes and medications. These services often involve hierarchical decisions, paternalism, control, coercion, chronicity and low expectations. They represent financial and sometimes professional interests rather than the preferences of people with mental illness.

People with a serious mental illness want opportunities for education, employment, decent housing, advance directives, psychosocial supports and therapies, choice of psychiatric medication and physical health. They want to access services in normalised, non-psychiatric, non-stigmatised settings such as primary care clinics and mainstream school, employment, housing and social centres. And they want freedom from the paternalism and coercion of the traditional mental health system. These preferred rehabilitation services are sometimes implemented in demonstrations and special programs but rarely in large-scale national service systems.

Are these changes possible? Yes, but such a radical reorientation would require shifting funding, decision-making, infrastructure, organisational arrangements, training and professional attitudes and behaviours. People with a serious mental illness would need to be empowered to co-produce services. Their voices would need to be included in considering available resources, services research and preferences.

Years of effort have broken down organisational, financing and professional siloes, but the approach is actually working to reduce homelessness and help people get the services they need and want. Research has supported the effectiveness of combining mental health and social services for years (Tsemberis, 1999; Drake *et al.* 2012), but large-scale demonstrations are needed to convince policy makers to overcome the resistance of vested interest groups.

Rehabilitation practice in Europe

Having described above the current framework for modern community treatment and psychiatric rehabilitation, the question remains what of all this has been put into practice in European countries.

Some caveats apply. First, Europe is not a unified entity, not even the countries belonging to the European Union. The European region includes approximately 900 million inhabitants in 53 countries with a huge variance in economic and political conditions and accordingly a similar diversity in the provision of mental health care. Deinstitutionalisation has taken place in most European countries since the 1950s, following different paces and different philosophies. While the reduction of inpatient treatment has significantly progressed, the implementation of respective outpatient services has not taken place at the same speed.

Mental health reforms started early in the UK during the mid 1950s. Health care, including mental health care, is mainly provided by the National Health Service (NHS), financed by national taxation and administered from the Department of Health in London. Quality and availability have become important areas of political debate. As a result, the National Health Service has been the subject of frequent and high profile government initiatives but has proved relatively slow to change (Glover, 2007).

German-speaking countries only started their reforms during the 1960s and 1970s, mostly because

their state mental hospitals were not as crowded as the ones in the UK, tragically in Germany and Austria due to the murder of hundreds of thousands of mentally ill people during the Nazi rule (Rössler *et al.* 1994). Switzerland traditionally maintained their cantonal mental hospitals much better and felt much less pressure for change.

Mental health care in German-speaking countries is organised as a subsidiary system, where the federal states or cantons are responsible for planning and regulating. Thus provision of mental health care in these countries is spread among many sectors and characterised by considerable regional differences (e.g. Salize *et al.* 2007).

Italian Psychiatry has been criticised over years because Italian reforms in the 1970s were more radical and more driven by ideology than any other reform process. But many important topics of the 21st century were anticipated in the Italian reforms, such as the concepts of patient- or individual-centred care and recovery. Even the caregiver perspective was made an issue, although many caregivers disliked the concept of complete responsibility for their family member. But Italian reforms also led to a separation of public mental health care for serious mental disorders and private mental health care for common metal disorders (Altamura & Goodwin, 2010). Today a marked quantitative and qualitative variation exists in the provision of outpatient and inpatient care throughout Italy, and service utilisation patterns are similarly uneven. Studies of patients' quality of life report a fairly high degree of patient satisfaction, whereas patients' families frequently bear a heavy burden (de Girolamo *et al.* 2007; Picardi *et al.* 2014).

All East European countries started psychiatric reforms only during the 1990s after the breakdown of the Soviet bloc. The burden of totalitarian history still influences many areas of their social and economic life, including mental health policy. All East European countries have reduced the numbers of psychiatric beds considerably, but they vastly lack respective community services. Knowledge about modern mental health care and the direction of needed reforms is available in documents, policies and programs, but after 25 years of health reforms, mental health systems struggle with transition. A balance of community and hospital mental health services has not been achieved yet and a custodial attitude towards mental health care prevails (Dlouhy, 2014).

The proportion of health budgets spent for mental health care reflects the diversity in Europe. For one half of 52 European countries, this proportion is unknown; 16 countries spend between 5 and 10%, four countries more than 10%, and eight countries below 5% of their total health budget (WHO, 2004). The proportion spent

for mental health care correlates with political interest in modern community and rehabilitative care.

The most pressing European problems concerning mental health care, which refer to European countries but to varying degrees, are (McDaid *et al.* 2005):

- resource inappropriateness when services do not match what is needed or preferred
- resource inflexibility when care is organised too rigidly
- resource dislocation when services are available but poorly coordinated
- resource timing when new services take too long to get implemented

The Report from the 'Economist Intelligence Unit' (2014) assessed the degree of commitment in 30 European countries to integrating people with mental illness in their communities. The report included 18 indicators including presence of social welfare benefits, control over personal finances, presence of community-based outreach services and other specialist community mental health services, funded schemes to provide individual vocational supports, legal duty for employers to make reasonable adjustments to accommodate such employees, legal criteria for coercive treatment, human rights treaties and review bodies to assess human rights protection of users of mental health services. Germany, the UK and some Scandinavian countries achieved the highest overall scores, while countries from South-East Europe were the lowest. Other reports confirm heterogeneity and extreme needs for progress in some countries (Almeida *et al.* 2015).

Conclusions

Europe is currently overwhelmed with political, immigration and economic issues. Differences between countries have created remarkably varied mental health service systems and patterns of psychiatric rehabilitation. Nonetheless, European countries could unite in endorsing and implementing evidence-based, client-centred approaches to psychiatric rehabilitation. Services could be driven by values, client preferences, outcomes research and implementation science. Common approaches could promote recovery, social inclusion and cost savings.

McCubbin & Cohen (1996) assume that the diverging interests of the actors involved in mental health care might be one of the reasons that sustainable reforms of mental health care were difficult or impossible to achieve. If one obstacle impedes reform, however, we believe it is the stigma associated with mental illness. Public attitudes inevitably form the basis on which decisions about resource allocation are made.

Thus, improving mental health care is not only a medical but also a political issue.

Conflict of Interest

None.

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