



LONG-TERM MENTAL HEALTH CARE FOR PEOPLE WITH SEVERE MENTAL DISORDERS

**Written by Jose Miguel Caldas
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I - Introduction

The provision of long-term mental health care for people with severe mental disorders has been, and still is, one of the major challenges for mental health systems reform in the last decades, for various reasons.

Firstly, although these disorders have a low prevalence, the impact they have on individuals, families and societies is huge. The group of schizophrenic disorders are the most important of the severe mental disorders since they are associated with the greatest impact on functioning. Schizophrenia has an estimated point prevalence of 0.4% and a lifetime risk of 1% i.e. one in a hundred people will suffer from schizophrenia during their lifetime (Goldner et al., 2002). It is the 7th most important disease in terms of years lived with disability, accounting for 2.8% of disability caused by all disease. For people aged 15 to 44 years, it is the 3rd most important disease, accounting for 4.9% of disability caused by all diseases (WHO, 2008).

Second, the experience in most countries is that the development of community services is a complex process that faces several important barriers.

Some of these barriers exist at the policy level, and may occur when there is a lack of adequate mental health policies and legislation, budgets are insufficient or where there is procedural discrimination against persons with mental disorders, in terms of limited or lack of health insurance. Other barriers are found at the level of the health system and include: difficulties in releasing resources from the large institutions (which absorb the greater part of the available funding), resulting in under investment in community-based services; lack of integration of mental health services with the general health system; lack of integration between mental health and social care systems, including poor co-ordination with housing, welfare and employment services; lack of co-ordinated partnership working between statutory and non-statutory mental health services, including the voluntary and independent sectors; and inadequate training of staff across systems (WHO, 2001).

Across Europe, much effort has been made over recent decades to overcome these barriers and to ensure high-quality longer-term care for people with severe mental disorders. These efforts started with the development of new pharmacological treatments for psychoses in the '60s, which radically changed the prognosis of severe mental disorders, and with the emergence of new psychosocial interventions and new concepts of mental health care organisation that occurred in several European countries in the '70s and the '80s. For example, sector psychiatry in France, social psychiatry and mental health in primary care in the UK, and psychiatric reform and deinstitutionalization in Italy became significant landmarks in this initial evolution.

These early initiatives have been followed by a multitude of further developments throughout Europe that have helped to advance mental health care in many countries. These include improvements in the living conditions in psychiatric hospitals, the development of community services, the integration of mental health care within primary care, the development of psychosocial care (housing, vocational training), the protection of the human rights of people with mental disorders and the increasing participation of users and families in

the improvement of policies and services (Muijen, 2008). Research into many of these developments has provided an increasing evidence base to guide investment into appropriate mental health care systems.

Nowadays there is a broad consensus on the need to shift from the model of care based on the traditional large psychiatric institutions to modern comprehensive community-based models of care, including acute patient units at general hospitals. The main reasons for this shift are the following:

- Accessibility to mental health care of people with longer-term mental disorders is much better with community-based services than with the traditional psychiatric hospitals. (Thorncroft & Tansella, 2003)
- Community-based services are associated with greater user satisfaction and increased met needs. They also promote better continuity of care and more flexibility of services, making possible to identify and treat more often early relapses, and to increase adherence to treatment (Thorncroft & Tansella, 2003; Killaspy, 2007).
- The community-based services better protect human rights of people with mental disorders and prevent stigmatisation of those people (Thorncroft & Tansella, 2003)
- Studies comparing community-based services with other models of care consistently show significant better outcomes on adherence to treatment, clinical symptoms, quality of life, housing stability, and vocational rehabilitation (Braun P. et al.,1981; Conway M. et al.,1994; Bond et al, 2001)
- Studies suggest that care in the community for acute psychoses is generally more cost effective than care in a hospital, although it is important to note that these results cannot be generalized to all patients requiring admission to psychiatric beds (Goldberg, 1991).
- Studies also show that, for patients who require prolonged stays in the hospital, hostel wards provide a cost-effective alternative that is preferred by the patients themselves (Goldberg 1991). Other studies show that, when deinstitutionalisation is correctly developed, the majority of patients who moved to from hospital to the community have less negative symptoms, better social life and more satisfaction (Leff, 1993;1996)

However, despite the strong arguments and all these efforts, much more has still to be done if we want to provide accessible, effective and high quality longer-term mental health care to all people with severe mental disorders in Europe. The stark reality is that in many countries, often those that are least economically developed, people with these disorders continue to reside in large psychiatric hospitals or social care institutions with poor living conditions, inadequate clinical assistance and frequent human rights violations (Muijen, 2008). In some countries, although progress has been made in the transition from psychiatric hospitals to community care, the resources allocated to the new services are very limited and responses to psychosocial needs are very scarce. We should also add that, even in countries where deinstitutionalisation is well advanced, there are concerns about an increasing “reinstitutionalisation” (in hospitals and community-based nursing and residential care homes) of people with longer-term and more complex mental health needs and those with a “forensic” history (Priebe et al, 2005). In the UK this is called the “OATs” (out of area treatments) issue, where concerns have been raised about the quality of care in some facilities, the social dislocation caused by being placed many miles from family and the local, responsible care system funding the placement, and poorly co-ordinated systems for reviewing individuals’ ongoing needs (Ryan et al., 2004; 2007).

Human Rights and Mental Health Care

Protection of human rights is a key issue in the delivery of care to people suffering from longer-term mental disorders. In fact, the principles and standards set by international organisations (e.g. Amnesty International, United Nations Human Rights System, European Human Rights System) have played a key role in driving the process of deinstitutionalisation across Europe.

The European Human Rights System, in particular, includes a significant number of components focusing on issues that are relevant for people with mental disorders: e.g. the Convention for the Protection of Human Rights and Fundamental Freedoms, Monitoring Body: European Court of Human Rights (ECHR); Convention for the Prevention of Torture and Inhuman and Degrading Treatment and Punishment; European Social Charter - housing, health, education, employment, social and legal protection, free movement of persons and non discrimination; Monitoring body: Rec (2004)10 and Rec (2009)3 Concerning the Protection of the Human Rights and Dignity of Persons with Mental Disorder; Towards the full social inclusion of persons with disabilities; Recommendation 1235 (1994) on psychiatry and human rights; Recommendation No R (83)2 of the Committee of Ministers to member states concerning the legal protection of persons suffering from mental disorders placed as involuntary patients.

Rights that are internationally recognised include the right to the highest attainable standard of physical and mental health, legal capacity and informed consent, the right to liberty and security, the right to non-discrimination and protection against inhuman and degrading treatment.

The right to the highest attainable standard of physical and mental health is particularly important, including dimensions such as:

1. Access to appropriate services;
2. The right to individualised treatment;
3. The right to rehabilitation and treatment promoting autonomy;
4. The right to community-based services;
5. The right to the least restrictive services;
6. Protection of human dignity.

The right to community-based services, expressly recognised in Article 19 of the United Nations Convention on the Rights of People with Disabilities (CRPD), has significant implications for the organisation of mental health services, since it implies that: 1) All persons with disabilities have the right to live in the community, choose their place of residence and have access to residential and domiciliary services as well as other community services; 2) States should facilitate the inclusion and full participation in the community of persons with disabilities; 3) Community services and facilities for the general population should also be available for people with disabilities.

Yet despite all the progress made in the last few decades to improve the situation for those with mental disorders, conditions remain inadequate in many countries (Muijen, 2008). The international legal framework continues to be a very important instrument in challenging abuses of human rights and unacceptable quality of care. For example, Amnesty International reported on major problems in institutional care in Bulgaria (2002; 2004) and in the UK, the House of Lords upheld the appeal of a compulsorily detained mental health patient that his being held *in seclusion* was a breach of Article 8 (1) of the European Convention for the Protection of Human Rights and Fundamental Freedoms (R (Munjaz) v Mersey Care NHS Trust).

Today, a large number of people with mental disorders continue to be ostracised and isolated from society, and experience discrimination in relation to employment, education and physical health care. For those in

hospital, many are subject to inhumane conditions, for example, being put in seclusion for long periods of time with no human contact, some are unjustifiably detained and have treatment imposed upon them without their informed consent. Many are denied their civil and political rights and lack access to mechanisms to protect their rights.

Given these issues, the quality of institutional care is a key area of concern across Europe, irrespective of the “official” level of deinstitutionalisation. Identification of the key aspects of care that are helpful in promoting individuals’ recovery from severe mental disorders, maximising their independence so that they can maintain or return to community living at the earliest opportunity, and protecting their human rights in the meantime, is obviously of paramount importance. Alongside this, systems to ensure that these aspects of care are delivered to an adequate standard are clearly required.

Challenges of the transition to new comprehensive community-based models of care

One of the main reasons why the rate of longer-term mental health service development is so often insufficient has to do with the lack of co-ordination between health services and services provided by other sectors, in particular the social sector. A close co-ordination, and in some cases joint funding and management of health and social care services is fundamental to cope with the new challenges mental health systems are now facing across Europe.

These challenges result, on one hand, from the rapid social and economic changes that have been taking place in most countries, and, on the other hand, from the changing characteristics of European populations, including people with severe mental disorders (Fioritti, 2010). Urbanization and demographic changes have contributed to the increase in geographical distance between generations and to a change in traditional family ties and community self-help mechanisms, making it increasingly difficult for families to ensure informal care to their members suffering from severe mental disorders. This has placed a greater burden on health and social services. In addition, immigration, unemployment and substance abuse further increase the social exclusion of people with severe mental disorders and present specific challenges to social services (Boardman et al., 2010). Separation of health and social care needs does not reflect the real life situation for those with severe mental health problems. Consider the example of a woman with schizophrenia living with her elderly mother, who has provided her with care and support throughout her adult life but has now developed cognitive problems, or the young man with schizophrenia made redundant from his job at the factory who becomes despondent and starts to relapse. Both scenarios are social and health problems requiring an integrated response from a sophisticated network of community services provided by the public and voluntary sector. Furthermore, there has been an increasing awareness of the co-morbid physical health issues faced by people with severe mental disorders who have a life expectancy 20 years lower than the general population and inequitable access to physical health care. Such discrimination is unacceptable and calls for further integration of mental health and physical health care systems (Maj, 2010).

The purpose of this paper is to explore issues around the key aspects of long-term care for those with mental health problems and the development of systems in different European countries to support these key aspects.

II - Organisation of mental health services

Based on the results from mental health policies and services research and the evaluation of mental health reforms developed in several countries, the World Health Organization gives important recommendations on how to organise mental health services, through its Mental Health Policy and Service guidance package (WHO, 2003), which provides practical information to assist countries to improve the mental health of their populations.

The recommendations, aiming at the implementation of an integrated system of service delivery, which attempts to comprehensively address the various needs of people with mental disorders, define the following key principles for organising mental health services:

“Accessibility: Essential mental health care should be available locally so that people do not have to travel long distances. This includes outpatient and inpatient care and other services such as rehabilitative care. An absence of services locally acts as a significant barrier to obtaining mental health care, especially for people living in remote rural areas. Services located close to persons with mental disorders can provide continuity of care in a comparatively satisfactory manner. It is difficult to address many social and psychological issues when people have to travel long distances in order to contact mental health services.

Comprehensiveness: Mental health services should include all facilities and programmes that are required to meet the essential care needs of the populations in question. The exact mix of services required varies from place to place. It depends on social, economic and cultural factors, the characteristics of disorders and the way in which health services are organised and funded.

Coordination and continuity of care: Especially for people with severe mental disorders it is of paramount importance that services work in a coordinated manner and attempt to meet the range of social, psychological and medical care needs. This requires input from services that are not directly related to health, e.g. social services and housing services. Persons with mental disorders often find it extremely difficult to gain access to various essential services, with the result that poor outcomes occur. Mental health services should therefore perform a coordination function and prevent the fragmentation of care.

One way of addressing the need for continuity of care is to apply the sectoral or catchment area method of organising services. During the 1960s and 1970s, health departments in North America and Western Europe divided their countries into health districts or catchment areas, i.e. they defined geographical areas with populations of between 50,000 and 250,000 (Breakey, 1996b; Thornicroft & Tansella, 1999). Catchment area health care teams covered all levels of service provision, i.e. primary, secondary and tertiary care, and were responsible for the provision of health care services for all the inhabitants of the areas concerned. Apart from the planning, budgeting and management advantages of this approach, one of the key clinical advantages is that there is an enhanced likelihood of providing continuity of care. This is of enormous benefit as many mental disorders tend to be long-lasting and require ongoing care for substantial periods.

Effectiveness: Service development should be guided by evidence of the effectiveness of particular interventions. For example, there is a growing evidence base of effective interventions for many mental disorders, among them depression, schizophrenia and alcohol dependence.

Equity: People’s access to services of good quality should be based on need. In order to ensure equity it is necessary to address issues of access and geographical disparities. Equity should be taken into consideration when priorities are being set. All too often the people most in need of services are the least likely or the least able to demand services and are thus likely to be ignored when priorities are being set.

Respect for human rights: Services should respect the autonomy of persons with mental disorders, should empower and encourage such persons to make decisions affecting their lives and should use the least restrictive types of treatment” (WHO, 2003).

Coordination of specialised services with primary care and intersectoral collaboration are also key principles for the organisation of mental health services. The first of these is important because primary care may have a major role in the identification and treatment of people with severe mental disorders. The second because health services have to work together with non-health services, particularly with those from the social sector, in the provision of housing support, day centres and psychosocial rehabilitation programmes.

III - Evolution of community care in Europe

All EU15 countries developed strategies to devolve the traditional hospital-based model of psychiatric care and to develop mental health care facilities in the community for people with severe mental disorders.

In England and Wales, for instance, the Hospital Plan in 1962 predicted the closure of half of all psychiatric hospitals by 1975. A Government Paper on ‘Hospital Services for the Mentally Ill’, in 1971, proposed the complete abolition of the mental hospital model with all services being delivered by general hospitals in close collaboration with primary care and social services. Alongside these developments there was a shift towards the provision of other community-based services, such as supported accommodation, day services and community based multidisciplinary mental health teams (Killaspy, 2007). Over the last 50 years there has been much further investment in community based mental health services, with the National Service Framework for Mental Health (Department of Health, 1999) being the most obvious recent example. It detailed the national implementation of further specialist community teams (over 200 assertive community treatment teams, 50 early intervention services and 300 crisis resolution/home treatment teams) across England, working alongside community mental health teams and local inpatient mental health units. Other policies have supported the integration of health and social care services and the provision of a range of supported accommodation by both statutory, independent (private) and voluntary sector providers. Over time the models of supported accommodation have recognised the real potential of service users to gain and regain independent living skills and there is increasing investment in less “institutional” models (such as (nursing/residential care homes) and more time-limited supported tenancies and “floating outreach” (non building based) support to people living in a permanent tenancy. More recent policy has refocused attention on the importance of the interface between primary and specialist mental health care for the treatment of common mental disorders, access to psychological therapies, attention to the physical health care needs of those with severe mental disorders and on the use of the Recovery approach (Department of Health, 2008; 2011).

In Italy, a mental health services reform was initiated in the 70’s with ‘Law 180’ of 1978. This law established psychiatric wards in general hospitals, each with a maximum of 15 beds; severe limitations in procedures for compulsory admissions and in their length (maximum 7 days, renewable weekly) were set; community mental health centres were established to provide psychiatric care to geographically defined areas; and all new and old public psychiatric services were integrated within the National Health Service (de Girolamo, 1989).

The reform in Trieste, which became a landmark of the Italian reform, led to the closure of the psychiatric hospital and development of an integrated network of community services, provided by the health sector, designed to meet all health and social needs of the severely mentally ill. This network includes mental health centres with a small number of beds, a psychiatric unit at the general hospital, housing facilities and a large and diversified number of rehabilitation programmes (vocational training, social cooperatives, among others) (Davidson et al, 2010). Other Italian regions developed mental health reforms with similar objectives and strategies, although each emphasized different specific aspects in accordance to their particular regional characteristics.

The development of community psychiatric services in Emilia-Romagna Region is a good example of the phases and strategies that had to be followed in this process (Fioritti et al, 1997; Fioritti, 2010). The first phase, in the '80s, was spent establishing community mental health centres, in deinstitutionalising patients from the mental hospitals, usually moving them into small-scale, non-hospital, residential facilities and establishing the network of psychiatric units in general hospitals. To attain these objectives, resources freed from the progressive closure of large scale mental hospitals were reallocated to the newly established community mental health services; many (not all) professionals accepted the move from old to new services, and a long period of intensive on-job training took place; collaboration among professionals, scientific societies and consumers' organisations was encouraged; dozens of regulations and guidelines were created; a substantial amount of resources was used in planning and coordination of this phase. A regional service for psychiatry to coordinate and supervise the whole process was established and is still in action. It has always been directed by a mental health professional and located within the regional administration. It has contributed greatly to drafting regional legislation, policy and plans, allocating resources, establishing and monitoring standards of care, promoting education, innovation and evaluation.

The second phase, in the '90s, was spent in establishing the coordination of all these facilities and in adapting existing services to the new chronic population that was emerging. Only in 1997 was the last regional mental hospital closed, bringing a 19-year process to an end. A critical issue of the '90s was also the integration of economic and quality assurance elements within the management of clinical teams, as required by policies and laws affecting all health services. The '90s and the first years of the new millennium can be regarded as an age of normalization, following on from the revolution of the '80s, perhaps with less enthusiasm, but probably more in contact with both the actual burden of suffering in the community and the socio-economical context where care develops.

In 1978 most resources were allocated to the mental hospitals (5191 beds) and little to the community (103 beds in general hospitals, 896 in residential facilities); in 2008 the proportion was reversed (no more beds in the psychiatric hospital, 237 beds in the general hospital, 2192 in residential facilities, and a large number of resources in the community) (Fioritti, 2010).

In Andalucía, one of the 17 regions of Spain, a profound change in the public mental health system was initiated in the '80s. Before the reform, mental health care was provided by a system separated from the general health system, with very limited resources, concentrated in eight psychiatric hospitals and a small number of outpatient clinics. Psychiatric hospitals had around 3,000 beds, of which 2,700 were occupied by long-term mental patients.

The reform led to the following developments:

- Closure of all psychiatric hospitals, through individual programmes of deinstitutionalization and reutilization of the spaces for other objectives (in most cases, related to general health care);
- Creation of a new network of specialised mental health services based in the community and integrated in the general health system. This network is organised in sectors, called Mental Health Areas, and

includes: community mental health teams which work in close liaison with primary care services; inpatient units in general hospitals, outpatient child mental health units, day centres, rehabilitation units and therapeutic communities (medium- term units for mental patients requiring a structured therapeutic setting).

- Creation of a new public organisation, the Andalucía Foundation for the Social Integration of People with Mental Disorders (FAISEM), which manages a network of social support services. This network includes residential, occupational and vocational facilities and programmes.
- The formulation of an intersectoral policy that promotes the collaboration of the health sector with services of other sectors (social affairs, justice, education) as well as with users and family associations.

The strategy adopted in Andalucía to create the network of social services to support the mental patients in the community, is one of the most original and creative aspects of this reform. Basically, the strategy consisted in the government creating a public foundation, jointly funded by the four government departments most closely related to the provision of social support for mental patients (health, social affairs, employment and technological development, and economy and finance). An additional agreement was subsequently signed with education. This strategy proved very successful in ensuring: public intersectoral funding; coordinated planning and management of social support services in close contact with health services; flexible and efficient administration of the resources; participation of local organisations, as well as staff, users and family associations in the development and monitoring of the programmes.

Currently, the Foundation provides housing support to more than 2,000 users, occupational activities to more than 2,500 users, vocational training to 200 users each year, employment in social firms to around 300 people with mental disorders, and develops many other activities (supported employment, social clubs, support to users and family associations, research, among others). Recent initiatives of the Foundation include programmes for health promotion and prevention of physical illnesses for residential facilities users, as well as of programmes for homeless people and the mentally ill in prisons. The access to the services provided by the Foundation is always made in coordination with the mental health services through coordination committees in each area, involving also the general social services of the area (Caldas de Almeida & Torres, 2005).

The Psychiatric Services in the South Stockholm Health District in Sweden are another good example of a successful development of community services for people with severe mental disorders. Up to the '80s, almost all resources were concentrated in a large psychiatric hospital and a psychiatric clinic in a general hospital. By the mid '90s significant advances had been made in shifting resources to community services in three catchment areas. The implementation of the Swedish Psychiatric Reform Bill passed in 1995 led to a structural change of the mental health care system and to the reallocation of financial resources from the counties to the municipalities. In 1997, the three separated sectors were transformed in one unit with six sub-sectors, which allowed a more reduced and effective administration. At the same time, outpatient and inpatient facilities were further extended and decentralised.

The current system provides integrated outpatient and inpatient care in community-based units that have a small number of beds. Services are organised in a way that reinforces accessibility to services, continuity of care, integrated care, and the involvement of families and key organisations in the community. There are no units directly connected with a psychiatric hospital and all of them are located in residential areas. There are a small number of in-patient care beds (75 beds for 270,000 inhabitants). Most of the efforts are concentrated on outpatient care and over 65% of the resources are directed towards outpatient care. Psychiatric health care at home with home visits is the primary working method. Daytime activities, working in groups and family- and network-oriented working methods are an important part of outpatient care. The

inpatient care facilities have an integrated responsibility for both in-patient and outpatient care of the long-term patients. The mental health teams have an extensive collaboration with the social services in each residential area. On-duty and open care centres have a long-term collaboration with primary health care centres in the residential areas. In order to provide care adapted to some specific needs, there are specialised units/programmes for forensic patients, people with eating disorders, geriatric patients and psychotherapy.

As part of the Reform, municipalities should provide acceptable housing and support connected to housing, employment and some leisure time options. The fact that psychiatric treatment in out-patient settings also is needed from time to time brought about a serious necessity for the two parties involved to collaborate and adapt to each other's organisations. The Reform involved a considerable shifting of financial resources from county councils to municipalities to cover the new obligations. By strengthening the legislation and also by giving specific directed subsidies over a three years period jointly to local communities and county councils the government encouraged co-operation between social welfare and psychiatric care organisations.

Strategies indicated to attain the same goal – to provide high quality community care for people with longer-term mental disorders – may differ from place to place, depending on the specific political, social and economic characteristics of the region/country where the reform is developed.

The psychiatric reform implemented in the eastern part of Lille is a good example of this principle. The reform was initiated in the end of the 70's, led by the Psychiatric Hospital of Armentières (a public hospital responsible for an area of 900,000 inhabitants, including the sub-area (86,000 inhabitants) of the Lille eastern suburbs, in which the reform took place), and a non-profit private Medical Psycho-Social Association (AMPS), where local council members, mental health professionals, social workers, users and carers representatives are involved.

The reform aimed at deinstitutionalization and the development of community based care in accordance with the principles of sector psychiatry. In the beginning, a Medical-Psychological Centre and a centre for housing and deinstitutionalization, specializing in the rehabilitation of long-term patients, financed by the AMPS, were created. Collaboration with the municipalities and contacts with social landlords, for the setting up of an associative and 'therapeutic flat', then for access to dispersed associative housing facilities, were initiated.

Several programmes were developed in the areas of advocacy, fighting against stigma, research supporting policy and services development, and psychosocial rehabilitation.

The reform occurred in two main steps. The first step (1975-1995) was the shift from the psychiatric hospital to the community, by the development of sectorisation, supported by a global budget. The second step (1995-2006) consisted of decentralising and opening the psychiatry service by integrating professionals in the health, social and cultural services of the counties. This integration increased the participation of other stakeholders (users, families, professionals and elected officials) in the decisions related to psychiatric care.

In 1975, 98% of the budget was allocated to full-time hospitalisation (i.e. 300 beds in Armentières). In 2009, 80% of professional staff was assigned to services in the community, while 20% remained assigned to full-time hospitalisation (26 beds).

In 2010, following the creation in France of mental health local councils, the AMPS was transformed into a mental health local council (MHLC) gathering the six municipalities of the eastern Lille mental health services territory and the Public Mental Health Trust (EPSM Lille Métropole). The MHLC provides a discussion platform for the six town mayors, citizens, users of mental services, families, artists, cultural services, housing services, curators, social services, sanitary services, and psychiatric services. No decision

regarding the creation of new services and care organisations in the city is possible without getting approval from MHLC.

Accessibility, continuity of care and intersectoral cooperation are basic characteristics of the system. Patients referred by general practitioners are attended by a nurse of the sector, who assesses the situation in less than 24 hours. If necessary, the user is seen on the very same day by a psychiatrist. Teams located in different places in the community provide outpatient care.

Therapeutic host families as an alternative to hospitalization were established in 2000 and there are currently 12 beds available, with an average length of stay of 21 days. Patients in an acute situation can be referred to the family either directly, after a consultation, or secondarily after a hospitalization, for some days or some weeks. A nurse and the social and medical team are responsible for mental health care during home visits. Support is similar to that offered within the full-time hospitalization unit located in the hospital.

Another alternative to hospitalisation is provided by an intensive care unit of 10 places located in users' home that responds to post emergency situations, in order to guarantee total continuity of care and guidance to the patients.

Services and programmes to promote social inclusion are integrated in the community. Access to associative apartments spread in the social fabric of the town is one of the major components of inclusion work. An "apartment committee" gather the members of the Mental Health Local Council (MHLC ex AMPS): the representatives of public housing offices social landlords, caregivers, the psychiatric services, the representatives of users and family associations and trustees. This committee decides on the allocation of apartments located in the public housing stock. Since the creation of the Committee, 150 apartments have been put at the disposal of patients. Currently, the "apartment committee" supports 57 apartments, and 95 people, who accepted a contract of social inclusion and care, are benefitting from this method of housing allocation. Other types of residential facilities (sheltered apartments, half-way houses, a block of low-rent accommodation) are also available, thanks to the collaboration of the municipalities.

Vocational rehabilitation and employment are also promoted through a large range of activities, including therapeutic workshops, vocational training programmes, supported employment schemes and vocational rehabilitation integrated in the city. Most of these programmes are developed thanks to the cooperation of the psychiatric services with MHLC, employment services and many other partners in the community.

An interesting characteristic of the Lille system is the important role played by art, culture and leisure activities. A devoted team organises inclusion and care activities in all artistic, sport and cultural places in the six counties of the sector and in one centre. Altogether, 48 different activities are offered per week, with 60% of them taking place in 21 places outside the service (associations, social centres, media library, retirement home, sports facilities, etc.).

These activities include plastic arts workshop, media library, sports, dance, music, singing and video activities, as well as psycho bodily activities. Also, a therapeutic workshop has been developed at the FRONTIERE\$ Centre in Hellemmes. This artistic centre in the inner city is co-located with a contemporary art gallery, financially supported by the Regional Direction of Cultural Action, which organises monthly exhibitions. The planning is meant to be diverse, as it opens towards inhabitants' leisure and daily life. No matter where they take place, activities are above all designed as a springboard to support the users' integration into local life and to give them the tools to break their social isolation. In the Eastern Lille Suburbs catchment area 2 mutual self-help groups (GEM: Groupes d'Entraide Mutuelle) were implemented. They are managed by users and are essential partners for rehabilitation and fight against social isolation.

The results of this community based services organisation appear clearly on the table below:

For 86 000 inhabitants	1971	2002	2010
People in care	589	1677	2572
Ambulatory care (number of acts)	0	23478	48315
Admission to hospital / acute beds	145	444	360
Compulsory treatments	145 (100%)	99(22%)	87(24%)
Mean length of stay (in days)	± 213	14,5	6,5
Number of days of hospitalisation	77.640	4248	2490
Number of people admitted in host families (AFAH)		87	63
Number of people admitted in intensive home care treatment (SIIC)			234

These five examples show, each one in its own way, the main aspects of mental health reforms developed in EU 15 countries in the last decades. Other examples of successful mental health reforms could be described in Europe, at the national, regional or local level, presenting with more or less emphasis the main aspects that can be seen in the examples described above.

Transformation of the mental health services in the newer Member States

Most new Member States, especially those which have operated under communist regimes, have been more or less isolated from modern developments in mental health care during the second half of the 20th century (Brown, 2001).

During this time, mental health systems were reconciled to a much greater degree with the excessive control of previous regimes; the more pronounced the role of traditional values in regulating communal, family and professional life prior to dictatorial times, the easier it was for health systems to yield to authoritarian pressure. This brought about a psychiatric institutional culture which has proven difficult and painful to leave behind, even to this day (Geneva Initiative on Psychiatry, 2000). However in the last twenty years, after the fall of the “iron curtain”, we can see a process of change in mental health care, in most of these countries, which, at a certain level, follows a reform pattern akin to that which started in Western Europe about 60 years ago (Domenighetti, 2003).

Obtaining accurate and comparable data on the actual number of psychiatric beds in psychiatric hospitals, general hospitals and other settings in a new Member States is difficult. Some countries estimates include beds that are not located in psychiatric hospitals, for example those in social care homes, whilst others do not. However, in most new Member States we can see a reduction in the recorded number of “mental health” beds over the last 20 years, and this is especially pronounced in Estonia, Lithuania and Cyprus (Knapp et al., 2007).

A reduction of beds is not always followed by the development of community services. We can see also another trend in which the development of community services does not follow on from a reduction of capacity in large, segregating mental health institutions. One obstacle to continued progress in mental health reform in many of these countries is the existing financial resource allocation system, which may still link resource allocation directly to psychiatric hospital bed occupancy, allowing little flexibility and providing little incentive for local planners to develop community-based alternative services.

Despite these barriers, in some new Member States we can see an increasing number of different kinds of community services. Examples of the development of Community Mental Health Centres (CMHC) can be found in Estonia (Estonian Healthcare Association, 2005) and the Czech Republic (Dlouhy, 2004), among others. These centres vary in size and the types of service they provide, but they mostly have multidisciplinary teams and work on the principles of catchment areas, case management and a recovery orientated approach. "Office based" practice is still very dominant in most of these community-based services, but good examples of outreach work, mobile and flexible crisis intervention are in progress. In both countries mentioned, the CMHC services mostly comprise a variety of programmes in supported housing, leisure activities and employment support. These services are very often provided by the NGO sector. In most new Member States we can now see a growing number of different NGOs, including those run and managed by mental health service users and family members, which are playing an ever more important role in the provision of services, as well as in advocacy for more robust and faster changes (Paldam & Svendsen, 2001)

In general, it is common that services have been set up largely on the basis of enthusiasm and individual initiative, rather than as a result of a coordinated, clear, policy led process. As a result, there is sometimes a fragmentation of newly set up community services, with little coordination and cooperation between them. In addition, the continuity of care between inpatient hospital and community services is often an issue (Roberts, 2002). On the other hand, in some of these countries, we can see recent positive examples of pilots for more structured de-institutionalization processes, but mostly in the social sector (housing and home care). These pilot projects are often carried out with the financial support of EU Structural Funds.

IV - Assessment of quality in long - term mental health facilities

In 2007, a systematic literature review was carried out to identify the key components of care for people with long-term mental health problems whose severity of needs necessitated their residence in a hospital or social care institution. This work was carried out as part of a three year project funded by the European Commission, the Development of a European Measure of Best Practice for people with longer term mental health problems in institutional care (DEMoBinc) to develop an internationally relevant quality assessment toolkit for longer term psychiatric and social care institutions (Killaspy et al, 2009). It involved eleven centres across ten countries at different stages of deinstitutionalisation (Bulgaria, Czech Republic, Germany, Greece, Italy, Netherlands, Poland, Portugal, Spain, and UK). The findings suggested that institutions should, ideally, be community based, operate a flexible regime, maintain as low a density of residents as possible and maximise privacy. For those with a diagnosis of schizophrenia, specific interventions should be provided (medication in accordance with the guidance of the American Psychiatric Association and the National Institute for Clinical Excellence (NICE) cognitive behavioural therapy, family interventions involving psycho-education, and supported employment) through integrated programmes. Restraint and seclusion should be avoided wherever possible and staff should have adequate training in de-escalation techniques to minimise their use. Regular staff supervision should be provided and the facility should support service user involvement in decision making at all levels, including the running of the facility as well as their personal treatment and care plans. Positive, respectful therapeutic relationships between staff and service users should be maintained and there should be clear lines of clinical governance that ensure adherence to evidence-based treatment guidelines that should be delivered through individualised care plans, drawn up in collaboration with service users and family. Attention should be paid to service users' physical health through regular monitoring of weight and blood tests (to screen for diabetes, cholesterol and specific side

effects of medication) and the promotion of smoking cessation programmes, physical exercise and healthy diets (Taylor et al., 2009).

These findings were further triangulated by the DEMoBinc group with two further forms of evidence: a review of care standards in each of the ten countries; and a Delphi exercise carried out with service users, mental health professionals, family members and advocates in each country that asked them to identify the most important aspects of care in mental health institutions that promoted recovery. The iterative Delphi process led to consensus on the most important domains as being: social policy and human rights; social inclusion; self-management and autonomy; therapeutic interventions; governance; staffing; staff attitudes; institutional environment; post discharge care; caregivers; and physical health care (Turton et al., 2010).

Further stages of the project led to the development of a toolkit, the Quality Indicator for Rehabilitative Care (QuIRC) (Killaspy et al., 2011). The toolkit was designed for completion by the manager of the facility and takes about 45 minutes to complete on-line. It provides a printable report of the percentage performance of the facility on seven domains of care (built environment, therapeutic environment, treatments and interventions, self-management and autonomy, social inclusion, recovery orientated practice, and human rights), comparing their scores with the national averages in an accessible “spider web” diagram. It also provides details of how the facility could improve their practice in areas where they score below the national average. The toolkit was found to have excellent inter-rater reliability and the association between the ratings (derived from the manager of the facility) and service users’ experiences of care and autonomy in the same facilities were found to be good. The toolkit has now been incorporated into the UK peer accreditation system for inpatient mental health rehabilitation units, co-ordinated by the Royal College of Psychiatrists’ Centre for Quality Improvement. It is translated into ten languages and is available, free for local and national (and potentially, international) quality assessment of longer term mental health inpatient and social care units (see www.quirc.eu).

V - Strategies to implement long-term community mental health care

As we have seen in the examples of reforms developed in several European countries, each country has to focus on its specific priority needs and to adopt policies that best respond to these needs. The implementation of long-term mental health care is not the same process in a country that still has the majority of resources allocated to large mental hospitals as it is in a country that has already made some advances in the development of community care. It is also different in a country where there is no tradition of cooperation of mental health services with social services, comparing to a country where inter-sectoral cooperation has been largely used in mental health care.

Essential ingredients

In spite of the different possible approaches, the experiences of mental health reform in Europe show that some ingredients are always indispensable for a successful development of high quality long-term community mental health care:

First, the **existence of a mental health policy**, that establishes the vision, the values, and the principles that guide the reform, define the objectives to be attained and determine the areas for actions.

Second, a **mental health plan** that defines the strategies and the time frame, sets the targets and the

indicators, and determines the major activities, the resources and the budget.

Third, it is essential that a **coordinating unit** will assume the responsibility for the implementation of the plan.

Finally, the plan should include the **strategies** and activities that are necessary to attain the following goals, which include:

1. **Development of community based mental health services and psychiatric units at general hospitals:** Community mental health services, based on mental health teams or mental health centres, are responsible for the provision of outpatient and home interventions, and form the cornerstone of cooperation with primary care, general hospital units and non health services and programmes. They are fundamental for prevention, treatment and rehabilitative interventions. General hospital units are essential for inpatient treatment of acute episodes and liaison with other medical specialties. If it is true that there are no studies proving that hospital treatment alone is sufficient for the treatment of people with longer-term mental disorders, it is also true that available evidence supports a balanced approach, including both hospital and community services (Thorncroft & Tansella, 2004)
2. **Integration of mental health services in primary care:** The integration and establishment of primary/secondary mental health care liaison schemes are indispensable for early identification of new cases, monitoring of longer term cases, and treatment of physical health problems of people with severe mental disorders.
3. **Equitable access to appropriate assessment and treatment of physical health conditions:** This goal is especially important as physical conditions of people with longer term mental disorders are frequently neglected. Regular assessment of physical conditions should be an obligatory part of individual care programmes and the participation of primary care services in these programmes should always exist for patients living in the community (Osborn, 2007).
4. **Development of the psychosocial network:** including supported housing facilities of different kinds, occupational and leisure activities, vocational rehabilitation programmes, supported employment, and other activities that are needed to promote social inclusion.
5. **Development of specialised institutional services for those with more complex needs:** these services should include forensic units as well as inpatient and community residential units prepared to respond to the therapeutic and rehabilitation needs of patients requiring longer term care. These services should not be considered the final point in a person's recovery journey and should liaise closely with services that can provide appropriate support once the person is ready for less institutional care.
6. **Training of mental health staff:** staff members need to have the appropriate skills to work professionally, effectively and compassionately with people with longer term mental health problems. All staff should be operating with a recovery orientation and have the relevant training to equip them to deliver evidence based interventions (such as medication management, psychological interventions etc) appropriate to their qualification and experience level in whichever component of the mental health service they work.
7. **Fighting against stigma and social exclusion:** including the dissemination of information on mental disorders that may fight against prejudices associated to these disorders, programmes promoting living in the community and employment, and measures to increase users participation in the organisation of services.

8. **Support to families:** Specific measures should be developed to support families coping with problems associated to the longer term mental disorder of their beloved ones. These measures must include access to crisis intervention services 24 hours a day, seven days a week, involvement in programmes designed to decrease family burden and psychological support if needed.
9. **Participation of service users and carers in all aspects of care:** the increasing participation of users and carers is one of the major advances made in mental health care in the last decades. It is essential to promote human rights of people with mental disorders and it is a key strategy to improve the quality of care.
10. **Promotion of research:** Epidemiological studies and services research are indispensable to develop better policies and services for people with longer term mental disorders. They can contribute to increase the knowledge on the needs for care of people with longer term mental disorders and to support decisions related to the development of effective services and interventions. They can also promote the creation of a critical mass that is key for the implementation and evaluation of innovative mental health services
11. **Establishment of robust systems to monitor the quality of care delivered**
12. **Improvement of quality of care in psychiatric hospitals and deinstitutionalization:** These activities continue to be very important in countries where psychiatric hospitals still are responsible for a significant part of care provided to people with severe mental disorders but they are also highly relevant for the specialised institutions described above under point 5. National Mental Health Plans should include strategies to maximise the living conditions of patients and the quality of care provided, including the promotion and respect for human rights. At the same time, rehabilitative programmes should be developed and implemented within and outside the institution to prepare patients for community living and social inclusion, whatever stage of deinstitutionalisation the country they happen to be living in is at.

VI - How can the EU support the Member States in Deinstitutionalisation?

The organisation and delivery of health services and medical care is a matter falling under the responsibility of Member States with their competent authorities themselves. However, the Commission has an important role to play by promoting the coordination and the exchange of best practice between Member States. Over the past years, a number of initiatives have addressed deinstitutionalisation in this regard: A European Commission Green Paper (2005) on improving the mental health of the population highlighted the importance of promoting the social inclusion of those with mental health problems and the protection of their rights and dignity (EC, 2005).

The European Pact for Mental Health and Well-being launched at a high-level conference in Brussels in 2008 has "Combating Stigma and Social Exclusion" as one of its priorities. As a key element to implement the Pact, in November 2009 the Commission organised a thematic conference on "Promoting Social Inclusion and Combating Stigma for better Mental Health and Well-being", jointly with the Ministries of Health and of Labour and Social Solidarity of Portugal. Two of the main objectives of the conference were, firstly, to encourage policy makers to support the transition towards community-based settings in mental health care and, secondly, to promote the coordination between health and social sectors in the delivery services for people with mental health problems.

In June 2011, the Council of Ministers adopted political conclusions, which invited Member States and the Commission to continue the cooperation, as a follow-up to the European Pact for Mental Health and Well-being (Council, 2011). The statement invited the setting up of a cooperation process ("Joint Action") on Mental Health and Well-being, and proposed that it should look into, inter alia, in particular into "managing the evolution of community-based and socially-inclusive approaches to mental health".

Member States can also make use of EU-Structural Funds for investments into deinstitutionalising mental health services and building up community-based services. These investments should focus on 'how' to implement these initiatives. Deinstitutionalisation is both changing systems, patient pathways and financing structure, and building capacity within these systems to allow people working in these changed environments. In principle, the European Regional Development Fund (ERDF) can be used to improve the physical mental health service infrastructure, while activities such as to promote the social inclusion of people with mental health problems or the training of mental health professionals can be eligible under the European Social Fund (ESF). During the Structural Funds period 2007-2013, Member States have allocated € 5.1 billion from the ERDF and additional funds from the ESF into health. Bulgaria is using Structural Funds to support the implementation of its "Vision for Deinstitutionalisation for children in Bulgaria". The Czech Republic is another Member State, which has decided to use Structural Funds to support the transformation of its social system and to de-institutionalise at least 27 institutions of social services in all regions across the country, with the exception of Prague.

The EU can certainly have a key role in the development of capacity building and evaluation initiatives that may contribute to enhance the capacity of Member States to implement new policies and services.

VII - Conclusions

Despite all the advances already made in Europe to improve mental health care for people with longer-term mental disorders, most European countries are still confronted with important challenges in order to complete this process of change.

These challenges are closely related to a paradigm shift that involves the change from an approach focused on the exclusion of the mentally ill for an approach that focuses mainly on their inclusion in society. This paradigm shift, which results from an increasing recognition of the importance of the recovery perspective - a perspective that emphasises self-determination and human rights of people with mental illness, also involves the evolution of a hospital-based model of care to a community-based integrated model of care.

From a scientific point of view, what is at stake is the replacement of the strict biomedical model by a more holistic and complex approach, which attempts to understand mental illness as a result of the complex interactions of biological, psychological and social factors; and combines a perspective of treatment with one of prevention and promotion

With respect to the organisation of services, the new paradigm is strongly influenced by new models of management of chronic diseases, which emphasise case management, collaborative models of care and participation of users and families in care delivery. It is also a paradigm that clearly implies a recognition of the importance of available scientific evidence on the costs and effectiveness of interventions and services to support the decision making process of clinicians and policy makers.

It is important to safeguard and further expand the achievements that have been made in embedding long-term mental health care into societies, and in recognising it as part of local community development. The

evolution to community-based and socially inclusive approaches to mental health needs to continue, and it should not be stopped or even reversed by the financial constraints which Member States have increasingly been facing in recent years.

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